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Parents of children with autism spectrum disorder: investigation into best practice intervention.

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PARENTS OF CHILDREN WITH AUTISM SPECTRUM DISORDER: INVESTIGATION

INTO BEST PRACTICE INTERVENTION

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Aude Etournaud

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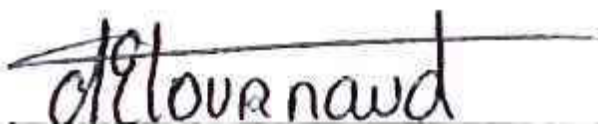
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CANDIDATE'S DECLARATION

This thesis is submitted to Bond University in fulfilment of the partial requirements for the Doctor of Philosophy degree.

This thesis contains no material which has been accepted for the award of any other degree in any other University and, to the best of the candidate's knowledge and belief, it contains no material previously published or written by another person except where due reference is made in the text of the project.

Signature _____

Date: 06th of March 2017

ABSTRACT

Parents of children with Autism Spectrum Disorder (ASD) are reported to experience greater levels of stress, anxiety, and depression than parents of children with other developmental disorders or physical impairments. This group of parents, which presents mental health professionals with unique support needs, is receiving increasing attention due (in part) to the reported worldwide increase in ASD prevalence. Australian figures suggest that approximately 115,400 Australians (0.5%) of the population were reported to have ASD in 2012 (SDAC, 2014). The research demonstrates that formal group support constitutes the most common method for assisting parents of children with ASD to deal with their children's autism-specific difficulties and their own mental health challenges. However, the literature which evaluates the effects of formal support groups reveals substantial variation in relation to content, delivery methods, and data-collection procedures for monitoring any changes to parent functioning (as a result of parents attending group support). This variation has contributed to poor clarity on what constitutes effective formal group support for parents of children with ASD, and limited translation of evidence-based support group processes to the professional field.

Study 1 sought to investigate the question of which model of formal group support (i.e., broad topic area) might be best suited to meeting the emotional and psychological needs of parents of children with ASD by delivering three six weeks groups, clearly differentiated in content (i.e., Functional Behavioural Assessment Training Group, Skills Training Group, and Combined Group), but kept equivalent in relation to delivery format, timing, and data-collection procedures. Those three groups were delivered to 36 parents of children with ASD, and changes in parent mental health (i.e., anxiety and depression), parent-child relationship quality, and ASD child challenging behaviours were measured across five time periods (i.e.,

Pre-Intervention, Post-Intervention, Follow-Up 1, Follow-Up 2, and Follow-Up 3). The results indicated there were no significant changes in parental mental health across the three support groups. A reduction in the frequency of challenging behaviours was reported across time for all three groups, and participants attending the Skills Training Group reported an increase in the quality of their relationship with their child.

The parent attendance records collected for study 1 indicated a strong trend towards inconsistent participation across all three groups. This finding was substantiated in the literature with researchers suggesting that the poor mental health outcomes reported by parents attending support groups are associated with low attrition and low participation rates. Consequently, study 2 investigated the specific aspects of parents' lives that might act as barriers to accessing support groups, by conducting semi-structured interviews with 33 parents of children with ASD. Interview findings propose reasonable large variation in the factors which prevent parents from accessing and remaining engaged in support groups. These findings lead to the recommendation that parents undergo individual profiling to understand their particular life circumstances and how these affect participation in support services.

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1. Introduction

The term Autism Spectrum Disorder (ASD) refers to a group of neurodevelopmental conditions characterised by atypical development in the domains of social communication, social interaction, adaptive behaviour plus presence of restricted and repetitive response patterns (Tobing & Glenwick, 2002). The term "spectrum" is used to denote the wide range of symptoms, skills and levels of functioning that individuals diagnosed with ASD can experience (APA, 2013). In addition to this variation in presentation of core autism features, children with ASD are highly likely to exhibit patterns of difficult behaviour which create major challenges for their parents. Researchers consistently report that parents of children with ASD are more likely than parents of children with other developmental or physical disabilities to experience poor mental health well-being and ill physical health. Multiple studies have shown that parents of children with ASD are more likely than other parents to report greater levels of anxiety (Weiss, 2002), and depression (Greenberg, Seltzer, Krauss, Chou, & Hong, 2004). Factors which contribute to the elevated stress levels of parents of ASD children relate to the unpredictability of their child's behaviour (Allik, Larsson, & Smedje, 2006; Benson, 2006; Blacher & McIntyre, 2006), their child's cognitive/learning difficulties (Bebko, Konstantareas, & Springer, 1987; Moes, 1995), the under-development of their child's communication skills (Bebko et al., 1987; Moes, 1995), the lack of understanding from the wider community of the nature of ASD (Farrugia, 2009; Gray, 2002), and the onset of marital difficulties (Hartley et al., 2010; Pottie, Cohen, & Ingram, 2009).

It is clear that parents of children with ASD require targeted assistance in dealing with their children's needs and their own difficulties. Formal support groups have received considerable research attention as a possible basis for delivering assistance to parents of children with ASD. Formal support groups for parents of children with ASD are clustered

around three foci: building parents' capacity to understand their child's autism-specific difficulties and the ramifications of these on daily functioning (Ferraioli & Harris, 2013); training parents to manage the atypical responses and challenging behaviour of their child (Bitsika & Sharpley, 2000); and more recently, assisting parents to learn basic psycho-social strategies to manage their mental health and adverse life circumstances (LaPlante, 2013). Interestingly, evaluations of research-based support groups such as these reveal two issues, which require further investigation in order to maximise clear recommendations on best-practice delivery of group support. First, there is large between-group variation which varies greatly in relation to content, delivery methods, and data-collection to measure effects on parent well-being changes and this has prevented effective cross-group comparisons (Dennis, 2003). Second, despite parents reporting positive outcomes as a result of participating in group support, researchers have consistently reported high levels of attrition and inconsistent attendance following enrolment in group support (Shadish & Haddock, 2009).

The thesis sought to address the question of how to best deliver group support to parents of children with ASD, using a two stage process. First, three different models for group support were delivered and evaluated in relation to their relative impacts on parent mental health (i.e., study 1). Second, and arising from the findings of the first study, a semi-structured interview was employed to conduct an in-depth examination of the particular circumstances of this parent group, as well as the life factors which might act as barriers to consistently accessing support.

Chapter 2 of this thesis discussed the defining features of ASD with a focus on the evolution of the diagnostic criteria for this condition. The biomarkers which might illuminate several possible causes of autism are briefly touched upon. The diagnostic criteria for ASD, from the perspectives presented in the Diagnostic and Statistical Manual of Mental Disorders

(i.e., DSM-IV-TR [APA, 1992] and DSM-5 [APA, 2013]) are discussed from a comparative focus which emphasises the changing conceptualisations of ASD and how those changes have affected detection. In addition to discussing the core features required for a diagnosis of ASD, this chapter also outlines the associated behavioural difficulties which adversely impact the daily functioning of children with ASD In acknowledgement that ASD often occurs with other psychiatric and behavioural conditions, the discussion will extend to the major co-morbid disorders which further impact on daily functioning.

Chapter 3 of this thesis outlines the psychosocial experiences believed to arise from parents who raise a child with ASD, with a particular focus on self-reported stress, anxiety and depression. The unique challenges confronted by these parents are highlighted via comparison of the mental health data from studies on parents of children with other developmental disorders, children with physical impairments, and neurotypical children. The discussion will also encompass the wider impacts of having a child with ASD on family, martial, and financial functioning.

Chapter 4 of this thesis seeks to contextualise and further explore the experiences of parents of children with ASD by presenting findings on the psychosocial factors which have been shown to enhance the capacity of parents to cope with the particular demands they confront. The chapter will begin with a description of the behavioural responses of parents to different levels of stress, and then introduce the specific factors which are believed to ameliorate effective stress coping. In-depth discussion will be presented in relation to coping style, social support, and personal resilience and the association between these pro-coping factors and positive parental functioning.

Chapter 5 presents an analysis of the studies which have implemented formal group support with parents of children with ASD in relation to the features of those groups. The

focus will be on the specific features of *implementation period* (i.e., the length of time groups were conducted), *content* (i.e., the overall theme plus specific topics covered), *delivery methods* (i.e., the procedures employed to facilitate delivery of content). The discussion will also extend to examination of the presence and type of data-collection implemented to monitor the effects of support group participation on specific aspects of parent functioning. This chapter will finish with an outline of the gaps in the research on group support implementation and briefly describe how those gaps might be addressed during development and delivery of such support in a community context.

Chapter 6 will discuss the first phase (i.e., study 1) of the research which aimed to compare the relative effects on parent mental health of three support groups which differed in content but were identical in implementation period, delivery methods, and data-collection processes used to monitor any changes in parent mental health (i.e., anxiety, and depression), parent-child relationship, and parent reports of their child's challenging behaviours. Specific descriptions will be provided in relation to the rationale for the study 1, self-report scales used to measure "parent change" plus the specific points at which those measures were applied, and support group implementation procedures. This chapter will also present discussion of the relative impacts of the three support groups on participant functioning. The relative satisfaction of parents with specific sessions (across the three groups) as well as their inconsistent attendance will be explained.

Chapter 7 will discuss the second phase (i.e., study 2) of the research which aimed to investigate the specific aspects of parents' lives that might act as barriers to accessing support groups. The delivery methods and data-collection processes used to administer the semi-structured interview and to monitor any changes in parent mental health (i.e., anxiety, and depression), parent-child relationship, and parent reports of their child's challenging

behaviours. The micro-counselling skills used during the implementation of the semi-structured interview will be described. Specific descriptions will be provided in relation to the rationale for the study 2, self-report scales to measure "parent change" and the implementation of the semi-structured interview.

Chapter 8 of this thesis explains the process used in Study 2 to conduct a Thematic Analysis of the self-report data obtained from the face-to-face semi-structured interview administered to parents to identify the life circumstances and factors which might have contributed to the inconsistent attendance observed during study 1. The data-collection process for phase two of the research (i.e., study 2) involved administration of a semi-structured interview (containing 13 open and 40 closed questions) and the same self-report survey package implemented in study 1. Therefore, the major findings of study 2 will be described in relation to major child- and environment-focused themes obtained from analysis of responses to open questions, basic trends obtained from review of responses to closed questions, and frequency/percentage figures obtained from responses to the survey package. Specific comment is made on the psycho-social barriers to parents accessing and consistently attending support. Finally, brief comparison (from studies 1 to 2) of parents' self-reported anxiety and depression levels and perception on their children's' difficulties will be presented.

Chapter 9 of this thesis draws together findings from the wider research and the results from studies 1 and 2 to create a number of practical recommendations to guide delivery of needs-based group support for parents of children with ASD. Those recommendations are designed for mental health practitioners interested in implementing group support in community contexts and, as such, are practical in focus. This chapter finishes with a discussion of the research limitations identified for study 1 and study 2 with

suggestions for overcoming those limitations plus the implications for the professional field

of the findings of this research.

2. Description of Autism Spectrum Disorder (ASD)

The term Autism Spectrum Disorder (ASD) refers to a group of neurodevelopmental impairments conditions characterised by uncommon atypical development in the domains of social communication, social interaction, adaptive behaviour plus presence of restricted and repetitive response patterns behaviour, communication, and socialisation (Tobing & Glenwick, 2002; Shu, 2009). The term "spectrum" includes is used to denote the wide range of symptoms, skills and levels of impairments in functioning that individuals diagnosed with ASD can experience (DSM-5; APA, 2013).

The Australian Bureau of Statistics revealed that in 2009 that 64,400 Australians between the ages of 0 to 29 years suffered from ASD. This was an increase of 34,200 from the 2003 Survey of Disability, Ageing and Carers (SDAC). It was also reported that of the 64,400 individuals diagnosed with ASD, only 18 per cent were females which corresponded to the statistics of other countries (The Australian Bureau of Statistics, 2014). The survey on the prevalence of ASD released in 2014 by SDAC showed an estimated 115,400 Australians (0.5%) had autism in 2012. These figures indicated a 79% increase on the 64,400-people estimated to have the condition in 2009. In SDAC 2012, ASD was reported to be more commonly found in males than females. Males were four times more likely than females to have the condition, with prevalence rates of 0.8% and 0.2% respectively. Such results remained consistent with overseas estimates. For instance, the Center for Disease Control and Prevention in the United States revealed that young males were 4.5 times more likely than young females to be diagnosed with ASD. According to SDAC, there were considerable variations in the prevalence of ASD across age groups, with a marked drop off in prevalence after a constant increase in diagnosis in the five to nine years age group. Survey scope and

diagnostic issues have been identified as possible reasons for the variations in prevalence of ASD across age groups (The Australian Bureau of Statistics, 2014).

Both Kanner (1943) and Asperger (1944) published clinical studies which contained the first detailed reports of autistic symptoms and behaviour patterns. In addition to redefining autism as a neurodevelopmental disorder, as opposed to a childhood form of schizophrenia (Bleuler, 1911), Kanner's and subsequently Asperger's clinical insights formed the basis for scientific studies in the conceptualisation, definition and detection of autism-based disorders. Kanner (1943) published an article entitled "Autistic Disturbances of Affective Contact", in which he described the cases of eleven children with autism who exhibited similar impairments and responses to social stimuli, presenting specific features across all children including, preoccupation with objects, repetitive behaviours, insistence on consistency, and deficiencies of language, among other behaviours. Kanner (1943) explained that children with autism seemed unable to relate to others, with specific social deficits involving children's failure to recognise and react to a caregiver when being picked up, or by children's inability to use language for the purpose of social communication. Kanner (1943) also observed that the initial group of 11 children reacted to loud noises and moving objects with horror, and with repetitious utterances. He interpreted these reactions to indicate that these children had an obsessive desire to maintain sameness in their environment.

The spectrum of clinical conditions labeled "autism" soon expanded beyond Kanner's first description. In 1944, Hans Asperger described a group of 4 children he also called 'autistic', but who seemed to have high non-verbal intelligence quotients and who used a large vocabulary correctly during conversations. In addition to the marked difficulties in social interaction, Asperger also noted other features present in these cases. Asperger (1944) described autistic children as possessing impaired nonverbal social skills, idiosyncratic

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communication, egocentric obsessions and special interests, intellectualisation of affect, gaucheness and poor body awareness, and behavioural problems. Unlike Kanner, Asperger (1979) argued that speech and language skills early in life were apparently normal, and that the condition was not able to be recognised before 36 months of age. Furthermore, Asperger (1944, 1979) specified that the core diagnostic features of this syndrome were: social impairment (i.e., poor empathy, failure to develop friendship), motor clumsiness, all absorbing interests, and language/communication impairments (i.e., impoverished imaginative play, idiosyncratic language). Kanner (1943) presented three diagnostic criteria pertaining to deficits in reciprocal social interactions; atypical development and use of language; repetitive and ritualised behaviours; and a narrow range of interests as the core features in individuals with ASD. The high similarity between this set of diagnostic criteria have led to the suggestion that both Kanner and Asperger were describing the same condition but had focused their investigations on two different sub-types of autism.

2.1. ASD as a neurodevelopmental disorder.

2.1.1. Possible biological underpinnings for ASD.

Biomarkers have been studied for the past fifty years as one basis for illuminating the possible causes of ASD, with minimal progress being made on identification of specific and reliable biological markers that might aid accurate diagnosis and subgroup categorisation (Anagnostou & Taylor, 2011). The focus of research into biomarkers has been on explaining the mechanisms that create the abnormalities associated with ASD in the hope of assisting in early identification, predicting risk and course, defining subgroups, and predicting treatment response. Genetic, biochemical, neuropsychological, neurophysiological and neuroimaging measures have been investigated and, at times, proposed various (often replicated)

biomarkers for autism (Cicchetti & Toth, 2009; Gottlieb, 2007; Yordanova, Kolev, Kirov, & Rothenberg, 2010).

Despite inconsistencies in the findings from Structural Magnetic Resonance Imagery (MRI) studies, there is some indication that volume anomalies in both grey and white brain matter exists in ASD, with identification of several region-specific differences. Early brain overgrowth appears to be the most replicated finding in a subgroup of people with ASD, and new techniques, such as cortical-thickness measurements and surface morphometry have begun to elucidate in more detail the patterns of abnormalities as they evolve with age, and are implicating specific neurodevelopmental processes (Amaral, Schumann, & Nordahl, 2008; Giedd et al., 1999; Herbert et al., 2003; Stanfield et al., 2007).

There has been much heterogeneity in the manifestation of core ASD features, varied occurrence of significant co-morbid conditions and generally small sample sizes for both MRI and post-mortem studies of ASD and these participant-oriented limitations are believed to have contributed to poor replication of findings across research groups (Anagnostou & Taylor, 2011). Researchers such as Happé's (1999) and Happé and Frith (2006) have argued that a more clear-cut pathology is likely to emerge once distinct phenotypes of the disorder are factored into the analysis of results. Furthermore, the variation in the ASD manifestation of core features was clearly identified, indicating that the heterogeneity within ASD is an inevitable consequence of the numerous differences along at least three fundamentally independent and interrelated dimensions of this disorder, known as social and communication difficulties, and repetitive and restricted behaviour and interests. Past research has acknowledged that seemingly simpler dimensions of ASD can themselves be quite complex genetically and biologically (Fisher, 2006; Naples, Katz & Grigorenko, 2012; Skuse & Gallagher, 2011).

Recently, a number of studies have analysed connectivity differences between subjects with autism spectrum disorders and typically developing control subjects in the absence of an overt task, while subjects were at rest (Müller et al., 2011). In resting-state functional connectivity studies (Fox & Raichle, 2007), correlations across brain regions reflect the covariation of spontaneous or internally generated brain activity. Spatially specific patterns of correlation in such studies are strongly, although not exclusively, influenced by anatomical connectivity (Honey et al., 2009) and exist independently of explicit thought in so far as they can be observed in anaesthetized monkeys and humans during sleep (Larson-Prior et al., 2009; Margulies et al., 2009). Several studies have demonstrated reduced correlation in autism spectrum disorders among regions of the so-called 'default' network (Kennedy & Courchesne, 2008; Monk et al., 2009), which overlap largely, but not completely, with social brain regions (Simmons & Martin, 2011). However, like task-based functional connectivity studies, resting-state studies of autism spectrum disorders have only evaluated a handful of seed locations in any individual study (Gotts et al., 2012).

2.1.2. Evolution of diagnostic criteria for ASD in the Statistical Manual of Mental Disorders (DSM).

This discussion on how conceptualisations and definitions of autism have been shaped over time will refer primarily to the diagnostic criteria and evaluation guidelines set out in the various editions of the Diagnostic Statistical Manual (DSM). This decision has been taken to reflect the diagnostic practices of Australia which are almost exclusively guided by the DSM.

Autism was first introduced as a distinct disorder of early childhood in the third edition of the DSM (APA, 1980), and was referred to as "Infantile Autism" (IA). The DMS-III (APA, 1980) presented six diagnostic criteria for IA and required that the child show early and pervasive evidence on all of the following diagnostic criteria: 1) pervasive lack of

responsiveness to other people; 2) gross deficits in language development; 3) peculiar speech patterns, if speech is present at all; 4) bizarre responses to the environment; and 5) an absence of delusions, hallucinations, loosening of associations, and incoherence as in schizophrenia; and 6) early onset (prior to thirty months) of criterion 1-5 impairments. These early DSM criteria, whilst representing formal recognition of the existence of autism, were also criticised because they primarily accounted for children exhibiting symptomatology close to birth, causing poor identification of the subgroup of children who experienced a loss of skills after some years of normal development (Volkmar, Cohen, & Paul, 1986; Wing, 1981). This diagnostic limitation was addressed in the DSM-III-R (APA, 1987) which maintained the IA diagnosis for children with early-onset neurological impairment and introduced the additional label of Regressive Autism (RA) to account for those cases in which deterioration of functional skill was evident. This inclusion of two diagnoses was significant as it provided the first acknowledgement that autism was not a single condition (APA, 1987). However, the DSM-III-R (APA, 1987) was also criticised because the diagnostic criteria for IA and RA were considered to be too narrow to account for the full range of symptoms/behaviours shown by children with autism, especially those who were high functioning.

The DSM-IV/DSM-IV-TR (APA, 1994/2000) sought to rectify this limitation by introducing a broad classification (i.e., Pervasive Developmental Disorder) which encompassed five specific diagnoses (i.e., Autistic Disorder, Pervasive Developmental Disorder-Not Otherwise Specified, Asperger's Disorder, Rett's Disorder, and Childhood Disintegrative Disorder). The DSM-IV/DSM-IV-TR formally introduced the diagnosis of Asperger's Syndrome as the diagnosis that would account for individuals with age-appropriate language and intelligence but atypical socialisation and adaptive skills.

The DSM-IV-TR (APA, 2000) used the "triad of impairment model" as the basis for establishing the diagnostic criteria for autism disorder. That model, which was developed by

Wing and Gould (1979), argued that autism could be identified by evidence of delayed development in reciprocal social interaction [i.e., poor eye contact and inability to engage in joint attention] (Hobson & Lee, 1999; Wimpory, Hobson, Williams, & Nash, 2000) (Criterion A); language and functional communication [i.e., poor person-to-person non-verbal communication of literal speech, and language comprehension difficulties] (Wimpory, et al., 2000) (Criterion B); as well as the presence of restricted and repetitive behaviours, interests and activities [i.e., hand flapping, complex and simple tics, and repetitive use of objects] (Canitano & Scandurra, 2011) (Criterion C). For an individual to receive a diagnosis of Autistic Disorder, a total of at least two items from the section on impairment in social interaction had to be selected. One item or more for the section on impairment in communication had to be identified. A minimum of one item from the section on restricted, repetitive and stereotyped patterns of behaviour, interests and activities needed to be identified. Furthermore, symptoms will have to be present during the early developmental period, at approximately three years old or younger. These areas comprised social interactions, language used in social communication, and symbolic or imaginative play.

The DSM-IV-TR (APA, 2000) has been credited with advancing the diagnostic field by aiding differentiation of subgroups via provision of specific diagnostic labels (Wimpory et al., 2000), including Asperger's Disorder to account for cases of high-functioning autism (Wimpory et al., 2000), and expanding the diagnostic criteria within the autism label to capture the intra-label heterogeneity discussed in the research (Canitano & Scandurra, 2011). Further, the DSM-IV-TR (APA, 2000) contributed to creation of the "autism spectrum" via provision of three related diagnoses (i.e., Autistic Disorder, Asperger's Syndrome and PDD-NOS). However, clinical researchers argued that the DSM-IV-TR (APA, 2000) required substantial revision because it did not effectively capture the wide range of variation in symptoms which represented the autism spectrum, nor did it include the full constellation of

difficulties (e.g., hypersensitivity to sensory stimuli in the environment, restricted diet, and poor sleeping patterns) which disrupt daily functioning and require clinical attention (Schuler & Fletcher, 2002; Tidmarsh & Volkmar, 2003).

2.2. Current conceptualisation of autism-related conditions.

The latest DSM-5 (APA, 2013) contains a number of changes to the criteria for detecting autism as well as the procedures for determining the severity of autism impairments. General alterations in classification focus have involved replacement of the PDD category with ASD; and the removal of specific diagnostic labels presented in the DSM-IV-TR (APA, 2000). These changes were driven by research which suggested that the previous diagnoses did not represent clearly differentiated autism subtypes and nor did they account for the variation presentation of symptoms (Waterhouse, 2013). In addition to offering one broad diagnostic category (i.e., ASD) to account for range of autism-based subgroups, the DSM-5 (APA, 2013) has incorporated research-driven refinement to the specific diagnostic criteria by: recognising that autism impairments (whilst being present prior to 36 months of age) might not become evident until social demands exceed the child's social competencies; collapsing the DSM-IV-TR Criteria A and B into one criterion which refers to impairments in social communication and social interaction; formally acknowledging the presence of hyper- and/or hypo-responsiveness to sensory stimuli as a key deficit in ASD; and further elaborating on interference in daily functioning via allocation of an autism severity level which ranges from 1 "requiring support", 2 "requiring substantial support", to 3 "requiring very substantial support".

The accuracy with which the DSM-5 was capable of identifying cases of ASD was examined via a number of validation studies that employed the proposed ASD criteria released in 2011. Frazier and colleagues (2012) analysed symptoms from 14,744 siblings

(8,911 ASD; 5,863 non-ASD), ranging in ages from two to 18 years. Caregivers reported on frequency of symptoms using the Social Responsiveness Scale and the Social Communication Questionnaire. Diagnostic efficiency statistics evaluated the proposed DSM-5 algorithm in identifying ASD. Empirical classifications from this hybrid model closely mirrored clinical ASD diagnoses (with a 90% overlap), implying that the DSM-5 criteria encompassed a broad ASD category distinct from non-ASD. Moreover, the DSM-5 criteria had greater diagnostic specificity relative to DSM-IV-TR criteria (Frazier et al., 2012). Another study conducted by Huerta, Bishop, Duncan, Hus, and Lord (2012) evaluated the proposed DSM-5 criteria for the single diagnostic category of ASD in over 4,000 children with a pre-existing DSM-IV-TR diagnoses of Pervasive Developmental Disorders (PDDs) and non-PDD diagnoses. Based on the data obtained from parents, the proposed DSM-5 criteria identified 91% of children with DSM-IV PDD diagnoses, suggesting that most children with DSM-IV PDD diagnoses would remain eligible for ASD diagnosis under the proposed DSM-5 criteria (Huerta et al., 2012). Studies such as these suggest that the DSM-5 diagnostic criteria provide a robust basis for accurately identifying the presence of ASD, but this finding is not uniformly confirmed in the research.

Contradictory results have been reported by Kulage, Smaldone and Cohn (2014), who conducted a systematic review and meta-analysis to determine the effect of changes to the DSM-5 (APA, 2013) on ASD detection. The findings revealed that 14 previous studies consistently reported decreases in previously-made ASD diagnosis using DSM-5 criteria. There were statistically significant pooled decreases in ASD and DSM-IV-TR subgroups of Autistic Disorder and PDD-NOS. However, the pooled decrease for previously-diagnosed Asperger's Syndrome was not significant. The researchers predicted that the DSM-5 would likely decrease the number of individuals diagnosed with ASD, particularly individuals

within the PDD-NOS subgroup. Similar findings were noted in a study by McPartland, Reichow and Volkmar (2012) who analysed the results from 933 participants evaluated during the DSM-5 field trial (APA, 2013). Their findings indicated that, whilst showing sound sensitivity, the DSM-5 (APA, 2013) risked exclusion of a portion of individuals with good cognitive abilities.

The DMS-5 (APA, 2013) revisions are believed by some researchers (Baron-Cohen, Golan, Wheelwright, & Hill, 2004; Huerta et al., 2012) to provide a sound basis for more specific, reliable, and valid diagnoses of ASD. These revisions have been made in the hope of providing more specific, reliable and valid diagnoses of ASD. For instance, clinical researchers such as Baron-Cohen and colleagues (2004) have argued that these revisions are necessary to accurately reflect the wide range of impairments and behaviour profiles seen in individual children on the autism spectrum. However, there are also some genuine concerns regarding the potential for those revisions to adversely impact individuals previously diagnosed with Asperger's disorder and PDD-NOS. One of the most recurrent concerns is that some higher functioning individuals, will no longer meet the requirements of the stricter diagnostic criteria, and consequently experience greater barriers in accessing services that would benefit them greatly (Compart, 2012). Other researchers (Mattila et al., 2011; Wing, Gould, & Gillberg, 2011) have proposed that the changes to the DSM-5 will decrease the accuracy with which high-functioning children are identified. This research team applied the draft of the DSM-V diagnostic criteria for ASD to 26 children with an autism condition (confirmed by their ADI-R and ADOS scores) and reported that the DSM-5 criteria were not of sufficient sensitivity to more able children with well-developed communication and few of stereotyped and repetitive behaviours.

In addition, there is ambiguity regarding how state and educational services, and insurance companies will adopt the changes proposed by the DSM-5. It seems evident that these changes will have an impact on families and people currently diagnosed with ASD. It remains to be seen how diagnosticians and clinicians will utilise the new criteria in evaluating children and the impact it will have on the availability of services provided. The DSM-5 criteria (like DSM-IV-TR) do not mention the lack of imagination leading to the inability to foresee the consequences of one's actions for oneself or for others. This is perhaps the problem that leads to the most severe social difficulties for the person with autism spectrum conditions and those involved with him/her. This should certainly be included in DSM-5. The third criterion in the DSM-5 draft is "Symptoms present in early childhood" (but may not become fully manifest until social demands exceed limited capacities). The problems of social interaction are present from birth in individuals with any autism spectrum disorder (unless a condition such as encephalitis or a brain injury at some time after birth leads to autistic behaviour). However, it needs an experienced observer (or a very observant parent) to recognise the earliest signs in infants. The problem in clinical work is that individuals presenting for the first time in later childhood, adolescence or adult life may not have anyone who knew them in early childhood to give an accurate history, or, in other cases, the informant is unable, for various reasons, to give a clear and accurate picture of the early years. If the DSM-5 is accepted in its present form, individuals in this situation may be denied appropriate help (Wing et al., 2011). It seems evident that these changes will have an impact on families and people currently diagnosed with ASD. It remains to be seen how diagnosticians and clinicians will utilise the new criteria in evaluating children and the impact it will have on the availability of services provided.

2.3. Factors leading to variation in ASD symptom presentation and daily functioning.

In addition to the primary impairments discussed on pages 13-16 of this thesis (which are currently required for a diagnosis of ASD), children with ASD have been reported to experience a range of additional difficulties (i.e., attention, behaviour, eating and sleeping patterns) which adversely impact their functioning. Those difficulties are often the cause of clinical referral, and if they are not understood and effectively treated, can cause exacerbation of autism-based impairments. Therefore, timely identification and remediation of such secondary difficulties is significant to improving the overall functioning of children with ASD. The discussion which follows, describes the secondary difficulties that are most commonly associated with ASD in an effort to provide a more holistic understanding of the overall profile of individuals on the autism spectrum. Reference will also be made to the relative strengths and talents which exist for those individuals. This discussion acknowledges the inter-individual differences in secondary difficulties and strengths/talents, and intends only to provide a broad profile.

Although secondary impairments can vary from one child to the next, it is usual for children on the autism spectrum to show evidence of poor attention, especially during social situations involving peers (Aman et al., 2009; Baranek, 1999). Poor attention has been identified as one precursor for the poor and/or atypical social responses and incapacity to identify salient social stimuli which is often seen in children with ASD. Aman and colleagues (2009) suggested that approximately 50% of children with ASD were affected by a short attention span, and this was believed to prevent them from extracting meaning from and responding to their social environment. Interestingly, Baranek (1999) reported a link between poor attention in one year old children and a risk of exhibiting autism-based impairments in

early childhood. In this study, approximately 65% of the parents of children with ASD reported that their child was prone to losing contact with their social environment, tuning out, and appearing to be in "*a world of his/her own*" at age of one (Baranek, 1999).

Several researchers (Bromley, Hare, Davison, & Emerson, 2004; Koydemir-Özden & Tosun, 2010; Souders, Freeman, DePaul, & Levy, 2002) have argued that the core communication and social interaction impairments required for ASD diagnosis predisposed children to engage in challenging behaviours, such as severe tantrums, aggression, and self-injury. Self-injurious behaviours were estimated to occur in up to 50% of children with ASD, with 15% of children exhibiting severe self-injury (Baghdadli, Pascal, Grisi, & Aussilloux, 2003). Matson et al. (2011) reported a relationship between the severity of self-injurious and stereotypic behaviours in children with ASD; and their degree of social and communication impairment, with children who showed a higher degree of social and communication impairment being at greater risk of engaging in self-injurious behaviours. Additionally, Browne (2006) revealed that children who lacked communication skills were often frustrated or even frightened by events in their immediate environment and these maladaptive behaviours acted as a mean for communicating such feelings. Findings such as these emphasise the inter-relationships between core ASD impairments and onset of secondary difficulties by suggesting that the former appear to be precursors for the latter.

Another area of interest in research investigated the symptoms and the affects these symptoms have on daily functioning in relation to severity level. Restricted, repetitive, and stereotyped patterns of behaviour were identified in previous research as key features of ASD and were believed to reflect a failure of inhibition and cognitive rigidity (Turner, 1997). In a study conducted by Militerni, Bravaccio, Flaco, Fico, and Palermo (2002) restricted and repetitive behaviours observed in ASD were described as being heterogeneous and seemed to

vary according to the developmental level and cognitive ability of the individual with ASD. For instance, higher functioning autistic individuals could display more insistence on sameness compared to individuals diagnosed with Asperger's disorder who on the other hand demonstrated a higher level of restricted interests (Ozonoff, South, & Miller, 2000). However, Militerni and colleagues (2002) noted that younger and lower functioning autistic individuals exhibited more often motor stereotypies such as hand flapping and rocking. These different behaviours were believed to reflect executive dysfunction in individuals with ASD.

Disturbances to sleep and eating patterns have been shown to occur regularly in individuals with ASD (Bauman, 2010; Matson & Cervantes, 2014). For instance, a study conducted by Souders and colleagues (2009) revealed that 66% of children with ASD experienced moderate sleep disturbances, with the predominant sleep disturbance being referred to as "behavioural insomnia sleep-onset" (Souders et al., 2009). Two other studies conducted with children with ASD reported that difficulties relating to falling asleep and sleep walking were the most common sleep difficulties identified by parents (Richdale & Schreck, 2009; Malow &McGrew, 2008). The aetiology of sleep difficulties in children with ASD is viewed as being multifactorial, comprising possible circadian rhythms disturbances and issues with melatonin regulation and sleep hygiene (Richdale & Schreck, 2009; Johnson & Malow, 2008). Even though the vast majority of research to address sleep problems in children with ASD has focused on the factors mentioned so far, another line of research has explored the impact that hyperarousal might have on sleep problems. White and colleagues (2009) have suggested that children with ASD are at increased risk of experiencing both anxiety and sensory over-responsivity (Watling, Deitz & White, 2001). The relationship between anxiety and sleep problems in children with ASD has been extensively investigated, with researchers such as Wiggs and Stores (2004) reporting that anxiety-related night time

behaviours and sleep disturbances were commonly observed in the sample of children with ASD they had examined. Moreover, anxiety was linked to insomnia in a study conducted with adults who received a diagnosis of Asperger's Disorder (Tani et al., 2004).

Disturbances to eating behaviour and pattern in children with ASD have generally been studied within the context of "*food selectivity*" which is a broad term that encompasses preferences for certain food at the expense of others, food refusal/aversion and a high-frequency of single food intake (Marí-Bauset, Zazpe, Mari-Sanchis, Llopis-González, & Molares-Suárez-Varela, 2013). There is evidence of higher prevalence of food selectivity in individuals with ASD compared to other individuals. For example, Bandini and colleagues (2010) noted that approximately 42% of children with ASD rejected food regularly compared to 19% for TD children. Furthermore, Schmitt, Heiss, and Campbell (2008) revealed that 70% of children with ASD selected the food they consumed according to the food's texture when only 11% of individuals without ASD engaged in the same behaviour. A large amount of studies has shown that children with ASD have selective dietary preferences, suggesting that they are at increased risk of experiencing nutritional deficiencies that could affect in term their anthropometrical dimensions (Marí-Bauset et al., 2013; Najdowski, Wallace, Doney, & Ghezzi, 2003; Zimmer et al., 2012).

The existence and detrimental effects (to functioning) of allergic responses on the daily functioning of individuals with ASD has received growing attention in the research over the past decade. Boso and colleagues (2010) found that young adults with ASD experienced worsened allergic symptoms at times when allergy seasons typically peaked, which in time resulted in escalation to behavioural difficulties. Furthermore, Sacco and colleagues (2010) identified a significant association between ASD diagnosis and a history of allergies. Fortuna and colleagues (2015) reported that compared to the neurotypical population, young adults

with ASD (between the ages of eighteen to twenty-nine years old) experienced a higher prevalence of allergies, with approximately 32% of them stating they suffered from one or more allergies compared to 8% for neurotypical individuals. A recent study revealed that about 87% of individuals with Asperger's Syndrome experienced immune allergic responses such as rhinitis, asthma, and atopic dermatitis (Magalhaes et al., 2009).

The historical focus has been on examination of core ASD symptoms plus secondary difficulties in relation to their detrimental impacts on daily functioning and long-term adaptation. Whilst this line of research has advanced understanding of the autism-related barriers to functioning it has neglected to recognise that ASD is associated with a number of strengths, capabilities and talents. More recent researchers have addresses the "positives of ASD" and the following discussion briefly describes these. Semantic fluency acknowledged as a relative strength for high functioning individuals with ASD. Researchers have noted that children with Asperger's Disorder generated as many words from a given category when compared to TD children (Boucher, 1988; Dunn, Gomes, & Sebastian, 1996; Manjiviona & Prior, 1999), even when those categories included an increased number of unusual category members (i.e. "yak" for animal) than what was predicted (Dunn et al., 1996). Turner (1999) found that people with HFA performed adequately in a nonverbal fluency test, considered to be a measure of the ability to generate novel designs. Hermelin (2001) and Howlin, Goode, Hutton, and Rutter (2009) reported that 'savantism' is more common in individuals with ASD with the estimated prevalence being 10 percent and one percent respectively. The term savant refers to an exceptional ability which is not present in the general population with such abilities having been identified in the areas of mathematical calculation, memory, art, and music (Treffert, 2009). Howlin and colleagues (2009) conducted a study in which the cognitive skills of individuals with ASD were assessed via performance on the Wechsler

Intelligence Scales and reported that about 29% of one 137 individuals showed strong evidence of either a savant skill and/or a superior cognitive ability (Howlin et al., 2009).

Interestingly, the presence of extraordinary musical memory was first commented on by Kanner (1943) in relation to the first group of children he assessed. Subsequent studies suggested that excellent musical memory was linked to knowledge about musical structure (Miller, 1989; Pring, Woolf & Tadic, 2008) and absolute pitch (Heaton, 2003). A generally agreed-upon research finding indicates that individuals with ASD demonstrate greater accuracy in processing the musical notes they hear (across the age range), causing them to surpass their neurotypical peers in memory of pitch. (Heaton, 2009).

It has been argued that individuals with ASD typically utilise a more detailed-focused processing style compared to neurotypical people (Heaton, 2009). Brown and colleagues (2003) discovered a link between autistic-like traits and special skills amongst musicians with absolute pitch when compared to musicians without such ability. Vital, Ronald, Wallace, and Happé (2009) reported on the results of a parent survey study which showed that children with special abilities possessed more autistic-like traits than children without such abilities. More specifically non-social autistic-like traits, restricted and repetitive interests/activities were strongly associated with special abilities (Vital et al., 2009). There is some evidence suggesting that a detailed-focused cognitive style, relating to attention to and memory for detail, predisposed children with ASD to being talented. Furthermore, those children's general cognitive aptitudes correlated with parental reports of special abilities in memory and mathematics. Such result has been substantiated by more recent conceptualisations of savantism, believed to accommodate HFA individuals (Heaton & Wallace, 2004; Miller, 1998).

An ever-expanding body of research shows that individuals with ASD outperform their typically-developing peers in a large range of perception tasks, such as spotting a pattern in a disrupting setting (Pellicano, Maybery, Durkin, & Maley, 2006). Further studies highlighted the fact that individuals with ASD outperformed TD individuals in auditory activities, such as discerning sound pitches (Heaton, 2003), detecting visual structures (Perreault, Gurnsey, Dawson, Mottron, Bertone, 2011) and mentally manipulating complex three-dimensional forms. It appears to also be the case that individuals with ASD do better non-verbal intelligence tests such as the Ravens Progressive Matrices (RPM) in which participants are required to use analytical skills to complete an ongoing visual pattern, with an experimental study by Soulières et al. (2009) showing that individuals with ASD completed the RPM an average of 40% faster than a non-ASD comparison group.

2.4. Comorbid disorders.

The research is clear on the issue of individuals with ASD also showing evidence of one or more additional co-existing behavioural, psychiatric, or developmental disorders (Cath, Ran, Smit, van Balkom, & Comijs, 2008). Comorbid disorders (i.e., anxiety and depression) are known to contribute to the severity of ASD features and to create further interference in daily functioning (Bellini 2004). Therefore, accurate and timely detection of co-existing conditions is significant to understanding ASD individuals' needs and development of targeted treatment plans.

It is suggested that there is temporal aspect to the onset of particular co-existing disorders with particular conditions being likely to occur during specific life periods. ASD common co-occurring disorders in late childhood include attention deficit hyperactivity disorder (ADHD), oppositional defiant disorder (ODD) and anxiety disorders, with emergence of depression and obsessive compulsive disorder in adolescence/adult life

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(Mazefsky et al. 2008; Simonoff et al. 2008; Skokauskas, Gallagher, Skokauskas, & Gallagher, 2010; van Steensel, Bögels, & de Bruin, 2013). A longitudinal study of youth and adults with ASD (aged 10-52 years) reported reductions in parent reported child internalizing symptoms over a 4.5-year period (Shattuck et al., 2007); suggesting that symptoms of sadness and withdrawal in individuals with ASD may lessen, not worsen, with development. While adolescents and young adults with ASD may have more insight than young children with ASD, and therefore, be more capable of conveying their emotional problems (Ehlers & Gillberg, 1993), it does not necessarily mean that younger children do not experience depressive symptoms. It makes clinical sense that while younger children with ASD might not be able to explain their emotional difficulties to the same extent as older youth; it is plausible that both age groups would struggle to explain emotional difficulties due to their autism related communication impairments (Strang et al., 2012). Further, it is suggested that anxiety disorder appears to decrease from childhood to adulthood (Davis et al., 2011) and depression increases with age (Ghaziuddin, Ghaziuddin, & Greden, 2002).

There is strong evidential support that children with ASD also suffer from anxiety (Gillot, Furniss, & Walter, 2001); depression (Lainhart & Folstein, 1994; Perry et al., 2001; Stewart, Barnard, Pearson, Hasan, & O'Brien, 2006); and Obsessive-Compulsive Disorder (OCD) (Gross-Isseroff, Hermesh, & Weizman, 2001; McDougle et al., 1995; Russell, Mataix-Cols, Anson, & Murphy, 2005). Several recent studies have indicated that a significant number of children with ASD have at least one comorbid anxiety disorder, with statistics ranging from 29% to 84% of individuals who are affected by ASD and some form of anxiety (De Bruin, Ferdinand, Meester, De Nijs, & Verheij, 2007; Muris, Steerneman, Merckelbach, Holdrinet, & Meesters, 1998; Simonoff et al., 2008). For instance, Cath and colleagues (2008) reported that individuals with ASD showed similar levels of general

anxiety symptoms, and had equivalent levels of social anxiety to those individuals with a diagnosis of Social Anxiety Disorder (SAD) but not ASD.

A systematic review by van Steensel, Bögels, and Perrin (2011) reported considerable comorbidity for anxiety in children and adolescents with ASD. It was estimated that about 40% of children and adolescents with ASD had clinical levels of anxiety or at least one anxiety disorder, and these substantiate those of previous research such as White, Oswald, Ollendick, & Scahill (2009). The study conducted by van Steensel and colleagues (2011), indicated that nearly 30% of children ASD suffered also from specific phobia, 17% suffered from OCD and SAD, 15% experienced Generalized Anxiety Disorder (GAD), 9% had Anxiety Disorder (AD) and only 2% experienced panic disorder. Avoidant and depressive and/or worrisome symptoms were considerably higher in children with ASD signifying a high level of comorbidity with anxiety disorders (Muris et al., 1998).

A number of studies have noted that children with ASD may suffer from other co-existing developmental or psychiatric disorders. Meyer, Mundy, Van Hecke, and Durocher (2006) mentioned that many children with HFA lack social and emotional reciprocity, have trouble maintaining eye contact, and have difficulty initiating and sustaining conversations. Often times, they misread social cues and misunderstand others' intentions (Meyer et al., 2006). They have difficulties with recognizing sarcasm and social faux pas (Baron-Cohen & Wheelwright, 1999; Kaland, Callesen, Moller-Nielsen, Mortensen, & Smith, 2008). When children with HFA also have an anxiety disorder, it may further impact their ability to interact with other children. Past studies have found positive correlations between social impairment and anxiety in children with ASD (Bellini 2004; Sukhodolsky et al. 2008), but these studies lacked diagnostic anxiety measures, instead relying on anxiety checklists completed by children or parents. The findings from the study conducted by Chang, Quan, and Wood (2012)

suggested that social anxiety in particular may be more impairing to social functioning in children with ASD than other anxiety disorders. However, the participants of these studies often do not have a formal diagnosis of anxiety disorder and anxiety level is established via completion of anxiety checklists, results such as these should be considered with caution.

Interestingly, there is minimal agreement on the age at which anxiety might peak and trough in individuals with ASD. There are contradictory results for the relationship between anxiety, age and ASD severity, with some studies (Kuusikko et al., 2008; Lecavalier, 2006) suggesting that older children with ASD were more likely to report anxiety, while other studies reported no age differences (Ando & Yoshimura 1979; Pea It is conceivable that the non-uniformity of these results is (in part) a consequence of variations in the specific anxiety subtype under investigation. These findings are consistent with the results of studies examining anxiety disorders in typically developing children, which discovered that rates of anxiety disorders typically increased with age (Ford, Goodman, & Meltzer, 2003); rates of GAD increased with age (Frala, Leen-Feldner, Blumenthal, & Baretto, 2010; Tracey, Chorpita, Douban, & Barlow, 1997); and rates of separation anxiety disorder were linked with a lower mean age (Kearney, Sims, Pursell, & Tillotson, 2003; Last, Perrin, Hersen, & Kazdin, 1992). Interestingly studies that included younger children with ASD reported higher prevalence rates of OCD than those that included older children with ASD. OCD in typically developing children, however, tends to have a relatively late age onset (Costello, Egger, & Angold, 2005) and is found to increase with age (Ford et al., 2003).

Research investigating depression in individuals with ASD suggests that high rates of depression range from 17 and 44%, depending on the age of the sample and measures used (Green, Gilchrist, Burton, & Cox, 2000; Kim, Szatmari, Bryson, Streiner, & Wilson, 2000; Strang et al. 2012). Lugnegård, Hallerbäck, and Gillberg (2011) conducted structured clinical

interviews with 54 adults with ASD, and reported that 70% had at least one major depressive episode in their lifetime, whilst 50% had recurring depressive episodes across the lifetime. Furthermore, suicidal behaviour amongst adolescents and young adults with ASD has been found to range from 7 to 42% (Hannon & Taylor, 2013), as opposed to 4 to 8% in TD adolescents and young adults (Cash & Bridge, 2009; Gmitrowiez, Szymczak, Kotlieka-Anezak, & Rabe-Jablonska, 2003; Resch, Parzer, & Romuald, 2008). Mazefsky and White (2014) discussed the characteristics of ASD that may hinder the emotion regulation needed to avoid onset of depression and pointed to processes such as, poor inhibition and problem solving, change inhibition, sensory sensitivities, and poor cognitive flexibility as contributors depressive events (Gyurak et al., 2009).

Sturm, Fernell, and Gillberg (2004) have noted that ASD is frequently associated with Attention Deficit Hyperactivity Disorder (ADHD). Holtmann, Bolte, and Postka (2007) reported that 30 to 80 per cent of children in their sample who were diagnosed with ASD also met the criteria for ADHD. Also, those researchers noted that children with ADHD appeared to exhibit significantly more symptoms of ASD than their typically-developing siblings (Mulligan et al., 2009). Leyfer and colleagues (2006) explained that 31% of children with HFA also met the criteria for an ADHD diagnosis. Approximately 24% of children with HFA experienced hyperactive symptoms as well as higher inattentiveness.

There appears to be substantial crossover of impairments and behavioural features between individuals with ASD and those diagnosed with ADHD, and this caused clinical challenge in differentiating between the two disorders (Clark, Feehan, Tinline, & Vostanis, 1999; Leyfer et al., 2006; Lovell, Moss, & Wetherell, 2012; Matsushima et al., 2008) Nonetheless, Poon (2012) advanced the theory that co-morbid psychopathology may escalate challenging behaviours in infants and toddlers diagnosed with ASD. For instance, Matson

and colleagues (2011) found that children with ASD, who typically exhibited aggressive and destructive behaviours, possessed higher levels of impulsivity and inattention than children with ASD who did not engage in such behaviours. Generally, greater levels of externalizing behaviours in children with ASD and ADHD were noted when compared to children with only a diagnosis of ASD or TD children (Yerys et al., 2009). With regards to children with ADHD, Tureck and colleagues (2013) discovered that children with ADHD presented with high rates of repetitive behaviours, tantrum behaviours, in addition to conduct behaviours when compared to children in the control group. Furthermore, this current study also established significantly high rates of internalizing and externalizing symptoms for both children with ADHD and children with ASD. However, the highest rates were noted for children diagnosed with ASD (Tureck et al., 2013). Significant rates of oppositional behaviour disorder (as opposed to conduct disorder) are suggested for children with ASD across studies and research groups (Chung, Luk, & Lee, 1990; Simonoff et al., 2008; Steinhausen & Merzke, 2004).

There are two major theories which attempt to explain the basis of these broad autistic impairments in cognitive terms. The theory of weak central coherence (Frith, 2003) suggested that people with autism are more inclined to process information in discrete units as opposed to perceiving integrated units as a larger whole. Thus, autistic individuals are faster and more accurate at seeing embedded figures within a more complex whole pattern (Mottron, Burack, Iarocci, Belleville, & Enns, 2003; Shah & Frith, 1983) and at matching whole patterns presented to them by arranging blocks of their constituent parts (Shah & Frith, 1993). This is in contrast to people with strong central coherence who have a preference for seeing the ''whole picture'' rather than composite features. Executive dysfunction theory (Hughes, Russell, & Robbins, 1994) posits that autistic individuals are primarily compromised in their

ability to control, manage and monitor simultaneous cognitive processes. Whilst each of these theories provides evidence of characteristic cognitive traits in autism, each is limited in its ability to explain the spectrum of autistic features and impairments and the neurophysiological basis of the disorder. The interrelationship between these cognitive traits and their causal relationship with the behavioural impairments in autistic spectrum disorder (ASD) remain a subject of debate, not least because of the widely differing level and range of ability in individuals within the spectrum. Assessing the prevalence and impact of cognitive traits in autism is particularly problematic as general intellectual impairment is common in ASD.

Research findings noted that 70% of individuals diagnosed with ASD have an IQ of less than 70 (Chakrabarti & Fombonne, 2005) and 30–40% of individuals with Intellectual Impairment meet criteria for ASD (Morgan et al., 2002). In the broader set of disorders included under the term pervasive developmental disorder (PDD), where behavioural and communication difficulties characteristic of autism are present but not to the extent that the criteria for a diagnosis of autism are met, assessing autistic traits is yet more problematic. Here, there may be further confounding factors from the inclusion of disorders which share some of the features of autism and are also associated with intellectual disability.

A relationship between social symptoms and metacognitive executive processes, like planning, organisational and monitoring skills, initiation, in addition to working memory, was different in children between six to fifteen years old diagnosed with ASD and not characteristic of the TD children. Therefore, stronger metacognitive aptitudes were related to less autistic social symptoms. Consequently, social symptoms of ASD seem to be linked to a precise set of executive functions (i.e., metacognitive skills) in which deficiencies have been noted (Geurts, de Vries, & van den Bergh, 2014). For example, Turner (1999) identified

deficiencies in ASD children aptitude to independently produce new ideas or information. Other researchers noted deficiencies in the ability to hold information "online" in the mind while carrying out an activity (Luna, Doll, Hegedus, Minshew, & Sweeney, 2007), decreased abilities in planning and/or organizational skills (Sumiyoshi, Kawakubo, Suga, Sumiyoshi, & Kasai, 2011), and self-monitoring (Grynszpan et al., 2012; Lombardo, Barnes, Wheelwright, & Baron-Cohen, 2007). A study conducted by Leung, Vogan, Powell, Anagnostou, and Taylor (2016) revealed that metacognitive deficits and behavioural regulation problems predicted social impairment in ASD children aged six to fifteen years old. This research proposed that children and adolescents with ASD may require more extensive usage of decision-making functions for social abilities compared to TD children and teenagers. The presence of co-occurring disorders in children with ASD is associated with lower quality of life, greater demands for professional help, poorer prognosis, greater interference with everyday life, and worse outcome (Lainhart, 1999; Matson & Cervantes, 2014; Seltzer, Abbeduto, Krauss, Greenberg, & Swe, 2004; Vannucchi et al., 2014; Wood & Gadow, 2010).

3. Challenges Faced by Parents of Children with ASD Compared to Parents of Typically Developing Children

Parents of children with ASD face a particular set of challenges that cause them to experience significant difficulties compared to other parent groups. Overall, the psychological impact of caring for a child with ASD is reported to be immense for parents (Cullen & Barlow, 2002). Parents of a child with ASD reported more stress compared to parents of Typically Developing (TD) children and were nearly three times as vulnerable to psychological ill health and distress (Brobst, Clopton, & Hendrick, 2009; Dillenburger, Keenan, Doherty, Byrne, & Gallagher, 2010; Gau et al., 2012). The first study to determine that parents (*n*=67) and siblings (*n*=37) of children with ASD obtained significantly higher scores of depression compared to parents and siblings of TD children was conducted by Piven and colleagues (1990). Any irregularities or disruptions in daily routines triggered anxiety in children with ASD and their mothers, the children's inability to participate in activities, resistance, and disruptive behaviours triggered anxiety in mothers (Larson, 2006). The ASD children's disruptive behaviours or autistic symptoms seemed to be significant determinant in parents' mental health status, with parents experiencing lower levels of distress as their child's behaviour improved over time and became less disruptive (Gray, 2006; Hoffman, Sweeney, Hodge, Lopez-Wagner, & Looney, 2009).

Kring, Greenberg, and Seltzer (2010) conducted a study with 406 mothers of children with ASD of various ages. The results indicated that children's health issues were a direct source of stress for mothers as such issues in children usually led to behavioural problems, which increased the mothers' stress levels. Approximately 41% of parents of a child with ASD reported experiencing some form of emotional, physical, financial, or marital relationship stress difficulties compared to parents of TD children (Higgins, Bailey & Pearce,

2005; Lecavalier, Leone, & Wiltz, 2006). A study conducted by Ingersoll and Hambrick (2011) revealed that 56% of parents of eight-year-old children with ASD obtained significant scores in depression and 85% of parents scored in the clinically significant range for parenting stress. It appeared that mothers and fathers of a child with ASD were affected differently in their mental health status, with mothers being more negatively affected by their child's impairment than fathers (Ekas, Lickenbrock, & Whitman, 2010). Similar results were observed in a study conducted by Davis and Carter (2008), in which more mothers (33%) of toddlers diagnosed with ASD than fathers (17%) reported clinically significant depressive symptoms. Furthermore, mothers who did not have a husband or a partner were more likely to be depressed than married mothers (Ekas et al., 2010).

Benjak, Vuletic Mavrinac, and Pavic Simetin (2009) discovered that parents of children with ASD reported significantly poorer self-perceived health compared to parents of TD children. Energy, vitality and social functioning were particularly low dimensions of self-perceived health. The only dimension of health in which there was no difference with the parents of TD children was physical health, which can be explained by the fact that 71% of surveyed parents with children with ASD were under 50 years of age. Another interesting finding was that 35% of parents of children with ASD perceived their health as worse compared to the previous year, and this was 18% higher in comparison to parents of typically developing children. This discrepancy in self-perceived health between parents was confirmed by the finding that 41% of parents of children with ASD, in comparison with 30% of parents of TD children, reported the existence of a chronic medical condition.

The stress experienced by parents of children with ASD was a strong predictor of heightened risk of divorce (Hartley et al., 2010). However, even though parents of a child with ASD reported more emotional stress, they remained more resilient compared to parents

of TD children (Lam, Wong, Leung, Ho, & Au-Yeung., 2010). According to a study conducted by Lai, Goh, Oei, and Sung (2015) parents of children with ASD reported significantly more parenting stress symptoms such as negative parental self-views lower satisfaction with the parent–child bond, and more depression symptoms, than parents of TD children. Despite findings such as these which suggest that parents of children with ASD are more anxious and depressed and under greater pressure than parents of typically developing children, the field has rarely focused on an in-depth investigation of psychological outcomes for this parent group (Benderix, Nordström, & Sivberg, 2006). Researchers such as Krauss, Seltzer, and Jacobson (2005) have argued that in-depth investigations into mental health outcomes have been difficult to initiate with parents of children with ASD because they are overburdened with numerous and long-term responsibilities in caring for their child during childhood, adolescence and adulthood as autism is a lifelong condition.

Parents of children with ASD also appear to be in greater distress when compared to parents of children with other disabilities. For instance, the level of general stress experienced by parents of a child with autism was significantly higher than for parents of a child with Down Syndrome (DS) (Dabrowska & Pisula, 2010). Studies conducted with mothers of children with ASD have reported higher levels of parenting stress and psychological distress than mothers of a child with Developmental Delay (DD) (Estes et al., 2009). Studies comparing parents of children with ASD with parents of children with another developmental disorder in relation to mental health status and coping strategies (Estes, et al., 2009; Greenberg et al., 2004) have generally reported that parents of children with ASD report more parenting stress and psychological distress compared to parents of children with other disabilities.

A study conducted by Greenberg and colleagues (2004) reported that mothers of a child with DS had lower levels of depressive symptoms compared to mothers of a child with autism. Differences in parents' mental health status were observed between parents of a child with ASD and parents of a child with another developmental disorder due to several factors. For instance, parents of a child with ASD reported significantly less satisfaction with the help they received since their child's diagnosis (Siklos & Kerns, 2006). In fact, about 93% of parents of a child with ASD did not receive adequate financial support for their child's therapy (Siklos & Kerns, 2006).

An investigation conducted by Wasserman and colleagues (2010) compared the mental health of parents of children with ASD to that of parents of children with schizophrenia. The findings indicated that parents of children with ASD experienced lower levels of depression and anxiety compared to parents of children with schizophrenia. Moreover, a study conducted by Abbeduto and colleagues (2004) indicated that mothers of young adults with autism experienced higher levels of depressive symptoms compared to mothers of children with DS and mothers of children with Fragile X syndrome. These findings might be due to the fact that mothers of children with autism tended to have lower family income, reported less use of problem-focused strategies and their children expressed greater numbers of disruptive behaviours (Abbeduto et al., 2004).

Many more studies have been conducted on the quality of life of parents of a child with ADD/ADHD compared to the amount of studies that have been conducted on the quality of life and parental concerns of children with ASD (Escobar et al., 2005; Spira & Fischel, 2005; Strine et al., 2006). A study by Lee et al. (2008) stated that parents of a child with autism experienced greater levels of child caring burden, a higher likelihood of quitting their job due to child care issues, less involvement in activities and community services compared

to parents of a child with ADD/ADHD. Furthermore, parents of children with autism also experienced a higher level of concerns about their child's well-being as they were more likely to miss school days and repeated more grades than children with ADD/ADHD (Lee, Harrington, Louie, & Newschaffer, 2008).

A study by Tarabek (2011) reported some differences between parents of a child with ASD and parents of a child with ADD/ADHD. The results indicated that mothers of a child with ASD obtained significantly lower scores for relationship satisfaction and lower mental health scores than mothers of children with ADD/ADHD (Tarabek, 2011). This finding seems to be in line with previous research which exposed that mothers of a child with autism experienced more symptoms of anxiety and depression compared to mothers a child with Intellectual Impairment (II) or TD children (Weiss, 2002). However, no significant differences in mental health scores between fathers of a child with ASD and fathers of a child with ADD/ADHD could be observed (Tarabek, 2011). Previous research suggested that fathers of a child with autism might cope by spending more time away from the home (Myers, Maackintosh, & Goin-Kochel, 2009).

3.1. Mental health impacts associated with parenting children with ASD.

Recent studies have investigated the impact that having children with ASD has on parents' psychological and physical well-being (Dardas & Ahmad, 2014; Lee, 2009). The most common negative mental health outcomes experienced by parents of a child with ASD encompassed feelings of stress, anxiety, and depression (Gau et al., 2010; Hoffman et al., 2009). A study conducted by Pottie and colleagues (2009) assessed the daily negative mood and its relation to parenting stress in 93 parents of children with ASD. Participants in this study were asked to complete initial measures of disruptive child behaviours, and support services, then biweekly measures of daily stress, received emotional and instrumental social

support, unsupportive social interactions, and mood over 3 months. The findings indicated that parents of a child with ASD were at higher risk of experiencing symptoms of parenting stress when they received low emotional support, experienced marital difficulties, and when their child engaged frequently in self-abusive and/or disruptive behaviours (Pottie et al., 2009). According to several authors (Benjak, Vuletić Mavrinac, Pavić Šimetin, & Kolarić, 2011; Olsson & Hwang, 2001), parents of children with ASD are a particularly vulnerable group as they take over practically the entire burden of family care for their severely disabled child.

Parenting children who have ASD was related to the impaired wellbeing of the parents themselves (Allik et al., 2006), their higher comorbidity of anxiety, depression (Olsson & Hwang, 2001; Bailey, Golden, Roberts, & Ford, 2007) and obsessive compulsive symptoms (Abramson et al., 2005). Cummins (2001) reviewed 12 studies which assessed the levels of anxiety and depression experienced by primary caregivers of children with ASD, the findings explained that caregiving was linked to higher than normal levels of anxiety and depression. Bebko and colleagues (1987) assessed the impact of symptoms of autism on parents of 20 children with ASD, by asking 20 therapists to independently estimate parents' perceived stress levels. The autistic child's language and cognitive impairment were judged by parents of children with ASD and by therapists as most severe and stressful. Findings revealed that individual parents agreed on both symptom severity and degree of stress. Parents of older children judged symptom severity to be lower, but fathers reported a continued high level of stress. Therapists judged families as more stressed by the child symptoms than did families themselves. Parents rated social impairment as one of the most stressful characteristics of raising children with ASD.

Specific sources of parental stress may include certain child characteristics such as expressive language difficulties and cognitive inconsistencies (Bebko et al., 1987; Moes, 1995). A study conducted by Baker-Ericzen, Brookman-Frazee, and Stahmerand (2005) assessed parental stress in 39 parents of children with ASD before and after their child entered an inclusive childcare toddler program. As ASD children entered the childcare program, 59% of mothers of children with ASD reported significantly elevated levels of child domain stress compared to 17% of mothers of TD children. At program exit, 46% of mothers of children with ASD reported significantly elevated levels of child domain stress compared to 13% of mothers of TD children. The results revealed that poor use of social interaction skills significantly predicted maternal child-related stress in mothers of children with ASD. Furthermore, a study by Mugno, Ruta, Genitori D'Arrigo, and Mazzone (2007) investigated the mental health of parents of children with PDD, Autistic Disorder, and HFA/AS. The results indicated that parents of children with PDD showed a significant impairment in their Quality of Life (QOL) as compared to the other groups, and parents of children with HFA/AS displayed a lower QOL compared to parents of children with AD. More specifically, mothers of children with PDD reported more decreased physical health, impairment in social relationship, impairments in their psychological state, and a decreased overall perception of QOL and health, while fathers displayed a worse perception of their psychological state and impairment in overall QOL and in social relationship (Mugno et al., 2007).

Stress proliferation is an additional factor that was posited as a potentially important mediator linking child impairment to parent distress. Stress proliferation refers to the tendency for an initial (primary) stressor or stressors to create additional (secondary) stressors in other areas of the affected individual's life, potentially resulting in increased psychological distress (Aneshensel, Pearlin, Mullan, Zarit, & Whitlatch, 1995; Pearlin, Aneshensel, &

LeBlanc, 1997; Pearlin, 2000). To date, only one study (Benson, 2006) has examined stress proliferation in the context of parenting children with ASD. In that study, multivariate analyses showed stress proliferation to be a powerful predictor of self-reported parent (n=68) depressed mood, uniquely accounting for a significant increase in variance in parent depression above and beyond that explained by child symptoms alone. In addition, analyses indicated that stress proliferation partially mediated the effect of child symptom severity on parent depression, with higher levels of child impairment leading in higher levels of stress proliferation, which, in turn, resulted in higher levels of depressed mood among participating parents.

Benson and Karlof (2009) replicated Benson's (2006) cross-sectional investigation of stress proliferation using a longitudinal design. This study utilised longitudinal data from 90 parents of children with ASD to replicate and extend the prior cross-sectional study on stress proliferation by Benson (2006). The regression analyses indicated change in stress proliferation to be a significant predictor of change in parent depressed mood. In addition, consistent with Benson (2006), stress proliferation was found to mediate the relationship between child symptom severity and parent depressed mood, with increases in child symptom severity leading to increase in stress proliferation which, in turn, resulted to increases in parent depressed mood. Olsson and Hwang (2001) assessed parental depression in 216 families of children with ASD and/or learning disability and in 214 control families. Findings revealed that mothers of children with autism showed the highest depression scores.

3.2. Physical impacts associated with parenting children with ASD.

Experiences of physical exhaustion and fatigue have been shown to adversely affect the health and wellbeing of parents of children with ASD. Unlike tiredness, which is typically alleviated by rest, fatigue has been defined as an enduring sense of physical and mental

exhaustion not easily relieved by rest (North American Nursing Diagnosis Association, 2001; Ream & Richardson, 1996). Fatigue has been conceptualized as a health outcome that can have an impact on cognitive functions, such as concentration, memory and decision-making (Hockey, Maule, Clough, & Bdzola, 2000; van der Linden, Frese, & Meijman, 2003). Although several qualitative studies have documented that exhaustion is common among parents of children with ASD and other disabilities (Benderix et al., 2006; Lopez-Wagner, Hoffman, Sweeney, Hodge, & Gilliam, 2008; Vickers, Parris, & Bailey, 2004), no known studies have explored the extent to which parents of children with ASD experience fatigue, and its potential impact on their well-being and parenting skills.

Fatigue is viewed as a serious health concern for parents of children with ASD (Fisher, Feekery, & Rowe, 2004; Ward & Giallo, 2008) and has been associated with reduced daytime functioning and impaired clarity of thinking (Fisher et al., 2004). It has also been linked to wellbeing difficulties, including depression, anxiety and stress (Ward & Giallo, 2008; Giallo, Wood, Jellett, & Porter, 2011). In a study conducted by Benderix and colleagues (2006), experiences of 10 parents from five families of a child with ASD were collected prior to and 2 years after entrusting their 10- to 11-year-old child with autism to a group home. Hermeneutic phenomenological analysis of narrative interviews with the parents before the child's moving showed them experiencing fatigue which contributed to cognitive decline at work and at home. Parents also reported that fatigue was the main reason why they did not socialize, which was the reason why they found a place for their child in residential care.

In a study conducted by Giallo and colleagues (2011) examined the extent to which parents of children with ASD experienced fatigue and its relationship to other aspects of wellbeing and parenting. Fifty mothers of children with ASD aged 2–5 years participated in

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the study. Mothers who reported high levels of fatigue reported higher depression, anxiety and stress. A range of demographic, child, and parent factors were associated with maternal fatigue, including lower educational attainment (high school or trade certificate), more problematic child behaviour, poorer quality diet, exercise and sleep and high perceived need for social support. The strongest predictors of fatigue were quality of maternal sleep, perceived need for social support, and quality of physical activity. It was not surprising that poor sleep quality was associated with higher levels of fatigue as parents of children with ASD are at particular risk of sleep disruption and poor sleep quality owing to the high rate of sleep problems for children with ASD (Hoffman, Sweeney, Gilliam, & Lopez-Wagner, 2006; Polimeni, Richdale, & Francis, 2005; Richdale & Prior, 1995). Finally, mothers who reported high fatigue were less efficacious and less satisfied in their parenting role.

Epel and colleagues (2004) found that compared to controls, mothers of 39 children with chronic medical illnesses or developmental disabilities (including ASD) had greater oxidative stress and accelerated shortening of their telomeres. Compared to mothers of TD children, mothers of children with ASD had cellular aging that was accelerated by nine to seventeen years, which may lead to earlier onsets of age-related diseases. Gallagher, Phillips, Drayson, and Carroll (2009) found that compared to mothers of TD children, mothers of children with ASD and other developmental disabilities mounted a poor antibody response to pneumococcal vaccinations, indicating a reduced capacity to ward off infections. As a group, mothers of adolescents and adults with ASD evidenced a profile of HPA hypoactivity as compared with normative patterns manifested by mothers whose similarly aged children do not have disabilities. This cortisol profile may initially seem counterintuitive given the endocrine response to acute stressors, but it is similar to findings on other groups experiencing chronic stress, including parents of children with cancer, combat soldiers,

Holocaust survivors, and individuals suffering from PTSD (Heim, Ehlert, & Hellmammer, 2000; Miller, Cohen, & Ritchey, 2002; Yehuda, Boisoneau, Lowy, & Giller, 1995; Yehuda, et al., 1995).

A study by Seltzer and colleagues (2010) demonstrated that mothers of children with ASD presented with the physiological profile characteristics of individuals with chronic stress. Participants were obtained from two longitudinal studies, the target group comprised 86 mothers of a child with ASD selected from the AAA study (Seltzer et al., 2010) and the comparison group comprised 171 mothers with TD children (the MIDUS study; Brim, Ryff, & Kessler, 2004). The down-regulation of hormone activity observed in parents of children with ASD may have undesirable consequences, such as contributing to fatigue and attention problems in parents of children with ASD.

The findings indicated that child's history of behaviour problems interacted with daily behaviour problems was a predictor for the morning rise of the mother's cortisol. A history of elevated behaviour problems moderated the effect of behaviour problems the day before on maternal cortisol level. Seltzer et al. (2010) found that relative to controls, mothers of adults with ASD had lower levels of cortisol throughout the day. Seltzer and colleagues (2010) mentioned that cortisol dysregulation associated with an increased vulnerability to hormone-related health issues in mothers of children with ASD should be further investigated. Another study conducted by Dykens and Lambert (2013) used a stress biomarker, diurnal cortisol, to detect the intensity of stress levels experienced by mothers of children with ASD and of children with other developmental disorders. Of 91 mothers of children with a developmental disorder, with 30 mothers having a child with AS, higher stress levels and lower health ratings were noted, especially for 89% of mothers with ASD children compared to 53% for mothers of children with other disabilities. Furthermore, uncommon cortisol awakening

responses and evening rises were differentially linked with anxiety, depression, health problems and employment status.

3.3. Social/Familial impacts associated with raising children with ASD.

Higgins and colleagues (2005) sent a survey to caregivers of children with ASD in Australia to assess the relationship between ASD characteristics, family functioning and coping strategies. A total of 53 participants completed and returned their survey to the researchers, the findings indicated that caregivers reported somewhat lower levels of marital happiness, disturbances in family cohesion, and family adaptability compared to normative data (Higgins et al., 2005). The results obtained by Higgins and colleagues (2005) suggested that levels of family cohesion and family adaptability with a child with ASD may be at risk of falling outside the healthy family functioning range. There are some obvious and practical explanations for the risk of family dysfunction in families with a child with ASD. Characteristics of children with ASD, such as low social competency and persistency make social outings for families with a child with ASD difficult (Kraijer, 2000).

Larson (2006) conducted a qualitative study in order to identify the development and use of routines, using data from nine mothers of children with ASD. Interview transcripts were coded by sorting data into categories and searching for variations within the category and the relationships between categories The findings revealed that mothers of children with ASD often expressed some feelings of loneliness when making decisions and strategizing about how to change daily routines and foster development of daily living skills and self-care in their child (Larson, 2006). Irregularly experienced events, especially holidays and family outings, were particularly difficult to manage for most families, although these difficulties, as a consequence extended and nuclear family togetherness was limited due to the child's

difficulties in participating in these events. Family traditions and rituals were often modified to accommodate the child's specific needs (Larson, 2006).

Gray and Holden (1992) sent a survey to parents of children with ASD, they used data from 172 Australian participants. The researchers surveyed factors that affected the psycho-social well-being of the parents of children with autism. In particular, this study examined a wide variety of sociodemographic and family variables in terms of their effects on depression, anxiety and anger. Gray and Holden (1992) discovered that parents of children with ASD reported greater conflicts with non-disabled children and more problems with family integration. The experience of raising a child with ASD can be quite stressful on individual parents, as both mothers and fathers of children with ASD have been shown to experience significant stress when compared to parents of TD children, as well as parents of children with other disabilities (Fisman, Wolf, & Noh, 1989; Rao & Beidel, 2009). These negative individual parent experiences could subsequently have a damaging impact on their spouses, as well as marital satisfaction (Fisman et al., 1989).

Existing research also recognises the positive influences of ASD on family functioning, including psychological and emotional strength, improved communication skills and higher levels of empathy and patience (Bayat, 2007; Davis & Gavidia-Payne, 2009; Pakenham, Sofronoff, & Samios, 2011). For example, Bayat (2007) investigated factors that contributed to making the family unit stronger in spite of dealing with the challenges of having a child with ASD. A survey was completed by 175 parents, and the results indicated that families of children with ASD displayed factors of resilience such as becoming united and closer as a family, making positive meaning of disability and finding greater appreciation of life in general. Research into the positive impacts of ASD on families is encouraging but is only relatively recent.

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Hartley and colleagues (2010) investigated the relative risks and timing of divorce in 391 families of children with ASD in a longitudinal study asking questions on family structure between 1998 and 2004, and they used a representative sample of parents of TD children to make comparisons. Results suggested that parents of children with ASD had a prolonged period of vulnerability to divorce. Specifically, there was a relatively high, and equivalent, risk of divorce for both the comparison group and families of children with ASD during the son or daughter's early childhood (until age eight years). When compared to parents of TD children, the risk of divorce remained high into the child's early adulthood for parents of children with ASD. More precisely, it was established that parents of children with ASD were at an increased risk for divorce when their child was between eight to thirty years old. Hartley and colleagues (2010) discovered that parents of children with ASD had an overall divorce rate about 24% compared to approximately 14% for parents to TD children. The heightened risk of divorce in parents of children with ASD is consistent with findings that these families experience an extraordinary level of stress (Seltzer, Greenberg, Floyd, Pettee, & Hong, 2001; Smith et al., 2010).

Freedman, Kalb, Zablotsky, and Stuart (2012) examined the relationship between ASD symptomatology and family structure. Participants' data for this study were collected from the 2007 National Survey of Children's Health, a population-based, cross-sectional survey. A total of 77,911 parent interviews were completed on children aged 3–17 years, of which 913 reported ASD diagnosis. Interestingly, the results suggested that symptom severity neither increased nor decreased the likelihood of a child with ASD to live in a two biological or adoptive parent household. These results were consistent with previous findings on the impact of symptom severity on divorce (Hartley et al., 2010) and overall family functioning (Bristol, 1987; Freeman, Perry, & Factor, 1991), in which other factors, including parental

depression and support, were more significant predictors of divorce. Such findings support the family systems theory suggesting that these families might in fact be more inclined to stay together.

Minuchin (1985) described a common phenomenon in which families maintain their relationships in the face of adversity. In essence, these families might stay together because it is safer to live in discord than to face the unknown change that marital separation inevitably brings. Other families might remain together, despite significant relationship difficulties, in order to ensure that they can provide financially for their child's multitude of needs. Based on this line of thought, minimal differences in divorce rates could be expected among parents of children with ASD when compared with the general population. Tomanik, Harris and Hawkins (2004) investigated the relationship between behaviours exhibited by children with autism, and maternal stress levels. The researchers administered self-report measures to 60 mothers of a child with autism. Children were between two and seven years of age. The results indicated that mothers' stress had been associated with the lack of independence of a child with ASD (Tomanik et al., 2004), low degree of self-sufficiency or low levels of social skills (Dabrowska & Pisula, 2010), and daily exposure to the child (Phelps, McCammon, Wuenshch, & Golden, 2009).

The stress fathers experience has been associated with the social acceptance of the child, whereas the mothers' stress has been linked to behaviours that are caused by the child's diagnosis of autism. Fathers of children on the spectrum seem to require more social support to parent effectively, whereas mother and father require each other's spousal support to lessen marital stress (Kersh, Hedvat, Hauser-Cram, & Warfield, 2006; Saloviita, Itälinna, & Leinonen, 2003). The negative consequences include a decrease in fathers' involvement in child care and greater stress in the family environment (Barbarin, Hughes, & Chesler, 1985;

Bristol, Gallagher, & Schopler, 1988). Furthermore, parents of children with special needs may have to offer not only more time, energy, and resources for their child's well-being but also offer these important qualities for a longer period (Seltzer et al., 2001).

For couples with satisfying relationships, in contrast, the challenge of dealing with a child's disability can strengthen and enrich their relationships (Havens, 2005). Although there is a risk that a couple may neglect their marriage when they have a child with a disability, parents are often aware of this challenge and are determined to keep their marriages strong (Pelchat, Lefebvre, & Perreault, 2003). In other cases, it pushed spouses away from each other, with mothers and fathers occupying distinct roles in their families (Aylaz, Yilmaz, & Polat, 2012). These distinct roles sometimes fostered resentment, particularly among mothers who believed they received inadequate support from their husbands (Gray, 2003; Luong, Yoder, & Canham, 2009). Strain also arose when one parent blamed the other for their child's diagnosis (Fletcher, Markoulakis, & Bryden, 2012).

A study by Brobst and colleagues (2009) investigated the balance of the roles of parent of a child with ASD and the roles of being a partner. Comparisons were made between 25 couples of a child with ASD and 20 couples of TD children for both stressor (i.e., child's behaviour problems) and relational (i.e., relationship satisfaction) variables. The findings explained that perceived spousal support, respect for one's partner, and commitment did not differ between parents of children with ASD and parents in the comparison group. On the other hand, the results indicated an important link between support from one's spouse and relationship satisfaction and found that when the mothers of children with ASD were faced with more intense behaviour problems in their children, they reported less support from their husbands (Brobst et al., 2009). Ultimately, some parents divorced (Meirsschaut, Roeyers, & Warreyn, 2010), and others worried that the constant care they provided to their child with

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ASD would put their marriage at risk for divorce (Divan, Vajaratkar, Desai, Strik-Lievers, & Patel, 2012).

A variety of social difficulties were identified as having adverse effects on parents of children with ASD. Parents reported that they received criticism from strangers when they were out in public (Farrugia, 2009; Gray, 2002; Lasser & Corley, 2008; Ludlow, Skelly, & Rohleder, 2011; Midence & O'Neill, 1999; Neely-Barnes, Hall, Roberts, & Graff, 2011; Safe, Joosten, & Molineux, 2012; Woodgate, Ateah, & Secco, 2008). According to parents' reports, stranger thought their children were acting out and should be disciplined (Farrugia, 2009; Lasser & Corley, 2008; Safe et al., 2012). In certain circumstances, parents connected such events to the fact that ASD is a disorder with no physical signs (Lasser & Corley, 2008; Midence & O'Neill, 1999; Neely-Barnes et al., 2011). Parents conveyed diverse reactions with regards to the judgment of strangers. In certain cases, parents made the decision to ignore such strangers, whereas other parents confronted strangers and others educated them about the nature of ASD (Gray, 2002; Neely-Barnes et al., 2011; Woodgate et al., 2008).

Previous studies have reported that children with ASD exhibit behaviours that are disruptive and challenging to manage, creating chaos throughout the household and extended family. It can leave parents feeling locked at home, as they fear taking the child out in public lest he create a scene or run into danger. Accordingly, these problematic behaviours are a major source of stress for parents (Allik et al., 2006; Blacher & McIntyre, 2006; Kersh et al., 2006; Konstantareas & Homatidis, 1989; Matson & Nebel-Schwalm, 2007). A study by Gray (2002) investigated the type of stigma experienced by parents of children with ASD. Thirty three families of a child with HFA were interviewed for the purpose of the study. The issues that were covered during the interview consisted of different categories: the onset of symptoms, referral experience and diagnosis, the nature of the child's present symptoms and

the effects of autism on the family. Gray (2002) found that parents of children with ASD experienced different types of stigmatisation and discrimination due to their child's diagnosis. The experience of stigmatisation among parents of children with ASD seems to be complex, as it includes biological differences of the children, the negative evaluation of those differences by others, adverse reactions of others, and negative social and emotional outcomes for parents (Green, Davis, Karshmer, Marsh, & Straight, 2005).

Glazzard and Overall (2012) investigated the experiences of parents raising a child with ASD. A mixed-method approach consisting of questionnaires and semi-structured interviews was used in order to elicit parental perspectives of raising a child with ASD. Two semi-structured interviews were conducted with parents of children with ASD and questionnaires were sent to parents in two special schools, with 20 participants completing the study. Glazzard and Overall (2012) reported that some parents of children with ASD found it easier to withdraw from society than to deal with the repercussions of putting their children through unfamiliar situations. Other studies have demonstrated the multiple challenges that parents of children with ASD face due to their child's difficulties to conform to social norms. Such difficulties have led families to make alterations to their day-to-day living circumstances which can be challenging to put into practice at times (Bristol, 1984; Dunn, Burbine, Bowers, & Tantleff-Dunn, 2001; Altiere & von Kluge, 2009). Family functioning has been detected as another area of difficulties for parents of children with ASD, it refers to the extent to which families communicate effectively, manage daily life, and foster positive relationships (Zubrick, Williams, Silburn, & Vimpani, 2000). Research findings suggested that when there was a child with ASD, family functioning was often affected in terms of greater strain on the family system; less participation in recreational activities (Myers et al., 2009); and less flexibility and connectedness (Higgins et al., 2005). Numerous

qualitative studies have shown that family life comes to centre on the needs of the child diagnosed with ASD (Hoogsteen & Woodgate, 2013; Myers et al., 2009). Family difficulties might be influenced by a number of individual, intra-familial, and social factors. For example, limited social support (Bromley et al., 2004; McConnell, Savage, & Breitkreuz, 2014), socio-economic status, individual wellbeing (Georgiades, Boyle, Jenkins, Sanford, & Lipman, 2008), children's behaviour problems, and difficulty coping (Khanna et al., 2011) are all factors that can make it difficult for families to function optimally.

Having a child with a disability often leads to the necessity to take responsibility for multiple roles including educator, caretaker, and advocate (Klein & McCabe, 2007). According to Lutz, Patterson, and Klein (2012) the needs for education and advocacy were recurring themes due to the struggles for securing medical care, behavioural health services, and educational services. The findings from this study are validated by Woodgate and colleagues (2008) study in which parents of children with ASD refereed to advocacy as "fighting all the way" and identified "being direct, learning all you can, and educating others" as essential to helping themselves and other families with autism. Woodgate and colleagues (2008) conducted qualitative interviews with 16 parents of children with ASD in order to describe the experiences of parents who have children with ASD. Even though parents had learnt to handle challenging behaviours or made the conscious decision to accept their children's unpredictable behaviours, it was the judgements and even the lack of understanding from others that made parents of children with ASD feel judged and it also made them feel like a "failure" (Ludlow et al., 2011).

Parents who participated in the study by Ludlow and colleagues (2011) also reported difficulty in finding a child-minder to look after the child, as the child presented particular challenges which minders were not typically experienced or trained to deal with. The

researchers addressed challenges faced by parents of children diagnosed with ASD. Reports were made from the 20 parents who participated in a qualitative interview, exploring parents' experiences, the daily challenges they faced, and what helped them to cope. A thematic analysis of the data identified five core categories: Dealing with challenging behaviour; dealing with judgements from others; lack of support; impact upon the family; coping and the importance of appropriate support. The results reported that parents of children with ASD had limited access to respite services. Grandparents were in some cases cited as a resource of respite in this regards, where grandparents could be called on to assist or look after the child for a short period of time. However, this was not always the case and a number of parents described the lack of understanding from grandparents, who did not understand autism and regarded the child's behaviour as a response to bad parenting. Furthermore, even though support was found to be beneficial for parents of children with ASD, other factors such as lack of available time, travel difficulties and childcare constraints can make it difficult for parents to seek and receive such support (Burke and Cigno, 1996).

Financial difficulties experienced by parents of children with ASD were investigated in a study conducted by Järbrink, Fombonne and Knapp (2003). Sixteen parents of children with ASD completed the Client Service Receipt Inventory (CSRI) questionnaire, which aimed to collect detailed information on the client's service use and family support in order to estimate component and total costs. The findings indicated that financial costs were high, with the total cost of raising a child with a disability estimated to be approximately three times greater than the cost incurred by raising a typically developing child (Järbrink et al., 2003). Results findings indicated that the financial costs of caring for a child with ASD can be associated with adverse effects in the lives of families of children with ASD (Järbrink et al., 2003; Sen & Yurtsever, 2007). Unfortunately, only a few studies have directly examined

the costs that families of children with ASD must face, but rather have implied the costs that families of children with ASD must pay.

Fletcher and colleagues (2012) interviewed eight mothers of children with ASD to analyse the costs and benefits related to all aspects of the participants' lives. Mothers acknowledged a number of expenses associated with their day-to-day experiences. For example, all mothers discussed the changes in their work or financial situations that resulted from raising a child diagnosed with ASD. Common expenses such as treatment costs, special dietary requirements, child care, private lessons, and cleaning / repairing homes were all mentioned as additional financial costs these families had to undergo. In addition, mothers mentioned the lack of funds available for family vacations, household renovations and/or for siblings' future educational pursuits/funds. The study by Järbrink and colleagues (2003) also explained the added financial strain of caring for children with ASD. Costs associated with out-of-pocket expenses and use of formal and informal services were reported as contributing to the strain experienced by mothers.

Fletcher and colleagues (2012) also reported the impact the ASD diagnosis had on parents' employment and reported that parents had to take off time of work or give up their employment due to the added responsibilities of caring (i.e., additional medical appointments) for a child with ASD, whereas one of the mothers reported having to work full time in order to pay for the additional costs associated with her child's treatment. Fathers' employment was also reported to be effected, but not to the same extent as mothers. Research by Järbrink et al. (2003) and Gray (2003) support the findings within this study regarding the alterations in employment resulting from the ASD. Further Gray (2003) reported that mothers' careers were more affected than fathers' employment. Interestingly enough, regardless of the costs reported and the hardships endured by these families, all of the women

expressed the positives that arose in their situations as well, a topic that has received limited exposure within the literature (Fletcher et al., 2012).

Gray's (2003) investigation highlighted the fact that the commitment of some fathers to work increased substantially after their child received a diagnosis of ASD. Gray (2003) reported on a father mentioning that he spent more hours at work even if he was not paid for working overtime so he would have to spend less time with his daughter diagnosed with ASD. For parents who had to stop working because of their child's numerous demands that conflicted with their work life, mixed feelings and emotions were usually reported (Altiere & von Kluge, 2009; McCabe, 2010). Furthermore, Altiere and von Kluge (2009) found that families of a child with ASD were hurt financially due to the pressure of having to rely on one income to provide for the family day-to-day expenses. Parents had to utilise their retirement funds and at times they also had to take a second mortgage (Altiere & von Kluge, 2009). Aylaz and colleagues (2012) unravelled the fact that some parents of a child with ASD could not cover the costs associated with caring for a child with ASD.

3.4. Limitations from previous research findings.

The research into the parent-oriented mental, physical, and social effects of raising a child with ASD, whilst revealing a number of interesting and reasonably uniform findings on parent experiences, also shows evidence of several limitations in relation to participant features and data-collection/analysis methods. The first key limitation relates to researchers' preference for collecting data via the usage of interviews or group responses in order to represent the "voices" of parents of children with ASD, and to provide a rich data pool for subsequent qualitative analyses (i.e., thematic analyses). Whilst qualitative data such as these allow for detailed individualised responses, they are often low on the standardisation required

for generalisation to other similar groups of parents of children with ASD (Glazzard & Overall, 2012; Larson, 2006; Ludlow et al., 2011).

The second key limitation consists of the utilisation of self-report from parents of children with ASD, which has the potential to bias not only interviews but also the completion of self-report scales. In the case of self-report scales researchers seek to minimise bias by using detailed, rather than brief scales, by selecting scales that measure specific aspects of performance and by giving parents a survey which allows for cross-referencing of information. However, these strategies are rarely used and consequently the potential for skewed data is greater (Brobst et al., 2009; Fletcher et al., 2012; Jellett, Wood, Giallo, & Seymour, 2015).

The third key limitation relates to participants' characteristics. Most studies report on findings mainly from Caucasian mothers, limiting the generalisability of the results obtained with regards to other groups of individuals such as, fathers of children with ASD and/or mothers and fathers of children with ASD from different ethnic backgrounds (Fletcher et al., 2012; Shtayermman, 2013). The fourth key limitation (which also relates to participants' characteristics), relates to a significant number of studies reporting on findings from highly educated participants with (mostly) above-average family incomes. These couples probably receive more professional services, have greater knowledge and access to existing resources, and, as a result, might have a lower stress than many other couples and single parents caring for children with ASD. This narrow selection of participants could have biased reported results on parental experiences (Brobst et al., 2009; Jellett et al., 2015; Park, Turnbull, & Turnbull, 2002).

The fifth limitation relates to the processes typically employed by researchers to recruit participants. Researchers tend to recruit parents of children with ASD through autism

organisations, websites and newsletters, meaning that parents of children with ASD not connected to those organisations will most likely be unable to participate in the research (Baker-Ericzen et al., 2005; Glazzard & Overall, 2012).

The sixth key limitation relates to researchers' using cross-sectional models to conduct their study instead of aiming to provide a lifespan perspective of parents of children with ASD by conducting longitudinal studies (Lutz et al., 2012). A majority of research is conducted on mothers with autistic children in specific life stages, instead of the same participants across different stages of their lives. Collecting longitudinal data would contribute to the understanding of the journey that parents of children with ASD go through (Benson & Karlof, 2009; Bolton, Golding, Emond, & Steer, 2012).

4. Psychosocial Factors Associated with Enhanced Stress-Coping Responses in Parents of Children with ASD

Parents of children with ASD do not react equally to the multiple challenges of parenting, more specifically parents' level of stress have been reported to vary with studies indicating that parents are sometimes likely to be affected by low or no discernible stress. Despite numerous problems, parents of children with ASD do cope with autism and often cope successfully (Bristol, 1984; Marcus, Kunce, & Schopler, 1997). The parents of children with ASD use coping strategies to tolerate and minimize stressful events. Managing the demands of stressors is vital because the outcome can escalate to unmanageable levels or crisis (Twoy, Connolly, & Novak, 2007). A moderate amount of cross-sectional research exists that looks at how families cope with autism at particular phases of the child's development (Marcus, 1977; Bristol, 1987; Gray, 1994; Hastings et al., 2005a). There is increasing interest in identifying the factors which might facilitate parent coping, in order for researchers to understand parents' of ASD children coping skills and to incorporate it into parent support interventions.

The specific conditions that contribute to higher stress are not always agreed upon in the scientific literature (Grant & Whittell, 2000). While studies show that the disability impact is mediated by a child's age and type of developmental disability (comorbidity, severity), others show that these static conditions are not in themselves factors that influence stress associated with parenting and caregiving. In fact, a number of recent studies suggest that the well-being of these parents depends not on static conditions but on dynamic conditions that are related to their situation and that can be changed. These conditions include the accessibility and availability of resources to help parents with their parental responsibilities (Kuhaneck et al., 2010; Kuhn & Carter, 2006; Weiss, 2002).These dynamic conditions also include the use of

positive cognitive reframing (Hastings et al., 2005a; Pozo, Sarriá, & Brioso, 2011); parents gaining access to perceived greater social support (Gray, 2002; Lin, Tsai, & Chang, 2008; Kuhaneck et al., 2010); parents ability to plan ahead their schedule (Kuhaneck et al., 2010; Weisner, Matheson, Coots, & Bernheimer, 2005).

Kuhaneck and colleagues (2010) conducted a qualitative study to explore the perceptions of effective coping strategies on parenting stress in mothers of children with ASD. In-depth interviews were conducted with 11 mothers of children with ASD with a focus on enquiring about their personal coping methods. The mothers who participated in Kuhaneck and colleagues' study (2010) reported the importance of obtaining knowledge about autism and sharing that knowledge with others. Kuhn and Carter (2006) found that the more time that had passed since the family received the diagnosis the greater were the feelings of self-efficacy and they suggested this was due to a mother having more time to gain knowledge about autism. The body of literature on self-efficacy suggests that the strategy of educating oneself may improve self-efficacy and thereby allow mothers to feel more in control, to feel more confidence in their parenting role, and to be less stressed with their parenting experience (Kuhn & Carter, 2006; Weiss, 2002).

Specific coping strategies used by parents of children with ASD that have been identified using a variety of research methods include accessing social and family supports, professional supports and services, support groups, and religion (Boyd, 2002; Bristol, 1987; Gray, 2006; Hastings et al., 2005a; Luther, Canham, & Young Cureton, 2005; Twoy et al., 2007). Social and spousal supports have been found to be extremely important in reducing stress and improving adaptation for families of children with disabilities. Social supports, including support groups, appear to be particularly effective in reducing parenting stress and are associated with better mental health (Boyd, 2002; Luther et al., 2005). Kuhaneck and

colleagues (2010) discovered through their results that parents' ability to share the workload with a spouse, in particular, was quite a significant factor that helped them cope with stress. The sample of mothers reported that they relied on their spouse to be aware of home routines and split the responsibilities. Similarly, Bayat (2007) found working together, being flexible, and communicating to be important characteristics in resilient families of children with autism. The mothers in the current study also felt a sense of relief knowing that in their spouse, they had someone who they could relate to. Higgins et al. (2005) reported that primary caregivers felt that it was important to talk over personal feelings and concerns with their spouses; spousal support was considered at least moderately helpful for coping.

Benson (2014) used a cohort sequential design and multilevel modelling on a sample of 113 mothers of children with ASD, to assess the effects of four coping strategies (engagement, disengagement, distraction, and cognitive reframing) on multiple measures of maternal adjustment were assessed over a seven years period. Benson (2010) has described cognitive reframing as a coping strategy which over time adjusts maternal psychological well-being by increasing parent self-efficacy. The effect of cognitive reframing, such as coping efforts made to perceive the stressful situation in a more positive light, on maternal adjustment was examined. Consistent with study hypotheses, cognitive reframing was found to exert a significant positive effect on parenting efficacy over time (Benson, 2014). In addition, consistent with prior cross-sectional work by Benson (2010), cognitive reframing was found to reduce the negative effects of maladaptive child behaviour on maternal distress. These findings support prior theory and research indicating the value of using positive cognitions as a coping method, particularly in stressful situations that are severe, chronic, or largely uncontrollable (Folkman & Moskowitz, 2004; Pakenham et al., 2011; Park, 2011). Planning and having a consistent or at least predictable routine is the typical advice offered to

parents of children with autism. While little is known about the effectiveness of family-based planning, Weisner and colleagues (2005) have found that sustainability of routine was an important outcome for families and one which varied greatly between families of children with a disability. Examining the efficacy of planning for family functioning may be an important avenue of research in the future.

4.1. Coping style, social support and personal resilience patterns in parents of ASD children.

4.1.1. Coping style definitions and research findings for parents of children with ASD.

This section of the chapter will present a review of the research on the copping styles and methods researchers have investigated in relation to parents of children with ASD. The link between coping and two widely researched dynamic factors, such as social support and personal resilience will be described. Coping has been described as one factor assisting parents to adjust successfully to their child's ASD, when other parents do not. Coping is a broad process referring to the manner in which parents respond, cognitively and behaviourally, to demands associated with their child's autistic disorder (Benson, 2014). Coping has been posited as a key mechanism by which parents adapt to stress, including the stress of parenting a child with ASD. Defined as "the process by which individuals respond to threats of stress" (Smith, Seltzer, Tager-Flusberg, Greenberg, & Carter, 2008), researchers have often grouped coping strategies into two major categories: problem-focused coping strategies which aim at directly solving the problem or changing the source of stress, and emotion-focused coping strategies which aim at reducing or managing feelings of distress associated with the stressor. In studies of caregivers, including parents of children with ASD

and ID, use of emotion-focused coping strategies have generally been associated with poorer mental health outcomes among parents, while use of problem-focused coping methods has often, but not always, been linked to improved parent adjustment (Abbeduto et al., 2004; Aldwin & Ravenson, 1987; Seltzer, Greenberg, & Krauss , 1995).

The two main approaches to investigating various aspects of coping and their impacts on parent functioning are quantitative methods qualitative methods. The first research approach has used quantitative methods and focused on the factors that serve to ameliorate the stressful effects of the disorder (Bristol, 1987; Milgram & Atzil, 1988; Gray & Holden, 1992; Hastings et al., 2005a). Among the various factors that are significantly related to various forms of parental distress and adjustment is the gender of the parent (Bristol et al, 1988; Milgram & Atzil, 1988; Gray & Holden, 1992) degree and type of social support (Bristol, 1987; Gray & Holden, 1992), additional life stresses (Bristol, 1987), age of the child (Bristol, 1987; Gray & Holden, 1992; Hastings et al., 2005a) and coping activities (Bristol, 1987; Hastings et al, 2005a).

The second research approach on coping and autism has been qualitative in its methodological approach and emphasized either the nature of the families' problems (Marcus, 1977; DeMeyer, 1979; Marcus et al., 1997) or the patterns of coping that parents employ to cope with their child's autism (Marcus, 1977; Gray, 2003). This type of research indicates that parents use a variety of coping strategies to deal with their child's autism including support from family and friends (Marcus, 1977; Gray, 1994), the use of service providers (DeMeyer, 1979; Gray, 1994), advocacy and support groups (DeMeyer, 1979) and religious beliefs (Gray, 1994). A significant amount of research that deals with general coping over the life course (Aldwin, 1991; Thoits, 1995) and it indicates that the coping activities of individuals change over time (Lazarus, 1996). In particular, research indicates

that there is a general tendency for young adults to use more problem-focused coping strategies and middle-aged adults to use emotion-focused coping strategies (Lazarus, 1996). The former refers to coping with the situation by changing the nature of the problem and the latter refers to coping that distracts the attention of the individual affected by a stressful situation. Included in this latter category of coping would be such activities as expressing feelings, praying, and withdrawal (Lazarus, 1996).

Parents of children with ASD use a range of coping strategies and resources when faced with parenting/caregiving stress (Hall & Graff, 2011; Hastings et al., 2005a; Lai & Oei, 2014; Luong et al., 2009). In a review paper, Lai and Oei (2014) highlighted that parents of children with ASD used both adaptive (i.e., cognitive reframing; seeking social support) and maladaptive (i.e., avoidance and disengagement) coping strategies, with an inclination towards adaptive coping methods such as seeking social support and positive reinterpretation. Among parents of children with ASD, the use of adaptive coping strategies has also been linked to positive mental health outcomes (Benson, 2010; Penley, Tomaka, & Wiebe, 2002; Taylor & Stanton, 2007). While it may then be expected that parents of children with ASD adapt well to parenting stress, past studies have also consistently reported elevated stress symptoms in these parents (Hayes & Watson, 2013). It is therefore unclear if parents of children with ASD are coping with parenting/caregiving stress adequately and effectively (Hayes & Watson, 2013).

Sivberg (2002) studied strain on the family system and compared the coping behaviours of parents of children with ASD to those of parents with non-ASD children. The results supported the hypothesis that there are differences in the types of coping behaviours employed. The parents with a child with ASD scored higher in coping behaviours of distancing and escape, a behaviour aimed at withdrawal from a stressful situation. The

parents in the control group, in contrast, scored higher in use of self-control, social support, and problem solving. The family's perception of stressful experiences also affects family-coping strategies. The use of reframing as a coping strategy was elucidated as a possible way of successful coping (Luther et al., 2005). Redefining personal goals and family goals and priorities, reframing helped the families cope with autism.

4.1.2. Social support definitions and research findings for parents of children with ASD.

Social support is a term that describes aspects of an individual's social context that may enhance psychological and physical well-being (Pottie et al., 2009). Two types of social support have been identified: received and perceived. Received support refers to the actual receiving of assistance from others. Perceived support refers to ones' perceptions of the availability of support and/or satisfaction with the support provided (Pottie et al., 2009). Professionals and agencies that provide specialized services to families of children with ASD should be monitoring parents' perceptions of their needs and of how well they are met by programs and finally responding to the needs identified by the families in order to promote healthy adaptation (Siklos & Kerns, 2006). They investigated parents of children with ASD own perceptions of needs, and whether parents felt their needs were being met. They administered the modified Family Needs Questionnaire (FNQ; Waaland, Burns, & Cockrell, 1993) to address needs for children with developmental disorders. Fifty-six parents of children with ASD and a comparison group of 32 parents of children with DS completed the FNQ. Siklos and Kerns (2006) identified fundamentals that family support should embody. According to their study, services should both enable and empower parents to make informed decisions regarding their disabled child, be open to the needs of the entire family and be flexible in accommodating to the unique needs of individual families.

Research indicates that stress proliferates in the sense that an initial stressor can increase the likelihood of additional stressors occurring in other areas of life (Benson & Karlof, 2009). For parents of children with ASD, the disability is the initial stressor, but raising a child with a disability introduces challenges throughout the life cycle for the child as an individual and the family as a unit. Perceived social support is an important means of coping because the extent to which individuals regard themselves as being cared for and supported by others is positive (Smith et al, 2010). Research indicates that mothers of children with autism spent more time providing child care, less time in leisure activities, had more stressful events, arguments, and fatigue than mothers from a nationally representative sample of children without disabilities (Smith et al, 2010). Evidence suggests that parents of children with ASD who perceived more social support reported better family adaptation and reduced stress (Lin, Orsmond, Coster, & Cohn, 2011).

Research on the presence of social support for ASD has been published in numerous peer-reviewed studies. Siklos and Kerns (2006) found that parents of children with ASD received similar support as parents of typically developing children. The difference was in the quality of the support received by the two groups of parents: the parents of children with ASD reported receiving aggravations from more of the same agencies compared to the parents of typically developing children. Parents' beliefs about receiving adequate social support for themselves and their child have been shown to be very important for successful family adaptation (Siklos & Kerns, 2006). Social supports identified as effective include support groups, support from one's spouse, family, and friends, the availability of leisure time, support from community programs, professional help, and the availability of services and programs geared towards families who have a child with autism. Families who receive these supports exhibit healthier adaptations to having a child with ASD (Siklos & Kerns, 2006).

Social support is reported to be a critical factor that reduces the negative psychological effects of raising a child with ASD (Bishop, Richler, Cain, & Lord, 2007; Bromley et al., 2004; Hassall, Rose, & McDonald, 2005). In particular, informal support, such as that provided by friends and family, has been shown to be effective in reducing stress among mothers of children with ASD. For example, mothers of children with autism who perceive receiving higher levels of support, especially from spouses and relatives, report lower levels of depression-related somatic symptoms and fewer marital problems (Dunn et al., 2001). Several studies have also shown that mothers of children with ASD first turn to their spouse for support, then to their immediate family, and finally to other parents of children with disabilities (Boyd, 2002).

Boyd (2002) reviewed research findings from eight peer-reviewed journals and two edited books (Schopler & Mesibov, 1983/1984) concerning the use of social support to alleviate stress in mothers of children with autism. Although different types of informal support have been associated with increased well-being, research has not systematically examined whether one source of informal support is more effective than another in helping mothers of children with ASD cope with stress. For example, even though mothers of children with ASD may turn to their spouse first to get support (Boyd, 2002), their spouse may not be the most effective support. It is possible that their spouse may be equally distressed and unable to provide effective support (Coyne, Ellard, & Smith, 1990) and that extended family (i.e., parents and siblings) or close friends may be more beneficial in promoting mothers' well-being. Indeed, research suggests that women turn to individuals outside their marriage (i.e., friends and other family members) when they do not receive adequate support from their spouse (Julien & Markman, 1991). Moreover, among mothers of critically ill children, social support from friends and family has been shown to buffer the

adverse effects of having low spousal support (Rini et al., 2008). The current study investigated the relative effects of three types of informal social support (support from partners, other family members, and friends) on the overall well-being of mothers of children with ASD.

Several studies differentiate social support into formal and informal supports. Formal social support is defined as aid that might be social, psychological, physical, or financial and is given through an organisation or agency (Bristol & Schopler, 1983). These types of formal social support include services from professionals such as therapists, psychologists, etc., who work in social service settings. Formal supports might also include structured organizations such as social clubs or churches (Boyd, 2002). Informal support was defined as "a network that may include the immediate and extended family, friends, neighbours, and other parents of children with disabilities" (Bristol & Schopler, 1983).

Examples of informal supports include other individuals close to the family who provide help and assistance (Boyd, 2002). Freedman and Boyer (2000) specifically looked at social support through a "family supports" lens in the context of developmental disabilities. They defined social support as "services, resources, and other types of assistance that enable individuals with developmental disabilities of any age to live with their families and to be welcomed, contributing members of their communities" (p. 59). In their focus group analysis, a number of supports reported by parents emerged. These types of family supports included: respite services, home health care, family education and training, family counselling, support groups and case management. These family supports were found to have directly benefitted parents and children on educational, emotional, and financial levels (Freedman & Boyer, 2000). In another study, Cassidy, McConkey, Truesdale-Kennedy, and Slevin (2008) asked parents ($n = 104$) about the social support they received. The findings indicated that more

stress was experienced when parents reported child's behaviour problems and the social limitations they experienced as a family. Another interesting finding indicated that support received from professionals or informally from family and friends, or from other parents of children with ASD, was not associated with reduced stress in this sample of parents (Cassidy et al., 2008).

It is suggested that optimism and social support are associated with increased well-being among mothers of children with ASD (Bishop et al., 2007; Greenberg et al., 2004). Although not systematically investigated, research has also suggested that informal supports, such as those provided by partners, friends, and family may be particularly beneficial in promoting maternal well-being in this population (Boyd, 2002). Moreover, research with other populations suggests that optimism and social support are positively related to each other and that social support mediates the optimism-psychological well-being relationship (Brissette, Scheier, & Carver, 2002; Dougall, Hyman, Hayward, McFeeley, & Baum, 2001; Shelby et al., 2008). An emerging literature, however, suggests that optimism may mediate the social support-psychological well-being relationship (Karademas, 2006). Little is known, however, about how these processes unfold in mothers of children with ASD. A study was directed toward understanding how these intrinsic and extrinsic factors promote well-being among this population which is especially susceptible to experiencing elevated levels of stress (Ekas, Whitman, & Shivers, 2009). Three different sources of informal social support, including partner, other family members, and friends were examined as mediators as well as moderators of the optimism-maternal well-being relationship.

According to Cobb (1976), social support aids in coping with crisis and adaption to change. This idea can be applied to a family systems perspective since it is similar to the Double ABCX Model with family coping to specific stressors (Bristol, 1987). Research

studies demonstrated an inverse relationship between stress and social support for parents of a child with ASD. For example, when mothers perceived social supports as being more available, they reported significantly less stress than those who did not perceive social support as being as available (Gill & Harris, 1991). The perceived availability of supports also applies to parents of children with disabilities. For example, one finding illustrated that there is a relationship between both mothers' and fathers' perceived stress levels and the support received from relatives and friends; this relationship yielded a negative correlation (Hadadian, 1994).

Sharpley, Bitsika, and Efrimides (1997) found, in relation to an Australian sample of parents, that lower parental stress was related to parents who had a higher level of understanding about their child's problem behaviours and had also received assistance by family members. Similar research demonstrated that as the higher number of perceived and experienced needs of mothers increased, a positive family relationship was established. In turn, there was less stress and greater well-being within the family system (Dyson, 1997; White & Hastings, 2004). Therefore, parents who reported using more social supports and more helpful social supports also reported higher levels of well-being than for parents who reported less (White & Hastings, 2004). Many researchers suggest that families experience high levels of stress in raising a child with ASD and that these levels of stress are significantly higher compared to 28 parents of typically developing children (Mancil, Boyd, & Bedesem, 2009). In turn, there may be a high need for social support because stress levels are so severe.

Therefore, this may be why families who experience high levels of stress in raising a child with ASD may seek out more social support than those who have lower levels of stress (Taylor-Dyches, Wilder, Sudweeks, Obiakor, & Algozzine, 2004). The idea that social

support can help decrease parental stress may be due to "perceived expertise" of the family member who offers respite care for the parents (Sharpley & Bitsika, 1997). This type of respite care includes emotional and social support that is made through members of the immediate family, such as grandparents, aunts, uncles, and siblings. Receiving social support from these types of individuals suggests a high degree of family support. Family social support from immediate family members has also been documented. For example, results of the supports used from the parents sampled in a study by Sharpley and Bitsika (1997) showed that 61.5% of parents reported having other family members help in the assistance of child care. However, this finding also suggests that there may be a higher need for family support within a number of families due to 38.5% of parents sampled who did not receive this type of support.

Tunali and Power (2002) found that social support from the extended family can be crucial in meeting the social and affiliative needs of parents. This finding was similar to an implication discussed by Sharpley and Bitsika (1997), which suggests that parents may value social support the most when assistance is provided by immediate family members. Also, the assistance to the family is most effective when it includes an understanding or knowledge of the child's diagnosis of ASD. Other sources of stress that are linked to social support included: the child's educational placement, especially for inclusion in mainstream classrooms; difficulty obtaining babysitters and respite care 29 providers; and managing daily life of the child with a developmental disability (Dyson, 1997).

4.1.3. Personal resilience patterns definitions and research findings for parents of children with ASD.

There is some variation in how researchers conceptualise and define personal resilience; however, most definitions are uniform in referring to an individual's ability to lead a more successful life than expected in the presence of adversity (Brooks, 1994). Resilience relates to a person's capacity to navigate through life regardless of harsh conditions or misfortune and to make the necessary adaptations to maintain equilibrium (Alvord & Grados, 2005). Masten (2001) describes resilience as a "class of phenomena characterized by good outcomes in spite of serious threats to adaptation or development" (p. 228). It can be described as a sense of competence in the context of significant challenges to adaptation or development (Ungar, 2004). Luthar (2000) describes resilience as a dynamic process encompassing positive adaptation within the context of significant adversity. Gordon (1995) defined resilience as the ability to flourish, mature, and increase ability and skills in the face of adverse situations. Parents of children with ASD are faced with a great deal of adversity in their daily lives. When they rise above these challenges and continue to develop a healthy adaptation despite their difficulties they can be considered resilient.

Resilience within families affected by autism in not yet a well-researched area but it is clear that this concept can assist in exploring the question of why some people cope well with stresses while others do not is a fascinating concept (Heiman, 2002). One's ability to cope or to seemingly be resilient is an admirable quality and identifying how they do this is of great importance if others wish to emulate their success (Mundy & Sigman, 1989). It is important to identify elements that enable families to cope effectively and emerge from a crisis or persistent stress. During the past decade, a number of family researchers have been interested in finding why some families facing adversity manage to function well and come out

stronger, while others when faced with a similar situation do not (Cowan, Cowan, & Schulz, 1966; McCubbin, Cauble, & Patterson, 1988; Patterson, 2002; Walsh, 1996). The concept of family resilience and its focus on factors leading to a family's well-functioning in view of a crisis is part of a movement in positive psychology (Seligman & Csikszentmihalyi, 2000) towards identifying factors of health as opposed to factors of pathology (Antonovsky, 1987; Antonovsky & Sourani, 1988) that has been the traditional approach in developmental and clinical psychology.

Family resilience has been looked at either as an interaction of two groups of risk and protectivefactors (Rutter, 1987), or as a flexible process indicating the family's strength at different points during the life cycle of the family, and within different circumstances (Walsh, 2003). This latter approach considers a family resilient when it demonstrates strength, even if it may not demonstrate the same attribute at another point in time (Walsh, 2003). Several key factors which contribute to a family's becoming resilient are: (1) making meaning of adversity, (2) affirming strength and keeping a positive outlook, and (3) having spirituality and belief system (Walsh, 1998). In addition, for a family to rebound in face of a challenging situation, the family needs to possess certain organizational qualities, such as flexibility, connectedness, communication and being able to utilize resources (Walsh, 2003).

Many families of children with autism have managed to overcome the constant challenges and trials of having a child with autism. Ungar (2004) describes a constructionist approach to resilience as the outcome from negotiations between an individual and his/her environment in which the individual remains healthy amidst conditions which are collectively viewed as adverse. Families that include a child with autism can be viewed in this context. A diagnosis of autism would collectively be viewed as an adversity to cohesive family life. The family's ability to remain healthy and cope with such adversity contributes to their

resilience. Ungar (2004) explains that "researchers of resilience continue to conduct studies in the hope of revealing ways to inoculate children against personal, familial, and environmental acute and chronic stressors" (p. 342-343).

Ungar (2004) clarifies that the constructionist's view of resilience is that the factors are unique to each individual and their social grouping and that the challenges are relative to the lived experience of the individuals. This is of particular interest when investigating resilience within the subject matter of autism, as the experience of each family affected by autism will be unique with exclusive entities. Resilience is the process of adapting well in the face of adversity, trauma, tragedy, threats, or even significant sources of stress (Masten, 2001). Stress is often associated with family and relationship problems, serious health problems, or workplace and financial stressors (Masten, 2001). The concept of resilience includes not only the ability to withstand but to also rebound from a crisis (Heiman, 2002). Harris and Glasberg (2003) explain that several families of children with autism demonstrate an impressive sense of resilience and strength in their experience, learning to balance hard demands with grace and humour.

O'Brien (2007) attributes resilience in families affected by autism to flexibility. Learning that your child has a lifelong developmental disorder is stressful and challenging to any family, yet it is clear that some families adapt and adjust more readily than others and their resilience comes from their malleable qualities and learning to live with uncertainty (O'Brien, 2007). Resilient parents of a child with autism invariably seek to develop the necessary skills to deal with their child's atypical behaviours. To succeed or to surpass the risk associated with adversity a person must draw upon all of his or her resources: biological, psychological, and environmental (Gordon, Longo & Trickett, 2000). Resilient parents of children with autism achieve this goal. Resilience can emerge with support and proper

intervention (Sivberg, 2002). Appropriate intervention can help to mitigate the likely feelings of guilt and vulnerability associated with diagnosis (Stern & Bruschweiler-Stern, 1998). Family members can be encouraged and their sense of order or control can be re-established with assistance from community, extended family, and friends (Naseef, 2006).

Heiman (2002) lists the contributing variables of resilience as, successful adjustment in terms of self-esteem, social support, problem solving skills, well-defined faith, coping skills, interdependence and the ability to reframe barriers and obstacles. These characteristics enable parents to function and to maintain their morale and optimism during times of crisis and to cope in a productive way (Heiman, 2002). Families of children with autism can be some of the strongest, most vibrant people. Moreover, it is their healthy adaptation that will prove to be one of the greatest prevailing resources for their children (Dunlop & Fox, 1999). Regardless of how many professionals are involved with the child, the most influential and significant effects will be achieved by the child's family (Alper, Schloss & Schloss, 1994). Families are truly instrumental in the growth and development their children with autism achieve. The extent to which a child and his or her family can meet everyday challenges can predict the ultimate outcome for the child as well as for the other family members (Dunlop & Fox, 1999).

Research findings presented by Bitsika, Sharpley and Bell (2013) explained that even though resilience could be seen as a potential buffer against anxiety and depression for parents of children with ASD, these findings required further examination before conclusive acceptance. Bitsika and colleagues (2013) also proposed that the data they obtained regarding resilience had the potential to advance understanding of the pathways by which parents of children with ASD progress from their experiences of intense daily stress to anxiety and depression. Further, because of the buffering effect noted for resilience, potential avenues for

intervention and training for these parents may be considered. For example, psychological resilience is associated with availability of social supports (Bonanno, Galea, Bucciarelli, & Vlahoz, 2007). Therefore, increasing the availability of social services to parents may lead to increases in parental resilience and, via a flow-on effect, increased ability to cope withthe stress of parenting a child with ASD (Bitsika et al., 2013).

In a qualitative case study Dale, Jahoda and Knott (2006) determined that mothers who felt that they were solely responsible for their child with autism suffered from feelings of isolation and depression. They also concluded that the role of social supports available to the family significantly contributed to the mother's reduction in stress. Social supports that were deemed useful included counselling for parents and their children and early intervention programs for the child with autism (Dale et al., 2006).   Families of children with autism are faced with great challenges (Herman, 1992). Parents of children with autism are inundated with difficult and persistent problems in parenting (Dale et al., 2006). Heiman (2002) conducted a qualitative study and interviewed thirty-two parents of children with autism, and determined that "families either adapt flexibly and mobilize into effective action or freeze in various degrees of rigid, ineffective reactions, whereas others tend to resist or even deny the diagnosis itself" (p. 160).

Previous research findings showed that resilient coping is a protective factor for health complaints in parents of people with ASD (Bekhet, Johnson, & Zauszniewski, 2012). As described before (Fernández-Lansac, Crespo López, Cáceres, & Rodríguez-Poyo, 2012, Nabors et al., 2013; Tang et al., 2013), higher scores in resilience have been associated with less anxiety, insomnia, depression and somatic symptoms in caregivers. Thus, high resilience was observed in caregivers who had the ability to maintain and look for new social support

resources, and in turn, this behaviour was believed to reinforce resilience (Lovell et al., 2012; Wilks & Croom, 2008).

A qualitative study conducted by Pastor-Cerezuela, Fernández-Andrés, Tárraga-Mínguez and Navarro-Peña (2015) indicated that parents of children with ASD perceived themselves as moderately resilient to adversity. Nonetheless, some comments collected in the interview in suggested good resilience levels, in some parents of the ASD group. The parents of children with ASD claimed that "their life makes more sense now than before having their child," "their child had helped them to be better people, to have the necessary energy to act, to overcome difficult situations, to solve problems . . ." (Pastor-Cerezuela et al., 2015, p.9) These comments suggest that, despite the challenges faced by parents of children with ASD, some of them show adaptive management and even a positive contribution to the family dynamics (Pastor-Cerezuela, et al., 2015). In this review, indicators of resilience in parents of children with ASD included two factors related to depression and competence, respectively, optimism and self-efficacy. This could explain the significant relationship found in this study between resilience and parental stress related to these two factors; depression and competence. Indicators of resilience, such as optimism and self-efficacy, are predictors of a greater ability to cope with the challenge of raising a child with ASD.

In relation to study 1, the delivery of a support group will act as the intervention, the effects of which will be measured via any changes (i.e., anxiety, depression) and personal resilience. It was suggested that increased knowledge/skill could impact resilience, and as a consequence an interest in building skills in three different content areas via three different support groups arose.

A vast majority of research conducted with parents of children with ASD appears to focus on social support. The proposed support groups for study 1 are an example of social support, and the aim of study 1 will be to detect the effects a group-based social support programme will have on parents' coping. As a consequence, social support is one of two areas of focus when investigating the psychosocial factors associated with enhanced coping in parents of children with ASD. Personal resilience is the second psychosocial factor investigated in relation to enhanced coping in parents of children with ASD. This factor has been given increasing interest in the research but it has not been formally addressed within that particular group of participants. Furthermore, a focus was given to personal resilience as resilience might be capable of change after parent participation in a programme designed to increase their level of skills in understanding their child's behaviour, managing their own lives, or both. The focus of the three support groups offered in study 1 will be on increasing knowledge and skill as a vehicle for positively affecting personal resilience in our participant groups.

5. Major Models of Support Developed for Parents of Children with ASD

An investigation of the different ways in which parents access social support and the different functions of support parents seek is essential to design more effective psychosocial support interventions for parents of children with ASD. Twoy and colleagues (2007) analysed the answers of 55 parents of children with autism who completed the Family Crisis Orientation Personal Evaluation Scales (F-COPES) in order to identify the types of support accessed by parents of children with ASD. The results indicated that 68% of the 55 parents pursued general support from friends, and 93% of parents wanted to gain information and advice from other parents of children with ASD. Of those 55 participants, 80% also sought support from professionals in the area of autism. These findings indicate that though general support from friends and family members is important, specific support from families who have had the same experiences or support from professionals with knowledge about ASD is especially desired.

Moh and Magiati (2012) addressed this gap: they found that parents' experiences with the support services were qualitatively different depending on their stress level. When parents consider their experiences with professionals as being positive (the support workers listen to their concerns, consider them as partners, and provide them with useful information), they report having a lower stress level. Another recent study concluded that there is an important link between parents' stress levels and their positive or negative perception of their experiences with the support services (Hall & Graff, 2011). The study indicated that parents who have a lower stress level have a more positive perception of their situation and the resources available to them and that they also have better coping strategies. The parents' perception and subjective evaluation of the services, based on their experiences, could be a key to both their well-being and their adaptation to their situation. Subjective interpretations

of careers can be of greater importance than the objective circumstances in which careers find them.

It appears that group support for parents of children with ASD can offer them the information, understanding, and acceptance they search for. Woodgate, and colleagues (2008), explained that 14 parents experienced extreme social isolation and lack of understanding from others as a result of having a child with ASD. This significant finding proposes that a crucial need of parents of children with ASD to cope with their child's diagnosis is to find acceptance and support from others. Little research has been done on outcomes for families and caregivers involved in support groups for autism or other developmental disabilities. Counselling services have also been offered to parents of children with ASD and the effectiveness of such services has been addressed in previous research. The different treatment modalities included cognitive behavioural therapy (Feinberg et al., 2014; Kenney, 2010), positive psychology strategies (LaPlante, 2013), relaxation therapy (Gika et al., 2012), acceptance and commitment therapy (Blackledge & Hayes, 2006; Kowalkowski, 2013). Finally, parents of children with ASD have been able to access support through family members and friends, which has been referred to as "informal support" in past research.

The focus and format of the support parents receive has the potential to not only to assist them in meeting the challenges they confront in their personal lives but can also impact on the methods they adopt in parenting their children with ASD (Robert, Leblanc, & Boyer, 2014). Therefore, the question of what constitutes effective support for this parent group is important to examine from the perspectives of the types of support models typically implemented with parents and any existing evidence of the effectiveness of particular models from the research. In this chapter, these issues will be examined in relation to three key

components of group-based parent support: the specific models used for support provision, the focus and content of information covered, and the procedures for support delivery.

The review of the research on group support for parents of children with ASD conducted for this thesis suggested that there is great inter-group variation in relation to multiple features which include: purpose, structure, facilitation processes, level and nature of training for facilitators, methods through which support was provided, and whether participants were exposed to set or are open-ended content and topics in nature. Despite these differences, parent support groups are underpinned by the philosophy that those with shared experiences are in a unique position to provide authentic empathy, support, and practical advice and suggestions (British Columbia Ministry of Health Services, 1993; Dennis, 2003; Mead & McNeil, 2004).

5.1. Informal group support models for parents of children with ASD.

In a conceptual analysis of peer support, Dennis (2003) identified peer support as a concept embedded within the social relationship construct. Dennis (2003) differentiated embedded social networks, such as family members, friends, neighbours from created social networks, which includes self-help groups and support groups. According to Dennis (2003) self-help groups can be viewed as unstructured as parents get together to talk among themselves, whereas support groups tend to be more structured as they are typically led by facilitators with a focus on covering specific content. Self-help groups are sometimes referred to as consumer-operated groups, peer-to-peer, family-to-family, or parent-to-parent groups have limited or no professional involvement, while support groups have included professional involvement (Dennis, 2003). Several different models of group support run by professionals were found in the literature. Many commonalities among these models are highlighted below as well as some innovative strategies to take into consideration. Peer support groups, which

operates to provide information as well as a sense of community in order to combat feelings of isolation in one's struggles, need to be implemented in ways that take into consideration the topic area, target population, and goals of the program.

Samadi, McConkey and Kelly (2012) provided information on families of a child with ASD sharing their experiences and learning from one another. Those researchers offered seven group-based sessions to two groups of parents (*n*=37) of children with ASD. The following information was addressed in the seven sessions offered to participants: 1) Session 1: Introducing parents to one another and providing an overview of the course: its aims, ethos and content, and expectations placed on parents; 2) Session 2: What is ASD? Definitions, features, causes. How does it affect your child; 3) Session 3: After the diagnosis. Parental reactions, what helps; 4) Session 4: Interventions and services. Overview of ASD approaches to promote communication, services available in Iran and internationally. Intensive interaction; 5) Session 5: Myths and reality of ASD. The talents of people with ASD. Identifying and building on a child's abilities and interests; 6) Session 6: Society and ASD. Reactions of others, parental advocacy and self-help, and changing attitudes; 7) Session 7: Looking to the future. Further information needed. Possible formation of parent NGO in Iran.

Samadi and colleagues (2012) used a pre-post, cross-over design to evaluate the specific impact of the group. The changes found among the parents in the first group were replicated with the second group. Moreover, the changes were sustained up to 15 weeks after the course ended. Although there were variations across the parents, in general they reported feeling less stress, had better emotional wellbeing and family functioning and made more use of problem-focused coping strategies. The changes were attributed mainly to an increase in the informal supports among the parents and their feelings of empowerment. A resource pack has been

developed to enable the group sessions to be easily repeated and for facilitators to be trained in its use.

Connolly and Gersch (2013) designed a qualitative, three-staged study to look at ways of supporting parents of children on the waiting list for assessment. Focus group discussions were analysed using thematic content analysis to identify themes to facilitate the development and evaluation of a pilot parent education group. The study comprised three different stages named, "Stage One: research", "Stage Two: intervention" and "Stage Three: evaluation". In stage one of the study, two parents participated in a focus group to explore their experiences of previously having children on a waiting list for an assessment for ASD.

In the second stage, five participants attended the intervention group. The group included four mothers and a father, representing four children. The group facilitators consisted of three members of the multi-disciplinary team who were present for each session. The content of the group was designed to reflect what the literature said about provision of appropriate supports and strategies for parents of children with ASD. The sessions took place once a week over four weeks and lasted two and a half hours. A total of six sessions were conducted, investigating the following topics: 1) Session 1: Introduction to the Autism Services, the Diagnostic Process; ASD; 2) Session 2: Communication – typical and atypical communication; developing communication skills; 3) Session 3: Behaviour – introduction to analysing and managing behaviours; 4) Session 4: Emotions, the family – introduction to emotional regulation strategies; self-care; considering needs of siblings; needs of the family (Connolly and Gersch, 2013).

In stage three of the study conducted by Connolly and Gersch (2013) four participants completed an evaluation form at the end of the final session. Three participants attended a post-programme focus group to evaluate the programme's usefulness to them. A semi-

structured interview schedule was followed. Data was transcribed and analysed as earlier. This study, regarded participants as experts and consulted with them to inform the design and delivery of a programme for parents with similar experiences. A parent programme was designed and implemented for parents of children on the waiting list. The programme was evaluated and found to be of use to parents, providing information, support and empowerment.

5.2. Formal group support models for parents of children with ASD.

Considering that seeking support and using support services are the strategies most used by parents of children with ASD in response to stress generated by their situation, researchers have postulated that parents' well-being and satisfaction greatly depended on the system's response of finding them formal support and the help they needed. Formal group support involves parents in structured interaction, often via completion of activities such as discussing a key topic of concern to the group, with other parents who are experiencing similar circumstances with their children with ASD led by a facilitator with a focus on covering specific content. This type of group support is believed to facilitate acceptance and provide valuable support and information for parents (Paluszny, 1979; Tommasone & Tommasone, 1989). The research suggests that parents of children with ASD are frequent participants in formal support groups run by autism associations and specialist government facilities and report valuing the opportunity to share opinions and experiences as well as provide information that might be useful to other group members (Tommasone & Tommasone, 1989). Also, because all parents are experiencing similar difficulties with their children, group members are less likely to edit what they say from fear of receiving disapproval or non-acceptance (Lin et al., 2011; McCabe, 2008).

Group-based support programmes developed for parents of children with ASD have generally focused on providing label-driven information on ASD as well as generic advice on treatments designed to build functional skills (i.e., in communication) and ways of managing children's atypical or challenging behaviour (Bitsika & Sharpley, 2004). Child-focused parent support programmes such as these have been shown to produce limited long-term positive outcomes in child and family functioning and researchers have proposed a number of reasons to account for this lack of effectiveness which include: minimal focus on the emotional state, mental well-being and resilience levels of parents; discussion of autism in general terms without elaborating on how this disorder would manifest for the individual children of these parents; and a bias towards presenting parents with generic behaviour management strategies without assisting them to develop a deeper understanding of the adaptive value of their children's apparently bizarre behaviour (Abbeduto et al., 2004; Altiere & von Kluge, 2009). Lyons, Leon, Phelps and Dunleavy (2010) have argued that these limitations, which arise from poor programme design, have led to parents feeling overwhelmed when attempting to implement behaviour management techniques (learned in-session) in the home environment and poor generalisation of learned "autism" knowledge to understanding their children's responses as these occur in day-to-day life. Those authors have also argued that the place to start in supporting parents of children with ASD is to build their emotional resilience and positive mental health status.

The search for research-based formal support group models for parents of children with ASD, with a focus on content and delivery was performed for this thesis. That search which extended from 1998-2014 identified 13 studies which met the criteria of: 1) Formal support involved a facilitator; 2) Structured groups had to be attended for a minimum of four sessions; 3) Specific content was delivered during the groups; and 4) Some form of measurement was

used to assess changes in some aspect of participant psychosocial functioning. The major findings of the review of these 13 studies are discussed below.

Eight of the 13 studies presented intervention sessions in group settings, while only five studies intervened with participants individually (Campbell, 2003; Feinberg et al., 2014; Kenney, 2010; LaPlante, 2013; Whitney & Smith, 2014). Group sessions incorporated either one or a combination of the following presentation formats: lectures or seminars, group discussions, guided practice/role playing, and/or experiential activities. Individual interactions were either one on one therapy sessions, individual coaching, phone interviews and instructions, or online intervention activities.

Most intervention activities were conducted at outpatient family clinics in 5 of the 13 studies (Ferraioli & Harris, 2013; Gika et al., 2012; Kenney, 2010; Kowalkowski, 2013; Peck, 1998). The second most utilised location was the family home or a location of the parents' choosing in 3 of the 13 studies (Campbell, 2003; Feinberg et al., 2014; Gika et al., 2012). Other intervention locations included ASD school sites in 2 of the 13 studies (Benn, Akiva, Arel, & Roeser, 2012; Bitsika and Sharpley, 2000), an ASD treatment centre in 1 of the 13 studies (Blackledge & Hayes, 2006), and convenient community locations in 1 of the 13 studies (Dykens, Fisher, Taylor, Lambert, & Miodrag, 2014). LaPlante (2013) and Whitney and Smith (2014) were the only studies conducted online. Trained professionals were the primary presenters of intervention content. Rather than utilising professionals, Dykens and colleagues used peer-mentors, and mothers of children with developmental disabilities, to lead group workshops. Three interventions were implemented using a self-administration method: Parents completed intervention activities at home using an instructional CD (Gika et al., 2012) or they received instructions and completed activities online (LaPlante, 2013; Whitney & Smith, 2014).

Nine of the 13 studies mentioned identified, conducted intervention sessions once per week with the exception of Benn et al. (2012), who held sessions twice per week. Most weekly group support interventions lasted six (Dykens et al., 2014; Feinberg et al., 2014; Gika et al., 2012) to eight weeks (Bitsika & Sharpley, 2000; Ferraioli & Harris, 2013; Kowalkowski, 2013; Whitney & Smith, 2014). Three studies ran intervention sessions which ranged from five (Benn et al., 2012; Kenney, 2010) to nine weeks (Peck, 1998) in duration. Blackledge and Hayes (2006) delivered an intensive 2-day intervention group support, which lasted seven hours per day. Two interventions focused only on writing tasks and clearly instructed participants to complete writing tasks over a period of three days for 20 minutes per day (Campbell, 2003) or participants were asked to complete writing tasks over a period of seven days for 10 minutes per day (LaPlante, 2013). Although Gika and colleagues (2012) implemented four coaching sessions over a period of six weeks, participants were also instructed to practice relaxation techniques for 20 minutes, twice per day, for the entire 6-week period.

Eight of the 13 reviewed studies used random assignment to place participants into a variety of treatment groups and control groups. Three types of control groups were implemented, (a) care as usual, (b) wait-list controls, and (c) active controls. Whereas only three studies used either a wait-list control or care as usual (Benn et al., 2012; Feinberg et al., 2014; Whitney & Smith, 2014), the remaining studies used a comparison intervention (active control). For example, Ferraioli and Harris (2013) compared differences between a parent-focused intervention, Mindfulness-Based Parent Training (MBPT), and traditional child-focused training, Skills-Based Parent Training. Kowalkowski (2013) examined differences between a therapist-led intervention (ACT) and a parent-led support group. Dykens et al. (2014) compared the effects of mindfulness training (MBSR) to strategies in positive

psychology (PAD). Two writing interventions, (Campbell, 2003; LaPlante, 2013) compared writing about an emotionally traumatic topic to writing on neutral topics as the control condition.

Seven of the 13 studies conducted follow-up assessments within two to three months after the completion of the intervention (Benn et al., 2012; Blackledge & Hayes, 2006; Campbell, 2003; Dykens et al., 2014; Feinberg et al., 2014; Ferraioli & Harris, 2013; Kowalkowski, 2013). Dykens and colleagues (2014) was the only reviewed study that assessed outcomes at six months (in addition to two months) following the intervention. Six studies used only an immediate post-assessment (Bitsika & Sharpley, 2000; Gika et al., 2012; Kenney, 2010; LaPlante, 2013; Peck, 1998; Whitney & Smith, 2014).

The overall findings from the 13 studies indicated that the treatment conditions outperformed the control conditions across modalities and across time. Six interventions produced a medium effect size across most outcome measures post-intervention, suggesting at least based on a single study in each case, a reasonable likelihood of efficacy (Benn et al., 2012; Campbell, 2003; Dykens et al., 2014; Feinberg et al., 2014; Ferraioli & Harris, 2013; Kowalkowski, 2013). Mindfulness Treatments (MT) demonstrated large effects with parents showing significant improvement in parenting stress (Ferraioli & Harris, 2013), general health (including anxiety, insomnia, and depression) (Ferraioli & Harris, 2013), and parental distress (Dykens et al., 2014). Acceptance and Commitment Therapy (ACT) resulted in significantly large reductions in depression and parenting stress (Kowalkowski, 2013). MT also demonstrated follow-up improvements of a medium magnitude (Benn et al., 2012) in anxiety and stress, and a large magnitude in general health (Ferraioli & Harris, 2013). These results point to MT as a promising treatment for parents caring for a child with ASD.

In contrast, treatment outcomes for the positive psychology intervention (LaPlante, 2013) resulted in small effects. Assuming homogeneity of participants randomly assigned into treatment conditions, the range of treatment outcomes should follow a normal distribution (Shadish & Haddock, 2009). The results presented here suggest such a normative curve including extremely high and low effect size values. Upon closer inspection, however, treatments with extreme values were vastly different in sample size. At post-intervention, the mindfulness interventions had a relatively small sample size with less than 20 participants. This may have contributed to greater heterogeneity between treatment and control conditions resulting in larger group differences and larger effect sizes. On the contrary, LaPlante (2013) had a sample size ten times as large ($n = 212$) but with a small treatment effect indicated by minimal differences between treatment and control group means. The author reported that within-subject variance across time changed in the direction of the study hypothesis. Specifically, post-intervention participants reported slight reductions in depression and negative affect and increased feelings of gratitude, life satisfaction, and positive affect.

Only one study assessed treatment effects past two-three-month follow-up. Dykens and colleagues (2014) reported generally medium effects sizes at six months follow-up for outcomes due to mindfulness-based stress reduction. Parents reported reductions in anxiety, depression, insomnia, and parental distress, and an increase in life satisfaction and psychological well-being. However, these results were based on only 39% of participants because of high (61%) attrition, raising concerns about this follow-up sample being biased in favour of positive outcomes. Therefore, it is yet unknown whether any parent-focused intervention has lasting positive effects. Several interventions, however, appear promising producing medium to large positive effects that remain two- to three-months after completion: Stress Management and Relaxation Techniques (Benn et al., 2012), Expressive Writing

(Campbell, 2003), Mindfulness-Based Stress Reduction (Dykens et al., 2014), Problem Solving Education (Feinberg et al., 2014), Mindfulness-Based Parent Training (Ferraioli & Harris, 2013), and Acceptance and Commitment Therapy (Kowalkowski, 2013).

Regardless of treatment modality or intervention procedure, a greater number of treatment effects were detected after longer follow-up time points. In some cases, the time period of follow-up made the difference between significant and non-significant results. An illustrative example occurred when examining results for Blackledge and Hayes (2006) and Kowalkowski (2013). Both studies tested Acceptance and Commitment Therapy, which were implemented in a group led by professionals at a clinic setting. Both studies also assessed outcomes at post-test and at 3-months follow-up. From baseline to post-test, results in parenting stress and psychological distress were non-significant for both studies. However, from baseline to the 3-month follow-up period, outcomes improved and showed a significant treatment effect. Additionally, Bitsika and Sharpley (2000) and Peck (1998) only measured assessments at baseline and post-intervention, immediately following the last intervention session. Here again, utilizing a short-term follow-up period, both studies were unable to show significant effects of their tested intervention. Hence, studies that reported significant mental health results assessed outcomes at least two-months post-intervention. Moreover, studies that assessed outcomes at multiple follow-up points reported a larger magnitude of change at later assessment points, such as three or six months (Dykens et al., 2014; Feinberg et al., 2014; Ferraioli & Harris, 2013; Kowalkowski, 2013). Quite possibly, this implies that transformations in mental health require more time before positive effects become apparent.

5.3. Methodological limitations of research-based informal and formal support group models for parents of children with ASD.

The studies reviewed in section 5.2 of this chapter presented a promising body of research on group support for parents of children with ASD. However, that research is also affected by significant limitations which adversely affect the robustness and the generalisability of findings and ultimately prevent clear indication about the best ways to support parents of children with ASD. As mentioned previously, a total of seven randomised control trials were utilised for the research design as they were considered to be valuable for testing intervention efficacy (Shadish, Cook, & Campbell, 2002). On average, randomised control trial studies lost 30% of participants at post-intervention, compared to quasi experimental design studies which lost on average only 11% of participants at post-intervention. For instance, in the study conducted by Kowalkowski (2013), the entire control group withdrew from the study after three weeks of participation. Parents of children with ASD mentioned that they withdrew from the study as they wished for more guidance from a professional instead of peer-to-peer support. Dykens and colleagues (2014) used an inactive control condition by testing a two-arm intervention of mindfulness versus positive psychology. At post intervention, only 17% of 243 participants withdrew from the study. Active comparison conditions could potentially reduce attrition rates in participants when using randomised control trials.

Of the eight randomised control trail studies, only two reported effect sizes across all assessment times. For the remaining five studies, effect sizes across assessment times needed to be calculated. It is expected that as research on interventions for parents of children will keep rising, future researchers should report effect sizes for all outcomes. Moreover, another significant limitation from all 13 studies indicated that only self-report instruments were used

to assessment outcome of interventions for parents of children with ASD. Future research should consider adding other objective measures such as stress and other physical measures which can provide correlational comparison with self-report instruments. Observation measures such as clinical interviews, reports from other sources and observational measures would allow for researchers to have multi-dimensional assessment of intervention outcomes and strengthen positive results.

Recruitment methods were used to make sure that participants would be representative of the general population of parents of children with ASD. On the other hand, Campbell (2003) obtained a low response rate for the recruitment in his study, as a consequence a majority of the participants in the study were married Caucasian mothers. Furthermore, participants from Kenney (2010) and Kowalkowski (2013) studies were mainly English-speaking stay-at-home mothers, who had time available to attend research sessions. Furthermore, participants at baseline seemed to have high baseline levels of stress, anxiety and depression. This information indicates that participants experiencing mental health problems self-selected to participate in interventions to address their psychological needs. However, Benn and colleagues (2012) mentioned that participants with higher baseline levels of depression and stress were more likely to withdraw out of interventions and less likely to complete follow-up measures. Bitsika and Sharpley (2000) and Kowalkowski (2013) noted limitations in performing certain statistical tests due to the small sample size of their participants which were a significant limitation to generalisability.

Caucasian mothers of children with ASD over thirty years old were over represented, as a consequence generalisability to a more diverse sample of participants was compromised. For instance, Kenney (2010) explained that results may not apply to fathers of children with ASD as few participated. Inferences should be made with extreme caution when considering

treatment effects of interventions in a multi-cultural, multi-generational population. Another significant limitation is the lack of independent replication of any of the interventions that have shown promising results. Each specific intervention has been analysed in one single study. Without replication of promising interventions, the interventions only offer preliminary support of their effectiveness.

Study 1 aimed to address parents' needs by taking into consideration limitations mentioned in previous research. A numerous amount of previous research findings indicated that parents of children with ASD benefited and valued group support services (Barnett et al., 2003; Bitsika & Sharpley, 1999; Mansell & Morris, 2004). Consequently, study 1 consisted of administering group support sessions for parents that would address different needs they had at the time of recruitment. A study conducted by Ellis and colleagues (2002) found that parents' greatest identified need was for information so they could better understand their ASD child. As a consequence, four different training groups were created to address different needs parents may have at the time of recruitment including: 1) Information on ASD; 2) Information on using Functional Behavioural Assessment (FBA); 3) Information on how to implement coping skills and strategies; 4) Information combined on the application of FBA and coping skills. Participants had the opportunity to select the group they believed would be more beneficial to them in order to make sure that parents would attend a group that presented information on an area of need for participants.

Furthermore, the decision was made in the creation of study 1 to conduct follow-up assessments to measure any long-term changes that would have occurred in participants after they attended the different training groups. Three different follow-ups were administered to participants as previous research findings have indicated that treatment effects reported generally medium effects sizes at six months follow-up (Dykens et al., 2014). Several

interventions also appear promising generating medium to large positive effects that remain two- to three-months after the completion of different training support groups (Benn et al., 2012; Campbell, 2003; Feinberg et al., 2014; Kowalkowski, 2013). The individual administering the sessions to participants in study 1 was a trained professional. This decision was made due to Dykens and colleagues (2014) research findings, indicating that participants withdrew from their control group due to the fact that it was not conducted by a trained professional.

As previous research findings ran sessions once per week and this format was proven to be efficient, sessions implemented in study 1 were ran once a week (Bitsika & Sharpley, 2000; Campbell, 2003; Feinberg et al., 2014; Kowalkowski, 2013). Previous research findings also indicated that most weekly interventions lasted six (Dykens et al., 2014; Feinberg et al., 2014; Gika et al., 2012) to eight weeks (Bitsika & Sharpley, 2000; Ferraioli & Harris, 2013; Kowalkowski, 2013; Whitney & Smith, 2014). Consequently, the decision was made to implement weekly interventions that would last eight weeks. The intervention sessions ranged from five (Benn et al., 2012; Kenney, 2010) to nine weeks (Peck, 1998) in duration. The intervention sessions in study 1 lasted six weeks, and two further sessions (Pre-Intervention and Post-Intervention) consisted of participants completing different measures to assess any changes in their depression, anxiety, parent-child relationship and in their child's use of difficult behaviours across time.

6. Study 1: Comparing Three Models for Delivering Group-Based Support to Parents of Children with ASD

6.1. Study rationale.

Parents of children with ASD are reported to experience greater levels of stress (Dabrowska & Pisula, 2010), anxiety (Weiss, 2002), and depression (Greenberg et al., 2004) than parents of children with other developmental disorders or physical impairments (Koegel, et al., 1992). Factors which contribute to the elevated stress levels of parents of ASD children relate to the unpredictability of their child's behaviour (Allik et al., 2006; Benson, 2006; Blacher & McIntyre, 2006), their child's cognitive/learning difficulties (Bebko et al., 1987; Moes, 1995), the under-development of their child's communication skills (Bebko et al., 1987; Moes, 1995), the lack of understanding from the wider community of the nature of ASD (Farrugia, 2009; Gray, 2002), and the onset of marital difficulties (Hartley et al., 2010; Pottie et al., 2009). A proliferation of formal support groups for parents of children with ASD has been noted in the research, but these vary greatly in relation to content, delivery methods, and data-collection on parents' changes. There is very little information regarding which parent-focused interventions would be most capable of creating positive mental health outcomes for parents, with a possible flow on effect to their children with ASD. Specifically, there have been few investigations into the ways in which resilience might reduce the onset or intensity of symptoms of depression and anxiety in parents of children with ASD (Lam et al., 2010; Mandell & Salzer, 2007).

Research into support groups for parents of children with ASD has traditionally focused on helping parents to better manage their children's behavioural and autism-based difficulties. There is a paucity of research into the development of targeted interventions designed to train parents of children with ASD to manage the adverse emotional and

psychological experiences they themselves confront on a day-to-day basis. Gaps and limitations were noted and discussed in Chapter 4 of the thesis. For example, one main limitation in the previous literature consisted of the utilisation of randomised control trials for certain research designs, which resulted in lower attrition rates of participants compared to studies using quasi experimental designs. Another significant limitation was noted in the measurement of the outcomes of interventions in several formal support groups. Self-report instruments were commonly used to assess the outcome of interventions for parents of children with ASD, which limited researchers' ability to have multi-dimensional assessment of intervention outcomes. This inability to generalise results to a diverse group of parents of children with ASD is a limitation, with Caucasian stay-at-home mothers over thirty years old being over-represented in past research. Moreover, studies that utilised a short-term follow-up period were unable to show significant positive effects from their tested intervention on parents' mental health well-being. The variation and limitations in this literature prevent clear conclusions being drawn on what content and delivery format would result in the best parent support. There is a need for a study which delivers and evaluates, in relation to parent change in mental health, the content and delivery format of the major group support models from the literature.

The three most common support group models from the review conducted in Chapter 5 of the thesis were selected and will be compared in this thesis. Study 1 aimed to overcome some of the main limitations observed in the implementation of support groups and in evaluating the efficiency of such groups. For instance, in depth and multiple pre-test and post-test measures of changes in mental health/functioning were administered to participants to detect any immediate changes and to examine the maintenance of any changes over time. Furthermore, participants were able to make choices about the group they wished to attend (FBATG or STG) and the time (morning or evening sessions) they wished to attend. This

recruitment strategy was used in order to reduce the number of participants withdrawing from the study, as they were able to select the group that suited their needs at the time and they were able to select a time that was most convenient for their busy schedules.

Another limitation that study 1 addressed was concerned with the lack of variety in participants' biographical backgrounds. Study 1 recruited mothers, fathers, and/or caregivers of children with ASD, and night sessions were offered to participants so parents working full-time or part-time could attend the groups more easily. Finally, another limitation which study 1 aimed to overcome consisted of participants' inability or reluctance to give their opinion on each session and which sessions they found to be most helpful. Parents' satisfaction with the FBATG and STG, and parents' satisfaction with the content of each session, was assessed at the end of the groups. This process allowed for the most highly-rated three sessions from each support group to be combined into a third support group. The aim was to assess whether participants' attending the CG would give similar ratings of satisfaction with the sessions and the group, as participants attending the FBATG and the STG (these four models are discussed in detail in section 6.2.3.3, pp.104-108).

Clarification on the issue of what constitutes effective parent-focused support might be gained via the investigation of two questions. First, is delivery of parent-focused intervention capable of assisting parents to manage the typical adverse emotional/psychological experiences they encounter? Second, is parent-focused intervention more effective in creating positive changes in parents' emotional/psychological states than child-focused approaches? The present study aimed to investigate these two research questions by examining the effects of four models for delivering group-based support to parents of children on parent mental state (i.e., anxiety and depression), parent resilience, and parenting satisfaction.

6.2. Methods.

6.2.1. Participants.

6.2.1.1. Parent participant features.

Participants for this study consisted of 36 adult biological parents and/or legal guardians of children with ASD. Of these 36 participants, twenty eight (78%) were mothers, six (17%) were fathers and two were grand-parents (5%) of children with ASD. They ranged in age from 30 to 59 years, with a mean age of 45 years ($SD = 6.31$). The majority of participants were married (72%), four participants were single parents (11%), another four participants were divorced (11%) and two participants were in a de facto partnership (6%). Twenty participants (55%) had two children, nine parents (25%) had three children, four parents (11%) had one child, two parents (6%) had nine children, and one parent (3%) had five children. Thirty parents (83%) reported having only one child diagnosed with ASD, five participants (14%) reported having two children diagnosed with ASD and one parent (3%) reported having five children diagnosed with ASD. Under half of the participants had a TAFE education level (47%), ten participants (28%) had a graduate university degree, six parents (17%) had high school Year 12 certificate, and three participants (8%) had a postgraduate university qualification. Of the thirty-six participants, thirteen parents (36%) were not employed, ten parents (28%) were employed part-time, seven parents (19%) were employed full-time and six parents (17%) were self-employed.

6.2.1.2. Parent participant support features.

Of the 36 participants, 28 parents (78%) reported not having access to government-funded respite services while 8 parents (22%) reported accessing government-funded respite services. Of the 8 participants who reported accessing government-funded respite services, 4 parents (50%) accessed out of home respite services, 1 parent (12%) reported accessing in

home respite services and 3 parents (38%) reported accessing both in home and out of home respite services. For parents who reported not accessing government-funded services (78%), brief explanations were given by 25 participants as to why they did not access these types of services and these reasons are presented in Table 1.

Table 1:

Brief Reasons Given by Participants as to why they did not Access Government-funded Respite Services

Participants' Reasons	Frequency (*n = 25*)	Percentage (%)
Difficulty in accessing respite services	7	28
Unaware of respite services being available	5	20
Difficulty trusting others to look after their child	4	16
Child struggles with new people	3	12
Child is High Functioning	2	8
Others need the services more	2	8
Assistance received by family	1	4
Funding was already spent	1	4

Furthermore, 19 parents (43%) mentioned that they received support from family members and friends, with 17 parents (47%) reporting that they did not receive any support from family members and friends. Of the 19 parents who reported receiving support from family members and friends, 7 parents reported receiving support sometimes from family members and friends and 12 parents reported receiving support most of the time. Only 12

parents (33%) reported having child care or recreational services available, with Gold Coast REC and Sports and before/after school care being reported by 50% of parents. For the 24 parents (67%) who did not access child care or recreational services, the following reasons were given: 1) Unaware of services available (18%); 2) Child does not like it (18%); 3) Difficulty trusting other people (18%); 4) Services were not needed (14%); 5) Time and money restrictions (9%); 6) Behavioural/Social difficulties of the child (9%). For the 17 parents (47%) who reported being able to access any other form of assistance for their child, 8 parents (47%) reported accessing other form of assistance from government agencies and 9 parents (53%) reported accessing other forms of assistance that were privately funded.

6.2.1.3. ASD Child features.

Although the children with ASD were not formal participants in the study, basic biographical data were collected on them to assist in contextualising the experiences of the parents in relation to their children's ages, sex, specific ASD and other diagnoses, and school type. Participants' children ranged in age from 6 to 30 years, with a mean age of 11 years ($SD = 4.43$). Participants' reported that the age of the children at the time when they received a diagnosis for ASD ranged from 2 to 17 years, with a mean age of 6 years ($SD = 3.48$). The majority of children were males (67%), with only 12 children being females (33%). Participants reported that they had to consult between 1 to 10 professionals before their child received a diagnosis for ASD, with an average of 3 professionals being consulted before the child received a formal diagnosis. It took an average of 4 months for the children's ASD diagnosis to be confirmed. Participants reported that 21 of the children diagnosed with ASD attended mainstream school (58%), while the remaining 15 children attended a specialist school (42%). Of the 21 children with ASD attending mainstream school, 14 children (67%) had access to one-to-one support from an integration aide. Children were able to access to

one-to-one aide support ranged from 1 to 20 hours per week, with an average of five hours per week of one-to-one aide support.

6.2.2. Procedure.

6.2.2.1. Recruitment of participants.

Participants were recruited through the Centre for Autism Spectrum Disorder (CASD) at Bond University, using the participants' database. The three inclusion criteria for this study required participants: to be the biological parent and/or legal guardian of a child with a confirmed ASD diagnosis, to have major caregiving responsibility for the child, and to be living in the same residence as that child. An email was sent to all of the parents of children with ASD on the CASD database, and the Explanatory Statement (ES) for the study was attached to the email so potential participants had immediate access to a description of the aims and procedures for the study (see Appendix B for the ES). Parents of children with ASD could contact the researcher by phone or by email if they wished to participate in the study.

Parents were provided with the opportunity to a select support group option and time for attending that group so as to increase the chances that they attended a group with the capacity to meet their particular needs. Therefore, parents were given the option of attending a Functional Behavioural Assessment Training Group (FBATG) or a Skills Training Group (STG). The parents could choose to attend an ASD Knowledge Group (ASDKG), but none chose it, and as a consequence, the group was dropped from the study, leaving the FBATG, STG, and CG for implementation. Subsequently, three different models for delivering group-based support to parents of children with ASD were offered instead of four. Table 2 presents the reasons why 26 parents found the ASDKG to be of minimal relevance to them. Also, participants could choose the time of day (i.e., morning versus evening support groups) when they preferred to attend their nominated group.

Table 2:

Participants' Reasons for not Choosing to Attend the ASDKG

Parent-Reported Reason	Frequency (*n* = 26)	Percentage (%)
FBATG or the STG would be more beneficial	16	62
Ability to attend only one group	6	23
Already knowledgeable on ASD	4	15

Participants were informed of two conditions before they selected the group they wished to attend: 1) a maximum of 15 parents could attend each group and that consequently they could be denied to attend their preferred group if it was already full; 2) they could be allocated to the Combined Group (CG) even after they had selected the specific group they wished to attend. Parents were allocated to the CG via a basic numeric system, in which every fourth participant who contacted the Centre to enrol in one of the support groups was allocated to the CG. When participants were allocated to the CG, they were informed that they would be put on a waitlist until the FBATG and STG were completed. Participants were sent an email by the researcher, informing them whether they were allocated to the group of their choice or whether they had been allocated to the CG (see Appendix C for an example of the email of confirmation sent to participant).

When participants came for the Pre-Intervention session, they were handed a consent form (see Appendix D for the consent form). The consent form provided participants with a formal basis to confirm that they understood the explanation offered in relation to procedures,

confidentiality, and voluntariness. All signed consent forms were collected and stored under lock and key for the duration of time specified by the Bond University Human Research Ethics Committee (BUHREC). In order to assess any changes in participants' anxiety and depression levels after they attended the support groups, the facilitator decided to implement a cut-off point that would allow for the data to be analysed. Consequently, participants had to attend a minimum of four sessions out of the six sessions offered in each group for the data collected to be used to perform analyses.

6.2.3. Setting, research design and assessment.

6.2.3.1. Setting.

All sessions were conducted at Bond University by the student researcher, using the same meeting room to maintain consistency in the environment in which participants would take part in the support groups. The meeting room was sound proof and approximately four by seven meters in size. It contained six large desks around which twenty people could sit in a square arrangement. A computer was accessible, which was used each week to deliver a PowerPoint presentation based on a pre-determined topic. Participants were also given a booklet with the information for each session they attended; they could take notes on the booklet during each session they attended for their convenience.

6.2.3.2. Research design.

The design for study 1 was a pre-post-test plus follow-up design in which the effects of three intervention groups were compared. This comparison looked at change or effects from during group delivery (pre-post measures) and for a period of time after the group was completed (follow-up measures). The present study aimed to evaluate three different content-models for delivering group-based support to parents of children with ASD. Six different

phases were implemented to assess potential changes in participants' mental health well-being across time and to measure the effect the three different content-models for delivering group-based support had on participants' mental health well-being.

The first phase consisted of the Pre-Intervention assessment. The aim of phase 1 was to obtain baseline measures on participants' anxiety, depression, and resilience, the quality of the relationship with their child, and the presence and frequency of their child's ASD behaviours. These baseline measures were an indicator of how participants felt prior to the commencement of the support group, so these measures could be compared to measures obtained after the implementation of the support groups. Participants came to Bond University to complete the survey one week prior to the commencement of the support groups. Participants were greeted by the facilitator of the support groups and taken in the room that was used for the remainder of the sessions. Participants were officially welcomed to the support group and they were given a consent form to sign (see Appendix D), indicating that they understood the requirements for their participation in study 1. Participants were asked to complete a survey and the facilitator was present to answer participants' questions. The completion of the survey took on average 60 minutes, as participants completed the survey the facilitator collected the surveys and reminded participants that session 1 will be conducted next week at the same location, time and on the same day.

Phase 2 comprised sessions 1 to 6. At the conclusion of each session participants were asked to evaluate the session they had just finished. Participants expressed how valuable they found each session in relation to topic practice strategies, and they shared which particular aspect of the session was valuable to them and why. The aim of phase 2 was to identify the top three sessions of six, scored as the most valuable sessions by participants attending the FBATG and the STG. The top three sessions scored by participants for each support group

were going to be implemented in the CG. Therefore, at the conclusion of each session participants were handed a "participant evaluation" form to complete. The completion of the form took approximately 5 to 10 minutes and participants' answers remained de-identified for confidentiality purposes. An example of a "participant evaluation" can be found in Appendix E.

The Post-intervention assessment was referred to as phase 3. The aim of phase 3 was to obtain measures on participants' anxiety, depression, and resilience, the quality of the relationship with their child, and the presence and frequency of their child's ASD behaviours after they completed the support group. A process was designed to assess the presence of effects Pre-Intervention and Post-Intervention for parents of children with ASD, which consisted of conducting paired-samples t-test to evaluate the impact of the FBATG, the STG, and the CG on participants' levels of anxiety (via GAD7 total score) and depression (via PHQ9 total score). The same t-tests comparisons were used across all variables. Participants completed the survey in the presence of the facilitator, in case they needed any assistance, and it took approximately 60 minutes for participants to complete the survey. Participants were also given a questionnaire to complete, aiming to identify their satisfaction with the support group they attended. Participants were able to mention what they found to be helpful in the group they attended, what they were satisfied with, and they had the opportunity to mention what they were not satisfied with. This questionnaire was administered so the facilitator could identify which areas of the support groups were efficient and which areas might require any modifications for future implementations of the support groups. Participants took on average 5 to 10 minutes to complete this questionnaire. At the end of phase 3 participants were reminded that they were going to receive "SurveyMonkey" links on

three different occasions to complete the survey they had already completed in phase 1 and in phase 3.

Phases 4 (Follow-Up 1), 5(Follow-Up 2), and 6 (Follow-Up 3) consisted of the online administration of the survey that participants had completed in phases 1 and 3. The survey was made available through "SurveyMonkey". The aim of phases 4, 5, and 6 was to assess the maintenance of effects (post-follow-ups) for parents of children with ASD, conducting paired-samples t-test to evaluate the impact of the FBATG, the STG, and the CG on participants' levels of anxiety (via GAD7 total score) and depression (via PHQ9 total score). Participants were sent an email each week they had to complete the online survey, and they were given instructions on how to complete the survey. Participants were provided with the contact details of the facilitator in case they required some assistance to complete the online survey. Participants were sent the Follow-Up assessment 1 (phase 4) at four weeks post-group implementation, the Follow-Up assessment 2 (phase 5) at eight weeks post-group implementation, and the Follow-Up assessment 3 (phase 6) at twelve weeks post-group implementation. An example of the email sent to participants can be seen in Appendix F. Furthermore, the measures given to participants at different phases of study 1 have been presented in Table 3.

Table 3:

Administration of Measures for Participants to Complete at Different Phases of the Support Groups

Measures	Phase 1	Phase 2	Phase 3	Phase 4	Phase 5	Phase 6
Survey	🟩		🟩	🟩	🟩	🟩
Sessions Evaluation		🟩				
Satisfaction with Overall Support Group			🟩			

6.2.3.3. Description of the three support groups delivered in study.

Even though four groups were created for the purpose of study, only three groups were used with participants. The ASDKG was dropped due to poor uptake from parents and as a consequence this group will not be described. Information as to why participants were not interested in attending the ASDKG has been listed in Table 2. The FBATG, STG and CG will be described in the subsequent sections of the thesis, placing an emphasis on describing the general focus of each group, presenting the headings of sessions, and describing the concepts/ideas taught in each session. As explained in the previous section on the recruitment of participants, parents attended either the support group of their selection or they were allocated to the CG. Information on participants such as the number of participants who attended each group, their sex ratio and participants' age group, has been presented in Table 4.

Table 4:

Sex Ratio and Age Range of Participants who Attended the Three Groups

Name of Groups	Number of Participants (N = 36)	Sex Ratio	Age Range (years)
FBATG	11	Fathers = 1 Mothers = 10	34 – 51
STG	12	Fathers = 3 Mothers = 9	30 – 58
CG	13	Fathers = 3 Mothers = 10	35 - 59

The focus of the FBATG was to familiarise parents with a framework, called Functional Behaviour Assessment (FBA), which they could use to understand the reasons for their child's behaviour and work towards changing it. Therefore, discussions on different ways of understanding why their child used particular behaviours and practicing some management strategies they could use at home were raised throughout the sessions. The aim of the FBATG was to help parents become systematic observers and problem-solvers in relation to their child's behaviour. The specific headings for each session conducted in the FBATG have been listed in Table 5. Furthermore, the concepts/ideas for each session taught in the FBATG have been presented in Appendix G.

Table 5:

Topics Addressed in Each Session of the FBATG

Sessions	List of Topics
1	Core features of ASD and its impact on child functioning.
2	Learning how to define child's problematic behaviours.
3	Identifying the antecedents for child's difficult behaviours.
4	Identifying the valued outcomes of child's difficult behaviours.
5	Discussing parental ability to understand, cope, and even prevent their child from engaging in difficult behaviours.
6	Reviewing the FBATG programme and its effect on parents' understanding of their child's problematic behaviours.

The focus of the STG was to familiarise parents with three components which are acceptance, optimism and self-efficacy. The goal of the STG was be to increase parents' resilience (ability to cope/deal with challenging events that might arise in their daily lives, without being negatively affected psychologically (i.e., depression and/or anxiety). The focus was on parents' positive emotional experiences, the active coping strategies that they implemented, increasing their self-confidence, identifying their beliefs and the type of social support they accessed, and identifying the goals that they set for themselves and their child. The specific headings for each session conducted in the STG have been listed in Table 6. Furthermore, the concepts/ideas for each session taught in the STG have been presented in Appendix H.

Table 6:

Topics Addressed in Each Session of the STG

Sessions	List of Topics
1	Identifying social/professional support received by parents of children with ASD.
2	Identifying and discussing beliefs that parents find helpful in accepting their child's impairment.
3	Identifying and discussing the positive emotional experiences in parents' life.
4	Introducing parents to coping strategies used by other parents of children with ASD to remain optimistic.
5	Identifying active coping strategies that assist parents in handling difficult situations related to their child's ASD.
6	Reviewing the STG programme and assessing parents' self-confidence.

The focus of the CG was to introduce parents to the sessions that parents attending the FBATG and parents attending the STG found to be most valuable. Parents in the CG received a combination of information and practice in applying basic principles of FBA to current child behaviours, as well as skills training and access to strategies relevant in day-to-day life. The three sessions from the FBATG that were scored as being the most valuable sessions by participants were administered to parents attending the CG. Similarly, the three sessions from the STG that were scored as being the most valuable sessions by participants were administered to parents attending the CG. The specific headings for each session conducted in the CG have been listed in Table 7. Furthermore, the concepts/ideas for each session taught in the STG have been presented in Appendix I.

Table 7:

Topics Addressed in Each Session of the CG

Sessions	List of Topics
1	Identifying and discussing beliefs that parents find helpful in accepting their child's impairment.
2	Introducing parents to coping strategies used by other parents of children with ASD to remain optimistic.
3	Identifying active coping strategies that assist parents in handling difficult situations related to their child's ASD.
4	Learning how to define child's problematic behaviours.
5	Identifying the valued outcomes of child's difficult behaviours.
6	Discussing parental ability to understand, cope, and even prevent their child from engaging in difficult behaviours.

6.2.3.4. Pre-and-Post support group self-report scales used to measure parent and child changes.

The effects of support group attendance were measured in relation to mental health (i.e., the Patient Health Questionnaire- 9 questions (PHQ-9) scale (Spitzer, Williams & Kroenke, 1999); and the Generalised Anxiety Disorder- 7 questions (GAD-7) scale (Spitzer, Kroenke, Williams, & Löwe, 2006), which were administered at Pre-Intervention, Post-Intervention, and Follow-Up 1, 2, and 3), and in relation to the quality of parent-child relationship (i.e., the Parent-Child Relationship Inventory (P-CRI) (Gerard, 1994), which was administered at Pre-Intervention, Post-Intervention, and Follow-Up 1, 2, and 3). The effects of support group attendance were also measured in relation to resilience (i.e., the Connor-Davidson Resilience Scale (CD-RISC) (Connor & Davidson, 2003), which was administered

at Pre-Intervention, Post-Intervention, and Follow-Up 1, 2, and 3), and in relation to child's ASD behaviours (i.e., the ASD Behaviour Checklist, which was administered at Pre-Intervention, Post-Intervention, and Follow-Up 1, 2, and 3). In addition to these four self-report scales, participants were required to complete the Parent Profile Questionnaire (PPQ) (Bitsika & Shapley, 2004), which was administered at Pre-Intervention. Furthermore, participants were asked to complete a questionnaire on their overall satisfaction with the support group they attended, which was administered at Post-Intervention. Table 8 gives an indication of the surveys and weeks of administration.

Table 8:

Lists of Scales used in Surveys in Relation to Measurement Point and Week Administered

Phase/Measurement Point	Scales in Survey	Week Scales Administered
Pre-Intervention	PPQ, PHQ-9, GAD-7, P-CRI, CD-RISC, and ASD Behaviour Checklist.	Week 0
Post-Intervention	PHQ-9, GAD-7, P-CRI, CD-RISC, ASD Behaviour Checklist, and Satisfaction Questionnaire.	Week 7
Follow-Up 1, 2, and 3	PHQ-9, GAD-7, P-CRI, CD-RISC, and ASD Behaviour Checklist.	Weeks 12, 16, and 20

6.2.3.4.1. The Patient Health Questionnaire- 9 (PHQ-9).

The PHQ-9 (Spitzer, Williams & Kroenke, 1999) is a self-report depression screening instrument based on the nine symptoms of the DSM–IV (Criterion A) for major depressive episode (MDE), which have not changed for the DSM-5. Those nine symptoms are depressed mood, anhedonia, appetite change, sleep disturbance, psychomotor agitation or retardation, loss of energy, feelings of worthlessness or guilt, diminished concentration, and suicidal thoughts or attempts. MDE is suggested if, of the 9 items, 5 or more are circled as at least "More than half the days", or if either the item on depressed mood or the item on anhedonia are circled as at least "More than half the days". The PHQ9 (Spitzer et al., 1999) was used to measure any presence of depression and pattern of depressive symptoms, which scores each of the 9 items in relation to the DSM-IV criteria for depression using a four-point Likert scale (0 = not at all, 1 = several days, 2 = more than half the days, and 3 = nearly every day). The PHQ-9 has a functional impairment item which asks participants to specify how depression affects their aptitude to 'do your work, take care of things at home, or get along with other people' (Kroenke et al., 2001). As a severity measure, the PHQ-9 scores can range from 0 to 27, since each of the 9 items can be scored from 0 (not at all) to 3 (nearly every day). PHQ-9 scores from 5 to 9 indicated mild levels of depression, scores from 10 to 14 indicated moderate levels of depression, scores from 15 to 19 indicated moderately severe levels of depression and scores of 20 and above indicated severe depression. This measure was designed for use in clinical settings and it has become a widely-used tool in health and rehabilitation research (Spitzer et al., 1999).

The PHQ-9 cut-off points to diagnose someone with major depression include if 5 or more of the 9 depressive symptom criteria have been present at least "more than half the days" in the past 2 weeks, and 1 of the symptoms is depressed mood or anhedonia. Other depression

is diagnosed if 2, 3, or 4 depressive symptoms have been present at least "more than half the days" in the past 2 weeks, and 1 of the symptoms is depressed mood or anhedonia (Kroenke, Spitzer & Williams, 2001). The original validation studies conducted in the United States by Spitzer and colleagues (1999; Spitzer, Williams, Kroenke, Hornyak, & McMurray, 2000) were of 3,000 patients from primary medical care clinics and 3,000 patients from obstetrics-gynecology care clinics. These reports suggested that the PHQ-9 has good internal consistency producing Cronbach's alpha of .86 and .89. Additionally, test–retest reliability had a high correlation at r = .84 and discriminant validity was established via a ROC analysis that produced an area under the curve for the PHQ9 of .95 when diagnosing depression (Kroenke et al., 2001). Moreover, criterion validity was demonstrated by both high sensitivity and specificity for the PHQ9. In addition, among the 6000 participants who completed the PHQ9, 580 were interviewed by mental health professionals, and results demonstrated strong agreement between diagnoses made by the PHQ9 and by the mental health professionals (Kroenke et al., 2001).

The PHQ-9 is an excellent tool for obtaining information about depression rates among individuals who typically present their concerns about depressive symptoms in primary care settings (Probst et al., 2006). According to Löwe, Schenkel, Carney-Doebbeling, and Göbel (2006) the PHQ-9 is equally valid in men and women. Lin and colleagues (2014) found that patterns in the total PHQ-9 score broadly reflected parents of children with Intellectual Disability (ID) accounts of the severity of their depression over time. Researchers have used the PHQ-9 to measure depression in parents of children with disabilities, describing this scale as suitable for use in screening for depression among parents of children with severe disabilities and to screen for depression in parents of children of children with ASD (Bitsika & Sharpley, 2016; Blucker, Elliott, Warren, & Warren, 2011; Gatzoyia, et al.,

2014; Resch, Elliott & Benz, 2012). The PHQ-9 was used to detect depression in parents in studies 1 and 2.

6.2.3.4.2. *The Generalised Anxiety Disorder- 7 (GAD-7).*

The GAD-7 (Spitzer et al., 2006) is a self-report measure to detect the presence and severity of Generalised Anxiety Disorder (GAD) as defined in the DSM-IV-TR and the DSM-5. The 2 core criteria (A and B) of the DSM-IV definition of GAD are captured by the first 3 items of the scale. Participants have to answer seven different questions related to anxiety, indicating how they have felt over the past two weeks. Participants responses are presented on a four-point Likert scale (0 = not at all, 1 = several days, 2 = more than half the days, and 3 = nearly every day). The sums of the scores for all seven items are added, with a total score ranging from 0 to 21. Some cut-off points have been introduced to identify the severity of anxiety experienced by individuals, with scores of 5 to 9 indicating mild levels of anxiety, scores of 10 to 14 indicating moderate levels of anxiety and scores of 15 and above indicating severe anxiety levels. A GAD-7 cut point of 15 or greater maximises specificity and approximates prevalence (9%) more in line with current epidemiologic estimates of GAD prevalence in primary care. However, sensitivity at this high cut point is low (48%). Most patients (89%) with GAD had GAD-7 scores of 10 or greater, whereas most patients (82%) without GAD had scores less than 10.

A criterion-standard study of the GAD-7 was conducted, in which 965 patients completed the GAD-7 and were also evaluated by a mental health professional. The GAD self-report scale diagnosis and the independent diagnoses made by the mental health professionals were compared and it showed that the GAD-7 had good reliability, criterion, construct, factorial, and procedural validity, thus making the GAD-7 a valid and efficient tool for screening for generalized anxiety disorders in a clinical practice setting. According to

Spitzer and colleagues (2006) the internal consistency of the GAD-7 was excellent (Cronbach =.92). Test-retest reliability was also good (intraclass correlation=0.83). Comparison of scores resulting from the self-report scales with those resulting from the MHP-administered versions of the same scales generated similar results (intraclass correlation=0.83), showing respectable procedural validity. The GAD-7 has been validated as a diagnostic tool and as a severity assessment tool, with a score of 10 or more having good diagnostic sensitivity and specificity. Higher scores on the GAD-7 correlate with more functional impairments experienced by individuals. The scale was developed and validated based on the DSM-IV criteria and it remains clinically useful after the publication of the DSM-5 due to the fact that differences in GAD diagnostic criteria are minimal (Locke, Kirst & Shultz, 2015).

The GAD-7 has been used to assess the effectiveness of treatment outcomes, measuring anxiety of participants prior to intervention and after intervention (Titov et al., 2009) and to assess the anxiety of mothers during and after their pregnancies (Simpson, Glazer, Michalski, Steiner, & Frey, 2014), and to assess the anxiety of adults seeking health services (Spitzer et al., 2006; Vasiliadis, Chudzinski, Gontijo-Guerra, & Préville, 2015) and to assess anxiety in individuals who met the diagnostic criteria, using the DSM-IV (Dear et al., 2011; Ruiz et al., 2011). As the GAD-7 has been described as a self-administered, easy to use and not time consuming scale (Ruiz et al., 2011), this instrument was selected to assess anxiety in parents of children with ASD in studies 1 and 2.

6.2.3.4.3. The Parent-Child Relationship Inventory (P-CRI).

The P-CRI (Gerard, 1994) is a self-report inventory that highlights how parents perceive the task of parenting and how they feel about their children. The P-CRI consists of 78 items such as "I talk with and listen to my child", "Parents should monitor their child's friendships", and "Having children was the right decision for me". The inventory assesses

parents' views on parenting and aspects of the parent–child relationship. The P-CRI focuses on seven distinct sections, as follows: 1) Parental support; 2) Satisfaction with parenting; 3) Involvement; 4) Communication; 5) Limit setting; 6) Autonomy; 7) Role orientation. Parents are asked to rate their responses using a four-point Likert scale (1 = strongly agree, 2 = agree, 3 = disagree, 4 = strongly disagree). Items are arranged in scales that are a reflection of the relationship between the parent and the child. High scores when rating the P-CRI are an indication of good parenting skills and low scores are an indication of poor parenting skills. Two validity indicators are used with the P-CRI, referred to as Social Desirability (SOC) and Inconsistency (INC). A low SOC suggests that parents are giving distorted responses that present their parent-child relationship in a positive light when it is probably not the case. High scores on the INC suggest that parents were inattentive when responding to the inventory and were potentially giving random responses.

The P-CRI was standardized on over 1,100 parents across the United States. Reliability, as determined by internal consistency, had a median alpha of 0.82, and the mean test–retest correlations were 0.81. P-CRI raw scores are converted to T scores, normalized standard scores with a mean of 50 and a standard deviation of 10. A T score which is more than one standard deviation below the mean (i.e., less than 40) suggests problems in the domain the scale reflects and very low T scores (i.e., below 30) indicate the possibility of very serious problems (Gerard, 1994). Coffman, Guerin, and Gottfried (2006) reported acceptable internal consistency for P-CRI subscales and also suggested strong temporal reliability and construct validity. Gerard (1994) reported alphas (Cronbach's alpha coefficient) for the seven scales ranging from .71 (SUP) to .87 (LIM). Test-retest reliability after 1 week ranges from .68 (COM) to .93 (LIM) and after 5 months from .44 (AUT) to .71 (SUP and ROL). According to Coffman and colleagues (2006) acceptable internal consistency for most

scales and moderate to high 1-year stability for all scales and parents' P-CRI scores correlated with their views of family climate.

In a sample of 249 adoptive families of special needs children, Satisfaction with Parenting, assessed using the P-CRI, was significantly correlated with child behaviour problems (Behavior Problem Index), but the correlation was of a small magnitude (r=-.19). The internal consistency of the scale reported in this sample was .70 (Reilly & Platz, 2003). The P-CRI has been used in previous studies of parent-child relationship in autism (Beurkens, Hobson, & Hobson, 2013; Karst, 2009; Osborne, McHugh, Saunders, & Reed, 2008), and was used in the current study as a standardised measure to assess the quality of the relationship between parent and child.

6.2.3.4.4. The ASD Behaviour Checklist (ASDBC).

The ASDBC (Bitsika, 2000) is used to identify the presence of a wide range of autism-based symptoms during diagnostic assessment and uses a "present" (1) vs "absent" (0) score for each participant's behavioural repertoire. The ASDBC consists of three sections of 8 items each which adhere to the three major areas of Communication, Social Interaction and Adaptive Behaviour impairment specified in the DSM-IV-TR (APA, 1994/2000) for Autistic Disorder and Asperger Disorder and retained within the DSM-5 definition of ASD (APA, 2013). Criterion validity has been established for the ASDBC with the Childhood Autism Rating Scale (Schopler, Reichler & Renner, 1999) ($r = .71$, $p < .01$) and the Adaptive Behaviour Composite scores from the Vineland Adaptive Behaviour Scale (Sparrow, Balla, & Cicchetti, 1984) ($r = .60$, $p < .01$), and reliability has been assessed via Cronbach's Alpha (.77) (Bitsika, Sharpley, & Orapeleng, 2008) which is satisfactory for research purposes (Anastasi, 1982).

The ASD Behaviour Checklist consists of 30 items used to rate the behaviour of an ASD child on three behavioural domains (communication, social interaction and behaviour). This checklist can be completed by parents and caregivers via direct observation of the ASD child in the natural environment and during an interview with a caregiver(s). Each behaviour is rated in relation to whether it is present (*Yes*) or absent (*No*) from the child's repertoire and, in cases where a "*Yes*" rating is earned, the frequency with which the behaviour occurs per week is noted using the four-point scale below. Ratings for the frequency of each of the behaviours on a weekly basis are given through the use of the following four-point Likert scale (0 = never, 1 = rarely, 2 = sometimes, 3 = most of the time) for the way that the individual under evaluation behaves during a typical week.

Some examples of the child's responses for the communication domain are: 1) No or minimal speech; 2) Physical strategies used instead of speech; 3) Atypical or odd use of spoken language and 4) Limited speech functions. Some examples of the child's responses for the social interaction model domain are: 1) Limited understanding of facial expressions/gestures; 2) Misinterpretation of others reactions; 3) Minimal social or emotional reciprocity and 4) Limited capacity to work in a group. Some examples of the child's responses for the behaviour domain are: 1) Obsessive and narrow patterns of interests; 2) Intense reactions to stressors; 3) Difficulty making transitions; and 4) inflexible adherence to non-functional routines. Each time parents identified an item as being present in their child's behavioural repertoire they were not only asked to score the frequency of the behaviour but they were also asked to give a few examples. The ASDBC has been used in previous research to identify the presence of a wide range of autism-based symptoms during diagnostic assessment (Bitsika, Sharpley, Andronicos, & Agnew, 2016; Bitsika, et al., 2008), therefore it was used in studies 1 and 2 to assess parents' reports of their child autism-based symptoms.

6.2.3.4.5. The Connor-Davidson Resilience Scale (CD-RISC).

The CD-RISC (Connor & Davidson, 2003) was utilised to assess participants' resilience. The CD-RISC consists of 25 items such as "I am able to adapt to change", "Things happen for a reason", "I know where to turn for help" and "I have pride in my achievements". Participants were asked to score all 25 items, using a five-point Likert scale ranging from 0 "Not true at all" to 4 "True nearly all of the time". Participants' responses are scored on a maximum of 4 points per responses, as follows: not true at all (= 0), rarely true (= 1), sometimes true (= 2), often true (= 3), and true nearly all of the time (= 4). The scale is rated based on how participants have felt over the past month. The total score ranges from 0 to 100, with higher scores reflecting greater resilience.

The CD-RISC focuses on five different features: 1) Personal competence, high standards and tenacity; 2) Trust in one's instincts, tolerance of negative affect, strengthening effects of stress; 3) Positive acceptance of change and secure relationships with others; 4) Control; 5) Spiritual influences. Total scores on the CD-RISC are negatively correlated (-.76) with total scores on the Perceived Stress Scale (Cohen, Kamarck, & Mermelstein, 1983) and significantly correlated (.83) with total scores on the Kobasa Hardiness Measure (Kobasa, 1979), demonstrating high concurrent validity. According to Connor and Davidson (2003) the CD-RISC has adequate reliability, ranging from 0.89 (Cronbach's alpha) to 0.87 (test-retest reliability).

The scale was administered to subjects in the following groups: community sample, primary care outpatients, general psychiatric outpatients, clinical trial of generalized anxiety disorder, and two clinical trials of PTSD. Sensitivity to treatment effects was examined in subjects from the PTSD clinical trials. The scale demonstrated good psychometric properties and factor analysis yielded five factors. A repeated measures ANOVA showed that an

increase in CD-RISC score was associated with greater improvement during treatment. The CD- RISC has sound psychometric properties and distinguishes between those with greater and lesser resilience. The scale demonstrates that resilience is modifiable and can improve with treatment, with greater improvement corresponding to higher levels of global improvement. The scale exhibits validity relative to other measures of stress and hardiness, and reflects different levels of resilience in populations that are thought to be differentiated; by their degree of resilience (i.e., general population vs. patients with anxiety disorders).

The CD-RISC has been used to assess the resilience of parents of children with ASD, with the aim of assisting parents to develop psychological resilience in dealing with the stress associated with parenting children with ASD (Bitsika et al., 2013). The CD-RISC was selected for studies 1 and 2 due to the fact that previous research assessing parents of children with ASD resilience described the scale as being reliable. Furthermore, Connor and Davidson (2003) mentioned that the CD-RISC could be applied in clinical practice with resiliency interventions. The scale could aid in identifying resilient characteristics but also to assess participants' response to the intervention.

6.2.3.4.6. The Parent Profile Questionnaire (PPQ).

The PPQ consists of a 15-item inventory developed for study 1, to identify child-based features (i.e., diagnosis, impairments, and services) and the parents' responses to these. This questionnaire was only administered to participants at Pre-Intervention. To begin, demographical information was collected on the child, such as the child's age and gender. Then participants were asked questions on the diagnostic process, such as the age of the child when he/she was diagnosed with ASD, the number of professionals that has to be consulted before the child was diagnosed with ASD and how long it took for the diagnosis to be confirmed.

The following section of the questionnaire gathered information on the child's siblings. Participants were asked if the child had any siblings. If the child had a sibling, parents were asked whether the sibling had also been diagnosed with a disorder. If the sibling(s) had received a diagnosis for a disorder, parents were then asked to name the disorder the sibling(s) had received and birth order of the sibling(s) compared to their ASD child. Afterwards, parents were asked some questions on the school environment of their ASD child. Parents were asked if their child attended a mainstream or a specialist school. Then, parents were asked if their child had access to an integration aide. If so, they were asked to list the number of hours their child accessed this aide on a weekly basis.

Finally, parents were asked questions about the types of government-funded respite services, in-home and/or out-of-home services that they were able to access. Parents were also asked to describe the type of assistance they received for their child and they were asked whether they received support from family members or friends to assist them with their ASD child. The questionnaire ended with parents being asked to describe a major difficulty they were experiencing with their child at the moment and having parents describe their major concerns for their child's future.

6.3. Participants' attrition and attendance patterns across the three support groups.

Despite self-selecting in relation to specific group and attendance time, overall attendance was inconsistent across all three groups. Furthermore, some participants dropped out from the groups at different stages. Specific findings on participants' inconsistent attendance and on participants dropping out from the study are presented in the following sub-sections.

Participants' attendance across the FBATG and the CG was less consistent than participants' attendance in the STG. Of the 16 participants enrolled in the FABTG, 5 participants (31%) missed one session out of the six sessions and 5 (31%) more participants missed two sessions out of the six sessions offered, meaning that 63% of participants missed at least one session of the FBATG while 37% attended all six sessions (Refer to Appendix J, Table J1). Of the 16 participants enrolled in the STG, 4 participants (25%) missed one session out of the six sessions and 3 (19%) more participants missed two sessions out of the six sessions offered, meaning that 44% of participants missed at least one session of the STG while 56% attended all six sessions. Participants attending the STG missed less sessions compared to participants attending the FABTG and the CG (Refer to Appendix J, Table J2).

Participants attending the CG missed more sessions than participants attending the FBATG and participants attending the STG. Of the 16 participants enrolled in the STG, 2 participants (13%) missed one session of the six sessions and 10 (63%) more participants missed two sessions out of the six sessions offered, meaning that 75% of participants missed at least one session of the CG while 25% attended all six sessions (Refer to Appendix J, Table J3). Detailed information on participants' attendance patterns has been presented in Appendix J for all three groups.

Four participants (25%) dropped out in the FBATG. Of these 4 participants, 2 participants dropped out of the training group after missing three sessions out of six and the remaining 2 participants never showed up to the training group even though they had enrolled in the group (See Appendix J, Table J1). The number of drop outs for the FBATG was similar to the number of drop outs for the STG. Of 16 participants, 1 participant dropped out of the training group after missing four sessions out of six. Another participant dropped out of the training group after missing five sessions out of six, and the remaining 2 participants

never showed up to the training group even though they had enrolled in the group (See Appendix J, Table J2). Overall, 4 participants (25%) out of 16 dropped out of the STG. The number of drop outs of participants attending the CG slightly decreased compared to the number of drop outs of participants attending the FBATG and the STG. Of 16 participants, 1 participant dropped out of the training group after missing three sessions out of six, and the remaining 2 participants never showed up to the training group even though they had enrolled in the group (See Appendix J, Table J3). Overall 3 participants (19%) out of 16 dropped out of the CG.

6.4 Findings on the three support group effects.

6.4.1. Data analysis plan.

This chapter investigated the impact that the FBATG, the STG, and the CG had on participants' anxiety and depression levels, parents' ratings of the quality of their relationship with their child, parents' frequency reports of ASD behaviour in their child, and parents' resilience. As outlined in Chapter 5 of this thesis, there are very few studies that have investigated the presence and maintenance of effects of content-models for parent support. Therefore, the process designed to assess the presence of effects (pre-post) and maintenance of effects (post-follow-ups) for parents of children with ASD consisted of conducting paired-samples t-test to evaluate the impact of the FBATG, the STG, and the CG on participants' levels of anxiety (via GAD7 total score) and depression (via PHQ9 total score) at these four time points: 1) Pre-Intervention (week − 1) versus Post-Intervention (week 7) total GAD-7 score and total PHQ-9 score; 2) Comparing participants' scores on the GAD-7 scale and on the PHQ-9 scale at Post-Intervention (Week 7) and at FU1 (Week 12); 3) Comparing participants' scores on the GAD-7 scale and on the PHQ-9 scale at Post-Intervention and at

FU2 (Week 16); 4) Comparing participants' scores on the GAD-7 scale and on the PHQ-9 scale at Pre-Intervention and at FU3 (Week 20).

Furthermore, as outlined in Chapter 5 of this thesis, very few studies have investigated the value that participants attributed to not only the topics addressed in different models of parent support groups but also each topic being addressed in different sessions. Participants rated how valuable they found each session and the four topics of each the session to be, on a scale from 1 to 7. A value of 1 out of 7 meant that participants considered the session and/or topic to be "Not valuable", and a value of 7 out 7 meant that participants considered the session and/or topic to be "Very valuable". Detailed information is presented on participants' satisfaction with each session of the FBATG, the STG, and the CG. Also, results on participants' satisfaction with the topics addressed in the FBATG, the STG, and the CG have been presented and participants' attendance throughout each group has been investigated. A comparison was conducted between the three most valuable sessions from the FBATG that were conducted in the CG and the three most valuable sessions from the STG that were also conducted in the CG, to identify whether participants rated similarly the value of sessions and the value of topics that were addressed in sessions that they shared.

A mixed between-within subjects analysis of variance was conducted to assess the impact of three different interventions (FBATG, STG, and CG) on participants' scores on the ASD Behaviour Checklist, in which parents reported on their ASD-related children's behaviours at four different times (Pre-Intervention to Post-Intervention, Post-Intervention to FU1, Post-Intervention to FU2, and Post-Intervention to FU3). A mixed between-within subjects analysis of variance was conducted to assess the impact of three different interventions (FBATG, STG, and CG) on participants' scores on the P-CRI scale, in which parents reported on the quality of their relationship with their ASD children at four different

times (Pre-Intervention to Post-Intervention, Post-Intervention to FU1, Post-Intervention to FU2, and Post-Intervention to FU3). In addition, a mixed between-within subjects analysis of variance was conducted to assess the impact of three different interventions (FBATG, STG, and CG) on participants' scores on the GAD-7, in which parents evaluate their anxiety level at four different times (Pre-Intervention to Post-Intervention, Post-Intervention to FU1, Post-Intervention to FU2, and Post-Intervention to FU3). A mixed between-within subjects analysis of variance was conducted to assess the impact of three different interventions (FBATG, STG, and CG) on participants' scores on the PHQ-9, in which parents evaluate their depression level at four different times (Pre-Intervention to Post-Intervention, Post-Intervention to FU1, Post-Intervention to FU2, and Post-Intervention to FU3).

6.4.2. Pre-and-Post Intervention measures of parent anxiety across the three support groups.

6.4.2.1. Functional Behavioural Assessment Training Group.

The paired-samples t-test conducted to evaluate the effect of FBATG attendance on participants' anxiety as measured via total GAD-7 scores indicated that there was no statistically significant decrease in GAD-7 scores from Pre-Intervention ($M = 7.18$, $SD = 4.70$) to Post-Intervention ($M = 6.36$, $SD = 3.80$), $t (10) = .938$, $p = .370$ (two tailed). The mean decrease in GAD-7 scores was .81 with a 95% confidence interval ranging from -1.12 to 2.76. The eta squared statistic (.079) indicated a moderate effect size. Although there was some positive effect (i.e., decrease in group GAD-7 score) for the FBATG, this was not statistically significant.

6.4.2.2. Skills Training Group.

The paired-samples t-test conducted to evaluate the effect of STG attendance on participants' anxiety as measured via total GAD-7 scores indicated that there was no statistically significant decrease in GAD-7 scores from Pre-Intervention ($M = 6.50$, $SD = 5.80$) to Post-Intervention ($M = 4.75$, $SD = 3.67$), $t(11) = 1.775$, $p = .103$ (two tailed). The mean decrease in GAD-7 scores was 1.75 with a 95% confidence interval ranging from-.41 to 3.91. The eta squared statistic (.222) indicated a large effect size. Although there was some positive effect (i.e., decrease in group GAD-7 score) for the STG, this was not statistically significant.

6.4.2.3. Combined Group.

The paired-samples t-test conducted to evaluate the effect of CG attendance on participants' anxiety as measured via total GAD-7 scores indicated that there was no statistically significant decrease in GAD-7 scores from Pre-Intervention ($M = 8.92$, $SD = 5.17$) to Post-Intervention ($M = 7.07$, $SD = 4.49$), $t(12) = 1.442$, $p = .175$ (two tailed). The mean decrease in GAD-7 scores was 1.84 with a 95% confidence interval ranging from -.94 to 4.63. The eta squared statistic (.147) indicated a large effect size. Although there was some positive effect (i.e., decrease in group GAD-7 score) for the CG, this was not statistically significant.

6.4.3. Post-Intervention and Follow-Up periods 1, 2 and 3 measures of parent anxiety across the three support groups.

6.4.3.1. Functional Behavioural Assessment Training Group.

The paired-samples t-test conducted to evaluate the effect of FBATG attendance on participants' anxiety as measured via total GAD-7 scores indicated that there was no statistically significant decrease in GAD-7 scores from Post-Intervention ($M = 6.36$, $SD = 3.80$) to FU1 ($M = 7.36$, $SD = 6.34$), $t(10) = -.498$, $p = .629$ (two tailed). The mean decrease

in GAD-7 scores was -1.00 with a 95% confidence interval ranging from -5.47 to 3.47. The eta squared statistic (.023) indicated a small effect size. Therefore, it can be concluded that there was no statistically significant difference in the participants' anxiety scores at Post-Intervention and at FU1.

The paired-samples t-test conducted to evaluate the effect of FBATG attendance on participants' anxiety as measured via total GAD-7 scores indicated that there was no statistically significant decrease in GAD-7 scores from Post-Intervention ($M = 6.55$, $SD = 3.84$) to FU2 ($M = 6.44$, $SD = 3.20$), $t(8) = .083$, $p = .936$ (two tailed). The mean decrease in GAD-7 scores was .11 with a 95% confidence interval ranging from -2.97 to 3.19. The eta squared statistic (.000) indicated no effect size. Although there was some positive effect (i.e., decrease in group GAD-7 score) for the FBATG, this was not statistically significant.

The paired-samples t-test conducted to evaluate the effect of FBATG attendance on participants' anxiety as measured via total GAD-7 scores indicated that there was no statistically significant decrease in GAD-7 scores from Post-Intervention ($M = 6.10$, $SD = 3.90$) to FU3 ($M = 7.20$, $SD = 6.14$), $t(9) = -.740$, $p = .478$ (two tailed). The mean decrease in GAD7+ scores was -1.10 with a 95% confidence interval ranging from -4.46 to 2.26. The eta squared statistic (.057) indicated small effect size. Therefore, it can be concluded that there was no statistically significant difference in the participants' anxiety scores at Post-Intervention and at FU3.

6.4.3.2. Skills Training Group.

The paired-samples t-test conducted to evaluate the effect of STG attendance on participants' anxiety as measured via total GAD-7 scores indicated that there was no statistically significant decrease in GAD-7 scores from Post-Intervention ($M = 4.75$, $SD = $

3.67) to FU1 (M = 4.58, SD = 5.35), t (11) = .109, p = .915 (two tailed). The mean decrease in GAD-7 scores was .166 with a 95% confidence interval ranging from -3.19 to 3.52. The eta squared statistic (.000) indicated no effect size. Although there was some positive effect (i.e., decrease in group GAD-7 score) for the STG, this was not statistically significant.

The paired-samples t-test conducted to evaluate the effect of STG attendance on participants' anxiety as measured via total GAD-7 scores indicated that there was no statistically significant decrease in GAD-7 scores from Post-Intervention (M = 4.75, SD = 3.67) to FU2 (M = 4.58, SD = 4.87), t (11) = .240, p = .815 (two tailed). The mean decrease in GAD-7 scores was .166 with a 95% confidence interval ranging from -1.36 to 1.69. The eta squared statistic (.005) indicated a small effect size. Although there was some positive effect (i.e., decrease in group GAD-7 score) for the STG, this was not statistically significant.

The paired-samples t-test conducted to evaluate the effect of STG attendance on participants' anxiety as measured via total GAD-7 scores indicated that there was no statistically significant decrease in GAD-7 scores from Post-Intervention (M = 5.10, SD = 3.95) to FU3 (M = 4.30, SD = 3.83), t (9) = 1.037, p = .327 (two tailed). The mean decrease in GAD-7 scores was .80 with a 95% confidence interval ranging from -.94 to 2.54. The eta squared statistic (.106) indicated a moderate effect size. Although there was some positive effect (i.e., decrease in group GAD-7 score) for the STG, this was not statistically significant.

6.4.3.3. Combined Group.

The paired-samples t-test conducted to evaluate the effect of CG attendance on participants' anxiety as measured via total GAD-7 scores indicated that there was no statistically significant decrease in GAD-7 scores from Post-Intervention (M = 6.66, SD = 4.43) to FU1 (M = 5.66, SD = 3.02), t (11) = 1.149, p = .275 (two tailed). The mean decrease

in GAD-7 scores was 1.00 with a 95% confidence interval ranging from -.91 to 2.91. The eta squared statistic (.006) indicated a small effect size. Although there was some positive effect (i.e., decrease in group GAD-7 score) for the CG, this was not statistically significant.

The paired-samples t-test conducted to evaluate the effect of CG attendance on participants' anxiety as measured via total GAD-7 scores indicated that there was no statistically significant decrease in GAD-7 scores from Post-Intervention (M = 6.80, SD = 5.07) to FU2 (M = 7.10, SD = 1.99), t (9) = -.310, p = .763 (two tailed). The mean decrease in GAD-7 scores was -.30 with a 95% confidence interval ranging from -2.48 to 1.88. The eta squared statistic (.000) indicated no effect size. Therefore, it can be concluded that there was no statistically significant difference in the participants' anxiety scores at Post-Intervention and at FU2.

The paired-samples t-test conducted to evaluate the effect of CG attendance on participants' anxiety as measured via total GAD-7 scores indicated that there was no statistically significant decrease in GAD-7 scores from Post-Intervention (M = 7.70, SD = 4.71) to FU3 (M = 8.20, SD = 5.86), t (9) = -.473, p = .647 (two tailed). The mean decrease in GAD-7 scores was -.50 with a 95% confidence interval ranging from -2.89 to 1.89. The eta squared statistic (.000) indicated no effect size. Therefore, it can be concluded that there was no statistically significant difference in the participants' anxiety scores at Post-Intervention and at FU3.

Overall, the GAD-7 group scores indicate that participants reported the greatest level of anxiety at Pre-Intervention for all three groups (M = 7.58, SD = 6.08). Parents reported lower levels of anxiety at Post-Intervention (M = 6.08, SD = 4.03) and slightly increased levels of anxiety at FU1 (M = 5.91, SD = 5.88). Parents' evaluations of their anxiety levels

decreased slightly at FU2 ($M = 5.38$, $SD = 4.00$) compared to FU1. At FU3, parents reported a slight increase in their anxiety levels ($M = 11.56$, $SD = 8.20$).

The impact of time (i.e., 5 months from Pre-Intervention to Follow-Up 3) upon parents' self-reports of anxiety varied for the three different support groups. When observing the results for the FBATG, parents' evaluations of their anxiety levels decreased significantly at Post-Intervention and at FU2. Parents' attending the STG self-reports of anxiety decreased at Post-Intervention and kept decreasing up to FU3. For parents attending the CG, it appears that parents' self-reports of anxiety decreased consistently from Pre-Intervention up to FU1. Then parents' anxiety levels increased at FU2 and they kept increasing at FU3, appearing quite different from parents attending the FBATG and parents attending the STG. The mean estimates of parents' self-report of anxiety across five time periods have been presented in Figure 1.

Figure 1. Mean estimates (comprising self-reported anxiety using the total score of the GAD7) calculated separately for the FBATG, the STG and the CG presented across five time periods.

6.4.4. Pre-and-Post Intervention measures of parent depression across the three support groups.

6.4.4.1. Functional Behavioural Assessment Training Group.

The paired-samples t-test conducted to evaluate the effect of FBATG attendance on participants' depression as measured via total PHQ-9 scores indicated that there was no statistically significant decrease in PHQ-9 scores from Pre-Intervention ($M = 9.00$, $SD = 6.82$) to Post-Intervention ($M = 7.81$, $SD = 5.30$), t (10) $= .702$, $p = .499$ (two tailed). The mean decrease in PHQ-9 scores was 1.18 with a 95% confidence interval ranging from -2.56 to 4.93. The eta squared statistic (.046) indicated a small effect size. Although there was some

positive effect (i.e., decrease in group PHQ-9 score) for the FBATG, this was not statistically significant.

6.4.4.2. Skills Training Group.

The paired-samples t-test conducted to evaluate the effect of STG attendance on participants' depression as measured via total PHQ-9 scores indicated that there was nearly a statistically significant decrease in PHQ-9 scores from Pre-Intervention ($M = 6.41$, $SD = 3.39$) to Post-Intervention ($M = 4.66$, $SD = 3.17$), t (11) $= 2.049$, $p = .065$ (two tailed). The mean decrease in PHQ-9 scores was 1.75 with a 95% confidence interval ranging from -.12 to 3.62. The eta squared statistic (.275) indicated a large effect size. Therefore, it can be concluded that there was nearly a statistically significant difference in the participants' depression scores at Pre-Intervention and at Post-Intervention.

6.4.4.3. Combined Group.

The paired-samples t-test conducted to evaluate the effect of CG attendance on participants' depression as measured via total PHQ-9 scores indicated that there was no statistically significant decrease in PHQ-9 scores from Pre-Intervention ($M = 9.07$, $SD = 5.83$) to Post-Intervention ($M = 9.23$, $SD = 6.32$); t (12) $= -.133$, $p = .896$ (two tailed). The mean decrease in PHQ-9 scores was -.153 with a 95% confidence interval ranging from -2.66 to 2.36. The eta squared statistic (.000) indicated no effect size. Therefore, it can be concluded that there was no statistically significant difference in the participants' depression scores at Pre-Intervention and at Post-Intervention.

6.4.5. Post-Intervention and Follow-Up periods 1, 2 and 3 measures of parent
depression across the three support groups.

6.4.5.1. Functional Behavioural Assessment Training Group.

The paired-samples t-test conducted to evaluate the effect of FBATG attendance on participants' depression as measured via total PHQ-9 scores indicated that there was no statistically significant decrease in PHQ-9 scores from Post-Intervention ($M = 7.27$, $SD = 4.64$) to FU1 ($M = 7.63$, $SD = 4.71$), t (10) = -.180, $p = .861$ (two tailed). The mean decrease in PHQ-9 scores was -.36 with a 95% confidence interval ranging from -4.86 to 4.13. The eta squared statistic (.000) indicated no effect size. Therefore, it can be concluded that there was no statistically significant difference in the participants' depression scores at Post-Intervention and at FU1.

The paired-samples t-test conducted to evaluate the effect of FBATG attendance on participants' depression as measured via total PHQ-9 scores indicated that there was no statistically significant decrease in PHQ-9 scores from Post-Intervention ($M = 7.44$, $SD = 5.02$) to FU2 ($M = 8.55$, $SD = 5.12$), t (8) = -.531, $p = .610$ (two tailed). The mean decrease in PHQ-9 scores was -1.11 with a 95% confidence interval ranging from -5.93 to 3.71. The eta squared statistic (.033) indicated a small effect size. Therefore, it can be concluded that there was no statistically significant difference in the participants' depression scores at Post-Intervention and at FU2.

The paired-samples t-test conducted to evaluate the effect of FBATG attendance on participants' depression as measured via total PHQ-9 scores indicated that there was no statistically significant decrease in PHQ-9 scores from Post-Intervention ($M = 7.10$, $SD = 4.86$) to FU3 ($M = 7.80$, $SD = 7.96$), t (9) = -.398, $p = .700$ (two tailed). The mean decrease in

PHQ-9 scores was -.70 with a 95% confidence interval ranging from -4.67 to 3.27. The eta squared statistic (.001) indicated no effect size. Therefore, it can be concluded that there was no statistically significant difference in the participants' depression scores at Post-Intervention and at FU3.

6.4.5.2. Skills Training Group.

The paired-samples t-test conducted to evaluate the effect of STG attendance on participants' depression as measured via total PHQ-9 scores indicated that there was no statistically significant decrease in PHQ-9 scores from Post-Intervention (M = 4.66, SD = 3.17) to FU1 (M = 5.08, SD = 5.14), t (11) = -.352, p = .731 (two tailed). The mean decrease in PHQ-9 scores was -.41 with a 95% confidence interval ranging from -3.02 to 2.18. The eta squared statistic (.001) indicated no effect size. Therefore, it can be concluded that there was no statistically significant difference in the participants' depression scores at Post-Intervention and at FU1.

The paired-samples t-test conducted to evaluate the effect of STG attendance on participants' depression as measured via total PHQ-9 scores indicated that there was no statistically significant decrease in PHQ-9 scores from Post-Intervention (M = 4.66, SD = 3.17) to FU2 (M = 5.25, SD = 4.39), t (11) = -.667, p = .426 (two tailed). The mean decrease in PHQ-9 scores was -.58 with a 95% confidence interval ranging from -2.50 to 1.34. The eta squared statistic (.038) indicated a small effect size. Therefore, it can be concluded that there was no statistically significant difference in the participants' depression scores at Post-Intervention and at FU2.

The paired-samples t-test conducted to evaluate the effect of STG attendance on participants' depression as measured via total PHQ-9 scores indicated that there was a nearly

statistically significant decrease in PHQ-9 scores from Post-Intervention (M = 4.90, SD = 3.44) to FU3 (M = 3.50, SD = 3.27), t (9) = 1.709, p = .122 (two tailed). The mean decrease in PHQ-9 scores was 1.40 with a 95% confidence interval ranging from -.45 to 3.25. The eta squared statistic (.244) indicated a large effect size. Although there was some positive effect (i.e., decrease in group PHQ-9 score) for the STG, this was not statistically significant.

6.4.5.3. Combined Group.

The paired-samples t-test conducted to evaluate the effect of CG attendance on participants' depression as measured via total PHQ-9 scores indicated that there was a statistically significant decrease in PHQ-9 scores from Post-Intervention (M = 9.00, SD = 6.55) to FU1 (M = 7.00, SD = 5.39), t (11) = 2.321, p = .040 (two tailed). The mean decrease in PHQ-9 scores was 2.00 with a 95% confidence interval ranging from .10 to 3.89. The eta squared statistic (.328) indicated a large effect size. Therefore, it can be concluded that there was a statistically significant difference in the participants' depression scores at Post-Intervention and at FU1.

The paired-samples t-test conducted to evaluate the effect of CG attendance on participants' depression as measured via total PHQ-9 scores indicated that there was no statistically significant decrease in PHQ-9 scores from Post-Intervention (M = 8.90, SD = 6.72) to FU2 (M = 8.40, SD = 7.04), t (9) = .745, p = .475 (two tailed). The mean decrease in PHQ-9 scores was .50 with a 95% confidence interval ranging from -1.01 to 2.01. The eta squared statistic (.058) indicated a small effect size. Although there was some positive effect (i.e., decrease in group PHQ-9 score) for the CG, this was not statistically significant.

The paired-samples t-test conducted to evaluate the effect of CG attendance on participants' depression as measured via total PHQ-9 scores indicated that there was no

statistically significant decrease in PHQ-9 scores from Post-Intervention ($M = 10.00$, $SD = 7.07$) to FU3 ($M = 10.70$, $SD = 6.84$), t (9) = -.500, $p = .629$ (two tailed). The mean decrease in PHQ-9 scores was -.70 with a 95% confidence interval ranging from -3.86 to 2.46. The eta squared statistic (.000) indicated no effect size. Therefore, it can be concluded that there was no statistically significant difference in the participants' depression scores at Post-Intervention and at FU3.

The impact of time (i.e., 5 months from Pre-Intervention to Follow-Up 3) upon parents' self-reports of depression varied for the three different support groups. Parents' highest self-reports of depression were identified at Pre-Intervention for all three support groups. For parents attending the FBATG ($M = 7.81$, $SD = 5.30$) and the STG ($M = 4.66$, $SD = 3.17$), self-reports of depression decreased at Post-Intervention and it decreased slightly again at FU1. Furthermore, parents attending the FBATG ($M = 8.55$, $SD = 5.12$) and the STG ($M = 5.25$, $SD = 4.39$) self-reports of depression increased at FU2 compared to FU1 and even compared to Post-Intervention. At FU3, parents' self-reports of depression decreased for parents attending the FBATG ($M = 7.80$, $SD = 7.96$) and for parents attending the STG ($M = 3.5$, $SD = 3.27$). For parents attending the CG, self-reports of depression only decreased at FU2 ($M = 7$, $SD = 5.39$). The mean estimates of parents' self-report of depression across five time periods have been presented in Figure 2.
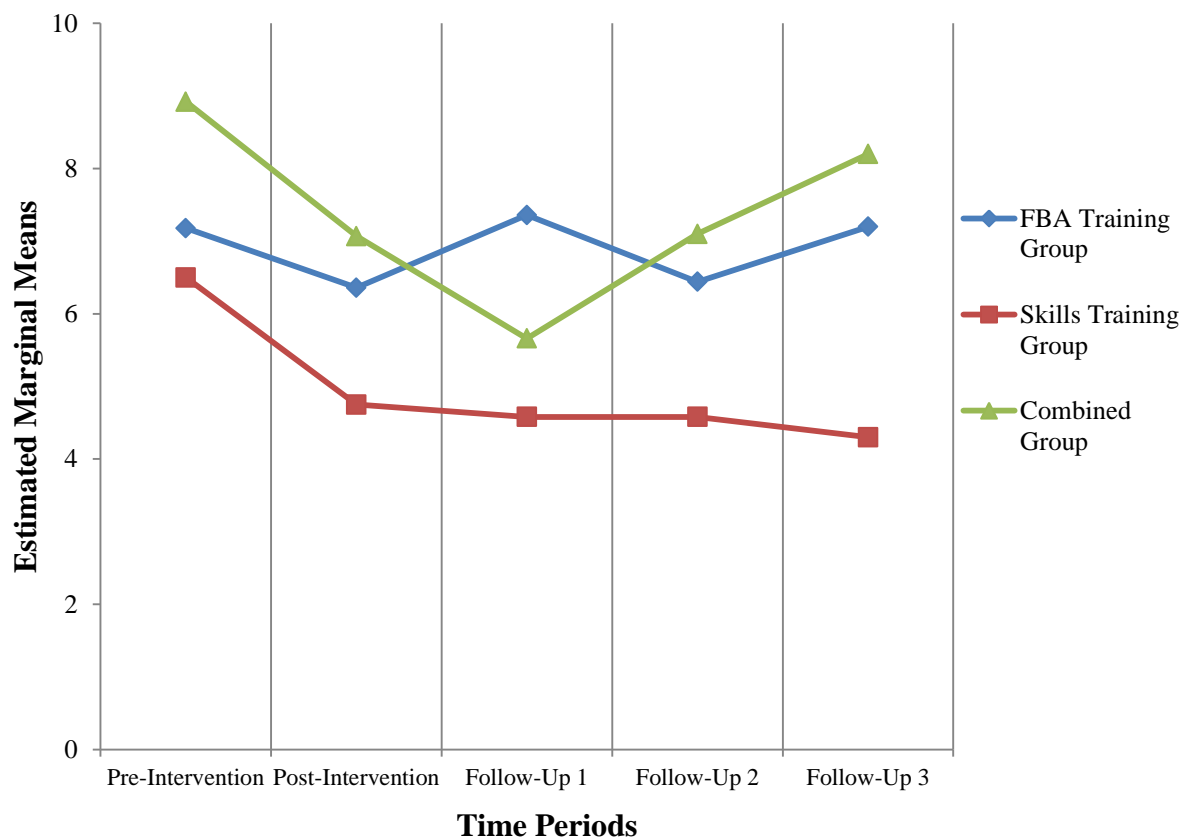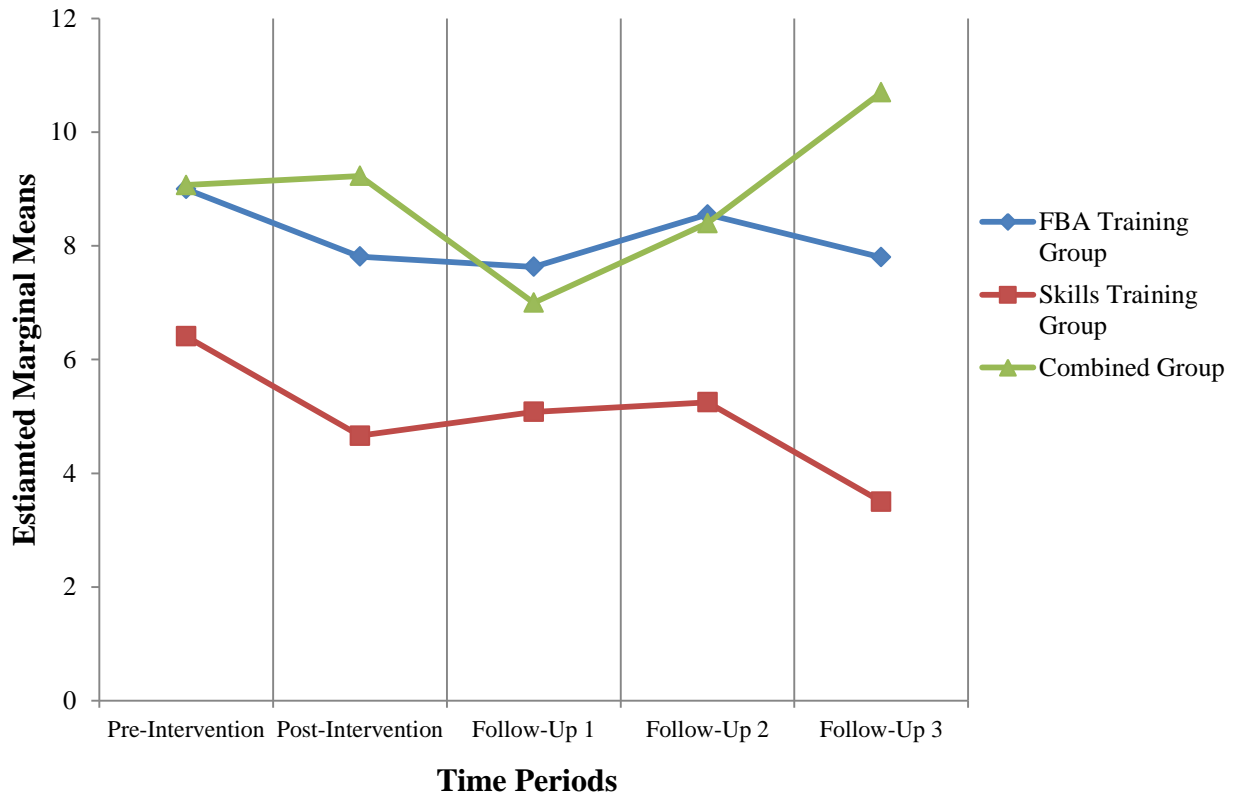
Figure 2. Mean estimates (comprising self-reported depression using the total score of the PHQ9) calculated separately the FBATG, the STG and the CG presented across five time periods.

6.4.6. Pre-and-Post Intervention and Follow-Up periods 1, 2 and 3 measures of parent-reported frequency of ASD behaviour in children across the three support groups.

The impact of time (i.e., 5 months from Pre-Intervention to Follow-Up 3) upon the parents' evaluations of their child's ASD-related behaviour was similar for the three different support groups. Parents reported a decrease in problematic behaviours upon the evaluations of their child's ASD-related behaviour at Post-Intervention and decreased even more at FU1 for all three support groups. Parents' evaluations of their child's ASD-related behaviour indicated that they identified an increase in their child's use of unwanted behaviours at FU2 compared to FU1. At FU3, only parents attending the STG reported a slight decrease in their

child's usage of problematic behaviours upon the evaluations of their child's ASD-related behaviour. The mean estimates of parents' self-report of their child's ASD-related behaviour across five time periods have been presented in Figure 3.
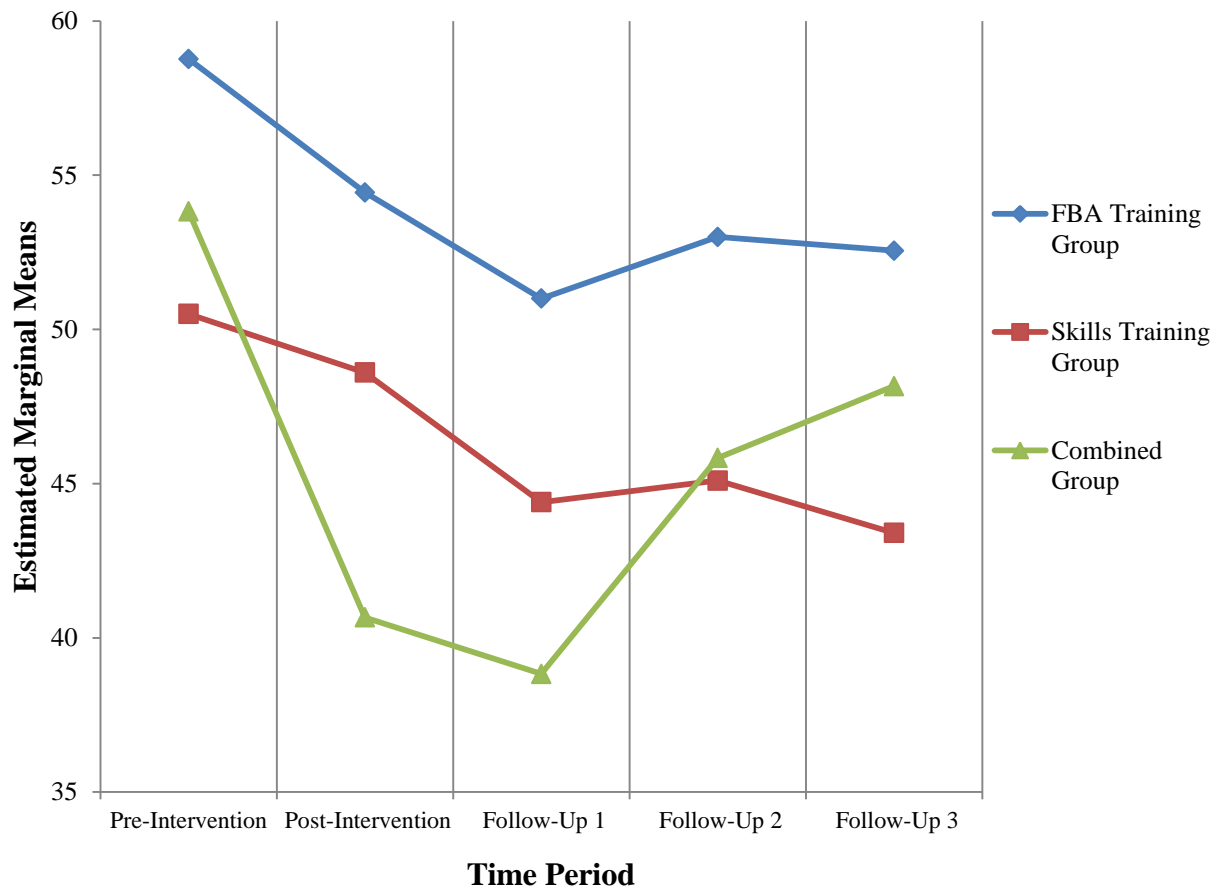
Figure 3. Mean estimates of child's ASD-related behaviour reported by participants from the FBATG, the STG and the CG across five time periods.

6.4.7. Pre-and-Post Intervention and Follow-Up periods 1, 2 and 3 measures of parent ratings of the quality of the relationship with their children across the three support groups.

The impact of time (i.e. 5 months from Pre-Intervention to Follow-Up 3) upon parents' evaluation of the quality of the relationship with their child varied for the three different support groups. Parents attending the FBATG reported a steady increase in the quality of the relationship with their child from Pre-Intervention ($M = 190.56$, $SD = 12.66$) to FU2 ($M = 195.56$, $SD = 14.05$). At FU3 parents attending the FBATG reported a decrease in the quality of the relationship with their child ($M = 186.11$, $SD = 17.17$) compared to FU2. Parents attending the STG reported steady results in the quality of the relationship with their child from Pre-Intervention ($M = 198.4$, $SD = 14.93$) to FU2 ($M = 197.1$, $SD = 11.91$). At FU3 parents attending the STG reported an increase in the quality of the relationship with their child ($M = 200.8$, $SD = 20.59$). Parents attending the CG reported a steady decrease in the quality of the relationship with their child from Pre-Intervention ($M = 209.28$, $SD = 11.25$) to FU3 ($M = 200.14$, $SD = 9.96$). The mean estimates of parents' self-report on the quality of their relationship with their child across five time periods have been presented in Figure 4.
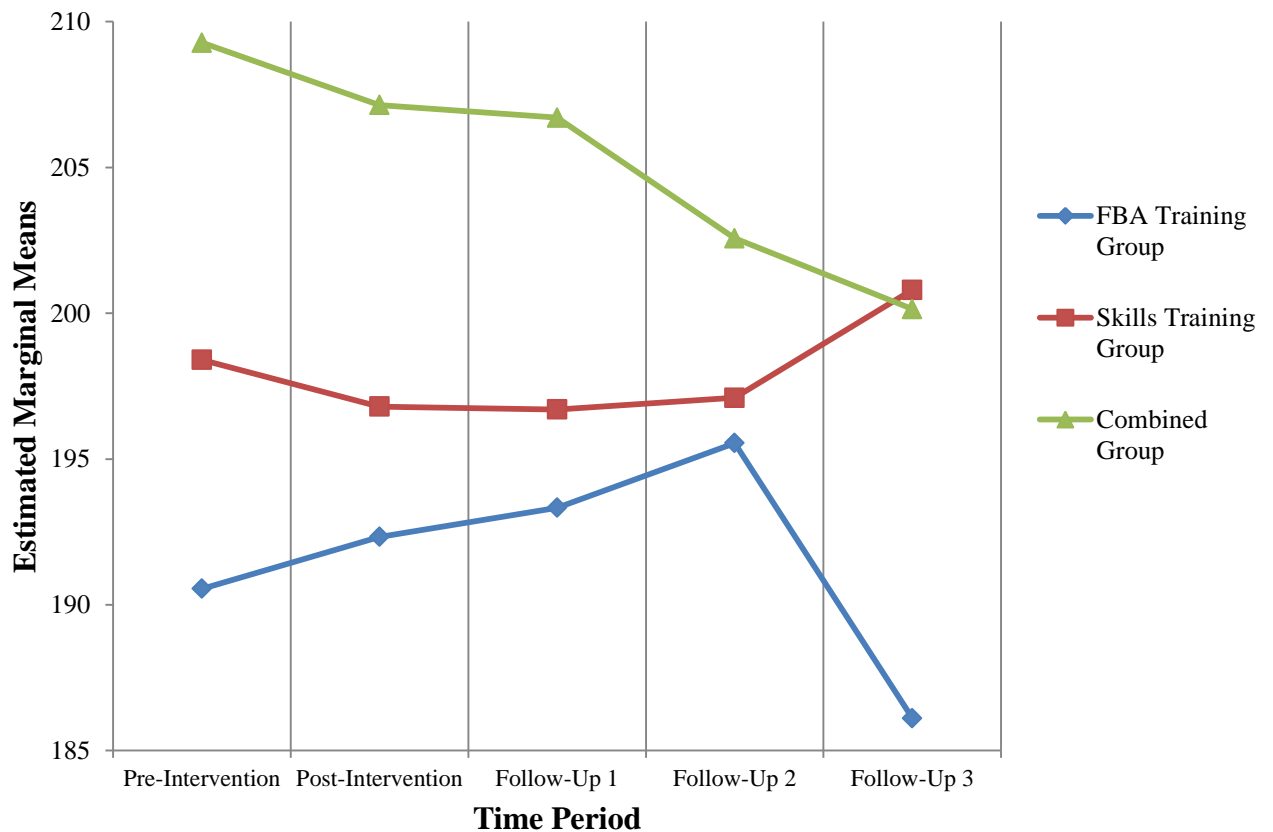
Figure 4. Mean estimates of PCR upon the parents' evaluations of the quality of their relationship with their child from the FBATG, the STG and the CG across five time periods.

6.4.8. Parent ratings of support group satisfaction/value in relation to session number and topic across the three support groups.

6.4.8.1. Parent ratings of support group satisfaction.

At Post-Intervention (week 7) participants were asked to complete a brief questionnaire to report of their overall satisfaction about the training group that they attended. Participants were asked ten different questions. To begin, parents were asked to rate how helpful the group sessions had been to them, using a ten-point Likert scale ranging from 1 "not at all helpful" to 10 "extremely helpful". Participants responses ranged from 4 to 10, with a mean score of 8.19 out of 10 ($SD = 1.47$). The most common examples of what

participants found most helpful when they attended their group included: 1) Talking to other parents ($n = 8$); 2) Goal setting assessment ($n = 5$); 3) Identifying triggers for unwanted behaviours ($n = 5$); 4) Coping strategies and optimism ($n = 4$); 5) Feeling empowered and confident in dealing with ASD child ($n = 4$). Then, parents were asked to rate on a ten-point Likert scale ranging from 1 "not at all satisfied" to 10 "extremely satisfied", how satisfied they were with the parent group sessions they attended. Again, participants' responses ranged from 4 to 10, with a mean score of 8.28 out of 10 ($SD = 1.47$). The most common examples of what parents were satisfied with from attending the groups were: 1) Opportunity to learn so much practical information ($n = 8$); 2) Experience and values of other parents in the group ($n = 7$); 3) Learning how to evaluate problems ($n = 5$); 4) Facilitator was calm and non-judgemental ($n = 4$); 5) Guidance received from the facilitator ($n = 3$); 6) Professionalism of facilitator for the delivery ($n = 3$).

Participants were asked if there was anything they were not satisfied with from the group sessions they attended. Of 36 participants, 6 parents (17%) mentioned that they were not satisfied with: 1) Even though the times offered were good, the sessions should not be run during school holidays ($n = 1$); 2) The programme was not needed ($n = 1$); 3) Some of the questions from the survey could have been worded easier ($n = 1$); 4) More sessions could be implemented to follow up what parents put in practice ($n = 1$); 5) Mother felt like a failure when other people in her group did not understand what she was going through ($n = 1$); 6) Information on how to target the child's unwanted behaviours at school could have been provided to assist the teacher ($n = 1$).

Parents were asked if the training sessions they attended helped them to cope with some issues of importance to them. Of 36 participants, 34 parents (94%) believed that the group they attended helped them to cope with some issues of importance to them. When

parents were asked whether they would attend similar parent group sessions run at CASD in the future, 33 parents said "yes" (92%), 2 parents replied "no" (5%) and 1 parent replied "maybe" (3%). When parents were asked whether they would be interested in attending programmes run by other organisations which aim to help with building their capacity to cope with the demands they face, 34 parents replied "yes" (94%), 1 parent replied "no" (3%) and 1 parent replied "maybe" (3%). Finally, parents were asked if the wished to make any final comments about the parent group sessions they attended at CASD and 21 parents (58%) of parents left a comment. Some examples of the comments made by participants included: 1) The facilitator was wonderful, likeable and understanding ($n = 4$); 2) The sessions were very well planned and professional ($n = 3$); 3) Thank the facilitator for the groups ($n = 3$); Very satisfied with the parent group sessions ($n = 3$).

6.4.8.2. Value ratings in relation to session number and topic attributed by participants attending the Functional Behavioural Assessment Training Group.

The overall values given by participants for each session of the FBATG are presented in Figure 5. Participants were asked to score how valuable they found the six sessions they attended in the FBATG to be, using a seven-point Likert scale ranging from 1 "not valuable" to 7 "very valued". Overall, participants attending the FBATG rated session 2 "getting to understand how your child reacts" ($M = 5.91$, $SD = 0.83$), session 4 "Understanding the ways in which behaviour leads to positive outcomes" ($M = 6.5$, $SD = 0.53$), and session 5 "Some tips for helping your child to learn" ($M = 6.44$, $SD = 0.52$) as the most valuable sessions of the entire training group. Even though session 6 "Reviews, questions, and final comments" ($M = 6.33$, $SD = 0.51$) was rated highly by participants, it was a review session in which participants could select the topics they wished to review with the facilitator. Consequently, session 6 was not selected as one of the three most valuable session rated by participants. As

can be seen in Figure 5, session 1 "Ways that autism affects your child" ($M = 5.6$, $SD = 1.07$), and session 3"Identifying the triggers for the behaviour you would like to change" ($M = 5.88$, $SD = 0.64$) obtained the lowest ratings out of all six sessions that participants attended and rated.
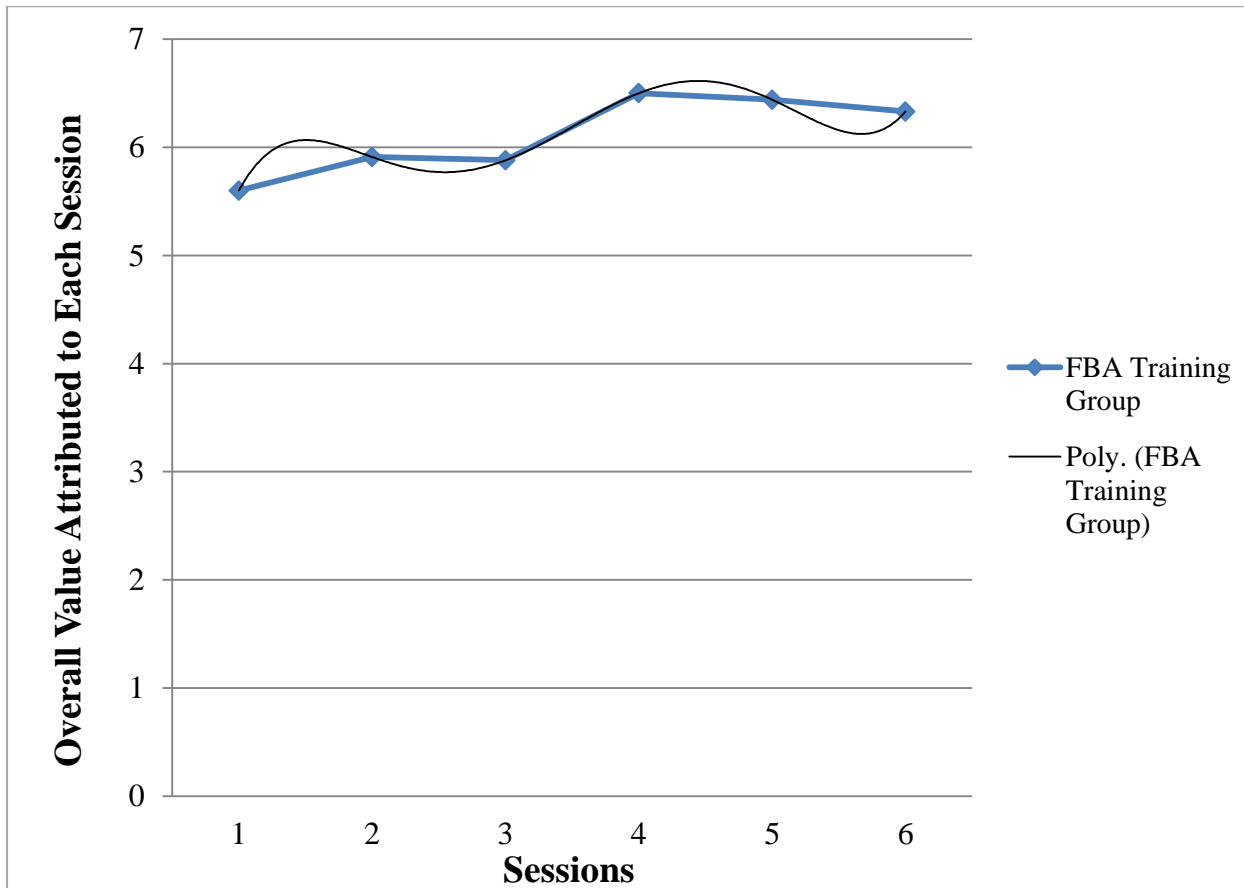
Figure 5. Mean scores attributed by participants ($n = 11$) to indicate how valuable they found each session of the FBATG to be, using a seven-point Likert scale.

Participants were also asked to rate the value they attributed to the four topics addressed in each session, using a seven-point Likert scale ranging from 1 "not valuable" to 7 "very valued". According to participants' ratings, the most valuable topic of session 1 was "Covert and overt modalities of behaviour" ($M = 6.2$, $SD = 0.91$). The topics participants scored as being most valuable in session 2 were "Target behaviour" ($M = 5.73$, $SD = 0.90$)

and "The functions of behaviour" ($M = 5.73$, $SD = 1.00$). The most valuable topic from session 3 was "Information on the antecedents and pre-behaviours" ($M = 5.88$, $SD = 1.12$). The most valuable topic reported by participants for session 4 was "The use of the A-B-C table" ($M = 6.62$, $SD = 0.51$). The most valuable topics identified in session 5 were "Manipulating the situation that triggers unwanted behaviour" ($M = 6.11$, $SD = 0.78$) and "the use of the A-B-C table" ($M = 6.11$, $SD = 0.78$). For session 6, participants were asked to list the information they wanted the facilitator to revisit with them. Participants rated "Covert and overt modalities of behaviour" ($M = 6.33$, $SD = 0.51$) and "The use of the A-B-C table" ($M = 6.33$, $SD = 0.81$) as the most valuable topics addressed in session 6. The value attributed to the topic "Use of the A-B-C Table" steadily increased from session 2 ($M = 5.45$, $SD = 1.12$) to session 6 ($M = 6.33$, $SD = 0.81$), with a pick observed in session 4 ($M = 6.62$, $SD = 0.51$).

6.4.8.3. Value ratings in relation to session number and topic attributed by participants attending the Skills Training Group.

Participants were asked to score how valuable they found the six sessions they attended in the STG to be, using a seven-point Likert scale ranging from 1 "not valuable" to 7 "very valued". Overall, participants attending the STG rated session 2 "Coping strategies" ($M = 5.6$, $SD = 0.84$), session 4 "One's personal strengths" ($M = 5.82$, $SD = 0.40$) and session 5 "Self-efficacy" ($M = 6$, $SD = 0.50$) as the most valuable sessions of the STG. Even though session 6 "Reviews, questions and final comments" ($M = 5.88$, $SD = 0.35$) was rated highly by participants, it was a review session in which participants could select the topics they wished to review with the facilitator. Subsequently, session 6 was not selected as one of the three most valuable sessions rated by participants. Session 1 "Support received" ($M = 4.58$, $SD = 1.16$) received the lowest rating out of all six sessions. An increase in score was observed in session 2, with a slight decrease in how participants scored session 3 "Positive

emotions" ($M = 5.33$, $SD = 0.65$). The variation in the value attributed by participants for each session from the STG has been represented in Figure 6.
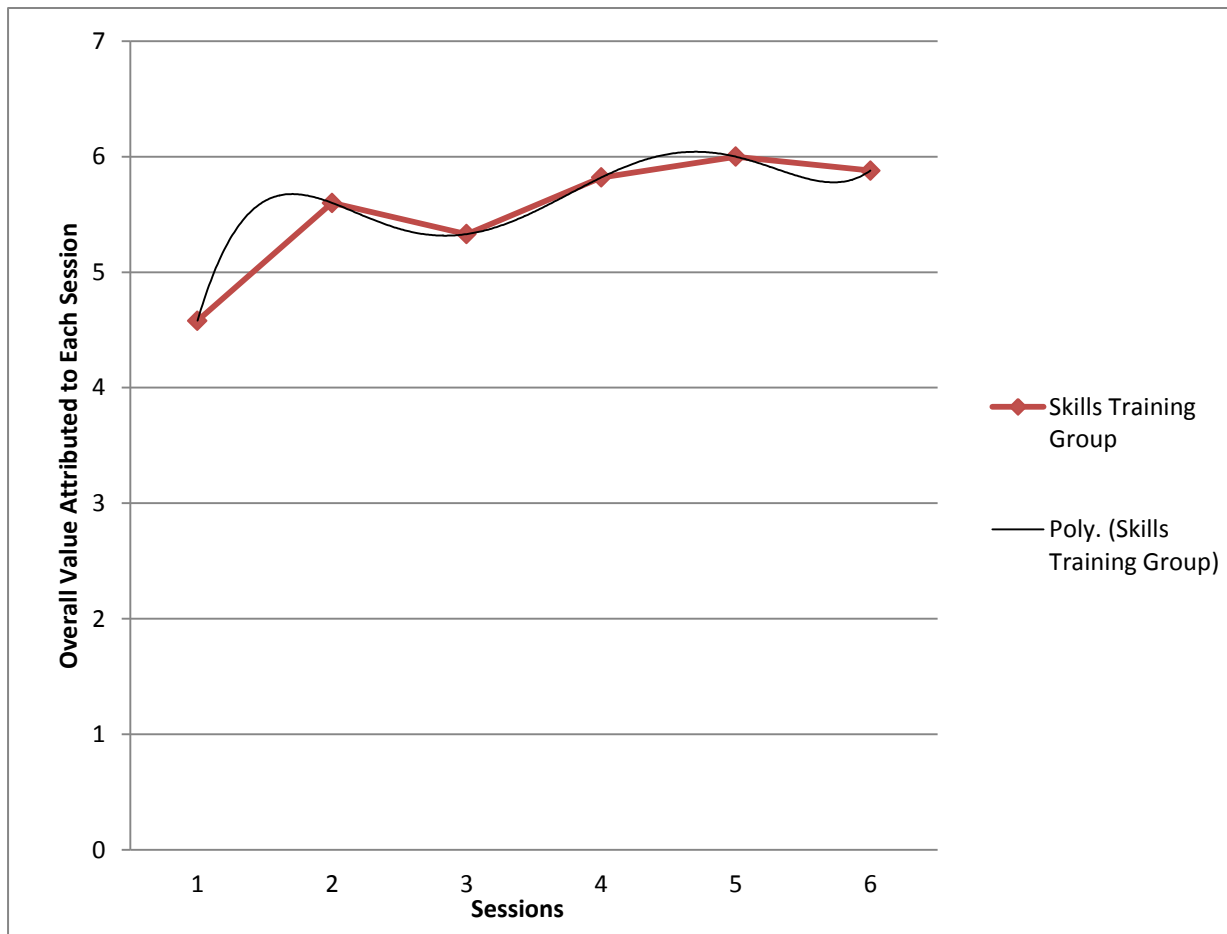
Figure 6. Mean scores attributed by participants ($n = 12$) to indicate how valuable they found each session of the STG to be, using a seven-point Likert scale.

Participants were asked to rate the value they attributed to the four topics addressed in each session, using a seven-point Likert scale ranging from 1 "not valuable" to 7 "very valued". Participants reported "Goal settings exercise and its functions" ($M = 5.17$, $SD = 1.46$) as the most valuable topic addressed in session 1. The most valuable topic of session 2 was "Coping strategies" ($M = 5.7$, $SD = 0.67$). The topic on "Positive experiences" in session 3 was rated as the most valuable topic ($M = 5.42$, $SD = 0.66$). In session 4, the most valuable

topic was "Positive outcomes when one is high on optimism" ($M = 5.91$, $SD = 0.30$). Two most valuable topics were identified in session 5, the first one being "Some coping strategies you apply in day-to-day life" ($M = 5.78$, $SD = 0.83$) and "Goal setting exercise" ($M = 5.78$, $SD = 0.66$). For session 6, participants reported "Coping strategies" ($M = 5.75$, $SD = 0.70$) and "Goal setting exercise" ($M = 5.75$, $SD = 0.46$) as the two most valuable topics. The value attributed to the topic "Goal setting exercise" steadily increased from session 1 ($M = 5.17$, $SD = 1.46$) to session 6, with a pick in session 5.

6.4.8.4. Value ratings in relation to session number and topic attributed by participants attending the Combined G.

The three most valuable sessions from both the FBATG and the STG were selected as the six sessions that would make up the sessions of the CG. Consequently, session 2 from the STG was used as session 1 for the CG. Likewise, sessions 4 and 5 were respectively used as sessions 2 and 3 for the CG. Sessions 2, 4 and 5 from the FBATG were referred to as sessions 4, 5 and 6 for sessions in the CG. When comparing the sessions that were utilised in both the FBATG and the CG, participants rated the overall value of each session similarly. For instance, in the FBATG participants attributed session 5 ($M = 6.44$, $SD = 0.52$) a similar score for overall value of the session compared to session 4 (FBATG = Session 6) of the CG ($M = 6.36$, $SD = 0.67$). The means for the value attributed by participants for the three sessions from the FBATG used in the CG, have been compared to the means for the value attributed by participants from the FBATG and can be seen in Table 9.

Table 9:

Means and Standard Deviations for the Value Attributed by Participants from the CG and by

Participants from the FBATG for the Same Three Sessions They Received

FBA Training Group	Mean	Standard Deviation	Combined Group	Mean	Standard Deviation
Session 2	5.91	0.83	Session 4 (FBATG = Session 2)	6	0.63
Session 4	6.5	0.53	Session 5 (FBATG = Session 4)	6.14	1.06
Session 5	6.44	0.52	Session 6 (FBATG = Session 5)	6.36	0.67

Similar results were obtained when comparing the results from parents who attended the STG than parents who received the same sessions in the CG. Participants in the STG rated the overall value of session 5 ($M = 6$, $SD = 0.5$) similarly to participants in session 3 (STG = Session 5) of the Combined Group ($M = 5.82$, $SD = 0.98$). The means for the value attributed by participants for the three sessions from the STG used in the CG, have been compared to the means for the value attributed by participants from the STG and can be seen in Table 10.

Table 10:

Means and Standard Deviations for the Value Attributed by Participants from the CG and by Participants from the STG for the Same Three Sessions They Received

Skills Training Group	Mean	Standard Deviation	Combined Group	Mean	Standard Deviation
Session 2	5.6	0.84	Session 1 (STG = Session 2)	5.67	0.86
Session 4	5.82	0.40	Session 2 (STG = Session 4)	5.8	0.78
Session 5	6	0.50	Session 3 (STG = Session 5)	5.82	0.98

Participants were asked to score how valuable they found the six sessions they attended in the CG to be, using a seven-point Likert scale ranging from 1 "not valuable" to 7 "very valued". The overall values attributed to each session of the CG are presented in Figure 8. Participants attending the CG rated session 4 "Getting to understand how your child reacts" ($M = 6$, $SD = 0.63$), session 5 "Understanding the ways in which behaviour leads to positive outcomes" ($M = 6.14$, $SD = 1.06$) and session 6 "Some tips for helping your child to learn new behaviour" ($M = 6.36$, $SD = 0.67$) as the most valuable sessions of the programme compared to the ratings participants attributed to session 1 "Coping strategies" ($M = 5.67$, $SD = 0.86$), session 2 "One's personal strengths" ($M = 5.8$, $SD = 0.78$) and session 3 "Self-

efficacy" ($M = 5.82$, $SD = 0.98$), obtaining significantly higher value in the sessions from the FBATG compared to the sessions from the STG. A steady increase in the value of the sessions reported by participants attending the CG was observed, as can be seen in Figure 7.
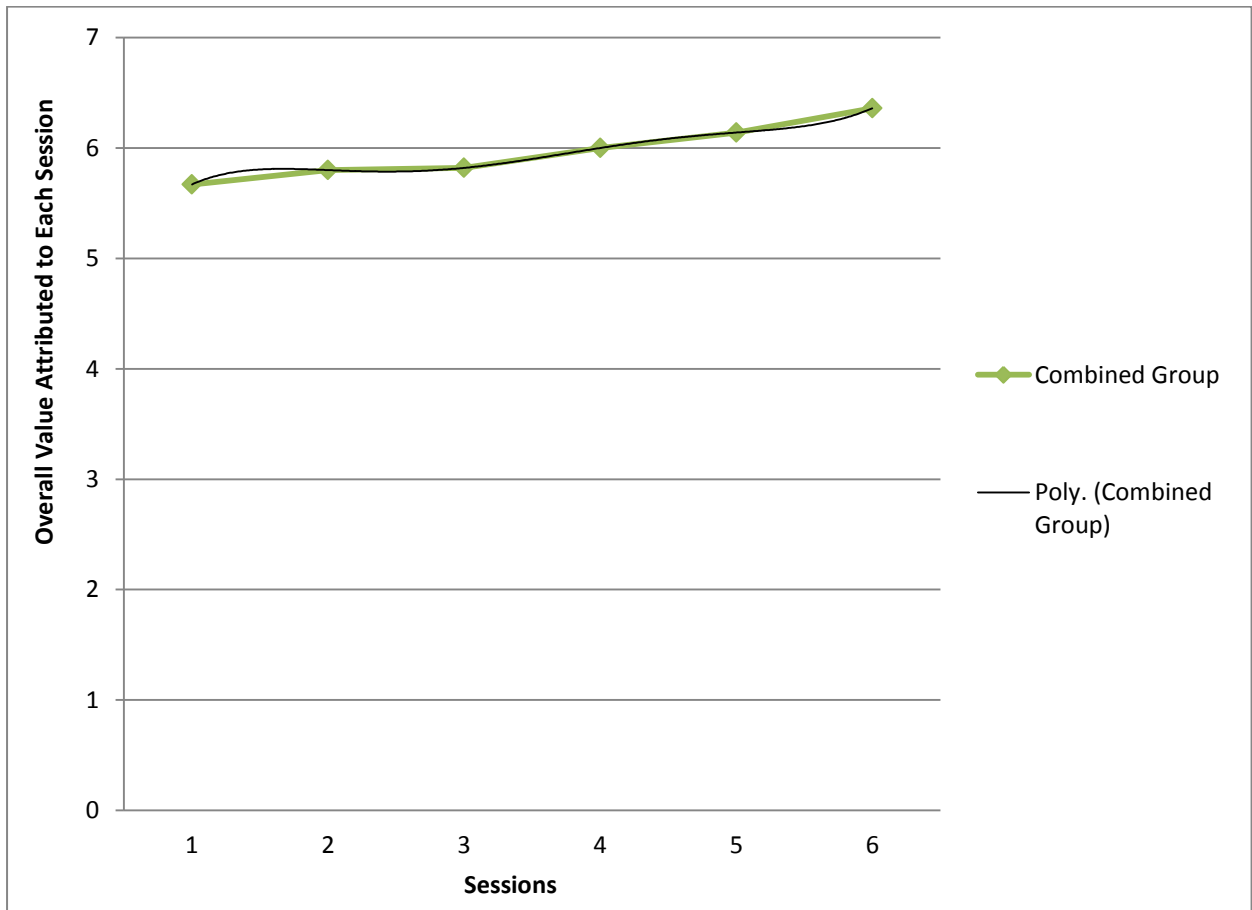
Figure 7. Mean scores attributed by participants ($n = 13$) to indicate how valuable they found each session of the CG to be, using a seven-point Likert scale.

Participants were asked to rate the value they attributed to the four topics addressed in each session, using a seven-point Likert scale ranging from 1 "not valuable" to 7 "very valued". According to participants' ratings, the most valuable topic of session 1 was "Goal setting exercise" ($M = 6$, $SD = 1$). The most valuable topic from session 2 was "Some coping strategies you apply in your day-to-day life" ($M = 5.8$, $SD = 0.91$). The most valuable topic identified in session 3 was "SPELL Framework" ($M = 6.09$, $SD = 0.83$). Participants reported

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the highest topic ratings for session 4, with "Target behaviour" ($M = 6.18$, $SD = 0.87$) and "The functions of behaviour" ($M = 6.18$, $SD = 0.60$) being scored as the two most valuable topics of the session. The most valuable topic identified in session 5 was "Review of the terminology learnt so far" ($M = 6.29$, $SD = 0.75$). Finally, participants rated "Use of the A-B-C Table" ($M = 6.45$, $SD = 0.68$) as the most valuable topic of session 6. The value attributed to the topic "Goal setting exercise" in the first half of the programme gradually decreased from session 1 ($M = 6$, $SD = 1$) to session 3 ($M = 5.45$, $SD = 1.50$). The value attributed to the topic "Use of the A-B-C Table" in the second half of the programme steadily increased from session 4 ($M = 6.09$, $SD = 0.53$) to session 6 ($M = 6.45$, $SD = 0.68$).

6.4.9. Summary of findings study 1.

6.4.9.1. Summary of parent-reported major difficulties and major concerns for their child with ASD.

Participants reported the current major difficulties that they encountered with their child, as can be seen in Table 11. Parents described the major concerns that they had about their child's future and the information has been presented in Table 12. This information clearly highlights some of the child-oriented motivators for parents to seek group support.

Table 11:

Major Difficulties Parents of Children with ASD Experienced at the time of Pre-Intervention

Major Difficulties	Frequency (*n*)	Percentage (%)
Behavioural difficulties	7	19
Anxiety and stress	6	17
Academic/School difficulties	5	14

Major Difficulties	Frequency (*n*)	Percentage (%)
Social skills difficulties	5	14
Lack of emotional regulation	4	11
Anger and unpredictability	4	11
Need for control	2	6
Lack of coping skills	1	2
Communication difficulties	2	6

Table 12:

Major Concerns Parents of Children with ASD Described at the time of Pre-Intervention for Their Child's Future

Major Concerns	Frequency (*n*)	Percentage (%)
Inability for child to become independent	10	28
Child's inability to control anger/aggression	6	17
Schooling challenges/difficulties	5	14
Child care after parents' death	5	14
Child's inability to socialise	4	11
Others taking advantage of child	3	8
Child's inability to fit into neuro-typical society	2	6
Child ending up in jail	1	2

6.4.9.2. Summary of parent-reported anxiety findings across the three support groups.

A mixed between-within subjects analysis of variance was conducted to assess the impact of three different interventions (FBATG, STG, and CG) on participants' scores on the GAD-7, across five time periods (Pre-Intervention, Post-Intervention, 1 month Follow-Up, 2 months Follow-Up and 3 months Follow-Up). There was no significant interaction between programme type and time, Wilks Lambda = .800, F (8, 40) = .590, p = .78, partial eta squared = .11. There was no substantial main effect for time, Wilks Lambda = .706, F (4, 20) = 2.08, p = .121, partial eta squared = .294, with all three groups not showing an amelioration in their anxiety levels across the five time periods. The main effect comparing the three types of intervention was not significant, F (1, 23) = 1.385, p = .270, partial eta squared = .107, suggesting no significant difference in the effectiveness of the three training approaches in terms of their effect upon the parents' anxiety levels.

6.4.9.3. Summary of parent-reported depression findings across the three support groups.

A mixed between-within subjects analysis of variance was conducted to assess the impact of three different interventions (FBATG, STG, and CG) on participants' scores on the PHQ-9, across five time periods (Pre-Intervention, Post-Intervention, 1 month Follow-Up, 2 months Follow-Up and 3 months Follow-Up). There was no significant interaction between programme type and time, Wilks Lambda = .804, F (8, 40) = .575, p = .79, partial eta squared = .10. There was no substantial main effect for time, Wilks Lambda = .949, F (4, 20) = .267, p = .895, partial eta squared = .05, with all three groups not showing an amelioration in their anxiety levels across the five time periods. The main effect comparing the three types of intervention was not significant, F (1, 23) = 1.574, p = .229, partial eta squared = .120,

suggesting no significant difference in the effectiveness of the three training approaches in terms of their effect upon the parents' depression levels.

6.4.9.4. Summary of parent-reported frequency of ASD behaviour in children across the three support groups.

A mixed between-within subjects analysis of variance was conducted to assess the impact of three different interventions (FBATG, STG, and CG) on participants' scores on the ASD Behaviour Checklist Test, across five time periods (Pre-Intervention, Post-Intervention, 1 month Follow-Up, 2 months Follow-Up and 3 months Follow-Up). There was no significant interaction between programme type and time, Wilks Lambda = .638, F (8, 38) = 1.198, p = .32, partial eta squared = .20. There was a substantial main effect for time, Wilks Lambda = .463, F (4, 19) = 5.518, p <.005, partial eta squared = .53, with all three groups showing a reduction in the frequency of unwanted behaviours scores across the five time periods. The main effect comparing the three types of intervention was not significant, F (1, 22) = .612, p = .55, partial eta squared = .053, suggesting no significant difference in the effectiveness of the three training approaches in terms of their effect upon the parents' evaluations of their child's ASD-related behaviour.

6.4.9.5. Summary of parent-reported quality of relationship with their child across the three support groups.

A mixed between-within subjects analysis of variance was conducted to assess the impact of three different interventions (FBATG, STG, and CG) on participants' scores on the PCR scale, across five time periods (Pre-Intervention, Post-Intervention, 1 month Follow-Up, 2 months Follow-Up and 3 months Follow-Up). There was no significant interaction between programme type and time, Wilks Lambda = .658, F (8, 40) = 1.163, p = .35, partial eta

squared = .19. There was no substantial main effect for time, Wilks Lambda = .916, F (4, 20) = .459, p = .77, partial eta squared = .08, with all three groups not showing an amelioration in the quality of the relationship with their child across the five time periods. The main effect comparing the three types of intervention was significant, F (1, 23) = 3.588, p = .04, partial eta squared = .238, suggesting a statistically significant difference in the three training approaches in terms of their effect upon the parents' evaluations of the quality of their relationship with their child.

6.5. Study 1 discussion.

Three different types of support group models (FBATG, STG, and CG) were compared through the implementation of in depth and multiple pre- and -post-measures of changes in mental health/functioning for participants to detect any immediate changes and to examine the maintenance of any changes over time. Study 1 aimed to overcome a limitation from previous research by enabling participants to give their opinion on each session and by asking participants which sessions from the support group they attended were most helpful. The aim was to measure whether participants attending the CG would give similar ratings of satisfaction with the sessions and the group, as participants attending the FBATG and the STG did.

The present study investigated the effects of three models for delivering group-based support to parents of children with ASD on parent mental state (i.e., anxiety and depression), parents' frequency reports on their child's autistic behaviours, parents' reports on the quality of the relationship with their child, and parenting satisfaction. Study 1 aimed to find solutions to ensure that participants would be able to attend sessions; by giving participants' the opportunity to select the support group and the time of day they wished to attend. This recruitment strategy was used in order to limit participants' withdrawing from the study, as

they were able to select the group that suited their needs at the time, and they were able to select a time that was most convenient for their busy schedules.

The discussion of the results presented for study 1 will address participants' inconsistent attendance across the three different support groups and participants' overall retention rates for the entirety of the support groups. The high recruitment of mothers in study 1, compared to the low recruitment of fathers will be briefly discussed. Information on the use of group content to assist parents of children with ASD will be discussed. The limitations from previous research on group support to assist parents of children with ASD will be addressed and used to explain some of the steps applied in our research. Participants reports of anxiety and depression across five different times (Pre-Intervention, Post-intervention, FU1, FU2, and FU3) will be discussed and compared to previous research findings. Parents' reports on the frequency of their child's autistic behaviours and on the quality of the relationship with their child across five different times will also be discussed and compared to previous research findings.

6.5.1. Participants' attendance patterns across the three support groups.

Recruitment and participants' retention were challenges noted in study 1, and similar difficulties were discussed in other studies of Parent Support Groups (PSG) use (Bitsika & Sharpley, 1999; Fontana, Fleischman, McCarton, Meltzer, & Ruff, 1988; Smith, Gabard, Dale, & Drucker, 1994). Such limitations were not only observed for research projects administering PSG in a face-to-face setting, but they were also noted in research projects that offered PSG online for parents of children with ASD. For instance, a study conducted by Clifford and Minnes (2013) explained that the majority of parents (N = 119) who indicated an interest in participating in their online PSG did not, in the end, register for a group. Of those who registered (n = 36), many did not attend even half of the sessions (n = 16). Other

researchers report similar issues with attendance in their studies of support groups for this population (Bitsika and Sharpley, 1999) and for parents of children with other disabilities (Smith et al., 1994) and for parents of children with special needs (Fontana et al., 1988). For example, Troester (2000) invited 200 parents of children in special education programmes to participate in PSG at the child's school, and only 20 parents registered to attend the groups offered. Of the 20 parents who registered their interest in attending the PSG, only 12 parents ended up attending a group. Eight more parents were registered with the groups, to reach a total number of 20 participants, with only 10 parents completing the post-group survey. Due to the low retention rate of participants in the study, Troester (2000) did not complete any quantitative data analyses.

The inconsistent attendance of participants in study 1 has been addressed in section three of Chapter 6. A few participants gave explanations for their inability to attend a session; this information will be discussed now. For one evening session, half of the participants attending the STG were unable to come to the session due to a thunderstorm. Parents explained that their child was highly anxious when there were thunderstorms, and as a consequence they were unable to attend the session. Furthermore, 12 parents were unable to attend a session because they could not find anyone to look after their child. Another 4 participants missed one session when their child was suspended from school; these parents had no one who could look after their child during the day. The reasons why parents were unable to attend sessions across the three support groups were mainly due to environmental factors that parents had very little control over.

Researchers who examine the implementation of PSG for parents of children with ASD in the future should expect a very low proportion of interested parents to actually register and attend the support group, and thus, efforts should be made to recruit many more

parents than are required for sufficient power in the study. Furthermore, the role of individual differences and preferences of parents could be important factors to consider in optimizing attendance and is worthy of further investigation, particularly as it is expected that self-selection bias in these studies can play a role in both attendance and outcomes. The sample of participants recruited in study 1 included a heterogeneous group of parents and children, which further limits our ability to assess the outcome of participation in study 1.

The increase in interest in fatherhood research has taken place because of the limited effort so far directed toward examining fathers' experiences, in contrast to the extensive literature on mothers. Indeed, recent research on father–child attachment has dramatically increased over the past two decades suggesting that fathers play a fundamental role in preserving a healthy psychosocial development for their children (Grossmann et al., 2002; Hazen, McFarland, Jacobvitz, & Boyd-Soisson, 2010). Carpenter and Towers (2008) noted that researchers have described fathers as 'hard to reach', 'the invisible parent', and the 'shadow'. In a larger study (Johnson, Frenn, Feetham, & Simpson, 2011), both parents were asked to fill out separate questionnaires, but more mothers ($n = 261$) than fathers ($n = 86$) completed the request. No information was available to explain why fewer fathers than mothers completed surveys in the larger study. However, it is interesting that in numerous autism studies that attempt to recruit both parents, more often than not, the majority of participants are mothers.

During the recruitment process for study 1, more mothers ($n = 28$) than fathers ($n = 6$) were recruited. Of the 6 fathers who participated in the research, 4 fathers (67%) participated in study 1 because their wife also participated in the research. The remaining 2 fathers (33%) participated in study 1 on their own and mentioned that they were the primary caregiver for their child. Our findings on participants' recruitment are in agreement with previous research

findings that have also experienced difficulties in recruiting more fathers to participate in their research (Carpenter & Towers, 2008; Johnson et al., 2011; Turbiville & Marquis, 2001). Even Johnson and Simpson, (2013) identified that for parents of children with ASD, studies that attempt to recruit both parents in the parental dyad to answer separate questionnaires have had difficulty in recruiting fathers. Moreover, there is a gap in the literature on the ramifications of interpreting this mother-only data, as a group, without taking into account whether their respective spouse was asked to participate in the study and chose not to. There may be a difference in parenting stress and family functioning across groups of mothers whose spouses do or do not choose to participate.

6.5.2. Group content.

Bitsika and Sharpley (1999, 2000) found that parents seemed to prefer more strategy-focused groups that had the goal of teaching parents to cope with stress rather than groups like those conducted in the current study that had a less direct focus, only connecting parents and allowing them to discuss topics of interest, although this preference is not supported by all researchers (Smith et al., 1994; Solomon, Pistrang, & Barker, 2001). Program evaluation of support groups that are implemented clinically could help to determine which of these variables may be the most important contributors to change in well-being for parents of children with ASD. Given that expectations for the group and parent needs may have an effect both on outcomes and attendance, it may be particularly useful to ask parents about their expectations and needs. This was a strategy that was used in our study in that participants had the option to select the group they wished to attend. As a consequence, one group referred to as "ASD knowledge" was discontinued, after a majority of participants expressed that they would rather access information from the FBATG or the STG groups.

Monitoring whether expectations are met across the sessions may make it possible to make changes to the group in order to retain more participants and provide the most appropriate support to these participants. Because of the small number of parents who registered for the online support groups, all parents who were available for a given time were included in that session. Some parents indicated that being in groups with others with similar experiences to themselves would have been more useful, especially with respect to parents of older children and parents of children who were lower functioning who were under-represented in this study. In the future, efforts should be made to offer separate groups to parents of younger and older children (or adult children) and to separate groups by child's level of functioning.

6.5.3. Limitations of previous research addressed in study 1.

Previous research on support groups for parents of children with ASD is sparse and predominantly exploratory (Bitsika & Sharpley, 1999; Carter, 2009). Those studies that have examined pre- to post-group changes (Bitsika & Sharpley 1999, 2000) are limited by small sample sizes (ranging from $n = 11$ to $n = 14$) and the use of unstandardized measures. Those studies that have examined the broader group of parents of children with special needs are qualitative (Kerr & McIntosh, 2000) and largely atheoretical (Singer et al., 1999; Solomon et al., 2001), focusing on a few general variables (i.e., helpfulness, group climate, empowerment) expected to change as a result of support group use. By establishing a theory base to measure the effects of PSGs systematically, research can better *assess* the role of PSGs in providing the most appropriate and effective support for parents of children with ASD.

In developing the format for the support groups in this study, the findings from previous research on parents' preferences for support groups were taken into consideration. Smith and colleagues (1994) surveyed parents of children with special needs about their

experiences with PSGs. Parents reported a preference for the support aspect of the group as opposed to information sharing and teaching from professionals; they enjoyed being able to meet other parents and share feelings. As well, parents reported that child care and transportation were both barriers to using support groups. Taking these findings into consideration, this study examined the impact of three different types of support groups that were designed to address different needs that participants may have, from sharing experiences and developing relationships with facilitation from a counselling professional to learning theoretical and practical information on understanding and managing challenging behaviours their child might engage in. Participants' ability to select the group that would assist them the most at the time was expected to reduce some barriers to participation; for example, parents were more likely to come to a group that addressed topics that were of interest to them. The topics addressed for the CG were based on parents' reports and ratings of the sessions conducted in the FBATG and the STG, so as to mirror both the approach taken by many community PSGs and previous research on in-person PSGs for parents of children with ASD (Bitsika and Sharpley 1999). Finally, this group design was chosen with a view to providing different models for agencies wishing to implement similar groups to support families of children with ASD.

6.5.4. Lack of significant changes in anxiety and depression symptoms.

Overall, no significant changes in anxiety and depression across the three different groups (FBATG, STG, and CG) participants attended and across time (Pre-Intervention, Post-Intervention, FU1, FU2, and FU3) were noted in study 1. One of twelve t-tests indicated a decrease in depression for parents attending the CG at FU1, which could be attributed by chance. No significant changes in anxiety and depression symptoms were observed following participation in the three support groups. The results obtained in study 1 are similar to results

obtained in one study conducted by Bitsika and Sharpley (2000), in which they evaluated the effects of a parent support program with a psycho-educational focus on learning stress management techniques that included time in each session to discuss parents' current concerns. The groups were scheduled for eight weekly 75-minute sessions, and parents completed questionnaires after each session and pre- and post-group. There were no significant changes in stress, anxiety, or depression symptoms following participation in this group (Bitsika & Sharpley, 2000). The lack of reported anxiety and depression symptoms in our study may have occurred because the pre-group assessment showed that the mean anxiety scores and the mean depression scores of participants fell outside the normal range prior to participation in the group.

The study conducted by Bitsika and Sharpley (2000) concluded that parents were especially satisfied with the focus on learning strategies for coping with stress, and the parents emphasized the value of learning with other parents with whom they could relate. Our study discovered similar findings, with participants mentioning that they enjoyed talking with other parents in the group they attended and with participants reporting learning practical information as being valuable. Bitsika and Sharpley (2000) also suggested that assisting parents in learning to cope with their stresses could improve their ability to learn strategies for managing their child's behaviour problems.

Study 1 explained that 94% of parents who attended the support groups believed that the group they attended helped them to cope with some issues of importance to them. Participants in this study were satisfied with learning information that would assist them to understand some of their child's challenging behaviours, teaching parents some 'Functional Behavioural Assessment' (FBA) techniques. However, these findings are in contrast to the recommendations of other researchers (Smith et al., 1994; Solomon et al., 2001) who have

found that parents prefer groups that focus on emotional support and developing a sense of belonging, rather than sharing information. Therefore, explaining the content of support groups to participants at the time of enrolment so they can decide whether the topics will be of interest to them might be valuable for future research. Such a procedure would allow participants to have more control over the information they wish to access at the time of recruitment.

6.5.5. Changes in parent-reported frequency of ASD behaviour in their child.

Studies from different countries have shown that behavioural problems in ASD can be effectively managed with parent-delivered behavioural interventions (Athens & Vollmer, 2010; Jocelyn, Casiro, Beattie, Bow, & Kneisz, 1998). A Canadian research team (Jocelyn et al., 1998) conducted a study in a community day-care centre over 12 weeks. They taught 35 parents the use of functional analysis to understand challenging behaviour in children with ASD and developed treatment strategies for managing such behaviours. They found significant improvements in post-test behavioural measures. In another study using reinforcement, antecedent-based techniques and environmental manipulations, Butler and Luselli (2007) demonstrated a reduction in aggression to near zero level among children with autism aged 1–13 years.

The finding of the present study is also in line with a large scale randomized clinical trial, conducted by Bearss et al. (2015), among 180 children aged 3–7 years with ASD and behavioural problems in the United States. The investigators randomized children and their mothers into two groups to receive either parent training or education aimed at examining the effect of either intervention on disruptive behaviour in their children with ASD. Bearss et al. (2015) reported a reduction in disruptive behaviour post behavioural intervention, especially in the parent training group. A study conducted in Nigeria (Bello-Mojeed, Ani, Lagunju &

Omigbodun, 2016) also suggests that the behavioural intervention was highly acceptable to the parents with the vast majority being very satisfied and all participants willing to recommend it to a friend whose child has similar difficulties. The fact that improvements were reported with a relatively short intervention of five sessions is particularly encouraging because brief interventions are more likely to be feasible in resource-limited settings like Nigeria. The use of a group format, which could be cheaper than individualised intervention in a poor resource setting, adds further to the feasibility.

Study 1 assessed parent-reported frequency of ASD behaviour in children across the three support groups at five different times (Pre-Intervention, Post-Intervention, FU1, FU2, and FU3). Even though there was no indication that any of the three training approaches were more effective in terms of their effect upon the parents' evaluation of their child's ASD-related behaviour, there was a substantial main effect for time. All three groups showed a reduction in the frequency of unwanted behaviours scores across the five time periods. Our findings suggest that parent reports of ASD behaviour in their children could have changed after they received detailed information on ASD behaviours and were better able to identify clearly their child's behavioural repertoire. Our findings and findings from previous research support the effectiveness of behavioural programmes that include identification of the functions of challenging behaviour, and developing a behavioural plan that specifies strategies to alter the antecedents and reduce the contingencies that increase the behaviour while enhancing those that terminate or reduce the challenging behaviour. The robustness of this evidence underlines its recommendation in guidelines for management of children with ASD (National Institute for Health and Clinical Excellence (NICE), 2013). However, while the principles of behavioural intervention based on FBA are now well established, putting

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them into practice especially with parents with a priori limited knowledge of ASD or behavioural psychology or even basic literacy can be a challenge.

6.5.6. Changes in parent-reported quality of relationship with their child.

In this study, participants were asked to report the quality of their relationship with their child diagnosed with ASD. Our findings indicated that there was no substantial main effect for time, with all three groups not showing amelioration in the quality of the relationship with their child across the five time periods. However, there was a statistically significant difference in the effectiveness of the three training approaches in terms of their effect upon the parents' evaluations of the quality of their relationship with their child. Participants attending the STG reported higher quality relationships with their ASD child than participants who attended the FBATG or the CG. Previous research findings discovered many forms of difficulty that can affect parent–child relationships. For instance, stresses in parenting an atypically developing child can create negative feelings toward the child, alter parent expectations, and lead to a reduced sense of parenting competence (Van Hooste & Maes, 2003).

Past research has placed an emphasis on the bi-directionality of parent–child relations (Bell, 1968; DeMol & Buysse, 2008; Kuczynski, Loulis, & Koguchi, 2003). Just as children's characteristics affect their relations with parents, interpersonal interactions and relationships with adults affect children's development and functioning (Sameroff, 2009). Over time, each participant and the relationship as a whole undergo transformation (Fogel, 2009). It would seem inevitable that a child's autism will influence parent–child interactions. However, there is limited evidence concerning the relation between autism severity and parent–child relationships, although these are clearly matters of importance (Markus, Mundy, Morales, Delgado, & Yale, 2000). On the level of relatedness, the more verbal and cognitively able the

child, the more caregivers tend to engage in mutual play and positive feedback, whereas parents of children with autism who have poorer joint attention and fewer expressive language skills spend more time keeping their child physically contained and oriented to tasks (Kasari, Sigman, Mundy, & Yirmiya, 1988). As toddlers with autism show higher levels of externalising problems, their mothers use significantly more active/physical coping strategies and report greater levels of parenting stress (Gulsrud, Laudan, & Kasari, 2010).

This study did not focus on identifying differences in quality of relationships between parents and children depending on the child's developmental level. Instead the aim of study 1 was to detect whether one training group would be most efficient in improving parent-child quality of relationship. Our results indicate that participants attending the STG had improved quality of relationships with their child at the end of the programme. Such results indicate that teaching coping strategies and skills that would assist parents to deal with their personal stress might in the long-term enhance the relationship they have with their child.

7. Study 2: Applying a Face-to-Face Semi-Structured Interview to Explore the Support Needs of Parents of Children with ASD

7.1. Study rationale.

The findings derived from study 1, in which three different approaches to delivering group-based parent support, explained a strong theme of inconsistent parent participation despite parents evaluating the value of sessions highly. The prevailing pattern of inconsistent attendance mapped in study 1 falls in line with previous findings derived from community and research-based support programmes developed for parents of children with ASD, which have shown a high likelihood of intermittent attendance or complete withdrawal from group-based support shortly after that support has been accessed (Lee et al., 2008; McCabe, 2008). Researchers (Bromley et al., 2004; Tehee, Honan, & Hevey, 2009) have reported persistent difficulties in encouraging parents of children with ASD to consistently attend formal support groups and therefore gain full benefit from those groups.Therefore, identification of the factors that might cause these parents to access support services minimally or irregularly is crucial to remediating those factors and creating support service approaches that meet specific parent needs and encourage their consistent attendance.

Factors that might cause parents of children with ASD to access support services minimally or irregularly relate to the time pressures involved in parents' addressing their children's complex needs (Sawyer, Bittman, La Greca, Crettenden, & Harchak, 2010); the ASD child experiencing health problems (Bearss et al., 2015), and parents' inability to find and sustain appropriate childcare due to the complex nature of their child's needs (Brennan & Brannan, 2005; Smith et al., 1994). Clifford and Minnes (2013) investigated the factors that predicted attendance of parents of children with ASD in Parent Support Groups (PSG), asking 149 participants to complete a series of questionnaires investigating their opinions

toward PSGs. The findings indicated that parents who were participating in support groups reported stronger beliefs in the benefits associated with support groups, greater support from important others to participate in PSGs, and fewer difficulties with participating than parents who were not currently attending (Smith et al., 1994). Based on the findings of this study, it would appear that parents are more likely to attend PSGs if they coped by seeking emotional and instrumental support and by planning and doing something about their problem, if they believed that support groups would be beneficial, and if they believed that they would not have difficulties attending PSGs (Clifford & Minnes, 2013). These findings suggest that parents' attendance to PSGs is related to parents' beliefs and coping styles.

Investigation into the factors that might predict non-attendance or inconsistent participation in support groups have primarily focused on child-oriented variables and research into predictive factors has been criticised due to a paucity of examination into parent-oriented variables. In response to this limitation, Falk, Norris, and Quinn (2014) surveyed 479 parents of children with ASD to propose a model for identifying the variables that significantly predicted stress, anxiety and depression in parents of those children (especially the variables which pertained to parents' daily lives). The results suggested that the relationship between 'child-centric' factors and parental mental health problems may be mediated by social/economic support and parental cognitions, with significant implications for support services for this parental group. Another study investigated both child centric factors and environmental-factors, while considering child's and parents' characteristics, services available and family context in the design (Derguy, M'Bailara, Michel, Roux, & Bouvard, 2016). They analysed the joint impact on self-reported parental stress in ASD of individual factors (children-related and parent-related factors) as well as environmental

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factors (family environment and services provided for children with ASD) from 115 parents of children with ASD.

The Falk et al. (2014) study, whilst advancing knowledge into ASD parent experiences, was limited due to data-collection exclusively via survey administration and this precluded in-depth investigation of parents' particular experiences and life circumstances. Furthermore, this approach might have missed any specific factors capable of revealing better ways of approaching support to assist this particular group of parents. The Derguy et al. (2016) study was also limited due to its data-collection, with parents completing a variety of self-administered questionnaires. Thus, Derguy et al. (2016) recruited solely married parents of children with ASD, limiting the generalisability of the results to a specific group of parents of children with ASD.

Study 2 aimed to undertake an in-depth investigation of the factors which might act as barriers to parents of children with ASD seeking and consistently accessing support. That study also focused on addressing three methodological limitations of the previous research. First, the limitation on the bias towards child factors as being predictive of poor parent mental health outcomes will be overcome in study 2 by exploring a greater range of parent-oriented factors that might be responsible for parents' minimal attendance to support groups. Secondly, the usage of generic nature of data survey to assess participants will be overcome in study 2 by using a combination of a semi-structured interview and the completion of the same survey that was administered in study 1 to examine a variety of predictive factors for poor parent mental health outcomes.

Thirdly, to our knowledge previous researchers have failed to gather standardised responses and in-depth responses from the same group of participants to compare their responses. This limitation will be overcome, as participants recruited for study 2 attended the

original support groups from study 1. A comparison between the standardised context from study 1 and the responses to the semi-structured interview, through which specific answers will be elicited, will allow for this third limitation from previous research to be overcome. This return to the original participant group for further investigation was believed to be practical in order to create methods for support delivery that compensated for the limitations arising from those circumstances. The repeated use of participants allowed to identify the particular life circumstances which might have affected participants' attendance in study 1.

Study 2 was designed to address the three limitations from previous research listed above. The semi-structured interview was created to gather in-depth information on parents' experiences and on the difficulties that parents of children with ASD experience. The aim of study 2 was to gather information on the models of support delivery that would most likely meet the individual needs of participants at a future time. Detailed information on the content and on the admiration of the face-to-face semi structured interview are provided in the subsequent sections of this chapter.

7.2. Methods.

7.2.1. Participants.

A total of 33 parents participated in study 2. Of those 33 participants, 30 parents had completed study 1, and the remaining 3 parents were participants who had enrolled in study 1 but withdrew from the study at some stage. Participants' ages ranged from 32 to 61 years (M = 46.90; SD = 6.52). Of 33 participants, 27 (82%) were female and the remaining 6 participants (18%) were male. The data gathered on the relationship of the parent and/or guardian to the child with ASD showed that 26 participants (79%) were mothers, 5 participants (15%) were fathers and 2 participants were grandparents (6%). The information on employment status noted that 10 participants (30%) were "stay at home", 10 participants

(30%) worked "part-time", 6 participants (18%) worked "full-time" and the remaining 7 participants (21%) were "studying and/or volunteering in their community". Of the 17 participants who were unemployed, 16 participants (94%) mentioned that they had to stop working to care for their child diagnosed with ASD.

Participants' children's ages ranged from 8 to 33 years ($M = 12.63$; $SD = 4.68$). Of those 33 children, 23 children (70%) were male and the remaining 10 children (30%) were female. Of the 33 children, 27 (82%) were reported to have at least one sibling. Of these 27 children, 17 children (52%) had a sibling who was also diagnosed with a disorder, with the following diagnoses being reported by parents: 1) ASD diagnosis ($n = 11$); 2) ADHD diagnosis ($n = 2$); 3) Clinical depression ($n = 2$); 4) Learning Disability ($n = 1$); 5) PANDAS syndrome ($n = 1$). The age range of the siblings also diagnosed with a disorder ranged from 7 to 24 years ($M = 13.58$; $SD = 4.66$).

7.2.2. Procedure.

7.2.2.1. Recruitment of participants.

All parents who had participated in study 1 were sent an email which contained a brief description of the study and an Explanatory Statement (ES) which provided specific details on the study aims, procedures, and data-collection methods (see Appendix K for the ES). Parents interested in participating in study 2 were directed to contact the Student Researcher who phoned them to further explain the procedures they would be involved in. In order to ensure that parents were comfortable with participating in the study, they were provided with three opportunities to indicate their agreement: first, via response to the initial email sent to them; second, via verbal confirmation at the conclusion of the researcher-initiated phone call; and third; via text message agreement 24 hours prior to the interview date. Parents had the option to select the date and time of preference for the face-to-face semi-structured interview to be conducted. Participants were informed that the interview would be followed by the

completion of the questionnaire they had already completed in study 1 on five different occasions.

7.2.3. Setting.

Ethical approval was obtained to conduct the semi-structured interviews in a single session either in the CASD at Bond University or in participants' homes, and participants were invited to select the location in which they preferred the interviews be conducted. Of the 33 participants who participated in study 2, 17 parents (52%) elected to do the interview in their home. Participants mentioned that it would be more practical for them to do the interview at home, especially for parents who were home schooling their child and for parents who did not have a car to come to Bond University. One participant (3%) moved in NSW, and consequently the interview was conducted on Skype. The 15 remaining participants (45%) elected to do the interview in the CASD at Bond University. These participants mentioned that they wished to come to the university, so it would give them a break from home or because their home was not presentable.

When participants elected to do the semi-structured interview in their homes, the interviews were conducted in the participants' living rooms. For the interviews that were conducted at the CASD, the same clinic room was utilised to maintain consistency in the environment in which participants completed the interview. The private interview room used to conduct the semi-structured interviews was sound proof and approximately four by five meters in size. It contained a desk and three chairs. A computer and a phone were on the desk. A bookshelf was against one wall and a filling cabinet was next to the desk. A sign was put outside of the private interview room, informing people that work was in progress and asking people not to disturb.

7.2.4. Data-collection methods.

The data-collection was conducted via the administration of a one face-to-face semi-structured interview and the administration of five self-report rating scales, requiring approximately 1 hour 30 minutes of participants' time. Participants' responses to the interview questions were logged via handwritten notes and audio recording using an iPad. The audio recordings were essential to ensure the accuracy of the data and were used for the purpose of transcription. Written consent was secured from participants before any audio recording took place (refer to Appendix L). All 33 participants gave their written consent for the semi-structured interview to be recorded on an I-Pad. All audio recordings were destroyed once participants' interview responses were transcribed.

At the end of the semi-structured interview, participants were provided with a survey package (containing the five self-report scales) which was completed in the presence of the Student Researcher who was available to clarify items and assist participants in recording their responses. This approach was adopted to minimise discomfort for the 5 parents who suffered from a medical illness or learning disorder (i.e., dyslexia, cancer, and Chronic Fatigue Syndrome). Participants' answers were written down by the facilitator, sitting next to them, and asking participants to check that the information was recorded accurately. Participants' answers were checked to make sure they had answered all the questions from the five self-report scales before ending the data-collection. The topic structure and content questions of the semi-structured interview plus the self-report scales which comprise the survey are described in detail in the subsequent sections of Chapter 6.

7.2.4.1. Description of the semi-structured interview.

A combination of 13 open questions and 40 closed questions were asked throughout the semi-structured interview. Participants were asked twice during the interview if there was anything else they wished to mention, once at the end of the section on parent mental state,

support and self-efficacy and lastly at the conclusion of the interview. The 11 open questions

investigating potential themes have been presented in Table 13.

Table 13:

Potential Themes Resulting from the Opened Questions Asked During the Semi-Structured
Interviews

Section	Question Number	Information Retrieved
Section 3	Parent Anxiety Check (Question 3)	Day-to-day situations that trigger the most anxiety in parents.
Section 4	Parent Depression Check (Question 3)	Day-to-day situations that trigger the most depression in parents.
Section 5	Parent Social Support (Question 5)	Sources, availability and social support being most helpful to parents.
Section 5	Parent Social Support (Question 6)	Sources, availability and access to social support lacking or being least helpful to parents.
Section 5	Parent Social Support (Question 11)	Access, availability and satisfaction with information to help assist child.
Section 6	Parent Self-Efficacy (Question 1)	Parent current concern for child and confidence in managing and resolving this difficulty.

Section	Question Number	Information Retrieved
Section 6	Parent Self-Efficacy (Question 4)	Concerns for child future identified and described by parent.
Section 7	Child Behaviour and Functioning (Question 3)	Presence, frequency and description of child aggressive behaviour(s).
Section 7	Child Behaviour and Functioning (Question 6)	Presence, frequency, and description of child repetitive behaviour(s).
Section 8	School Behaviour (Question 11)	Parents' description of their relationship with their child's teacher(s) and school.
Section 8	School Behaviour (Question 12)	Parents' description of school-based situations that would affect their well-being negatively

The semi-structured interview comprised 54 questions, which were categorised under 8 sections. Section 1 (6 questions) was used to collect biographical details about the child. The purpose of section 1 was to collect information on the child's age, gender, and to gain some knowledge on the child's developmental stage. Section 2 (8 questions) focused on parents' biographical details. The purpose of section 2 was to collect information on participants' age,

gender, and to identify participants' employment status and financial comfort to detect whether parents of children with ASD experienced any financial difficulties.

Section 3 (3 questions) focused on collecting information on parents' anxiety. The Student Researcher accumulated information on participants' anxiety, checking the intensity of anxiety that participants felt at the time of the interview and identifying situations in parents' day-to-day life that would cause them to feel most anxious. Section 4 (3 questions) collected information on participants' depression, checking the intensity of depression symptoms that participants felt at the time of the interview and identifying situations in participants' day-to-day life that would cause them to feel most depressed.

Section 5 of the semi-structured interview gathered information on parent social support (12 questions), with the following sub-sections being investigated: 1) emotional support received from family and friends (2 questions); 2) practical support received from family members and friends (2 questions); 3) the type of support received from family members and friends that parents believed was most helpful (1 question); 4) the type of support received from family members and friends that parents believed was least helpful (1 question); 5) financial support (3 questions); 6) informational support (3 questions). Section 5 aimed to collect information on the type of support received by parents of children with ASD, and to check whether the type of support parents accessed was helpful or not in their opinion.

Section 6 collected information on parent self-efficacy (7 questions). The questions aimed to identify concerns that parents had for their child at the moment and concerns that parents

had about their child's future. Furthermore, the questions aimed to gather ratings on participants' confidence in handling the concerns they had for their child, the confidence parents had about handling their own personal stress and their other children's personal needs. This section aimed to detect the extent or strength of parents' belief in their own ability to handle concerns they had for their ASD child. At the end of section 6, participants were given the opportunity to mention any information or topic that the Student Researcher did not address yet (1 question).

Section 7 (10 questions) focused on the ASD child behaviour and functioning, with three sub-sections being investigated. The first sub-section assessed the child's aggressive behaviour in order to identify the type of aggressive behaviour the child might use, how often the child might use it on a weekly basis and around whom the child would be most likely to use such aggressive behaviour (3 questions). In the second sub-section parents were asked whether their child ever used repetitive behaviour, how often their child would use repetitive behaviour on a weekly basis and to describe the types of repetitive behaviour used by their child (3 questions). In the last sub-section, parents were asked 4 questions on their child's sleep behaviour. The aim was to gather information on children's potential sleep difficulties and to check whether children were taking any type of medication for their sleep difficulties.

Section 8 (3 questions) of the semi-structured interview collected information on school behaviour. The goal of this section was to get some detailed information on the type of relationship that parents experienced with their child's teacher and school, to get some

examples of school-based situations which could be detrimental to parents' well-being and asking parents if teacher(s) had a clear vision of their child's long-term future. At the conclusion of the semi-structured interview participants were offered the opportunity to mention any information or topic of relevance that the Student Researcher did not address so far (1 question).

The remaining 40 questions consisted of closed questions with the aim of collecting targeted information capable of being compared across the participant group, and therefore restricting the information gathered from participants. The closed questions can be found through the template of the semi-structured interview utilised with participants (refer to Appendix M). The closed questions investigated the following areas: 1) ASD child biographical details; 2) Parent biographical details; 3) Parent anxiety check; 4) Parent depression check; 5) Parent social support; 6) Parent Self-Efficacy; 7) Child behaviour and functioning. It should be noted that participants answered some of the closed questions they were asked in more detail than was required. Thus, 10 participants that were interviewed would often refer back to the support group they accessed in study 1. As a consequence, one last question was added to the semi-structured interview at the end for participants who completed study 1, asking "Did you find the programme helpful in overcoming some challenges you have faced?" The question was asked to 21 participants of 33.

Participants were asked 6 closed questions under the section "ASD child biographical details", asking detailed information on the ASD child's age, gender, formal diagnosis. In this

section parents were asked whether the ASD child had any siblings and whether the siblings had received any diagnosis. In the following section of the semi-structured interview "Parent biographical details", participants were asked 7 questions on their age, gender, employment status, their financial comfort, and on the expenses they had for their ASD child on a yearly basis. Participants were asked 2 closed questions in the section "Parent anxiety check", checking if parents felt anxious at the time of the interview and asking parents to rate their anxiety level on a 10-point Likert scale how anxious they felt from 1 (not anxious) to 10 (extremely anxious). In the section "Parent depression check" participants were asked 2 closed questions to check their depression level at the time of the interview and to rate their depression level on a 10-point Likert scale how depressed they felt from 1 (not depressed) to 10 (extremely depressed).

Under the section "Emotional support" of the semi-structured interview participants were asked 2 closed questions to rate on a 10-point Likert scale how emotionally supported they felt by their family members and emotionally supported they felt by their friends, from 1 (not at all) to 10 (all the time). Participants were asked 2 closed questions on "Practical support" to rate on a 10-point Likert scale how much help they received from family members in caring for their ASD children and how much help they received form friends in caring for their ASD children, from 1 (not at all) to 10 (all the time). Participants were asked 3 closed questions on "Financial support", checking whether participants received any resources for their child with ASD from the Government or from other organisations, and asking parents if

they received or had received in the past any financial support from family members and friends. The next section of the semi-structured interview focused on "Informational support", asking participants 2 closed questions to check if they could access information that would help them to assist their ASD child and checking if parents were happy with the information they had been able to access to assist their child.

Participants were asked 5 closed questions under the section on "Parent self-efficacy". Parents were asked to use a 10-point Likert scale to score how confident they felt in managing and resolving their child's difficulties, their personal difficulties and in managing their other children's needs, using a scale from 1 (not at all confident) to 10 (completely confident). Parents were asked if they had any concerns for their child's future and if they felt confident in handling their own stress and personal difficulties. The following section of the interview focused on "Child behaviour and functioning". Under the section on "Aggressive behaviour" parents were asked 2 closed questions. The first closed question asked parents if their child ever used aggressive behaviour when interacting with other people. For participants who replied "yes", they were then asked to rate on a 10-point Likert scale how often their child used violent or aggressive behaviour towards other people, ranging from 1 (not at all) to 10 (all the time). Under the section on "Repetitive behaviour" parents were asked 2 closed questions. The first closed question asked parents if their child ever used repetitive behaviour or made unusual hand/body movements repeatedly. For participants who

replied "yes", they were then asked to rate on a 10-point Likert scale how often their child used repetitive behaviour, using a scale from 1 (not at all) to 10 (all the time).

Under the section on "Sleep behaviour" parents were asked 4 closed questions. The questions asked parents if their child experienced any sleep difficulties or if their child took any medication to help them with their sleep. For participants who replied "yes", they were then asked to rate on a 10-point Likert scale how often their child experienced sleep difficulties, using a scale from 1 (not at all) to 10 (all the time). And participants were asked to name the type of medication their child took to help them sleep. The subsequent section focused on "School behaviour" parents were asked 1 closed question, checking if parents believed that their child's teacher had a clear vision for their child's long-term future.

Numbers or percentages of people with certain characteristics, conditions or going through certain experiences were calculated by the mean or average of the number of times a response was documented in the semi-structured interviews administered to participants. This method of analysis was conducted for questions 1, 2, 3, 4, 5, and 6 of the section on "ASD child biographical details". It was also used for questions 2, 3, 4, 5, 6, 7, and 8 of the section "Parent biographical details". The student researcher applied this type of analysis for question 1 of the "Parent anxiety check" section and for question 1 of the "Parent depression check" section. The numbers or percentages of people reporting on the type of "Financial support" they were able to access or not for questions 7, 8, and 9 were calculated. The same method of analysis was used under section "Informational support" for questions 10 and 12.

It also applied to the section of the semi-structured interview named "Parent self-efficacy" for question 3. And this type of analysis was conducted in different sub-sections of the main section of the semi-structured interview known as "Child behaviour and functioning": 1) Aggressive behaviour (question 1); 2) Repetitive behaviour (question 1); 3) Sleep behaviour (questions 7, 9 and 10); 4) School behaviour (question 13).

Numbers to the levels of intensity of an observed feeling or behaviour were assigned. The frequencies rate of intensity of specific behaviours or conditions were assessed and the information was presented in pie charts and bar graphs to give a visual representation of the rates given by participants. This method of analysis was applied for the following sections of the semi-structured interview: 1) Parent anxiety check (question 2); 2) Parent depression check (question 2); 3) Parent social support – Emotional support (questions 1 and 2); 4) Parent social support – Practical support (questions 3 and 4); 5) Parent self-efficacy (questions 2, 6 and 7); 6) Child behaviour and functioning – Aggressive behaviour (question 2); 7) Child behaviour and functioning – Repetitive behaviour (question 5); 8) Child behaviour and functioning – Sleep behaviour (question 8). Detailed information on the results obtained from the different methods of analyses discussed so far has been presented in Chapter 8.

7.2.4.2. Process for administering the semi-structured interview.

A range of micro-counselling skills were used during the delivery of the semi-structured interview in order to secure two objectives. First, to assist participants in exploring the issues

embedded within the interview in detail and to comfortably reflect and report on the particular circumstances which challenged them. Second, micro-counselling skills were implemented to build rapport and develop a professional relationship between the Student Researcher and the participants (McLeod, 2013). The overall administration of the semi-structured interview adhered the first stage of Hill's (2004) Helping Skills Model, which utilises three distinct stages in implementing counselling therapy: Stage 1-exploration; Stage 2-insight; and Stage 3-action. The interview for study 2 was restricted to "exploration" (i.e., Stage 1) as its focus was on in-depth examination of participants' unique experiences with no accompanying therapeutic intention.

The following 4 micro-counselling skills were used throughout the semi-structured interview: attending, restatements, verbal and non-verbal encouragers, and questioning as means of establishing rapport with participants. The skill of attending was implemented by genuinely focusing on participants' internal experiences (i.e., emotions, cognitions) and exhibiting non-verbal responses at an external level which clearly conveyed careful attention to participants' statements. Examples of attending skills applied during the interview process included: 1) finding the right balance of eye contact depending on participants; 2) using opened postures; 3) using a balanced tone of voice. The skill of restatements was used to verbally encourage participants to continue talking; it involved repeating the main content and repeating key words shared by participants during the semi-structured interview.

The skill of encouragers was used to assist participants toward deeper meaning and to maintain the flow of information coming throughout the semi-structured interview. Examples of non-verbal encouragers used during the interviews process included: 1) positive facial expressions; 2) open gestures; 3) silence so participants continued to share information. The skill of questioning was another micro-counselling skill which consisted of being sensitively aware of the impact that the questions had on participants (Ivey & Ivey, 1999). Closed questions were utilised to elicit specific information from participants that could be answered in a few words, whereas open questions aimed to encourage participants to expand on themes or topics. The micro-counselling skills described above have been listed in the basic listening sequence described by Corey (2013) and have been used throughout the semi-structured interview to enhance participants' experience and to make sure that participants would feel comfortable opening up to the Student Researcher.

A significant focus was placed on encouraging participants to share their story, their thoughts and their feelings throughout the semi-structured interview. The use of these specific skills assisted the facilitator to learn about participants' perspectives on problems and challenges they experienced on a day-to-day basis. Furthermore, some micro-counselling skills retrieved from the 'skilled helper model' developed by Egan (2004) were utilised. This model proposes a three-stage approach not unlike Hill's model (2004), however some of the skills proposed in Egan's model (2004) differ and were utilised during the semi-structured interview with participants. For instance, some skills applied in the first stage untitled

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"helping the client to tell their story" were used: 1) tuning in – empathic presence; 2) listening to verbal and non-verbal communication from participants; 3) communicating back to participants what the interviewer understood; 4) probing and summarising the information shared by participants.

Lastly, prompts were used throughout the interview to encourage participants to be more detailed or to expand on a topic discussed, or in certain cases to redirect participants to the initial question they were asked. The use of prompts depended on participants' answers throughout the interview. The prompt "is there anything else you would like to mention?" was utilised 22 times. Prompts used to encourage participants to be more detailed with the answer they shared were used 21 times. The prompt "can you give me a few examples of…?" was used 12 times throughout the semi-structured interview. And finally, the facilitator repeated the question that was asked initially 4 times to redirect participants to the initial question they were asked to answer.

7.2.4.3. Description of the self-report scales.

Participants were required to complete a survey at the conclusion of the interview, which contained the following five self-report scales: the PHQ9 (Spitzer et al., 1999) was used to ascertain the overall level of depression; the GAD7 (Spitzer et al, 2006) was used to ascertain the overall level of anxiety; the P-CRI (Gerard, 1994) was used to assess the quality of parent-child relationship, the CD-RISC (Connor & Davidson, 2003) was used to assess participants' resilience; and the ASD Behaviour Checklist (Bitsika & Shapley, 1997) was

used to assess the presence and intensity of ASD behaviours in children. All five self-report scales have been described in relation to focus, item content, recording process, and psychometric properties on pages 108-115 of Chapter 6 in this thesis.

7.2.4.4. Process for completion of the self-report scales.

A printed out copy of the five self-report scale was given to participants to complete in the following order: 1) ASD Behaviour Checklist; 2) P-CRI; 3) CD-RISC; 3) GAD7; 4) PHQ9. The ASD Behaviour Checklist scale assessed the presence and intensity of ASD behaviours in children. The P-CRI (Gerard, 1994) assessed the quality of relationship between parents and children. The CD-RISC (Connor & Davidson, 2003) assessed parents' resilience levels. The GAD-7 (Spitzer et al., 2006) examined the presence and intensity of symptoms of anxiety reported by parents of children with ASD. The PHQ-9 (Spitzer et al., 1999) assessed the intensity of symptoms of depression experienced by parents.

The instructions were read carefully to participants for the successful completion of each scale and each time participants finished completing one of the self-report scales, the answers were checked to make sure that every question was answered. The micro-counselling skills applied throughout the administration of the self-report scales were described in the previous section of this chapter, and each micro-counselling skill was used as participants completed the self-report questionnaires.

8. Thematic Analysis Findings on Parent Support Barriers and Needs

    8.1. Data analysis procedures for the semi-structured interview and the self-report scales.

    8.1.1. Thematic analysis procedures for the semi-structured interview.

Thematic Analysis (TA) is conducted as part of qualitative research. Several definitions of qualitative research have been proposed in the literature, and each of these influences how qualitative data analysis is characterised and the types of analyses that will be performed on one's data. Holloway and Todres (2003) have described qualitative approaches as being multifaceted, nuanced and incredibly diverse and recommended that TA should be regarded as a foundational method for qualitative analysis, as TA requires core skills applicable to–many other forms of qualitative analysis. TA is used in a multitude of areas such as psychology (Betenson, 2013; Nkadimeng, Lau, & Seedat, 2016; Pack, Hemmings, & Arvinen-Barrow, 2014), behaviour management (Jones, Monsen, & Franey, 2013; McLean & Pratt, 2006), and medicine (Correa-Velez, Clavarino, & Eastwood, 2005; Hudon et al., 2012). Boyatzis (1998) described TA as a tool that could be used across different methods instead of characterising it as a specific method in itself. In contrast, Braun and Clarke (2006) argued that TA should be viewed as a method in its own right. TA has been described as a useful and flexible research tool due to its theoretical freedom, which can provide a complex, thorough and rich account of data in certain instances. It is a method used to identify, analyse and

report themes within data which aims to interpret different aspects of a research topic (Boyatzis, 1998).

Despite these proposed benefits for interpreting qualitative data, TA has received criticism over the past decade. The critics made about TA have been addressed by several researchers (Antaki, Billig, Edwards, & Potter, 2002; Attride-Stirling, 2001; Tuckett, 2005) and some solutions have been offered to remediate to such criticisms of TA. For instance, Antaki et al (2002) proposed a common critic on the absence of succinct and specific guidelines around TA, implying that the 'anything goes' criticism can be justified. A solution was offered by Holloway and Todres (2003) to remediate to the critic made by Antaki and colleagues (2002). Holloway and Todres (2003) encouraged researchers to make their assumptions about the data explicitly, so they would expose clear guidelines for this process.

Another critic of TA advanced that this type of analysis was perceived as a poorly branded method, not holding a similar status to other methods such as narrative analysis and grounded theory (Attride-Stirling, 2001; Tuckett, 2005). However, Clarke and Braun (2006) identified that previous research should have identified TA as the qualitative methods they used or they should have used very specific terms to describe the qualitative analyses they ran, explaining in detailed terms that the data was subjected to qualitative analysis to identify common themes. Another critic of TA is that the research cannot be evaluated if researchers do not explain how they conducted the analysis of their data, making it even more

challenging to compare the research with other studies on the same topic (Attride-Stirling, 2001).The solution offered by Attride-Stirling (2001) to remediate this critic was for researchers using qualitative methods of analysis needed to clearly indicate what they were doing and explain the reasons why certain qualitative analysis were performed.

Another common critic of TA voiced by Fine (2002) described the researcher's method using TA as simply giving a voice to participants and therefore reputing the active role the researchers took in identifying themes, selecting which themes are of interest and reporting on these themes to the readers. Severall researchers offered a solution to remediate this critic in previous years, mentioning that researchers must take an active role in explaining how they identified themes, how they selected which themes are of interest and reporting on these themes to the readers (Rubin & Rubin, 1995; Taylor & Ussher, 2001).

8.1.*2. Stepwise process for conducting Thematic Analysis of interview data.*

8.*1.2.1. Outlining the specific analysis process to be performed within the Thematic Analysis framework.*

TA has been described as a process designed to organise and classify data in relation to themes, which are descriptors for particular trends in the data. A theme might be given considerable space in some data items, and little or none in others, or it might appear in relatively little of the data set. Researcher's judgement is necessary to determine what a theme is. Braun and Clarke (2006) encourage researchers to retain some flexibility during

that process of TA. A method implemented when conducting TA consists of not reporting prevalence on participants' responses and to use general terminology to refer to themes such 'many participants' or 'a number of participants' (Braun, Gavey, & McPhillips, 2003; Taylor & Ussher, 2001). Such descriptors work linguistically to propose a theme truly existed in the data, and to persuade readers that they were reporting honestly about the data. This seems to be an area where more discussion is needed about how and why we might characterize the occurrence of themes in the data, and, whether, if, and why prevalence is on the whole imperative.

The six phases involved within TA, as described by Braun and Clarke (2006) can be quite similar to the phases of other types of qualitative research, so these stages are not essentially exclusive to TA. The process starts when patterns are being noticed, and when patterns of meaning within the data set are being collected from participants' responses, occurring during data collection at times. The process ends when reports are made on the content and meaning themes obtained through the data, where themes are theoretical concepts being categorized before, during, and after analysis (Ryan and Bernard, 2000). The analysis process comprises a persistent moving back and forth between the entire data set, the coded extracts of data that researchers are analysing (Patton, 1990). Writing can be described as an essential part of TA, not something that typically takes place at the end, as can be the case with other statistical analyses. Therefore, writing during phase one of the analyses is highly encouraged, with suggestions on making notes of ideas and potential coding schemes, and

continuing this writing process right through the entire analysis process. According to Ely and colleagues (1997) this process will develop over time and should not be hurried.

Braun and Clarke (2006) have provided an outline for researchers using TA to work through, using six different phases of analysis. The guidelines provided by Braun and Clarke (2006) on using six phases when conducted TA have been well supported and are prominent in the field of TA. The authors explained that these TA guidelines were created not as rules for researchers to follow but more as uncomplicated principles that will be applied in a flexible fashion to fit with the data obtained from participants and to fit the research questions. The six phases described by Braun and Clarke (2006) are summarised in Table 9 and discussed in detail below to elaborate on their distinct purpose and data outcomes.

8.1.2.2. Familiarisation with the data.

Riessman (1993) clearly explained that the process of transcription was an excellent technique to use in TA for a researcher to become familiar with the data collected from participants. Bird (2005) refereed to this first step as a crucial phase of data analysis within qualitative methodologies. Just like there is no one way to conduct thematic analysis, there is no one set of guidelines to follow when typing a transcript. Nevertheless, at a minimum it involves a laborious and comprehensive 'orthographic' transcript, such as a 'verbatim' account of all verbal and even at times non-verbal utterances from participants. The most important quality for a transcript to be considered as thorough is that the transcript retains the

information the researchers need, in a manner which is 'true' to its original form (Poland, 2002).

 In order to conduct a TA with the verbal data obtained through the semi-structured interviews done with parents of children with ASD, each interview conducted was transcribed into written form. The transcription of the semi-structured interviews was conducted, with the aim of becoming familiar with the data set (Riessman, 1993). A methodical and rigorous 'orthographic' transcription of each semi-structured interview was conducted, in which a verbatim account of all verbal utterances from participants during the interview were recorded, as suggested by Poland (2002).

After the finalisation of each transcript, the Student Researcher checked the transcript back against the original audio recordings to make sure that accuracy of the data collected was maintained. This process was part of "Phase 1" described in Braun and Clarke's (2006) model of TA (refer to Table 9). Each interview was listened to on two different occasions to make sure that the transcription of the data was completed efficiently. The transcripts were read several times during this phase, but also during the following steps involved in the TA.

8.1.2.3. Generalisation of initial codes.

Braun and Clarke (2006) referred to this process as "Phase 2", through which researchers are encouraged to generate a list of ideas about what is in the data set and what is interesting about these ideas. According to Boyatzis (1998), this second phase involves the

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formulation of initial codes obtained from the data set. The data is then organised into meaningful groups as part of the coding analysis (Miles & Huberman, 1994; Tuckett, 2005). Bryman (2001) recommended that researchers code for as many potential themes as possible, as no one could predict what might be interesting later on in the analysis and that researchers keep some of the surrounding data when coding, so the context is not lost.

For the purpose of our TA, the data was approached with specific questions in mind that would be coded around. The questions that were coded around can be seen in Table 13. Furthermore, the data set was worked through in a systematic manner, giving full and equal attention to each data item, and identified interesting aspects in the data items that formed the basis of repeated themes across the data set. The data was coded from the open questions asked to participants during the semi-structured interviews (see Table 13).

Potential patterns were noted for each open question asked in each individual interview. All data extracts were coded separately and then collated together within each code and relevant data extracts. This process was conducted using a computer software known as NVivo11, through which the information was tagged and coded within each data item. The frequency by which participants used specific words or concepts during the interview was identified, as recommended by Elo and colleagues (2014).

For each open question asked to participants, the codes that were extracted were written down on a different piece of paper out of the data; this technique was previously used

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by Clarke, Burns and Burgoyne (2005). A qualitative content analysis also referred to as deciding on informative name for each theme was utilised as a classification technique to identify codes that were formed within complex data sets obtained through participants' responses. A cut off point was utilised to decide whether certain codes should be disregarded in the TA. A code had to be mentioned by at least 3 participants out of the 33 participants, to be included in the TA. Consequently, the focus was placed on codes that appeared to be more common, mentioned at least by 3 participants, and codes that appeared atypical, mentioned by less than 3 participants were removed out of the TA. An example of the process is presented in Appendix N.

8.1.2.4. Location of themes within the interview data set.

A number of decisions need to be made in order to conduct a reliable and valid TA. It is highly recommended that a number of questions should be taken into consideration before analysis and at times even before the data is collected by researchers. Throughout TA, researchers should have an ongoing reflexive dialogue with regards to the issues they will be confronted with; this process is referred to by Braun and Clarke (2006) as "Phase 3". To begin, researchers should ask themselves what information captured could be classified as a theme. A theme would be defined as something significant about the data collected from participants in relation to the research question. Two crucial questions should be asked in terms of coding: 1) what data can be defined as a theme? 2) What 'size' does a theme need to

be? The second question refers to the prevalence, in terms of space within each data item and of prevalence across the entire data set. Ideally, there will be a number of instances of the theme across the data set, but more instances do not necessarily mean the theme itself is more crucial.

A theme might be given considerable space in some data items, and little or none in others, or it might appear in relatively little of the data set. So, the researcher's judgement is necessary to determine what a theme is. Braun and Clarke (2006) encourage researchers to retain some flexibility during that process of TA. Decisions can be made not to report prevalence on participants' responses and previous researchers have used general terminology to refer to themes such 'many participants' or 'a number of participants' (Braun et al., 2003; Taylor & Ussher, 2001). Such descriptors work linguistically to propose a theme truly existed in the data, and to persuade readers that they were reporting honestly about the data. This seems to be an area where more discussion is needed about how and why we might characterize the occurrence of themes in the data, and, whether, if, and why prevalence is on the whole imperative.

The data obtained through the open questions asked during the semi-structured interviews conducted with participants was coded and collated. The different codes were gathered into potential themes and all the relevant coded data was organised under different themes. The name of each code was written on a different piece of paper for each open

question asked during the semi-structured interview. Then, codes were organised into theme-piles. Thematic maps were created for each open question asked to participants (see Appendix O). Themes and subthemes were identified, and a quantitative content analysis was utilised to identify which themes were reported more often by participants.

8.1.2.5 *Refinement of initial themes.*

Themes or patterns within data can be identified in one of two primary ways in TA: in an inductive or 'bottom up' way (Frith & Gleeson, 2004), or in a theoretical or deductive or 'top down' way (Boyatzis, 1998; Hayes, 1997). An inductive approach means the themes identified are strongly linked to the data themselves (Patton, 1990). In this approach, if the data have been collected specifically for the research (i.e., via interview or focus group), the themes identified may bear little relation to the specific questions that were asked of the participants. They would also not be driven by the researcher's theoretical interest in the area or topic. Inductive analysis is therefore a process of coding the data without trying to fit it into a pre-existing coding frame, or the researcher's analytic preconceptions.

In contrast, a 'theoretical' thematic analysis would tend to be driven by the researcher's theoretical or analytic interest in the area, and is thus more explicitly analyst-driven. This form of TA tends to provide a diminished rich description of the overall data, and a more detailed analysis of some aspect of the data. Additionally, the choice between inductive and theoretical maps onto how and why you are coding the data, you can either

code for a quite specific research question (which maps onto the more theoretical approach) or the specific research question can evolve through the coding process (which maps onto the inductive approach).

Another decision revolves around the 'level' at which themes should be identified: at a semantic or explicit level, or at a latent or interpretative level (Boyatzis, 1998). TA typically focuses exclusively or primarily on one level. With a semantic approach, the themes are identified within the explicit or surface meanings of the data, and the researcher is not looking for anything beyond what a participant has said or what has been written. Ideally, the analytic process involves a progression from description, where the data have simply been organized to show patterns in semantic content, and summarized, to interpretation, where there is an attempt to theorize the significance of the patterns and their broader meanings and implications (Patton, 1990), often in relation to previous literature (Frith & Gleeson, 2004). This process refers to "Phase 4" described by Braun and Clarke (2006).

The TA conducted for study 2 was data-driven and consequently an inductive analysis was used for the purpose of our research. The aim of study 2 was to gather information on a topic that was poorly investigated in previous research through the use of a qualitative data analysis. The themes were identified through the combination of a semantic and interpretative level of analysis. The major themes were generated only from information that participants had explicitly discussed during the interview, to make sure that the themes generated could

not be questioned. Interpretations of participants' responses during the semi-structured interview were made in order to define clearly each theme generated from the TA.

8.1.2.6 *Definition and naming of themes.*

Braun and Clarke (2006) described defining and refining themes that will be presented within the analysis and analysing the data within those themes, as "Phase 5". Detailed analysis should be conducted and written for each theme during this fifth phase, to make sure that there is no overlap between themes and that the themes are telling the overall story of the data set. As part of the refinement, identification of any subthemes should be performed under each a theme. Subthemes are essentially themes-within-a-theme. They can be useful for giving structure to a particularly large and complex theme, and also for demonstrating the hierarchy of meaning within the data (Braun & Wilkinson, 2003). It is important that by the end of this phase, themes be clearly define for what they are and for what they are not. Although working titles will have been given already, this is also the point to start thinking about the names to give themes in the final analysis. Names need to be concise, punchy, and immediately give the reader a sense of what the theme is about (Braun & Clarke, 2006).

The major themes identified were reflected upon under each concept reviewed during the semi-structured interview, trying to identify whether they highlighted a compelling story about the data obtained from participants. The main themes were then clearly defined,

explaining which factors were regarded or disregarded in each theme definition. The nature

of each individual theme was clearly defined and different relationships between themes were

also addressed. Decisions were made on how to develop themes and how to identify

subthemes within themes. An example of a participant's response for each theme was

presented and the student researcher defined whether the theme identified was child-focused

or environment focused.   A summary of the description of the different phases of TA

described by Braun and Clarke (2006) can be seen in Table 14. The detailed definitions and

naming of each theme for the purpose of study 2 have been presented in Table 15.

Table 14:

Description of the Process Used Within Six Different Phases of TA Developed by Braun and

Clarke (2006)

Number	Phase	Description of Process
1	Familiarising oneself with the data	Transcribing data, re-reading the data, noting down ideas.
2	Initial codes generated	Using a systematic technique across the data set to code features of the data
3	Looking for themes	Gathering codes into potential themes, organising data under each theme

Number	Phase	Description of Process
4	Reviewing thermes	Checking that themes work in relation to coded extracts and the entire data set
5	Defining and naming themes	Generating clear definitions and names for each theme
6	Producing a report	Relating back analysis to research questions and previous literature

8.1.3. The benefits associated with using Thematic Analysis.

TA has been considered the most appropriate type of analysis for any study that seeks to discover information using interpretations. TA provides a systematic element to data analysis, allowing researchers to associate an analysis of the frequency of a theme with one of the whole content. This will confer accuracy and intricacy and enhance the whole meaning of a research. Qualitative research requires understanding and collecting diverse aspects and data. According to Marks and Yardley (2004) TA is a type of analysis that would give an opportunity to understand the potential of any issue more widely.

Namey, Guest, Thairu, and Johnson (2008) said that TA moves beyond counting the number of explicit sentences or words shared by participants. But it focuses on identifying and describing explicit but also implicit ideas. The data obtained from participants is coded

for the development of new ideas or themes, so it can be analysed later. The analysis conducted from the coding of the data can include comparing how often themes or topics were mentioned within a data set, identifying any code co-occurrence, or displaying relationships within codes through the use of a graph (Namey et al., 2008).

8.1.4. Reasons why Thematic Analysis is suited to interview data.

The "interview" has been described as a managed verbal exchange (Ritchie & Lewis, 2003; Gillham, 2000) and as such its usefulness heavily rests on the communication skills of the interviewer (Clough & Nutbrown, 2007). These include the ability to clearly structure questions (Cohen, Manion, & Morrison, 2007); listen attentively (Clough & Nutbrown, 2007); pause, probe or prompt appropriately (Ritchie & Lewis, p.141); and encourage the interviewee to talk freely, "Make it easy for interviewees to respond" (Clough & Nutbrown, 2007, p.134). Interpersonal skills (Opie, 2004) such as the ability to establish rapport, perhaps with humor and humility, are also important. This last point draws attention to the relational aspect and trust which is needed between participants.

A useful concept in describing the types of interview processes is the pre-determined organizational continuum along which any particular interview can be placed which ranges from 'unstructured' (i.e., spontaneous content and "reactive" question asking) and 'structured'(i.e., pre-determined content and strict question asking). The 'unstructured' pole is closer to observation, while the 'structured' use 'closed' questions is similar to types of

questionnaire. The interview implemented with the participants of Study 2 fits somewhere at the mid-point of the continuum due to its 'semi-structured' nature. Cohen and colleagues (2007) draw attention to the variety of interview models discussed in methodology literature. Patton (1990), for example, describes four types including the "interview guide approach". This resembles closely the current interview in its use of a schedule. What is common to the majority of the differences in approach is the extent to which one interview can be compared with another.

This ultimately relates to broader questions about qualitative and quantitative methodologies, a point suggested by Cohen et al. (2007, p.355).The decision to interview implies a value on personal language as data. Face-to-face interviewing may be appropriate where depth of meaning is important and the research is primarily focused in gaining insight and understanding (Gillman, 2000, p.11; Ritchie & Lewis, 2003, p.138). It could also be argued the researcher choosing to interview face-to-face recognises the potential significance of context. In relation to this, there is debate between 'naïve' realism and constructivist perspectives. However, from a critical realist position it is possible to recognise the collaborative qualities of research data while maintaining a belief in its validity in revealing knowledge beyond itself of the social world within which the interview event has occurred (Banfield, 2004). Semi-structured interviewing is therefore consistent with participatory and emancipatory models.

Interviews are a widely used tool to access people's experiences and their inner perceptions, attitudes, and feelings of reality. Based on the degree of structuring, interviews can be divided into three categories: structured interviews, semi-structured interviews, and unstructured interviews (Fontana & Frey, 2005). Semi-structured interviews (see the later chapter on this method) are more flexible. An interview guide, usually including both closed-ended and open-ended questions, is prepared; but in the course of the interview, the interviewer has a certain amount of room to adjust the sequence of the questions to be asked and to add questions based on the context of the participants' responses. In semi-structured interviewing, a guide is used, with questions and topics that must be covered. The interviewer has some discretion about the order in which questions are asked, but the questions are standardized, and probes may be provided to ensure that the researcher covers the correct material. This kind of interview collects detailed information in a style that is somewhat conversational. Semi-structured interviews are often used when the researcher wants to delve deeply into a topic and to understand thoroughly the answers provided.

A combination of closed questions and open questions were asked to participants throughout the semi-structured interview. The closed questions collected quantitative information from participants, whereas the opened questions collected qualitative information from participants. Consequently, two different types of analyses were conducted on the data collected from participants. Qualitative TA was conducted on the data collected from the open questions asked to participants during the semi-structured interview. Quantitative

analyses were performed on the closed questions asked to participants during the semi-structured interview and from the self-report questionnaires completed by participants. In this section of the chapter, the focus will be on the analysis of the qualitative data obtained from the open questions (see Table 13), using TA.

8.2. Findings on Thematic Analysis on participants' answers to the open questions of the semi-structured interview.

The open questions asked during the semi-structured interview aimed to gain a thorough account of qualitative data from participants, and potential themes were retrieved, analysed and reported upon from 11 open questions of the 13 open questions asked to participants (refer to Table 13) As mentioned previously, only information that was mentioned by a minimum of 3 participants was included in the TA. Overall, 10 major themes were identified and defined (presented in Table 15). Steps were taken to determine whether themes were child-focused or environment focused. The environment-focused questions related to parental social and experiential such as the type of support (i.e., social, economic, and informational) they could access. The child-focused questions explored factors directly related to their children's challenging behaviour, repetitive behaviours, sleep difficulties, and school difficulties. The themes and sub-themes identified for each open question are discussed on pages 200-218 below.

8.2.1. Major themes identified through the Thematic Analysis.

Major themes were classified under two different categories, referred to as "child-focused" or "environment focused" themes. Child-focused themes encompassed information that related specifically to some aspect of the child's ASD diagnosis or the outcomes (to the child's daily functioning) of that diagnosis. Child-focused themes included parent concerns centred on the following issues: areas of diagnostic impairment and the presence of restricted repetitive behaviour patterns and fixated interests; their children's' ability to make age-appropriate transitions across the lifespan; their children's' mental well-being, physical health and sleep patterns; and their children's' aggressive and/or self-injurious behaviour.

Environment focused themes encompassed information that related specifically to external factors present in parents' lives that were not linked to their ASD child but related to their personal environment. Environment-focused themes included parent concerns on the following issues: some aspect of their financial circumstances; some aspect of their child's classroom learning behaviour difficulties and some of the difficulties encountered within the school-environment; work deadlines and/or other work demands; child's current difficulties; child's future; and the most helpful and the least helpful types of support received by parents of children with ASD. Detailed definitions of each major theme and their classification can be observed in Table 15.

Table 15:

Major Themes Named and Defined, and Examples Retrieved from Data Coding for Each Theme Defined.

Theme	Definition	Response Example	Theme Focus
ASD Symptoms	The parent expressed concern about some aspect of their child's ASD diagnosis. This theme included concerns related to areas of diagnostic impairment (i.e., social communication, non-verbal communicative behaviours, deficits in developing and maintaining relationships and reciprocal social interactions) plus presence of restricted and repetitive behavioural patterns and fixated interests. This theme excluded associated behavioural problems, sleep and/or eating difficulties and medical conditions.	"We have the flap with the skip…Her new thing now is watching something that she finds to be funny on TV and she will repeat that one little section over and over."	Child
Financial	The parent expressed concern about some aspect of their financial circumstances. This theme included concerns related to areas of direct financial demands and/or stressors (i.e., worrying about money, experiencing financial difficulties and having to pay bills). This theme excluded associated work difficulties and expenses for their child.	"All our finances were completely drained. So we had no reserves and then went into debt. So when bills come in, we struggle on that."	Environment

Theme	Definition	Response Example	Theme Focus
School	The parent expressed concern about some aspect of their child's learning difficulties at school. This theme included concerns related to areas of their child's classroom learning behaviour difficulties plus some of the difficulties encountered within the school environment (i.e., teachers' limited understanding of child difficulties and miscommunication with teachers). This theme excluded associated behavioural problems related to their child.	"We were so disappointed with her report card at the end of semester because her teacher was telling us verbally "oh she is doing great", but her report card reflected nothing in fact it was scathing about her. So we were shocked."	Environment
Transitions	The parent expressed concern about some aspect of their child's abilities to make transitions throughout their lifespan. This theme included concerns related to areas of their child's difficulties with making transitions (i.e., transition from primary school to high school, child's ability to get a job after high school). This theme excluded associated excessive resistance to change, persistence on following precise routines and the child's reactivity to sensory input.	"Transitioning from school to post-school because I don't want him sitting at home doing nothing."	Child

Theme	Definition	Response Example	Theme Focus
Work	The parent expressed concern about some aspect of their work demands. This theme included concerns related to parent's work deadlines and/or other work demands. This theme excluded associated child symptoms and difficulties that would require parent to adjust their work schedule.	"I am probably not overly anxious at the best of times; you know maybe a bit of stress with work at times. Okay probably work commitments."	Environment
Health	The parent expressed concern about some aspect of their child's health. This theme included concerns related to their child's mental health well-being (i.e., child's anxiety and child's suicidal ideations) plus their child's physical health (i.e., child's inability to self-care and child's weight gain) plus their child's sleep difficulties. This theme excluded associated concerns parent had about their personal health and/or the health of their partner.	"I guess we truly worry about her health at the moment, her oral health and her weight…and her sleep patterns are not very good either."	Child
Aggressive Behaviours	The parent expressed concern about some aspect of their child engaging in aggressive behaviours. This theme included concerns related to their child's aggressive behaviours (i.e., emotional aggressiveness and physical aggressiveness) plus child's self-injurious behaviours. This theme excluded associated communication and social interaction difficulties.	"He will just even sometimes walk past me and just flick at me, or I will say "go back to your room" and he will say "what are you looking at Bitch"	Child

Theme	Definition	Response Example	Theme Focus
Concerns for Child	The parent expressed concern about some aspect of their child current and/or future needs and difficulties. This theme included parent concerns about their child's current difficulties (i.e., poor self-control and their child's performance at school) plus parent concerns about their child's future (i.e., child post-school independence, poor child expression of needs, and continued care of child post parent death). This theme excluded associated parent concerns for siblings of the ASD child.	"My major concern would be him understanding how it is that he is supposed to fit into society. And he is never going to be part of mainstream society, but he needs to be able to engage with it sufficiently to be able to function."	Environment
Most Helpful Support	The parent described the type of support they received from friends and family that was most helpful to them. This theme included support parent received for their child (i.e., acceptance of ASD child) plus support they received personally (i.e., emotional and physical support offered, and receiving financial support). This theme excluded associated information on support parent received that was not helpful.	"I am more concerned if they can do something that is beneficial for her, but it also benefits me and that I have got a few hours or whatever time away from her."	Environment

Theme	Definition	Response Example	Theme Focus
Least Helpful Support	The parent described the type of support they received from friends and family that was least helpful to them. This theme included information on communication difficulties (i.e., negative verbal comments made about child and/or parenting abilities, and people being judgemental) plus friends and family having limited understanding of ASD. This theme excluded associated information on support that parent described as being most helpful to them.	"Oh, I suppose it would be well-meaning advice. Probably from someone who doesn't have a child on the spectrum."	Environment

8.2.2. Child-focused major themes identified.

8.2.2.1. Theme 1: Aggressive behaviours.

The first child-focused major theme identified was labelled as "Aggressive Behaviours", and this comprised information on parents' concerns about some aspect of their child engaging in aggressive behaviours. This theme included concerns related to their child's aggressive behaviours, including emotional aggressiveness and physical aggressiveness. This theme also included information on their child's self-injurious behaviours. This theme excluded associated communication and social interaction difficulties.

This theme arose from one question asked to participants during the semi-structured interview. Participants' answers were gathered from question 3 of the "Child Behaviour and Functioning" (refer to Table 13). The themes were numbered according to the frequency parents used to endorse them. The responses from participants were organised through the use of a process referred to as "deciding on informative name for each theme", which is part of the fifth phase in the Braun and Clarke model of TA (2006). The cut-off system and the naming process were applied to all of the subsequent TA conducted for the open questions asked during the semi-structured interview.

Overall, thirty parents (91%) expressed concerns on their child engaging in at least one type of aggressive behaviour. Participants' responses have been included under theme 1: "Aggressive behaviours". Three sub-themes emerged from parents' responses labelled as

major theme 1 "Aggressive Behaviours". One sub-theme was identified from participants'

responses and labelled "ASD Child Emotional Aggressiveness". This sub-theme included

information shared by thirty parents on their child's changes in voice when engaging in

aggressive behaviours and on their child's using manipulation emotionally when engaging in

aggressive behaviours. This is one example of emotional aggressiveness shared by a parent

"He tried to manipulate me to get what he wants" and *"He starts shouting and using*

manipulative words like "you don't love me".

A second sub-theme was identified and referred to as "ASD Child Physical

Aggressiveness". This sub-theme included information shared by twenty-one on their child

using physical aggressiveness towards other people such as pushing, kicking and punching.

One example from a parents' report was *"he will try to physically push or hit"*. A third

subtheme was labelled "Self-Injurious Behaviours", and six parents reported that their child

would engage in self-injurious behaviours when being aggressive. This example was given

by a parent *"She will scratch quite deep, like really deeply and draw blood"*.

8.2.2.2. Theme 2: ASD symptoms and difficulties.

The second child-focused major theme identified was labelled as "ASD

Symptoms/Difficulties" and this comprised information on parents' concerns about some

aspect of their child's ASD diagnosis. These parents' concerns related to areas of diagnostic

impairment including: social communication, non-verbal communicative behaviours, deficits

in developing and maintaining relationships and reciprocal social interactions. Parents' reports of the presence of restricted and repetitive behavioural patterns and fixated interests were also included in the definition of this theme. This theme arose from two questions asked to participants during the semi-structured interview. Participants' answers were gathered from question 3 of the "Parent Anxiety Check" and from question 3 of the "Parent Depression Check" (refer to Table 13).

Twenty-two parents (66%) expressed concerns for their child's ASD symptoms difficulties; these responses have been included in theme 2. Two sub-themes emerged from parents' responses labelled as major theme 2 "ASD Symptoms/Difficulties". One sub-theme identified was named "Child's Progress Difficulties" and consisted of examples of difficulties the child experienced in progressing in different areas of his/her life due to their ASD. Fourteen parents expressed concerns on their child's progress due to their ASD symptoms. An example given by a parent during the interview was *"...My major concern for [child's name] is her progression and the way she relates to other people"*. A second sub-theme was identified and named "Child Social Communication Difficulties" and included information shared by eight participants on their child's difficulties with communication and their child's difficulties with social interactions. An example given by a participant during the interview around the child's communication difficulties consisted of *"...his communication now is just non-existent a lot of the time."*

8.2.2.3. Theme 3: Health.

The third child-focused major theme identified was labelled as "Health", and this theme comprised information on parents' concerns about some aspect of their child's health. This theme included concerns related to their child's mental health well-being such as their child exhibiting anxiety and experiencing suicidal ideations. This theme also included information on their child's physical health including their child's inability to self-care and their child weight gain. Finally this theme also comprised their child experiences of sleep difficulties. This theme arose from one question asked to participants during the semi-structured interview. Participants' answers were gathered from question 1 of the "Parent Self-Efficacy" (refer to Table 13).

Eleven parents (33%) expressed concerns about their child's physical health and/or their child's mental health well-being. Two sub-themes emerged from parents' responses labelled as major theme 3 "Health". One sub-theme was named "Physical Health" and this theme only comprised information on the child's physical overall health. Five parents mentioned their child's physical health as being a concern they had for their child at the time of the semi-structured interview. For example, one parent said *"He is one hundred and twenty kilos and he is only five foot six….weight gain is a huge concern"*. The second sub-theme identified was labelled "Mental Health", and it comprised information on concerns parents had for their child's mental health well-being. Altogether, six parents shared concerns they

had about their child's mental health well-being. One example shared by a parent was "*We think he is extremely suicidal*".

8.2.2.4. Theme 4: Transitions.

The fourth child-focused major theme identified was referred to as "Transitions", and this major theme focused on parents' concerns about some aspect of their child's abilities to make transitions throughout their lifespan. This theme included concerns related to areas of their child's difficulties with making transitions including their child transitioning from primary school to high school, and their child's ability to get a job after high school. This theme arose from two questions asked to participants during the semi-structured interview. Participants' answers were gathered from question 1 of the "Parent Self-Efficacy" and from question 3 of the "Parent Anxiety Check" sections of the semi-structured interview (refer to Table 13).

Ten parents (30%) reported being concerned about their child's ability to make transitions at the present time and in the future. One sub-theme that was clearly identified was named "school transitions". Two sub-themes emerged from parents' responses labelled as major theme 4 "Transitions". The first sub-theme included parents' reports of their child's experiencing major difficulties with transitioning from one school to another, and was labelled "School Transitions". Seven parents mentioned their child experiencing difficulties with making transitions to go to school in the mornings or parents reported concerns for their child's ability to transition from primary school to high school. One parent mentioned "*I fear*

high school and I fear whether it is gonna work or not". Another example shared by parents

was concerned with the challenges children experienced with transitioning in the mornings

from home to school and in the afternoons from school to home. One parent mentioned *"We*

have got issues with transitions in the mornings and then in the afternoons". The second sub-

theme identified referred to parents concerns about their child's ability to make life

transitions in the future, and it was labelled "Life Transitions". Three parents reported that

concern and one parent shared the following example *"Well my concern for her is that she is*

not going to get a job".

8.2.3. Environment-focused major themes identified.

8.2.3.1. Theme 1: Concerns for child.

The first environment-focused major theme identified was labelled "Concerns for

Child". This major theme focused on parents' expressed concern about some aspect of their

child current and/or future needs and difficulties. This theme included parents' concerns

about their child's current difficulties such as their child's poor self-control and their child's

performance at school. Parents' concerns about their child's future were also included within

that major theme (i.e., child post-school independence, poor child expression of needs, and

continued care of child post parent death). This theme arose from one question asked to

participants during the semi-structured interview. Participants' answers were gathered from

question 4 of the "Parent Self-Efficacy" (refer to Table 13).

All participants (N = 33) reported having one concern for their child at the time of the semi-structured interview. Two sub-themes emerged from parents' responses labelled as major theme 1 "Concerns for Child". One sub-theme was named "Current Concerns for Child" and it included information shared by parents on concerns they currently had for their child. This sub-theme was reported on by all parents during the semi-structured interview. Seven parents reported that they were currently concerned for their child as he/she was going through transitions at school. One parent said *"The biggest concern is that he just started High School, so that is a major transition"*. Eleven parents mentioned that they were currently concerned for their child's physical health, with parents mentioning issues with self-care, general health and weight gain. An example would be *"I guess we truly worry about her health at the moment, her oral health and her weight"*. Seven parents mentioned being currently concerned for their child's difficulties with social interactions and for their child's communication difficulties in general. One example shared was, *"I am concerned that she doesn't listen in the mornings or I am concerned about her social interactions at school"*.

The second sub-theme identified was named "Concerns for Child's Future". This sub-theme was reported on by 29 parents (88%), with the 4 remaining parents (12%) mentioning that they were confident for their child's future. Eighteen parents mentioned that they were concerned for their child's care, including their child's future living arrangements and their child's inability to self-care. For instance, one parent said *"the major concern is [child's name] ability to do things on his own, to live on his own."* Another six parents mentioned that

they were concerned for their child's ability to get through High School, and also parents were concerned about their child's future school environment. One parent said *"My concern is to continue education that he can learn…and be able to function in a school environment where he is not bullied"*. Thirteen parents explained that they were concerned for their child's independent living. Parents were concerned that their child might not get a job after school, that their child would be unable to live independently and that their child would have no involvement in the community. A parent's answer was *"My major concern would be him understanding how he is supposed to fit into society and his inability to look after himself"*. And seven parents mentioned that they were concerned about their child's low self-control abilities *"he is just defiant to any law or structure"*. Another nine parents indicated that they were concerned about communication and social skills, such as their child's inability to communicate their needs and their child's inability to make friends *"she doesn't have appropriate speech to be able to get what she wants in life"*.

8.2.3.2. Theme 2: Most helpful support.

The second environment-focused major theme identified was referred to as "Most Helpful Support". This major theme focused on parents' description of the type of support they received from friends and family that was most helpful to them. This theme included support parent received for their child such as friends and family members being accepting of their ASD child. This theme also included the support they received personally such as emotional and physical support offered, and receiving financial support. This theme arose

from one question asked to participants during the semi-structured interview. Participants' answers were gathered from question 5 of the "Parent Social Support" (refer to Table 13).

All participants ($N = 33$) reported on different types of support that received from family members and friends that were most helpful. Four sub-themes emerged from parents' responses labelled as major theme 2 "Most Helpful Support". One sub-theme identified was labelled as "Receiving Physical Help". This sub-theme included examples of parents receiving help to look after their child, so they could have time for themselves or so they could get time to spend with their spouse. Parents also mentioned that the support they found to be most helpful consisted of people offering to help them. Overall, twenty-four parents (73%) mentioned examples of receiving physical help from family members and friends as being the most helpful type of support they received. For example, one parent said *"the assistance that they give us…some nights we will go out to dinner with friends and the mother in law will stay here and look after her"*.

The second sub-theme identified was referred to as "Receiving Emotional Support". This sub-theme included information shared by parents on their friends and family members offering them emotional support, and understanding their circumstances. This sub-theme was addressed by sixteen participants (49%) during the semi-structured interview. For example, one parent mentioned *"just being able to unload and being able to say everything to them"*. The third sub-theme that emerged was labelled as "Receiving Financial Assistance". This sub-theme was addressed by three parents (9%) and included information on some examples

of financial support they received from friends and family members, one example being *"The biggest support we ever got was that front fence, and we did not pay for that, three different people paid for it"*. A forth sub-theme was named "people interacting with ASD child" and consisted of friends and family members communicating actively with the ASD child and people accepting the ASD child. This sub-theme was mentioned by eight parents (24%) during the semi-structured interview. For instance, one parent mentioned *"Engaging with him in conversation that would be the most important support"*.

8.2.3.3. Theme 3: Least helpful support.

The third environment-focused major theme identified was labelled as "Least Helpful Support". This major theme focused on parents' description of support they received from friends and family that was least helpful to them. This theme included information on communication difficulties such as negative verbal comments made about child and/or parenting abilities, and people being judgemental. This theme also included information on friends and family having limited understanding of ASD. This theme arose from one question asked to participants during the semi-structured interview. Participants' answers were gathered from question 6 of the "Parent Social Support" (refer to Table 13).

All participants ($N = 33$) reported on different types of support that received from family members and friends that were least helpful. Three sub-themes emerged from parents' responses labelled as major theme 3 "Least Helpful Support. One sub-theme identified referred to "Communication Difficulties with Friends and Family". In this sub-theme twenty-

two parents (67%) mentioned the difficulties they encountered with family members and friends being judgemental, making hurtful comments and giving advice. For example one parent said *"Telling me how to parent them, receiving their ideas on what to do with their autism"*. A second sub-theme was labelled as "Limited Understanding of ASD", 17 parents (52%) mentioned experiencing difficulties with people having a poor understanding of ASD in general, people having communication difficulties with their ASD child and people changing the ASD child's routine. For example, one parent said *"I suppose their limited knowledge and their understanding of what is going on, they don't realise that there are other things to deal with."* The third sub-theme identified was labelled "Wrong Type of Support". This sub-theme was mentioned by eleven parents (33%) during the semi-structured interview. Parents described family members and friends offering the wrong type of support at times. For instance, one parent mentioned *"my mum will come up and do the dishes, meanwhile she is saying you should have done it this morning. To her she is helping me because she is physically doing it but it's not helpful"*.

8.2.3.4. Theme 4: Financial.

The fourth environment-focused major theme identified was labelled as "Financial". This major theme focused on parents' concerns expressed about some aspect of their financial circumstances. This theme included concerns related to areas of direct financial demands and stressors such as worrying about money, experiencing financial difficulties and having to pay bills. This theme excluded associated work difficulties and expenses for their

child. This theme arose from two questions asked to participants during the semi-structured interview. Participants' answers were gathered from question 3 of the "Parent Anxiety Check" and question 3 of the "Parent Depression Check" (refer to Table 13).

Eleven parents (33%) reported having experienced in the past or experiencing at the moment financial difficulties. Two sub-themes emerged from parents' responses labelled as major theme 4 "Financial". One sub-theme identified was referred as "Past Financial Stressors" and included information shared by four participants on financial difficulties they experienced in the past, such as having to overcome bankruptcy. One example given by a participant was "*We almost were driven into bankruptcy...we are still feeling the effects of that*". The second sub-theme identified was labelled as "Current Financial Worries" and comprised information shared by seven participants on financial worries they had such as paying bills or worrying about money in general. One example shared by a parent was "*Definitely financial. I don't like owning people money and I owe the bank a fair bit for this house so that is probably the only thing, apart from day-to-day expenses*".

8.2.3.5. Theme 5: School.

The fifth environment-focused major theme identified was labelled as "School". This major theme comprised information on parents' concern about some aspect of their child's learning difficulties at school. This theme included concerns related to areas of their child's classroom learning behaviour difficulties. This theme also focused on some of the difficulties encountered within the school environment such as teachers' having limited understanding of

child difficulties and parents' experiences of miscommunication with teachers. This theme excluded associated behavioural problems related to their child. This theme arose from two questions asked to participants during the semi-structured interview. Participants' answers were gathered from question 3 of the "Parent Anxiety Check" and question 1 of the "Parent Self-Efficacy" (refer to Table 13).

Ten parents (30%) reported having concerns for their child due to their learning difficulties within the school environment. Two sub-themes emerged from parents' responses labelled as major theme 5 "School". One sub-theme was labelled as "Child School Difficulties" and related mostly to the child's difficulties to adapt to the school environment, five parents experienced such difficulties. For instance, one parent said "Definitely when he does something wrong or bad, I guess it makes me feel as if it reflects on me as a parent". The second sub-theme was labelled as "School Difficulties with Child" and this sub-theme focused on the difficulties that five parents experienced with schools being unable to handle difficulties related to the child's ASD symptoms. One parent said *"I let the school know that scratching and bitting behaviours might happen…the head of the unit called me and said they wanted to try to handle it first. They had to evacuate the classroom. He had smashed the desks over, was banging his head into the wall"*.

8.2.3.6 Theme 6: Work.

The sixth environment-focused major theme identified was referred to as "Work". This major theme focused on parents' concerns about some aspect of their personal work

demands. This theme included concerns related to parent's work deadlines and other work demands. This theme excluded associated child symptoms and difficulties that would require parent to adjust their work schedule. This theme arose from two questions asked to participants during the semi-structured interview. Participants' answers were gathered from question 3 of the "Parent Anxiety Check" and question 3 of the "Parent Depression Check" (refer to Table 13).

Eight parents (24%) reported having concerns about meeting work deadlines and fulfilling work demands. Two sub-themes emerged from parents' responses labelled as major theme 6 "Work". The first sub-theme was labelled as "Work Schedule" and three parents mentioned having difficulties handling their work schedule, such as changes in shifts and working at night. One parent said "*Today coming here, I have had to rearrange work around that…so organising appointments and keeping them*". The second sub-theme was mentioned by five parents and it was labelled as "Work Deadlines". This sub-theme included information shared by parents on the difficulties they experienced having to complete work deadlines while making sure that they could assist their child on a daily basis. One parent said "*You know trying to travel to work but the majority of it is deadlines that I have got to meet at work*".

8.3 Findings on participants' answers to the closed-questions from the semi-structured interview.

Results obtained through participants' answers to the 40 closed questions asked during the semi-structured interview have been presented in the subsequent sections of Chapter 8 below: 1) Participants' financial bracket of income; 2) Participants' anxiety check; 3) Participants' depression check; 4) Participants' social support; 5) Participants' description of child behaviour and functioning; 6) Activities participants' reported as being most helpful from the programme conducted for study 1. Participants' figures of their financial comfort were explained, as well as information on the amount of money parents spent on their ASD child per year on average. Participants' self-reports of anxiety and depressions were exposed, and some pie charts were created to present a visual representation of the findings. Participants' ratings of the emotional, practical, financial, and informational support they accessed were presented.

8.3.1 Participants' financial bracket of income.

Participants were asked to nominate their financial status, using figures of their average household's gross income per year. About 52% of participants ($n = 17$) reported that their average household gross income consisted of $81,000 and above per year. An additional 5 participants (15%) reported having an average households' gross income between $61,000 to $80,000 per year and 5 more participants (15%) reported having an average households' gross income between $41,000 to $60,000 per year. The remaining 6 participants (18%)

indicated that their average households' gross income was between $20,000 to $40,000 per year. Participants were asked to indicate the amount of the household gross income that would go into expenses for their child with ASD per year.

Overall, 1 participant was able to give a clear figure on the expenses for her ASD child per year. This mother explained that the expenses were budgeted at the beginning of each year. The remaining 32 participants found the question to be challenging to answer. The results indicated that participants spent from $480 up to $24,000 per year on expenses for their child with ASD, with participants spending on average approximately $6,305 per year on expenses for their child with ASD ($M = 6305.45$; $SD = 5848.85$).

8.3.2 Participants' anxiety check.

Participants were asked one closed question to assess their anxiety level at the beginning of the interview (i.e., "Are you feeling anxious right now?") and instructed to choose from two response options (i.e., "yes" or "no"). If participants reported feeling anxious, they were then asked to rate the intensity of that anxiety on a 10-point Likert ranging from 1 (not anxious) to 10 (extremely anxious). Overall, 26 parents reported not feeling anxious during the interview, 3 parents rated their anxiety at a 5 out of 10, 2 parents rated their anxiety at a 4 out of 10, 1 parent rated their anxiety at a 7 out of 10 and 1 parent rated their anxiety at an 8 out of 10, as can be seen in Figure 8.
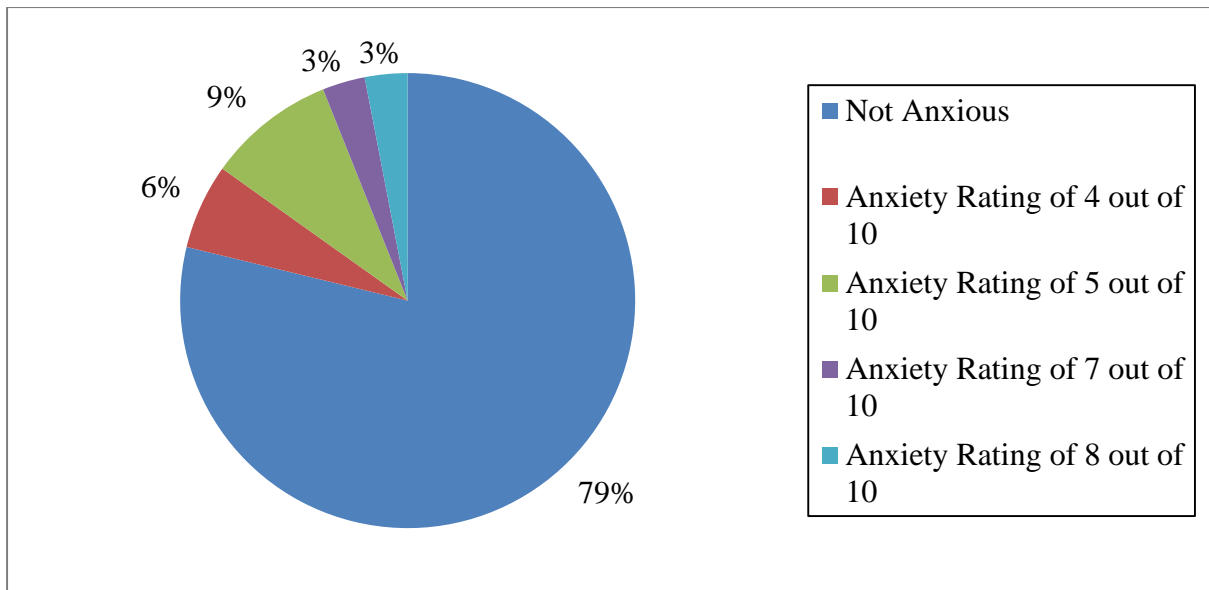
Figure 8. Participants' (*N* = 33) self-report anxiety rating during the semi-structured interview process.

8.3.3 Participants' depression check.

Participants were asked one closed question to assess their depression level at the beginning of the interview (i.e., "Are you feeling depressed right now?") and instructed to choose from two response options (i.e., "yes" or "no"). If participants reported feeling depressed, they were then asked to rate the intensity of that depression on a 10-point Likert scale ranging from 1 (not depressed) to 10 (extremely depressed). Overall, 26 parents reported not feeling depressed during the interview, 2 parents rated their depression at a 3 out of 10, 2 parents rated their depression at a 4 out of 10, 1 parent rated their depression at a 5 out of 10, 1 parent rated their depression at a 6 out of 10 and 1 parent rated their depression at an 8 out of 10. These ratings can be seen in Figure 9.
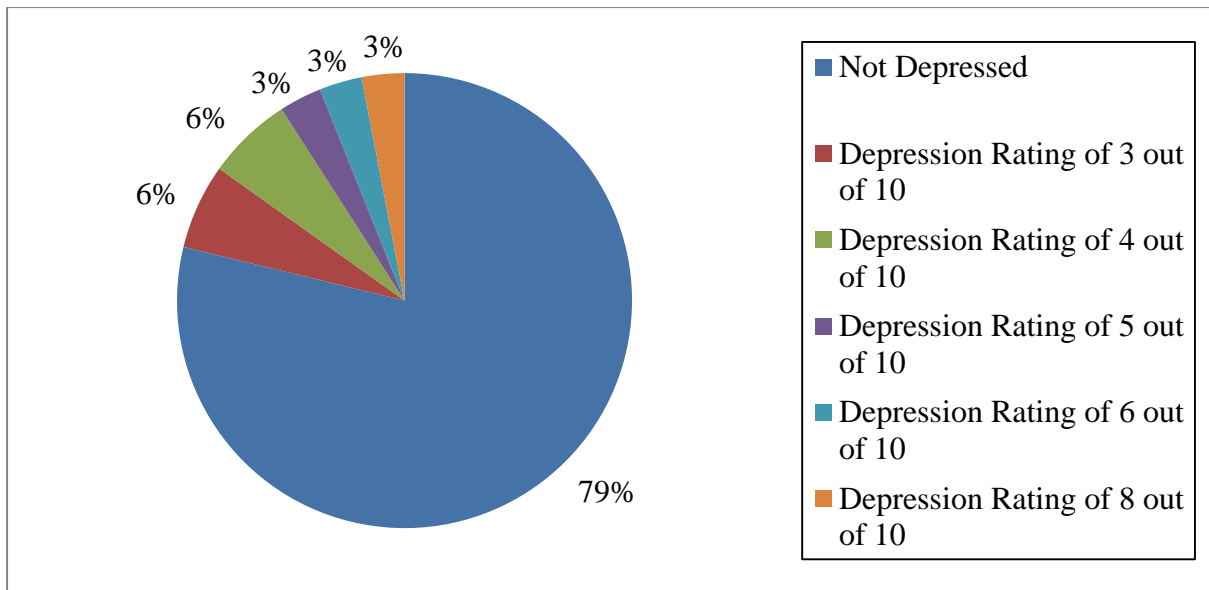
Figure 9. Participants' *(N = 33)* self-report depression rating during the semi-structured

interview process.

8.3.4 Participants' social support.

8.3.4.1. Emotional support.

Participants were asked two different closed questions to assess the frequency of

emotional support they received from family members first and to assess the frequency of

emotional support they received from friends second. When answering both questions,

participants were asked to score on a scale from 1 (not at all) to 10 (all the time) how

emotionally supported they felt by their family. On average, participants scored the emotional

support they received from family members as 7 out of 10. Subsequently, participants were

asked to use the same rating scale to identify how much emotional support they received

from friends. On average, participants scored the emotional support they received from

friends as 6 out of 10. Participants either scored the emotional support received from family

members and friends under average or over average, meaning that no participants allocated a score of 5 (sometimes) for the emotional support received from friends and family members.

Figure 10 shows the ratings participants allocated to family members and friends for the emotional support they received.
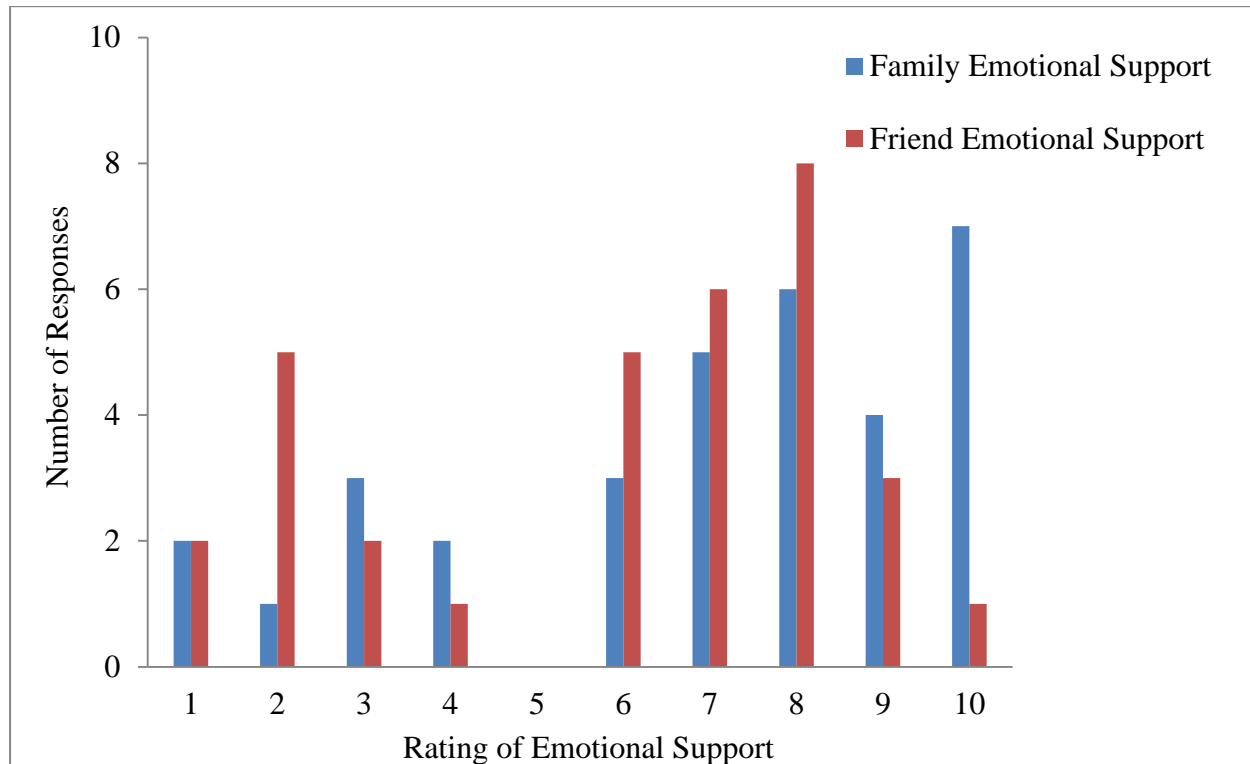
Figure10. Participants' ($N = 33$) rating of the emotional support they received from family members and friends on a 10-point Likert scale, from 1 (not at all) to 10 (all the time).

8.3.4.2. Practical support.

Participants were asked two different closed questions to assess the frequency of practical support they received from family members first and to assess the frequency of practical support they received from friends second. When answering both questions, participants were asked to score on a scale from 1 (not at all) to 10 (all the time) how much

help they received from family in caring for their child diagnosed with ASD. On average parents scored the practical support they received from family members as 7 out of 10. Afterwards, participants were asked to use the same rating scale to identify how emotionally supported they felt by their friends. On average, participants scored the emotional support they received from friends as 2 out of 10.

A significantly lower rating for practical support received from friends was reported compared to the rating given for emotional support received from friends. As observed previously, participants either scored the practical support received from family members as "under average" or "over average", no participants allocated a score of 6 for the practical support received from family members. Furthermore, when parents were asked to rate how much help they received from friends in caring for their child diagnosed with ASD, participants did not allocate scores of 4, 6, 9 or 10 out of 10. On average, 70% of participants allocated a score of 1 out of 10, indicating that they did not receive any help from friends in caring for their ASD child. Figure 11 exposes the ratings participants allocated to family members and friends for the practical support they received.
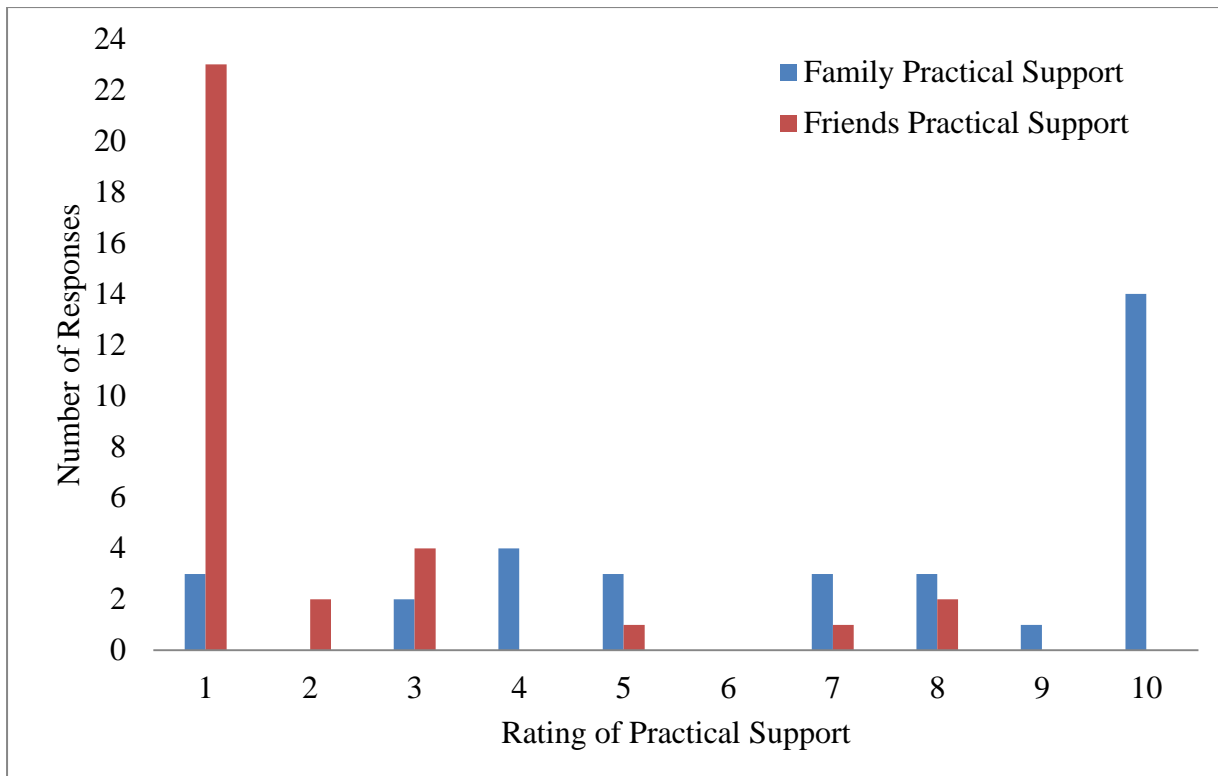
Figure11. Participants' (*N* = 33) rating of the practical support they received from family members and friends on a 10-point Likert scale, from 1 (not at all) to 10 (all the time).

8.3.4.3. Financial support.

Participants were asked to answer three different closed questions in this section of the semi-structured interview. Firstly, participants were asked if they received any type of financial support from the government or other organisations to assist their child diagnosed with ASD. A majority of participants (*n* = 29) reported having access to financial support to assist them with the costs associated with caring for a child with ASD, with 4 participants reporting not having access to any financial support to assist them with the costs associated with raising a child with ASD. Of the 4 parents who reported not getting any financial support, 2 parents mentioned that they did not know how to access these services, 1 parent

explained that she was on waitlists to access funding through different organisations and 1 parent mentioned that the funding run out when the child turned 7 years-old. Of the 33 participants, 11 parents reported receiving financial support through more than one organisation. The funding accessed through the government that parents reported accessing the most was the "carer's allowance" ($n = 19$), parents also specified that this funding could not be accessed anymore when the child turned 16 years old. Another source of financial support that 6 participants accessed for their ASD child was "Disability QLD", through Centrelink.

A few parents ($n = 3$) mentioned that they gained financial support through schools to assist their child with ASD. For instance, the schools provided the following services for free: 1) Psychology services; 2) Occupational Therapist (OT) services; 3) Bus transport services. Furthermore, 2 parents of children over the age of 16 years-old explained that their child accessed "disability support" pensions; consequently these parents did not personally receive any financial support to assist their ASD children. The other financial supports listed below have been reported by participants on one occasion: 1) A government-funded package called "Children with Autism"; 2) The Smith Family Learning for Life scholarship; 3) Gold Coast REC and Sports; 4) A government-funded "Early Intervention" package; 5) Monetary assistance for food through "Act for Kids"; 6) Monetary assistance through the Commonwealth Bank; 7) Family tax benefits; 8) Monetary assistance for home schooling "Distance Education".

Secondly, participants were asked whether they had any family members who had given them financial support in the past or were currently giving them financial support. The results indicated that 76% of participants ($n = 25$) reported that they had never received any financial support from family members, 2 participants out of 25 mentioned that if they asked their parents for financial support, then they would receive it. The remaining 8 participants mentioned that they had received in the past or that they regularly received financial support from their parents specifically. Some participants ($n = 8$) listed the following ways in which they received financial support from their parents: 1) receiving money directly; 2) Groceries being purchased for participants; 3) Loans being given by parents; 4) Receiving gifts from parents for ASD child's specific needs; 5) Living with parents.

Thirdly, participants were asked whether they had any friends who had given them financial support in the past or were currently giving them financial support. Participants' responses indicated that 91% of parents ($n = 30$) had never received any financial support from friends. Out of these 30 participants, 2 parents mentioned that they had supported their friends financially in the past. The remaining 3 participants explained the type of financial support that they had received from friends in the past: 1) Giving money so parents could put it aside for the ASD child's expenses; 2) Receiving gifts or being taken out to lunch by friends; 3) Airflight tickets paid by a friend to go on a holiday.

8.3.4.4. Informational support.

In this section of the semi-structured interview participants were asked to answer two closed questions. To begin, parents were asked if they were able to access information that would help them assist their child with ASD. Then, participants were asked if they were happy with the information they had been able to access so far to assist their child diagnosed with ASD. The majority of participants ($n = 29$) reported that they were able to access information that would help them assist their ASD child. Only 1 participant stated not being able to access information that would help them assist their ASD child. The remaining 3 participants mentioned that they were able to access information to assist their ASD child, but that they accessed the information with great difficulty.

Lastly, participants' responses varied when they were asked whether they were happy with the information they had been able to access so far to assist their child diagnosed with ASD. Even though participants were asked to give a 'yes' or 'no' answer to this question, some participants answered the question differently. For instance, 5 participants mentioned that they found the information they were able to access for their ASD child to be sometimes helpful and 3 participants stated that the information was helpful most of the time, then 19 participants said that the information they accessed for their ASD child was helpful and the remaining 6 participants mentioned that the information they had accessed so far was not helpful. Furthermore, over a quarter of participants ($n = 9$) mentioned that they found it

challenging to access information that applied specifically to their ASD child's difficulties and needs.

8.3.5. Participants' description of child behaviour and functioning.

8.3.5.1. Findings on child's aggressive behaviour.

Participants were asked two closed questions to assess their ASD child's behaviour and functioning. To begin with participants were asked if their child ever used aggressive behaviour when interacting with other people (i.e., adults, siblings…). If participants responded 'yes', they were then asked to rate on a 10-point Likert scale, from 1 (not at all) to 10 (all the time) how often their child was violent or aggressive towards other people on a weekly basis. Results indicated that 29 parents of children with ASD reported that their child used aggressive behaviours when interacting with other people, 3 parents mentioned that their child did not use any type of violent behaviour when interacting with other people and 1 parent mentioned that her child used self-harming behaviours but was not aggressive towards other people.

Out of the 29 participants who mentioned that their child used aggressive behaviours towards others when interacting, 10 participants mentioned that their child also used verbal aggressive behaviour towards other people. The frequency by which ASD children used aggressive behaviour when interacting with other people, according to parents' reports has been presented in Figure 12. The parent who mentioned that her child engaged in self-harming behaviour reported a frequency rating of 3 out of 10.
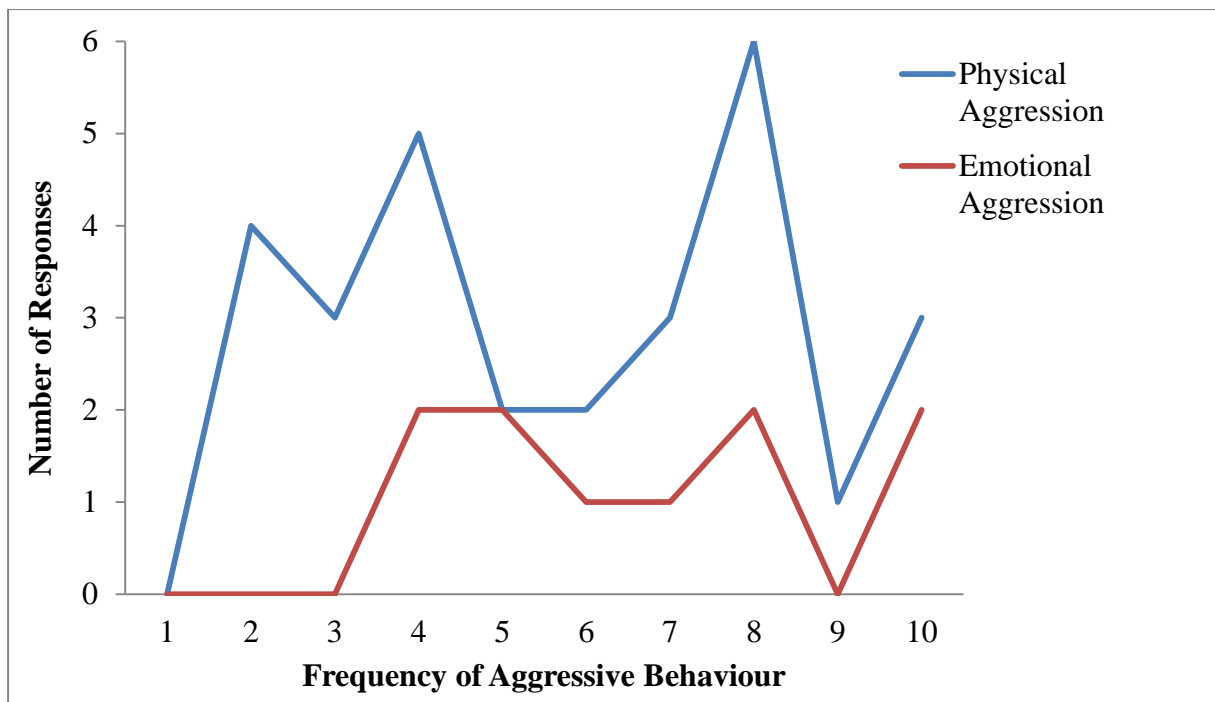
Figure 12. Participants' (*n* = 29) rating of their child's use of physical aggression and emotional aggression towards other people on a 10-point Likert scale, from 1 (not at all) to 10 (all the time).

8.3.5.2. Findings on child's repetitive behaviour.

In this section of the semi-structured interview, participants were asked two closed questions. Participants were asked if their child ever did or said the same thing repeatedly or whether their child made any unusual hand/body movements repeatedly. If participants responded 'yes', they were then asked to rate on a 10-point Likert scale, from 1 (not at all) to 10 (all the time) how often their child used repetitive behaviours on a weekly basis. The data explained that 26 parents out of 33 identified that their child used repetitive behaviour, with the remaining 7 parents indicating that their child did not use any type of repetitive behaviour.

The 26 participants who mentioned that their child used repetitive behaviours were then asked to rate the frequency of their child's repetitive behaviour on a weekly basis. About 54% ($n = 14$) of parents indicated that their child used repetitive behaviours on a daily basis and scored it as a 10 out of 10. The remaining scores given by participants to report how often their child used repetitive behaviours on a weekly basis were the following: 1) 15% allocated a score of 8 out of 10 for their child's use of repetitive behaviours on a weekly basis ($n = 4$); 2) 12% allocated a score of 9 out of 10 for their child's use of repetitive behaviours on a weekly basis ($n = 3$); 3) About 15% allocated a score of 5 out of 10 ($n = 2$) or a score of 4 out of 10 ($n = 2$) for their child's use of repetitive behaviours on a weekly basis; 5) 4% allocated a score of 7 out of 10 for their child's use of repetitive behaviours on a weekly basis ($n = 1$).

8.3.5.3. Findings on child's sleep behaviour.

Participants were asked four different closed questions in this section of the semi-structured interview. To begin with, parents were asked if their child experienced any difficulties falling and/or staying asleep. If participants answered that question by selecting 'yes', they were then asked to rate on a 10-point Likert scale from 1 (not at all) to 10 (all the time) how often their child would experience sleep difficulties on a weekly basis. The third question was asked to all 33 participants and aimed to identify whether participants' children took any medication to help with sleep difficulties. If participants replied 'yes' to question three, they were asked to name the medication that their child took to relieve sleep difficulties

they experienced. About 67% of participants (n = 22) mentioned that their child experienced sleep difficulties, 1 additional participant mentioned that her child only experienced difficulties falling asleep and the 10 remaining participants mentioned that their child did not experience any sleep difficulties.

8.3.5.4. Findings on child's school behaviour.

Parents were asked whether, in their opinion, their child's teacher had a clear vision for his/her long-term future. Of 33 parents, 20 parents (61%) believed that their child's teacher did not have a clear vision for their child's long-term future and the 13 remaining parents (39%) believed that their child's teacher had a clear vision for their child's long-term future. Even though participants were asked to answer a close question, all 33 participants explained the reason why they answered the question the way they did. For participants who believed that teachers did not have a clear vision of their child's long –term future the following reasons were mentioned: 1) Teachers and schools focused on the child's curriculum over a yearly period (*n* = 15); 2) Teachers had no interest in getting to know the child and his/her potential (*n* = 6), 3) Principals and teachers commented negatively on child's dream of a future career (*n* = 3).

8.3.6 Activities participants reported as being most helpful from the programme conducted for study 1.

Participants (*n* = 21) mentioned some activities that they had found most helpful when they undertook the FBATG, the STG and the CG, as can be seen in Table 16. Participants

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reported more than one activity as being helpful at times and 2 participants mentioned that they had found the training group they attended to be helpful in general, but they could not mention any specific activity that had been most helpful to them.

Table 16:

Activities from Study 1 that Participants Found to be Most Useful

Activities	Number of Responses ($n = 21$)
Gaining insight from other parents' experiences	10
Focusing on self-care	08
Use of problem solving skills	05
Identifying triggers for unwanted behaviours	05
Brainstorming	03

8.5. Participants' anxiety and depression scores compared between study 1 and study 2.

The student researcher conducted SPSS analyses to determine the interaction between programme type and time across five different time periods (Pre-Intervention, Post-Intervention, 1 month Follow-Up, 2 months Follow-Up, 3 months Follow-Up, and Study 2). This analysis was performed also to check the effectiveness of the three training groups offered to participants in study 1 and their long-term effects on parents' anxiety levels, depression levels, on parents' evaluations of their child's ASD-related symptoms, and on parents' evaluation of their relationship with their child. This type of analysis has been referred to as a "mixed between-within subjects ANOVA" by Tabachnick and Fidell (2001).

8.*5.1. Summary of parent-reported anxiety findings across parents who attended the three support groups.*

A mixed between-within subjects analysis of variance was conducted to assess the impact of three different interventions (FBATG, STG, and CG) on participants' scores on the GAD-7, across six time periods (Pre-Intervention, Post-Intervention, 1 month Follow-Up, 2 months Follow-Up, 3 months Follow-Up and Study 2). There was no significant interaction between programme type and time, Wilks Lambda = .76, F (10, 28) = .392, p = .93, partial eta squared = .12. There was a substantial main effect for time, Wilks Lambda = .437, F (5, 14) = 3.61, p = .026, partial eta squared = .563, with all three groups showing an increase in their anxiety levels across the six time periods. The main effect comparing the three types of intervention was not significant, F (2, 18) = .546, p = .589, partial eta squared = .057, suggesting no significant difference in the effectiveness of the three training approaches in terms of their effect upon the parents' anxiety levels. The estimated marginal means of participants' anxiety levels at different times of the training groups have been presented in Figure 13.
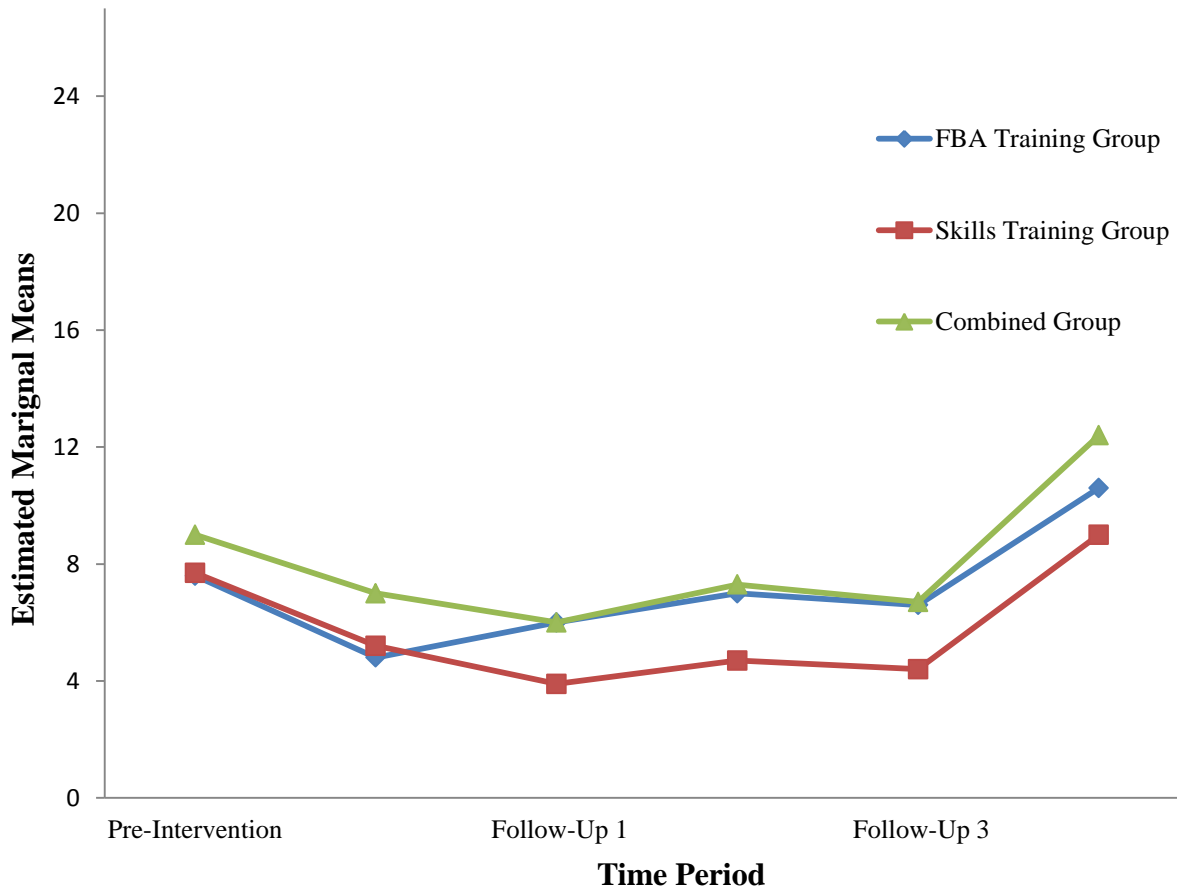
Figure 13. Mean estimates of parents' anxiety self-report from the FBATG, STG and CG across six time periods.

8.5.2. Summary of parent-reported depression findings across parents who attended the three support groups.

A mixed between-within subjects analysis of variance was conducted to assess the impact of three different interventions (FBATG, STG, and CG) on participants' scores on the PHQ-9, across six time periods (Pre-Intervention, Post-Intervention, 1 month Follow-Up, 2 months Follow-Up, 3 months Follow-Up and Study 2). There was no significant interaction between programme type and time, Wilks Lambda = .439, $F (10, 28) = 1.424$, $p = .221$, partial eta squared = .33. There was no substantial main effect for time, Wilks Lambda = .759, $F (5, 14) = .889$, $p = .514$, partial eta squared = .24, with all three groups not showing an amelioration

in their depression levels across the six time periods. The main effect comparing the three types of intervention was not significant, $F_{(2, 18)} = 1.143$, $p = .341$, partial eta squared = .113, suggesting no significant difference in the effectiveness of the three training approaches in terms of their effect upon the parents' depression levels. The estimated marginal means of participants' depression levels at different times of the training groups have been presented in Figure 14.
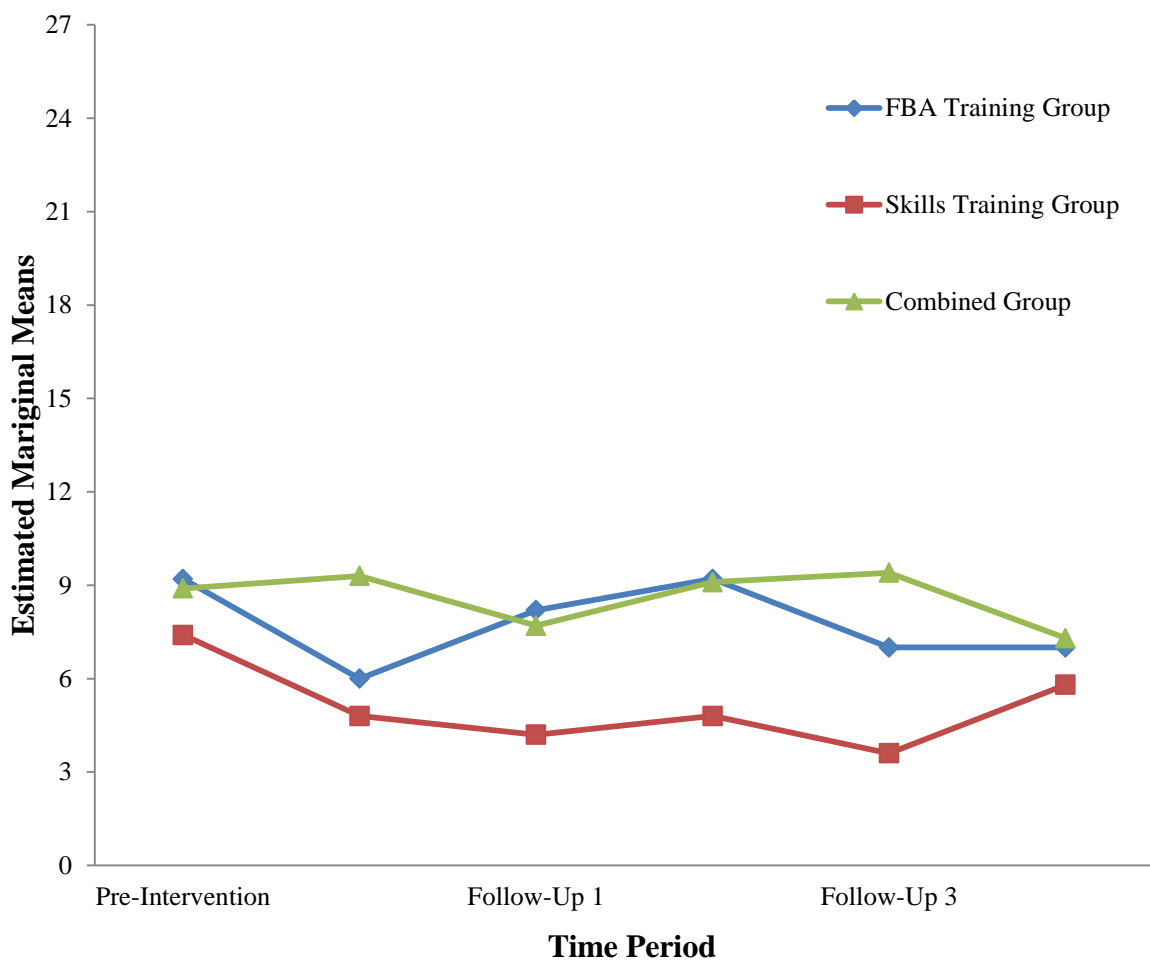
Figure 14. Mean estimates of parents' depression self-report from the FBATG, STG and CG across six time periods.

8.6. Study 2 discussion.

The findings derived from study 1, were used as the foundation for study 2. Study 1 findings from a comparison of three different approaches to delivering group-based parent support, indicated a robust theme of inconsistent parent participation despite parents evaluating the value of sessions they attended highly. This significant limitation of participants' inconsistent participation was investigated through study 2, which aimed to gather information on the plausible barriers which prevented parents of children with ASD from attending regularly PSG. Therefore, study 2 aimed to undertake an in-depth investigation of the factors which act as barriers to parents of children with ASD seeking and consistently accessing support. That study also focused on addressing three methodological limitations from previous research findings.

First, the limitation on the bias towards child factors as being predictive of poor parent mental health outcomes was overcome in study 2 by exploring a greater range of parent-oriented factors that might be responsible for parents' minimal attendance to PSG. Secondly, the usage of generic survey methods to assess participants was overcome in study 2 by using a combination of a semi-structured interview and the completion of the same survey that was administered in study 1 to examine a variety of predictive factors for a lack of positive parent mental health outcomes. And thirdly, participants recruited for study 2 attended the original support groups from study 1, allowing for a comparison to be made between the standardised context from study 1 and the responses to the semi-structured interview, through which specific answers were elicited. This return to the original participant group for further investigation was believed to be practical in order to create methods for support delivery that compensated for the limitations arising from those circumstances.

Study 2 was designed to address the three limitations from previous research listed above. The semi-structured interview was created to gather in-depth information on parents' experiences and on the difficulties that parents of children with ASD experience. The aim of study 2 was to gather information on the models of support delivery that would most likely meet the individual needs of participants at a future time. The discussion of study 2 will address the mismatch between parents seeking/valuing support and them accessing that support. The discussion from study 2 will address the difficulties encountered by parents to attend this second study, and a thorough discussion will be undertaken on the plausible barriers which prevent parents of children with ASD from accessing PSG.

8.6.1. Support seeking/accessing barriers.

The results obtained in study 1 indicated that 23% of participants withdrew from the groups they attended. The findings from the parent satisfaction questionnaire indicated that participants valued the sessions they attended. Parents were asked if the training sessions they attended helped them to cope with some issues of importance to them. Overall, 94% of participants believed that the group they attended helped them to cope with some issues of importance to them. Similar findings have been identified in previous research. Clifford and Minnes (2013) conducted an online PSG for parents of children with ASD. They identified that participants reported being satisfied with the support they received and the topics discussed in the sessions even though 30% of the 119 participants invited to the support group registered to attend a group and 20 participants completed the post-group survey. Interestingly, most of the parents who completed the post group survey (75%) in Clifford and Minnes (2013) study specified that the low attendance was not something they would change or consider to be an issue.

Recruitment and participant retention were significant challenges in studies I and II, and these difficulties have been observed in previous studies that have used PSG (Bitsika & Sharpley, 1999; Fontana et al., 1988; Smith et al., 1994). Overall, 23% of participants did not complete study 1 and only 70% of participants who were recruited in study 1 agreed to participate in study 2. Other researchers have described comparable problems with attendance in their studies when offering PSG to parents of ASD children (Bitsika & Sharpley, 1999), for parents of children with other disabilities (Smith et al., 1994), and for parents of children with special needs (Fontana et al., 1988). For instance, In a study conducted by Fontana and colleagues (1988), 53 parents of infants in a neonatal intensive care unit were invited to participate in a PSG, and 60% (n = 32) agreed to participate in the research. However, of those who agreed to participate in the PSG, only 12 (38%) attended at least one session. As a consequence, the researchers were unable to calculate changes over time.

In their research, Bitsika and Sharpley (1999) concluded that the group was of value and was helpful to participants, but the methodological limitations of the study, such as small sample size and the use of unstandardized measures that the participants found difficult to answer, may have reduced the effects seen on standardized measures of well-being. The authors recommended that further research be conducted to examine the benefits of support groups for parents of children with ASD. These research findings (Bitsika & Sharpley, 1999, 2000; Clifford & Minnes, 2013) suggest there is a mismatch between parents requesting/valuing support and them accessing that support, and similar findings were noted in study 1. Therefore, it would be reasonable to proceed with an investigation on the specific barriers that parents of children with ASD experience and that could affect their support access. In study 1, the focus of the research was on the members of the support group themselves in relation to the content of each group and in relation of the methods used to present the information in session to participants. However, participants were not assessed in

relation to their capacity to attend groups consistently and no investigation was conducted on plausible barriers that might prevent participants to access that support. This issue has been reported in the research but it has not been investigated in a systematic manner. Consequently, study 2 aimed to explore in detail the particular life circumstances of parents of ASD children and how those circumstances might act as barriers to seeking and consistently accessing support.

8.6.2. Parents' participation difficulties in study 2.

As mentioned in the discussion section of study 1, participants' retention rate and inconsistent participation were significant difficulties, which have been discussed in previous research findings on PSG use (Bitsika & Sharpley, 1999; Fontana et al., 1988; Smith et al., 1994). Previous research obtained a retention rate for their participants' attendance in PSG for parents of children with ASD from 60% to 71% (Nguyen, Fairclough, & Noll, 2015; Troester, 2000). Altogether, a high retention rate was observed in study 1 with 77% of participants remaining in the groups until the end of the sessions; however, some questions were raised on identifying factors which negatively impacted on parents' attendance to sessions.

Some difficulties were observed when trying to book a 90-minute session for participants to complete study 2. More specifically, 17 parents (52%) cancelled the first appointment scheduled for study 2. Different reasons were given for parents' inability to attend the semi-structured interview, such as health problems experienced by parents, problems experienced with scheduling multiple appointments, and parents undergoing medical treatments. These findings from study 2 are similar from the findings obtained in study 1. Findings from study 1 indicated that 78% of participants did not gain access to government-funded respite services, with most participants reporting that they experienced

difficulties in accessing respite services (28%) or that they were unaware that they could access respite services (20%). According to previous research findings, parents of children with ASD experience more limits on family and community activities, have more caregiving burden and are more likely to quit their work to look after their child with ASD compared to parents of TD children (Lee et al., 2008).

A study conducted by Dabrowska and Pisula (2010) advanced similar findings to Lee and colleagues (2008), with increased burden of parents of children with ASD on dependency and management, life span care, family disharmony and personal burden. Numerous participants were unable to attend the initial semi-structured interview scheduled in study 2 due to personal challenges they were facing at the time, such as personal medical problems or having to handle unpredictable events that would affect their daily schedule. Lack of respite services had a negative impact on participants' ability to attend most of the sessions offered in FBATG, STG and CG. Participants' inability to plan their schedules too far ahead impacted upon their capacity to attend the initial semi-structured interview, even though parents had the option to do the semi-structured interview in their home.

8.6.3. Possible barriers to group access/attendance.

8.6.3.1. Financial burden as a possible barrier to group access/attendance.

It is important to acknowledge that parents also have to deal with many other co-occurring difficulties of having a child with ASD, such as financial and time burden of medical treatment, restrictions on social activities and changes to family goals and achievements (McCubbin et al., 1982; Lecavalier et al., 2006). Financial costs are high, with the total cost of raising a child with a disability estimated to be approximately three times greater than the cost incurred by raising a TD child (Järbrink et al., 2003). This financial

impact is exaggerated by the shortfall that exists between the costs of bringing up a child with severe disabilities and benefits received (Broach, 2003).

As pointed out in a previous study (Bailey & Simeonsson, 1988), the financial difficulties faced by parents concern the purchase of suitable equipment, the payment of specialised services, and funding for leisure activities outside the family. In addition, French parents have often complained about the non-funding of psycho-education by public authorities, which is often paid for entirely by the family (Prado, 2012). They also point to the lack of adequate facilities to cater for the specificities of their children, including relay institutions allowing them to get some respite during weekends. This point was highlighted in the studies by Siklos and Kerns (2006), Ahmadi, Sharifi, Zalani, Bolouk, & Amrai (2011), and Brown, Ouellette-Kuntz, Hunter, Kelley, & Cobigo (2012) as being one of the most important needs for parents.

In study 2, 11 participants (33%) reported being affected by direct financial demands/stressors that affected their anxiety. These parents reported feeling most anxious when they experienced: 1) Financial difficulties; 2) worrying about money; 3) experiencing bankruptcy; and 4) having to pay bills. Experiencing such financial difficulties could make it challenging for participants to travel to access PSG, and consequently might be a possible barrier to group access and attendance. As a consequence, participants' precarious financial circumstances could negatively affect their ability to access and attend PSG.

8.6.3.2. Child care as a possible barrier to group access/attendance.

A study conducted by Smith and colleagues (1994) investigated parental opinions about attending PSG. These researchers found that even though PSG initially grew enthusiasm, they were often poorly attended by parents of children with ASD. Overall, child care arrangements seemed to be the most significant barrier to attendance parents faced, with

56% of parents mentioning that they needed child care to attend a meeting during day-time or night-time hours. Another study explained that a third of parents reported experiencing avoidance and rejection from their family, while other parents identified lack of interest or understanding of their child (Papageorgiou & Kalyva, 2010). Such findings could partly explain the difficulties parents of children with ASD have in accessing child care so they can attend support groups.

In study 1, a majority of parents who were unable to attend a session mentioned that they were unable to find someone to look after their ASD child at the time of the session. Furthermore, participants in study 2 rescheduled the semi-structured interview due to the numerous appointments that parents had to prioritise for their ASD child. These findings are in accordance with previous research (Papageorgiou & Kalyva, 2010; Smith et al., 1994) indicating that parents experience great difficulties with finding childcare that will fit their child's specific needs. Such findings indicate that a significant proportion of parents might be unable to attend PSG due to the fact that they are the sole careers for their child and receive no support for childcare.

In study 2, parents explained during the semi-structured interview that the practical support they valued the most was from their spouse and that, even though they received support from family members in looking after their child, it was not always helpful. Some parents even mentioned that they would rather not ask family members to look after their child. Parents mentioned that their child would be highly anxious when they were looked after by a family member, and that the child was more challenging to handle afterwards. This information reveals that, even though parents of children with ASD find practical support to be most helpful to them, the type of practical support received is a crucial factor in parents' decision to ask someone to look after their child.

8.6.3.3. *Work commitment as a possible barrier to group access/attendance.*

Work and employment demands have been found to be challenging for parents of children with ASD. For instance, parents of children with ASD are seven times more likely to report that childcare problems substantially affect their employment decisions compared to parents of TD children (Montes & Halterman, 2008). Two factors seem to have a negative impact on parents' ability to manage their work demands and their child's needs: (1) the inability to find and sustain adequate childcare given the complex and idiosyncratic nature of their child's needs (Brennan & Brannan, 2005; LeRoy & Johnson, 2002; Rosenzweig, Brennan, Huffstutter, & Bradley, 2008) and (2) finding employment which offers enough flexibility that the demands of caregiving and work can coexist (Freedman, Litchfield, & Warfield, 1995; Rosenzweig et al., 2002; Todd & Shearn, 1996).

These results fall in line with the results obtained in studies I and II. For instance, in study 1, fourteen participants (70%) enrolled in the night-time sessions due to the fact that they worked full-time and would have been unable to attend the sessions during day-time. Of the 11 participants who withdrew from study 1, three participants (27%) withdrew due to work related demands that prevented them from attending the groups anymore. Furthermore, for study 2, eighteen participants (55%) requested to participate in the study outside of their work hours. Therefore, parents of children with ASD who work full-time can experience significant challenges in their ability to attend PSG.

In a study conducted by Papageorgiou and Kalyva (2010) one third of parents stated that they had not mentioned to people from their work environment that they had a child with ASD. In another study (Gray, 1993) some parents indicated that people in their work environment were unaware of their child's ASD as they did not want to be pitied by their work colleagues, and that they wished to obtain equal chances of promotion. Lee (2009)

explained that decisions to hide something important from people in parents' work environment created more stress for them. These difficulties experienced by parents of children with ASD within their work place could potentially prevent parents to access and attend support groups. In study 2, 24% of parents mentioned that work demands and work shifts were factors likely to trigger the most anxiety and depression for them. These findings reveal that the work circumstances of parents of children with ASD can have a detrimental impact on their ability to access and attend PSG, even if they would benefit greatly from such groups.

8.6.3.4. Parents' personal needs as a possible barrier to group access/attendance.

Smith and colleagues (1994) conducted semi-structured interviews to identify some of the barriers to group access and attendance for parents of children with ASD. Their results indicated that participants left a PSG for the following reasons: 1) Parents felt they no longer needed it; 2) The PSG was run at an inconvenient time; 3) Parents felt they had nothing in common with other parents in the group; 4) The PSG was run too far from their home. Smith and colleagues (1994) found that a minority of parents (11%) were willing to travel from 10 to 90 minutes to attend a PSG while 28% of parents were willing to travel 20 minutes to attend a PSG, suggesting that traveling time was a decisive factor in parents' willingness to attend a PSG. Furthermore, the amount of attendance required was also a decisive factor, with 44% of parents preferring to meet one time per month, 39% of parents preferring to meet two times per month and 6% of parents wishing to meet one time per week.

Participants were asked if child care and transportation needed to be considered for them to attend a PSG. About 34% of parents mentioned that they had no car and would have to rely on public transport or they would have to borrow a car so they could attend a PSG. Parents also reported that the experience or credentials of the group leader would influence

their attendance to a PSG, with 33% of parents mentioning that their first choice would be to have a counselling professional as a group leader. Smith and colleagues (1994) identified that 68% parents found PSG most helpful when their child was doing "better". This finding seems quite significant as support groups are often geared toward parents who are experiencing a crisis. This information suggests that PSG might focus primarily on parents who are settled into a routine and who need ongoing support. Findings from study 1 indicated that parents who had no car, parents who home-schooled their child, and single parents were unable to attend the support groups or found it challenging to attend most sessions. In study 2, a majority of participants asked for the semi-structured interview to be conducted in their home environment, indicating that this option was most suited to parents' need at the time.

Clifford and Minnes (2013) gave online questionnaires to 149 parents of children with ASD to measure their beliefs about support groups. The findings explained that parents who are more likely to be well supported by traditional in-person PSGs will: 1) tend to cope by seeking emotional and instrumental support and by planning and doing something about their problem; 2) believe that support groups will be beneficial; and 3) believe that they will not have difficulties attending PSGs. However, those parents who have not tried a support group and believe them to be beneficial may be well supported by alternatives to traditional groups such as online support groups, which will alleviate many of the difficulties associated with attending in-person group meetings.

Finally, there is a subgroup of parents, including those who have tried support groups and not found them beneficial and those who do not seek support as a form of coping, who would be better supported by other methods. These parents might also prefer a parent-to-parent support model or a parent-led group, which would be more focused on bonding with other parents. These results indicate the need to determine through discussion with parents what they feel would be the best support match for them. If a parent has expressed an interest

in participating in a support group, it will be important to determine his/her goals for the support group.

To assist parents, it is therefore important to take into account physical constraints, allowing them to choose the right course of care for their child from among the different types of support available. In addition, parents of a child with ASD need help to identify the right professionals for undertaking the administrative procedures for obtaining the financial support they deserve. The information provided to families should therefore focus on the procedures for accessing services (Divan et al., 2012; Siklos & Kerns, 2006) as well as the pathology itself and how it can be managed (Auert, Trembath, Arciuli, & Thomas, 2012; Mockett, Khan, & Theodosiou, 2011; Papageorgiou & Kalyva, 2010; Siklos & Kerns, 2006).

8.6.3.5. *Family demographics as a possible barrier to group access/attendance.*

Mandell and Salzer (2007) appear to have published the only quantitative study of predictors of support group use for parents of children with ASD. This study examined family demographics (i.e., age and gender of child, ethnicity, household income, parent education, marital status, and geographic location), health systems interactions (i.e., clinician referral to group and child inpatient stay in hospital) and child's clinical characteristics (i.e., specific ASD diagnosis; co-morbid diagnoses of mental retardation, hearing impairment, seizures, self-injurious behaviour, sleep problems, aggression, and severe language deficits) as predictors of PSG use. The authors found that about two-thirds of the sample had participated in a PSG (defined as "support advocacy group for parents") at some time, and parents who were involved in support groups had higher household incomes and educational attainments, were more likely to be in two-parent families, and were less likely to be African-American than parents who were not involved. The authors reported that this finding is consistent with the literature on support group use in other populations, which generally finds

that participants tend to be in higher income brackets, more educated, married, living in suburban areas, and white (Katz et al., 2002).

The demographic profile of the majority of participants who attended studies I and II consisted of a majority of married mothers with a mean age of 45 years, having one child diagnosed with ASD. A majority of participants had a TAFE education level and worked. Half of the participants had a second child diagnosed with a disorder. Over half of the participants reported their average household gross income to be $81,000 and above per year. Participants reported spending on average approximately $6,305 per year on expenses for their child with ASD. These findings reveal that participants with different demographic background might find it more challenging to access and attend PSG and seem to be in line with previous research findings (Katz et al., 2002; Mandell & Salzer, 2007). As a consequence, future research might want to investigate the needs of different demographic groups of parents of children with ASD to identify the different support needs they might have.

8.6.4. Parents' concerns expressed in study 2.

A variety of concerns were reported by parents of children with ASD during the implementation of study 2. The qualitative analysis performed in study 2 indicated that 10 major themes were identified from participants' responses. Major themes were classified under two different categories, referred to as "child-focused" or "environment focused" themes. Child-focused themes encompassed information that related specifically to some aspect of the child's ASD diagnosis or the outcomes (to the child's daily functioning) of that diagnosis. Child-focused themes included parent concerns centred on the following issues: areas of diagnostic impairment and the presence of restricted repetitive behaviour patterns and fixated interests; their children's' ability to make age-appropriate transitions across the

lifespan; their children's' mental well-being, physical health and sleep patterns; and their children's' aggressive and/or self-injurious behaviour. Environment focused themes encompassed information that related specifically to external factors present in parents' lives that were not linked to their ASD child but related to their personal environment. Environment-focused themes included parent concerns on the following issues: some aspect of their financial circumstances; some aspect of the difficulties encountered within the school environment; work deadlines and/or other work demands; child's current difficulties; concerns for the child's future; and the most helpful and the least helpful types of support received by parents of children with ASD.

Some of the major themes identified in study 2 have been reported on in previous research findings. For instance, the theme 1 of the child-focused major themes labelled as "Aggressive Behaviours" was also reported on in previous research findings, revealing that the challenging behaviours of children with ASD can be a significant source of stress for parents (Myers et al., 2009). Therefore, providing parents with skills to manage challenging behaviours is essential (Benson & Karlof, 2009; National Research Council, 2001, p. 153). Not surprisingly, nearly all "best practice" ASD programs provide parents with the opportunity to learn and practice specialised skills they can use to teach their children with ASD, and some even make this a requirement of program participation (National Research Council, 2001, p. 153).

An environment-focused major theme identified in study 2 labelled as theme 5: "School" included information on parents' concerns about some aspect of their child's difficulties within their school environment. This theme included concerns related to areas of their child's classroom learning behaviour difficulties plus some of the difficulties encountered within the school environment (i.e., teachers' limited understanding of child difficulties and miscommunication with teachers). As the child enters the school system, the

IDEIA (the Individuals With Disabilities Education Improvement Act) ensures the right to appropriate education for children with disabilities such as ASD, but there is often tension between parents and schools with regard to how the child's needs are met (Mulick & Butter, 2002). Thus, parents increasingly find themselves playing an advocacy role on behalf of their child. This can have both positive and negative effects on parents, leading to increased stress and decreased quality of life, in some cases, and feelings of confidence, empowerment, and increased support, in others (Nachshen & Jamieson, 2000).

High-quality parent–professional and parent–educator relationships are central to meeting the needs of families with a child with ASD (Carter, 2003; Rao & Kalyanpur, 2002). While parent involvement is the single biggest predictor of satisfaction with school services for parents of children with ASD (Renty & Roeyers, 2006), and parent–professional collaboration is strongly and consistently related to parental sense of self efficacy in managing their child's condition (Reich, Bickman, & Heflinger, 2004), families express a desire for interactions with educators and other professionals to be more responsive and collaborative (Renty & Roeyers, 2006; Stoner & Angell, 2006). However, the findings from study 2 reveal that a majority of parents had a challenging relationship with teachers and schools and these parents believed that teachers did not have a clear vision of their child's future, which triggered anxiety in some parents.

Another major environment-focused theme identified in study 2 was labelled as theme 1: "Concerns for Child" and included information on parents' concerns about their child's current difficulties (i.e., poor self-control and their child's performance at school) plus parents' concerns about their child's future (i.e., child post-school independence, poor child expression of needs, and continued care of child post parent death). Past research identified that transitions continue to occur throughout the child's school years, as the child moves from preschool to school age, and from building to building (Marcus, Kunce, & Schopler, 2005).

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At each transition, the family is likely to take on new advocacy roles, sharing their knowledge about the child with professionals from each new classroom and system, while building new relationships and partnerships.

Transition planning for adulthood for a child with ASD is easily one of the most confusing and emotionally draining times for parents. While transition planning is recommended to begin by age 16 (IDEIA, 2004), parents report little guidance in the process (Carbone, Behl, Azor, & Murphy, 2010). Schools typically perform the first steps in transition planning, but this process often does not fully address family needs. As families move into the adult service system, they are challenged with navigating complex eligibility requirements and funding streams, as well as dealing with new service systems, new providers, and a loss of previously held, familiar supports. Families can also easily become overwhelmed by the new factors that they need to consider: post-secondary educational options, employment and volunteer opportunities, community living, sexuality, and guardianship.

Findings from study 2 explained that parents' mental health (i.e., anxiety and depression) could be negatively impacted upon due to the 10 major themes identified during the semi-structured interviews. The findings showed that a majority of the themes mentioned by parents were environment-focused themes, which questions the efficacy of PSG purely focused on the ASD child symptoms as triggering anxiety and depression in parents of children with ASD (Altiere & von Kluge, 2009; Lyons et al., 2010). Therefore, these findings support further that there is a need for research in PSG for parents of children with ASD to target interventions designed to train parents to manage the adverse emotional and psychological experiences they themselves confront on a day-to-day basis that might not be child-focused necessarily.

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9. Recommendations for Effective Delivery of Support for Parents of Children with ASD.

Study 1 aimed to investigate two research questions by exploring the effects of four models for delivering group-based support to parents of children on parent mental state (i.e., anxiety and depression), parent resilience, and parenting satisfaction. The first aim of study 1 was to identify whether the delivery of parent-focused intervention was capable of assisting parents to manage adverse emotional and psychological states they experienced. The second aim of study 1 was to identify if parent-focused intervention was more effective in creating positive changes in parents' emotional and psychological states than child-focused approaches. The results obtained in study 1 found overall no significant changes in anxiety and depression across the three different groups of participants and across time (Pre-Intervention, Post-Intervention, FU1, FU2, and FU3). Furthermore, results from study 1 indicated that parents' attendance was intermittent and likely to cease after brief access to support.

Consequently, the results obtained in study 1 proposed that the identification of the factors that might cause parents of children with ASD to access support services minimally or irregularly was identified as being crucial to remediating those factors and create support service approaches that meet specific parent needs and encourage their consistent attendance. Study 2 aimed to gather information on the models of support delivery that would most likely meet the individual needs of participants at a future time. The bias towards examining child features as being predictive of poor parent mental health was addressed via emphasis on exploring a greater range of parent-oriented factors in study 2.

This section of the thesis aims to provide recommendations on how support might be delivered to parents of children with ASD in a more efficient manner. The limitations of

studies 1 and 2 will be discussed in the sub-sequent section of Chapter 9. And finally, the clinical implications for studies 1 and 2 will be discussed.

9.1. Recommendations on how support might be delivered to parents of children with ASD.

It was hypothesised that improved retention rates reflected the researchers' ability to make home visits, but there were still a number of participants who did not participate in study 2. Possible reasons for the dropout rates in parents of children with ASD include embarrassment or stigma, busy schedules and inability to make time to participate in research projects, and more personal resources spent on finding information that would assist their diagnosed child. A recent study that used an adapted depression therapy called problem-solving education (PSE) offered six 30-minute workbook sessions to mothers and PSE supplemental school services to the child if they were not already enrolled in an early intervention program; a 91% retention rate was reported from use of this strategy (Feinberg et al., 2014). A combination of a shorter meeting period and additional incentive of supplemental services for the child may have been a factor in getting higher retention rates both in study 1 and in study 2.

Another area that could be focused on in further studies is to increase engagement with participants by making training support groups more geared toward the participants' most pressing problems about their child. We could rearrange training support groups' interventions to focus on problems directly related to helping their child with ASD, such as helping them problem-solve on how to receive services for their child and family (advocacy training). Focusing support training groups on parents' current stressors and challenges may increase retention, especially if it is being provided by a trainer who has experience with ASD. This approach is believed to further engage participants and increase attendance.

The information shared by parents of children with ASD during the semi-structured interviews proposed a wide variety of needs including: access to quality information, access to coordinated services within the community, understanding and managing challenging behaviours in their child, gaining support that will be most helpful from friends and family members, high-quality parent–teacher/school collaboration, and transition/long-term planning supports. All these different needs can be addressed through the utilisation of several models. Findings from study 1 indicated that group support training models were not necessarily the most efficient way to assist parents of children with ASD. Findings from study 2 showed that parents of children with ASD felt most anxious or depressed in different circumstances and that not only child-focused but also environment-focused factors could impact their well-being negatively. Consequently, a systematic process could be beneficial to determine which parent support models could be most helpful to parents, depending on the main difficulties or concerns parents have for their child.

In order to identify the specific needs of parents of children with ASD, the semi-structured interview used for study 2 could be used as part of an intake process that would gather enough information to profile parents' needs. The semi-structured interview used in study 2 gathers information on child-focused factors and information on environment-focused factors that could negatively impact on parents' well-being. The answers gathered from this type of interview could provide a clinician with detailed information on areas of need for parents of children with ASD, helping clinicians avoid making assumptions about the needs of this parent group. A variety of models to assist parents of children with ASD have been developed from the responses that participants have shared in study 2. The first model consists of giving the opportunity to parents to access in-home or out-of-home support. The second model consists of identifying the most prominent areas of need described by parents,

by classifying the most anxiety- and depression-triggering factors in the two categories of "child-factors" or "environment-factors".

Parents of children with ASD are challenged by a host of issues across the life span. The utilisation of the semi-structured interview created for study 2 would allow clinicians to identify the major areas of need in parents' life circumstances and to decide what type of treatment would be most helpful for parents in addressing the concerns they mentioned during the interview. Some parents might benefit more from individual treatment than they would benefit from group treatment. If clinicians were to use a group treatment option, several factors should be taken into consideration such as: identify parents in terms of their child's autism severity (high functioning, moderate functioning and low functioning), in terms of their child's age group (toddler, child, adolescent, and adult), and in terms of their child's gender (male or female). Furthermore, group treatment options should be offered to parents who wish to gain and share experiences with other individuals. Individualising treatment plans and using more flexible approaches to tailor the content offered within group treatment options would be most beneficial to parents of children with ASD and would potentially remediate some of the difficulties encountered around attrition rates of participants attending support groups.

9.2. Limitations of studies 1 and 2.

Some limitations were detected in studies 1 and 2. The first limitation that should be acknowledged consists of the small sample size for both studies and, as a consequence, statistical testing was fraught by limited cell sizes. However, none of the major conclusions are based on non-significant differences, suggesting that the samples were satisfactory for the purposes they were designed to achieve, but replication would enable greater generalisation of these results. Also, it should be noted that this cohort of participants may not adequately

represent the larger population of parents of children with ASD, although this is an almost-universal limitation of human research. Second, this study had no control group of mothers of children with ASD who did not receive training in FBATG, STG or CG, and therefore the possible effect of extraneous variables cannot be ruled out. Future work with the implementation of parent support groups might consider randomization of caregivers to FBATG, STG or CG. Third, in order to further increase retention rates, additional strategies (Feinberg et al., 2014) might be explored to see whether (for example) linking up with caregivers when the diagnosis is made to establish a system of care, listing parent support as part of the wider resources for respite care, using trainers with experience working with children with ASD, and focusing the support training groups on ASD-specific issues, are all possible ways of increasing retention.

9.3. Clinical implications for studies 1 and 2.

Parents of children with ASD respond differently to treatment options available to them, depending on their circumstances at the time. Given that parents fulfil a range of roles for their child with ASD including advocate, teacher, collaborator, and decision maker (Stoner & Angell, 2006), it is perhaps unsurprising that a family-centred approach to care increases parent satisfaction with care and leads to more favourable outcomes (Law et al., 2003). Addressing the issues faced by parents of children with ASD has been a challenge because the issues are broad, and they evolve over the course of the child's development and across the life cycle of the family (Stoner et al., 2005; White & Hastings, 2004). The success with which professionals are able to address issues faced by parents of children with ASD may have critical implications for child and family outcomes, as parents' perception of low levels of support or having unmet needs is associated with higher levels of emotional distress (Hare, Pratt, Burton, Bromley, & Emerson, 2004).

Lack of access to appropriate information, both early on and as the child ages, is a significant barrier to adjustment for families of a child with ASD (Mitchell & Sloper, 2002; Turnbull, Turnbull, Erwin, & Soodak, 2006). Even when parents find quality information to address the child's and family's needs in one developmental phase, they often must start the search over again because the types of information that are required vary over the life span of the child. The Internet offers a wealth of information not previously available to parents, but parents often have difficulty discriminating high-quality information among the overwhelming amount of information that they find online (Carter, 2009). Misinformation about ASD on the web is abundant (Jordan, 2010), and parents can waste precious time.

Access to coordinated services is another challenge. ASD is a complex diagnosis, often requiring interventions by multiple providers and agencies. Many families experience difficulties in identifying the services and supports they need, determining where they can find these services, and readily accessing those (McLennan et al., 2003). Once services are identified, navigating the service systems requires knowledge, time, and persistence, since families rarely have a care coordinator to assist them through the process. Kogan and colleagues' (2008) review of the National Survey of Children with Special Health Care Needs found that children with ASD were more likely than children with other special health care needs to have unmet needs, and families with ASD also received fewer family support services. For example, poor access to respite care is a problem that often restricts the family's activities (Bromley et al., 2004). Few providers are trained to care for a child with ASD, and the lack of available respite may lead to community restriction that disconnects the family from broader sources of support. One possible means of addressing this problem is to increase access to training in ASD for care workers. A recent study demonstrated preliminary success in training undergraduate students in characteristics of ASD and behavioural analysis to provide respite care for families with a child with ASD (Murphy & Verden, 2013).

The results obtained from studies 1 and 2 highlight the complexities of parents' life circumstances. Study 1 found that participants in the CG who attended the same three sessions as participants attending the FBATG and participants attending the STG rated similarly the value for the three sessions from the FBATG and the value for the three sessions from the STG. Therefore, study 1 highlights the advantages of combining the three most valuable sessions from the FBATG and the three most valuable sessions from the STG. Also, study 1 indicates that participants know which sessions they find to be most helpful/ satisfying and can help a researcher identify clearly which sessions would likely benefit most parents. Study 2 identified that parents experience a lower number of child-focused factors difficulties than they experience environment-focused factors difficulties. Such results could assist clinicians early in the treatment (at the intake phase) to identify which difficulties parents are experiencing at the time of the semi-structured interview so they can identify which treatment options parents would benefit most from. Studies 1 and 2 both demonstrate that multiple treatment options should be considered when working with parents of children with ASD and that no two families will need the same assistance. As a consequence, individual-based treatment plans would be most likely to benefit parents of children with ASD.

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Diagnostic Criteria for Autism Spectrum Disorder (ASD) - DSM-5 (2013)

A.   Persistent deficits in social communication and social interaction across multiple contexts, as manifested by the following, currently or by history (examples are illustrative, not exhaustive, see text):

1.   Deficits in social-emotional reciprocity, ranging, for example, from abnormal social approach and failure of normal back-and-forth conversation; to reduced sharing of interests, emotions, or affect; to failure to initiate or respond to social interactions.

2.   Deficits in nonverbal communicative behaviors used for social interaction, ranging, for example, from poorly integrated verbal and nonverbal communication; to abnormalities in eye contact and body language or deficits in understanding and use of gestures; to a total lack of facial expressions and nonverbal communication.

3.   Deficits in developing, maintaining, and understanding relationships, ranging, for example, from difficulties adjusting behavior to suit various social contexts; to difficulties in sharing imaginative play or in making friends; to absence of interest in peers.

Specify current severity:

   Severity is based on social communication impairments and restricted repetitive patterns of behavior (see Table A1).

B.   Restricted, repetitive patterns of behavior, interests, or activities, as manifested by at least two of the following, currently or by history (examples are illustrative, not exhaustive; see text):

1.   Stereotyped or repetitive motor movements, use of objects, or speech (e.g., simple motor stereotypies, lining up toys or flipping objects, echolalia, idiosyncratic phrases).

2.   Insistence on sameness, inflexible adherence to routines, or ritualized patterns or verbal nonverbal behavior (e.g., extreme distress at small changes, difficulties with transitions, rigid thinking patterns, greeting rituals, need to take same route or eat food every day).

3.   Highly restricted, fixated interests that are abnormal in intensity or focus (e.g, strong attachment to or preoccupation with unusual objects, excessively circumscribed or perseverative interest).

4.   Hyper- or hyporeactivity to sensory input or unusual interests in sensory aspects of the environment (e.g., apparent indifference to pain/temperature, adverse response to specific sounds or textures, excessive smelling or touching of objects, visual fascination with lights or movement).

Specify current severity:

Severity is based on social communication impairments and restricted, repetitive patterns of behavior (see Table A1).

C.   Symptoms must be present in the early developmental period (but may not become fully manifest until social demands exceed limited capacities, or may be masked by learned strategies in later life).

D.   Symptoms cause clinically significant impairment in social, occupational, or other important areas of current functioning.

E.   These disturbances are not better explained by intellectual disability (intellectual developmental disorder) or global developmental delay. Intellectual disability and autism

spectrum disorder frequently co-occur; to make comorbid diagnoses of autism spectrum disorder and intellectual disability, social communication should be below that expected for general developmental level.

Note: Individuals with a well-established DSM-IV diagnosis of autistic disorder, Asperger's disorder, or pervasive developmental disorder not otherwise specified should be given the diagnosis of autism spectrum disorder. Individuals who have marked deficits in social communication, but whose symptoms do not otherwise meet criteria for autism spectrum disorder, should be evaluated for social (pragmatic) communication disorder.

Specify if:

With or without accompanying intellectual impairment

With or without accompanying language impairment

Associated with a known medical or genetic condition or environmental factor

(**Coding note:** Use additional code to identify the associated medical or genetic condition.)

Associated with another neurodevelopmental, mental, or behavioral disorder

(**Coding note:** Use additional code[s] to identify the associated neurodevelopmental, mental, or behavioral disorder[s].)

With catatonia (refer to the criteria for catatonia associated with another mental disorder, pp. 119-120, for definition) (**Coding note:** Use additional code 293.89 [F06.1] catatonia associated with autism spectrum disorder to indicate the presence of the comorbid catatonia.)

Table A1. Severity levels for autism spectrum disorder

Severity Level	Social Communication	Restricted, Repetitive Behaviors
Level 3 "Requiring very substantial support"	Severe deficits in verbal and nonverbal social communication skills cause severe impairments in functioning, very limited initiation of social interactions, and minimal response to social overtures from others. For example, a person with few words of intelligible speech who rarely initiates interaction and, when he or she does, makes unusual approaches to meet needs only and responds to only very direct social approaches	Inflexibility of behavior, extreme difficulty coping with change, or other restricted/repetitive behaviors markedly interferes with functioning in all spheres. Great distress/difficulty changing focus or action.
Level 2 "Requiring substantial support"	Marked deficits in verbal and nonverbal social communication skills; social impairments apparent even with supports in place; limited initiation of social interactions; and reduced or abnormal responses to social	Inflexibility of behavior, difficulty coping with change, or other restricted/repetitive behaviors appear frequently enough to be obvious to the casual observer and interfere with functioning in a variety of

	overtures from others. For example, a person who speaks simple sentences, whose interaction is limited to narrow special interests, and how has markedly odd nonverbal communication.	contexts. Distress and/or difficulty changing focus or action.
Level 1 "Requiring support"	Without supports in place, deficits in social communication cause noticeable impairments. Difficulty initiating social interactions, and clear examples of atypical or unsuccessful response to social overtures of others. May appear to have decreased interest in social interactions. For example, a person who is able to speak in full sentences and engages in communication but whose to- and-from conversation with others fails, and whose attempts to make friends are odd and typically unsuccessful.	Inflexibility of behavior causes significant interference with functioning in one or more contexts. Difficulty switching between activities. Problems of organization and planning hamper independence.

The Explanatory Statement (ES) Sent to Participant for Study 1

Project Title: Evaluation of Three Group Support Models Developed for Parents of Children with Autism Spectrum Disorder

Project Number: RO-1494

Date: 13th of April 2012

My name is Aude Etournaud and I am conducting research under the supervision of Professor Vicki Bitsika in the Department of Counselling and Behaviour Management at Bond University. The research is conducted for a thesis for a Doctorate of Counselling.

The aim of this research is to examine some ways we might support parents of children with Autism Spectrum Disorder to cope with the demands they face in their day-to-day lives. We have developed three models for delivering group-based parent support and will be randomly allocating parents to one of these groups. Some parents will participate in a 'wait list' group and receive subsequent access to material derived from all three models. This method for allocating parents to a group means that we will have no prior knowledge of which groups parents will attend and cannot make a commitment to placing parents in a preferred group. All group models will require parents to attend six sessions (of 60 to 80 minutes duration each) over six consecutive weeks. In order to help us evaluate the effectiveness of each group model, we will be collecting information at five points in time, these being: two weeks before you begin the group; on the last session of the group; one week after completion of the group, four weeks after completion of the group; eight weeks after the completion of the group you attended; and twelve weeks after the completion of the group you attended. We will be collecting information via survey and you will be asked to

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answer questions on your child's difficulties and the ways in which you handle these, the satisfaction you derive from parenting your child, your own mental health status (for instance feelings of depression and anxiety), and strategies you use in coping with the demands you confront.

We are aware that that attending groups and helping us gather information will require a large time commitment from you and would like to emphasize that your participation in this study is completely voluntary and you may withdraw at any time without risking any adverse consequences. If you chose to withdraw from the study then any gathered information will be immediately destroyed. All the data collected in this study will be treated with complete confidentiality, viewed only by the two researchers and reported in relation to group trends. These data will be stored in a secured location for a five year period in accordance with the guidelines set out by the Bond University Human Research Ethics Committee.

It is anticipated that the information collected during this study will be used to develop group-based support programmes which meet the specific personal and parenting needs of parents with a child or children on the autism spectrum.

If you have any queries as a result of participating in this research or would like to receive a summary of overall research findings, please contact Professor Vicki Bitsika via email on vbitsika@staff.bond.edu.au or telephone on (07) 5595 4142.

Should you have any complaints concerning the manner in which this research is conducted please contact the Bond University Human Research Ethics Committee quoting the Project Number: R01494. Contact details are as follows:

Ethics Officer - Complaints

Bond University Human Research Ethics Committee

C/O Bond University Research and Consultancy Services.

Level 2 Central Building

Bond University, Gold Coast, 4229

Tel: +61 7 5595 4194 Fax: +61 7 5595 1120 Email: buhrec(5)bond.edu.au

We thank you for taking the time to assist us with this research.

Yours sincerely,

Professor Vicki Bitsika,	Aude Etournaud,
Principal Researcher,	Student Researcher,
Faculty of Humanities & Social Sciences,	Faculty of Humanities & Social Sciences,
Bond University,	Bond University,
Gold Coast, QLD., 4229	Gold Coast, QLD., 4229

APPENDIX C

Example of the Email of Confirmation Sent to Participants

Dear (parent's name),

This is a confirmation e-mail with regards to your participation in the Skills Training Group.

You have agreed to take part in 8 consecutive sessions (90 minutes per session) that will be held on <u>Wednesday mornings from 9.30am until 11.00am</u>.

The *first session* will be held on *Wednesday the 14th of August at 9.30am*. The facilitator will be waiting for you to arrive in the HSS foyer from 9.15am, and she will take you to the room in which every session will be held.

<u>A map</u> with car park directions and indications on the location of the HSS foyer has been attached to this e-mail for your convenience. Please do not hesitate to contact the facilitator if you need any help finding your way around campus.

Your participation to this research project is markedly appreciated.

Best wishes,

Aude Etournaud, **PhD Candidate**
Researcher at the Centre for Autism Spectrum Disorders (CASD)
Teaching Fellow
Counselling and Behaviour Management
Faculty of Humanities and Social Sciences
Bond University
aetourna@bond.edu.au
(07) 5595 2502

Participant Consent Form

I hereby consent to participate in the research project titled **Evaluation of Three Group Support Models Developed for Parents of Children with Autism Spectrum Disorder** (Protocol Number **RO-1494**).

I have read and understood the Explanatory Statement and acknowledge that I have been provided with the opportunity to ask any questions I might have regarding this study.

I understand my participation in this study will involve my participation in a parental group training that will explore my understanding of Autism Spectrum Disorder and the coping skills that can be used to deal with challenging situations.

I understand that all information collected by the researchers will be treated with complete confidentiality and that no details which could identify me will be reported on. I also understand that my participation in this study is **voluntary** and that I can choose to **withdraw** at any stage in the research process without incurring any adverse consequence.

NAME OF PARTICIPANT:

_____ **(please print)**

SIGNATURE: _____   **DATE:** _____

Example of Participant Evaluation Form

Session 1 Participant Evaluation

We are interested in your feedback and invite you to evaluate all six sessions of the group programme. This evaluation will involve you in telling us how valuable you found each session in relation to topic and practice strategies. We will also invite you to tell us the reasons why you might have found a particular aspect of a session <u>most</u> valuable to you.

We ask that you record your feedback in the table below. Some of your responses will be recorded using the seven-point scale shown here (please avoid making a mark between numbers) and other response will require you to write a short statement.

1	2	3	4	5	6	7

Not Valuable　　　　　　　　**Somewhat Valuable**　　　　　　**Very Valuable**

Session Feature	Your Feedback
Please use the scale to rate how valuable the overall session was to you.	*1—2—3—4—5—6—7*
Please use the scale to rate how valuable the material on "<u>myths</u>" about autism was to you.	*1—2—3—4—5—6—7*
Please use the scale to rate how valuable the material on <u>behavioural concepts and terms</u> was to you.	*1—2—3—4—5—6—7*
Please use the scale to rate how valuable the material on <u>behaviour being internal (thoughts and feelings) and external (actions and statements)</u> to you.	*1—2—3—4—5—6—7*
Please use the scale to rate how valuable the material on the <u>Functional Behaviour Assessment model</u> was to you .	*1—2—3—4—5—6—7*
Briefly tell us which specific aspect of the session was most valuable to you.	

An Example of the Email Sent to Participants for Follow-Up Assessments

Dear (parent's name),

The link in this e-mail will allow you to have access to the survey for you to complete as part of the third evaluation of the parent group sessions.

Please click on the link provided to you below, it will take you to the survey. It is very important that you use the identification **number** below to start the survey (it is the same number that you were allocated in session) and that you answer all questions within the survey.

If you have any difficulties completing the online survey, please contact me and I will assist you in completing it. We ask that you *complete the survey by the end of this week,* ***Sunday the 1st of December***.

Link: https://www.surveymonkey.com/s/Parent_Training_Models_FollowUp2_Post_Session _Evaluation3

Identification number:

Thank you very much for your continued support and participation in the research.

Best wishes,

Aude Etournaud, **PhD Candidate**
Researcher at the Centre for Autism Spectrum Disorders (CASD)
Teaching Fellow
Counselling and Behaviour Management
Faculty of Humanities and Social Sciences
Bond University
aetourna@bond.edu.au
(07) 5595 3030

Concepts/Ideas for Each Session of the FBATG

Session Number	Session Title	Skills Taught
One	Core features of ASD and its impact on child functioning	<u>Main Skill</u>: Demystifying some common myths about autism and key terms and defining key terms and concepts. <u>Session Topics/Strategies</u>: The Functional Behavioural Assessment (FBA) model introduced: • Define behaviour; • Internal versus external behaviours; • Form descriptions and function descriptions of behaviour; • Exercise to practice identification of overt and covert behaviours.
Two	Learning how to define child's problematic behaviours	<u>Main Skill</u>: Introduction to functions of problematic behaviours. <u>Session Topic/Strategies</u>: Define child's problematic behaviours and identify functions of behaviours: • Explain positive and negative reinforcement; • Present some functions of behaviours; • Present information on behavioural repertoire; • Exercise to practice the recording of problematic behaviours, using the A-B-C table.

Session Number	Session Title	Skills Taught
Three	Identifying the antecedents for child's difficult behaviours	Main Skill: Introduction to events or antecedents that might precede child's behaviours. Session Topics/Strategies: Identifying the different types of antecedents that act as triggers for the behaviour to occur: • Investigation of pre-behaviours events; • Going through the A-B-C table to identify familiar patterns in child's behaviours; • Exercise to classify child's antecedents; • Introduction to the use of a table to record pre-behaviour events and antecedents to child's unwanted behaviour.
Four	Identifying the valued outcomes of child's difficult behaviours	Main Skill: Strategies to use to investigate function(s) of a problematic behaviour. Session Topics/Strategies: Analysing the effects of the antecedents, consequences, setting events and valued outcomes: • Review of antecedents, consequences, and setting events; • Introduction to the term valued outcomes and its meaning; • Group discussion on child's unwanted behaviour; • Exercise practice to complete entire A-B-C table.

Session Number	Session Title	Skills Taught
Five	Discussing parental ability to understand, cope, and even prevent their child from engaging in difficult behaviours	Main Skill: Strategies to help your child learn appropriate replacement behaviour. Session Topics/Strategies: Group discussions raised on building capacity to understand, cope, and even prevent child's challenging behaviours: • Eliminating known triggers where possible; • Introducing alternative positive events; • Introducing alternative positive events that act as cues or prompts for new coping behaviour; • Introduce consequent behavioural strategies; • Manipulate the situation that triggers the unwanted behaviour; • Intervention planning.
Six	Reviewing the FBATG programme and its effect on parents' understanding of their child's problematic behaviours	Parents were presented with the list of the skills they were thought during the 5 previous group sessions. Parents had the opportunity to choose the skills that they would like to review in the last session.

Concepts/Ideas for Each Session of the STG

Session Number	Session Title	Skills Taught
One	Identifying social/professional support received by parents of children with ASD	<u>Main Skill</u>: Introduction to goal setting exercise and its functions. <u>Session Topics/Strategies</u>: Identify different types of social support (formal, informal and professional support): • Identify parent's access to these supports • Identify the amount of support they receive • Parent's satisfaction with the support they receive • Did the support help them to achieve some goals they have set for themselves?
Two	Identifying and discussing beliefs that parents find helpful in accepting their child's impairment	<u>Main Skill</u>: Identify any barriers, resources or methods that can be used to fulfil your goals. <u>Session Topics/Strategies</u>: Train emotionally focused palliative coping skills, especially when participants have to deal with unchangeable and uncontrollable stressors • Parent's personal beliefs; • Are your beliefs helpful in coping with your child's autism? • How your beliefs might be helpful to cope with your child's impairment.

Session Number	Session Title	Skills Taught
Three	Identifying and discussing the positive emotional experiences in parents' life	<u>Main Skill</u>: Identification of positive experiences in specific environments/setting events. <u>Session Topics/Strategies</u>: Assessment and recording of positive emotional experiences experienced by parents: • How often do parents experience positive emotional experiences? • The most common types of positive emotional experiences; • In which settings do parents experience positive emotional experiences?
Four	Introducing parents to coping strategies used by other parents of children with ASD to remain optimistic	<u>Main Skill</u>: Definition of the term "Optimism" and the positive outcomes which occur when one is high on optimism. <u>Session Topics/Strategies</u>: Identification of techniques used by parents to remain optimistic and identification of positive outcomes experienced through optimism: • Use existing social supports more effectively; • Focus on stressful events that are changeable; • Focus on best options available; • Positive reframing or positive imagery.

Session Number	Session Title	Skills Taught
Five	Identifying active coping strategies that assist parents in handling difficult situations related to their child's ASD	<u>Main Skill</u>: Active coping strategies that can be useful for parents of a child with ASD (Bandura's self-efficacy model). <u>Session Topics/Strategies</u>: Some coping strategies that might be efficient: • View daily problems as challenges; • Problem solving strategies; • Planning activities in advance. The four major sources of self-efficacy according to Bandura: 1. Enactive mastery; 2. Vicarious modelling; 3. Social persuasion; 4. Psychological responses.
Six	Reviewing the STG programme and assessing parents' self-confidence	Parents were presented with the list of the skills they were thought during the 5 previous group sessions. Parents had the opportunity to choose the skills that they would like to review in the last session.

Concepts/Ideas for Each Session of the CG

Session Number	Session Title	Skills Taught
One	Identifying and discussing beliefs that parents find helpful in accepting their child's impairment	<u>Main Skill</u>: Identify any barriers, resources or methods that can be used to fulfil your goals. <u>Session Topics/Strategies</u>: Train emotionally focused palliative coping skills, especially when participants have to deal with unchangeable and uncontrollable stressors: • Parent's personal beliefs; • Are your beliefs helpful in coping with your child's autism? • How your beliefs might be helpful to cope with your child's impairment.
Two	Introducing parents to coping strategies used by other parents of children with ASD to remain optimistic	<u>Main Skill</u>: Definition of the term "Optimism" and the positive outcomes which occur when one is high on optimism. <u>Session Topics/Strategies</u>: Identification of techniques used by parents to remain optimistic and identification of positive outcomes experienced through optimism: • Use existing social supports more effectively; • Focus on stressful events that are changeable; • Focus on best options available; • Positive reframing or positive imagery.

Session Number	Session Title	Skills Taught
Three	Identifying active coping strategies that assist parents in handling difficult situations related to their child's ASD	<u>Main Skill</u>: Active coping strategies that can be useful for parents of a child with ASD (Bandura's self-efficacy model). <u>Session Topics/Strategies</u>: Some coping strategies that might be efficient: • View daily problems as challenges; • Problem solving strategies; • Planning activities in advance. The four major sources of self-efficacy according to Bandura: 5. Enactive mastery; 6. Vicarious modelling; 7. Social persuasion; 8. Psychological responses.
Four	Learning how to define child's problematic behaviours	<u>Main Skill</u>: Introduction to functions of problematic behaviours. <u>Session Topic/Strategies</u>: Define child's problematic behaviours and identify functions of behaviours: • Explain positive and negative reinforcement; • Present some functions of behaviours; • Present information on behavioural repertoire; Exercise to practice the recording of problematic behaviours, using the A-B-C table.

Session Number	Session Title	Skills Taught
Five	Identifying the valued outcomes of child's difficult behaviours	<u>Main Skill</u>: Strategies to use to investigate function(s) of a problematic behaviour. <u>Session Topics/Strategies</u>: Analysing the effects of the antecedents, consequences, setting events and valued outcomes: • Review of antecedents, consequences, and setting events; • Introduction to the term valued outcomes and its meaning; • Group discussion on child's unwanted behaviour; • Exercise practice to complete entire A-B-C table.
Six	Discussing parental ability to understand, cope, and even prevent their child from engaging in difficult behaviours	<u>Main Skill</u>: Strategies to help your child learn appropriate replacement behaviour. <u>Session Topics/Strategies</u>: Group discussions raised on building capacity to understand, cope, and even prevent child's challenging behaviours: • Eliminating known triggers where possible; • Introducing alternative positive events; • Introducing alternative positive events that act as cues or prompts for new coping behaviour; • Introduce consequent behavioural strategies; • Manipulate the situation that triggers the unwanted behaviour; • Intervention planning.

APPENDIX J

Attendance Patterns for Participants in all Three Groups

The boxes coloured in green indicate that participants attended the sessions, the boxes coloured in white indicate that participants missed one to two sessions of the training group and the boxes coloured in red indicate that participants did not attend three to six sessions of the training group. This colour coding has been applied for Table E1, Table E2 and Table E3 presented below.

Table J1

FBATG Attendance Patterns for Participants Sessions

Participants' Number	Session One	Session Two	Session Three	Session Four	Session Five	Session Six
01	red	red	red	red	red	red
02	green	green	green	green	green	green
03	green	green	green	white	green	white
04	green	red	green	green	red	red
05	green	green	green	green	green	white
06	green	green	green	green	green	green
07	green	red	green	green	red	red
08	green	green	green	green	green	white

09	green	green	green	white	green	white
10	white	green	green	white	green	green
11	green	green	white	green	white	green
12	green	green	white	green	green	green
13	pink	pink	pink	pink	pink	pink
14	green	green	green	white	green	green
15	green	green	white	green	white	green
16	green	green	green	green	green	white

Table J2

STG Attendance Patterns for Participants Sessions

Participants' Number	Session One	Session Two	Session Three	Session Four	Session Five	Session Six
17	green	green	green	green	white	green
18	green	white	green	green	green	white
19	green	white	green	green	green	green
20	green	green	green	white	green	white
21	pink	pink	pink	pink	pink	pink

Participants' Number	Session One	Session Two	Session Three	Session Four	Session Five	Session Six
22	Pink	Pink	Pink	Pink	Pink	Pink
23	Green	Green	Pink	Pink	Pink	Pink
24	Green	Green	Green	Green	Green	Green
25	Green	Green	Green	Green	Green	White
26	Green	Green	Green	Green	Green	Green
27	Green	Pink	Pink	Pink	Pink	Pink
28	Green	Green	Green	Green	Green	Green
29	Green	Green	Green	Green	White	Green
30	Green	Green	Green	Green	Green	Green
31	Green	Green	Green	Green	Green	Green
32	Green	Green	Green	Green	White	White

Table J3

CG Attendance Patterns for Participants Sessions

Participants' Number	Session One	Session Two	Session Three	Session Four	Session Five	Session Six
33	Green	Green	White	White	Green	Green
34	White	Green	White	Green	Green	Green

#						
35	green	white	green	white	green	green
36	green	green	green	white	white	green
37	pink	pink	pink	pink	pink	pink
38	green	green	green	green	white	green
39	green	green	green	green	green	green
40	green	green	green	white	green	white
41	white	green	green	green	white	green
42	white	white	green	green	green	green
43	green	green	green	green	white	green
44	green	green	green	green	white	white
45	green	white	white	green	green	green
46	pink	pink	pink	pink	pink	pink
47	white	green	green	green	white	green
48	pink	green	green	green	pink	pink

ES Sent to Participant for Study 2

Project Title: Tailored Support for Parents of Children with ASD: Impacts of Mental Health, Social Support, Child Features, and Parent-Child Relationship.

Project Number: 0000015207

Date: 17th of April 2015

My name is Aude Etournaud and I am conducting research under the supervision of Professor Vicki Bitsika, in the Department of Counselling and Behaviour Management at Bond University. I am currently completing a PhD.

The aim of this research is to gather information about your experiences, the barriers you face, and the assets you have as a parent of a child with ASD. We are specifically interested in examining which factors might have more of an impact on your well-being.

If you choose to take part in this study, we will require you to answer an interview. You will be contacted by the researcher to plan a meeting. The interview will last approximately one hour and a half. There will be a series of topics that will be looked at throughout the interview. At the end of the interview, you will be asked to answer a few questionnaires.

Participation in this study is completely voluntary and you may withdraw at any time without risking any adverse consequences. If you chose to withdraw from the study then any gathered

information will be immediately destroyed. All the data collected in this study will be treated with complete confidentiality, viewed only by the two researchers and reported in relation to group trends. These data will be stored in a secured location for a five year period in accordance with the guidelines set out by the Bond University Human Research Ethics Committee.

It is anticipated that the information collected during this study will be used to work out the best methods for parent support which might not necessarily be face-to-face parent training model. In fact, our research might provide a basis for developing guidelines for a flexible and parent specific models to deliver support.

If you have any queries as a result of participating in this research or would like to receive a summary of overall research findings, please contact Professor Vicki Bitsika via email on vbitsika@staff.bond.edu.au or telephone on (07) 5595 4142.

Should you have any complaints concerning the manner in which this research is conducted please contact the Bond University Human Research Ethics Committee.

Contact details are as follow –

Ethics Officer – Complaints

Bond University Human Research Ethics Committee

C/O Bond University Research and Consultancy Services.

Level 2 Central Building

Bond University, Gold Coast, 4229

Tel: +61 7 5595 4194 Fax: +61 7 5595 1120 Email: buhrec@bond.edu.au

We thank you for taking the time to assist us with this research.

Yours sincerely,

Professor Dr Vicki Bitsika,   Teaching Fellow Aude Etournaud,

Principal Researcher,   Student Researcher,

Faculty of Society and Design,   Faculty of Society & Design,

Bond University,   Bond University,

Gold Coast, QLD., 4229   Gold Coast, QLD., 4229

Participant Written Consent for Study 2

PARTICIPANT CONSENT FORM

I hereby consent to participate in the research project titled **"Tailored Support for Parents of Children with ASD: Impacts of Mental Health, Social Support, Child Features, and Parent-Child Relationship" (Project Number: 0000015207)**.

I have read and understood the Participant Information Sheet and acknowledge that I have been provided with the opportunity to ask any questions I might have regarding this study.

I understand my participation in this study will involve me in answering a series of interview questions on topics including parent anxiety, parent depression, parent social support, parent self-efficacy and child behaviour and functioning. I also understand that I will be completing four surveys designed to gather information on parent anxiety, parent depression, parent-child relationship and child ASD behaviour.

I authorise the researcher to audiotape my responses to interview questions and understand that, subsequent to the interview, my responses will be typed in an anonymous transcript and (when this process is completed) the audiotape of the interview will be destroyed.

I understand that all information collected by the researchers will be treated with complete confidentiality and that no details which could identify me will be reported on. I also understand that my participation in this study is **voluntary** and that I can choose to **withdraw** at any stage in the research process without incurring any adverse consequence.

If you are willing to be involved would you please sign the form below that acknowledges that you have read the Participant Information Sheet, you understand the nature of the study being conducted and the risks and likely benefits of participation in this study, and you give permission for the research to be conducted.

Yours sincerely,

Professor Dr Vicki Bitsika, Principal Researcher, Faculty of Society and Design,

Bond University

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<u>Consent for participation in the interview</u>:

NAME OF PARTICIPANT:

_____ (please print)

SIGNATURE: _____   **DATE: _____**

<u>Consent for the interview to be recorded</u>:

NAME OF PARTICIPANT:

_____ (please print)

SIGNATURE: _____   **DATE: _____**

TRANSCRIPT OF INTERVIEW

Interviewer: Date: Place:

Person being interviewed:

Mother   Father   Other (state relationship to child) ………………………………………

ASD CHILD BIOGRAPHICAL DETAILS:

1. Gender of this child is **Male/Female**:

2. Child's age now:

3. Was this child officially diagnosed with an ASD?   **Yes**   **No**

4. Does this child have any brothers or sisters?   **Yes**   **No**

5. Do any of the child's brothers or sisters also have a diagnosed disorder?   **Yes**   **No**

6. **If Yes**, provide the name of the disorder and the child's age.

Disorders: Child's Age (**in years**):

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PARENT BIOGRAPHICAL DETAILS:

1. Parent's ID:

2. Parent's age:

3. Parent's gender**: Male**   **Female**

4. What is your employment status? **Full-Time**   **Part-Time**   **Stay at Home**

5. If unemployed, did you have to stop working to take care of your child? **Yes**   **No**

6. How would you classify your household financial comfort, using figures of your average household's gross income?

7. *20,000 to 40,000* ———— *41,000 to 60,000* ———— *61,000 to 80,000* ———— *81,000 and above*

        1   *2*   *3*   *4*

8. How much of the household gross income goes to expenses for your child with an ASD?

A. PARENT ANXIETY CHECK

1. Are you feeling anxious right now?   **Yes**   **No**

2. If yes, on a scale from 1 (not anxious) to 10 (extremely anxious), how anxious are you feeling?

1 ——— 2 ——— 3 ——— 4 ——— 5 ——— 6 ——— 7 ——— 8 ——— 9 ——— 10

Not anxious   Moderately   Extremely anxious

3. What are the situations in your daily life which cause you to feel most anxious?

B. PARENT DEPRESSION CHECK

1. Are you feeling depressed right now?   **Yes**   **No**

2. If yes, on a scale from 1 (not depressed) to 10 (extremely depressed), how anxious are you feeling?

1 _____ 2 _____ 3 _____ 4 _____ 5 _____ 6 _____ 7 _____ 8 _____ 9 _____ 10

Not depressed   Moderately   Extremely depressed

3. What are the situations in your daily life which cause you to feel most depressed?

C. PARENT SOCIAL SUPPORT

a. EMOTIONAL SUPPORT

1. How emotionally supported do you feel by your family?

1 _____ 2 _____ 3 _____ 4 _____ 5 _____ 6 _____ 7 _____ 8 _____ 9 _____ 10

Not at all   Sometimes   All the time

2. How emotionally supported do you feel by your friends?

1 _____ 2 _____ 3 _____ 4 _____ 5 _____ 6 _____ 7 _____ 8 _____ 9 _____ 10

Not at all   Sometimes   All the time

b. PRACTICAL SUPPORT

3. How much help do you receive from family in caring for your child/children with an ASD?

1 _____ 2 _____ 3 _____ 4 _____ 5 _____ 6 _____ 7 _____ 8 _____ 9 _____ 10

Not at all   Sometimes   All the time

4. How much help do you receive from friends in caring for your child/children with an ASD?

1 _____ 2 _____ 3 _____ 4 _____ 5 _____ 6 _____ 7 _____ 8 _____ 9 _____ 10

Not at all   Sometimes   All the time

5. In thinking about the support you receive from family and friends, can you describe the support which is most helpful to you?

6. In thinking about the support you receive from family and friends, can you describe the support which is least helpful to you?

c. FINANCIAL SUPPORT

7. Do you receive any resources for your child with an ASD from the government or other organisations? **Yes**   **No**

8. Do you have family members who have given/do give you financial support? **Yes**   **No**

9. Do you have friends who have given/do give you financial support? **Yes**   **No**

d. INFORMATIONAL SUPPORT

10. Are you able to access information to help you assist your child with an ASD? **Yes**   **No**

11. If Yes, Can you describe the information you have access to?

12. Are you happy with the information you have been able to access? **Yes**   **No**

D. PARENT SELF-EFFICACY

1. Can you tell me about a concern you currently have about your child that you are currently dealing with?

2. On a scale from 1 (= not at all confident) to 10 (=completely confident), rate how confident you are in managing and resolving this difficulty?

    1 _____ 2 _____ 3 _____ 4 _____ 5 _____ 6 _____ 7 _____ 8 _____ 9 _____ 10

Not at all confident   Somehow confident   completely confident

3. Are there any concerns you might have about your ASD child's future? **Yes**   **No**

4. Describe your major concerns you might have about your ASD child's future.

5. Do you feel confident in your capacity to manage your own stress and personal difficulties? **Yes**   **No**

6. On a scale from 1 (= not at all confident) to 10 (=completely confident), rate how confident are you in managing your own stress and

   personal difficulties?

   1 _____ 2 _____ 3 _____ 4 _____ 5 _____ 6 _____ 7 _____ 8 _____ 9 _____ 10

Not at all confident   Somehow confident   completely confident

7. On a scale from 1 (= not at all confident) to 10 (=completely confident), rate how confident are you in managing your child (ren)'s needs?

   1 _____ 2 _____ 3 _____ 4 _____ 5 _____ 6 _____ 7 _____ 8 _____ 9 _____ 10

Not at all confident   Somehow confident   completely confident

E. CHILD BEHAVIOUR AND FUNCTIONING

a. *AGGRESSIVE BEHAVIOUR*

1. Does your child ever use aggressive behaviour when interacting with other people (e.g., adults, siblings…)? **Yes**   **No**

2. If yes, how often is your child violent or aggressive towards other people?

1 ——— 2 ——— 3 ——— 4 ——— 5 ——— 6 ——— 7 ——— 8 ——— 9 ——— 10

Not at all   Sometimes   All the time

3. Can you give me some specific examples of the types of things your child might say and/or do when (s)he is behaving aggressively?

b. *REPETITIVE BEHAVIOUR*

4. Does your child ever do or say the same thing repeatedly or does (s) he make any unusual hand/body movements repeatedly?

Yes   **No**

5. If yes, how often does your child uses repetitive behaviour?

1 ——— 2 ——— 3 ——— 4 ——— 5 ——— 6 ——— 7 ——— 8 ——— 9 ——— 10

Not at all   Sometimes   All the time

6. Can you give me some examples of the repetitive statements, activities or actions you child might engage in?

c. *SLEEP BEHAVIOUR*

7. Does your child have any difficulty <u>falling</u> and/or <u>staying</u> asleep? **Yes**   **No**

8. If yes, how often does your child experience sleep difficulties?

1 ——— 2 —— 3 ——— 4 —— 5 —— 6 —— 7 ——— 8 —— 9 ——— 10

Not at all   Sometimes   All the time

9. Does your child take any medications to help with his/her sleep difficulties? **Yes**   **No**

10. If yes, which medication does your child take?

d. *SCHOOL BEHAVIOUR*

11. Can you tell me a little about your relationship with your child's teacher and school in general?

12. What are some of the school-based situations which, when they happen, can have a negative impact on your well-being?

13. Do you think that your child's teacher has a clear vision for his/her long-term future?

14. Is there anything else you would like to mention before we conclude the interview?

Prompts Used by the Interviewer throughout the Interview

1. Prompt from interviewer so participant gives a more detailed answer for the question.

2. Anything else you can think of?

3. Are there any other concerns that you might have that you can think of?

APPENDIX N

Example of Process to Extract Codes

Talking to people about ASD child (ID 28)

Giving more attention to my ASD child than to my other child (ID 01)

Child struggling at school (ID 08)

Anything that has to do with ASD child in general (ID 10) (ID 23) (ID 30) (ID 37) (ID 39) (ID 42) (ID 12)

Progress of ASD child (ID 10) (ID 16) (ID 31) (ID 35)

ASD child social abilities (ID 11) (ID 16) (ID 35)

Getting ASD child ready to go to school in the mornings (ID 19) (ID 29) (ID 36) (ID 09) (ID 43)

Getting ASD child to do anything (ID 19) (ID 36) (ID 29)

Getting ASD child to go to sleep (ID 19) (ID 36) (ID 12)

ASD child engaging in unpredictable or difficult behaviour (ID 23) (ID 29) (ID 32) (ID 37) (ID 38) (ID 44) (ID 02)

Transitions for ASD child (ID 29) (ID 09) (ID 43)

Health of ASD child (ID 44) (ID 41)

ASD child engaging in self-harming behaviour (ID 25)

RELATED TO ASD

Not being able to afford things for my child (tuition, sports team, activities) (ID 01)

Being treated poorly by other people because of ASD child's behaviours (ID 01)

Having to leave work to get ASD child from school (ID 10)

Expenses for ASD child's activities (ID 16)

Picking up and dropping off ASD child (ID 17)

Worrying about ASD child's future (ID 18)

Transporting ASD child to a destination (ID 18)

Making sure child's anxiety level is low (ID 20)

Having to reschedule work to assist spouse with ASD child (ID 21)

School mentioning that lateness in the mornings was officially reported on (ID 29)

Anything that has to do with the school (ID 29) (ID 38) (ID 02)

Cleaning child's faeces around the house (ID 37)

Working through homework with child (ID 40) (ID 12)

Friends' perceptions of child's ASD (ID 02)

Getting a phone call from the school (ID 11) (ID 39) (ID 02) (ID 03)

Scared of being out in public with ASD child (ID 30) (ID 31) (ID 43) (ID 02)

NOT RELATED TO ASD

Frightening situations (e.g., road rage or vicious dogs) (ID 28)

Depression diagnosis of my other child (ID 28)

Health of my family (ID 28) (ID 21) (ID 35)

Being a single parent (ID 01) (ID 18) (ID 33) (ID 37)

Parent feeling exhausted (ID 01)

Not having friends (ID 01)

Having debt collectors crawling over us (ID 08)

Experienced bankruptcy (ID 01) (ID 08) (ID 16) (ID 37)

Financial difficulties (ID 08) (ID 16) (ID 33) (ID 37) (ID 44)

Work commitments (ID 10) (ID 25) (ID 27) (ID 40) (ID 12)

Having to pay bills (ID 16) (ID 18) (ID 27)

Husband's plans change because of work (ID 17)

Working different shifts (ID 17) (ID 18) (ID 21)

Having a husband who presents like my ASD children (ID 20)

Organising appointments while having to work (ID 21)

The condition of the house (ID 21) (ID 38) (ID 03) (ID 37)

Worrying about money (ID 21) (ID 23) (ID 27) (ID 44) (ID 20)

Traveling time getting to work every day (ID 27)

Time management (ID 29) (ID 31) (ID 33)

Personal health issues (ID 32) (ID 41)

Not being able to afford another car (ID 37)

Having a spouse that works from home (ID 42)

Making sure there is enough money in the bank (ID 20)

Example of Thematic Map

Events that cause parents to feel most anxious.

1 **ASD CHILD SYMPTOMS/ DIFFICULTIES** ASD Symptoms/Difficulties: Progress of ASD child (X4); ASD child social abilities (X3); getting child to do anything (X3); anything that has to do with child (X7). *14 Parents Responded*	**2** **FINANCIAL** Direct Financial Demands/Stressors: Experience of bankruptcy (X4); financial difficulties (X5); having to pay bills (X3); worrying about money (X5). *11 Parents Responded*
3 **SCHOOL** Child School Difficulties: Getting child ready to go to school (mornings) (X5). School Difficulties with Child: Anything that has to do with school (X3); getting a phone call from the school (X4). *10 Parents Responded*	**4** **WORK** Work Demands: Work commitments (X5); work different shifts (X3). *08 Parents Responded*