

FATHERS OF CHILDREN WITH AUTISM: THE IMPACT OF A SUPPORT GROUP ON  
FATHERS' STRESS, DEPRESSION, COPING, AND MARITAL SATISFACTION

by

Miriam Elfert

B.A., Simon Fraser University, 1998

M.A., University of British Columbia, 2003

M.Ed., University of British Columbia, 2007

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## ABSTRACT

The purpose of this study was to design and evaluate the impact of a support group for fathers of children with autism, using quantitative measures to examine participants' psychological experiences. Twelve fathers of children with autism participated in the study, which employed a two-group pretest-posttest design and a measure of social validity. The two groups were comprised of six fathers each, who attended eight weekly 2-hour sessions that focused on various topics related to parenting a child with autism. Sample topics included fathers' experiences with the diagnosis, dealing with the education system, the impact on personal and professional relationships of parenting a child with autism, and future hopes and fears. All participants completed the Beck Depression Inventory-II, the Dyadic Adjustment Scale (DAS), the Parenting Stress Index 4<sup>th</sup> Edition, the Life Orientation Test-Revised, the Ways of Coping Questionnaire, a demographic form, and a social validity questionnaire regarding participation in the group. Group 1 completed the formal test measures prior to the start of their group, upon completion, and 4 months later. Group 2 completed these measures prior to the start of their own group, and upon completion. Data were analyzed using a 2X2 mixed model analysis of variance with Group as the between-subjects factor and Time as the within-subjects factor. Results indicated no significant main effects for either Group or Time between baseline and post-treatment for any of the measures. However, there was a significant interaction effect for marital adjustment via the DAS, and follow-up independent sample t-tests showed a significant improvement for Group 2 only. For Group 1, paired samples t-tests indicated no change in scores between post-treatment and follow-up on any measure. Responses to the social validity measure indicated that all fathers found the groups to be meaningful and helpful, enjoyed listening to and

sharing personal experiences with other men in similar circumstances, and strongly recommended a similar group to other fathers of children with autism. Results are discussed in terms of their contribution to the literature, limitations and cautions, and implications for practitioners and researchers who support and study fathers of children with autism.

## **PREFACE**

This research was approved by the UBC Behavioural Research Ethics Board on February 12, 2013, as per certificate H12-03119. The research was designed and executed by Miriam Elfert. The written document was produced by Ms. Elfert with input from her supervisory committee. This research has not been published.

## TABLE OF CONTENTS

ABSTRACT.....	ii
PREFACE.....	iv
TABLE OF CONTENTS.....	v
LIST OF TABLES .....	xiii
ACKNOWLEDGEMENTS.....	xiv
CHAPTER 1: INTRODUCTION.....	1
My Autism Journey .....	1
Research on Fathers of Children with ASD .....	3
Why Study Fathers?.....	5
CHAPTER 2: REVIEW OF THE LITERATURE.....	10
Autism Spectrum Disorder.....	10
Negative Psychological Variables.....	13
Stress.....	13
Parents of children with ASD compared to other parents.....	13
Mothers compared to fathers of children with ASD.....	17
Depression .....	20
Parents of children with ASD compared to other parents.....	21
Mothers compared to fathers of children with ASD.....	23

Positive Psychological Variables .....	24
Marital Satisfaction.....	24
Parents of children with ASD compared to other parents.....	25
Mothers compared to fathers of children with ASD.....	27
Optimism .....	28
Parents of children with ASD compared to other parents.....	28
Mothers compared to fathers of children with ASD.....	29
Coping Strategies.....	31
Parents of children with ASD compared to other parents.....	33
Mothers compared to fathers of children with ASD.....	37
Summary of Research on Experiences of Parents of Children with ASD.....	40
Parent Skills Training.....	45
Therapy Groups.....	48
Types of Therapy Groups .....	49
Psychotherapy groups. ....	49
Counselling groups. ....	50
Psychoeducational groups.....	50
Task groups.....	51
Self-help and support groups. ....	51
Therapeutic Factors in Support Groups.....	53

Group cohesiveness. ....	53
Giving and receiving support.....	53
Hope.....	54
Knowledge and coping. ....	54
Autism Support Groups.....	56
Efficacy of Support Groups.....	58
Differentiating Between Self-Help and Support .....	58
Efficacy of Support Groups for Parents of Children with a Disability Other than ASD	59
Support groups for fathers of children with a disability. ....	62
Efficacy of Support Groups for Parents of Children with ASD .....	65
Support groups for fathers of children with ASD.....	69
Limitations of Research on Support Groups.....	73
Designing and Running Groups for Fathers.....	74
Structural/Physical Considerations.....	77
Interpersonal Considerations .....	77
Leadership Considerations .....	78
Group Recruitment and Membership Considerations .....	80
Group Content Considerations .....	82
Statement of the Problem and Research Questions.....	84
Question 1.....	86

Question 2.....	86
Question 3.....	86
CHAPTER 3: METHODS.....	88
Recruitment.....	88
Participants.....	88
Age and Ethnicity.....	90
Marital Status and Spousal Age.....	90
Children With and Without ASD.....	90
Household Income.....	90
Education.....	91
Setting and Materials.....	91
Research Design.....	91
Dependent Variables and Measurement.....	92
Instrumentation.....	92
Beck Depression Inventory-II (BDI-II).....	92
Dyadic Adjustment Scale (DAS).....	94
Life Orientation Test – Revised (LOT-R).....	96
Parenting Stress Index – 4 <sup>th</sup> Edition Short Form (PSI-4-SF).....	97
Ways of Coping Questionnaire (WCQ).....	99
Demographic Form.....	102

Social Validity Questionnaire.....	102
Independent Variables.....	102
General Session Structure.....	103
Leadership Style .....	104
Session Topics .....	104
Procedures .....	106
Pretest .....	106
Support Group .....	106
Posttest.....	107
Follow-Up.....	107
Data Analysis .....	107
CHAPTER 4: RESULTS .....	110
Quantitative Results .....	110
Question 1.....	110
Depression (BDI-II).....	110
Marital Satisfaction (DAS).....	111
Optimism (LOT-R).....	112
Parenting Stress (PSI-4-SF).....	113
Coping (WCQ) .....	115
Question 2.....	117

Follow-Up Assessment.....	117
Individual Differences .....	118
Social Validity.....	119
Question 3.....	119
Attendance and Post-Group Meetings.....	120
Primary Responses to Social Validity Questions .....	120
Supplementary Comments from the Social Validity Questionnaire .....	121
Least enjoyable aspects of participating in the group.....	121
Thoughts about the frequency, duration, and timing of the sessions (2 hours/week for 8 weeks).....	122
Topics covered.....	122
Summary .....	123
CHAPTER 5: DISCUSSION.....	124
Quantitative Results .....	124
Depression (BDI-II) Pre- to Post-Treatment .....	124
Marital Adjustment (DAS) Pre- to Post-Treatment.....	125
Optimism (LOT-R) Pre- to Post-Treatment .....	128
Parenting Stress (PSI-4-SF) Pre- to Post-Treatment .....	129
Coping (WCQ) Pre- to Post-Treatment.....	130
Pre-and Post-Treatment to Follow-Up .....	132

Social Validity.....	134
Perceived Helpfulness and Utility of the Group.....	134
Limitations .....	137
Research Design .....	137
Sample Size .....	137
Participant Characteristics .....	138
Support Group Design.....	139
Measurement .....	140
Reactivity.....	142
Future Research.....	143
Experimental Design .....	143
Support Group Structure and Design.....	144
Participant Characteristics .....	144
Dependent Variables.....	145
Clinical Recommendations .....	146
Conclusion.....	150
REFERENCES .....	152
APPENDIX A: Open-Ended Interview Form.....	176
APPENDIX B: Recruitment Flyer for Support Group .....	177
APPENDIX C: Standard Interview Form to Screen Potential Participants.....	179

APPENDIX D: Demographic Form ..... 180

APPENDIX E: Shop Talk Social Validity Questionnaire ..... 182

APPENDIX F: Support Group Code of Conduct ..... 185

## LIST OF TABLES

Table 1: Self- and Other-Directed Types of Coping.....	32
Table 2: Coping Strategies of Parents of Children with ASD Compared to Other Parents....	35
Table 3: Coping Strategies of Fathers Compared to Mothers of Children with ASD .....	38
Table 4: Summary of Study Results for Stress, Depression, Marital Satisfaction, Optimism and Coping in Parents of Children with ASD.....	44
Table 5: Demographic Information for Participants.....	89
Table 6: Timeline for Study Conduct and Data Collection .....	107
Table 7: Total Raw Score Means and Standard Deviations for the BDI-II.....	111
Table 8: Total Raw Score Means and Standard Deviations for the DAS.....	112
Table 9: Total Raw Score Means and Standard Deviations for the LOT-R.....	113
Table 10: Raw Score Means, Percentiles, and Standard Deviations for the PSI-4-SF.....	114
Table 11: Total Raw Score Means and Standard Deviations for WCQ Scales Across Time and Groups .....	116
Table 12: Total Raw Score Means and Standard Deviations for Group 1 Follow-Up Analyses .....	118
Table 13: Individual Score Changes of $\pm 10$ Points .....	119

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## **CHAPTER 1: INTRODUCTION**

The aim of this study was to add to the literature on fathers of children with autism spectrum disorder (ASD) by examining the impact of a support group designed specifically for them, using psychometrically sound outcome measures and a measure of social validity. In this first chapter, I will provide the reader with background information about my professional and educational experiences that laid the foundation for the present study. This will be followed by a brief overview of the state of current research on fathers of children with ASD and other psychological disorders. Finally, I will conclude this chapter by providing a rationale for the importance of studying fathers of children with ASD and designing interventions that accommodate their unique needs.

### **My Autism Journey**

I have worked in the field of autism spectrum disorder (ASD) for 18 years in a number of roles, including behaviour interventionist, special education assistant, behaviour consultant, consultant to the provincial government regarding autism policies and procedures, autism course instructor, and counsellor. My first introduction to ASD was as a behaviour interventionist (BI) working directly with children in families' homes. The first family I worked for had three young children, the oldest of whom (a 4-year-old boy) had been diagnosed with ASD a few months before I met him. The couple's other two children (a 2-year-old girl and 6-month-old boy) were both subsequently diagnosed with ASD as well. The two boys were severely autistic, had no verbal language, and never developed any functional speech. My main point of contact was the mother, who was at home full-time with the children and who would often leave and go up to her bedroom for one to two hours at a time, to sleep and to have some time away from the demands of parenting. I occasionally saw the father, who worked full time outside of the home as an

engineer. When I did see and interact with him, it was clear to me that he was silently suffering behind the scenes with little support, and was struggling to keep moving forward in the face of enormous adversity.

I was part of an intervention team with 2-3 other BIs who provided a total of 25-30 hours of intervention per week under the supervision of a behaviour consultant who flew in from California every 2 months to review and make changes to the program. I also provided overnight respite to the family for their oldest son once monthly for one year. The family was under a tremendous amount of stress, and both parents often appeared fatigued, discouraged, and depressed as they worked to raise their children while managing a full team of people whom they had hired with their own money to help all three children learn and develop important communication and life skills. I wanted so much to help the family and the children, but progress was slow, I was young and inexperienced, and I often felt quite discouraged and helpless myself. It was difficult enough to enter this family's home and work for a number of hours each week with their son, with little support from and little communication with other team members about the challenges of the work. On top of this, I was a frequent witness to the parents' ongoing struggles and suffering, and was unable to abate their distress. Eventually, after a number of years of struggling to care for their three children at home, the family made the difficult decision to put their two sons in foster care. They had reached their limit, and thought that the boys could be better cared for by two foster families whom they had known for years as respite providers. The boys still live with the original foster families who took them into care over 10 years ago.

It was a very revealing insight into some of the chronic and severe psychological, emotional, and financial challenges that parents of children with autism encounter and must deal with every day. This was a powerful and transformative experience that truly changed the course

of my academic and professional life: from that first encounter with ASD, I never looked back, and continued to develop my skills and knowledge in working with these children and their families. Over the next several years, I accumulated numerous other professional experiences in the field of ASD, and I completed two graduate degrees – one in special education with an emphasis in ASD and a second in counselling psychology with an emphasis on family-centred group work. I chose to pursue a second master's degree in counselling psychology in an effort to combine the fields of autism and psychology in a way that would broaden my knowledge and skill set, particularly with respect to working with parents. During the counselling degree program, to meet a practicum requirement, I designed and facilitated three support groups for fathers of children with ASD. In doing so, my intent was to provide fathers with opportunities to talk to other men in similar circumstances, to counteract their social isolation, and to increase their social support. I did so because, in my experience, mothers were typically the primary and most visibly involved parents who almost always received the most support and guidance from service providers. In facilitating the groups, I was gratified to hear from the fathers that they found them to be meaningful, helpful, and worthwhile, and that they desired contact with other fathers. I found myself thinking back to the father of the three children in that first family and wishing that such a group had been available to him for emotional support as well. I resolved to conduct research on the effectiveness of support groups for fathers of children with ASD, based on both my clinical impressions of their utility and my awareness of the paucity of support available to fathers, even today.

### **Research on Fathers of Children with ASD**

“The psychiatric literature is rife with studies of childhood disabilities in which detailed and particular attention is given to personality traits in the mother presumed relevant to

the disorder in her child....Father has been the forgotten man” (Eisenberg, 1957, p. 715).

“There continues to be a dearth of research on fathers and developmental psychopathology... [and, furthermore]...[t]he lack of fathers in clinical research is consistent with studies of the lack of fathers in research on pediatric psychology and school psychology” (Phares, Fields, Kamboukos, & Lopez, 2005, p. 735).

These two quotations – separated by almost 50 years – provide a backdrop for the present study. The first quote was taken from a paper entitled “The Fathers of Autistic Children,” in which Leon Eisenberg, a prominent child psychiatrist, described the personality characteristics of fathers of children with ASD, using three case studies as representative examples. His lament about the father as “the forgotten man” was echoed in a recent systematic review that found that, of 26 studies on families of ASD that were published in the past 20 years, only three included fathers as participants (and two of those included only one father each) (Flippin & Crais, 2011). This is not to say that fathers are entirely absent in the ASD literature, as evidenced by studies in which fathers were the target of intervention (e.g., Elder, Valcante, Yarandi, White, & Elder, 2005) or those in which the psychological experiences of mothers and fathers were compared (e.g., Hastings, Kovshoff, Ward et al., 2005). However, almost 50 years after Eisenberg’s observations, the vast majority of research conducted with parents of children with ASD still includes mothers—either exclusively or primarily—as participants.

As is evident in the second quote (by Phares and colleagues), this maternal-centric pattern persists, not only in the autism literature, but in other parent-child research domains as well. For example, Phares et al. (2005) compared the current representation of fathers in the developmental psychopathology literature to that found in a previous review (Phares & Compas, 1992). Of a total of 514 studies published between 1996 and 2003, 231 studies (45%) involved

mothers only; 127 (24.7%) involved both mothers and fathers and analyzed for maternal and paternal effects separately; 100 studies (19.4%) did not specify parental gender and simply referred to participants as “parents;” 45 studies (8.8%) included both mothers and fathers but did not analyze for separate effects; and only 11 (2.1%) involved fathers only. When compared with previous data reported by Phares and Compas (1992) that was extracted from the same journals across 577 articles published between 1984 and 1991, no significant differences were found for the proportion of fathers included in this body of research. These findings were also echoed in a study examining doctoral dissertation research in developmental psychology and developmental psychopathology, in which 60% of studies involved mothers only, 30% studied “parents,” and 10% explored fathers only (Silverstein & Phares, 1996).

A similar pattern can be found in the literature on child psychopathology. Cassano, Adrian, Veits, and Zeman (2006) found that the proportion of paternal-focused studies in this area remained at 1% between 1992 and 2005. However, they did note a trend over the 13 year period, with a greater number of studies examining paternal influence after 1998 compared to studies prior to 1998. In addition, they noted that fathers were more likely to be included and analyzed as a separate group in research studying children beyond the early years. Specifically, only 13% of studies investigating infant and toddler adjustment examined parental gender separately, compared with 23% in early childhood, 34% in middle childhood, and 41% in adolescence. Another interesting finding was that articles published in clinical psychology journals were more likely to include fathers and analyze parental gender separately than were studies published in developmental psychology journals.

### **Why Study Fathers?**

Given these persistent and pervasive patterns, one might ask: Does it matter that autism

research has been focused primarily on mothers? In other words -- why study fathers of children with ASD? There are a number of reasons why fathers of children with ASD should be considered as essential participants in research. First, we know that mothers and fathers have different psychological experiences as both parents and partners. For example, Hastings, Kovshoff, Brown, et al. (2005) found that fathers employed different coping strategies than mothers when dealing with the stresses of raising a child with ASD. Important differences between mothers and fathers of children with ASD have also been found on other psychological variables, including depression (Hastings, Kovshoff, Ward et al., 2005; Lee, 2009; Ornstein Davis & Carter, 2008); anxiety (Lee, 2009); marital satisfaction (Lee, 2009); and stress (Ornstein Davis & Carter, 2008), with mothers typically reporting higher levels of distress. Therefore, given the unique psychological profile of fathers, it behooves researchers to investigate and more fully understand fathers as a separate group.

Second, a bidirectional influence exists between mothers and fathers, whereby one parent's experiences can affect the other. For example, a study by Hastings (2003) of 18 married couples who were parents of children with ASD found that fathers' mental health was associated with mothers' stress. Specifically, after controlling for child behaviour problems, Hastings found significant associations between maternal stress and both paternal anxiety and paternal depression. Interestingly, there were no significant correlations between maternal mental health and paternal stress, even though fathers and mothers reported similarly high stress levels, suggesting that there were other factors associated with paternal stress. However, in an extension of this study, Hastings, Kovshoff, Ward et al. (2005) studied parents of preschoolers with ASD and found that fathers' stress was positively correlated with both maternal anxiety and maternal depression. Furthermore, in examining causal relationships, separate regression models

demonstrated that maternal and paternal depression significantly predicted the partner's stress. Similarly, Kayfritz, Gragg, and Orr (2010) found that fathers', but not mothers', positive experiences were negatively related to their partners' reports of parenting stress. The interrelationships between mothers and fathers were also explored in a qualitative (i.e., interview-based) analysis by Gray (2003), who examined the coping strategies utilized by parents of children with high functioning ASD. Mothers highly rated the support they received from family members, including spouses. Consistent with this appraisal, husbands described themselves as being a reserve source of support for their wives, and as people who could be relied upon for support during periods of extreme stress. Thus, it is evident that the psychological experiences of one parent can affect the other parent and that, by extension, understanding and addressing fathers' psychological needs can positively influence mothers' mental health.

A third reason for the importance of studying fathers of children with ASD is that fathers are influential and direct contributors to their children's development. Research has demonstrated that paternal characteristics add unique and positive contributions to the development of offspring, beyond those made by mothers (Pleck & Masciadrelli, 2004). For example, a study by Videon (2005) found that higher levels of satisfaction with the father-adolescent relationship were associated with fewer adolescent depressive symptoms, a finding that remained significant after controlling for the mother-adolescent relationship. Khaleque and Rohner (2012) examined the relationship between children's perceptions of parental acceptance and the children's psychological adjustment. They conducted a meta-analysis of 66 studies involving 19,511 respondents from 22 countries. The instruments used were the Parental Acceptance-Rejection Questionnaire (PARQ) and the Personality Assessment Questionnaire (PAQ), which measures dimensions of psychological adjustment such as hostility/aggression,

positive self-esteem, dependence, and emotional responsiveness. The results showed that the mean effect size of the correlation between perceived paternal acceptance and children's psychological adjustment was significantly stronger than the mean effect size of the correlation between perceived maternal acceptance and children's psychological adjustment.

Allen and Daly (2007) conducted a research review on the impact of fathers' involvement on children's developmental outcomes. Higher levels of father involvement (measured by the time a father spent with his child, the quality of the father-child relationship, and investment in paternal role) were associated with a plethora of positive outcomes, including higher cognitive development (e.g., higher academic achievement, better problem solving, higher IQ); higher social-emotional development and well-being (e.g., greater life satisfaction, less depression, fewer conduct problems, more long-term friendships, higher moral development); and better physical health (e.g., less obesity, asthma, and substance abuse). An important corollary of this is that fathers themselves benefit from being more involved with their children: Higher paternal involvement has been associated with higher self-confidence, higher parenting efficacy, greater psychosocial maturity, less substance abuse, less psychological distress, greater marital satisfaction, and greater community involvement for fathers (Allen & Daly, 2007).

The fact that fathers are influential and direct contributors to their children's development is particularly relevant when considering the increasing role of fathers over time in providing childcare. Hoffman (2011) cited various Canadian statistics demonstrating how maternal and paternal roles have shifted over the past two decades. For example, whereas 30% of couples reported that fathers were the sole household income earners in 1986, only 17% of couples reported fathers as the sole earners in 2008. The percentage of women in two-income families who earned more than their partner increased from 18% in 1982 to 29% in 2003. The percentage

of fathers with preschoolers who reported daily participation in childcare increased from 57% in 1986 to 73% in 2005. Based on these statistics, “fathers tend to be more involved with children when their partners are employed and/or work non-standard hours, and when the mother earns more than the father” (p. 15).

From the aforementioned examples, it seems evident that, if most of the research in ASD is based primarily on data from mothers, the paternal risks and protective factors that affect the developmental pathways of this disorder are likely to remain unexplained or misattributed. The premise of the proposed research project is that it is important to understand and support fathers’ experiences of parenting a child with ASD, and that increased knowledge about paternal contributions to the research on parenting are both necessary and valuable. From an empirical perspective, studying fathers provides important information about their unique experiences and how those differ (or are similar to) those of mothers. Furthermore, it gives fathers their own collective voice and identity, separate from that of their spouses. From a clinical perspective, the information that is gathered via applied research can be used to develop interventions that will support and assist fathers to be better parents and partners. Thus, the goal of this study was to add to the literature on fathers of children with ASD by examining the impact of a support group designed specifically for them, using psychometrically sound outcome measures and a measure of social validity.

## **CHAPTER 2: REVIEW OF THE LITERATURE**

In this chapter, I begin by describing the characteristics and prevalence of ASD, followed by a section addressing parents' psychological experiences (both negative and positive) that are related to raising a child with this disorder. I will then describe some of the supports that have been developed to assist parents in the task of raising a child with ASD, focusing mainly on therapy groups, with specific emphasis on support groups. Next, I will review the existing research on the effectiveness of support groups and summarize the limitations of this research. This will be followed by a section describing factors to consider when designing and running support groups. Finally, this chapter will conclude with a summary of the problem and with the specific research questions that were addressed in this study.

### **Autism Spectrum Disorder**

ASD is characterized by severe and pervasive impairment in social communication and social interaction; and the presence of stereotyped behaviour, interests, and activities (American Psychiatric Association [APA], 2013). In order to meet the criteria for ASD, an individual must display the following symptoms:

- A. Persistent deficits in social communication and social interaction across multiple contexts, as manifested by the following, currently or by history:
  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 behaviour to suit various social contexts; to difficulties in sharing imaginative play or in making friends; to absence of interest in peers.
- B. Restricted, repetitive, and stereotyped patterns of behaviour, interests and activities, as manifested by at least two of the following, currently or by history:
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 behaviour (e.g., extreme distress at small changes, difficulties with transitions, rigid thinking patterns, greeting rituals, need to take same route).
  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).
- 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 must 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.

In 2014, the prevalence of ASD was estimated at 1 in 68 children, with a male:female ratio of approximately 4.5:1 (Centers for Disease Control & Prevention, 2014). Over the past decade, there has been a significant linear increase in the number of individuals diagnosed with ASD, with most of the increase accounted for by changes in diagnostic concepts and criteria, as well as by improved awareness and identification by parents, educators, and clinicians such as medical professionals (Fombonne, 2005). Based on population statistics for Canada, approximately 63,000 children ages 19 years and younger are estimated to be diagnosed with ASD (Lazoff, Zhong, Piperni, & Fombonne, 2010). In British Columbia, over 6,000 children and youth are diagnosed with ASD (Ministry of Children and Family Development [MCFD], 2009). In 2001, the B.C. provincial MCFD budget for autism intervention and funding programs was \$4.1 million, increasing more than eleven-fold to \$46 million in 2009/10. Funding for diagnostic and assessment services, provided by the Ministry of Health Services (MoHS) and delivered through provincial health authorities, increased from \$100,000 in 2001/02 to \$3.4 million in 2008/09 (MCFD, 2009). Thus, it is clear that ASD is a significant public health issue requiring considerable resources and attention, not only from families, but also from clinicians, medical practitioners, educators, and government.

Given the pervasiveness and chronicity of impairments in ASD, it is not surprising that parenting a child with this disorder can present significant challenges for caregivers. The sections that follow review the experiences of parents of children with ASD by examining a number of psychological variables pertaining to them. Research has indicated that “positive and negative

aspects of psychological functioning may be separate dimensions with different influences, whereas in times of elevated stress these two dimensions become highly related” (Ekas, Lickenbrock, Whitman, 2010, p. 1275). Thus, and in light of the fact that parents of children with ASD experience high levels of distress, Ekas et al. contended that research on these parents of should evaluate both positive and negative psychological variables, in order to achieve a more comprehensive and holistic understanding of their experiences. Hence, research on both negative and positive psychological factors will be reviewed in the subsequent sections, beginning with negative variables (i.e., stress and depression) and followed by positive variables (i.e., marital satisfaction, optimism, and coping). These are among the most commonly studied variables pertaining to parenting a child with ASD.

### **Negative Psychological Variables**

#### **Stress**

Stress is perhaps the most researched psychological variable in the literature on parents of children with ASD. A number of measures have been used to operationalize stress in the ASD literature; some of the most commonly used instruments include the long and short forms of the Parenting Stress Index (PSI; Abidin, 1995) and the Questionnaire on Resources and Stress (QRS; Holroyd, 1974). This domain of parental stress literature can be divided into two categories, based on who was studied and how the data were analyzed. The first category is research comparing parents of children with ASD to parents of other children, and the second category is research comparing mothers and fathers of children with ASD.

**Parents of children with ASD compared to other parents.** The research in this area has consistently demonstrated that parents of children with ASD experience higher levels of stress than parents of either typically developing children or children with disabilities other than

ASD, such as Down syndrome, nonverbal learning disorders, and cystic fibrosis (Baker-Ericzen, Brookman-Frazer, & Stahmer, 2005; Bouma & Schweitzer, 1990; Brobst, Clopton, & Hendrick, 2009; Dabrowska & Pisula, 2010; Dumas, Wolf, Fisman, & Culligan, 1991; Ekas, Lickenbrock, & Whitman, 2010; Epstein, Saltzman-Benaiah, O'Hare, Goll, & Tuck, 2008; Ingersoll & Hambrick, 2011; Noh, Dumas, Wolf, & Fisman, 1989; Osborne & Reed, 2010; Sanders & Morgan, 1997). A recent, representative study from this domain was conducted by Dabrowska and Pisula (2010), who examined the stress profiles of parents of young children (ages 2-6) with developmental disabilities (ASD and Down syndrome) and compared their perceptions of parenting stress with those of parents of children without disabilities. Participants were 51 parents of children with ASD, 54 parents of children with Down syndrome, and 57 parents of typically developing children. Stress was measured with the QRS (Holroyd, 1974). The results showed that parents of children with ASD had significantly higher total stress scores on the QRS than parents in the other two groups. Specifically, parents of children with ASD reported significantly higher levels of stress than parents of typically developing children on 8 of the QRS subscales, and significantly higher stress than parents of children with Down syndrome on 3 of the subscales (i.e., dependency and management, limits on family opportunities, and life span care).

This pattern—parents of children with ASD endorsing higher levels of stress than other parents—has not only been found when comparing parents as a homogenous group (i.e., mothers and fathers treated as one group), but also when comparing mothers to other mothers (Bouma & Schweitzer, 1990; Fisman, Wolf, & Noh, 1989; Holroyd & McArthur, 1976; Little, 2002; Pisula, 2007; Quintero & McIntyre, 2010; Sanders & Morgan, 1997; Weiss, 2002); and fathers to other fathers (Baker-Ericzen et al., 2005; Fisman et al., 1989; Herring, Gray, Taffe, Tonge, Sweeney,

& Einfeld, 2006; Sanders & Morgan, 1997). For example, Baker-Ericzen et al. (2005) examined the stress levels of parents of children with ASD (37 mothers and 27 fathers) and parents of typically developing children (23 mothers and 16 fathers) before and after their involvement in an inclusive toddler program in California. Parents completed the Parenting Stress Index (PSI; Abidin, 1995), which consists of both child domain and parent domain subscales. The child domain subscales (Adaptability, Acceptability, Demandingness, Mood, Distractibility/Hyperactivity, and Reinforces Parent) assess the presence of child behaviours and characteristics that are stressful to parents. The parent domain subscales (Depression, Attachment, Restriction of Role, Sense of Competence, Social Isolation, Relationship with Spouse, and Parent Health) assess dimensions of parent stress related to the parent's personal adjustment and family functioning. The authors found that mothers of children with ASD reported significantly higher levels of stress in both the child and parent domains than parents of typically developing children. Specifically, 59% of mothers of children with ASD reported significantly elevated levels of child domain stress and 24% reported significantly elevated levels of parent domain stress, compared to 17% and 9%, respectively, of mothers of typically developing children. This is consistent with other research indicating that approximately two-thirds of mothers of children with ASD experience clinically significant levels of stress in the child domain of the PSI (Tomanik, Harris, & Hawkins, 2004).

In the same study, Baker-Ericzen et al. (2005) found that fathers of children with ASD also reported significantly higher levels of both child and parent domain stress than fathers of typically developing children. Specifically, 35% of fathers of children with ASD reported significantly elevated levels of child domain stress compared to 13% of fathers of typically developing children, and 15% of fathers of children with ASD reported significantly elevated

levels of parent domain stress compared to 0% of fathers of typically developing toddlers. This outcome is similar to the results of an earlier study by Rodrigue, Morgan, and Geffken (1992), who compared fathers of children with ASD to fathers of children with Down syndrome and fathers of typically developing children. They found that fathers of children with ASD reported significantly greater financial burden and greater disruption to family planning than fathers of typically developing children, but not fathers of children with Down syndrome.

Recently, Hayes and Watson (2013) conducted a systematic review to examine parenting stress as reported by families of children with ASD in comparison to families of typically developing children and those diagnosed with other disabilities (e.g., Down syndrome, cerebral palsy, intellectual disability, fetal alcohol spectrum disorder). In one meta-analysis of 10 studies they found that parents of children with ASD experienced significantly higher levels of stress compared to parents of typically developing children (mean effect size = 1.58). In another meta-analysis of 16 studies, they found that families of children with ASD reported significantly more stress than families of children with other disabilities or disorders, with a mean effect size of 0.64. The authors noted the variability of results among these 16 studies; despite the fact that five of the studies found no difference in stress between groups, the overall effect size still suggested that parents of children with ASD experience higher levels of parenting stress. The authors concluded that the question in comparative studies is not whether parents of children with ASD experience more parenting stress, but “why are [these] families under more stress and what are the specific moderators of stress that facilitate family resilience?” (p. 639). In discussing limitations of the research and directions for future research, the authors noted that “one challenge is the [limited] number of father participants included in research...Due to limited information, this meta-analysis could not make any conclusions about the overall effect of

parenting stress on fathers in comparison to mothers” (p. 638).

**Mothers compared to fathers of children with ASD.** The second category in the stress literature compares mothers and fathers of children with ASD to one another. In this body of research, the results are mixed. Some studies have demonstrated no significant differences between maternal and paternal stress levels (Bebko, Konstantareas, & Springer, 1987; Epstein et al., 2008; Hall & Graff, 2011; Hartley, Barker, Seltzer, Greenberg, & Floyd, 2011; Hastings, 2003; Hastings, Kovshoff, Ward et al., 2005; Kayfitz et al., 2010; Ornstein Davis & Carter, 2008; Wolf, Noh, Fisman, & Speechley, 1989). One example of this outcome was a study conducted by Orstein Davis and Carter (2008) on parents of toddlers with ASD in the United States. Fifty-four mothers and 54 fathers completed a number of self-report and child report questionnaires, including the Parenting Stress Index-Short Form (PSI-SF; Abidin, 1995), which assesses parenting stress in parents of children ages 3 months to 10 years. The PSI-SF is comprised of three subscales: Parental Distress, Parent–Child Dysfunctional Interaction, and Difficult Child Characteristics. Thirty-nine percent of the mothers reported parenting stress scores that were in the “clinically significant” range, as indexed by the total score on the PSI-SF. Analysis of the domain scores suggested that the most stressful area of parenting for mothers related to the parent–child relationship; 50% of mothers scored in the “clinically significant” range on the Parent–Child Dysfunctional Interaction domain. In contrast, 24% of mothers had clinically significant scores on the Difficult Child domain and 26% had clinically elevated scores in the Parent Distress domain. A similar pattern was evident for fathers, with 28% achieving clinically elevated total PSI-SF scores. As with mothers, the highest subscale scores were in the area of parent–child relationships, with 39% of fathers achieving clinically significant scores in the Parent–Child Dysfunctional Interaction domain. Again, like mothers, 11% and 13% of

fathers achieved clinically elevated scores on the Difficult Child and the Parent Distress domains, respectively. Although there were no statistically significant differences between mothers and fathers in the percentage of parents above the PSI-SF clinical cut-points, there was a trend suggesting greater stress for mothers.

Although many studies have found no differences when comparing the stress levels of mothers and fathers of children with ASD, others have found that mothers typically report higher levels of stress than fathers (Dabrowska & Pisula, 2010; Herring et al., 2006; Little, 2002; Moes, Koegel, Schreibman, & Loos, 1992; Tehee, Honan, & Hevey, 2009). A representative example of this general outcome is a study conducted by Tehee et al., (2009), who examined factors contributing to stress in 23 mothers and 19 fathers of children with ASD in Ireland. Parents completed two stress measures. Mothers reported significantly higher levels of general perceived stress than fathers, and significantly higher levels of stress and coping related to caregiving than fathers. Mothers also reported significantly higher levels of involvement than fathers in childcare, which the authors speculated might be related to their elevated stress levels. The differential effect of childcare involvement on mothers and fathers was examined in correlational analyses split according to gender, where general perceived stress and involvement resulted in a significant positive relationship for mothers, with no corresponding relationship for fathers. Similarly, Moes et al. (1992) found that mothers of children with ASD reported significantly higher levels of stress compared to fathers, with the observed pattern suggesting an association with the differing responsibilities and roles associated with child rearing. Gray (2003) provided additional support for this association in a qualitative study on parents of children with ASD. Mothers and fathers in this study described adhering to traditional gender roles, with fathers mostly working out of the home, being the primary “breadwinners,” and having more limited

involvement in childcare, and mothers assuming disproportionate responsibility for domestic labour, including caring for the child with ASD. Thus, mothers were more likely to experience the negative impact of their child's disability on their daily lives, including emotional distress over the child's disability, career disruption, and dealing with medical and educational professionals regarding the child's problems. Sadly, in a study of 184 mothers of children with ASD, Zaidman-Zait et al. (2014) found that parenting stress scores remained quite stable across the 3 to 4-year period after children's diagnoses.

Finally, in contrast to research which has found that mothers experience higher levels of stress than fathers, one recent study by Rivard, Terroux, Parent-Boursier, and Mercier (2014) found that fathers reported significantly higher stress levels than mothers. A total of 118 fathers and 118 mothers whose children were recently diagnosed with ASD and had just started early intensive behavioural intervention completed a variety of measures, including the Parenting Stress Index – Short Form (PSI-SF; Abidin, 1995). Fathers reported significantly higher stress levels than mothers on the Total Stress scale, and all three subscales of the PSI-SF. Sixty percent of fathers in the sample had total stress scores in the “clinical” range, compared to 54% of mothers. Higher paternal stress levels were associated with having a child who was female, was older, had less severe autistic symptoms, had higher IQ, and had more adaptive behaviours. Similar associations were found among mothers. Similarly, paternal stress was predicted by less severe autistic symptoms and having a female child. The results also found that maternal and paternal stress levels were significantly and positively correlated.

To summarize, a number of studies have examined stress in parents of children with ASD, comparing mothers and fathers of children with ASD to one another as well as to parents of other non-ASD children. Most of the variables that have been found to be positively correlated

with, and/or predictive of stress in parents of children with ASD can be categorized into child- and partner-specific variables. Child-specific factors include the child's age; challenging behaviours (e.g., non-compliance, self-injury); social deficits; communication deficits; activity level; dependency; cognitive impairment; and autism severity (Baker-Ericzen et al., 2005; Bebko et al., 1987; Brobst et al., 2009; Bromley, Hare, Davison, & Emerson, 2004; Ekas & Whitman, 2010; Hastings, Kovshoff, Ward et al., 2005; Koegel et al., 1992; Konstantareas & Papageorgiou, 2006; Lecavalier, Leone, & Wiltz, 2006; Ornstein Davis & Carter, 2008; Rezendes & Scarpa, 2011; Rivard et al., 2014; Tomanik et al., 2004; Zaidman-Zait et al., 2014). However, in contrast to some of these findings, Rivard et al. (2004) found that child factors that were positively correlated with parent stress included higher IQ, more adaptive behaviours, and less severe autistic symptoms. Partner-specific variables that have been positively correlated with, and/or predictive of stress in parents of children with ASD include lower relationship satisfaction, lower spousal support, and higher levels of partner depression, stress, and anxiety (Brobst et al., 2009; Hastings, Kovshoff, Ward et al., 2005; Rivard et al., 2014). Other, "miscellaneous" variables that have been found to be correlated with or predictive of higher stress include low levels of social and parenting support, use of active avoidance coping, use of emotion-focused coping, and being a single parent (Bromley et al., 2004; Cappe, Wolff, Bobet, & Adrien, 2011; Hartley et al., 2011; Hastings, Kovshoff, Brown, et al., 2005).

### **Depression**

A number of measures have been used to operationalize parental depression in the autism literature; some of the most commonly-used instruments are the Beck Depression Inventory (BDI; Beck, Ward, Mendelson, Mock, & Erbaugh, 1961) and the Center for Epidemiologic Studies Depression Scale (CES-D; Radloff, 1977). In empirically examining the concept of

depression in parents of children with ASD, the body of literature can again be divided into two broad categories: 1) research comparing parents of children with ASD to parents of other children, and 2) research comparing mothers and fathers of children with ASD.

**Parents of children with ASD compared to other parents.** It should be noted that, in the research on depression, most studies are based primarily on maternal reports, with fathers rarely included as informants. Thus, the term “parents” in this section refers almost exclusively to mothers only. The research in this area has demonstrated that, for the most part, parents of children with ASD experience higher levels of depression than parents of typically developing children (Benson & Karlof, 2009; Ekas & Whitman, 2010; Hodge, Hoffman, & Sweeney, 2011; Ingersoll & Hambrick, 2011; Lee, 2009; Olsson & Hwang, 2001; Quintero & McIntyre, 2010; Weiss, 2002; Wolf et al., 1989). Two exceptions to this finding are a study by Bristol, Gallagher, and Schopler (1988), which found no differences between parents of autistic and non-autistic groups; and a study by Gau et al. (2012), which analyzed gender separately and found that mothers, but not fathers, of children with ASD reported significantly higher levels of depression than the control groups. However, most studies have found that parents of children with ASD score higher on measures of depression. For example, Benson and Karlof (2009) studied a group of 90 parents (84 mothers and 6 fathers) as part of a larger longitudinal study of families of children with ASD receiving public school services in Massachusetts. Parents’ level of depressed mood was measured using a short form of the CES-D. Specifically, respondents were asked, “On how many days during the past week did you (a) feel you couldn’t get going? (b) feel sad? (c) have trouble going to sleep or staying asleep? (d) feel everything was an effort? (e) feel lonely? (f) feel you couldn’t shake the blues? and (g) have trouble keeping your mind on what you were doing?” Responses on the 7 items were added for each respondent to produce an index

score ranging from 0 to 49. Parents of children with ASD reported significantly higher levels of depression and were significantly more “at risk” for elevated levels of depressed mood than a large probability sample of U.S. adults. Similarly, in a study comparing 48 parents (25 mothers and 23 fathers) of children with high functioning ASD to 26 parents (13 mothers and 13 fathers) of children without disabilities, parents of children with ASD scored significantly higher on the CES-D (Lee, 2009). Furthermore, a significantly higher proportion of mothers and fathers in the ASD group were classified as being clinically depressed (28% and 17%, respectively) compared to mothers and fathers in the control group (both 7.7%). Similarly, a study by Ingersoll and Hambrick (2011) of 149 parents of children with ASD (136 mothers, 13 fathers) found that more than half (55.7%) of the parents scored in the “clinically significant” range of depression on the CES-D.

From this research, it is clear that parents of children with ASD characteristically report higher levels of depression than parents of typically developing children. However, for studies comparing parents of children with ASD to parents of children with other disabilities, the findings are mixed. Some research has shown that parents of children with ASD report higher levels of depression than parents of children with intellectual disability (Olsson & Hwang, 2001; Weiss, 2002). For example, a recent study by Hartley, Seltzer, Head, and Abbeduto (2012) studied mothers and fathers of adolescents and young adults with Down syndrome ( $n = 59$ ), Fragile X syndrome ( $n = 46$ ), and ASD ( $n = 135$ ), and found that ASD parents of both genders reported a significantly higher level of depressive symptoms than parents of the other two groups. However, this is not always the case. For example, Wolf et al. (1989) found that neither mothers nor fathers of children with ASD reported significantly higher levels of depression than mothers or fathers of children with Down syndrome. In another comparative study, Abbeduto et

al. (2004) found that mothers of adolescents and young adults with ASD ( $n = 174$ ) reported significantly higher levels of depressive symptoms compared to mothers of individuals with Down syndrome ( $n = 39$ ), but not compared to mothers of those with Fragile X syndrome ( $n = 22$ ). Thus, research is mixed when comparing parents of children with ASD to parents of other children with disabilities.

**Mothers compared to fathers of children with ASD.** When comparing mothers and fathers of children with ASD on measures of depression, mothers consistently report significantly higher levels of depression (Gray & Holden, 1992; Gau et al., 2012; Hastings, Kovshoff, Ward, et al., 2005; Lee, 2009; Olsson and Hwang, 2001; Ornstein Davis & Carter, 2008; Sharpley, Bitsika, & Efremedis, 1997). A representative example from this research domain is a study by Ornstein Davis and Carter (2008), who examined 54 mothers and 54 fathers of children with ASD whose average age was 26.9 months. The authors found that significantly more mothers (33%) than fathers (17%) reported depression symptom levels in the “clinical” range of the CES-D. Also, there was a trend toward higher depressive symptoms among mothers when compared to fathers. Similarly, in a study of 48 parents of children with ASD, Lee (2009) found similar rates of “clinical” depression for mothers (28%) and fathers (17%) on the same measure, the CES-D. A study by Little (2002) found that a significantly higher percentage of mothers of children with ASD (45%) reported taking medication for depression as compared to fathers (25%). Sadly, in a longitudinal study of 234 mothers of adolescents and young adults with ASD living in the United States, Barker et al. (2011) found that depressive symptoms remained stable over a 10-year period.

It is clear that the research comparing mothers to fathers of children with ASD consistently shows that mothers experience higher levels of depression, a finding which has been

replicated in many studies comparing mothers and fathers of typically developing children and children with other disabilities (Bristol et al., 1988; Olsson & Hwang, 2001; Wolf et al., 1989). Variables that have been found to be positively correlated with, and/or predictive of depression in parents of children with ASD include levels of the broad autism phenotype in the parent, the presence of other children with a disability in the family (including ASD), child behavior problems, child sleep disturbances, parents' feelings of helplessness, parental anxiety, maternal depressive symptoms, negative or low level of social support, religious-based coping, use of psychological denial, and use of emotion-focused and avoidant coping (Abbeduto et al., 2004; Benson, 2010; Ekas & Whitman, 2010; Gray & Holden, 1992; Hartley et al., 2012; Hastings, Kovshoff, Brown, et al., 2005; Ingersoll & Hambrick, 2011; Smith, Greenberg, & Seltzer, 2012; Weiss, 2002). Variables that have been found to be negatively correlated with depression in this group of parents include social support, size of the social network, family income, family adaptability, problem-focused coping, positive coping, parental self-efficacy, self esteem, and maternal age (Abbeduto et al., 2004; Baker, Seltzer, & Greenberg, 2011; Barker et al., 2011; Gray & Holden, 1992; Ingersoll & Hambrick, 2011; Hastings, Kovshoff, Brown, et al., 2005; Smith, Greenberg, & Seltzer, 2012; Rezendes & Scarpa, 2011; Weiss, 2002).

### **Positive Psychological Variables**

#### **Marital Satisfaction**

Overall, only a few studies have examined the impact of a child with ASD on the marital relationship; most research in this area has focused more broadly on couples of children with a range of disabilities. A variety of measures have been used to measure the relationship between couples, or their marital functioning, including the Dyadic Adjustment Scale (DAS; Spanier, 2001) and the Locke-Wallace Marital Adjustment Test (Locke & Wallace, 1959). Other research

has focused on divorce/separation rates.

A recent example of this research is a study by Risdal and Singer (2004), who conducted a meta-analysis on comparable levels of divorce and marital satisfaction/discord in parents of children with and without developmental disabilities. A total of 13 studies (both published studies and unpublished dissertations) between 1975-2003 met the inclusion criteria; two of the studies examined couples of children with ASD and only one was a peer-reviewed, published article (Bristol et al., 1988). Overall, parents of children with disabilities reported slightly less marital adjustment than parents of typically developing children; the overall weighted effect size was  $d = .21$ , considered a small effect size, meaning that having a child with a disability was not correlated with severe marital strain. In examining the divorce rates between the two groups, Risdal and Singer found an average increase of 5.97% (range 2.9% – 6.7%) in couples of children with disabilities.

**Parents of children with ASD compared to other parents.** Some research has found that couples of children with ASD report significantly less marital satisfaction/poorer marital adjustment than couples of typically developing children (Bristol et al., 1988; Brobst et al., 2009; Higgins, Bailey, & Pearce, 2005; Lee, 2009). For example, Higgins et al. (2005) examined family functioning and coping in a study of 52 primary caregivers (97% mothers) of children with ASD. Respondents completed a measure of marital quality and marital happiness. Overall, parents of children with ASD reported lower marital happiness compared to normative data. A study by Lee (2009) comparing 48 parents (24 couples) of children with high functioning ASD to 26 parents (13 couples) of typically developing children found that parents of children with ASD scored significantly lower than the control group on the General Relational Satisfaction subscale and the total score of the DAS. Similarly, Rodrigue, Morgan, and Geffken (1990) found

that mothers of children with ASD reported less marital satisfaction than mothers of either typically developing children or children with Down syndrome. However, in a separate study on fathers, the same authors (Rodrigue et al., 1992) found no differences on marital satisfaction between fathers of children with ASD compared to fathers of children in the other two groups. One positive predictor of relationship satisfaction for couples with a child with ASD appears to be respect for partner (Brobst et al., 2009).

There have also been two published studies examining the divorce rates of parents of children with ASD. Although this research does not measure marital satisfaction per se, it can be argued that divorce is the most extreme outcome of marital dissatisfaction. As part of an ongoing longitudinal study in the U.S., Hartley et al. (2010) examined the occurrence and timing of divorce in 391 parents of adolescents or adults with ASD, compared with a closely matched, nationally representative sample of 391 parents of adolescents and adults without a disability. The authors found that the prevalence of divorce was significantly higher among the parents of children with ASD ( $n = 92$ , 23.5%) than those in the comparison group ( $n = 54$ , 13.8%). Interestingly, there was no significant difference in the prevalence of divorce between parents of children with ASD and the comparison group during the early childhood years (i.e., prior to age 8). However, whereas the risk of divorce began to decrease in late childhood for parents of children without a disability and was extremely low by the time the son or daughter was a young adult, the risk of divorce for parents of children with ASD remained steep throughout the child's adolescence and early adulthood and did not decrease until the child reached age 30. Predictors of divorce in parents of children with ASD included maternal age (with higher risk of divorce in younger mothers) and the birth order of the child with ASD (with higher risk associated with later birth order) (Hartley et al., 2010).

Freedman, Kalb, Zablotzky, and Stuart (2012) also examined relationship status among parents of children with ASD, based on the 2007 National Survey of Children's Health, a population-based, cross-sectional survey in the United States. A total of 77,911 interviews were completed with parents of children aged 3 to 17 years, of which 913 reported an ASD diagnosis. Contrary to Hartley et al. (2010), Freedman et al. found no evidence to suggest that children with ASD (including those with more severe symptoms) were at an increased risk for living in a single parent household. Freedman et al. noted that this difference might be due to the sampling difference for parents of children with ASD in the two studies, because their data was based on a nationally representative sample. Additionally, the Hartley et al. (2010) sample examined the relationship status of parents of children with ASD into adulthood, which may have impacted differences in the rates of divorce, since parents of older children often have had less access to the types of resources and supports that have become commonly available to families of children with ASD over the past 10 to 15 years. Furthermore, they noted that the older cohort in the Hartley et al. sample reflected many parents who would have been married in the 1970s and 1980s, a period in which there was a greater divorce rate than couples who were married more recently.

**Mothers compared to fathers of children with ASD.** Hartley et al. (2011) conducted a study on marital satisfaction in 91 married couples of adolescents and adults with ASD. The results indicated that mothers and fathers reported similar levels of marital satisfaction. Not surprisingly, parents with above-average marital satisfaction were less burdened by their adolescent or adult son or daughter. Interestingly, marital satisfaction was related to feelings of emotional closeness in the father-child relationship but not the mother-child relationship. In contrast, in a study of 49 mothers of children with ASD, Lickenbrock, Ekas, and Whitman

(2011) found that mothers who reported higher levels of marital adjustment reported higher positive perceptions of their children.

### **Optimism**

Very limited research has been done on optimism in parents of children with ASD, and, as in other areas, the research that does exist has been primarily conducted with mothers. Some of the most common instruments used to measure optimism include the Life Orientation Test (LOT; Scheier & Carver, 1985) and the State Hope Scale (Snyder et al., 1996).

**Parents of children with ASD compared to other parents.** No research has compared parents of children with ASD to parents of typically developing children, but a few studies have compared parents of children with ASD to parents of children with other disabilities. A study by Greenberg, Seltzer, Krauss, Chou, and Hong (2004) examined the effects of the quality of the relationship between maternal caregivers and their adult children with disabilities on maternal well-being and whether this effect was mediated by dispositional optimism. Mothers caring for an adult child with Down syndrome ( $n = 126$ ), schizophrenia ( $n = 292$ ), or ASD ( $n = 102$ ) completed measures of psychological well-being, psychological distress, physical health, quality of the mother-child relationship, and dispositional optimism. There were no differences among the three groups with respect to levels of optimism, depression, psychological well-being, and physical health. Mothers of adults with schizophrenia and ASD had better psychological well-being when the mother/adult child relationship was positive, but this effect was mediated totally or partially by optimism. For all three groups, optimism was related to better mental and physical health.

Ogston, Mackintosh, and Myers (2011) investigated the relationship between hope and worry in mothers of children with ASD and Down syndrome. A total of 259 mothers of children

(77.6% males; range: 1–21 years; mean age 8.7 years) with ASD (n = 199) or Down syndrome (n = 60) completed five self-report measures on hope, worry, and autism severity. Overall, mothers with higher hope reported lower worry. Mothers who reported lower worry had more education and also had either older children or children who were higher functioning, regardless of diagnosis. Mothers of children with ASD reported higher levels of future-related worry than mothers of children with Down syndrome. In contrast to Greenberg et al. (2004), who found no differences in optimism levels among mother of children with ASD and other disabilities, Ogston et al. found that mothers of children with ASD reported lower levels of hope, compared to mothers of children with Down syndrome.

Parental optimism appears to have effects that extend beyond the psychological well-being of the parent him- or herself. For example, although not specific to ASD, Durand (2001) conducted important research on how parental optimism/pessimism impacts the development of later challenging behaviors in young children with cognitive and/or developmental disabilities. His longitudinal study measured a number of parental variables that were hypothesized to predict the development of severe behavior problems. The best predictor was a measure of parental optimism; parents who had less confidence in their ability to influence their children's behavior by the time the children were 3 years old were more likely to have children with difficult behaviors later in life.

**Mothers compared to fathers of children with ASD.** There are no published studies that compare the optimism levels of mothers and fathers of children with ASD. However, Lloyd and Hastings (2009) conducted research on hope and its relationship to well-being in 138 mothers and 58 fathers (56 couples from the same families) of school-aged children with intellectual disability, 56 of whom were also diagnosed with ASD. Participants completed a

number of self-report measures on child behaviour problems; parental well-being (positive affect, stress, anxiety and depression); and dispositional hope. Hope was measured as a goal-driven behaviour comprising two components: agency (the perception that one can reach his/her goals) and pathways (the perception that one can find alternative routes to reach these goals should the need arise). The results indicated that, for mothers, lower levels of hope (both agency and pathways) and more child behaviour problems predicted maternal depression. Positive affect was predicted by less problematic child behaviour and by higher levels of hope agency. For fathers, anxiety and depression were predicted by low hope agency and positive affect was predicted by high hope agency; however, hope pathways was not a significant predictor of paternal well-being. Mothers reporting high levels of both hope dimensions also reported the lowest levels of depressive symptoms.

A study by Ekas et al. (2010) did not compare mothers and fathers, but is included here because it examined the relationship between multiple sources of social support, optimism, and well-being among mothers of children with ASD. Three types of informal social supports (spouse, friends, and family) were examined as potential mediators of optimism and maternal well-being. A total of 119 mothers completed measures of social support, parenting stress, positive and negative affect, depression, life satisfaction, and psychological well-being. The results revealed that higher levels of maternal optimism were positively correlated with positive affect, life satisfaction, and psychological well-being. In addition, a significant positive association was found between optimism and each of the informal social support variables. Thus, although the research in this area is limited, optimism is clearly positively correlated with parental mental health and is also predictive of fewer child behaviour problems. This is

consistent with the research on optimism in other populations (Carver, Scheier, & Segerstrom, 2010).

### **Coping Strategies**

Given that parents of children with ASD consistently report higher stress profiles than other parents, ASD parents' use of a wide range of coping strategies – which help mitigate the experience of stress – is an important area of research. The coping strategies that have been identified in the research literature can be divided into two broad categories – self-directed and other-directed coping (see Table 1).

**Table 1: Self- and Other-Directed Types of Coping**

<b>Self-Directed Coping</b>		<b>Other-Directed Coping</b>
<b>Constructive Strategies</b>	<b>Non-Constructive Strategies</b>	
Active coping/problem focused – attempting to remove, circumvent, or reduce stressor	Worrying – constant or frequent thinking about negative or difficult aspects of a stressful situation	Seeking support/advice/ information from family and friends
Planning - thinking about how to cope with a stressor; coming up with action strategies	Denial – denying that a stressor exists or is real	Seeking support/advice/ information from outside resources
Suppression of competing activities – focusing on the stressful situation; trying to avoid becoming distracted by other events	Mental disengagement/distraction – attempting to take one’s mind off of the problem (e.g., daydreaming, sleeping, watching TV, waiting)	Seeking religious/spiritual support
Positive reinterpretation and growth - reframing stressful event in a positive light	Behavioral disengagement – reducing efforts to deal with a stressor, surrendering control	
Acceptance – learning to live with or accepting that reality of what has happened	Withdrawal – avoiding certain people or preventing others from knowing about the stressful situation	
Emotional regulation – controlling or expressing emotional distress in a constructive, appropriate way	Substance use – using alcohol or drugs to feel better	
Maintaining family integration, cooperation, and optimism – strengthening family life and relationships	Blaming self or others – actions involving frustration, anger, blaming, or passive aggression	
Maintaining self esteem/psychological stability – engaging in self-esteem building activities; managing tensions and strains		
Compromising – negotiating between priorities/needs of individual and limits of the stressful situation		
Humor – joking about the situation		

Self-directed coping strategies include cognitive and behavioural activities which an individual uses to manage a stressor. Self-directed coping strategies can be further divided into (a) constructive strategies that generally involve addressing a stressor in a productive/effective way (e.g., reframing a stressful event in a positive light); and (b) non-constructive strategies that generally involve avoiding a stressor (e.g., denying that a stressor exists).

Other-directed coping strategies include actions whereby the person seeks guidance, information, and/or support from others, such as family, friends, professionals, and community resources. Also included in this category is spiritual support, or using religion/faith to cope.

**Parents of children with ASD compared to other parents.** A few studies have examined the degree to which other-directed coping strategies – specifically, social supports – are available to parents of children with ASD compared to other parents. One study found no differences between mothers of children with ASD, Down syndrome, and typically developing children on the quantity of, and satisfaction with, social support (Rodrigue et al., 1990). However, other studies have found that parents of children with ASD believe that they have access to significantly less social support than parents of either typically developing children (Brobst et al., 2009; Weiss, 2002), or children with intellectual/learning disabilities (Heiman & Berger, 2008; Weiss, 2002). For example, in the study by Weiss, 40 mothers of children with ASD, 40 mothers of children with Down syndrome, and 40 mothers of typically developing children completed a packet of self-report questionnaires, including measures of both informal and formal support. Results indicated that mothers of children with ASD perceived emotional support and esteem-boosting friendship as considerably less available than mothers of the other children. Not surprisingly, mothers who reported high self

esteem and high degree of social support reported lower levels of depression and higher levels of self-efficacy in parenting. Also, perceived social support from a spouse was predictive of fewer somatic complaints and feelings of greater accomplishment in parenting. Similarly, in the only published study examining fathers, Rodrigue et al. (1992) found that fathers of daughters with ASD reported significantly less social support than fathers of children with Down syndrome and fathers of typically developing children, although their satisfaction with the social support they received was comparable to the other two groups. In general, social support has been positively correlated with optimism, positive affect, and life satisfaction (Ekas et al., 2010), and negatively correlated with the intensity of child behaviour problems, parenting stress, depression, and negative affect (Brobst et al., 2009; Ekas et al., 2010).

In addition to the availability of, and satisfaction with social support, a number of studies have measured the extent to which self-directed and other-directed coping strategies are employed by parents of children with ASD and other parents. Table 2 summarizes the results of these studies.

**Table 2: Coping Strategies of Parents of Children with ASD Compared to Other Parents**

Study	Coping measure	Control group(s)	Self-directed constructive	Self-directed non-constructive	Other-directed
Abbeduto et al., 2004	MCI	DS, FX	NSD	NSD	n/a
Brobst et al., 2009	SSQ6	TD	n/a	n/a	Lower on social support from friends and family; NSD on spousal support
Hartley et al., 2012 (fathers only)	MCI	DS FX	NSD	NSD	n/a
Lee, 2009	F-COPES CHIP	TD	Lower on reframing Lower on maintaining self esteem and psychological stability	NSD	Lower on social support from friends/family; Higher on using community resources/professionals
Luther, Canham, & Cureton, 2005	F-COPES	Norm group from F-COPES	Higher on reframing**		No group differences on social support from friends/family**; Lower on spiritual support**; Higher on using community resources/professionals**
Montes & Halterman, 2007	one item asking how well mothers cope	U.S. national health survey	NSD	NSD	n/a
Pisula & Kossakowska, 2010	WCQ	TD	NSD	Higher on escape avoidance	NSD
Rodrigue et al., 1990	WCS (modified)	TD DS	NSD	Higher on mental disengagement and self blame than TD	Higher on information seeking than TD; NSD on quantity and satisfaction with social support

<b>Study</b>	<b>Coping measure</b>	<b>Control group(s)</b>	<b>Self-directed constructive</b>	<b>Self-directed non-constructive</b>	<b>Other-directed</b>
Rodrigue et al., 1992 (fathers only)	WCS (modified)	TD DS	NSD	Higher on wish fulfillment than TD and DS	Higher on information seeking than TD
Sivberg, 2002	WCQ	TD	Lower on playful problem solving and positive reappraisal than TD	Higher on escape avoidance and distancing than TD	Lower on social support than TD
Twoy, Connolly, & Novak, 2007	F-COPES	Norm group from F-COPES	No group differences**	Higher on mental and behavioural disengagement**	Lower on social support from friends/family**; Lower on spiritual support**; Higher on using community resources/professionals**
Weiss, 2002	ISEL	TD MR	n/a	n/a	Lower on esteem-boosting friendship and emotional support than TD and MR
Heiman & Berger, 2008	MSPSS	TD LD	n/a	n/a	Lower on friend and “other” support than TD and LD

*Note.* MCI = Multidimensional Coping Inventory; DS = Down syndrome; NSD = No significant differences; FX = Fragile X Syndrome; SSQ6 = Social Support Questionnaire, six-item version; WCS = Ways of Coping Scale; TD = typically developing; F-COPES = Family Crisis Oriented Personal Evaluation Scales; \*\* = no statistical analysis of data; WCQ = Ways of Coping Questionnaire; CHIP = Coping Health Inventory for Parents; ISEL = Interpersonal Support Evaluation List; MR = mental retardation; MSPSS = Multidimensional Scale for Social Support; LD = learning disabilities

Seven of eight studies (including one study of fathers only) found no differences between the groups on self-directed constructive coping (Abbeduto et al., 2004; Hartley et al., 2012; Montes & Halterman, 2007; Rodrigue et al., 1992; Rodrigue et al., 1990; Tway et al., 2007; Pisula & Kossakowska, 2010), and one study found that parents of children with ASD used fewer constructive strategies (Lee, 2009). Four of the eight studies (including one study of fathers only) found no group differences on self-directed non-constructive strategies (Abbeduto et al., 2004; Hartley et al., 2012; Lee, 2009; Montes & Halterman, 2007), and the remaining four studies found that parents of children with ASD engaged in higher levels of non-constructive coping as compared to other parents (Pisula & Kossakowska, 2010; Rodrigue et al., 1992; Rodrigue et al., 1990; Tway et al., 2007). Finally, eight studies examined a variety of other-directed coping strategies, including social support from friends and family, spousal support, spiritual support, and using community resources/professionals. Of these, two studies found no group differences (Pisula & Kossakowska, 2010; Rodrigue et al., 1990), and the other six studies reported a generally consistent pattern: Parents of children with ASD scored higher on seeking information/professional support and lower on social support from friends and family (Heiman & Berger, 2008; Lee, 2009; Rodrigue et al., 1992; Rodrigue et al., 1990; Tway et al., 2007; Weiss, 2002).

**Mothers compared to fathers of children with ASD.** Two recent studies examined mothers' and fathers' perceptions of social supports as an other-directed coping strategy. Hall and Graff (2011) compared the self-reports of 75 mothers and fathers of children with ASD using a measure of family support. Participants were asked to rank the support they received from five different social networks on a Likert-scale that ranged from 0 (not available) to 5 (extremely helpful). There were no differences between mothers and fathers in their ratings of

the helpfulness of social supports, which were rank ordered as follows from most to least helpful: (a) spouse/partner; (b) formal kinship (relatives/family); (c) professional services (e.g., physicians, early intervention programs); (d) informal kinship (e.g., friends, other parents, church); and (e) social organizations (e.g., school, daycare, coworkers). More recently, Hall (2012) conducted a cross-sectional study of 38 parents (including 10 fathers) of children with ASD. Both mothers and fathers identified professionals and the services they provide, autism specialists, other parents, family members, child care, respite services, personal finances, and insurance coverage as important supports and resources for themselves, their children with ASD, and their families.

In addition, three studies have compared both self- and other-directed coping strategies used by mothers and fathers of children with ASD (see Table 3).

**Table 3: Coping Strategies of Fathers Compared to Mothers of Children with ASD**

Study	Coping measure		Self-directed non-constructive	Other-directed
	Self-directed constructive			
Hastings et al., 2005	BC	Fathers lower on active coping	Fathers lower on mental and behavioural disengagement	Fathers lower on social support from friends/family
Lee, 2009	F-COPES CHIP	Fathers lower on maintaining self esteem and psychological stability	NSD	Fathers lower on social support from friends/family; using community resources/professionals; spiritual support
Little, 2002	CHIP	NSD	n/a	Fathers lower on using community resources/professionals

*Note.* F-COPES = Family Crisis Oriented Personal Evaluation Scales; CHIP = Coping Health Inventory for Parents; NSD = No significant differences; BC = Brief COPE

In the domain of self-directed coping, the results are mixed for the three studies which exist: One study reported no differences between mothers and fathers (Little, 2002), and the other two reported that fathers scored lower than mothers on some types of constructive coping (Hastings, Kovshoff, Brown et al., 2005; Lee, 2009). Similarly, for the two studies that examined non-constructive coping, one reported no gender differences (Lee, 2009) and the other found that fathers engaged in lower levels of some types of non-constructive coping than mothers (Hastings, Kovshoff, Brown et al., 2005). In the domain of other-directed coping, all three studies reported similar results: Generally, fathers scored lower than mothers on social support from family/friends, using community resources/ professionals, and spiritual support.

In addition to quantitative studies that have examined coping strategies with various psychometric instruments, a number of studies have also utilized qualitative methodology (e.g., semi-structured interviews, open-ended written questions) to examine coping in parents of children with ASD. In general, the findings are consistent with those of quantitative research. Examples of self-directed constructive strategies described by parents include maintaining a positive outlook, accepting reality, being hopeful, planning, strengthening the relationship with the child with ASD and the family, expressing/experiencing emotions, using humour, and engaging in work and/or recreation (Bilgin & Kucuk, 2010; Gray, 1994, 2003, 2006; Greeff & van der Walt, 2010; Hall & Graff, 2011; Koydemir-Ozden & Tosun, 2010; Meirsschaut, Roeyers, & Warreyn, 2010). Non-constructive coping techniques identified by parents include social withdrawal, using alcohol and/or drugs, and suppression of emotion (Bilgin & Kucuk, 2010; Hall & Graff, 2011; Gray, 1994, 2003). In the category of other-directed coping, parents reported seeking out professional help/advice; seeking out support from family, friends, professionals, and community members; and relying on faith/religion (Bilgin & Kucuk, 2010;

Gray, 1994, 2003, 2006; Greeff & van der Walt, 2010; Koydemir-Ozden & Tosun, 2010).

One qualitative study compared the experiences of mothers ( $n=32$ ) and fathers ( $n=21$ ) coping with having a child with ASD (Gray, 2003) and thus provides some unique and interesting comparative information about both genders. When asked to describe “practical” coping strategies for parenting a child with ASD, the most common reply among both mothers and fathers was anticipating the difficulties that were likely to arise and planning an appropriate response to deal with them if they happened, followed (conversely) by “taking things one day at a time and dealing with problems as they happened” (p. 638). Parents were also asked to describe how they coped with their emotional distress of raising a child with ASD. The most common responses concerned either the control or expression of emotions. Fathers were much more likely to report that they tried to suppress their feelings, whereas mothers more often described venting their emotions. Mothers were also more likely to report that they relied on talking to friends and family as a way of coping.

### **Summary of Research on Experiences of Parents of Children with ASD**

To summarize, research has examined a number of psychological variables – namely, stress, depression, marital functioning, optimism, and coping strategies – in parents of children with ASD, comparing mothers and fathers to one another as well as to parents of other children (e.g., typically developing, children with Down syndrome). The most commonly studied psychological variable has been stress; research has consistently demonstrated that parents of children with ASD experience higher levels of stress than parents of typically developing children and children with other disabilities. This pattern exists when comparing parents as a homogenous group (i.e., mothers and fathers together), and also when comparing mothers to other mothers and fathers to other fathers. When comparing mothers and fathers of children with

ASD, the results are mixed: Some studies have demonstrated no significant differences in maternal and paternal stress levels, while others have found significant gender differences, with mothers generally reporting higher levels of stress than fathers, with the exception of one study (Rivard et al., 2014).

With respect to depression, parents of children with ASD typically report that they experience higher levels of depression than parents of typically developing children. However, research on depression is mixed when parents of children with ASD are compared to parents of other children with disabilities. When mothers and fathers of children with ASD are compared on measures of depression, mothers consistently report significantly higher levels of depression.

Regarding marital functioning, few studies have examined the impact that a child with ASD has on a couple's relationship. Most of the research has focused more broadly on couples of children with various disabilities, with parents of these children reporting slightly less marital adjustment than parents of children without disability. One study reported that the prevalence of divorce was significantly higher among the parents of children with ASD (Hartley et al., 2010), but this finding was contradicted by another study which found no evidence to suggest that children with ASD are at an increased risk for living in a divorced household (Freedman et al., 2012). One study compared mothers to fathers of children with ASD, and found that both parents reported similar levels of marital satisfaction (Hartley et al., 2011).

In the handful of studies that have examined optimism in parents of children with ASD, optimism was positively correlated with better mental and physical health, and was also predictive of fewer child behaviour problems. Research by Greenberg et al. (2004) on mothers and their adult children with schizophrenia, Down syndrome, and ASD found no differences among the three groups with respect to levels of optimism, which was in contrast to research by

Ogston et al. (2011), which found that mothers of children with ASD had lower levels of optimism than mothers of children with Down syndrome. To date, no studies have compared the optimism levels of 1) parents of children with ASD and parents of typically developing children, and 2) mothers and fathers of children with ASD.

Finally, in the literature examining coping strategies of parents of children with ASD, research has identified self-directed (both constructive and non-constructive) and other-directed coping strategies. In general, parents of children with ASD score higher on seeking information/professional support and lower on social support from friends and family of children than parents of either typically developing children or children with other disabilities. The majority of studies found no differences between the groups on self-directed constructive coping. For self-directed non-constructive strategies, the findings are mixed: Some studies reported no group differences, and others found that parents of children with ASD engage in higher levels of non-constructive coping as compared to other parents. Finally, in comparing mothers to fathers of children with ASD, in the domain of self-directed constructive coping, the results are mixed: One study reported no differences between mothers and fathers (Little, 2002), and the other two reported that fathers scored lower than mothers on some types of constructive coping (Hastings et al., 2005 and Lee, 2009). Similarly, for the two studies that examined non-constructive coping, one reported no gender differences (Lee, 2009) and the other found that fathers engaged in lower levels of some types of non-constructive coping than mothers (Hastings et al., 2005). In the domain of other-directed coping, fathers generally score lower than mothers on social support from family/friends, using community resources, and spiritual support. Mothers and fathers score similarly when ranking the utility of various sources of social support, including spouses, relatives, professional services, friends, other parents, church, and social organizations (e.g.,

school, coworkers). The results of all of these studies are summarized in Table 4.

**Table 4: Summary of Study Results for Stress, Depression, Marital Satisfaction, Optimism and Coping in Parents of Children with ASD**

Variable	Parents of ASD vs. other disabilities	Parents of ASD vs. typically developing	Mothers vs. fathers of ASD
Stress	Higher	Higher	Mixed – 1) mothers higher, 2) fathers higher, and 3) no differences
Depression	Mixed	Higher	Mothers higher
Marital satisfaction	Mixed – 1) ASD lower and 2) no differences	Mixed – 1) ASD lower and 2) no differences	No differences
Optimism	Mixed – 1) ASD lower and 2) no differences	No research	No research
Coping	Other-directed: Higher on information/ professional support Lower on social support from friends and family Self-directed constructive: no differences Self-directed non-constructive: mixed – 1) ASD higher and 2) no differences	Other-directed: Higher on information/ professional support Lower on social support from friends and family Self-directed constructive: no differences Self-directed non-constructive: mixed – 1) ASD higher and 2) no differences	Other-directed: mothers higher on social support from friends and family, using community resources/professionals and spiritual support Self-directed constructive: mixed – 1) mothers higher and 2) no differences Self-directed non-constructive: mixed – 1) mothers higher and 2) no differences

Clearly, living with a child with ASD, regardless of the child's age, can be a stressful and challenging experience. Not only is it difficult to parent a child with a multitude of special needs who may also engage in challenging behaviours (e.g., self injurious behaviour), but many of these issues are also chronic and lifelong, requiring constant attention and effort. Furthermore, a child with ASD impacts parents on numerous levels, including financial, interpersonal, and psychological. Thus, it follows that a wide range of supports have been developed to assist parents in the significant task of raising a child with ASD. One type of support, educational groups/skills training (hereafter referred to as parent skills training), will be reviewed briefly in the section that follows. However, because parent training is not the focus of this study, research in this area will not be reviewed in detail.

### **Parent Skills Training**

In general, parent training is designed to teach parents the skills that are required to manage or interact with their child with ASD more successfully, and/or to increase the child's functional skills while decreasing challenging behaviours. Furthermore, "[i]ncreased parental skills allow for continual opportunities for children's learning in a range of situations. Training parents as 'co-therapists' allows consistent handling, and ensures that intervention is appropriate in enhancing children's earliest social relationships. The potential benefits of parent training are increased skills, renewed confidence and reduced stress for parents as well as for children" (McConachie & Diggle, 2007, p. 121).

Using Prizant and Wetherby's (1998) conceptualization of teaching approaches for individuals with ASD, parent skills training can be viewed along a continuum, with discrete trial, traditional behavioural (DT-TB) intervention models at one end, social pragmatic-developmental (SP-D) approaches at the other end, and contemporary behavioural approaches falling between

the two extremes. Parent training approaches on this continuum differ on a number of dimensions, such as degree of directiveness, adult- versus child-centred procedures, naturalness of the learning context, developmental focus, focus on generalization of skills to other environments, type of reinforcement, response to challenging behaviour, and type and intensity of data collection (Prizant & Wetherby, 1998). Parent skills training can be provided in formats such as lectures, videotaped modules, in vivo training, discussion groups, and pencil-and-paper tasks. Training may be conducted in groups, or with individuals or individual families. Parent skills training is usually evaluated in terms of both parent and child outcomes. Examples of parent outcomes include mental health (e.g., stress, depression); autism knowledge; parent-child interactions (e.g., ability to praise the child); parents' sense of competence or self-efficacy; and marital functioning. Examples of child outcomes include social skills, communication skills, challenging behaviours, autism severity, and adaptive skills.

McConachie and Diggle (2007) conducted a systematic review of parent-implemented early intervention studies for children with ASD. Studies that utilized single subject research designs (SSRDs) were excluded and, of the 12 studies that met the inclusion criteria, only 4 met the full Cochrane review criteria for randomized controlled trials (RCTs). The authors concluded that few of these group design studies showed evidence of an adequate research design; however, based on the available data, parent-implemented intervention appeared to produce a positive effect on children's social communication behaviour, parental performance, and parent-child interactions. Furthermore, parent training may also serve to reduce maternal depressive symptoms. In a more recent systematic review, Patterson, Smith, and Mirenda (2012) examined 11 single subject research design studies that met a set of comprehensive inclusion criteria. Only 2 of the 11 studies in their review involved fathers in addition to mothers. Overall, the studies

were of moderate quality and reported short-term increases in parent skills and child language and communication outcomes that were supported by an analysis of the percentage of non-overlapping data. However, limited generalization and follow-up data suggested that only one intervention demonstrated parents' accurate and ongoing intervention implementation beyond the training period.

Flippin and Crais (2011) conducted a systematic review of fathers' participation in parent-implemented interventions for children with ASD spanning 20 years. Of the 26 eligible studies, only 3 specifically reported the involvement of fathers in parent training, and one of these (Elder et al., 2005) involved more than one father. Yet, Flippin and Crais argued that, because fathers are unique contributors to children's play and communication development, their contributions should be both acknowledged and studied. Furthermore, in order for father-implemented interventions to be successful, they must be responsive to and incorporate the unique interaction and communication styles of fathers; this includes making training more father friendly, based on fathers' unique learning styles and needs.

In contrast to the majority of research on parent training (which has focused primarily on mothers), a few studies by Elder and colleagues (Bendixen et al., 2011; Elder, Valcante, Won, & Zylis, 2003; Elder et al., 2011) have evaluated the impact of Father-Directed In-Home Training (FDIT), in which fathers are trained to implement interventions designed to increase a child's social and communication skills and promote parent-child reciprocity and social interaction. Specifically, fathers in these studies were taught to follow the child's lead; imitate the child's vocalizations and movements; wait expectantly; and comment on the child's actions, responses, or verbalizations instead of asking questions. All of the training took place in the family homes, and fathers were coached to use the strategies with their child. In one study (Elder et al., 2011),

fathers also watched videotapes of themselves interacting with their child, in addition to practicing their skills in the moment. Overall, this research has demonstrated that (a) fathers can be successfully trained to implement skills that promote father–child social interactions, (b) the approach is both valued and well-accepted by fathers, and (c) children with ASD respond positively to the intervention.

In addition to parent training, parent supports may also be available in the form of group interventions focusing on parents' emotional and psychological concerns and issues. The research on therapy groups, with a specific emphasis on support groups, will be reviewed in the section that follows.

### **Therapy Groups**

Therapy groups date back to the early 1900s in the United States, when Dr. Joseph Pratt began running groups in Boston as a cost-effective treatment for patients with tuberculosis (Burlingame & Baldwin, 2011). These “Thought Control Clinics” consisted of 80 to 100 patients each and were conceived to help patients understand their illness, teach them skills to manage it, and help them cope with living with a chronic ailment. Over the next two decades, groups also began to be used to treat people with diabetes, hypertension, ulcers, and schizophrenia, and eventually led to the formal development of an approach termed “group analysis” by Dr. Trigant Burrow in the 1920s (Burlingame & Baldwin, 2011). From a strictly pragmatic perspective, one of the advantages of using groups is that they are more economic and efficient with respect to both time and money, allowing a practitioner to work with multiple clients simultaneously (Corey, 2000).

The theory and practice of therapy groups has expanded and evolved over time, and has included significant contributions from well-known and influential figures in psychology,

including Fritz Perls, Carl Rogers, Donald Meichenbaum, Kurt Lewin, and Irvin Yalom. In the past 30 years, research in this area has witnessed a shift from studies that examine the efficacy of therapy groups organized around a particular theoretical orientation (e.g., humanistic, experiential, psychodynamic), to examining the efficacy of specific types of therapy groups (e.g., cognitive behavioural therapy) on specific populations (e.g., adolescent females with eating disorders). For a historical review of therapy groups, see Burlingame and Baldwin (2011).

### **Types of Therapy Groups**

Therapy groups vary widely on a number of dimensions, including ideological/theoretical orientation; the group's objectives; the role of the leader; group composition; and the emphasis on various issues such as growth and development, problem prevention, remediation, and treatment (Corey, 2000; Yalom, 1995). Corey (2000) and Burlingame and Baldwin (2011) classified groups into five broad types: (1) psychotherapy, (2) counselling (3) psychoeducation, (4) task, and (5) self-help or support. Similar classification schemes have been described by the Association for Specialists in Group Work (ASGW; Wilson, Rapin, & Haley-Banez, 2000). However, there are no clear boundaries differentiating group types, and much overlap exists. The section below will describe the five broad types of groups, with an emphasis on support groups, which is the focus of this thesis.

**Psychotherapy groups.** Psychotherapy groups address the “treatment of emotional or psychological disorders or problems of adjustment through the medium of a group setting, the focal point being the interpersonal (social), intrapersonal (psychological), or behavioral change of the participating clients or group members” (Burlingame & Baldwin, 2011, p. 505).

Psychotherapy groups attempt to address group members' psychopathology, which may be in the form of severe emotional problems such as psychotic states, anxiety, depression, and/or socially

deviant behaviour; thus, these groups tend to be more long-term than other groups. Similarity of problem is not a requirement for membership in most psychotherapy groups; rather, heterogeneity among group members is often valued (Kurtz, 1997). Group psychotherapists are usually clinical or counseling psychologists, psychiatrists, and clinical social workers who help group members to achieve a “corrective emotional experience” and make new decisions about “the world, others, and themselves” (Corey, 2000, pp. 10-11).

**Counselling groups.** Counselling groups involve an “interpersonal process that stresses conscious thoughts, feelings, and behaviour” (Corey, 2000, p. 6), and have an educational, vocational, social, or personal focus. Counselling groups are often problem-oriented, whereby members might be facing temporary conflicts or issues, or trying to change self-defeating behaviours. The group provides the supportive and trusting atmosphere necessary to help individuals explore and share these concerns. Counselling groups are also growth-oriented, in that the emphasis is on discovering internal resources of strengths and on developing existing skills that will equip the individual to more successfully deal with similar issues in the future. The members are basically “well-functioning individuals who don’t require extensive personality reconstruction and whose concerns relate to the developmental tasks of the life span” (Corey, 2000, p. 6). The role of the group counsellor is to facilitate interaction amongst the members, help them listen to and learn from one another, assist them in setting their own personal goals, and encourage them to apply the newly learned skills outside of the group setting.

**Psychoeducational groups.** Psychoeducational groups focus on “developing members’ cognitive, affective, or behavior skills through a structured and sequenced set of procedures and exercises within and across group sessions” (Burlingame, Fuhrman, & Johnson, 2004, p. 651). These groups contain certain content themes that help structure the sessions. The purpose of

psychoeducational groups includes sharing information and knowledge, skill acquisition, connecting people through common experiences, teaching problem solving, and offering support (Corey, 2000; Roffman, 2004). Depending on the purpose of the group (e.g., education, skill acquisition, self-knowledge), the leader may act as a teacher, trainer, and/or counsellor (Roffman, 2004). Psychoeducational groups are time limited and short term, typically lasting from 4-16 sessions. Examples of psychoeducational groups include stress management groups and groups for children of divorced parents.

**Task groups.** Task groups are “designed to assist task forces, committees, planning groups, community organizations, discussion groups, study circles, learning groups, and other similar groups to correct or develop their functioning” (Corey, 2000, p. 13). The focus is applying group dynamics to assist either individual clients or an organization in decision making and problem solving tasks to meet specific community needs (e.g., developing a mission statement for an organization).

**Self-help and support groups.** Finally, self-help and support groups are groups whereby members “share their experiences, provide one another with emotional and social support, learn from one another, offer suggestions for new members, and provide some direction for people who do not see any hope for their future” (Corey, 2000, p. 14). Although self-help and support groups have common characteristics and are often treated as interchangeable—which results in confusion of the terms—there are a number of important distinctions with respect to group leadership; sponsoring organization, including the organization’s program and philosophy; the structure and organization of sessions; and the extent and type of the group’s change orientation (Kurtz, 1997, 2004; Schopler & Galinsky, 1993). Whereas the leadership of self-help groups is indigenous to the group’s members, support groups are often led by professional facilitators, or

sometimes co-led by professionals and members. The leader's role is not to be directive, but to facilitate discussion of the emotional issues and personal experiences of the group members (Hogan, Linden, & Najarian, 2002). Self-help groups are often chapters of large federations of affiliated groups (e.g., Alcoholics Anonymous; AA) that welcome anyone who shares the concerns of the group, whereas support groups are oftentimes sponsored by local organizations (e.g., hospitals) where membership is closely controlled by the leader or agency. Furthermore, in self-help groups, there is a shared ideology and standardized group structure/format amongst the chapters of a particular group (Schopler & Galinsky, 1993). Self-help groups often focus on personal or social change, whereas support groups focus more on receiving and providing emotional support and information. This is not to say that "support groups do not produce personal change, but rather that reform and change are not their primary purpose" (Kurtz, 1997, p. 4).

Thus, although there is overlap between self-help and support groups, there are important distinguishing features with respect to leadership, membership, and change orientation. For the purposes of this review and following the guidelines established by Kurtz (1997, 2004), a group will be classified as a "support group" (regardless of what it was called by the original researcher) if (a) its members come together to share their experiences about a similar issue and provide both information as well as emotional and social support to one another, (b) it is led by a professional who facilitates discussion rather than provides didactic instruction, (c) the leader controls group membership, and (d) the focus of the group is more on providing support than on personal or social change. In other words, even if a researcher identifies the therapy group in the study as a "self-help group," if it meets the foregoing four criteria, it will be construed as a support group for the research review which follows.

## **Therapeutic Factors in Support Groups**

There is a dearth of research on the process of support groups, and therefore a lack of understanding about how group members change and develop over the course of participating in such a group (Kurtz, 1997). However, in reviewing the research on therapeutic factors in support groups, Kurtz (1997) used Yalom's (1995) original conceptualization of factors relevant to group psychotherapeutic change and applied the most relevant among them to support groups. Kurtz identified a number of therapeutic factors that operate in effective support groups: group cohesiveness, sense of belonging, universality, giving and receiving support, instilling hope, altruism, obtaining information and experiential knowledge, and learning methods of coping. These individual factors will be described in the next section.

**Group cohesiveness.** Group cohesiveness is the degree to which members feel trusting and close to one another. Related to this is a sense of belonging to the group, as well as universality, or the finding of similarity amongst group members. Goodman and Jacobs (1994) noted that, "[s]imilarity of suffering from a specific common problem creates environments with a high frequency of expressed empathy" (p. 501). The group offers understanding and support in a non-judgmental atmosphere, which fosters members' willingness to discuss and explore their problems. Furthermore, being part of a group can help normalize a person's experience; seeing and listening to other people with similar thoughts, feelings, and experiences helps the person understand that others also think and feel this way and that he/she is not the only person dealing with a particular issue. For some, the realization that one is not alone in his/her suffering may be a powerful source of comfort and relief, and may help to counteract feelings of isolation (Seligman, 1982).

**Giving and receiving support.** Another broad therapeutic factor is giving and receiving

support, which is a primary purpose of the support group and comprises other factors, such as altruism. Altruism refers to participants' ability to derive satisfaction from helping others; for example, veteran members may give advice to younger members who are less knowledgeable about an issue of concern, or parents of older children may help parents of younger children. Being useful by contributing to another person's well-being can be an important source of self-esteem (Seligman, 1982). Furthermore, in the process of giving and receiving support, members can explore their individual styles of relating to others and learn more effective social skills; in this sense, the group can be viewed as a microcosm of society, a place where participants can develop and hone their interpersonal skills.

**Hope.** Instillation of hope is viewed as one of the most essential therapeutic factors operating in a support group – as Kurtz (1997) noted, the “belief that therapy will help is fundamental to the individual's willingness to engage in the therapeutic process” (pp. 17-18). A support group member may be heartened and encouraged by the belief and/or realization that he/she is experiencing positive changes. Furthermore, seeing others in the group make progress (particularly those who have faced considerable adversity) can also help to instill optimism and the belief that meaningful changes can and do occur (Seligman, 1982).

**Knowledge and coping.** Finally, two similar therapeutic factors pertain to more tangible benefits of being in a group, namely, obtaining information and experiential knowledge, and learning methods of coping. Group members learn important information from one another in the form of concrete information (e.g., how to access respite services); personal stories of learning (e.g., how other group members came to accept a child's disability); and coping methods (e.g., stress management). Thus, support groups satisfy members' needs for affiliation, recognition, and security in a number of meaningful and multifaceted ways (Toseland, Jones, & Gellis, 2004).

Haggman-Laitila and Pietila (2009) conducted group interviews to determine what the criteria are for a “good” support group, as rated by parents (63 mothers and 14 fathers) who had participated in various time-limited, fixed membership support groups on parenting, child rearing, and marital relationships in Finland. A good support group was defined by the participants as one that (a) is informative (e.g., provides information related to the family’s life situation); (b) allows parents to contribute to the discussion (i.e., includes a combination of parent and group leader interactions); (c) encourages activity (e.g., includes games, relaxation exercises, field trips, etc.); (d) includes reciprocal and mutual interactions that help to establish ongoing interpersonal relationships and a positive atmosphere; and (e) is supervised by a competent group leader who has a number of responsibilities, such as planning the program and schedule, serving as an expert, taking care of the group, moderating and facilitating discussion, taking a neutral stance, and ensuring all members are heard.

Group research on therapeutic factors has been conducted with parents of children with disabilities, and has identified many of the same factors described by Kurtz (1997). Typically, the research has been qualitative in nature, wherein parents are interviewed about their experiences of being in a support group. Factors that are valued by support group members include (a) being able to express feelings safely to other parents who understand the group member’s experience (Bennett, DeLuca, & Allen, 1996; Law, King, Stewart, & King, 2002); (b) developing a sense of trust and belonging and counteracting social isolation (Law et al., 2002; Lo, 2008), (c) obtaining and providing resources and supports to fellow group members (Bennett et al., 1996; Law et al., 2002; Lo, 2008; Smith, Gabard, Dale, & Drucker, 1994); (d) learning how to resolve problems and advocate for the child and family (Law et al., 2002); and (e) feeling empowered and confident (Lo, 2008).

## **Autism Support Groups**

Some research has also been conducted on support groups designed exclusively for parents of children with ASD. Mandell and Salzer (2007) examined the extent to which families of children with ASD use support groups, and the factors associated with support group participation. Participants were 1,005 parents (70 fathers) of children with ASD living in the United States. Forty-one percent of respondents attended an ASD support group for parents at the time of the study, and 12% attended both ASD-specific and non-ASD support groups. A total of 66% of the sample had ever belonged to a support group. Those who belonged to a support group were more likely to have male children, be white, have an annual income above \$40,000, live in a suburban area, be a college graduate, and be married or living with a partner. Fewer than 1 in 4 parents reported that they were referred to the group (usually by the clinician who diagnosed their child with ASD), suggesting that most parents find support groups on their own. Those who had been in a support group were also more likely to have children who engaged in self-injurious behaviour, had sleep problems, and/or had severe language deficits. The authors noted that the majority of respondents were mothers, cautioning that this demographic pattern may not be generalizable to fathers or other caregivers.

In a related vein, Clifford and Minnes (2013a) examined psychological characteristics associated with parent support group (PSG) participation in parents of children with ASD. There was a total of 149 participants (142 mothers, 1 grandmother, and 6 fathers), ranging in age from 24 to 65 years ( $M = 41$  years,  $SD = 7.11$  years), and with a median household income of \$75,000. The majority of the parents lived in Canada (56 %) or the United States (40 %). The children with ASD ranged in age from 2 to 23 years ( $M = 9$  years,  $SD = 4.62$ ). Parents completed online questionnaires about their anxiety, depression, coping, social support, and perceptions of

support groups. The authors did not report providing survey respondents with a definition of support group. Three-quarters of respondents ( $n = 113$ ) of parents had participated in a PSG at some time, whereas 19 % ( $n = 29$ ) reported current participation in an in-person PSG and 31 % ( $n = 47$ ) reported current participation in an online PSG. Those currently using PSGs reported using more adaptive coping strategies including seeking emotional and instrumental support, active coping, and planning than the two other groups. Past PSG users reported that they did not find the groups as beneficial as current users, and parents who had never participated in PSGs reported difficulties with the accessibility of PSGs (e.g., location, meeting time, transportation, childcare). Based on the study findings, the authors suggested that traditional in-person PSGs are best for those parents who (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) do not perceive barriers to accessing PSGs. However, those parents who have not tried a support group and believe them to be beneficial may be well supported by alternatives to attending in-person groups such as online support groups. Finally, for those parents who have tried support groups and not found them beneficial and those who do not seek out support to help them cope, other supports should be investigated.

Papageorgiou and Kalyva (2010) studied the self-reported needs and expectations of 299 parents of children with ASD (227 mothers and 72 fathers) who participated in support groups in Greece. Parents completed a demographic questionnaire and answered open-ended questions about their children with ASD and their participation in support groups. The most common problem that the families had faced was the child's communication difficulties (e.g., not being able to understand what their child wanted). The main reason that most of the parents (64.5%) participated in a support group was wanting to learn about new developments in the area of ASD

(e.g., learn about new treatments). This important motive was followed by a desire for practical support (19.5%), such as learning how to manage temper tantrums or improve their child's toileting skills. Eight percent of parents participated either because they wanted to meet other parents of children with ASD (e.g., to learn how others coped with behavioural problems or to share experiences with others in a similar situation) or because they wanted psychological support (e.g., to cope with stress and feelings of guilt and inadequacy). When asked about their expectations of support groups, parents responded that they hoped to be informed about new developments in the area of ASD (42.1%), improve their child's condition (23.7%), meet with other parents (21.1%), and/or understand their child better (13%). Interestingly, mothers and fathers did not differ in the reasons why they participated in support groups and in the expectations that they had for those groups.

Overall, there are multiple components that, in combination, contribute to parents' expectations of support groups as well as their perceived success and therapeutic value. "Good" support groups simultaneously address the social, psychological, and pragmatic needs of group members, regardless of whether or not they have a child with ASD. In general, as Davison, Pennebaker, and Dickerson (2000) aptly noted, the social validity of a group is perhaps the most important criterion for success, because, "as a measure of basic value to participants, participation is its own index of success: Groups without value cease to be groups. Members vote with their feet" (p. 206).

### **Efficacy of Support Groups**

#### **Differentiating Between Self-Help and Support**

As noted previously, there is considerable confusion about the distinction between self-help and support groups, and the terms are often used interchangeably (Schopler & Galinsky,

1993). For example, in investigating the prevalence of “self-help groups,” Lieberman and Snowden (1993) found that 60% of these groups were led by paid professionals, and thus could more accurately be termed “support groups.” As Lieberman and Snowden noted, the “apparent blurring of traditional boundaries between professional services and mutual aid [i.e., self-help] groups magnifies the problem of correctly reporting rates of [self-help group] participation” (p. 178). This caution also applies to issues regarding research on support groups. Drawing clear distinctions between these overlapping groups has been described as “not only difficult, but impractical” and points to “the difficulty of categorical boundaries and the problematic nature of research in real-world social patterns” (Davison et al., 2000, p. 204).

This difficulty and impracticality create an especially challenging task when attempting to impose an empirical framework on a body of research, because, although there is overlap between self-help and support groups, each group has important features that distinguishes it from the other. Thus, as noted in a previous section, research on support group efficacy was to be included in the following section only if (a) group members came together to share their experiences about a similar issue and to provide both information and emotional and social support to one another, (b) the group was led by a professional who facilitated discussion rather than provided didactic instruction, (c) the leader controlled group membership, and (d) the focus of the group was primarily on providing support rather than on facilitating personal or social change.

### **Efficacy of Support Groups for Parents of Children with a Disability Other than ASD**

Shapiro (1989) conducted research on the relationship between participation in support groups and levels of both maternal stress and depression with 56 mothers of children who had various disabilities, including Down syndrome, cerebral palsy, and developmental delay..

Twenty-two mothers in the study had never been a member of any type of support group associated with their child's condition; these mothers formed the control group. The remaining 34 mothers were members of 1 of 3 different support groups; each group met for 60 to 90 minutes per week and was led by a licensed psychologist. The groups were discussion-oriented, including topics such as grieving, the impact of having a child with a disability on family life, how to manage problem behaviours, problem-solving approaches for use in daily life, and networking amongst group members.

Mothers participated in semi-structured interviews regarding the impact of their child on their personal lives and their experiences in a support group. They also completed measures of depression and parenting stress. Results indicated that mothers who participated in a support group had significantly lower levels of depression and engaged in significantly higher levels of problem-solving coping than mothers in the control group. No other significant relationships were found between participation and either stress or coping. Shapiro concluded that, "while it is premature for therapists to conclude that support groups provide the easy answer for all mothers of developmentally delayed children, the findings are highly suggestive of a role for support groups in the treatment of these patients" (p. 172).

Krauss, Upshur, Shonkoff, and Hauser-Cram (1993) conducted a study on participation in parent support groups with 150 mothers who were receiving early intervention services for their infants and toddlers with disabilities (Down syndrome, motor impairment, and developmental delay). Of the 150 mothers, 67 did not attend any parent group meetings and the remaining 83 attended at least one session. Weekly parent groups consisted of 4-8 parents and were led by a professional (e.g., social worker). Generally, groups were structured to enable parents to share information, provide and receive emotional support, and identify concerns or issues such as

parenting skills and techniques and advocacy training. Research staff interviewed mothers and completed standardized assessments of the child prior to initiation of the groups (i.e., at Time 1, or T1). Mothers also completed various self-report questionnaires, including the Parenting Stress Index, Impact-on-Family Scale, and EICS Parent Support Scale. The process was repeated one year later, at Time 2 (T2).

No significant differences between T1 and T2 were found between mothers who did and did not participate in parent groups for parent- or child-related stress, adverse impacts on family, and mother-child interactions. However, significant differences were found from T1 to T2 for the size of mothers' support networks and the perceived helpfulness of peers, with mothers in support groups reporting increases in these areas. In addition, mothers of children with developmental delay, older children, and children with more severe cognitive impairments reported significantly higher levels of support group participation. Surprisingly, higher levels of group participation were associated with significantly higher reported levels of adverse effects on social/familial relationships and personal strain, after controlling for potentially confounding variables (e.g., initial levels of parenting stress). The authors considered three possible explanations for these unexpected findings: (a) mothers who experienced increasing strain over the 12-month study period were more likely to join parent groups and attended them more frequently; (b) increased personal and familial/social strain reflected a healthy awareness of the realities of raising a child with a disability and helped mothers adjust over time; or (c) higher levels of group participation precipitated adverse family impacts; in other words, perhaps some aspects of group participation (e.g., listening to others describe their struggles and concerns) were aversive and psychologically burdensome to mothers, resulting in increased personal and familial strain.

Hogan et al. (2002) conducted a narrative review of studies published between 1970-2000 that examined the overall usefulness of various types of social support interventions for a diverse range of medical and psychological issues. Of the 100 studies reviewed, 16 examined the effects of professionally-led support groups to address various medical and/or psychological disorders (e.g., cancer, Hodgkin's Disease, HIV, stroke, avoidant personality disorder). The groups included discussions of specific topics; exploration of member's experiences, thoughts, and feelings; discussions of coping strategies; and opportunities for members to give and receive feedback. Although some groups included specific information to help participants learn more skills (e.g., stress management), Hogan et al. noted that formal skill training was not a primary component of these groups. Eight of the 16 studies reported favourable outcomes of the support groups on both psychological and medical outcome measures. Four studies reported moderate improvements on psychological outcome measures only; and in the remaining four studies, no benefits were identified for support groups. Interestingly, 8 of the 16 studies targeted similar populations (i.e., cancer patients), but only 4 of these 8 studies reported favourable results.

**Support groups for fathers of children with a disability.** Scant research has been conducted on support groups for fathers of children with disabilities. A study by Vadasy, Fewell, Meyer, and Greenberg (1985) was an empirical evaluation of a pilot program (the "Father's Program") designed for fathers of young children. The program was intended to support fathers and strengthen their ability to cope with the stress of parenting a child with a disability by (1) facilitating sharing about how to cope with parenting stress, and (2) providing fathers with information and social support that might increase their ability to handle these stressors. Each meeting followed a similar format, which included a 40-minute group session facilitated by professional leaders to discuss issues or problems of concern, activities for fathers and children

to engage in together, and a guest speaker who spoke about a particular topic of interest (e.g., a lawyer who described how to set up wills and trusts). In addition, several times each year, families were invited to take part in social activities; and “fathers only” meetings were held in which the fathers met without their children and spent time talking to other group members, or meeting with a panel of guest speakers.

A total of 23 fathers and their wives participated, and were divided into two groups -- those who had been enrolled in the program for a period of 1-3 years ( $n = 7$ ) and those were newly enrolled ( $n = 16$ ). Twenty of the participating families had children with Down syndrome; the disabilities of the remaining three children were not described. Measures included the Beck Depression Inventory (BDI); the Family Environment Scale (FES); the Inventory of Parents’ Experiences (IPE) that measured types of supports and satisfaction with that support; and the Questionnaire on Resources and Stress – Short Form (QRS-SF). Results indicated that fathers who had participated in the program for at least one year had significantly lower depression scores on the BDI than newly enrolled fathers. Program fathers also reported significantly less sadness, less fatigue, more satisfaction, less pessimism about the future, less guilt, and better decision-making ability than newly enrolled fathers. Interestingly, there were no significant group differences on BDI scores for mothers. Regarding FES scores, program fathers reported significantly higher levels of expressiveness than new enrollees. On the IPE, both program fathers and their wives reported significantly more satisfaction with people, compared to parents who were newly enrolled. Program fathers also reported significantly more satisfaction with people with whom they could share their most private feelings, and greater satisfaction with their level of religious involvement, compared to new enrollees. Finally, on the QRS-SF, program fathers reported significantly less child-related stress and fewer problems than new enrollees.

The authors described the preliminary results as “positive” and as providing support for the need for future research on the potential impact of this program.

In a follow-up study of 45 participants one year later, the program effects were maintained (Vadasy, Fewell, Greenberg, Dermond, & Meyer, 1986). Specifically, fathers who had participated in the program reported (a) a significant decrease in child-related stress, (b) a significant decrease in total depression scores, (c) a significant decrease in grief, and (d) a significant decrease in information needs over time. However, perhaps not surprisingly, there was also a significant increase in fathers’ pessimism about the future. Correlational analyses indicated that depression at the time of follow-up was positively correlated with child-related stress, family problems concerning the child, and father’s pessimism about the future. Interestingly, fathers’ satisfaction with spousal supports was negatively related to their child’s age, meaning that fathers’ satisfaction was greater when their children were younger. Also, fathers with lower reports of parent- or family-related stress reported more satisfying friendships. Fathers with a higher level of program attendance reported lower information needs. Overall, the wives of program participants also reported significant decreases in total stress and total depression scores, and a significant increase in their satisfaction with social supports over time. However, the authors cautioned that “we can only speculate whether these changes are primarily attributable to the intervention or to other confounding factors, including self-selection, history, maturation, testing effects, or interactions thereof” (p. 25).

West (1998) described the impact of a pilot group for fathers of children with Down syndrome. The group was led by a professional facilitator who helped fathers explore and discuss their experiences and feelings; thus, it meets the definition of a support group. Four fathers participated in a total of four weekly, one-hour sessions covering a range of topics

including receiving the diagnosis; being strong for their partner; ongoing worries about health; and reactions of relatives, work colleagues, and the public. During interviews that were conducted two weeks after the group had ended, all four fathers reported that participation had been valuable, particularly with regard to the “openness and warmth of the group members and the honesty and extent of sharing” (p. 291). All four fathers indicated that they would like to participate in such a group again in the future.

### **Efficacy of Support Groups for Parents of Children with ASD**

There has been negligible research examining the effects of support groups for parents of children with ASD and – as is the case in other areas – most of what exists has involved mothers rather than fathers. For example, Bitsika and Sharpley (1999) studied the effectiveness of what they termed “information counselling,” which (a) conveyed information to parents about their child’s disability and how they and other family members coped with that disability, and (b) focused on support rather than specific behavioural strategies to help parents respond to personal stress and psychological discomfort. Fourteen parents (but just one father) of children with ASD were divided into three groups of 4-6 people each and attended eight 75-minute sessions every 2 weeks. Sessions were led by a psychologist and topics included caring for others and self-care; parental reactions to the ASD diagnosis; relationships with members’ partners, child with ASD, and other children; relationships with extended family and friends; and significant life events and their impact. Although there was a psychoeducational component to the intervention, the group primarily focused on creating opportunities for members to provide information and emotional support to one another, and discussions were facilitated by a professional; thus, this study falls clearly within the definition of support group.

Bitsika and Sharpley (1999) developed two self-report measures for the study. One

measure evaluated group cohesion, self concept, self-efficacy, health and wellness, and members completed it at the beginning and end of each session. The other measure evaluated perceived value of the program and was completed six weeks after the program had completed. Pre-post session differences indicated that both self-concept and group cohesion increased over time, self-efficacy decreased over time, and distress decreased following the first and the final two sessions. The authors cautioned that these data should be treated as “exploratory.” Participants reported that the group was valuable; that it was helpful in dealing with child, family, and everyday hassles; and that they would recommend such a group to others and would like to participate in such a group in the future. Major benefits cited by participants included receiving understanding and empathy from other group members, and being of assistance to other members.

Shu and Lung (2005) employed a quasi-experimental research design to explore the effect of support groups on the mental health and quality of life for Taiwanese mothers of children with ASD. A total of 27 mothers participated in the study; 8 were assigned (based on willingness) to the support group and the remaining 19 were assigned to the control group. The treatment consisted of ten 90-minute weekly sessions, with each session focused on a main issue, such as caring for a child with ASD, coping strategies, social networks, interpersonal relationships, and community resources. The group was led by a psychiatric nurse who focused on facilitating members’ interactions with one another. Participants completed measures of psychological well-being and quality of life at pre-test, post-test, and after one month follow-up. Results indicated no significant differences for any of the total or domain scores of the two measures, either within or between groups, at any of the three time points. The authors noted that the support group effect on the psychological well-being score was “borderline” significant

( $p=.06$ ), suggesting that a larger sample size might have resulted in statistically significant findings.

Banach, Iudice, Conway, and Couse (2010) conducted a pilot study on the effects of two 6-week support groups for 11 parents (2 fathers) whose children had recently received a diagnosis of ASD. The groups were facilitated by two senior graduate students, one from the area of social work and the other from early childhood special education. Topics included a discussion of parents' reactions to the diagnosis; successes and challenges regarding the child's behaviour; sharing skills, techniques, and resources; developing a social story; advocacy skills; and the Individual Education Plan (IEP) process. The sessions also included a panel of parents and an adult with ASD, and opportunities to set goals and share contact information. Thus, this could be considered a multi-component intervention, in that there were elements of both a psychoeducational group (e.g., information about the IEP process) and a support group (e.g., discussion of reactions to the ASD diagnosis).

The effect of participation on parents' sense of empowerment was measured in the first and last weeks of each session. In addition, the group process was evaluated with a qualitative parent satisfaction survey administered in the final session. Results showed significant changes for each of the empowerment subscales, indicating that parents felt more confident in their ability to handle problems, advocate for their children with ASD, and affect changes in services. Satisfaction surveys indicated that the most helpful components of the group included meeting other parents with similar experiences and concerns, listening to the panel of autism experts, and receiving a "100 Day Kit" that provided information and resources relevant to the first 100 days following an ASD diagnosis.

Clifford and Minnes (2013b) conducted a study to determine whether involvement in an

online parent support group (PSG) for parents of children with ASD affected parent reported stress, anxiety, depression, and positive perceptions of their child. A total of five online PSGs were held, with 5–10 parents registered in each of the groups; an average of three parents attended each session. Based on parent preference, 4 of the 5 groups were held on weekday evenings, and the fifth was held at noon on a weekday. Parents also chose the frequency of meetings, with 4 of the 5 groups held bi-weekly and one held weekly. Each meeting lasted one hour, for a total of 8 sessions, and topics included treatment issues, the impact of ASD on families, managing behaviour problems, coping with stress, advocacy, dealing with schools and the community, useful resources, and transitions. In general, the group sessions focused on providing mutual support and a sense of belonging among the participants, with specific topics structuring the discussion. The groups were facilitated by a doctoral student in clinical psychology with experience in working with families of children with ASD and in group facilitation. A total of 119 mothers indicated an interest in participating; of these, 36 registered for the online support groups, 30 attended at least one session, and 20 completed all of the post-group measures. Twenty-five parents who did not participate in the online support group formed the control group and completed all of the post-group measures. Participants were asked to complete measures on parenting stress, anxiety, depression, and their perceptions of their child with ASD, both pre-and post-treatment.

With respect to attendance, 64% ( $n = 23$ ) of the parents who initially registered attended three or more of the support group sessions, 25% ( $n = 9$ ) attended 6 or more sessions, and only one parent attended all of the sessions in her group. Seventy-five percent ( $n = 15$ ) of the parents who had participated in at least one session said they would not recommend changing anything about the group in order to increase attendance. Changes in the well-being of the parents (i.e.,

parenting stress, anxiety, depression, and positive perceptions) were examined between the treatment and control groups, both pre- and post-treatment. There were no main effects for either group or time, and the interaction was also non-significant. The authors noted that the participants had relatively high pre-group well-being scores. Overall, parents rated the group as useful; however, there was no significant relationship between the perceived usefulness of the PSG and parenting stress, anxiety, depression, or positive perceptions. The parents reported being “satisfied” with both the support received and each of the topics discussed. Responses about the least useful aspects of the group were variable, but included issues related to being online (e.g., delay in receiving responses); differences in parental experiences (e.g., having children of various ages); having to listen to other parents complain; and finding some topics too difficult to talk about.

**Support groups for fathers of children with ASD.** No research exists on the impact of support groups specifically designed for fathers of children with ASD. However, several unpublished qualitative studies have identified the types of supports that fathers say they need, many of which fall within the purview of a support group. For example, Hunt-Jackson (2007) interviewed 14 fathers of children with ASD about their parenting experiences. When asked what should be examined in research on fathers of children with ASD, fathers described an overall need for more research on fathers, as well as programs specifically for fathers of children with ASD, including concrete services such as a website, hotline, or support group where they could share experiences of parenting a child with ASD. Participants also wanted to learn more from other fathers, such as reactions to the diagnosis, whether other fathers would “trade” their child with ASD for a “normal” child, effective coping strategies/stress management techniques, and how having a child with ASD affected personal relationships.

Similarly, Long (2005) conducted interviews on the experiences of four fathers of children with ASD. Among other topics, participants all lamented their lack of contact with other fathers of children with ASD; although all four attended various support groups, few other fathers were present in these groups. When asked to reflect on possible obstacles to participation in support groups and related activities, participants cited the emotional difficulty of talking about their experiences and time constraints. Yet, these fathers clearly valued opportunities to share their experiences: When asked what advice they would give to other fathers of children with ASD, they recommended attending support groups and meeting other parents (especially fathers) of children with special needs.

Collins (2008) also conducted interviews with 15 fathers of children with ASD. When asked about coping with having a child with ASD, some fathers talked about support groups and noted that they would benefit from being in such a group. As one father stated, “You know women are supported more when it comes to kids with autism. Even if we go to the [Autism] Society meetings, there are only one or two dads there and we feel out of place. They have many activities and support groups for the moms. Nothing is really aimed at dads and how any of this affects us” (p. 70). Another father stated, “If support groups had been available in the beginning, you could have counted me in. I would go now. I think we need informal support groups for dads....If we could just get together....and share our experiences, we could let down our hair so to speak, and let our real feelings be heard. Those of us that have been advocating, struggling, and starting to make headway could give these younger guys or newer fathers some help on how to handle this overwhelming process between recognizing a problem exists, accepting it, and getting the help needed” (p. 70-71). All 15 fathers stated that they would welcome a support group dedicated to fathers, and that having such a group would help give them a voice and an

opportunity to be heard as an advocate.

Finally, the author (Miriam Elfert) had prior experience facilitating a support group for fathers of children with ASD on three separate occasions from 2005 to 2007. Two of the groups were conducted as part of a practicum placement to fulfill the requirements for a master's degree in Counselling Psychology at UBC. Although not designed as a pilot for the present study, these experiences serve as a rich resource for an empirical study of the effectiveness of a support group for fathers. A total of 14 fathers participated in the three groups, which were held either weekly or bi-weekly. The content of the session topics was based on (a) the author's readings of relevant counseling and autism literature, (b) her experience working with families of children with ASD, and (c) informal surveys of fathers of children with ASD (conducted by the author) that asked what they would like to discuss in a support group with other fathers. Based on this information, the following topics were generated: first experiences with diagnosis and disability; father's roles and responsibilities; relationships with coworkers and friends; dealing with the education system and working with professionals; relationships with immediate and extended family; dealing with the loss of a 'normal' or expected father-son relationship; benefits of having child with ASD; looking to the future; and a "toolbox" of information/ resources (sharing tips, tools, strategies). Participant feedback was collected at the completion of each group, using a written feedback form. Specifically, fathers were asked to provide, anonymously, written responses to a number of questions pertaining to the session topics and their experiences in the group (see Appendix A).

Overall, all of the fathers said that they found the group helpful and would attend such a group again. Across responses, a number of themes emerged that reflected fathers' perceived benefits of participation in the support group. These included:

- Learning that one is not alone, and that other fathers have similar thoughts and feelings and

therefore understand the experience of parenting a child with ASD;

- Being validated and valued by other fathers, including giving and getting advice/strategies and emotional support from group members;
- Being able to share private thoughts and feelings that normally would not be discussed in a public forum. A number of fathers said that the trust established within the group helped them to think and talk about private and personal matters, which was a new and (for some) liberating experience;
- Gaining new perspectives and understandings about parenting a child with ASD by talking and listening to group members, which helped them to learn the value and significance of the father-child relationship;
- Knowing that things could always be worse and seeing that there were fathers who had even more challenging life experiences than their own;
- Enjoying the homemade baked goods and refreshments that were provided in each group. Surprisingly, the majority of respondents commented specifically and favourably about this aspect of the group!

Participants also identified several elements of group leadership that were helpful, including the facilitator's ability to ensure a balance between guiding participants and letting the conversation flow freely; ensuring that all group members had an opportunity to talk and contribute to the discussion; and creating a "safe" environment in which participants were able to share their private thoughts and feelings. When asked about ways to improve the group, the fathers provided various suggestions, including having longer group sessions and having the group continue for a longer duration (i.e., more than eight sessions); having a brief break after the first hour of group; being given more reading materials/resources and more didactic

instruction; bringing in more experienced fathers of older children to impart their knowledge; and eliminating the session on working with school staff and other professionals.

Fathers also reflected on the group process, and emphasized the benefits of participating in the group. A number of fathers stated that they had initial reservations about participating, but found the experience to be worthwhile, meaningful, and valuable; in some cases, fathers admitted that the value of the group had exceeded their expectations. Participants expressed appreciation for having had the opportunity to participate in the group, and a number said that they would recommend such a group to other fathers. Thus, overall, participation in the support group was perceived as a worthwhile, meaningful, and valuable endeavour for most of the 14 father participants.

### **Limitations of Research on Support Groups**

A number of methodological flaws plague the research on support groups in general. First, and most central to the argument of this thesis, is that there is a paucity of male (i.e., father) participants, which seriously limits the generalizability of the findings. As discussed in the beginning of this chapter, fathers and mothers have different experiences, and assuming that what has been used with mothers can simply be extended or applied to fathers is both misguided and inappropriate. Furthermore, there is no empirical evidence to suggest that fathers will benefit from support groups that have been designed for and/or have almost exclusively included mothers.

Another methodological shortcoming pertains to potential confounding variables. Many studies have used measures that are not psychometrically valid, or have relied almost exclusively on self-report and interview data. Additionally, many studies have been qualitative in nature, which can provide important and rich information about participant's experiences, but does not

allow for the examination of associations between participation in a support group and participants' well-being. Other methodological problems include outdated research, small sample sizes, absence of control groups, and a lack of random assignment to control and support groups. Finally, many studies either provided no follow-up data, or examined the effects of a support group for only a short period of time after its conclusion (e.g., one month). However, in some cases there may be a "sleeper effect," in which the impact of an intervention increases over time (Capon & Hulbert, 1973). For example, in a study examining the effects of a program that combined behaviour management training program and counselling for parents of children with ASD, Tonge et al. (2006) noted that there were greater treatment effects 6 months after the intervention, which "may point to a cumulative benefit as parents apply skills learned" (p. 568).

### **Designing and Running Groups for Fathers**

Hoffman (2011) conducted an online survey of Canadian father involvement networks, to determine what sort of father-focused programs are available nationally. A total of 70 respondents completed the survey (including 21 from British Columbia). Hoffman found that a variety of fathers' programs are offered, the most popular of which were father-child activity programs wherein fathers have an opportunity to play with their children and meet and interact with other fathers (41%). The next most common categories of programs were parenting skills programs (31%) and peer support/discussion groups (17%). With respect to gender of group facilitators, 65% of groups were facilitated by a man, 16% by a woman, and the remaining 19% by both. Eighty percent of the programs were exclusively for fathers, and 13% of respondents indicated that their program specifically served fathers of children with special needs. The three most popular and successful recruitment strategies employed by the various programs were (1) referrals from other agencies, (2) giving information to mothers to pass on to their partners, and

(3) putting up posters advertising the program in the facility.

Although there continues to be a dearth of research on fathers overall, father-involvement initiatives have increased in recent years both in Canada and around the world (Hoffman, 2011). Examples of such national initiatives include the Father Involvement Research Alliance (FIRA), an “alliance of individuals, organizations and institutions dedicated to the development and sharing of knowledge focusing on father involvement, and the building of a community-university research alliance supporting this work” (<http://www.fira.ca/page.php?id=9>). Another Canadian example is the Father Involvement Initiative – Ontario Network (FII-ON), which “leads initiatives linked to the concerted actions of fathers, agencies, community groups and the business sector in order to support their efforts to create welcoming communities and promote father involvement as a supportive and protective condition for healthy child development and resiliency” ([http://www.cfii.ca/our\\_history](http://www.cfii.ca/our_history)). In British Columbia, the B.C. Council for Families (BCCF) provides information and resources about numerous issues related to families and parenting, including fathering. BCCF provides access to various brochures, booklets, and books about paternal topics such as playing with young children, parenting in the context of separation and divorce, and how to be an involved father. Thus, various groups are addressing the topic of increasing father involvement.

To this end, task forces, advisory groups, and committees have been formed to develop written strategies and describe successful models of father-friendly programs. Much of the information is clinically derived (i.e., based on the experiences of individuals who have developed and run programs for fathers, as well as fathers who have previously attended, or want to attend, such groups) but is not based on empirical research. None of the information is specific to support groups for fathers of children with ASD or other disabilities; however, the relevant

principles and recommendations can be adapted and applied to such groups. For example, the Canadian Association of Family Resource Programs (FRP Canada) published a handbook entitled *Supporting Fathers* (Beauregard & Brown, 2000), which aimed to help family resource programs better engage fathers in their parenting role. Research for the handbook involved a national meeting of experts, a review of print resources, focus groups with fathers and staff across Canada, interviews with key informants, and surveys of resource and program materials. Similarly, *The Father Toolkit* (<http://www.mydad.ca/tool-kit.php>) was developed from the “*My Daddy Matters Because...*” project, funded by Health Canada. The *Toolkit* evolved from the work of an advisory committee and 14 pilot sites across Canada. Both the *Toolkit* and the *Supporting Fathers* handbook identified a number of considerations aimed at attracting fathers to attend programs and/or support groups.

In addition to these father-specific resources, Nichols and Jenkinson (2006) published a book entitled *Leading a Support Group* which outlines, in concrete and pragmatic terms, the benefits of support groups and the essential aspects of forming, beginning, and running a support group. Nichols and Jenkinson (a clinical psychologist and counselor, respectively) wrote the book based on their extensive experiences running support groups. The book is written for professionals (e.g., nurses, social workers, psychologists) who value support group work but who lack the clinical experience to lead such a group. The authors do not provide information about leading groups specifically for fathers; however, *Leading a Support Group* can certainly be used to plan support groups for fathers. Thus, the next section is an amalgamation of support group strategies from this book, *The Father Toolkit*, and the *Supporting Fathers* handbook discussed previously.

## **Structural/Physical Considerations**

Both *The Father Toolkit* and the *Supporting Fathers* handbook emphasize the importance of creating a “father friendly environment” that will help men feel comfortable and at ease. This includes making the physical space appealing by, for example, utilizing a “clubhouse” design, using neutral colours/tones (versus pinks/pastels), providing a gross motor area for fathers to play with their children (if children are part of the program), displaying pictures of fathers with their children on the walls, and playing adult music. In addition, Nichols and Jenkinson (2006) recommended avoiding harsh lighting such as fluorescent lights; and having comfortable, similar chairs for all group members, arranged in an approximate circle, with no undue spaces or empty chairs between people. All three resources described the importance of establishing a quiet, uninterrupted, private meeting space that encourages men to talk, yet is still reasonably accessible. When providing or displaying reading materials (i.e., books, pamphlets, program brochures), programs should try to ensure that the materials are either gender neutral or geared specifically towards fathers. Another recommendation is to provide fathers with appropriate food and beverages (which was certainly a successful strategy in the previous fathers’ support groups facilitated by the author).

## **Interpersonal Considerations**

Some general suggestions have been provided to help support group staff establish rapport and relationships with fathers. As a starting point, it is important to ensure that staff in the program are supportive of and knowledgeable about fathers in general and the benefits of positive father involvement to the family. Related to this is the need for staff to examine and check any pre-existing expectations, biases, and negative social images they might have about working with fathers/men (e.g., that men are less experienced parents and not as competent as

women). Staff should also work on establishing personal, one to-one contact with fathers and, when appropriate, use humour. Finally, staff should also work to maintain father involvement by establishing follow-up contact after fathers have attended a program.

### **Leadership Considerations**

Based on the two fathers' handbooks, the characteristics of an effective group leader (as identified by program staff and fathers) include: (a) the ability to relate to fathers from different backgrounds, (b) knowledge about fathers' issues, (c) the ability to call upon real-life experiences, (d) resourcefulness and a good memory, (e) a positive attitude and optimistic outlook, (f) a non-judgmental and open-minded attitude, and (g) personal qualities such as empathy, optimism, and humility. Effective group leaders are also respectful, professional, and possess both good listening skills and good communication skills, including the ability to provide concrete factual information in an understandable way. With regard to the gender of a group leader, opinions are mixed and there is no real consensus on whether only a man, only a woman, or both a man and woman should facilitate the groups. This is reflected in the results of Hoffman's (2011) survey (discussed previously), which indicated that 65% of fathers' groups were facilitated by a man, 16% by a woman, and the remaining 19% by both.

In addition, Nichols and Jenkinson (2006) devoted an entire chapter to group leadership, in which they described a number of basic leader abilities. They emphasized that,

The manner in which you set up and run a group is very important. The kind of person you are as a leader will be assessed by the group based on how they see you acting, what you do and say, and the timing and manner of your delivery. Conclusions will be drawn and inferences made, based largely on your behaviour. This will have great significance because members...will be searching for a 'role model,' that is, an example of the

behaviour required in a group. You need to give the appropriate example. (p. 58)

Nichols and Jenkinson asserted that group leaders must value personal change and growth, and that an “effective leader will tolerate constructive emotional pain [experienced by group members] as a means to growth” (p. 59). Furthermore, helping group members find ways to relieve psychological pain, distress, and discomfort is a central value and objective of the group leader. In this regard, group leaders need to be aware of and able to discuss feelings, in order to help group members discover, express, and share those feelings. Other attributes of an effective support group leader include being a keen observer of verbal and non-verbal behaviours (e.g., facial expressions, who in the group is talking or not); making sense of themes that arise in the discussion by reviewing, discussing, and analyzing these themes; keeping an open mind and looking for alternative explanations to themes and issues that surface in the group; and being mindful of group norms and rules that emerge (e.g., level of permissible self-disclosure) and how these influence group member’s behaviour. Most importantly, the leader’s basic responsibility is to make sure that members feel safe and are thus “free to explore and work psychologically” (p. 65). This safety is created by the group norms and operating principles outlined and enforced by the leader, the leader modeling appropriate behaviour in the group, and the leader’s ability “to make people feel equally valued, worthwhile, and supported” (p. 65).

Nichols and Jenkinson also noted that, once the structure is established and members are settled in, the group leader should attempt to be “hands off” and give the group freedom to develop and unfold. However, some strategic assistance by the leader is useful, such as helping members who seem overwhelmed or unable to speak; and creating space for less assertive members to talk, if there are dominant group members who use up a disproportionate amount of the conversation time. They also suggested that group leaders deal with emotions (e.g., crying) in

a natural and relaxed way, and not to become tense or awkward.

### **Group Recruitment and Membership Considerations**

The two main father recruitment methods identified in the *Supporting Fathers* handbook included seeking the support of mothers to inform fathers about the availability of the group; and directly asking fathers what they wanted to learn/get from such groups. Additional recruitment methods included using word of mouth; and advertising groups through practitioners, organizations in the community (e.g., child development programs), and/or mass media (e.g., internet, newspaper, radio, posters, brochures). Related to this is to try to link with other networks/agencies and health care professionals to build networks of support for men/fathers (which can also help with “word of mouth” program promotion amongst fathers).

Nichols and Jenkinson (2006) emphasized the importance of carefully screening members to ensure that they are suitable for participating in a group. Useful characteristics of potential members include: (a) a willingness to listen, consider, and have respect for other people’s experience; (b) not to have so great a need that they are likely to dominate the group to the exclusion of others; (c) to be able to fit in with the general profile of other group members and group objectives (e.g., to explore experiences instead of giving members instant advice); (d) the ability to accept the stated aims and methods used in the group; and (e) trustworthiness in respecting group member’s confidentiality. They also recommend excluding people who have obvious major psychological or behavioural problems.

Nichols and Jenkinson also emphasized the importance of preparing group members for what to expect before starting the group, cautioning that -- without this preparation -- group cohesion may fail to develop, which can ultimately undermine the group’s success. They listed several potential hazards of having unprepared members attend a group, and five ways to

effectively prepare group members: (a) preparatory interviews that provide an introductory explanation and briefing about the group; (b) issuing carefully prepared written notes that convey a clear outline of the support group approach and the behaviour required for effective participation; (c) the use of an audio recording that describes support groups, as well as recorded extracts from a former group to illustrate what happens in a constructive meeting; (d) the use of a video recording that describes support groups illustrated by real or role-played sequences showing a group in progress; and (e) the negotiation of a group contract, whereby new group members formulate a set of agreed upon goals and criteria to guide interaction in the group. Which approach is used depends on the type of group and the leader's objectives for the group; for a simple, straightforward support group, Nichols and Jenkinson suggested providing a verbal explanation of the reasons for attending the group, along with a short set of written guidelines.

In further preparing members for participation in a support group, Nichols and Jenkinson noted that members may not understand the nature of support; therefore, it might be helpful for the leader to clarify what giving and receiving support mean in the context of a group. To successfully *give* appropriate support, members should adopt a relaxed approach, not attempt to solve the other person's problems, listen carefully and give full attention, be at ease with the expression of feeling and the exploration of experiences, and communicate non-judgmental acceptance to the person being supported so that he feels safe and free to talk openly, at his own pace. Thus, in giving support, group members should try to avoid giving advice, sharing too much of their own personal experiences, asking too many questions, and conveying a judgmental attitude. To successfully *receive* support from other group members, it is important for the recipient to understand that seeking and receiving support is not a weakness, but a necessary strength that enables him to cope with stress. It is also important for the recipient to be able to

identify, accept, and value his own feelings, and be able to talk openly about these feelings. Finally, the recipient should try to trust those providing the support, and to receive their time, attention, and care without guilt or defensiveness.

With respect to the meeting schedule, both of the father handbooks recommended being flexible about how and when to meet in order to encourage greater father participation. For example, some programs reported providing childcare and bus fare, and other groups met in the evenings and on weekends to accommodate father's work schedules. Another suggestion was to schedule the program to occur at the same time and day each week, to provide consistency and predictability. Nichols and Jenkinson recommended meeting once weekly, for 60 to 90 minutes each time.

The three resources varied with respect to the recommended size of a support group, ranging from a minimum of three to a maximum of 10 members; Nichols and Jenkinson suggested that a support group with one leader should have between 6 and 10 members. None of the resources provided firm guidelines regarding the number of sessions; Nichols and Jenkins asserted that this depends on the aims of the support group, the leader's commitment to running the group, and whether the group is of fixed or open membership. They described one possible approach of running a group for a fixed term (e.g., 10 sessions) and then deciding, as a group, whether to run for another set number of sessions.

### **Group Content Considerations**

The topic content addressed in a fathers' group will vary widely, depending on the type of group being run. All of the resources discussed the importance of a successful first session, because this session represents member's first impression of the group and sets the tone for the remaining sessions. Nichols and Jenkinson emphasized the importance of the leader having a

relaxed, gentle style, and helping members settle down and feel welcome in the group. To this end, the leader has three specific objectives: (a) greeting members and settling them into the circle; (b) introducing members to each other; and (c) ensuring that members understand the objectives of the group and how it will be run, so that they know what is expected and agree on standards for appropriate, acceptable, and productive behaviour (e.g., one person talks at a time while others listen, group discussions are confidential, etc.). The group leader should try to set realistic goals and identify participants' expectations from the outset. The two fathers' handbooks also recommended spending adequate time on "ice breakers," informal activities designed to help participants get to know one another and feel more at ease with conversing and sharing information. Although it might be helpful to design activities that encourage group participation and discussion, Nichols and Jenkinson (2006) cautioned against imposing a set of pre-determined activities upon the group. Rather, they urged group leaders to maintain a flexible approach and respond to the "here and now" of the group, meaning that the direction and content of the discussion will vary, depending on group member's individual contributions and their interactions with one another (i.e., the group dynamics). In this regard, there are few prescribed procedures regarding how a group discussion should unfold. In general, all of the resources suggested establishing an appropriate amount of structure, but still having a flexible agenda that allows for fathers' input. Nichols and Jenkinson also asserted that, oftentimes, process and content are equally important, meaning that "the act of belonging to a group and experiencing its atmosphere and activity is as important as the specific ground covered and specific things said" (p. 99).

### **Statement of the Problem and Research Questions**

ASD is a lifelong disorder characterized by significant deficits in social skills and communication, as well as the presence of repetitive or stereotyped behaviours. Given the pervasiveness and chronicity of these impairments, parenting a child with ASD can understandably present significant challenges for caregivers. Research has examined the psychological functioning of both mothers and fathers of children with ASD and how they compare to each other, as well as how they compare to other parents of children (both with and without disabilities).

Regarding parental stress, research has consistently demonstrated that parents of children with ASD experience higher levels of stress than parents of typically developing children and children with other disabilities. When comparing mothers and fathers of children with ASD, some studies have found no gender differences, whereas in other studies, mothers generally report higher levels of stress than fathers. In examining depression, parents of children with ASD typically report higher levels of depression than parents of typically developing children, but the findings are inconsistent when compared to parents of other children with disabilities. Mothers of children with ASD consistently report significantly higher levels of depression than fathers. Few studies have examined the impact that a child with ASD has on a couple's relationship, and there is conflicting evidence on whether families of children with ASD are at a higher risk of divorce. In general, mothers and fathers of children with ASD report similar levels of marital satisfaction. In examining the research comparing the optimism levels of parents of children with ASD to other groups, the findings are mixed, with some studies showing no differences, and others showing lower levels of optimism in parents of children with ASD. However, optimism is positively correlated with better mental and physical health, and predictive of fewer child

behaviour problems. Finally, with regard to coping strategies, some studies report no differences between mothers and fathers, whereas other research indicates that fathers score lower than mothers on some types of constructive and non-constructive coping. Fathers generally report lower levels of social support from family/friends, using community resources/professionals, and spiritual support than mothers, although both parents score similarly when ranking the utility of various sources of social support.

To help parents of children with ASD manage their significant caregiving responsibilities, a range of parent support approaches have been developed, including support groups. Unfortunately, most of the information on support groups is based on mothers' anecdotal experiences; no research exists on the effectiveness of support groups specifically designed for fathers of children with ASD. Anecdotal accounts suggest that support groups are perceived as valuable and meaningful, and that participants find it helpful to talk about and share their experiences in a safe, supportive environment with other people in similar circumstances. Furthermore, participants enjoy receiving empathy and understanding from others, and being of assistance to others by listening, and giving advice and emotional support to them.

In addition to the paucity of empirical research on the effectiveness of support groups, particularly for fathers of children with ASD, a number of methodological flaws plague the research on support groups that does exist. They include a failure to control for potentially confounding variables; the use of measures that are not psychometrically valid; a reliance on self-report and interview data; small sample sizes; an absence of control groups; a lack of random assignment to control and support groups; and minimal or no follow-up data.

In light of these factors, the primary objective of the proposed study was to design and evaluate the impact of a support group for fathers of children with ASD, using psychometrically

sound instruments to measure participants' psychological experiences with regard to depression, parenting stress, coping, optimism, and marital satisfaction. A secondary aim of the study was to examine fathers' experiences of participating in the support group, using a measure of social validity.

Because this study was exploratory in nature (i.e., it was the first study to use psychometrically valid measures to assess the impact of a support group on fathers of children with ASD), it was not possible to generate directional hypotheses based on previous research. Thus, the study was designed to answer the following research questions:

**Question 1.** After completion of the support groups for both Group 1 and Group 2, is there a significant main effect for Group or for Time, or a significant Time X Group interaction with regard to measures of depression, marital adjustment, optimism, parenting stress, and coping strategies? Hypothesis: There will be no Time X Group interaction on any of the measures. There will be no significant effect for Group on any of the measures. However, there will be a significant main effect for Time, with significant differences between pre- and post-support group scores on one or more of the measures.

**Question 2.** For Group 1, are there significant differences on measures of depression, marital adjustment, optimism, parenting stress, and coping strategies between pre-treatment and 4-month follow-up or between post-treatment and 4-month follow-up? Hypothesis: There will be significant differences between pre-treatment and 4-month follow-up, and between post-treatment and 4-month follow-up, on one or more of the measures.

**Question 3.** What is the social validity of the intervention? Specifically, will participants attend the support group regularly? Will participants report that the group was helpful? What will they identify as being most helpful about attending the group? Will they recommend the group to

other fathers of children with ASD? Hypothesis: Attendance will be regular. Participants will describe the group as being helpful. The aspects of the group that will be described as most helpful will be the opportunity to meet with and talk to other fathers in similar circumstances, getting new ideas and perspectives from group members, reducing social isolation, and experiencing validation and support from group members regarding the challenges of parenting a child/children with ASD. The majority of participants will recommend the group to other fathers of children with ASD.

## CHAPTER 3: METHODS

### Recruitment

Participants were recruited through six autism agencies providing services to families of children with ASD in a large urban area of a western Canadian province. The directors of the agencies emailed the recruitment notice through their client mailing list. In addition, participants were recruited through a provincial information and referral agency that supports individuals with ASD and their families in the province. Directors of this agency posted a study recruitment notice on their website and also emailed the notice in the bi-annual newsletter to a provincial mailing list. The recruitment notice (Appendix B) asked interested fathers to contact the researcher via phone or email for more information, in order to determine if they were eligible to participate in the study. It also informed potential participants that they would receive \$10 for every session they attended (to cover the cost of transportation and parking), plus an honorarium of \$20 for participating in the study, up to a maximum of \$100. Recruitment spanned a 6 month period.

In order to be eligible, fathers had to (a) be fluent in written and spoken English, (b) have parental responsibility for a child with ASD between the ages of 4-16, (c) be married or in a common-law relationship, (d) be committed to attending all eight weekly group sessions, and (e) not be receiving psychotherapy or taking medication for mental health issues. The researcher interviewed all potential participants by phone to describe what participation in the study would entail and to determine eligibility for the study, using a standard interview form (Appendix C).

### Participants

The first 12 fathers who expressed an interest in the study were all eligible and subsequently participated. Table 5 summarizes their demographic information.

**Table 5: Demographic Information for Participants**

<b>Participant (group)</b>	<b>Age</b>	<b>Ethnicity</b>	<b>Education</b>	<b>Relationship status</b>	<b>No. children (gender)</b>	<b>No. children with ASD (gender)</b>	<b>Annual gross household income</b>	<b>Occupation</b>
1 (Group 1)	42	Caucasian	College/trade school	Common law	2 (M, M)	1 (M)	High	I.T. Systems Administration
2 (Group 1)	43	Caucasian	Bachelors	Married	1 (M)	1 (M)	High	Software developer
3 (Group 1)	43	Persian	College/trade school	Married	1 (M)	1 (M)	Medium	Sales
4 (Group 1)	53	Caucasian	College/trade school	Married	2 (M, F)	2 (M, F)	Medium	Graphic designer
5 (Group 1)	56	Asian	College/trade school	Married	2 (F, F)	1 (F)	High	Banker
6 (Group 1)	54	Caucasian	College/trade school	Married	4 (M,M, F, F)	1 (M)	Medium	Business owner
7 (Group 2)	44	Caucasian	College/trade school	Married	2 (M, M)	1 (M)	Medium	Game artist
8 (Group 2)	43	Caucasian	Bachelors	Married	3 (M, M, F)	2 (M, M)	Low	Freelance writer – editor
9 (Group 2)	41	Caucasian	College/trade school	Married	3 (M, F, F)	3 (M, F, F)	Low	Auto upholstery
10 (Group 2)	34	Caucasian	College/trade school	Common law	1 (M)	1 (M)	High	Construction superintendent
11 (Group 2)	34	Asian	College/trade school	Married	2 (M, M)	2 (M,M)	High	Assistant service manager
12 (Group 2)	52	Caucasian	High school	Married	3 (M, F)	1 (M)	High	Flooring installer

*Note.* M = male; F = female ; High = \$100,000 - 150,000; Medium = \$70,000-99,000; Low = \$35,000-69,000;

**Age and Ethnicity**

Participants' mean age was 44.9 years ( $SD = 7.35$ ), ranging from 34 to 56 years. Two participants were Asian, one participant was Persian, and the remaining nine were Caucasian.

**Marital Status and Spousal Age**

Two participants were in common-law relationships and the remaining 10 were married. With the exception of one participant who was divorced and living in a common-law relationship with a new partner, all of the men were in relationships with the biological mothers of their child(ren) with ASD. The mean age of the spouses was 41 years ( $SD = 7.06$ ), ranging from 33 to 55.

**Children With and Without ASD**

The total number of children across all participants was 26 (9 females and 17 males). The mean age across all children was 9.19 years (range = 3-31;  $SD = 7.18$ ). The total number of children per family ranged from 1 to 4 ( $M = 2.17$ ,  $SD = .94$ ). The total number of children with ASD across all participants was 17 (3 females and 14 males). The mean age across all children with ASD was 7.06 years (range = 3-15;  $SD = 3.44$ ). The total number of children with ASD per family ranged from 1 to 3 ( $M = 1.42$ ,  $SD = .67$ ); 8 participants had one child with ASD, 3 had two children with ASD, and 1 had three children with ASD. Of the 12 participants, 6 fathers had children with autism only (i.e., they had no non-autistic offspring). For three of these fathers, the child with autism was an only child; the other three men had two or three children with autism each.

**Household Income**

Gross annual household income was divided into three categories: (a) low (\$35,000-\$69,000); (b) medium (\$70,000-\$99,000); and (c) high (\$100,000 - \$150,000). Two of 12

participants reported gross household annual incomes in the low range, 4 participants reported incomes in the medium range, and 6 participants reported incomes in the high range.

### **Education**

One of the participants did not complete high school, 9 completed college or trade school, and 2 completed a bachelor's degree.

### **Setting and Materials**

Group 1 took place in the board room of the provincial agency that distributed the recruitment forms, and Group 2 took place in a family meeting space belonging to a child development society. Snacks and refreshments (e.g., baked goods, fruit, coffee, water) were provided at each session. Participants were given name tags, to help them identify each other during group discussions. At the conclusion of all eight sessions for each group, participants were emailed two documents (one research article and one booklet) summarizing research on father involvement (*Father Factors: What Social Science Research Tells Us About Fathers and How to Work With Them*; Hoffman, 2011 and *The Effects of Father Involvement: An Updated Research Summary of Evidence*; Allen & Daly, 2007). The leader had described these resources to participants in the final two sessions and participants asked to have the documents sent to them for further reading. They were also emailed the title of a book of short essays written by fathers on the topic of parenting a child with special needs (*Uncommon Fathers: Reflections on Raising a Child with a Disability*; Meyer, 1995), which had also been described to participants in the final session.

### **Research Design**

This study employed a two-group pretest-posttest design (Creswell, 2003). Participants were assigned to one of the two groups based on their availability and geographic location; thus,

assignment to the groups was not random. Group 1 and Group 2 ran consecutively, beginning with Group 1. Both Group 1 and Group 2 consisted of eight weekly 2-hour sessions. During the eight weeks that Group 1 was underway, Group 2 engaged in no formal activities related to the study. The day after Group 1 completed its eighth and final session, Group 2 commenced and ran for eight weeks. During the eight weeks that Group 2 was underway, Group 1 engaged in no formal activities related to the study.

### **Dependent Variables and Measurement**

#### **Instrumentation**

All participants completed five standardized instruments: (a) the Beck Depression Inventory-II (BDI-II; Beck, Steer, & Brown, 1996); (b) the Dyadic Adjustment Scale (DAS; Spanier, 2001); (c) the Life Orientation Test – Revised (LOT-R; Scheier, Carver, & Bridges, 1994); (d) the Parenting Stress Index – 4th Edition – Short Form (PSI-4-SF; Abidin, 2012); and (e) the Ways of Coping Questionnaire (WCQ; Folkman & Lazarus, 1988). Participants in Group 1 completed the five instruments prior to beginning their group, upon completion of their group, and 4 months later. Participants in Group 2 completed the study instruments prior to beginning their own group and upon completion of their group. In addition, all participants completed a demographic form designed for the study at the time of initial data collection, and a social validity questionnaire regarding their experience of participating in the support group after the final session. The instruments were presented in random order to control for order effect.

**Beck Depression Inventory-II (BDI-II).** The BDI-II (Beck et al., 1996) is a 21-item self-report inventory designed to measure the severity of depression. Each item assesses a different symptom or attitude by asking the examinee to consider a group of graded statements that are weighted from 0 (not present) to 3 (severe) (e.g., “I feel sad much of the time”). A total

score is derived by summing the weights corresponding to the statements endorsed, over 21 items. The current item content includes: (a) sadness, (b) pessimism, (c) past failure, (d) loss of pleasure, (e) guilty feelings, (f) punishment feelings, (g) self-dislike, (h) self-criticalness, (i) suicidal thoughts or wishes, (j) crying, (k) agitation, (l) loss of interest, (m) indecisiveness, (n) worthlessness, (o) loss of energy, (p) changes in sleeping pattern, (q) irritability, (r) changes in appetite, (s) concentration difficulty, (t) tiredness or fatigue, and (u) loss of interest in sex. The BDI-II is interpreted using raw scores. Low raw scores are indicative of less depression, with scores between 0 and 13 indicating minimal depression, scores between 14 and 19 indicating mild depression, scores between 20 and 28 indicating moderate depression, and scores between 29 and 63 indicating severe depression. The BDI-II can be completed in 5 to 10 minutes.

Two samples were retained to evaluate the psychometric characteristics of the BDI-II: (a) a clinical sample (N = 500; 63% female; 91% White) who sought outpatient therapy at one of four outpatient clinics on the U.S. east coast, and (b) a convenience sample of Canadian college students (N = 120; 56% women; described as 'predominantly White'). Reliability was evaluated with multiple methods. Internal consistency was assessed using corrected item-total correlations (ranges: .39 to .70 for outpatients; .27 to .74 for students) and coefficient alpha (.92 for outpatients; .93 for students). Test-retest reliability ( $r = .93$ ) was assessed over a one-week interval among a small subsample of 26 outpatients from one clinic site. The test authors also examined the item-option characteristic curves for each of the 21 BDI-II items as endorsed by the 500 outpatients. In general, response option weights of the BDI-II items do discriminate across estimated levels of depression severity, although the manual does not provide a detailed discussion of item-option characteristic curves and their interpretation.

The validity of the BDI-II was evaluated with outpatient subsamples of various sizes.

Regarding convergent validity, the BDI-II displayed moderately high correlations with the Beck Hopelessness Scale ( $r = .68$ ) and the Revised Hamilton Psychiatric Rating Scale for Depression ( $r = .71$ ). The correlation between the BDI-II and the Revised Hamilton Anxiety Rating Scale ( $r = .47$ ) was significantly less than that for the BDI-II and HRSD-R, which was cited as evidence of the BDI-II's discriminant validity. The BDI-II, however, did share a moderately high correlation with the Beck Anxiety Inventory ( $r = .60$ ), a finding consistent with past research on the strong association between self-reported anxiety and depression (e.g., Kendall & Watson, 1989).

**Dyadic Adjustment Scale (DAS).** The Dyadic Adjustment Scale (DAS; Spanier, 2001) is a 32-item self-report instrument designed to measure the quality of adjustment between marital couples or other partners in a dyadic relationship. Respondents indicate the extent to which they agree or disagree with their partner on some items, and they rate how often they engage in various activities with their partner on other items. The items are scored on a Likert scale, ranging from 5- to 7-point responses. Two items are answered either “yes” or “no.” Example items include “How often do you or your mate leave the house after a fight?” with ratings ranging from “All the time” to “Never;” and “Do you and your mate engage in outside interests together?” ranging from “All of them” to “None of them.” The DAS yields a total adjustment score and four subscales, each of which can be calculated and used separately. The four subscales are Dyadic Consensus (13 items), which measures the extent of agreement between couples on matters such as finances, recreation, friends, and religion; Dyadic Satisfaction (10 items), which measures satisfaction with the current relationship and willingness to continue; Dyadic Cohesion (5 items), which measures activities and interests shared by the couple; and Affectional Expression (4 items), which measures satisfaction with expression of affection

between the couple. Scores of one respondent can be analyzed individually, or the independent ratings of both partners can be compared to ascertain how their ratings converge and differ. Scores range from 0 to 151, with higher scores reflecting a higher perception of the quality of the relationship. In the DAS manual, Spanier (2001) noted that, although not recommended for individual clinical use, the practice of using total raw scores of less than 100 as a criterion for identifying poor dyadic adjustment is “frequently used in the research literature” (p. 14). The DAS can be completed in 5 to 10 minutes.

The DAS was developed in 1976 by compiling a pool of 300 items that had appeared in approximately 17 previously used inventories dating back to 1933. After eliminating duplicate items, three judges other than the author deleted those items they deemed to be lacking in content validity. The remaining pool of 200 items was submitted to two test groups whose responses were used to construct the 32-item instrument. The normative data included a sample of 218 married individuals and 94 newly divorced individuals. These two test groups yielded the norms that are often used as a standard against which couples' responses are evaluated. The mean total raw scores for the married and divorced individuals were 114.8 (SD = 17.8) and 70.7 (SD = 23.8), respectively, and differed significantly ( $p < .001$ ).

Cronbach's alpha of the total scale and the subscales in the original study was .96 (Total Scale), .90 (Dyadic Consensus), .73 (Affectional Expression), .94 (Dyadic Satisfaction), and .86 (Dyadic Cohesion). Alpha reliabilities for the total scale of .90 and above have been found consistently by other researchers (e.g., Kim, 2012). Data collected by other investigators showed that partners achieve a moderate level of agreement (from .44 to .87 for various subscales) in ratings of their relationship, and it has been shown that the DAS has moderate to high test-retest reliability (e.g., Carey, Spector, Latinga, & Krauss, 1993).

Data from a variety of studies were presented by the author to establish the concurrent and predictive validity of the DAS. For example, low scorers have a higher probability of domestic violence, greater depression, more family dysfunction, and poorer communication. Not surprisingly, high convergent validity is reported between the DAS and the Locke-Wallace Marital Adjustment Scale (Locke & Wallace, 1959), to which it is closely related.

**Life Orientation Test – Revised (LOT-R).** The Life Orientation Test – Revised (LOT-R; Scheier, Carver, & Bridges, 1994) is a 10-item self-report instrument designed to assess generalized expectancies for positive versus negative outcomes. Of the six items that are scored, three are worded in a positive direction and three are worded in a negative direction; there are also four filler items that are not scored. Respondents are asked to indicate the extent of their agreement with each of the items, using the following response format: 0 = strongly disagree, 1 = disagree, 2 = neutral, 3 = agree, and 4 = strongly agree. Examples include, “In uncertain times, I usually expect the best” and “I hardly ever expect things to go my way.” Negatively worded items are reverse coded before scoring. Responses to the six items are scored, yielding a total score that can range from 0 to 24, with higher scores representing greater optimism.

Despite its popularity, the original LOT scale (Scheier & Carver, 1985) was criticized by others, with most of the criticism focusing on the third variable problem, namely, whether effects attributable to optimism might be due to variance that optimism shares with a third variable such as neuroticism, trait-anxiety, or coping. Hence, the LOT-R, a revised version, was developed by deleting two items that were more strongly associated with coping than with positive outcome expectancy (Scheier et al., 1994).

The normative sample for the LOT-R consisted of 2,055 undergraduates (622 women, 1,394 men, and 39 who did not indicate their gender) from Carnegie Mellon University in

Pittsburgh. Item-scale correlations ranged from .43 to .63, suggesting that each item was partially measuring the same underlying construct, but not to such an extent as to be redundant with other items. Cronbach's alpha for the entire six items was .78, suggesting an acceptable level of internal consistency. Test-retest reliability of the LOT-R was tested at 4 months (.68), 12 months (.60), 24 months (.56), and 28 months (.79), suggesting that the LOT-R is fairly stable across time. To determine convergent validity, correlations were calculated between the LOT-R and conceptually related measures, measuring self mastery ( $r = .48$ ), self esteem ( $r = .50$ ), and the original LOT ( $r = .95$ ). Divergent validity was calculated by correlating the LOT-R with measures of anxiety ( $r = -.53$ ) and neuroticism ( $r = -.36$ ).

Despite its strong psychometric properties and widespread use, population-based norms for the LOT-R have not been available until recently, which has meant an inability to compare individual or group scores with reference data, and a lack of interpretive guidelines. However, Glaesmer et al. (2013) conducted a population survey in Germany to investigate the psychometric properties of the LOT-R and deliver population-based norms. A representative sample (with respect to age, gender, and education) of the German general population was selected, for a total of 2,372 participants (1,073 males and 1,299 females) between ages 18-93. The total mean raw score for the entire sample of men was 15.3 (SD = 4.0, range = 14.6 – 16.1), which was comparable to both the total mean raw score for women ( $M = 15.0$ , SD = 3.7, range 14.4 – 15.5) and for all participants combined ( $M = 15.2$ , SD = 3.8, range 14.6 – 15.8)

**Parenting Stress Index – 4<sup>th</sup> Edition Short Form (PSI-4-SF).** The PSI-4-SF (Abidin, 2012) is an abbreviated version of the full (120-item) PSI-4, and is similarly designed to evaluate the magnitude of stress in the parent-child system. The 36 items in the PSI-4-SF are drawn verbatim from the full-length form, and are broken into three domains: (a) Parental Distress

(PD), (b) Parent-Child Dysfunctional Interaction (P-CDI), and (c) Difficult Child (DC), which combine to form a Total Stress scale. The Parental Distress scale assesses the level of stress a parent reports as a function of personal factors directly related to parenting. The Parent-Child Dysfunctional Interaction scale assesses the extent to which the parent perceives the child as not meeting expectations and finds that interactions with the child are not reinforcing his/her parenting role. The Difficult Child scale assesses the temperament or behavioural characteristics of the child that influence the parent-child relationship. The Total Stress scale assesses the overall level of parenting stress experienced by the respondent. Items are scored on a 5-point Likert scale, with a response of 5 indicating “strongly agree” and 1 meaning “strongly disagree” (e.g., “I feel trapped by my responsibilities as a parent”). There is also one validity scale (Defensive Responding), which aims to determine whether the parent is responding in a defensive manner. Total raw scores can range from 36 to 180, with higher scores reflecting higher levels of parenting stress. Administration time is approximately 10 minutes.

The PSI-4-SF utilizes both *T* scores and percentiles for normative metrics. Like the full-length PSI-4, the primary interpretive framework of the PSI-4-SF is percentile-based, although *T* scores are used when comparing scores across subscales. The “normal” range for total raw scores is between the 16<sup>th</sup> to 84<sup>th</sup> percentiles (i.e., scores between 54-109). Scores between the 85<sup>th</sup> to 89<sup>th</sup> percentiles are considered “high” (i.e., scores of 110-113), and scores at or above the 90<sup>th</sup> percentile (i.e., scores of 114 and above) are considered “clinically significant.”

The PSI-4-SF was originally developed through a series of factor analyses, using data gathered from the 534 mothers who completed the full-length PSI-4. Only items that loaded greater than .40 on a given factor were retained. Replications of the original three factor structure suggested that the factor structure was fairly stable and adequately described the instrument.

Internal consistency on the four subscales ranges from .88 to .95. Test-retest reliability was assessed over a 6-month period and was .84 for the Total Stress scale, .85 for Parental Distress, .68 for Parent-Child Dysfunctional Interaction, and .78 for Difficult Child. Correlations between the PSI-4-SF and the full-length PSI-4 normative sample have been calculated. The correlation between the Total Stress scale of the full-length PSI-4 and the Total Stress scale of the PSI-4-SF was .98. The correlation between the Parental Distress subscale score and the Parent Domain score of the full-length PSI-4 was .94. The correlation between the Difficult Child subscale score and the Child Domain score of the full-length PSI-4 was .95. The correlations between the Parent-Child Dysfunctional Interaction subscale and the Child Domain and Parent Domain scores of the full-length PSI-4 were .91 and .82, respectively. Correlations between the PSI-SF and the PSI-4-SF ranged from .97 to .99. The manual states that “because the PSI-4-SF is a direct derivative of the full-length PSI, it likely will match the full-length PSI in validity” (p. 62). Validity in the full-length PSI has been investigated in studies examining at-risk children, attachment, ADHD, child abuse, forensic contexts, medical treatment adherence, substance abuse, and parental depression.

**Ways of Coping Questionnaire (WCQ).** The Ways of Coping Questionnaire (Folkman & Lazarus, 1988) is 66-item instrument designed to “identify the thoughts and actions an individual has used to cope with a specific stressful encounter” (Folkman & Lazarus, 1988, p. 6). The WCQ is described as an “evolving strategy for measurement” rather than a test, and that it measures coping processes rather than coping styles. The authors defined coping as “the cognitive and behavioral efforts to manage specific external and/or internal demands appraised as taxing or exceeding the resources of the individual” (p. 7). They described this definition as containing four key features: (1) it is process-oriented, (2) it emphasizes management rather than

mastery, (3) it makes no a priori judgment about the quality of coping processes, and (4) it implies a stress-based distinction between coping and automatic adaptive behaviours. The rationale underlying the instrument is that it examines how people cope with stress, rather than stress per se, and is related to a person's physical, social, and psychological well-being. Coping is viewed as a dynamic, multidimensional interaction between the individual and the environment. Furthermore, the quality of coping is viewed within the context in which it occurs; therefore, a coping strategy may be maladaptive in one situation but adaptive in another.

To complete the WCQ, respondents are asked to think about the most stressful situation they have experienced in the past week, and then to rate the frequency with which they used various strategies on a 4-point Likert scale ranging from 0 (does not apply) to 3 (used a great deal). Administration time is 5 to 10 minutes. Both raw and relative scores can be calculated for the WCQ. High raw scores indicate that the person used the behaviours described by a scale often, in order to cope with a stressful event. Relative scores describe the proportion of effort represented by each type of coping and are expressed as a percentage between 0 and 100. Lapp and Collins (1993) argued that the relative scoring method "introduces an artifact that...ignores an individual's general reactivity to problems" (p. 483) and suggested that raw scores be used to more accurately reflect the strength of specific coping strategies.

The sample for the derivation of the WCQ coping scales consisted of 750 observations from 75 married, Caucasian couples ( $n = 150$ ) with at least one child living at home. Three separate factor analyses yielding similar factor patterns were performed on: (a) the entire set of 750 observations; (b) a subset of 150 stressful encounters, one per participant equally representing the five occasions; and (c) a second set of 150 observations selected from the remaining 600 items, with one observation per person equally representing the five occasions.

Those items that did not load consistently on the same factor were eliminated, and a final principle factor analysis was performed on the remaining 50 items, resulting in eight factors. The eight scales and their means and standard deviations (based on normative data from the 150 participants) are Confrontive Coping ( $M = 3.94$ ,  $SD = 2.09$ ); Distancing ( $M = 3.05$ ,  $SD = 1.78$ ); Self-Controlling ( $M = 5.77$ ,  $SD = 2.87$ ); Seeking Social Support ( $M = 5.40$ ,  $SD = 2.40$ ); Accepting Responsibility ( $M = 1.87$ ,  $SD = 1.44$ ); Escape-Avoidance ( $M = 3.18$ ,  $SD = 2.48$ ); Planful Problem Solving ( $M = 7.25$ ,  $SD = 2.34$ ); and Positive Reappraisal ( $M = 3.48$ ,  $SD = 2.96$ ). Confrontive Coping describes aggressive efforts to alter the situation and suggests some degree of hostility and risk-taking (e.g., “I expressed anger to the person(s) who caused the problem”). Distancing describes cognitive efforts to detach oneself and to minimize the significance of the situation (e.g., “I went on as if nothing had happened”). Self-Controlling describes efforts to regulate one's feelings and actions (e.g., “I kept others from knowing how bad things were”). Seeking Social Support describes efforts to obtain informational, tangible, and emotional support (e.g., “I talked to someone about how I was feeling”). Accepting Responsibility acknowledges one's role in the problem and attempts to rectify the situation (e.g., “I criticized or lectured myself”). Escape-Avoidance describes wishful thinking or escape behaviours (e.g., “I refused to believe it had happened”). Planful Problem-Solving describes deliberate, analytic problem-focused efforts to remedy the situation (e.g., “I made a plan of action and followed it”). Finally, Positive Reappraisal describes efforts to create positive meaning through personal growth (e.g., “I changed or grew as a person in a good way”).

With respect to reliability, Folkman and Lazarus (1988) asserted that test-retest measures are not appropriate because the WCQ measures coping *processes*, “which, by definition, are variable” (p. 17). Instead, they reported internal consistency estimates for each scale using

Cronbach's coefficient alpha, ranging from .61 to .79. The authors presented references to current research supporting the reliability and stability of the factor structure across various populations, but specific information (e.g., means, standard deviations, levels of significance, factor loadings) from the research was not provided in the manual.

Regarding validity, the authors reported that the items have face validity because they are directly derived from interviews with individuals who have reported how they coped with the demands of stressful situations. The authors reported that “[e]vidence of construct validity is found in the fact that the results of our studies are consistent with our theoretical predictions,” p. 18), but they did not provide specific information to support this claim.

**Demographic Form.** The demographic form for the study (see Appendix D) was a two-page inventory that asked participants to provide personal information including age, occupation, income, level of education, marital status, age of the child with ASD, date of the child’s ASD diagnosis, ages of other children in the family, and diagnoses of other children with a disability.

**Social Validity Questionnaire.** A form with seven open-ended questions was used to solicit information about participants’ experiences in the support group, including information about the most and least enjoyable aspects of participating in the group, suggested changes to the group structure and session content, and the group leader’s performance (see Appendix E).

### **Independent Variables**

Group 1 and Group 2 were structured identically. Both groups consisted of eight weekly, 2-hour sessions and were led by the researcher, who is a Board Certified Behavior Analyst (BCBA) with masters degrees in both special education (with emphasis on ASD) and counselling psychology. Both groups were of fixed/closed membership, meaning that the same participants attended a group from beginning to end, and no new participants were added after a group had

begun.

### **General Session Structure**

Both groups followed the same general format. Snacks and refreshments were situated on a table in the centre of the group and available throughout the session. No formal breaks occurred during the session. Participants were given the first 5 minutes to enter, greet other members, get settled and seat themselves, and prepare themselves to participate in the group discussion. During this time, the group leader recorded attendance. The group leader then began the session by greeting the members and briefly summarizing some of the main themes and discussions that had occurred during the previous group meeting. She then asked the group members to talk about their own impressions or reflections regarding the previous week's discussion, typically by asking, "What did you take away from the group last week?" Once group members had discussed their impressions and thoughts about the previous session, the leader introduced the current session topic and began facilitating the discussion.

Approximately 10 to 15 minutes before the session concluded, the leader reminded the group that the session would be ending soon and assisted group members to wrap up the discussion and "tie up loose ends," ensuring that there were no unresolved or outstanding issues and that group members were ready to end the group and leave. Before officially ending the group, the leader reminded group members about the next meeting date, time, and proposed topic to be discussed.

## **Leadership Style**

The leader's role in the group was that of a facilitator who primarily assisted the group rather than overtly leading or directing it (Nichols & Jenkinson, 2006). Thus, the leader adopted more of a suggestive, guiding interaction style with the aim of connecting relevant information; she identified themes that emerged in the course of the discussion and helped group members identify, explore, and share their thoughts, feelings, and experiences. This took the form of statements/observations about what was occurring in the group (e.g., "A number of you have said that you want to get your wife to step back and take a break from childcare, but you don't know how to convince her to do this, and it's frustrating"); or asking questions of the group or of specific individuals that were designed to prompt further discussion and reflection (e.g., "How will you take what you've learned in this group with you into your everyday life, to help you keep making changes and moving forward?") When appropriate, the leader provided ASD-specific resources or information on how and where to access such resources, typically by emailing the group after it had been discussed during a session. The leader was also responsible for monitoring time and adhering to the agreed-upon schedule, and for monitoring the group's behaviour to determine whether the group was "on-track" and making progress towards the objectives. In some cases, if the group appeared to be engaged in unproductive work that interfered with its progression (e.g., if a significant amount of time was spent joking and avoiding deeper discussion of a topic), the leader intervened to redirect the discussion.

## **Session Topics**

Although there were specific topics to be addressed each week, session content varied slightly based somewhat on the group members' experiences, interests, and interpersonal interactions. Thus, the agenda was somewhat flexible, to allow for group member input, which

(when agreed upon) sometimes resulted in minor changes to the session structure and content.

The following topics were used to guide the agenda for each group:

- Session 1: Introduction to the support group (discussion of group norms, session structure, group leader and members' roles); introduction of individual group members, including information about each participant's child with ASD and other immediate family members; and a discussion of participants' first experiences with their child's difference/disability and the diagnostic/assessment process;
- Session 2: Being an advocate and team player; working with professionals (e.g., teachers, speech-language pathologists); finding effective, quality treatment for the child;
- Session 3: Being a coworker/supervisor, friend; how having a child with ASD impacts relationships with colleagues and friends; social concerns and considerations;
- Session 4: How having a child with ASD affects relationships with immediate and extended family members (e.g., spouse, other children); cultural concerns and considerations;
- Session 5: Being a spouse/husband/partner; how having a child with ASD affects the relationship with the wife/partner;
- Session 6: Looking to the future and contemplating lifespan issues regarding the child's development; hopes, dreams, fears, reflections;
- Session 7: Re-defining and re-developing one's self as a parent, partner, and person; new identities; new directions and how to continue making changes that promote improved mental health and quality of life;
- Session 8: Reviewing/debriefing the support group, wrap up, feedback; recognition and validation of fathers; completion of questionnaires.

## **Procedures**

Group 1 and Group 2 each ran consecutively for eight weeks, beginning with Group 1. The following section describes the data collection procedures for both groups for the specific phases of the study.

### **Pretest**

One to two weeks prior to the commencement of each group, the researcher met with each participant individually in both Group 1 and Group 2 in a private and convenient location (e.g., the participant's home) to complete the study measures. The researcher provided an instruction sheet related to the study measures and asked the participant to read the instructions. The participant was asked if he had any questions, and the researcher answered any questions. The participant completed all of the study forms except for the social validity questionnaire, a process that required approximately 45 to 60 minutes. The researcher remained in attendance until all of the forms were completed and checked each form to ensure that it had been accurately completed. If any of the forms were incomplete, the participant was asked to answer the unanswered questions, and the researcher departed after all paperwork had been entirely completed.

### **Support Group**

Following pretest data collection for each group, each support group commenced for 8 weeks, as described in a previous section (see Independent Variables). Group 1 and Group 2 ran consecutively, beginning with Group 1. During the time that Group 1 was underway, the researcher had no contact with Group 2 participants. During the time that Group 2 was underway, the researcher had no contact with the Group 1 participants.

## Posttest

Upon conclusion of each support group, all participants in both Group 1 and Group 2 completed the same set of measures as in Pretest except for the demographic form. In addition, all participants filled out the social validity questionnaire. Participants in both groups completed measures at the end of the final group session in the same room where each group had met.

## Follow-Up

Approximately 4 months after Group 1 concluded, participants in this group completed all measures except for the demographic form and the social validity questionnaire. With the exception of one participant, the other five participants met as a group to complete the questionnaires, in the same room where the support group had originally taken place. The researcher met with the sixth and final participant (who was unable to attend the group meeting to complete the questionnaires) in a café the following night.

Table 6 summarizes the timeline for study conduct and data collection for both groups.

**Table 6: Timeline for Study Conduct and Data Collection**

Group	Weeks						
	1-2	3-10	11-12	13-20	21	22-25	26
Group 1	Pretest	Support group	Posttest	No activity	No activity	No activity	Follow- up
Group 2	No activity	No activity	Pretest	Support group	Posttest	No activity	No activity

## Data Analysis

Data analysis for Questions 1 and 2 was conducted using SPSS, Version 21. Question 1, which compared pre- and post-treatment scores for Group1 and Group 2 after completion of the

intervention, was addressed via a series of 2X2 mixed model analyses of variance (ANOVAs) with Time as the within subjects factor and Group as the between subjects factor. Because of the small sample size and because this study was exploratory in nature (i.e., it was the first study to use psychometrically valid measures to assess the impact of an ASD support group for fathers), a Bonferroni adjustment was not applied during the analysis. In addition, two-tailed t-tests were conducted when an ANOVA indicated a significant main effect or interaction, because it was not possible to generate directional hypotheses based on previous research. Question 2, which compared 4-month follow-up scores for Group 1 with pre- and post-treatment scores for this group, was addressed using a series of paired samples t-tests. Question 3, which assessed participants' impressions about the utility of the group and what they found most helpful about participation, was addressed by analyzing participants' written responses to a social validity questionnaire.

The first step for the ANOVA analyses was to examine the data to determine whether the relevant assumptions were met. Checking the studentized residuals revealed no outliers (i.e., any residuals  $\geq \pm 3$ ) for all pre-treatment and post-treatment variables for both Group 1 and Group 2. The assumption of sphericity was not evaluated because this assumption is always met for two levels of a repeated measures analysis (Hinton, Brownlow, & McMurray, 2004). The assumption of normality was evaluated using both the Shapiro-Wilk and Kolmogorov-Smirnov tests, because there is considerable disagreement among statisticians about which test is preferred, especially when examining small samples (Razali & Wah, 2011). According to both tests, the normality assumption was met for all pre-treatment and post-treatment variables for both Group 1 and Group 2, with the exception of the BDI pre-treatment scores. The normality assumption was also met for the follow-up data for Group 1 on all measures. For both groups, the normality

assumption for the pre-treatment BDI was met using the Kolmogorov-Smirnov test but not using the Shapiro-Wilk test. Thus, the skewness of the pre-treatment BDI was further evaluated by calculating Fisher's coefficient, which requires dividing the SPSS-generated skewness scores by the standard errors for skewness to produce z-scores (Pett,1997). If a z-score exceeds 1.96 ( $p>.05$ ), the distribution is asymmetric and significantly skewed. Results indicated the pre-treatment BDI z-score was .788 which was not significant. Given this result, combined with the controversy that exists about the applicability of normality tests for small samples in general (Razali & Wah, 2011), a decision was made to proceed with parametric analysis using a mixed-model ANOVA, since the indicators of normality appeared to be met.

## CHAPTER 4: RESULTS

The objectives of the study were to design and evaluate the impact of an 8-week support group for 12 fathers of children with ASD, using quantitative measures to examine participants' psychological experiences and a measure of social validity.

In the following sections, each of the research questions will be presented, along with the hypothesis and results for each.

### Quantitative Results

**Question 1.** After completion of the support groups for both Group 1 and Group 2, is there a significant main effect for either Group or Time, or a significant Time X Group interaction with regard to measures of depression, marital adjustment, optimism, parenting stress, and coping strategies? Hypothesis: There will be no Time X Group interaction on any of the measures. There will be no significant effect for Group on any of the measures. However, there will be a significant main effect for Time, with significant differences between pre- and post-support group scores on one or more of the measures.

### Depression (BDI-II)

The BDI-II is interpreted using raw scores. Low scores on the BDI-II are indicative of less depression, with total scores between 0 and 13 indicating “minimal” depression, scores between 14 and 19 indicating “mild” depression, scores between 20 and 28 indicating “moderate” depression, and scores between 29 and 63 indicating “severe” depression (Beck, Steer, & Brown, 1996). Table 7 displays the outcomes of the BDI-II for both groups.

**Table 7: Total Raw Score Means and Standard Deviations for the BDI-II**

Group	Mean (Range)		SD	
	Pre	Post	Pre	Post
1	8.50 (2-17)	9.83 (0-18)	6.83	6.08
2	8.67 (1-20)	7.0 (0-15)	8.36	6.20

The mean raw BDI-II scores for both groups fell within the “minimal” depression range at both pre- and post-treatment; thus, neither group showed evidence of clinically significant levels of depression at any point during the study. Examination of the ranges indicates that, with the exception of one Group 2 father who was moderately depressed pre-treatment, fathers in both groups ranged from minimal to mild depression throughout the study. The outlier Group 2 father moved from borderline moderate to mild depression (i.e., his BDI-II raw scores decreased 14 points, from 20 to 6) following completion of the support group.

Results of a mixed model ANOVA showed no Group X Time interaction,  $F(1,10) = .651$ ,  $p = .438$ , partial eta squared ( $\eta^2$ ) = .061. Similarly, there was no main effect for either Time,  $F(1,10) = .008$ ,  $p = .930$ , partial  $\eta^2 = .001$ , or Group,  $F(1,10) = .142$ ,  $p = .714$ , partial  $\eta^2 = .014$ . The hypothesis was partially confirmed: there was no significant Group X Time interaction, and no significant main effect for Group. However, contrary to the hypothesis, there was no significant main effect for Time.

### **Marital Satisfaction (DAS)**

Total raw scores on the DAS can range from 0 to 151, with higher scores reflecting a higher quality marital relationship. Total raw scores of less than 100 are indicative of “poor dyadic adjustment.” Table 8 displays the outcomes of the DAS for both groups.

**Table 8: Total Raw Score Means and Standard Deviations for the DAS**

Group	Mean (Range)		SD	
	Pre	Post	Pre	Post
1	99.50 (62-128)	95.83 (62-119)	31.66	24.34
2	97.67 (74-115)	104.83 (87-125)	15.28	15.97

Examination of the total raw score means indicates that both Group 1 ( $M = 99.50$ ) and Group 2 ( $M = 97.67$ ) scored at the borderline of “poor dyadic adjustment” at pre-treatment. At post-treatment, the total raw score mean of Group 1 (95.83) was in the “poor dyadic adjustment” range, whereas the score for Group 2 (104.83) was slightly above the cutoff score of 100. Five of the 6 Group 1 participants reported increased levels of dyadic satisfaction from pre- to post-treatment, as reflected in total raw score changes that ranged from +5 to +13. Group 2 scores showed the opposite pattern, with 5 of the 6 participants in this group reporting decreased levels of dyadic satisfaction from pre- to post-treatment, with raw score changes ranging from -1 to -15.

Results of a mixed model ANOVA showed a significant Group X Time interaction,  $F(1,10) = 5.52, p = .041, \text{partial } \eta^2 = .356$ . To evaluate significance, paired samples t-tests were computed separately for each group. Results indicated no significant difference over time for Group 1,  $t(5) = .954, p = .384$ , but a significant difference for Group 2  $t(5) = -2.812, p = .037$ . Thus, the hypotheses were partially confirmed; there was a significant Group X Time interaction, and Group 2 showed improvement in this measure while Group 1 did not.

### **Optimism (LOT-R)**

Total raw scores on the LOT-R can range from 0 to 24, with higher scores reflecting greater optimism (Scheier, Carver, & Bridges, 1994). Table 9 displays the outcomes of the LOT-

R for both groups.

**Table 9: Total Raw Score Means and Standard Deviations for the LOT-R**

Group	Mean (Range)		SD	
	Pre	Post	Pre	Post
1	14.67 (1-22)	15.0 (5-19)	7.45	5.55
2	18.17 (12-24)	17.83 (12-21)	4.83	4.22

Examination of the total raw score means indicates optimism scores that were stable from pre- to post-treatment for both groups. Group 1 scores showed greater variability, as indicated by the standard deviations and ranges. Overall, Group 2 reported slightly higher levels of optimism both pre- and post-treatment ( $M = 18.17$  and  $17.83$ , respectively) than Group 1 ( $M = 14.67$  and  $15.0$ , respectively). Group 1's mean raw scores at pre- and post-treatment were similar to the population-based norm mean of  $15.3$  (for men) reported by Glaesmer et al. (2012), while Group 2's pre- and post-treatment mean raw scores were slightly higher than the norm.

Results of a mixed model ANOVA showed no Group X Time interaction,  $F(1,10) = .328$ ,  $p = .58$ , partial  $\eta^2 = .032$ , and no significant difference for Group,  $F(1,10) = .976$ ,  $p = .347$ , partial  $\eta^2 = .089$ . The total pre -and post-treatment mean scores across groups were identical ( $M = 16.42$ ), so the main effect for Time could not be computed. The hypothesis was partially confirmed: there was no significant Group X Time interaction, and no significant main effect for Group. However, contrary to the hypothesis, there was no main effect for Time.

### **Parenting Stress (PSI-4-SF)**

Total raw scores on the PSI-4-SF can range from 36 to 180, with higher scores reflecting higher levels of parenting stress. The “normal” range of scores is between the 16<sup>th</sup> to 84<sup>th</sup>

percentiles (i.e., total raw scores of 54-109). Scores between the 85<sup>th</sup> to 89<sup>th</sup> percentiles are considered “high” (i.e., total raw scores of 110-113), and scores at or above the 90<sup>th</sup> percentile (i.e., total raw scores of 114 and above) are considered “clinically significant” (PSI-4-SF; Abidin, 2012). Table 10 displays the outcomes of the PSI-4-SF for both groups.

**Table 10: Raw Score Means, Percentiles, and Standard Deviations for the PSI-4-SF**

Group	Mean (Range)		Percentile		SD	
	Pre	Post	Pre	Post	Pre	Post
1	96.17 (63-133)	92.83 (56-130)	75	74	23.91	28.72
2	104.67 (81-125)	99.83 (80-116)	81	77	15.40	13.64

Examination of the mean percentiles indicates that both groups scored within the “normal” range of parenting stress (i.e., between the 16<sup>th</sup> and 84<sup>th</sup> percentile) at both pre- and post-treatment. However, examination of the ranges indicates variability among the participants in both groups, with 4 of the 12 fathers scoring at or close to the “clinically significant” range of stress (i.e., at or above the 90<sup>th</sup> percentile) at pre-treatment. Of these four fathers, two (one in the Group 1 and one in Group 2) continued to report elevated parenting stress at post-treatment, and the other two (both in Group 2) reported parenting stress in the normal range at post-treatment.

Results of a mixed model ANOVA showed no Group X Time interaction,  $F(1,10) = .042$ ,  $p = .843$ , partial  $\eta^2 = .004$ . There was no significant main effect for either Group,  $F(1,10) = .435$ ,  $p = .525$ , partial  $\eta^2 = .042$ ; or Time,  $F(1,10) = 1.232$ ,  $p = .293$ , partial  $\eta^2 = .110$ . Thus, the hypothesis was partially confirmed: there was no significant Group X Time interaction, and no significant main effect for Group. However, contrary to the hypothesis, there was no significant main effect for Time.

**Coping (WCQ)**

The WCQ examines specific coping strategies that are classified into eight individual scales, so scores are not calculated for the measure as a whole. Higher raw scores indicate that the person used the behaviours described by a scale more often, in order to cope with a stressful event (Folkman & Lazarus, 1988). Table 11 displays the total raw score means, standard deviations, and outcomes of 2X2 ANOVAs for the eight scales.

**Table 11: Total Raw Score Means and Standard Deviations for WCQ Scales Across Time and Groups**

Scale	Group 1 Pre		Group 1 Post		Group 2 Pre		Group 2 Post		Significant results?
	<i>M</i>	SD	<i>M</i>	SD	<i>M</i>	SD	<i>M</i>	SD	
Confrontive coping	4.0	1.90	5.0	2.28	10.0	4.0	9.50	5.01	$p = .019$ , Group
Distancing	4.67	2.58	5.17	3.25	8.0	4.86	5.33	5.28	no
Self-controlling	10.83	3.49	8.67	4.08	9.83	3.43	8.33	6.31	no
Seeking social support	7.5	1.38	5.83	3.43	7.17	3.49	4.17	4.40	no
Accepting responsibility	1.83	1.72	3.50	2.26	5.17	3.87	4.83	2.99	no
Escape avoidance	3.83	3.43	3.67	3.50	9.50	4.32	8.83	3.71	$p = .025$ , Group
Planful problem solving	9.33	3.93	10.33	3.33	7.67	4.27	10.0	4.29	no
Positive reappraisal	3.83	2.64	5.0	3.23	7.33	4.13	5.17	4.07	no

There was no Group X Time interaction and no main effect for Time for any of the coping strategies. However, there was a main effect for Group with regard to Confrontive Coping,  $F(1,10) = 7.81$ ,  $p = .019$ , partial  $\eta^2 = .439$ ; and Escape Avoidance,  $F(1,10) = 6.89$ ,  $p =$

.025, partial  $\eta^2 = .408$ . To follow up, independent sample t-tests were then conducted to examine the pre-treatment scores for the two relevant scales in more detail. Results indicated that, for Confrontive Coping, there was a significant difference in pre-treatment scores  $t(10) = -3.320, p = .008$ , with Group 2 showing higher mean scores ( $M = 10.0$ ) than Group 1 ( $M = 4.0$ ). Similarly, for Escape Avoidance, there was a significant difference in pre-treatment scores  $t(10) = -2.515, p = .031$ , with Group 2 showing higher mean scores ( $M = 9.5$ ) than Group 1 ( $M = 3.83$ ). Thus, both before and after the support group intervention, Group 1 was more prone to use both Confrontive Coping and Escape Avoidance strategies than Group 2; however, no changes over time were evident for either group. Thus, the hypothesis was partially confirmed: there was no Time X Group interaction. However, contrary to the hypothesis, there was a significant main effect for Group and there was no significant main effect for Time.

**Question 2.** For Group 1, are there significant differences on measures of depression, marital adjustment, optimism, parenting stress, and coping strategies between pre-treatment and 4-month follow-up or between post-treatment and 4-month follow-up?

Hypothesis: There will be significant differences scores between pre-treatment and 4-month follow-up and between post-treatment and follow-up on one or more of the measures.

### **Follow-Up Assessment**

Paired samples t-tests were used to compare both pre-treatment and follow-up scores and post-treatment and follow-up scores on all measures for Group 1. Table 12 displays the outcomes of the follow-up analyses.

**Table 12: Total Raw Score Means and Standard Deviations for Group 1 Follow-Up****Analyses**

Comparison	Mean			SD		
	Pre	Post	Follow-up	Pre	Post	Follow-up
BDI-II total	8.5	9.83	8.83	6.83	6.08	6.88
DAS total	99.5	95.83	102.33	31.66	24.34	29.73
LOT-R total	14.67	15.0	15.83	7.45	5.55	4.67
PSI-4-SF total	96.17	92.83	100.67	23.91	28.72	28.24

*Note:* Pre = pre-treatment scores; Post = immediate post-treatment scores

Results of the statistical analyses revealed no significant differences between pre-treatment and follow-up scores for any of the measures (BDI-II:  $t(5) = -.111, p = .916$ ; DAS:  $t(5) = -.741, p = .492$ ; LOT-R:  $t(5) = -.782, p = .470$ ; or PSI-4-SF:  $t(5) = -1.79, p = .133$ ). Similarly, no significant differences were found between post-treatment and follow-up scores for any of the measures (BDI-II:  $t(5) = .791, p = .465$ ; DAS:  $t(5) = -2.33, p = .067$ ; LOT-R:  $t(5) = -1.27, p = .259$ ; or PSI-4-SF:  $t(5) = -1.79, p = .133$ ). Thus, the hypothesis was confirmed with regard to the stability of scores between post-treatment and follow-up but not with regard to a change between pre-treatment and follow-up.

**Individual Differences**

Although the majority of the quantitative findings were statistically non-significant and – with the exception of Group 2 DAS scores – no improvements in psychological functioning were observed within or between groups, there were a number of changes in individual scores in the positive direction, indicating improvements in well-being. Table 13 lists the change scores of

individual participants who showed improvements of  $\pm 10$  raw score points or more on specific measures from pre- to post-treatment.

**Table 13: Individual Score Changes of  $\pm 10$  Points**

Measure	Group 1	Group 2
Depression (BDI-II)		-14*
Parenting stress (PSI-4-SF)	-24	-22*, -22
Marital adjustment (DAS)	+10	+10, +12, +13

*Note.* \* denotes the same participant

Two participants in Group 1 showed changes of  $\pm 10$  raw score points from pre- to post-treatment, in a direction that indicates reduced parenting stress or improved marital adjustment. In Group 2, five participants reported change scores ranging from +10 to -22 points in a direction that indicates improved marital adjustment, reduced depression, or reduced parenting stress. Overall, 7 of 12 participants reported changes of  $\pm 10$  points in the direction of improved psychological functioning on one measure (and in the case of one father, on two measures) from pre-to post-treatment.

### Social Validity

**Question 3.** What is the social validity of the intervention? Specifically, will participants attend the support group regularly? Will participants report that the group was helpful? What will they identify as being most helpful about attending the group? Will they recommend the group to other fathers of children with ASD? Hypothesis: Participants will regularly attend the support group. Participants will describe the group as being helpful. The aspects of the group that will be described as most helpful will be the opportunity to meet with and talk to other fathers in similar circumstances, getting new

ideas and perspectives from group members, reducing social isolation, and experiencing validation and support from group members regarding the challenges of parenting a child/children with ASD. The majority of participants will recommend the group to other fathers of children with ASD.

### **Attendance and Post-Group Meetings**

All six Group 1 participants attended 89.58% of support group sessions ( $M = 7.17$ ), and all six Group 2 participants attended 97.92% of sessions ( $M = 7.83$ ). For both groups combined, the 12 participants attended 93.75% of the total sessions ( $M = 7.50$ ). In addition, both groups spontaneously expressed a desire to continue meeting on a social basis after the support group had concluded. At the time this was written, Group 1 was setting up its first meeting and Group 2 had met twice, with the goal of trying to meet approximately once monthly.

### **Primary Responses to Social Validity Questions**

The hypothesis for this question was confirmed; a tally of responses to the questions, “Did you find the group helpful?” and “Would you recommend [the group] to other fathers of children with autism?” revealed that all 12 participants answered in the affirmative to both. An analysis of responses to the question about what was most helpful about participating in the group indicated that participants valued hearing from and sharing their own experiences with other men in similar circumstances; being able to talk about issues in a caring, open, and accepting atmosphere; and getting new perspectives, insights, and information on how to parent a child with ASD and how to manage other interpersonal relationships (e.g., spousal relationships). The following is a representative quotation from one Group 1 participant: “It was a good experience to hear from other fathers having similar or varying degrees of difficulty. It helped me be more at peace with my situation (thank God I am where I am!). Things seem so

much better when you can compare with others.” Another Group 1 participant said, “Overall, I found the group helpful. The level of sharing and care was great.” A Group 2 participant wrote, “I found I gained a lot of insight into how other fathers deal with various situations.” Similarly, another Group 1 participant commented that “It was insightful. An excellent introspection into the group and one’s own thoughts.” A Group 1 participant stated that “All the experiences and stories that were shared were useful in my day-to-day life, and I’ve tried to practice and change lots of things that I was somehow not aware of or not paying too much attention to.” One Group 2 participant described the group as “therapeutic” and that it was “nice to hear other horror stories.” A Group 1 participant offered that the group “was a worthwhile adventure. I hope we can build on it and keep the group going in some form.” Another Group 1 participant said that he enjoyed getting “feedback on how others are dealing with problems, to get ideas on what can be done to help” and that “it was great to have a professional facilitator to guide the sessions. It was time well spent.” One Group 2 participant was especially enthusiastic about his experiences in the group, saying, “I think this type of service would be a tremendous contribution to the autistic community and their families. I honestly feel this type of interaction is as important as an AA group is for an alcoholic.”

### **Supplementary Comments from the Social Validity Questionnaire**

In addition to questions for which hypotheses could be formulated, the social validity questionnaire also asked participants to provide supplementary information about a number of topics. Participants’ replies to these additional questions are summarized in this section, with illustrative statements from participants as appropriate.

**Least enjoyable aspects of participating in the group.** Three participants in Group 1 expressed some concerns about the nature of the group discussions. One noted that “Sometimes

[there was] too much wallowing for too much of the session,” while another commented that he disliked it when “participants’ responses were ‘prescriptive’ towards others.” A third participant was concerned that “Maybe some others had reservations about opening up. There were many ideas floating about but they never came out.” Aside from these comments, no other themes were apparent in response to this question.

**Thoughts about the frequency, duration, and timing of the sessions (2 hours/week for 8 weeks).** In general, participants in both groups endorsed the frequency, duration, and timing of the groups. Two participants suggested that meeting every 2 weeks might have been equally useful; and one participant suggested that he would have preferred a 16-week group with more detailed discussion of each topic. Several participants commented that, despite their busy schedules, the group “wasn’t too long but wasn’t too short either.”

**Topics covered.** Several participants felt that there was “a good balance of topics and time spent on each.” One father noted that “some topics [meant] less to me personally but more for other dads, so to meet the topics of interest to every dad it has to be wide and varied.” Suggestions for additional topics included information on how to access additional community resources for children with disabilities; health and nutrition; and a problem-solving exercise where participants could brainstorm specific strategies to address an issue.

**Facilitator’s strengths and areas for improvement.** Seven participants described the group facilitator as a good moderator who “was able to bring the group back to the topic without dampening the mood of the discussion.” At least two of the participants described her as patient, accepting/open-minded, professional (i.e., without biases), a good listener, and informed/knowledgeable/experienced. Other positive descriptors included diplomatic, congenial, perceptive, a good communicator, humorous, and well-organized. In contrast, one participant

noted that the facilitator “could be too patient when people tended to ramble on or discuss matters that were not related to the topic” and another suggested that she could be “perhaps a little more aggressive in balancing the individuals contributing to the group.”

### **Summary**

The study aimed to design and evaluate the impact of a support group for fathers of children with ASD, using quantitative measures to examine participants’ psychological experiences and a measure of social validity. Quantitative data were analyzed using a 2X2 mixed model ANOVA with Group as the between-subjects factor and Time as the within-subjects factor. Results indicated no significant main effects for either Group or Time for any of the measures, with the exception of marital satisfaction (DAS), which improved significantly in Group 2 only. There was no change in test scores between pre-test and follow-up, or between completion and follow-up for Group 1. An analysis of the social validity data indicated that all fathers found the groups to be meaningful and helpful, enjoyed listening to and sharing personal experiences with other men in similar circumstances, and strongly recommended a similar group to other fathers of children with ASD.

## CHAPTER 5: DISCUSSION

This study was exploratory in nature, as it was the first to examine the impact of a support group for fathers of children with ASD using standardized measures to assess participants' psychological experiences pre- and post-treatment. The study employed a two-group pretest-posttest design (Creswell, 2003), with both groups receiving the support group treatment 2 months apart. The primary research questions investigated differences from pre- to post-treatment, pre-treatment to follow-up, and post-treatment to follow-up in depression, marital adjustment, optimism, parenting stress, and coping scores for the two groups. A secondary question examined participants' perspectives about the utility of the support group.

### Quantitative Results

The results for each of the quantitative dependent variables will be discussed in the sections that follow.

#### Depression (BDI-II) Pre- to Post-Treatment

For both Group 1 and Group 2, no significant differences were found on BDI-II scores, either within or between groups, from pre-to post treatment. The primary reason for this may be that participants were screened for depression prior to being accepted into the group; one of the criteria for inclusion was that they not be receiving psychotherapy or taking medication for mental health issues at the time of the study. This was verified again during the telephone interview, when the researcher spoke with each of the potential participants to describe the purpose of the study and to determine eligibility. Hence, and perhaps not surprisingly, scores across both groups ranged from 1-20 on the BDI-II, with total raw score means for Group 1 (8.50) and Group 2 (8.67) that were well within the range of "minimal" depression. Because of this, there was little room for change in depression scores from pre- to post-treatment, similar to

the results of previous support group studies by Bitsika and Sharpley (2000) and Clifford and Minnes (2013b). The most notable change in depression scores was exhibited by one father in Group 2, whose score decreased 14 points from pre- to post-treatment, moving him from the “moderate” to “minimal” depression category upon completion of the group.

The literature on depression in parents of children with ASD is based primarily based on maternal reports, with mothers consistently reporting higher levels of depression than fathers; however, some research has also been conducted on fathers of children with ASD, who report higher levels of depression compared to the general population. For example, Ornstein Davis and Carter (2008) found that 17% of fathers of children with ASD ( $n = 54$ ) scored in the clinical range of depression (i.e., scores of 16 or more) on the Center for Epidemiological Studies – Depression (CES-D) scale, the same proportion that was reported by Lee (2009) in a sample of 23 fathers who also completed the same measure. Hartley et al. (2012) found even higher rates of depression in their sample of fathers of adolescents and young adults with autism: 30% ( $n = 41$ ) reported clinical rates of depression on the CES-D. Although these three studies used a different measure than the current study (the BDI-II), both instruments purport to measure a similar construct and have been reported to have high convergent validity ( $r = .74$ ; González, Carter, & Blanes, 2007). Thus, in contrast to the rates of 17% and 30% published in the three previous studies, it appears that the prevalence of moderate to severe depression was much lower – essentially nonexistent – in fathers who were enrolled in the current study.

### **Marital Adjustment (DAS) Pre- to Post-Treatment**

There was a significant interaction effect for scores on the DAS, such that that Group 2 showed improved marital adjustment from pre- to post-treatment while Group 1 did not. At pre-treatment, Group 2 scored at the DAS borderline of 100 that indicates “poor dyadic adjustment”

( $M = 97.67$ ) and moved slightly above this score at post-treatment ( $M = 104.83$ ). In fact, 5 of the 6 Group 2 participants reported increased levels of dyadic adjustment from pre- to post-treatment, as reflected in total scores changes that ranged from +5 to +13. In contrast, while Group 1 also scored at the borderline of “poor dyadic adjustment” pre-treatment ( $M = 99.5$ ), their mean score decreased to an even lower level (95.83) at post-treatment, with 5 of the 6 participants showing raw score changes that ranged between -1 to -15. The two Group 1 participants with the lowest total DAS scores ( $M = 62$  and 63) reported levels of dyadic adjustment below the DAS total mean score of 70 that was found in Spanier’s (1976) normative divorced sample. In contrast, none of the Group 2 fathers reported scores at or below 70; the lowest individual total score pre-treatment was 74, and at post-treatment the lowest score was 87. There was also greater variability in Group 1 scores compared to Group 2, as evidenced by larger standard deviations and broader ranges.

Given that both groups started with mean DAS scores that were essentially equivalent, one can only speculate about the differences that were evident in the two groups after the support group was completed. The researcher/facilitator’s observation was that Group 2 members spent more time explicitly discussing and examining their spousal relationships over the course of the group than did Group 1 members, and they appeared to gain increased appreciation for and understanding of their wives over the 8 weeks that the group met. In fact, when participants in Group 2 were asked during the final group session what they had learned or what had changed for them over the course of the group, most of the men agreed that they had more appreciation for their spouses. For example, one father talked about being less impatient and angry with his wife, and of having more understanding of the responsibilities she had undertaken. In particular, he described feeling more compassion for the challenges she encountered as a stay-at-home

mother who was responsible for both their son with ASD and the burden of running his intensive home-based early intervention program. This anecdotal report was reflected in the +13 point change in his DAS score from pre- to post-treatment, which represented the largest individual change in DAS scores in this group.

The research on marital functioning in couples of children with ASD is minimal and the findings are mixed, with some studies reporting lower levels of marital satisfaction/adjustment compared to couples with both typically developing children and children with other disabilities, and other studies showing no differences. One study by Lee (2009) examined marital functioning using the DAS in 24 couples of children with ASD compared to a control group of 13 couples with typically developing children. The data were not analyzed separately according to gender, but were grouped together and analyzed as parental scores (although, in separate analyses, Lee did not find any significant differences between men and women on total DAS scores). The results indicated that parents of children with ASD scored significantly lower on total DAS scores ( $M = 91.11$ ,  $SD = 5.25$ ) compared to the control group ( $M = 94.42$ ,  $SD = 7.92$ ). This finding (i.e., lower marital functioning in parents of children with ASD) is consistent with the results of other ASD studies that used different measures of marital satisfaction (e.g., Higgins, Bailey, and Pearce, 2005). However, although Group 1 and Group 2 mean scores pre- and post-treatment were close to the borderline level of 100 that reflects poor dyadic adjustment, they were much higher than the total DAS mean score of 70.7 that was found in Spanier's divorced sample. They were also higher than the DAS total mean of 84.5 that was reported in a study of couples in marital therapy who subsequently divorced (Prouty, Markowski, & Barnes, 2000). Thus, the mean DAS scores in the current study appear to represent slightly less dyadic

adjustment than the most satisfied couples in Spanier's (1976) normative sample, but greater dyadic adjustment than couples who had already divorced or were contemplating doing so.

### **Optimism (LOT-R) Pre- to Post-Treatment**

For both Group 1 and Group 2, no significant differences were found on LOT-R scores, either within or between groups, from pre-to post treatment. Examination of the means indicated optimism scores that were stable from pre- to post-treatment for both groups. In comparison to the mean of 15.3 for men in Glaesmer et al.'s (2012) population-based study, Group 1's mean raw scores at pre- and post-treatment (14.67 and 15, respectively) were essentially equivalent, while Group 2's mean raw scores at both pre- and post-treatment (18.17 and 17.83, respectively) were slightly higher. The Group 1 scores were more variable, as reflected in the greater range of scores and larger standard deviations. Although there were no significant between group differences, it is interesting to note that, based on Glaesmer et al.'s calculations, a total raw score of 15 is equivalent to a percentile rank of 50 and a score of 18 is equivalent to a percentile rank of 77; thus, while the Group 1 mean reflected an average level of optimism, the Group 2 mean was the same or higher than 77% of the people completing the LOT-R.

In general, optimism is considered to be a trait that is stable over time; in studies measuring optimism using the LOT-R, test-retest correlations have been reported to be quite high, ranging from  $r = .58$  to  $r = .79$  over periods from a few weeks to 3 years (Carver et al., 2010; Scheier et al., 1994). Thus, it is perhaps not surprising that LOT-R scores in this study showed a high level of stability and minimal change from pre- to post-treatment. To date, no studies have compared the optimism levels of either parents of children with ASD and parents of typically developing children or of mothers and fathers of children with ASD. However, in the scant research that has examined optimism in parents of children with ASD (primarily mothers),

optimism has been positively correlated with better mental and physical health, and has also been shown to predict fewer child behaviour problems. Thus, it is an important area for further research and warrants additional study.

### **Parenting Stress (PSI-4-SF) Pre- to Post-Treatment**

Group 1 and Group 2 mean scores were within the normal range on the PSI-SF-4 (i.e., between the 16<sup>th</sup> and 84<sup>th</sup> percentile) at both time points, and there were no significant changes from pre- to post-treatment. However, there was considerable variability among the participants in both groups, with 4 out of 12 fathers (33%) scoring at or close to the “clinically significant” level of stress (i.e., at or above the 90<sup>th</sup> percentile) pre-treatment. Specifically, one Group 1 father scored >99<sup>th</sup> percentile both pre- and post-treatment; one Group 2 father reported stress that was borderline clinically significant (i.e., at the 87<sup>th</sup> percentile) pre-treatment and increased slightly post-treatment (i.e., to the 92<sup>nd</sup> percentile); and two Group 2 fathers had scores between the 90<sup>th</sup> to 99<sup>th</sup> percentiles pre-treatment that decreased by 22 points to move into the normal range of parenting stress post-treatment (interestingly, one of these fathers was the same father whose BDI-II score decreased by 14 points from pre- to post-treatment, moving him from the “moderate” to the “mild” depression category). The rate of elevated stress (33%) among fathers in the current study is comparable to rates previously reported in the literature on ASD (e.g., Baker-Ericzen et al., 2005), although lower than the 60% rate of clinical stress reported in one recent study of 118 fathers (Rivard et al., 2014).

Previous research consistently shows that stress in parents of children with ASD tends to be quite stable over time, which was also the finding of the current study. Given the chronic and pervasive impairments exhibited by individuals with ASD, this is perhaps not surprising. For example, Lecavelier et al. (2006) conducted longitudinal research on 50 parents of children and

adolescents with ASD over a period of 12 months. Parents (primarily mothers) completed the PSI-SF as well as measures of child problem behaviours and social competence. Results indicated that parenting stress did not change over the 12-month period, and that child behaviour problems and parental stress exacerbated one another over this time period. Similarly, in a recent study of 184 mothers of children with ASD, Zaidman-Zait et al. (2014) found that parenting stress scores remained stable across a 3- to 4-year period after children's ASD diagnoses, and also found a bidirectional relationship between scores on the PSI-SF and child problem behaviours during the period from 12 months post-diagnosis to age 6. Finally, Baker Ericzen et al. (2005) investigated stress levels (using the PSI) in mothers and fathers, both before and after they and their children with ASD were involved in an inclusive toddler program that included a family education component. Family education consisted of weekly 2-hour home visits, during which the parents were taught a variety of positive behaviour support techniques and strategies for interacting productively with their child during play and communication routines. Although this research differs from the other studies in that there was a focused parent training component, the findings were similar: no significant changes were evident in fathers' stress levels over an 8-month period. Although few previous studies have specifically examined paternal stress, it seems clear that more longitudinal research is needed to better understand its progression and its association with both parent- and child-related variables.

### **Coping (WCQ) Pre- to Post-Treatment**

As noted in Chapter 1, the cognitive and behavioural coping strategies that individuals use to manage a stressor can be divided into two broad categories – self-directed and other-directed coping. Self-directed coping consists of both constructive strategies (i.e., those that address a stressor in a productive/effective way) and non-constructive strategies (i.e., those that

involve avoiding a stressor in some way). Other-directed coping consists of actions whereby a person seeks guidance, information, and/or support from others, such as family, friends, professionals, spiritual/religious leaders, and community resources. In applying this categorization framework to the WCQ subscales, the constructive subscales include Planful Problem Solving, Self Control, Accepting Responsibility, and Positive Reappraisal. Conversely, the non-constructive subscales include Confrontive Coping, Distancing, and Escape Avoidance. The eighth and final subscale, Seeking Social Support, can be classified as an other-directed coping strategy.

Results of this study demonstrated significant group differences for Group 2 on two of the four non-constructive coping subscales, but no significant changes on any of the subscales for either group over time. Specifically, Group 2 had higher pre-treatment mean scores than Group 1 for both Confrontive Coping ( $M = 10.0$  and  $4.0$ , respectively) and for Escape Avoidance ( $M = 9.5$  and  $3.83$ , respectively). The findings for Group 2 are similar to those reported by Sivberg (2002), who also used the WCQ to examine coping strategies in parents of children with ASD and those with typically developing children. Sivberg (2002) found that parents of children with ASD used significantly more non-constructive coping strategies such as Distancing and Escape Avoidance, while parents of typically developing children used more constructive and other-directed strategies that included Self-Control, Planful Problem Solving, and Social Support. Thus, it appears that Group 2 in the present study may be more typical of parents of children with ASD than Group 1 was. Although speculative, this might be related to differences in the composition of the two groups. Half of the Group 2 participants had more than one child with ASD; one had three children with this diagnosis and two had two children each. In contrast, only one Group 1 father had two children with ASD. In addition, two of the Group 2 fathers

(both of whom had two diagnosed children) reported household incomes in the “low” range for this study (i.e., ≤\$69,000 annually), while none of the Group 1 fathers reported similarly low incomes. Perhaps, the combination of a higher burden of caregiving and a generally lower socioeconomic status in Group 2 contributed to this group’s tendency to use less constructive coping strategies that are also reflective of feeling somewhat disempowered and less hopeful (Folkman & Lazarus, 1988).

Finally, it is important to note that, during the support group intervention, the discussion was not focused on specific coping strategies or the need to learn new ways of coping. Of course, incidental conversations focused at various times on positive reappraisal, as participants came to a fuller understanding and appreciation of their children with ASD as well as their spouses and other family members. At other times, some of the fathers talked about their struggles to maintain a level of self control rather than reacting with anger or frustration to their children’s difficult behaviours. And, by its very nature, the intervention itself provided social support, which was perceived as valuable by almost all of the group members. However, because there was no deliberate attempt to teach coping skills, it is perhaps not surprising that scores on the WCQ did not change over the time period of the study.

### **Pre-and Post-Treatment to Follow-Up**

In a randomized control trial evaluating the impact of a 20-week parent education and behavior management intervention on the mental health and adjustment of parents with children with ASD, Tonge et al. (2006) found evidence of a post-treatment “sleeper effect.” Specifically, although no significant changes were found between pre- and post-treatment measures of parent-reported psychiatric symptomatology, anxiety, and depression, participants reported significant reductions in all of these variables at 6-month follow-up. Tonge et al. noted that “the evidence of

greater treatment effects 6 months after the intervention may point to a cumulative benefit as parents apply skills learned” (p. 568). Similarly, Vadasy et al. (1986) conducted a 12-month follow-up study of 45 fathers who had participated in a program designed to strengthen their ability to cope with the stress of parenting a child with a disability. Each program meeting followed a similar format, which included a 40-minute support group session facilitated by professional leaders to discuss issues or problems of concern, activities for fathers and children to engage in together, and a guest speaker who spoke about a topic of interest. One year post-treatment, fathers who participated in the program for at least one year had significant decreases on measures of child-related stress, depression (measured using the BDI), grief, and information needs. Like Tonge et al., these authors also suggested that the program might have had “residual positive influences” (p. 29) on the fathers, although they acknowledged that other explanations for the decreased scores could not be ruled out.

On the basis of these studies, it seemed important to examine the possibility of sleeper effects in the present study, even though the support group intervention was quite different from those implemented by previous researchers, both in terms of content and duration. Unfortunately, no significant group differences were found in this study between pre-treatment and follow-up scores, or between post-treatment and follow-up scores for any of the dependent variables (i.e., depression, marital adjustment, optimism, parenting stress, and coping). However, given the findings in Tonge et al. (2006) and Vadasy et al. (1986), perhaps more substantive changes would have been observed in the current study if the treatment had been of a longer duration, or if the follow-up period had been longer, points that will be examined further in the section on limitations.

### **Social Validity**

This section examines the written responses to the social validity questionnaire that asked participants about their experiences of participating in the group.

#### **Perceived Helpfulness and Utility of the Group**

All 12 participants unanimously reported that the group was helpful and said that they would recommend it to other fathers of children with ASD. When asked to describe what they found to be most useful about the group, participants said that they valued the opportunity to meet with and talk to other fathers in similar circumstances and to share ideas and perspectives. They believed that the group reduced their feelings of social isolation, and they appreciated the validation and support they received from other group members regarding the challenges of parenting a child/children with ASD. Thus, despite the lack of significant findings based on the standardized, quantitative measures, the social validity findings show that fathers did value participating in the group and perceived it to be worthwhile.

These findings are similar to other published research on support groups. For example, West (1998) facilitated a brief, four-session support group for fathers of children with Down syndrome. In interviews conducted 2 weeks after the group ended, all four fathers reported that participation had been valuable, particularly with regard to the “openness and warmth of the group members and the honesty and extent of sharing” (p. 291), and all fathers indicated that they would like to participate in such a group in the future. Similar to the current study, Bitsika and Sharpley (1999) also failed to find statistically significant changes post-treatment for parents of children with ASD participating in a face-to-face support group; yet, parents reported that the group was helpful, especially because of the opportunity to connect with other parents. Similarly, Clifford and Minnes (2013b) found no significant findings regarding the impact of participating

in an online support group for parents of children with ASD; however, most parents reported that having other parents to chat with was helpful, and said that the support, understanding, and validation received from other parents were the most useful aspects of participating in the group.

The excellent attendance statistics obtained in this study can be interpreted as additional verification of the perceived utility of the group. As Davison, Pennebaker, and Dickerson (2000) aptly noted, the social validity of a group is perhaps the most important criterion for success, because, “as a measure of basic value to participants, participation is its own index of success: Groups without value cease to be groups. Members vote with their feet” (p. 206). In this study, all Group 1 participants attended 90% of the sessions, all Group 2 participants attended 98% of sessions, and both groups combined attended 94% of the sessions. These attendance rates contrast quite markedly with those reported in previous literature on support group attendance. For example, Clifford and Minnes (2013b) developed a support group for parents of children with ASD that was convened online, in part to increase attendance by eliminating the need for transportation, child care, and so forth. Thus, parents were able to participate from their homes at any time (e.g., after their children went to bed) and were also able to choose the times, dates, and frequency of meetings. Yet, of the 36 parents who registered for the group, only 64% attended three or more of the support group sessions, 25% attended six or more sessions, and only one parent attended all eight sessions. This relatively poor attendance occurred despite the fact that parents rated the group as being useful overall, and 75% said they would not recommend changing anything about the group in order to increase attendance.

It is possible that the financial compensation offered in this study contributed to the high attendance rates: participants were paid an honorarium of \$20, plus \$10 for each session they attended, up to a maximum of \$100. However, such minimal financial compensation would not

appear to be a sufficiently strong motive for participating in a fairly time-intensive and extended group (i.e., 2 hours per week for 8 weeks); and, for many of the participants, the \$10 per session barely covered the cost of gas and parking. The more likely explanation (as reported by most of the group members) is that the group met a genuine need and offered a unique opportunity to meet other fathers, counteract the social isolation that participants reported feeling, and provide validation for the unique and oftentimes challenging issues related to parenting a child with ASD. In fact, a number of the fathers reported that this was really the first time they had an opportunity to meet and talk to other fathers of children with ASD. The group provided a structured, formal opportunity for fathers to come together and discuss personal issues relevant to them for 2 hours each week. Furthermore, the group was designed exclusively for fathers, which meant that they were able to participate on their own, without their spouses or other family members present. Some group members commented that this gave them permission to speak freely and openly about their experiences in a safe, supportive environment. Some unpublished, qualitative research on fathers of children with ASD provides supporting evidence of fathers' desire to connect with and share their experiences with other men, in order to learn from and provide support to them (e.g., Collins, 2008; Hunt-Jackson, 2007; Long, 2005).

As additional anecdotal evidence of the utility of the group, participants all expressed interest in continuing to meet socially after the support groups ended, and made concrete plans to stay in touch. The researcher shared the emailing list with participants in each group, and group members have copied her on their communications when setting up meetings. Group 1 is still in the process of setting up its first meeting and finding a time, date, and activity that members can agree upon. To date, Group 2 has met three times, with the goal of meeting approximately one time per month.

## **Limitations**

A quotation from Clifford and Minnes (2013b), describing the limitations of their research on online parent support groups, aptly summarizes some of the challenges of the current study:

“It is difficult to know whether the lack of differences over time... was due to relatively high wellbeing scores among the participants prior to participation in the group or one of the following possible limitations: small sample size, an ineffective intervention, the variables chosen to measure change over time, the measurement tools chosen, or some other problem. Future research with this population should focus on ruling out these potential problems when examining the effectiveness of support groups for parents of children with ASD” (p. 1671-1672).

This section describes these limitations and others that are relevant to the current study, including issues related to the research design, participant characteristics, measurement, and reactivity.

### **Research Design**

The lack of random assignment is the first limitation of this study. The original plan was to randomly assign members to the two groups, but in order to narrow down the geographic area and make the groups as accessible as possible to participants, group members were assigned to Group 1 and Group 2 based on where they lived.

### **Sample Size**

The current study was also limited by its sample size, which affected statistical power and the conclusions that can be drawn from the statistical analyses. The study included 6 participants from each of two groups for a total 12 participants. This sample size is not unusually

small for studies of this type; for example, in a study on support groups by Banach et al. (2010), 14 participants were assigned to two support groups; similarly, Bitsika and Sharpley (1999) conducted research with 14 participants assigned to three support groups. The original plan was to recruit a total of 14 to 16 participants, with 7 or 8 participants per group, which is considered an appropriate number of participants for a discussion group led by one facilitator (Nichols & Jenkinson, 2006). However, there was a protracted recruitment period (6 months), during which time the researcher had to expand recruitment efforts to additional autism agencies in order to find eligible fathers who were interested in participating. Hence, once 12 eligible participants consented to participate and were roughly grouped based on geographic location (which coincidentally resulted in the participants being evenly divided with 6 fathers per group), and in light of the fact that the first participants to sign up had already waited for 6 months, a decision was made to begin running the groups with fewer than 7-8 members per group. It is possible that a larger sample size would have resulted in significant changes.

### **Participant Characteristics**

According to Statistics Canada (2012), 3.3% of individuals in the province where this study was conducted speak a primary language other than English. Thus, in a representative sample of 30 adults, there should be one individual whose primary language is not English. The present study had a sample of 12 participants, all of whom spoke and wrote fluently in English; this is proportionally representative of the population from which the sample was drawn. This level of verbal and written English language proficiency was necessary for successful participation, because the fathers were required to complete a number of questionnaires at three different time points and also participate in weekly discussions. However, although this was a representative language sample, it was not representative of the cultural diversity of the province.

Visible minorities make up 38% of the population in the region of the province where this study took place (British Columbia Multicultural and Immigration Branch, 2008). Thus, in a sample of 12 participants, 4.5 should have been from a visible minority; however, only three of the men fit this description (two were Asian and one identified as Persian).

There is also the issue of self-selection, which is always a limitation in a study of this type. The fathers in this study were there either because they themselves chose to participate in a discussion group with other fathers, or because their spouses encouraged them to do so. Such self-selection can lead to biased data, because the respondents who participate do not represent the entire target population. Perhaps, this can account (at least in part) for the fact that the fathers in this study reported relatively high psychological well-being at the start of the group (e.g., low levels of depression, average levels of optimism), as fathers who were more distressed might have been less motivated to volunteer. Significant improvements might have been evident in individuals who were more distressed pre-treatment; for example, Tonge et al. (2006) found that family functioning significantly improved over time in the 33% to 43% of families who had the highest levels of dysfunction.

### **Support Group Design**

Numerous variables related to the design of the support groups themselves might have affected the study outcomes. Perhaps a longer course of treatment (i.e., more group sessions) would have yielded more changes in fathers' well-being, or perhaps longer or more frequent sessions would have had a different effect. Evidence for this possibility comes from research by Vadasy et al. (1986), who found that fathers who participated in a support group for at least one year had significantly lower levels of depression and less child-related stress compared to pre-treatment levels, although the authors cautioned that "we can only speculate whether these

changes are primarily attributable to the intervention or to other confounding factors, including self-selection, history, maturation, testing effects, or interactions thereof” (p. 25).

Fathers in the current study reported that the weekly discussion topics were valuable, but it is possible that other topics might have led to more significant changes in well-being. The support group was intended to provide a safe environment within which members could share their experiences and provide both information as well as emotional and social support to one another. However, a different type of group, such as a psychoeducational group focused on teaching fathers specific skills (e.g., stress management or coping skills), might have resulted in different outcomes. Perhaps a support group is not the appropriate format for inducing changes in major psychological variables such as stress and depression, especially with parents who are in chronically stressful and challenging situations. Indeed, research has shown that stress and depression in parents of children with autism are relatively stable constructs that are quite difficult to change over time (Barker et al., 2011; Zaidman-Zait, 2014). As Clifford and Minnes (2013b) suggested, “evaluation of support groups that are implemented clinically could help to determine which [programmatic] variables may be the most important contributors to change in well-being for parents of children with ASD” (p. 1673). Clearly, further research is needed to determine the effectiveness of support groups for fathers of children with ASD.

### **Measurement**

Although the measures chosen for this study have been widely used in other research and have good psychometric properties, they may not have been sensitive and/or specific enough to detect changes in fathers of children with ASD who participated in this short-term support group. This concern is especially relevant to the WCQ which, although widely used to measure coping, was developed in the 1980s and has not changed much over the decades. The normative sample

consisted of 75 married middle- and upper-middle class Caucasian couples, none of whom were identified as parents of children with disabilities. Although the test manual reports acceptable internal consistency for the subscales, no empirical evidence is provided for either construct validity or test-retest reliability (Folkman & Lazarus, 1988). Furthermore, because participants are asked to think about a specific stressful situation and select their responses based on that situation, the coping strategies they identify are likely to be both diverse and situation-specific. In retrospect, it might have been more appropriate to use a measure such as the Family Crisis Oriented Personal Evaluation Scales (F-COPES; McCubbin & Olson, 1991) which was specifically designed to assess coping in families of children with disabilities and has been used in previous ASD research (e.g., Lee, 2009; Twoy et al, 2007). Similarly, alternative measures of stress, depression, and so forth might have tapped into other aspects of these psychological constructs that might have changed significantly over the course of the group.

In addition, in order to be conservative with regard to the number of statistical analyses conducted with a small sample, only total scale scores were analyzed rather than individual subscales. However, it is possible that one or more of the individual subscales would have shown subtle or more specific changes in fathers' well-being (Clifford & Minnes, 2013b). Similarly, measuring dependent variables that are known to be correlated with parents' psychological functioning (e.g., child outcomes, partners' mental health) might have better reflected changes in the participants' well-being scores over the course of the group. Finally, the exclusive use of self-report measures to assess participants' experiences may have been problematic. Given that the variables of interest were about participants' feelings, values, and beliefs, self-report measures were appropriate; however, they may not represent psychological health accurately,

especially in individuals with limited personal insight and/or those who are prone to social desirability bias. This issue will be discussed in more detail in the next section.

### **Reactivity**

There is a possibility that data collection was influenced by social desirability bias -- the tendency of respondents to provide answers that they deem to be more socially acceptable than a "true" answer. Spector (2004) noted that this type of response bias is more likely to occur for items or questions that deal with personally or socially sensitive content, which was certainly the case for the measures used in this study. In addition, the researcher was also the group facilitator and participants were aware that this was her doctoral dissertation. This might have influenced fathers to complete the measures -- particularly the social validity questionnaire that asked them to describe their experiences in the group -- with responses that were biased toward positivity or social acceptability.

It is also important to note that the facilitator was a woman, and thus was the only female in a group consisting exclusively of males. It is unclear what influence, if any, this might have had on the outcome. Bowman, Scogin, Floyd, and McKendree-Smith (2001) conducted a meta-analysis of 64 studies to determine the effect of therapist sex on the outcome of psychotherapy, and found that therapist sex was a poor predictor of outcome for both male and female clients. Similarly, Blow, Timm, and Cox (2008), in examining the role of the therapist in therapeutic change noted that "there is extensive research indicating that in general, neither gender is significantly better than the other in terms of therapeutic outcome (especially as years of experience increase)" and that "good therapists are good therapists in spite of their gender" (p. 83). They also argued that research needs to move beyond a "simplistic investigation of sex (biologically male or female) and move to look at gender qualities. There may be some

characteristics traditionally thought of as masculine or feminine that all therapists should develop in order to be effective. There is as much diversity within gender as between genders, and to categorize all women (or men) into one group and expect them to all be the same because they share the same anatomy is simplistic at best” (p. 82).

### **Future Research**

A number of recommendations for future research are evident, based on the results and limitations of this study. These include recommendations related to experimental design, support group structure and design, participant characteristics, and dependent variables.

### **Experimental Design**

Future research on support groups should endeavour to assign participants at random to groups. Random assignment prevents the results from being confounded by experimenter bias, and including a randomly assigned control group significantly increases the scientific rigor of the experiment by isolating the effects of the independent variable (treatment) in order to help rule out alternative explanations (e.g., individual group characteristics) of the results. Future studies should also use a larger sample size, which would increase the power available to detect statistically significant differences. A larger sample size would also enable (a) the addition of other instruments to measure a greater variety of dependent variables and/or (b) the inclusion of more subscales of existing instruments, which would permit a more fine-grained examination of the constructs being measured. It would also be valuable to assess the psychological variables of interest (e.g., depression, optimism, marital functioning, etc.) both pre- and post-treatment in the fathers who participate in the group and in their spouses/partners who do not.

### **Support Group Structure and Design**

As a logical starting point, it would be reasonable to conduct additional research on similarly-structured support groups of different sizes, lengths, and compositions (e.g., married and divorced fathers; heterosexual and homosexual fathers), to better determine whether such groups have an impact on participants' psychological functioning and which elements of the group structure have the most impact. This course of action is particularly salient in light of fathers' feedback throughout and upon completion of the group; all 12 fathers reported that participating in the group was helpful and valuable, and highly recommended the group to others. In addition, research is needed to compare the impact of different types of groups for fathers of children with ASD, such as a self-help group that is run by fathers themselves without a professional facilitator; and/or a psychoeducational group that focuses on providing didactic instruction about specific autism topics, such as managing challenging behaviour, increasing a child's communication skills, and/or learning new skills for stress management and/or coping.

### **Participant Characteristics**

The sample in this study was not proportionately representative of the culturally and ethnically diverse population from which it was drawn. Thus, future research should aim to recruit participants from more diverse backgrounds in an effort to better represent the broader cultural and ethnic population. In addition, as noted previously, the fathers in this group reported relatively high psychological well-being at the start of the group (e.g., low levels of depression, average levels of optimism), which meant that there was less room for improvement in their psychological functioning. Future studies should recruit fathers with mental health concerns/higher levels of distress, to see whether such a support group could help alleviate more serious mental health problems. This could include recruiting fathers of newly diagnosed

children with ASD, as recent research has shown that parents of such children experience especially high levels of stress (Rivard et al., 2014). Additional variables that have been found to be predictive of psychological distress, such as having more than one child with ASD, having older children, and being a single parent, could also help guide future recruitment efforts. Indeed, if research were to demonstrate significant improvements in highly distressed participants' well-being upon completion of the group, the findings would prove to be even more important and valuable with regard to the implications for clinical practice.

### **Dependent Variables**

Future research could also measure additional or different dependent variables than those that were included in this study, such as social support, self efficacy, and partner mental health. Similarly, feedback from the social validity questionnaire indicated that participants valued the understanding/acceptance, validation, and giving and receiving of support; thus, it might be more clinically meaningful and relevant if measures were used to assess/evaluate these aspects of the group experience. On another note, future research could employ different measures to assess the same/similar psychological constructs; perhaps other measures might be more sensitive or specific and therefore better able to detect changes in participants' psychological experiences and hence would achieve different results.

Finally, research has indicated that "positive and negative aspects of psychological functioning, under typical conditions, may be separate dimensions with different influences, whereas in times of elevated stress these two dimensions become highly related" (Ekas et al., 2010, p. 1275). Thus, and in light of the fact that parents of children with ASD experience higher levels of distress, Ekas et al. contended that research on parents of children with ASD should evaluate both positive and negative psychological variables, in order to achieve a more

comprehensive and holistic understanding of these parents. Therefore, future research should formally assess factors that are both associated with distress and that promote resilience in parents of children with autism.

### **Clinical Recommendations**

Based on the researcher/facilitator's experiences and participants' feedback, a number of recommendations can be made to clinicians who are interested in designing and implementing support groups for fathers of children with autism. First, it is important to ensure that the group facilitator is knowledgeable about and has experience with (a) children with ASD and their families, including knowledge of best practices/current research, prevalence, intervention, prognosis/developmental trajectories, managing challenging behaviours, and government funding; (b) specific strategies for working and interacting with fathers/men; and (c) group counselling. This represents a unique combination of skills, but someone who is trained in counselling techniques and is also quite knowledgeable about ASD is best able to facilitate group discussion, help fathers understand and process their psychological/emotional experiences, and provide them with accurate and important ASD-specific information. All of these skills are necessary for successfully facilitating this kind of support group.

A second recommendation is to be transparent about the group's purpose and describe the expectations regarding group participation, both when recruiting potential participants and also when meeting as a group for the first time. It is helpful to screen participants prior to beginning the group, either by talking to them on the phone or meeting with them in person, to ensure they understand the purpose of the group and what group members' roles and responsibilities are. For this study, the researcher clearly explained to potential participants that this group was a discussion group and was not based on didactic instruction. She also emphasized that the focus

was on men talking to one another about their personal experiences of parenting a child with ASD, with a group leader facilitating the discussion. This information was reiterated and further clarified in the first session during the discussion of group norms.

Similarly, it is important to spend adequate time at the beginning of the first session discussing group norms -- the informal rules that set the standard for how members of a group should behave. This is particularly important when group members have never participated in such a group, and might feel some confusion or anxiety regarding their behaviour and what to expect when interacting with other members. The discussion of group norms should help to make potentially sensitive and/or ambiguous topics more transparent and meaningful (e.g., understanding and maintaining confidentiality, communicating respectfully with group members, being open-minded and nonjudgmental when listening to others); and should also help establish a trusting, safe, supportive group atmosphere. After spending time discussing group norms in the first session via a brainstorming activity, the researcher/facilitator then formalized these norms by creating a written code of conduct (Appendix F) that was distributed to all group members after the first session. Creating such a written code helps participants think about and respect the importance of conducting themselves appropriately and respectfully; in addition, it makes it clear that safeguards are in place to protect group members and promote discussion in a safe, trusting environment. The brainstorming activity also creates an opportunity to discuss group members' expectations regarding participation and what they want to get out of being in the group (i.e., why they are coming to the group). It is important to emphasize to participants that the experiences and benefits of participation will vary among the group members, because people have different reasons/motivations for attending.

A third suggestion is to ensure that the topics being discussed reflect the interests and needs of the group members, which can be accomplished by giving group members input into the weekly topics. In this study, the researcher/facilitator gave each group member a tentative list of weekly topics for the eight sessions, and then reviewed this list in the first session to determine whether the topics were relevant and valued by the group members. In a group situation, there is always the challenge of balancing individual needs with group needs, and participants will vary in terms what they most want to discuss (i.e., what is relevant to them). Sometimes, a particular topic will be of interest to one or to a select few members, and spending time discussing it will detract from that session's topic. When this is the case, one option might be to write these tangential topics down on a piece of paper (the "parking lot") to be reviewed at a later session; sometimes part of a session might be devoted to discussing these random topics so that they have been adequately addressed, but at a time when they do not distract participants from a more focused discussion about a particular theme. Participants may also have diverse opinions about the frequency, number, and duration of meetings. Admittedly, eight sessions was somewhat arbitrarily chosen for this study (in part based on the facilitator's previous experiences facilitating groups), and some members may prefer less sessions while others will prefer more. These are all variables that can be adjusted and experimented with to find the right combination to suit the needs of the group.

A fourth recommendation is to encourage group members to develop relationships and regular contact outside of the group, especially after the group ends. In the current study, the group was being evaluated as part of a formal study; thus, group members were explicitly asked to delay contact outside of the group until the group had ended. This, however, does not apply to community-based clinical groups that are created primarily to encourage social support and

decrease social isolation amongst the group members. The group creates a formal, structured opportunity for men to come together and share their experiences, thereby laying a foundation that will help them establish supportive, intimate relationships that will hopefully continue to develop after the group officially ends. Ultimately, one of the goals is of the formal support group to transform itself into an informal group, wherein participants continue to have regular, ongoing contacts that allow them to deepen their interpersonal relationships with one another and to derive support, information, and advice/assistance on parenting a child with ASD.

Finally, it is important to encourage a diverse group that consists of members who have children of different ages and developmental stages. One of the incidental advantages of both Group 1 and Group 2 was the valuable role that the fathers of older children played in the group. Fathers of younger children respected and valued the input from fathers of older children, and the overall message from the fathers of older children often was that “things get better over time,” which appeared to provide some comfort and hope to fathers who were struggling with challenges often associated with younger children. For example, in Group 2, there were two fathers of older children (one father had a teenage son, and the other had three children who were all diagnosed with ASD), as well as two fathers whose younger children who were still developing speech and many self help skills. The two fathers of the younger children often described their struggles and frustrations with teaching their children life skills (e.g., toileting), which in part was due to the slow rate of progress and the amount of work required to achieve any small gains. The fathers of the older children validated these frustrations by assuring the younger fathers that they had also experienced these difficulties but that, over time, things had improved with their own children, who were now much more independent, easier to manage, and enjoyable to interact with. Conversely, the fathers of the older children appeared to value taking

on the role of a “wise elder,” a person from whom other group members often sought advice, support, comfort, and hope. The older fathers in both Group 1 and Group 2 shared a lot of important advice and wisdom with the group members, in ways that were both reassuring and supportive without being patronizing.

### **Conclusion**

Sadly, the vast majority of research conducted with parents of children with ASD still includes mothers—either exclusively or primarily—as participants. Research on the experiences of fathers of children with ASD has increased over time, but much more information is needed. This study represents an effort to learn more about these fathers and the potential impact of participation in a support group on their psychological experiences. As Meyer (1986) poignantly argued almost 30 years ago, fathers’ participation should be more than mere tokenism:

“[F]uller involvement will result when programs and other services directly and immediately reflect the concerns of fathers. By providing fathers with options, professionals who serve families will not only address fathers’ concerns and need for support, but also may offer the special child’s mother needed respite and support in her efforts. Finally, an involved father helps ensure that the special child will have two active, informed, and available parents to meet the child’s many physical, emotional, and intellectual needs” (p. 250).

From an empirical perspective, studying fathers provides important information about their unique experiences and how those differ (or are similar to) those of mothers. It demonstrates respect and appreciation for the unique identity and contributions of fathers, separate from that of their spouses. From a clinical perspective, the information that is gathered via research can be used to develop effective interventions to support and assist fathers to be

better parents and partners. In this study, although few significant changes were observed on standardized measures of fathers' well-being, the participants reported that the group was valuable and worthwhile and recommended it highly to other fathers, pointing to an important and exciting area for future research and community intervention.

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### **APPENDIX A: Open-Ended Interview Form**

1. Did you find this group helpful? If so, how and why was it helpful? If not, why was it not helpful?
2. What were the things that you enjoyed most about participating in the group?
3. What were the things that you enjoyed least about participating in the group?
4. a) The group was organized in 8 sessions of 2 hours duration, with meetings every week. What are your thoughts about the frequency, duration, and timing of the sessions?
- b) We covered the following 8 topics, focusing on one topic per week:
  - 1) Introduction to support group; first experiences with diagnosis & disability
  - 2) Father's roles and responsibilities; relationships with coworkers and friends
  - 3) Dealing with the education system; working with professionals
  - 4) Relationships with immediate and extended family
  - 5) Dealing with loss of 'normal' or expected father-son relationship; benefits of having child with autism
  - 6) Looking to the future; long-term implications
  - 7) A toolbox of information/resources—sharing tips, tools, strategies
  - 8) Wrap up and feedback

Do you have any suggestions for changes to these topics? Any topics to be deleted, or reduced in emphasis? Any other topics to add or suggest?

5. Please describe the group facilitator's strengths:
6. Please describe how the group facilitator could have improved her performance:
7. Additional comments:

## APPENDIX B: Recruitment Flyer for Support Group



### “SHOP TALK” GROUP FOR FATHERS OF CHILDREN WITH AUTISM

Miriam Elfert is a graduate student at UBC and is conducting a study to learn about what it’s like for fathers of children with autism to participate in a weekly discussion group with other fathers. You are invited to participate in this study.

#### **What is Shop Talk?**

Shop Talk is a group developed specifically for fathers of children with autism to meet and talk about their experiences of parenting. Each group will consist of 6-8 fathers who will talk about different topics every week, including the challenges of parenting a child with autism, stress management, and how having a child with autism has affected their relationships with friends and family members.

#### **Why should I join Shop Talk?**

The purpose of the group is to enable fathers of children with autism to talk to one other about their experiences and challenges. Fathers of children with autism must deal with a number of daily pressures and expectations regarding the support (financial, emotional, social, recreational) that they provide to their families. Many of these issues are unique to fathers, and can affect fathers in unique and important ways. Shop Talk will provide fathers with a supportive environment where they can talk about their experiences, exchange ideas and approaches, and help other fathers. Fathers can also learn new strategies and skills to cope with parenting a child with autism, and may increase their understanding of how to be a more effective parent and partner/spouse.

#### **Who can attend Shop Talk?**

You are eligible to participate if you: 1) are the father of a child diagnosed with autism, 2) are currently married or in a common-law relationship, 3) are committed to attending all of the weekly group sessions, and 4) are **not** currently receiving psychotherapy or taking medication for mental health issues.

#### **When, where, and for how long will Shop Talk take place?**

Participants will be assigned to 1 of 2 groups, which will run consecutively. Each group will consist of eight, 2-hour weekly group sessions, for a total of 16 hours. Sessions will take place at a central and convenient location and time for group members—the specific location, day, and time will be determined once enrolment has been achieved. In addition to attending the group, you will be asked to complete questionnaires at three different time points, which ask you to rate statements related to parenting-related stress, depression, coping resources, your relationship with your spouse/partner, and optimism. You will also complete a form about what it was like to participate in the group. Filling out the forms will require approximately 45-60 minutes each time and can be done in your home or another convenient location. In total, the time commitment for the study will be 16 hours for the group sessions and approximately 3 hours for completion of the questionnaires, for a total of 19 hours.

#### **Who will lead Shop Talk?**

Miriam Elfert will guide the Shop Talk group. Miriam has experience leading similar groups for fathers of children with autism in the past. Miriam has worked with children with autism and their families for

over 15 years, in many roles, including behavior interventionist in family homes and special education assistant in schools; currently, she works as a program manager and behaviour consultant at the Reach ABA program for children with autism. Miriam has master's degrees in both Special Education and Counselling Psychology, and is currently completing her Ph.D. in Special Education at UBC. She is also the mother of a boy and a girl, and the stepmother of a young adult male.

**What is the cost to join Shop Talk?**

Shop Talk is offered free of charge to participants. To cover the cost of transportation, participants will receive \$10 for every Shop Talk session they attend, plus an honorarium of \$20 for participating in the study, for a maximum of \$100.

**How do I get more information and/or sign up for Shop Talk?**

Please call Miriam Elfert at XXX-XXX-XXXX or email her at XXX.

## APPENDIX C: Standard Interview Form to Screen Potential Participants

### Introduction to the support group:

I'd like to start off by telling you a bit about Shop Talk, in order to give you some information about its purpose, the general structure and content, and expectations regarding participation in the group. Shop Talk is a group for fathers of children who have been recently diagnosed with autism. Essentially, the purpose of the group is to create a forum in which fathers can talk about their experiences of raising a child with autism, which can be a valuable and worthwhile endeavour. Not only does it provide fathers with a supportive environment where they can discuss their individual experiences as the father of a child with autism, but it gives them an opportunity to hear from other men who face many of those same challenges.

The group will meet one time per week for 2-hour sessions, and will last for 8 weeks. Topics of discussion will include learning about your child's disability and how this has affected you; the implications of being a "breadwinner" and supporting your family; and how raising a child with ASD has affected your relationships with other people in your life such as friends, coworkers, and family members. These topics are flexible and can be changed or altered based on group member's input.

*I want to emphasize that this group is NOT an educational group where fathers attend lectures or learn strategies about a specific topic such as managing problem behaviours. The group is designed to have fathers participate in group discussion about their personal experiences in parenting a child with autism, and to connect to, and hear from other fathers in similar circumstances.*

I will be the person leading the group. I have worked in the area of autism for over 16 years in a variety of roles, including special education assistant, behaviour consultant, and program manager for an autism program in Delta. I am also a doctoral student at UBC in the special education program. I have a masters degree in counseling psychology and have run these groups for fathers of children with autism a number of times before. My role is to facilitate discussion amongst the group members, and to help fathers examine and talk about their thoughts, ideas, and experiences in parenting a child with autism.

Based on this information, do you have any questions about the support group so far?

### Interview regarding eligibility to participate in the group:

- How old is your child(ren) with autism?
- When was/were your child(ren) with autism diagnosed?
- What is your current relationship status?
- Are you currently taking any medication for psychological or emotional problems (e.g., anti-depressant or anti-anxiety medication)?
- Are you currently receiving psychotherapy or counseling for any psychological or emotional reasons?
- The group is scheduled to run one time per week for 2 hours, for a total of 8 weeks. If you are available to attend and agree to join the group, do you commit to attending all sessions?
- The support group is tentatively scheduled to start on [date] and will be held in the evenings, on the same day and at the same time each week. What is your availability to attend the group?

### APPENDIX D: Demographic Form

Please complete the following form, which asks for information about yourself and your family members. The information will be kept confidential and you will remain anonymous.

#### Questions about *you*

1. Age

2. Occupation (job title)

3. Annual *gross* household income  
(you and spouse combined)

4. Highest level of education completed (please check ONE)

High school diploma     College/trade school diploma/certificate     Bachelor's degree

Master's degree     Other (please describe) \_\_\_\_\_

5. Current relationship status

Married     Common-law

In a relationship, but not cohabitating     Other (please describe) \_\_\_\_\_

#### Questions about *your spouse/partner*

6. Age

7. Occupation (job title)

8. Highest level of education completed (please check ONE)

High school diploma     College/trade school diploma/certificate     Bachelor's degree

Master's degree     Other (please describe) \_\_\_\_\_

#### Questions about *your child/children*

9. Number of children \_\_\_\_\_

Ages of child/children: Child 1 \_\_\_\_\_ Child 2 \_\_\_\_\_ Child 3 \_\_\_\_\_ Child 4 \_\_\_\_\_

10. Of these children, how many are diagnosed with autism?

11. Date of diagnosis of child(ren) with autism (month/year)

12. Age(s) of child(ren) with autism

13. Are any of the children diagnosed with a disability other than autism (e.g., ADHD)?

Yes  No

If yes, please describe the diagnosis \_\_\_\_\_

14. Regarding the child(ren) with autism, what service providers are currently providing *autism-specific services* to your child(ren)? CHECK ALL THAT APPLY

Speech language pathologist  Occupational therapist  Behaviour consultant

Behaviour interventionist/One-to-one worker  Other (please describe) \_\_\_\_\_

***THANK YOU!***

**APPENDIX E: Shop Talk Social Validity Questionnaire**

**Please answer the following 7 questions in point form. Please be honest. Your feedback and comments will help the facilitator improve the group for other fathers of children with autism.**

1. Did you find this group helpful? If yes, how and why was it helpful? If no, why was it **not** helpful?

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2. What were the things that you enjoyed **most** about participating in the group?

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3. What were the things that you enjoyed **least** about participating in the group?

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4. a) The group was organized in 8 sessions of 2 hours duration, with meetings every week. What are your thoughts about the frequency, duration, and timing of the sessions?

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- b) We covered the following 8 topics, focusing on one topic per week:
- 1) Introduction to group and members; first experiences with diagnosis & disability
  - 2) Being an advocate and team member; working with professionals; finding quality treatment
  - 3) Being a coworker/supervisor, friend – how autism impact relationships with colleagues and friends
  - 4) Being a father, son, brother, uncle, etc. – how autism impacts relationships with immediate and extended family members
  - 5) Being a spouse/husband/partner – how autism affects the relationship with your wife/partner
  - 6) Looking to the future; hopes, dreams, fears, reflections
  - 7) Re-definition and re-development of one's self as a parent, partner, and person; new identities; new directions
  - 8) Wrap up and feedback; recognition and validation of fathers

Do you have any suggestions for changes to these topics? Any topics to be deleted, or reduced in emphasis? Any other topics to add or suggest?

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5. Please describe the group facilitator's strengths:

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6. Please describe how the group facilitator could have improved her performance:

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7. Would you recommend Shop Talk to other fathers of children with autism? **YES**    **NO**

8. Additional comments:

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*Thank you for completing this form. Your comments are appreciated.*

## APPENDIX F: Support Group Code of Conduct

### CODE OF CONDUCT

As members of the Shop Talk group, we have agreed to strive to do the following:

1. Maintain the confidentiality of group members by not divulging private and personal information shared in group sessions outside of the group. In other words, “What’s said in the group stays in the group.” You can talk about your own experiences as it relates to *your* participation in the group, but protect the anonymity of the other group members.
2. Behave respectfully towards other group members. Respect is the essential foundation to the group process, as it provides a safe environment for the group and allows members to share their experiences more openly with each other. Respect includes:
  - Using humour carefully and knowing what the limits are—if unsure, check with group members about their perceptions.
  - Making an effort to be transparent by speaking honestly and openly about your experience, but in a way that is not offensive to other group members.
  - Telling another group member when you are hurt or offended by what he/she has said and making an effort to work the problem out between you within the group setting.
3. Try not to judge other group members by creating an atmosphere of acceptance and tolerance. We want to try and help each other, not judge the choices or decisions group members have made. You may not necessarily agree with a group member’s actions, but try to understand his experience and choices from his perspective.
4. Participate to the degree and at the level you are comfortable with. A group member can choose to pass and not speak about a particular topic if he is uncomfortable doing so. There is no pressure to have to comment and participate.
5. Be aware of “air time” and how much you are talking. Remember that there are other group members who want to talk about their experiences too. Group members can remind each other about the air time that they are using by telling the person directly (e.g., “Hey, can I say something now?”) or using a gesture (e.g., raising a hand to indicate the desire to speak). Miriam also has permission to ask one group member to wrap up so that others can speak.
6. One person speaks at a time while others listen.
7. Group members will try to arrive to group on time (7:00) and to finish on time (9:00).
8. If a group member is going to be late or absent from a group session, he will contact Miriam by email or phone to let her know of his absence/lateness so that she can inform the group.
9. There will be no formal breaks during the group session. If group members need to leave to go to the washroom etc., they can simply get up and go and quietly rejoin the group.

This list is subject to revision, addition, etc. at any time based on discussion amongst the group.