FAMILY EMPOWERMENT: THE USE OF ONLINE PARENT DISCUSSION GROUPS FOLLOWING DIAGNOSIS OF ASD IN YOUNG CHILDREN

BY

LAURIE MARIE JEANS

DISSERTATION

Submitted in partial fulfillment of the requirements for the degree of Doctor of Philosophy in Special Education in the Graduate College of the University of Illinois at Urbana-Champaign, 2013

Urbana, Illinois

Doctoral Committee:

Associate Professor Rosa Milagros Santos, Chair
Professor Brent A. McBride
Professor Susan A. Fowler
Clinical Associate Professor Mary-Alayne Hughes
Abstract

The overarching purpose of this research study was to examine the usefulness of online discussion groups for mothers and fathers of young children (prior to the entry in kindergarten) with an autism spectrum disorder. Over a 12 week time period, parents (15 mothers and 7 fathers) participated in gender-divided online discussion groups. Three online surveys were used to determine discussion topics of importance, to identify services and supports already accessed, and to report parent satisfaction in participation. Fathers and mothers identified similar topic choices for discussion although mothers indicated sleeping and toilet training as higher priorities than fathers. Similarities and differences were identified between the parent groups in their styles of discussion postings. Fathers engaged in more lurking (viewing without posting) behavior and only mothers used emotional support statements (indicating understanding and sympathy) and esteem supportive-compliments in their discussions. New subthemes of Sharing Statements-Information, Sharing Statements-Questions, and Building Relationships through Humor emerged. Mothers found the online discussion groups more useful than fathers, but both indicated they would recommend online discussion groups such as this one. The access to new ideas, the presence of others in a shared situation, and a sense of belonging to a supportive community were reasons mothers found participation useful. Fathers noted the access to others’ perspectives and contact with others sharing the same challenges as reasons the online groups were useful. Limitations of the study and implications for research and practice are discussed.
For my family
Acknowledgments

There are many people to acknowledge for their assistance during this research project. I wish to thank the 15 families of young children who participated in the online discussion groups. I am immensely grateful for their willingness to share their lives over the course of 12 weeks. I am so fortunate to have had the opportunity to learn from such a supportive and interactive group of mothers and fathers. Our online parent discussion groups have enriched my work as a researcher and a family practitioner.

Among my colleagues who have supported me in this journey, I sincerely appreciate the pathway paved by Bernie Laumann in her use of online groups for research. Her work was a guiding template for my own and I am thankful for her mentoring. A special thank-you goes to Kimberly Hile for assistance with coding and for her thoughtful ideas and insights about the data. I am especially grateful to my committee members who helped design and shape this project: Susan Fowler, Mary-alayne Hughes, Brent McBride, and my exceptional adviser Amy Santos. The supports and insights you have shared over the years are immeasurable and extend far beyond this project. I am blessed by your presence in my life as mentors, colleagues, and friends.

Finally, the guiding light in all my research has been the cares and concerns of families of little ones with disabilities. I am blessed to be able to study something for which I care deeply. My own family has accompanied me in this journey and words cannot begin to express my gratitude to my husband and children for their caring support.
# Table of Contents

Chapter 1: Introduction ........................................................................................................... 1

Chapter 2: Literature Review ................................................................................................. 16

Chapter 3: Methods ............................................................................................................... 40

Chapter 4: Results ................................................................................................................ 65

Chapter 5: Discussion ............................................................................................................ 89

References ............................................................................................................................... 106

Appendix A: Recruitment Forms ......................................................................................... 121

Appendix B: Participant Consent Form ................................................................................ 124

Appendix C: Online Parent Discussion Group Policies ....................................................... 128

Appendix D: Initial Recruitment Survey Questionnaire .................................................... 130

Appendix E: IRB Approval ..................................................................................................... 140

Appendix F: Current Services and Supports Survey Questionnaire .................................. 141

Appendix G: Post Participation Survey Questionnaire ......................................................... 149
Chapter 1

Introduction

In 2012, the Center for Disease Control and Prevention estimated the prevalence of autism spectrum disorder (ASD) in the U.S. to be 1 in 88 children. No longer a rare disability, more parents are facing the numerous challenges to raising a child with ASD (e.g., obtaining a diagnosis, finding an appropriate treatment or educational program, struggling with the financial burden of paying for services, and addressing the possible behavior problems associated with the disability) (Ekas, Lickenbrock, & Whitman, 2010). Currently in the U.S., the median age of diagnosis of ASD is 4 years (Center for Disease Control and Prevention, 2012), but many parents of children with ASD have identified developmental concerns by the age of 12 to 18 months (Ozonoff et al., 2009; Robins, Fein, Barton, & Green, 2001). Burack and colleagues (2001) emphasized that ASD is a family disability where an individual child may be identified with the disorder, yet the entire family is affected by the emotional and financial strain. Parenting a child with the unique identifiable characteristics of ASD has multiple challenges, as Myers, Mackintosh, and Goin-Kochel (2009) reported:

In addition to having difficulties in social interactions and communication, children in the autism spectrum often exhibit behaviors that are disruptive and hard to manage, and this can create chaos throughout the household and extended family. It can leave parents feeling locked at home, as they fear taking the child out in public lest he create a scene or run into danger (p. 671).

Adding to the demanding family routines, children with ASD received an average of 3.5 different services simultaneously (range = 1-9 different types of services), with younger children receiving the highest number of services (Ruble & McGrew, 2007). Further, when compared to children in general, children with ASD required more outpatient visits, physician visits, and medications (Liptak, Stuart, & Auinger, 2006). Clearly, large amounts of parent time are
expended for a child with ASD and little remains for the needs of the rest of the family (Hall & Graff, 2010).

**Need for Support**

Much of the existing research demonstrates that mothers and fathers of children with ASD reported significantly more stress than parents of children without disabilities, as well as more than parents of children with other disabilities and chronic illnesses (Hastings et al., 2005). Bromley and colleagues (2004) observed that social support provided by family and friends was effective in reducing stress among mothers of children with ASD. Additionally, Boyd (2002) found that mothers sought support by turning first to their spouses then their immediate families, followed by other parents of children with ASD. To reduce levels of family stress and anxiety, Howlin and Moore (1997) suggested the diagnosis of ASD should be accompanied by practical help and support, particularly in the early years.

Hall and Graff (2010) reported that the diagnosis of a child brings increased parental stress as parents adapt to meet the needs of the child with ASD and the needs of their family. Family stress theory seems well-suited for studying the family system following the diagnosis of ASD in early childhood. Boss (2002) noted that family stress is a normal occurrence where family routines and patterns of interaction are changed, as in the birth of a child. But families can reach a crisis point when there is a pileup of stress from the behaviors and characteristics of ASD interfering with the daily functioning of the family. Luther, Canham, and Cureton (2005) stated, “autism affects the family so intensely that families require strong coping skills and formal and informal support” (p. 41). Further, in order for families to manage their lives effectively, they need to be empowered to become competent and capable rather than dependent upon
professional helping systems (Dunst, Trivette, & Deal, 1994). “This is accomplished by creating opportunities for families to acquire the necessary knowledge and skills to become stronger, and better able to manage and negotiate the many demands and forces that impinge on them in a way that promotes individual and family well-being” (Dunst, Trivette, & Deal, p. 5).

Researchers indicated that parents of young children with ASD, who received social support, adapted more successfully to the difficulties encountered when raising their children (Dunn, Burbine, Bowers, & Tandeff-Dunn, 2001; Mandell & Salzer, 2007; Papageorgiou & Kalyva, 2010; Siklos & Kerns, 2006). Turnbull and colleagues (2011) described social support as the practical and emotional support that parents received from family and friends, including physical assistance, information and resource sharing, and psychological support. Singer and Powers (1993) described a family support network for families and their children with disabilities and within this network were formal and informal means of social support. The present research study included elements of both formal and informal social support in that the online discussion groups were organized by the researcher, a family practitioner, who provided discussion prompts and information of value, as requested by parents. Trondsen and Sandaunet (2009) described the facilitator as a “hostess” or moderator of discussion, who welcomes the participants and responds with information when requested. It was hoped that parents would consider themselves as collaborators in the discussion groups rather than subjects of a research investigation (Brownlow & O’Dell, 2002).

Turnbull and colleagues (2011) described two types of emotional support programs, Parent-to-Parent programs and parent support groups, both of which are very helpful in addressing emotional and informational needs of families of children with disabilities. Parent-to-Parent programs use one-to-one matches between a trained, experienced parent of a child with a
disability and a parent in need of emotional support. The authors noted there is at least one Parent-to-Parent program in every state, with 155,000 parents matched with 70,000 “veteran” parents annually. While Parent-to-Parent programs have an established history of success, the research study and accompanying review of the literature focused on the second form of emotional support described by Turnbull and colleagues, the parent support group.

**Support Groups for Families of Children with ASD**

Researchers have shown that parents of children with ASD seek contact with parents in similar circumstances for support and information (Mackintosh, Myers, & Goin-Kochel, 2006; Mandell & Salzer, 2007; McCabe, 2008; Murray, Ackerman-Spain, Williams, & Ryley, 2011). While the literature identified that parents of children with ASD were well-suited for support services due to the stress they experience, particularly in the time period following diagnosis (Davis & Carter, 2008), there were a limited number of studies exploring the use of support groups. Two studies assessed the use of 2-3 hour weekly training sessions for parents of children with ASD (aged 4-18 years). Results of these studies indicated parent satisfaction and improved knowledge of working with their children (Murray et al., 2011; Pillay, Alderson-Day, Wright, Williams, & Urwin, 2011). Yet the social support component was secondary to learning to manage challenging behaviors and navigating community services. An additional six studies evaluated support groups for parents of children with ASD in Taiwan, China, Greece, and the U.S. (Banach, Iudice, Conway, & Couse, 2010; Hall & Graff, 2010; McCabe, 2008; Papageorgiou & Kalyva, 2010; Shu & Lung, 2005). Common characteristics emerged from four of the six studies including: (a) three studies had small sample sizes, with less than 12 parents participating, (b) three studies had large age ranges of children (e.g., 2-12 years), (c) three studies
had group meetings for 6-12 sessions, (d) four studies collected interview data for content analysis and only one used a quantitative measure (i.e., a mental health questionnaire), and (e) four studies had two or fewer fathers participating.

A unique study from Greece (Papageorgiou & Kalyva, 2010) included 299 parents (72 fathers and 227 mothers) who answered an open-ended questionnaire about their participation in support groups across every prefecture in the country. While the study focused on the self-reported needs of parents of children with ASD, it is important to note that 42.8% were parents of preschoolers and were likely to have different needs than parents of school-aged children. In an even larger survey study of 1005 parents (86% mothers) in ASD support groups in Pennsylvania, Mandell and Salzer (2007) identified factors associated with participation (e.g., demographic information and child behavior characteristics). In the study, the age range of the individuals with ASD was 2 to 53 years, which is useful for comparisons of demographic information but makes it difficult to address the wide variety of family needs likely to be present in the support groups.

**Variables that impact access to social support.** Characteristics of families and family members influence their access to social support. Hall and Graff (2010) found that some parents were unable to attend support groups due to lack of respite care or a family member to take care of their child with ASD. As Banach and colleagues (2010) emphasized, time and day of a parent support group are important considerations for reaching families who may benefit but may be reluctant to participate. Potential participants refused to attend a support group for mothers of children with ASD in Taiwan, citing “no time available” and “too far to travel” as explanations (Shu & Lung, 2005).
Mandell and Salzer (2007) reported that face-to-face support groups for parents of children with ASD were “underutilized by certain segments of the population, especially those from lower socioeconomic backgrounds” (p. 119). Several studies showed that families, with lower income levels or lack of transportation, had difficulty accessing support groups (Luther, Canham, & Cureton, 2005; Murray et al., 2011; Shu & Lung, 2005). In addition, parents with household incomes between $40,000 and $80,000 per year and those with college degrees were more likely to participate in support groups than parents with incomes below $40,000 or who had no college education (Mandell & Salzer).

Furthermore, researchers have found that African American parents of children with ASD were less likely to participate in face-to-face support groups than Caucasian parents (Hall & Graff, 2004; Mandell & Salzer, 2007). In a survey of 72 parents of children with autism (ages 5 to 13 years) in California, Luther, Canham, and Cureton, (2005) described the ethnicity of participants as one third of the total were Hispanic or Latino, one third were Asian or Filipino, and one third were Caucasian. The researchers reported approximately half of the parents indicated they had attended or were interested in attending a support group. The ethnicities of these parents responding to the attendance question were unreported and Luther and colleagues pointed out that the inability to speak English prevented some of the parents’ access to support groups. Similarly, parent age was rarely reported in the studies of parent groups for families of children with ASD and the social support needs of parents of different ages remains unclear.

In a study of Greek parents in support groups, parents of girls reported more acceptance and understanding from their families and their work environment (Papageorgiou & Kalyva, 2010) and parents of boys were more concerned with potential social problems that could lead to social exclusion or trouble with the law. The authors described how gender roles (e.g., a boy is
seen as the continuation of the family name) in Greek society may influence what information parents wished to access in a support group. Mandell and Salzer (2007) stated that parents of male children were more likely to belong to support groups (86.5% versus 80.3%). In addition, when organizing face-to-face support groups, an important consideration is that parents of children with more severe levels of functioning (e.g., significant challenging behaviors) may have difficulty relating to parents of children with milder forms of ASD (Murray et al., 2011).

In any discussion of the family system, it is important to consider participation and outcomes of fathers and male caregivers (Johnson, Frenn, Feetham, & Simpson, 2011; Little, 2002; McCabe, 2008). Multiple studies described the need to better understand the experiences of the families (including mother and fathers) as more children with ASD enter the early intervention system (Boyd, 2002; Davis & Carter, 2008; Hastings et al., 2005; Little, 2002), but participation of two or fewer fathers in a support group makes it difficult to determine guidelines for providing social support to men (McCabe, 2008). Yet, as mentioned previously, fathers were more likely to report stress when parenting a child with ASD, compared to fathers of children with other disabilities and children who were typically developing (Hastings et al., 2005).

Ways Families Access Information and Support

One of the basic foundations of family support is the use of the principles of enabling and empowering to encourage competence in the family and its members (Singer & Powell, 1993). Dunst and Trivette (1996) stated that empowerment includes a belief that parents have existing strengths and capabilities, as well as the capacity to become more competent. “Knowledge is power” according to Turnbull et al. (2011) and parents of children with ASD need access to knowledge that is current, accurate, and accessible. Parents of children with ASD reported the
most frequent source of information and support was other parents of children with ASD (Mackintosh, Myers, & Goin-Kochel, 2006; McCabe, 2008). This quest for parent connections with other parents of children with ASD has led families to the Internet and online support groups (Huws, Jones, & Ingledew, 2001). Baum (2004) found the three most identified outcomes of online support groups for parents of children with special health care needs were finding parents with similar challenges, receiving advice and information, and feeling accepted and understood.

The Internet has created a “global village” where people can easily communicate and interact online (Barak, 1999). Skinner and Shaffer (2006) suggested that the Internet empowers users by providing scientific information and social support networks needed to become knowledgeable partners in their health services. With a small number of studies exploring the impact of Internet use and support on families of children with ASD (Fleishmann, 2005; Huws, Jones, & Ingledew, 2001; Mackintosh, Myers, & Goin-Kochel, 2006), it is prudent to explore the use of online groups focused on parenting young children (Brady & Guerin, 2010; Plantin & Daneback, 2009; Sarkadi & Bremberg, 2005). Social support and information were key components of these online groups and parents routinely reported having their perceived needs met around the clock, given the 24 hour accessibility of the Internet. Likewise, parents participating in online support groups focused on special health care needs reported benefits to interacting with other parents that included: accessing information, sharing experiences, receiving general support, and venting feelings (Baum 2004; Han & Belcher, 2001).

Notably, very few comparisons have been made between fathers’ and mothers’ use of online support groups (Fletcher & St. George, 2011), so a review of the gender-specific Internet cancer support groups (i.e., prostate and breast cancers) provides some insights into gender
differences in dialogue postings. As Blank and colleagues (2010) noted, there is a need to recognize the differences between men and women when designing discussion groups as a way to provide support for participants using them. Researchers of these online cancer support groups have found that men and women seek different types of support (e.g., informational versus emotional) and that communication styles were different as well (Mo, Malik, & Coulson, 2009).

In addition to the need for research on the use of discussion forums by fathers in their parenting role, there is a need for studies involving comparisons of the use of online support and discussion groups by both fathers and mothers engaged in parenting children with ASD. Johnson and colleagues (2011) stated, there is a need to effectively recruit fathers because “even parents of the same child may well have different experiences and views” (p. 249).

Key findings from research on the use of the Internet and parents of children with ASD indicate that the Internet allowed stressed parents to create bonds among themselves and relieved feelings of isolation (Fleishmann, 2005; Huws, Jones, & Ingledew, 2001; Mackintosh, Myers, & Goin-Kochel, 2006). In addition, parents of children with ASD praised the Internet for their access to information providing a sense of empowerment (Fleishmann). Clearly, “parents of individuals with ASD are the single most effective support system to other parents of individuals with ASD” (Murray et al., 2011, p. 29) and the literature indicated that group support can be provided online or face-to-face. It should be mentioned that the few studies documenting online discussions between parents of children with ASD have rarely included the age range of the children. Yet inferences can be made from the messages, where parents described 2½ year olds and 30 year olds, that the age range included toddlers, teenagers, and adults with ASD in the same parent support group (Huws, Jones, & Ingledew).
In a systematic review of the effects of health-related online peer support groups, Eysenbach and colleagues (2004) noted many of the studies incorporated outcome measurements of depression, yet did not show a significant effect in reducing the symptoms of depression. This is unsurprising as Barak and colleagues (2008) cautioned, “Support groups, including their online version, are not a substitute for the treatment of any kind of distress. A common mistake, or myth, holds that a good support group might replace therapy” (p. 1869). Melling and Houghuet-Pincham (2011) suggested that the primary aim of online support groups should focus on providing support, compassion, and understanding with the outcomes of improved self-esteem, empowerment, self-efficacy, and coping strategies. Thus, Barak and colleagues urged measurements of these changes in general well-being (therapeutic changes) should be chosen in place of clinical outcomes in symptom reduction.

In a ten year review of the literature on families of children with disabilities, Canary (2008) found “research clearly indicates that support influences well-being for family members, family-functioning, and the utilization of social resources” (p. 413). It is well-known that families of children with autism spectrum disorders will require long-term support from professionals, family members, and friends (Myers, Mackintosh, & Goin-Kochel, 2009; Stuart & McGrew, 2009). Banach and colleagues (2010) reported, “in the immediate aftermath of receiving a diagnosis, the encouragement and assistance gained through the mutual aid process of a support group can be invaluable in helping parents to get through the challenging time” (p. 81). Effective supports are essential for families of young children with ASD, yet little is known about parent’s needs and desires for support.

Limitations of the Current Research
In what has been termed the Genomic and Internet Age (Skinner & Schaffer, 2006), online parenting and chronic illness support groups have a strong presence on the World Wide Web. However, there is an absence of research studies on parent support groups focused on parenting children with ASD. The research literature emphasized that parents of children with ASD experience high levels of stress, particularly following their child’s diagnosis (Osborne, McHugh, Saunders, & Reed, 2008). Likewise, studies showed that parents want information and organizations like Autism Speaks™ believe parents spend the first 100 days following the diagnosis of ASD becoming informed on terminology, traits, and treatments via the Internet.

The concept of an online discussion group for parents of children with ASD is supported by three studies. Researchers studied messages sent to an email group (Huws, Jones, and Ingledew, 2001), 33 self-published websites (Fleischmann, 2005) and web-based questionnaires sent to 220 web pages and email listservs of autism-related organizations (Mackintosh, Myers, & Goin-Kochel, 2006). The narratives and information provided by parents of children with ASD confirmed that parents established connections with others in similar circumstances and the information and support gained empowered them to handle the challenges they face. However, the literature on parents of children with ASD has not delved into creating an online supportive network for families new to diagnosis or into examining ways to best help them in the years prior to entering the education system. Parents of toddlers and preschoolers have unique needs, different from parents with children in the early elementary grades and will seek help in age-related topics such as toilet-training, sleeping schedules, nutritional concerns, and play skills.

Families have difficulties attending face-to-face support groups, particularly when their children are young and newly diagnosed. The challenging behaviors associated with ASD often isolate parents from their typical informal supports of friends and extended families. In addition,
the large number of treatment services used to intervene early and intensively following diagnosis prevents sufficient time to participate in an activity away from home (e.g., a face-to-face parent support group). The sparse literature on Internet support and parents of children with ASD employed qualitative methodology, with a focus on content analysis of narrative texts. Conversely, Mackintosh and colleagues (2006) gathered data on sources of information and support from 498 parents of children with ASD, but the blending of these two methods is necessary to understand what information parents seek and to identify important aspects that make an online support group effective. The literature on general online support groups specified a facilitator was needed to sustain a group and that men were difficult to recruit. Yet there has been more success in online versus face-to-face support groups, particularly when gender-specific groups were organized.

Internet access is becoming more commonplace in American homes and is serving as an equalizing force across socioeconomic lines. In 2002, over 90% of teenagers and 20 year olds were using the Internet and the U.S. Department of Commerce predicted that people who used the Internet when they were younger would continue to do so as they age. This suggests that a vast majority of the parents recruited for this study’s online discussion groups were Internet users in 2012.

The Research Study

This research study was based on a conceptual framework that fathers and mothers parenting young children with ASD have unique as well as overlapping needs for information and support when participating in online discussion groups. A mixed-methods design was used to perform a content analysis according to methods described by Miles and Huberman (1994) for
emerging themes of the postings to the discussion groups, in addition to analyses of the data collected from surveys of demographic information, discussion topic preferences, services currently receiving, and satisfaction of participants. Training programs for parents of children with ASD have some limited research support and have noted the absence of racially and ethnically diverse participants. Moreover, the study sought to provide materials and information from reputable sources to address topic areas of concern generated by the groups. In addition, the recruitment of a diverse group of parents was targeted through the early intervention service providers in Illinois, as well as through online forums typically accessed by parents of young children with disabilities. Participation was not bound by location due to the far reach of the Internet. For this reason, the groups were able to include families from rural and urban settings.

Literature on parental stress suggests there should be a focus on families of children with recent diagnoses of ASD, but this has not been addressed through an online discussion group. As the target of recruitment efforts were U.S. families of young children with ASD, prior to entry to kindergarten, early intervention service providers and online forums for parents of children with ASD permitted access to parents willing to participate. The asynchronous online discussion group allowed parents to access the forum at a time convenient for them, while in the privacy of their home. The ongoing dialogue generated in a discussion group provided more immediate support and feedback than a single, weekly face-to-face meeting, a possible benefit to parents facing challenging moments in their day. In a discussion of face-to-face therapeutic groups, Yalom and Leszcz (2005) noted that group size was inversely proportional to interaction, with groups of 12-16 meeting productively in therapeutic groups. In keeping with the interactive nature of the face-to-face groups, rather than the very large discussion and support groups currently available on the Internet, recruitment of 12-25 parents for each of the two gender-
specific discussion groups was targeted as an adequate sample size for analyzing participation (or lack of participation) and information supplied by parents.

The literature indicated that parents of children with ASD found comfort and were empowered by their interactions and discussions with parents facing similar challenges in parenting. The underlying purpose of parent empowerment matched the purpose of the online parent discussion groups in the desire to provide a forum for discussion of topics pertinent to parents raising young children with autism spectrum disorders. King and Moreggi (1998) stated, “All self-help and mutual aid organizations have in common the fact that members participate with the expectation of receiving emotional support, sharing personal experiences, and finding new ways to help themselves cope with their shared problems” (p. 82). The overarching purpose of this research study was to examine and gain an understanding of the utility of discussion forums for parents of young children (prior to entry in kindergarten) recently diagnosed with an autism spectrum disorder. The discussion groups served as a safe setting for parents to share trials and triumphs about parenting their children with ASD and offered reliable support to empower parents to address the current and future challenges they face. In addition, a major intent of this research study was to inform the field of methods and strategies useful for designing future online parent support for families of young children with ASD. To explore the needs of parents of children with a recent diagnosis of ASD, using quantitative and qualitative measures, four overarching research questions were addressed in this research study:

1. What kinds of information do parents seek following their child’s diagnosis of an Autism Spectrum Disorder (ASD)? Are there differences in the kinds of information requested by parents based on salient factors (e.g., parent gender, parent age, child gender, family SES)?
2. What are the sources of support that parents of young children with ASD report upon entry into the online parent discussion group?

3. What types of support-intended postings do parents engage in when participating in the online discussion group?

4. To what extent are parent participants satisfied with their use of the online discussion groups? What do parents report are the factors that promote participation and prevent participation in online parent discussion groups?
Chapter 2

Literature Review

The challenges to family life of raising children with Autism Spectrum Disorders (ASD) are well-detailed in the literature. Burack and colleagues (2001) emphasized that ASD is a family disability where an individual child may be identified with the disorder, yet the entire family, including extended family, is affected by the emotional and financial strain. As Osborne and colleagues (2008) noted, the current emphasis on early diagnosis of ASD may not be helpful to parents unless it is combined with support for those parents. From a practitioner’s perspective, helping families successfully adapt to the stressors of caring for children with ASD first requires identification of those stressors followed by intervention to reduce or eliminate those with negative impact on family function (e.g., family relationships in daily activities). It should be noted, when ASD occurs in early childhood, “the very high parenting stress levels observed may be in part due to what has been considered a crisis period of the early adaptation to the diagnosis” (Davis & Carter, 2008, p. 1289). This time point in a family, soon after the diagnosis of ASD, was the starting point for this study. The following literature review focuses on four areas salient to this investigation: (a) a description of characteristics and needs of parents (mothers and fathers) of young children with ASD, (b) an overview of social supports available and accessed by parents of children with disabilities and with ASD, in specific, (3) the extant literature on online support and discussion groups accessed by parents, as well as family members and persons with chronic diseases and disabilities, and (d) the general use of the Internet by parents of children with ASD.

In total, 85 articles were collected, with 55 empirical articles included in this literature review based on reported outcomes using standardized measures of stress and family function,
survey questionnaires, interviews, and discussion postings on Internet support groups. One important procedure of this study of online discussion groups was the use of the qualitative measure of “content analysis” of discussion texts. Thirty-one of the 55 studies were noted to use some form of content analysis. Through the University of Illinois Library (online), databases searched included ERIC, EBSCO, and PsychInfo. Key terms and phrases included autism, Autism Spectrum Disorder (ASD), preschool children, parents, mothers, fathers, online support groups, social support, and discussion boards. Initially, literature searches were limited to journal articles published since 2000, due to the wealth of information available on the use of the Internet in discussion and support groups by a variety of adults. Ancestral searches were conducted using the reference lists from the initial articles found through key word searches with the final time span included in this review from 1991 to 2012, with the vast majority published since 2000. Seminal chapters of five scholarly works focused on families of children with disabilities and 10 pertinent literature review articles were also included.

Characteristics and Needs of Parents of Children with ASD

Literature on children with disabilities consistently describes a strong relationship between challenging behavior problems and stress reported by mothers and fathers (Hastings, 2002; Herring et al., 2006; Hudson, Cameron, & Matthews, 2008; Luther, Canham, & Cureton, 2005). Likewise, the difficult traits and behaviors exhibited by young children with ASD which contribute to maternal stress are a common theme (e.g., Baker-Ericzén, Brookman-Frazee, & Stahmer, 2005; Davis & Carter, 2008; Hoffman et al., 2008; Tobing & Glenwick, 2006; Tomanik, Harris, & Hawkins, 2004). Researchers have noted that families of children with ASD feel restricted in their interactions in society, at times to the point of isolation (Cassidy et al.,
Further, the literature indicates that informal social support can have an impact on reducing stress in mothers of children with ASD (e.g., Boyd, 2002; Bromley, Hare, Davison, & Emerson, 2004; Gill and Harris, 1991; Luther, Canham, & Cureton, 2005). Herring et al. (2006) argued that when working with young children with ASD “an emphasis on providing early intervention for behaviour and emotional problems, along with additional support, education and skills training for parents, is justified” (p. 880).

As Hastings and colleagues (2005) reported, much of the research to date has demonstrated that mothers and fathers of children with autism report significantly more stress than parents of children without disabilities, as well as more than parents of children with other disabilities and chronic illnesses. Likewise, this researcher’s own study of mothers of young children with ASD, present in a nationally representative dataset (the Early Childhood Longitudinal Study-Birth cohort), revealed a significantly higher incidence of depressive symptoms and stress than found in mothers of typically developing children (Jeans, Santos, Laxman, McBride, & Dyer, 2013). In addition, these high levels depressive symptoms were unrelated to the gender of the child, the race or ethnicity of the child, the number of children in the family, or the presence of a father figure. As Hall and Graff (2010) observed, following the diagnosis of a child with ASD, “challenges for the family continue to build and parental stress rises as parents strive to adapt to meeting the needs of not only their child diagnosed with ASD, but also for the positive functioning of their family” (p. 189). Thus, there is a need to prioritize effective and accessible resource support for both families and children.

**Theoretical foundation for studying families of children with ASD.** The timing of diagnosis of ASD in early childhood and its effects on the family seem well-suited for the
application of family stress theory for exploring family function. Early intervention services for children under the age of three primarily focus on the context of the family rather than the individual child with a disability or delay. This makes a family stress theory approach a good match for this family focus.

Boss (2002) defined family stress as “pressure or tension in the family system—a disturbance in the steady state of the family” (p. 16) and family as a “continuing system of interacting persons bound together by processes of shared rituals and rules” (p. 18). Stress in families is seen as a normal occurrence, particularly after the birth of a child, where family routines and patterns of interaction are changed. The meaning a family gives to a stressor event and perceptions of the family are central to understanding family stress. Important points to remember about families raising a child with ASD include: (a) not all families are the same nor do they hold the same values and beliefs, (b) how the family perceives and reacts to a stressor event (in this instance, the diagnosis of ASD) will determine how the family changes, (c) the same event may not be viewed in the same way by all members of a family, (d) a family constructs a symbolic reality (with roles, language, and rules) on the basis of their shared meaning of a stressful situation they are experiencing, and (e) family stress must be studied in the larger context in which the family is living.

Prior to the diagnosis of ASD, the family may already be undergoing strain where the family is still functional but there is a mismatch between current supports and what is needed. The family may be moving toward a crisis level as they incur the ongoing stress pileup of a child who is not talking, who requires specific routines to prevent behavior problems, who engages in unusual or stereotypical behaviors, and who is avoiding the age-appropriate social interaction with parents and others. A family crisis would occur when there is severe stress and the family
cannot function and becomes immobilized. Families who are in crisis prior to the diagnosis of ASD may be characterized by parents who are not sleeping well, who are avoiding outside social contacts with friends, and who feel powerless as the behaviors of the child with autism dictate how a family will function on a daily basis.

A family’s values and beliefs have an impact on how they cope with the possibility of the diagnosis of ASD. Beliefs and values predict “their vulnerability to stress and how they manage stress levels” (Boss, 2002, p. 146). Levels of family stress will vary according to culture, religion, gender, and generation of family members. In a discussion of self-blame, Boss pointed out that a cognitive recovery was needed where “the family must recognize and accept what is under its control, what is not, what will never be, and why” (p. 164). Following the diagnosis of ASD, it is not uncommon for families to do extensive searches for answers on causes, therapy, education and school options, and family functioning in order to become experts on the disability. This, of course, is not always the case and some families stay immobilized for a period of time. Maturation of the child and mandatory school attendance does, at times, force the issue to the forefront.

**Parenting a child with ASD.** Lefley (1997) noted that “caregivers’ capabilities in coping with the stresses of parenting a child with disability are dependent on their personal strengths and their social resources and support systems.” (p. 443). When looking at the amount and different types of stress present in mothers and fathers of young children with ASD, it is important to return to the family as a system where the interconnected nature of family members recognizes that parents affect one another’s wellbeing (Hastings et al., 2005). This is particularly salient as Hwang and Lamb (1997) described “contemporary fathers (especially those with very young children) are assuming more responsibility for day-to-day child care and spend more time with
their children than fathers did in the past” (p. 621-622). Likewise, McBride (1991) found that intervention programs specifically targeted to support fathers “may be an effective means of reducing the perceived parental stress fathers experience as they attempt to become more actively involved in raising their children” (p. 144). Multiple studies described the need to better understand the experience of the families (including mothers and fathers) as more children with ASD enter the early intervention system (Boyd, 2002; Davis & Carter, 2008; Hastings et al., 2005; Jeans et al., 2013; Little, 2002)

**Social support needs of families.** In a study from Greece, Papageorgiou and Kalyva (2010) conducted a survey of 299 parents of children with ASD (72 fathers and 227 mothers) and their self-reported needs and expectations when participating in support groups. The primary reason the majority of parents participated in support groups was to learn the new developments in the area of ASD (64.5% of parents), followed by practical support (19.5% of parents). Additionally, 8% of the parents indicated their main reason for participation was to meet other parents of children with ASD and the final 8% specified psychological support as their primary motive for participation. The authors did not find a difference between mother and father reports of problems identified in their children with ASD (e.g., child’s communication skills, social skills, educational skills, behavioral problems, and self-occupation), problems in their family (e.g., communicating with child, behavioral problems affecting family members, practical daily activities, psychological well-being, social interaction with the public, financial strain), their extended family interaction with their child, and their social environment reaction to their child. However, fathers perceived the reaction of their work environment to their child with ASD was more negative, with a greater lack of understanding and support. Consequently, fathers were more likely than mothers to withhold that they had a child with ASD from their work colleagues.
Education levels of the parents (secondary versus university) were related to differences in social and work environment reactions to their child with ASD, with university educated parents reporting more lack of understanding in social situations and more acceptance in work environments. In addition, parents differed by education on reasons for participating in support groups, with university educated parents expecting psychological support and secondary educated parents expecting practical support. Interestingly, the study focused on the self-reported needs of parents of children with ASD and 42.8% were parents of preschoolers.

In a study of primary caregivers (n = 78) of children diagnosed with ASD in the previous 6 months, Stuart and McGrew (2009) found higher levels of social support were correlated \( (p < 0.001) \) to decreases in measures of individual \( (r = -0.69) \) and family \( (r = -0.59) \) burden (i.e., high level of stress that may be experienced by people who are caring for another person). Yet autism-specific social support, when compared to general social support, had a weaker correlation to decreased individual and family burden. Stuart and McGrew suggested that families who were only recently introduced to the autism community may not have had a chance to create strong social bonds. As Howlin and Moore (1997) noted, diagnosis of ASD should be accompanied by practical help and support, particularly in the early years, to reduce levels of family stress and anxiety. Likewise, Benson (2006) found that parents of children with ASD reported reduced stress when informal supports (e.g., spouse, extended family, and friends) were combined with support group participation.

Johnson and colleagues (2011) described the historic challenge of recruiting fathers of children with ASD for research studies but noted there is a need to effectively recruit fathers because “even parents of the same child may well have different experiences and views” (p. 249). As Davis and Carter (2008) reported in their study of families of toddlers with ASD,
“despite overall similarity in parents’ stress ratings and similarity in parent report of child behaviors, different aspects of children’s behaviors are predictive of parenting stress for mothers and fathers” (p. 1288). For example, while characteristics of a child with ASD (e.g., challenging behavior) may be perceived as more stressful to a mother, the lack of perceived social acceptance may be more stressful to a father (Davis & Carter; Saloviita et al., 2003).

**Overview of Social Supports Available and Accessed by Parents**

Mandell and Salzer (2007) described the historical use of support groups for families of children with disabilities dating back to the early 1980s. Such groups provided parents with a sense of belonging, improvement of parenting skills, access to important information about services, reduction in feelings of isolation, and increased sense of emotional support. “Parents report these groups develop a sense of belonging, a sense of ‘normalcy’ about feelings, an opportunity to share family stories, experiences, and accomplishments, and a sense of empowerment and commitment” (Turnbull et al., 2011, p. 237). The limited research on social support groups for families of children with ASD necessitates a look at the larger literature base on parents of children with disabilities.

**Definitions of social support and empowerment.** Turnbull and colleagues (2011) define social support as the practical and emotional support that parents receive from family and friends, including physical assistance, information and resource sharing, and psychological support. In a synthesis of early intervention studies, Friend and colleagues (2009) found that parent training programs improved parenting skills and parent satisfaction, while reducing parental stress. They noted that models of family-centered practice, with an array of support, improved overall family cohesion and parental emotional well-being. As Pillay and colleagues
(2011) concluded, parents very positively rate support groups with an educational component because it “empowers them rather than singling them out as ‘struggling’” (p. 18).

In a noteworthy review of the literature surrounding professional and social support for families of children with disabilities, Canary (2008) reviewed 103 research studies from 1996-2005 and found a strong link between support and family well-being. Indicators of well-being included measures of stress, adaptability, family functioning, self-esteem, marital satisfaction, empowerment, social competence, and child development. Canary found that a majority of the studies reported informal support (from families and friends) was related to parent well-being across disability types and severities. In addition, she found several studies indicating that parents received an important source of “support for effective life management within the family” when they had contact with other parents of children with disabilities (p. 415). She concluded that formal professional support alone did not seem to reduce stress levels of parents of children with disabilities but a combination of social support and family-centered formal support (a support system network) led to greater parental empowerment and lower levels of parental stress.

According to Dunst and Trivette (1996), the foundation of empowerment ideology includes the belief that parents have existing strengths and capabilities, in addition to the capacity to become more competent. Through family-focused services, interventionists are called to build on strengths with the likelihood that parents will become empowered to gain control over important life events and situations. Further, the authors stated that an empowerment perspective views an intervention as effective when it provides parents opportunities to strengthen and develop their abilities, which leads to a sense of control in both solutions to problems and resolution of concerns. “Social supports empower the mothers by giving them
hope and leading them to positively appraise the future, in turn reducing negative affect and engendering positive affect” (Ekas, Lickenbrock, & Whitman, 2010). Koren and colleagues (1992) suggested that the family empowerment construct grew from self-help and self-reliance models, as well as practice models that focused on family strengths rather than deficits. According to the authors, parents’ empowerment can be expressed in attitudes, knowledge, and behaviors. Thus, the underlying purpose of parent empowerment matches the purpose of this study of online parent discussion groups in the desire to provide a forum for discussion of topics pertinent to caregivers raising young children with autism spectrum disorders.

**Accessing face-to-face social support groups.** Singer and Powers (1993) described one of the basic principles of family support as, “operate according to enabling and empowering principles that enhance and promote competence of the family and individual family members” (p. 6). In this way, families are given opportunities to acquire knowledge and skills to become more capable and competent. Support programs are designed to maximize family control and encourage informed decision-making. In a qualitative look at nine self-help groups for Canadian parents of children with special needs, King and colleagues (2000) found groups met some or all of three basic needs for social support, practical information, and a sense of shared purpose or advocacy. The authors defined self-help groups as voluntary mutual support groups that are led by parents rather than by service providers. King and colleagues found, through group observations and interviews of leaders and participants, that support groups had a positive climate and worked to balance the group activities to meet the needs of the parents. Groups had varying levels of focus on funding and fundraising and there were changes in activities and philosophy noted over time. All groups recognized the need for motivated and organized leaders and faced the difficulties associated with encouraging new leaders, maintaining membership, and
improving attendance. Notably, many of the participants commented that group participation gave them a sense of empowerment and validated their experiences. In an important implication of their study, King and colleagues reviewed the literature and found that service providers can be useful sources of advice on starting self-help groups and that one out of three self-help groups begin with such help. They suggested that service providers should maintain a resource role and foster the self-help function of the group, eliminating the threat to the members of the group being taken over by professionals.

In a comprehensive review of effective programs supporting fathers, Bronte-Tinkew and colleagues (2012) identified 15 promising practices to guide interventionists. Among the list, pertinent practices relating to development of supportive discussion groups included targeting a few core issues of concern to fathers, lasting a sufficient time to complete core activities, using an incentive to fathers to participate, and delivering materials in engaging and interactive ways. Likewise, Fagan and Palm (2004) noted that fathers cared deeply about their children and were committed to raising them. They suggested that supportive programs must listen carefully to fathers’ needs. For fathers of children with disabilities, these needs included both personal needs of the parents, as well as the needs of their young children (McBride & Lutz, 2004).

In addition, parenting issues and content of supportive programs should reflect a male perspective or approach to parenting (Fagan & Palm, 2004). Flexible and creative formats of services (including supportive discussions) are critical and emotional issues should be addressed in a safe and reassuring manner. Recognition of the whole family system and the unique relationships between family members (e.g., father and child; father and mother) is particularly critical when considering ideal supports for fathers of young children with disabilities. Carpenter and Towers (2008), in their interviews of 21 British fathers of children with disabilities,
described that fathers identified their main source of assistance and support as their spouse, with only three fathers describing a comprehensive network of support across family and friends. Support groups for fathers require thoughtful planning and purposeful design, particularly when a mutual aid style of support may be challenging for men in its requirement to share stories and experiences openly with others (McBride & Lutz, 2004).

To examine methods of delivery of support, Hudson, Cameron, and Matthews (2008) conducted an evaluation of an 18-month Australian support program (*Signposts for Building Better Behavior*) for parents of children with intellectual disability and difficult behavior. The researchers found positive outcomes on measures of parenting sense of competence, depression/anxiety and stress, and perceptions of parenting hassles \( (p = .000) \) for parents who used the group, individual, and telephone methods of delivery of support, but found no measurable effect for the self-directed method of support. On standardized measures of parental depression and stress, sense of efficacy and competence, and daily difficulties, participating parents “reported they were less depressed, less anxious, and less stressed, were more confident and satisfied with managing their child, and were less hassled by their child’s behavior” by the end of the study (Hudson, Cameron, & Matthews, p. 117). It should be noted that 396 of the 2119 participants were fathers, and the authors considered the number too low for comparative analyses on the measures. In addition, 80% of the participants agreed to evaluate the program but a large number did not complete the post-tests \( (n = 889) \) or follow-up assessments \( (n = 277) \).

In a qualitative look at challenges experienced by parents of children with disabilities, Resch and colleagues (2010) found that extended family members were not available to provide support to many of the parents. Likewise, in a study of families of children with severe disabilities in China, Wang and Michaels (2009) identified that families desired more
information, more family and social support, and more opportunities to meet and talk with others who had children with disabilities. The geographical and social isolation were thought to contribute to these identified needs.

The absence of support and feelings of isolation are emergent themes in studies of the relationship between stress and families of children with ASD. Bromley and colleagues (2004) noted that mothers of children with ASD experienced a significant amount of psychological distress related to the lack of support when raising their children. In addition, mothers in areas where face-to-face services were not easily obtained or unavailable (e.g., inner-city or rural areas) had higher levels of stress than mothers from areas of high socioeconomic status. Akin to the families of children with disabilities, Murray and colleagues (2011) asserted, “Parents of individuals with ASD are the single most effective support system to other parents of individuals with ASD” (p. 29). Likewise, parents of children with ASD reported the most frequent source of information and support was other parents of children with ASD (Mackintosh, Myers, & Goin-Kochel, 2006; McCabe, 2008). Mandell and Salzer (2007) pointed out that contact with other families of children with ASD in similar situations may reduce stress and social isolation as well as increase access to information about available services. In an extensive literature review, Meadan, Halle, and Ebata (2010) found that “support groups also have been an important source of instrumental, informational, and emotional support” for parents of children with ASD (p. 31). Additionally, Shu and Lung (2005) recommended training services should be provided in conjunction with regular support group meetings to assist parents of children with ASD with the unique issues they face. In their quest for connections with other parents of children with ASD, parents have come to the Internet and found virtual support groups as a way of coping with their struggles (Huws, Jones, & Ingledew, 2001).
The Use of Online Support and Discussion Groups by Parents and Others

Recently, the Pew Research Center’s Internet and American Life Project published a report entitled *The Social Life of Health Information, 2011* (Fox, 2011). Their data “consistently show that doctors, nurses, and other health professionals continue to be the first choice for most people with health concerns, but online resources, including advice from peers, are a significant source of health information in the US” (Fox, p. 2). Interestingly, the report indicated that 75% of adults (and 95% of teenagers) in the U.S. have Internet access and six in 10 adults used wireless technology to go online with a laptop, mobile device, or tablet. Caregivers for loved ones, including children with health conditions or disabilities, used social network sites as information resources and support more than any other adults. In addition, the vast majority of people living with chronic conditions never attended traditional, face-to-face support group meetings but often interacted online with their social network of family, friends, colleagues, and peers with similar conditions. The U.S. Department of Commerce (2002) stated:

> The Internet has become a tool that is accessible to and adopted by Americans in communities across the nation. Approximately two million more people become Internet users every month, and over half of the population is online. Those who have been the least traditional users—people of lower income levels, lower education levels, or the elderly—are among the fastest adopters of this new technology (p. 91).

In a discussion about Internet support groups and discussion groups, Barak (1999) explained that efficient group communication allows people to deliver messages to a whole group in a synchronous (i.e., in real time) or in an asynchronous (i.e., receiver-initiated time delay) manner. Further, although online communication often occurs between people who have not met in person, participants can “develop a sense of community and are able to offer a virtual shoulder” and content analysis of written messages are useful indicators of emotional well-being (Barak, p. 238).
Overview of online support. Plantin and Daneback (2009) conducted a literature review of research on parents and professionals online. They found 109 articles relevant to the topic of parenthood and the Internet and in their review, they reported that the majority of today’s parents searched for information and social support on the Internet. New mothers, who were middle class and aged 30-35 years, were the most engaged in online activities for health and parent information. Notably, several of the studies reviewed by Plantin and Daneback reported diminishing social class differences on parent web sites. The reason given for the increasing number of parents turning to online support and information was the weakened support current parents experienced from their own parents, relatives, and friends. The authors explained that women have traditionally turned to their own mothers when becoming new parents, but society’s increased mobilization makes close maternal support difficult and at times, isolating, for new mothers. Reported benefits of Internet use included parents’ ability to remain anonymous in contact with professionals and the ability for parents’ perceived needs to be met around the clock. An important finding of the review from Plantin and Daneback was the absence of rude, disrespectful, or disruptive communication in parent discussion groups, with group users adhering to Internet etiquette, “netiquette,” in their formal and informal communication online.

Additional online support group studies of new parents indicated that women use the groups to “develop community connections, request and provide emotional support, share information and facilitate learning, and normalize infants’ developmental and mothers’ parenting experiences” (Hall & Irvine, 2008, p. 178). Support groups in parenting web sites were seen as safe and supportive spaces where mothers could develop a better understanding of the role of parenting (Brady & Guerin, 2010). In their study of a large Swedish parenting website, Sarkadi and Bremberg (2005) found no social bias in the use of the 250 discussion groups on the website.
Additionally, mothers of lower educational and income levels, as well as those living without a partner, all perceived higher levels of support from the online groups than their counterparts. Skinner and Schaffer (2006) reported, “the Internet may empower users by providing them with the scientific literacy, personal validation, and social support networks they need to become proactive partners with the medical establishment” (p. 18). A wide array of Internet support groups for parents of children with cancer (Han & Belcher, 2001), traumatic brain injuries (Wade, Carey, & Wolfe, 2006), asthma (Sullivan, 2008), rare genetic disorders (Gunderson, 2011), and disabilities (Baum, 2004; Kirby, Edwards, & Hughes, 2008) indicated that parents wished to become knowledgeable about their child’s condition in order to comprehend and manage a situation that seemed distressful. “Online support groups can help people overcome mobility, access or communication-related challenges associated with face-to-face groups” (Sullivan, p. 217). Parents’ perceived benefits of interaction with other parents online included accessing information, sharing experiences, receiving general support, and venting feelings (Han & Belcher).

Baum (2004) conducted an exploratory study of the use of Internet Parent Support Groups (IPSGs) by primary caregivers of Children with Special Health Care Needs (CSHCN). In her online survey, 114 participants, caring for 140 CSHCN and accessing 100 different Internet support groups, completed the survey. The typical participant was a Caucasian, married, higher educated female in her late 30s and residing in the U.S. On average, two children with disabilities were found in the average four person households. The mean age of the children was 6.5 years for males and 8.7 years for females with 66% of the sample as male children. The outcomes of participation in an online support group that parents perceived to have the most lasting effect on well-being were (in order of importance): (a) finding people with similar
challenges, (b) receiving information and guidance, (c) feeling accepted and understood, (d) relatively anonymous global access to information and support, (e) opportunity to help others, (f) change in perspective to hope and gratitude, and (g) opportunity to vent. The parents spoke of a sense of empowerment gained from participation and strongly advised others to “begin participating in an IPSG ‘as soon as possible’” (Baum, p. 388).

In a study of online social support for parents of children with asthma and allergies, Stewart and colleagues (2011) reported that parents desired a parental support network to be accessible, comprehensive, and reliable. Additionally, the authors noted that the online format of a social support group addressed parental need for support from others in similar situations, particularly since they believed their extended family and friends had difficulty understanding their fears and needs. For parents of children with chronic illnesses or disabilities, the consensus of the researchers was that knowledge and information played an important role in their emotional well-being (Baum, 2004; Han & Belcher, 2001). “By becoming informed, they become increasingly able to comprehend and manage a situation that at first seemed unmanageable and distressful. As their understanding increases, they develop a sense of control over emotional as well as practical issues” (Gunderson, 2011, p. 92). But as several researchers pointed out, Internet information alone was insufficient in reducing stress (Beaudoin & Tao, 2008; Wade, Carey, & Wolfe, 2006).

In a study of computer-mediated support group intervention for parents of children with cancer in Iceland, Bragadóttir (2008) found that online support groups were particularly useful for geographically separated populations as well as groups with time restrictions. “Computer-mediated support groups have been shown to be a valuable addition to, or substitute for, a traditional face-to-face mutual support group and might suit both genders equally” (Bragadóttir,
In addition, she suggested that to strengthen computer-mediated support groups for children diagnosed with cancer, semi-structured groups that required active participation and parent gender-specific groups were needed. As Han and Belcher (2001) noted, “The peer-support group approach has demonstrated its value in enhancing the ability of parents to cope with their child’s chronic condition” (p. 27).

While many studies pointed to the usefulness of support provided via the Internet, several researchers have voiced concerns about the use of online discussion. Potential disadvantages listed by van Uden-Kraan and colleagues (2008) include: (a) online communication limits non-verbal communication between conversation partners (e.g., hugs and facial expressions of encouragement), (b) posted information (e.g., medical information) may be incorrect or potentially dangerous, (c) negative comments or advice may delay contacting a trained professional, (d) negative postings that indicate a lack of understanding of other participants or criticize or scold others and (e) privacy issues. Eysenbach and colleagues (2004) found no evidence of negative effects or harm in their review of health-related virtual communities and electronic support groups, but cautioned that high dropout rates found in most of the studies may indicate a negative effect of participation.

Literature reviews of Internet support groups have indicated that unfacilitated peer-to-peer support groups (lead by participants) have no robust evidence of effectiveness on measures of depression and social support (Eysenbach et al., 2004; Griffiths, Calear, & Banfield, 2009). As Jones and Meier (2011) suggested, “Literally thousands of online mutual-aid groups now exist whose leaders can benefit from coaches or professional co-facilitators” (p. 118). In addition, Kirby, Edwards and Hughes (2008) recommended that an extension of a support group or discussion board would be to develop a website with practical fact sheets, video clips, and
Beaudoin and Tao (2008) suggested that there is a third factor in the relationship between Internet support groups and health outcomes. Their research on cancer patients indicated that the effects of Internet use were not directly on health outcomes (e.g., stress and depression) but instead influenced the development of social capital. They defined social capital as “the actual and potential resources that result from the social connections and the senses of reciprocity and trust, which, when mobilized, can stimulate various outcomes at the collective and individual levels” (Beaudoin & Tao, p. 324). The more social capital (e.g., social networks, reciprocity, and trust) was developed, the lower the stress and depression a person experienced.

**Gender differences in online support.** In their research on supporting aspects of early fatherhood in an online forum, Fletcher and St. George (2011) found that men have become increasingly aware of “the promise of involved fathering” but noted there has been limited evidence of how to best offer support (p. 1101). In an asynchronous online chat room, the researchers found that new fathers requested, offered, and received social support from their peers and used communication styles that included humor and self-disclosure. Although the study focused on a chat room rather than a dedicated support site, the study participants engaged in imparting information, fostering confidence in others who joined the discussion, and providing empathetic support in messages across topics. One limitation noted by Fletcher and St. George was they did not compare discussions from a mothers’ chat room to the fathers’ for similarities or differences in concerns and modes of expression.

Interestingly, the literature on online support groups has compared the differences in messages and dialogue postings from gender specific cancer patients (i.e., breast cancer and
prostate cancer). Researchers suggested that in separate support groups, men and women sought
different types of support (e.g., informational versus emotional) and that communication styles
were different as well (Blank et al., 2010; Mo, Malik, & Coulson, 2009). Conversely, Gooden
and Winefield (2007) studied online groups for prostate and breast cancers and found the
postings were equivalent for information seeking and emotional support but men provided longer
accounts of research findings and used lengthy jokes and humorous exchanges to cope with their
prostate cancer. Women, on the other hand, used short humorous statements, incidental to breast
cancer. The authors also noted that women clearly expressed emotions while men tended to
imply their emotions and encouraged others through the use of battle-like terminology (e.g. war
against cancer).

Mo and colleagues reported inconsistent findings in their literature review of mixed
gender support groups and noted in some instances there were similarities in the way men and
women engaged and interacted in online support groups. Blank and colleagues (2010) observed
the need for recognizing the differences between men and women when designing Internet
message boards and discussion groups as a way to provide support for the participants using
them. Plantin and Daneback (2009) emphasized that typical maternal and child health services
have had difficulties in reaching and engaging fathers new to parenthood. The authors noted an
increased need for discussion forums to address the specific needs of fathers and their roles. In
addition, Sullivan (2008) discovered that even though fathers were not prohibited from
participating in online caregiver groups (in this case, groups supporting caregivers of children
with asthma), none of the fathers chose to participate. In addition, no online groups were
organized specifically for fathers of children with asthma and she urged investigation of ways to
encourage father participation in online support. As Hall and Irvine (2008) pointed out,
“Marginalizing fathers from parenting conversations has the potential to contribute to men’s withdrawal from active parenting” (p. 181).

The Use of the Internet by Parents of Children with ASD

A recent Internet Google search of the phrase “autism support groups” received 14,700,000 hits, indicating as Mackintosh and colleagues (2002) noted, “Literally millions of Internet websites deal with autism—some with solid information and some that are useless or even harmful—but because there are so many sites, it is hard to sort through them” (p. 41). Unlike face-to-face support groups, an interesting phenomenon can occur on Internet discussion boards where parents can obtain information or vicarious support without disclosing their presence (Mickelson, 1997). This “lurking” may allow parents’ feelings to be validated without having to disclose those feelings to others.

Via web-based questionnaires, Mackintosh, Myers, and Goin-Kochel (2002) asked parents of children with ASD what sources they used for information and support. Request-for-participation notices were sent to more than 220 newsletters, web-pages, and email list-serves of autism-related organizations, with 498 parents responding. Participating parents indicated their largest source of information was other parents of children with ASD (72%) followed by autism specialists (57%) (e.g., early interventionists, speech therapists, occupational therapists, psychologists, etc.). Physicians and educators were sources of information for about 49% of the parents, and family members, friends, and spouses were sources of information for about 19% of the parents. Parents reported that much of their information came from written sources with books cited by 88% of the parents, followed by web pages and email list-serves cited by 86% of the parents. Autism newsletters were information sources for 69% of the parents and scientific
journals for 44% of the parents. Less than half of parents considered conferences (48%), workshops (43%), and autism support group meetings (44%) to be sources of information. In addition to sources of information, the researchers asked parents about sources of support. Personal relationships were the largest sources of support with other parents of children with ASD cited by 68% of the parents, family members and spouses cited by about 56% of the parents, and friends and neighbors cited by 43% of the parents. Approximately 48% of parents considered autism specialists and educators as sources of support and 36% indicated physicians were a source of support. Parents found support in web pages (43%), autism support group meetings (37%), autism newsletters (30%), books (28%), conferences (23%), workshops (21%) and scientific journals (7%). Mackintosh and colleagues noted that parents with lower income were less likely to obtain information or support from workshops, conferences, and autism support groups than parents with middle or upper income. Additionally, parents with lower income were more likely to be single parents and were less likely to indicate their friends and neighbors as sources of support.

Huws, Jones, and Ingledew (2001) conducted an analysis of messages sent to an email discussion group by parents of children with autism. They found that the email group provided more than an interactive social network by allowing parents to actively attempt to make sense of autism by searching for meaning, adjusting to life changes, providing support and encouragement to others, and sharing experiences. In addition, Huws and colleagues found that parents of children with autism had similar common concerns to parents in the general population and messages on these issues, unrelated to disability, were thought to promote friendships and overcome some of the aspects of social isolation experienced by parents of children with autism. Likewise, Fleischmann (2005) stated “the Internet allows stressed parents
of children with autism to forge ties among themselves and extricate themselves from their isolation” (p. 299). Huws and colleagues highlighted that for families of children with autism, the support offered in this type of email discussion group was beneficial to a group of parents, even though they were likely to be receiving multiple services for their families.

Fleischmann (2005) reported that parents of children with ASD praised the Internet “as a tool that enabled them to collect information as a path to self-empowerment by enhancing their efficacy and aiding them in breaking out of the social isolation that parents of exceptional children often face” (p. 312). Further, Higgins, Bailey, and Pearce (2005) noted the isolation and restricted level of community contact experienced by families of children with ASD was due to the inability of family, friends, teachers, and other members of the community to understand behavioral characteristics of the disability. Twoy, Connolly, and Novak (2007) also noted that the stress for families of children with ASD was chronic and considerable and that support for caregivers was essential. They suggested that providing information, including Internet resources about ASD, in addition to “surrounding national and regional parent support organizations can be a great benefit to families” (Twoy, Connolly, & Novak, p. 258).

**Conclusion**

A focus on families of children with recent diagnoses of ASD has been suggested in the literature on parental stress, but has not been addressed through an online discussion group. Low income and diverse families, in addition to fathers, are groups traditionally underserved by face-to-face support groups but have not been studied in online support groups for parents of children with ASD. The asynchronous nature of ongoing dialogue generated in an online discussion group provides more immediate support and feedback than a single, weekly face-to-face meeting, a
benefit noted by parents of children with chronic illnesses. The literature indicated that parents of children with ASD found comfort and were empowered by their interactions and discussions with parents facing similar challenges in parenting. The underlying purpose of parent empowerment matches the purpose of this study of online parent discussion groups in the desire to provide a forum for discussion of topics pertinent to parents raising young children with autism spectrum disorders. Clearly, parents of children with a recent diagnosis of ASD are becoming investigators of traits, terminology, and treatments on the Internet. Yet, as Huws, Jones, and Ingledew (2001) pointed out, “parents of children with autism have difficulties obtaining adequate information and support to guide them in the care of their children” (p. 569).

“Acknowledging the need to identify and assess child and family outcomes, in 2003, the Office of Special Education Programs (OSEP) funded the Early Childhood Outcomes (ECO) Center to propose appropriate child and family outcomes and aid in the development and implementation of outcome measures for use by states and federal programs to evaluate EI/Part C and preschool Part B programs” (Epley, Summers, & Turnbull, 2011, p. 202).

The ECO Center proposed five family outcomes which included the following two: “Families have support systems” and “Families are able to gain access to desired services and activities in their communities.” With the ultimate goal of early intervention to be a high quality of family life, it stands to reason that the needs for support and access must be met for families of young children with ASD.
Chapter 3

Methods

Research shows online support groups and social networks are “important arenas for mutual help and encouragement among parents facing similar situations, especially in difficult times” (Gunderson, 2011, p. 82). Effective supports are essential for families of young children with ASD, yet little is known about parents’ needs and desires for support. The overarching purpose of this research study was to examine and gain an understanding of the utility of discussion forums for parents of young children (prior to entry into kindergarten) recently diagnosed with an autism spectrum disorder (ASD). In addition, a major intent of this research study is to inform the field of methods and strategies for designing future online parent support for families of young children with ASD. To explore the needs of parents of children with a recent diagnosis of ASD, using quantitative and qualitative measures, four overarching research questions were addressed in this research study:

1. What kinds of information do parents seek following their child’s diagnosis of an Autism Spectrum Disorder (ASD)? Are there differences in the kinds of information requested by parents based on salient factors (e.g., parent gender, parent age, child gender, family SES)?

2. What are the sources of support that parents of young children with ASD report upon entry into the online parent discussion group?

3. What types of support-intended postings do parents engage in when participating in the online discussion group?
4. To what extent are parent participants satisfied with their use of the online discussion groups? What do parents report are the factors that promote participation and prevent participation in online parent discussion groups?

**Research Design**

Guided by the aforementioned research questions, this research study of asynchronous online discussion groups used a mixed methods design employing qualitative and quantitative measures. Greene, Caracelli, and Graham (1989) described using “complementarity” mixed methods study “to measure overlapping but also different facets of a phenomenon, yielding an enriched elaborated understanding of that phenomenon” (p. 258). The rationale behind this style of mixed methods study is to increase the meaningfulness and interpretability of the results while capitalizing on the strengths of each method (Greene et al.).

The qualitative descriptive component of this study allowed the researcher to explore the experiences of parents as they actively engaged in gender-specific online discussion groups. In order to use the research method of content analysis of the discussion postings, the researcher was guided by the definition provided by Hsieh and Shannon (2005), where content analysis is “the subjective interpretation of the content of text data through the systematic classification process of coding and identifying themes or patterns” (p. 1278). In addition, the seminal method of content analysis recommended by Miles and Huberman (1994) was used and included multiple readings of the discussion groups’ texts and developing matrices to confirm or disconfirm themes and categories. Data analysis procedures are described in detail below.

All quantitative data were entered into a SPSS version 21.0 database (IBM Corp., 2012) for analyses. Through the use of three online questionnaires developed by the researcher and
conducted through SurveyMonkey® (a 13-year-old online survey development website), quantitative data analysis included descriptive statistics (e.g., means, standard deviations, response rate, percentages), correlations (e.g., parent gender and topic), and $t$-tests.

Participants

A purposive sample of parents or caregivers of children with autism spectrum disorder (ASD) were recruited for this research study. Participation in this study was open to parents of young children (prior to entry into kindergarten at the start of the study) who had received a diagnosis of ASD from a medical professional. In order to capture important concerns and perceptions of parents raising children with ASD in the preschool years, only families of children prior to entry into kindergarten were included. The target of recruitment efforts included the early intervention service providers (serving families of the birth to three year old population), the preschool parent networks served by online groups, preschool agencies, and autism support agencies. In total, 22 mothers and 8 fathers indicated interest through an emailed response to invitation to participate or phone call to the researcher. Fifteen of the mothers and 7 of the fathers completed consent forms and were included in the study. Throughout the study, all 22 parents completed all three surveys. One father participated in the surveys but did not participate in the online discussions, reducing the number of participant fathers in the discussions to six.

The online discussion group format was in English and required parents to have functional English language skills. Additionally, in order to explore the parenting concerns of both mothers and fathers, parallel discussion groups were developed and divided according to parent gender. There was no requirement for both parents to participate, assuring the opportunity of participation by single parents and only one interested parent partner. While the initial
recruitment was limited to the state of Illinois, the national reach of the Internet permitted participation by parents in states outside of Illinois.

**Recruitment.** Families identified by local help organizations (e.g., The Autism Project (TAP) in the local community, a local Autism Walk and Resource Fair, and early intervention service providers and agencies in Illinois and Iowa), as well as self-selected parents or caregivers, who heard through online listservs (focused on families of children with ASD) or online social media pages, were given the opportunity to participate (see Appendix A for Recruitment Forms: flyer, invitations, and TAP newsletter with invitation to participate). The most effective means of garnering mothers to participate was through social media (e.g., Facebook™) and autism support websites that agreed to post an online recruitment flyer (53% of mothers participating). Participating parents were from Illinois, California, Hawaii, Florida and North Carolina. Interestingly, one mother reported finding the group invitation on a Chicago lawyer/disability advocate’s Facebook™ page reposted from the Autism Speaks™ organization page. In addition, 27% of the mothers reported joining at the suggestion of early intervention personnel or early childhood teachers in the local area and 20% did not recall or did not report how they found out about the online parent discussion groups. All seven fathers participating reported they did so at the suggestion of their wife.

When parents initially responded with interest to participate via phone or email, the researcher determined whether their child met criteria of “not yet in kindergarten” and mailed or emailed (based on parent preference) a Consent Form (see Appendix B) and Online Parent Discussion Group Policies for completion (see Appendix C). For mailed copies of the Consent Form and Policies, a stamped self-addressed envelope was enclosed for return mailing of signed forms to the researcher. Parents choosing emailed copies of the forms were permitted to sign the
appropriate documents, scan, and return them via email. After obtaining written consent, the researcher emailed a link to the online Initial Recruitment Survey Questionnaire posted on SurveyMonkey® to interested parents (see Appendix D). Following completion of the initial survey, an invitation to participate in the gender-matched online discussion group was sent to each parent with their pseudonym and password included.

In accordance with approval of this research study by the Institutional Review Board on Human Subject Research at the University of Illinois (see Appendix E) pseudonyms for all participants were created using a random name generator (http://www.kleimo.com/random/name.cfm) in order to assure anonymity within the online groups’ discussions. Likewise, the email addresses visible to all the participants contained four letters from the participants’ real names but did not lead to an actual email server and were written thus: ed-xxxx12@abcd.com. In addition, an online statement was visible at the beginning of each discussion reminding participants of the confidentiality of the information posted in the discussion and included the recommendation for parents to use a pseudonym when speaking about their child. Throughout the course of the research study, particularly during the use of the surveys, participants were reminded that their participation was voluntary.

**Demographic information.** The majority of the mothers and fathers participating in the study were over the age of 35 years (66% and 57% respectively). While all the fathers were married, 80% of the mothers were married. Parents were evenly spread across education levels with 20% of the mothers and 29% of the fathers having high school diplomas, 27% of the mothers and 14% of the fathers having technical or associate degrees, 33% of the mothers and 43% of the fathers having bachelor degrees, and 20% of the mothers and 14% of the fathers having graduate/professional degrees. The ethnicity/race of the 22 parents included a majority of
Caucasian mothers (87%) and fathers (86%), as well as one Latino couple and one Asian mother participating. With all the fathers married to mothers participating in the online discussion groups, there were a total of 15 families participating. Four of the 15 families participated, with some overlap, in state or federal assistance programs (e.g., WIC, SNAP, SSI, Food Stamps). In addition, a majority of the families (53%) were not currently receiving any assistance or not reporting assistance (20%). Prior to joining the group, over half of the mothers (53%) had participated in an online support group, while over half of the fathers (57%) reported never participating in any form of support group. The demographic information about the parent participants is reported on Table 1.
Table 1

*Parent Demographic Information as a Percentage of the Sample*

<table>
<thead>
<tr>
<th>Variable</th>
<th>Mothers (n = 15)</th>
<th>Fathers (n = 7)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Parent age</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>30 years and younger</td>
<td>27</td>
<td>14</td>
</tr>
<tr>
<td>31-35 years</td>
<td>7</td>
<td>29</td>
</tr>
<tr>
<td>36-40 years</td>
<td>33</td>
<td>43</td>
</tr>
<tr>
<td>41-45 years</td>
<td>33</td>
<td>14</td>
</tr>
<tr>
<td><strong>Marital status</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Married</td>
<td>80</td>
<td>100</td>
</tr>
<tr>
<td>Divorced</td>
<td>7</td>
<td>0</td>
</tr>
<tr>
<td>Living with partner</td>
<td>7</td>
<td>0</td>
</tr>
<tr>
<td>Unanswered</td>
<td>7</td>
<td>0</td>
</tr>
<tr>
<td><strong>Highest level of education completed</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>High school graduate</td>
<td>20</td>
<td>29</td>
</tr>
<tr>
<td>Technical or associate degree</td>
<td>27</td>
<td>14</td>
</tr>
<tr>
<td>Bachelor degree</td>
<td>33</td>
<td>43</td>
</tr>
<tr>
<td>Graduate/professional degree</td>
<td>20</td>
<td>14</td>
</tr>
<tr>
<td><strong>Ethnicity/Race</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>White</td>
<td>87</td>
<td>86</td>
</tr>
<tr>
<td>Latino/a</td>
<td>7</td>
<td>14</td>
</tr>
<tr>
<td>Asian</td>
<td>7</td>
<td>0</td>
</tr>
<tr>
<td><strong>State or federal assistance programs participated in</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Women, Infants, and Children (WIC)</td>
<td>20</td>
<td>14</td>
</tr>
<tr>
<td>Supplemental Nutritional Assistance Program (SNAP)</td>
<td>7</td>
<td>0</td>
</tr>
<tr>
<td>Food Stamps</td>
<td>13</td>
<td>14</td>
</tr>
<tr>
<td>Child Care Assistance Programs (CCAP)</td>
<td>7</td>
<td>0</td>
</tr>
<tr>
<td>Supplemental Security Income (SSI)</td>
<td>7</td>
<td>0</td>
</tr>
<tr>
<td>None</td>
<td>53</td>
<td>71</td>
</tr>
<tr>
<td>Not Reported</td>
<td>20</td>
<td>0</td>
</tr>
<tr>
<td><strong>Parent services participated in</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Counseling</td>
<td>20</td>
<td>0</td>
</tr>
<tr>
<td>Respite care for children with autism</td>
<td>27</td>
<td>14</td>
</tr>
<tr>
<td>Face-to-face support groups</td>
<td>20</td>
<td>14</td>
</tr>
<tr>
<td>Online support groups (excluding this one)</td>
<td>53</td>
<td>43</td>
</tr>
<tr>
<td>Community parenting groups</td>
<td>27</td>
<td>14</td>
</tr>
<tr>
<td>Religious or prayer groups</td>
<td>7</td>
<td>14</td>
</tr>
<tr>
<td>None</td>
<td>20</td>
<td>57</td>
</tr>
</tbody>
</table>
Discussion group parents provided demographic information about their children found in Table 2. Children ranged in age from 24 to 66 months with the majority of children between 3 and 4 years old (53%). Eleven of the 15 children were male and all but one child were either an only child or the youngest of multiple children. There were instances where mothers described all their children, including adult children who were no longer living in the household. Thus, the number of current one-child families is different than the reported only children born to families. All of the children were receiving speech therapy services and most were receiving occupational therapy (80%), as well. More than half of the children received some form of behavior therapy (53%) and to a lesser extent, some children received developmental therapy (33%), physical therapy (27%), and nutrition services (20%). All the children had an Individualized Family Service Plan (IFSP) or an Individualized Education Program (IEP), with one child having both just prior to his third birthday.
Table 2

*Child Demographic Information as a Percentage of the Sample*

<table>
<thead>
<tr>
<th>Variable</th>
<th>Children (n = 15)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Age of child</strong></td>
<td></td>
</tr>
<tr>
<td>24-36 months</td>
<td>33</td>
</tr>
<tr>
<td>37-48 months</td>
<td>53</td>
</tr>
<tr>
<td>49-66 months</td>
<td>13</td>
</tr>
<tr>
<td><strong>Gender of child</strong></td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td>73</td>
</tr>
<tr>
<td>Female</td>
<td>27</td>
</tr>
<tr>
<td><strong>Age of child at diagnosis of ASD</strong></td>
<td></td>
</tr>
<tr>
<td>18-23 months</td>
<td>27</td>
</tr>
<tr>
<td>24-30 months</td>
<td>40</td>
</tr>
<tr>
<td>31-36 months</td>
<td>33</td>
</tr>
<tr>
<td><strong>Birth order</strong></td>
<td></td>
</tr>
<tr>
<td>Oldest</td>
<td>7</td>
</tr>
<tr>
<td>Middle</td>
<td>0</td>
</tr>
<tr>
<td>Youngest</td>
<td>67</td>
</tr>
<tr>
<td>Only</td>
<td>27</td>
</tr>
<tr>
<td><strong>Number of children currently living in household</strong></td>
<td></td>
</tr>
<tr>
<td>1 child</td>
<td>40</td>
</tr>
<tr>
<td>2 children</td>
<td>40</td>
</tr>
<tr>
<td>3 children</td>
<td>13</td>
</tr>
<tr>
<td>4 children</td>
<td>7</td>
</tr>
<tr>
<td><strong>Services child receives</strong></td>
<td></td>
</tr>
<tr>
<td>Speech therapy</td>
<td>100</td>
</tr>
<tr>
<td>Occupational therapy</td>
<td>80</td>
</tr>
<tr>
<td>Physical therapy</td>
<td>27</td>
</tr>
<tr>
<td>Developmental therapy</td>
<td>33</td>
</tr>
<tr>
<td>Behavior therapy (e.g., ABA therapy, social skills therapy)</td>
<td>53</td>
</tr>
<tr>
<td>Nutritionist or dietician services</td>
<td>20</td>
</tr>
<tr>
<td>IFSP</td>
<td>20</td>
</tr>
<tr>
<td>IEP</td>
<td>73</td>
</tr>
<tr>
<td>IFSP and IEP</td>
<td>7</td>
</tr>
</tbody>
</table>
Setting

The online parent discussion groups were created through a password protected gateway on the University of Illinois website at learn.illinois.edu. Surveys posted on SurveyMonkey® and the online discussion forums posted on the Moodle™ website were accessible from family or work computers at the convenience of the participants. No face-to-face meetings were required for participation. The Moodle™ website can be described as course management or virtual learning environment. Weekly topics and supporting resources were displayed similar to the methods used in the creation of an online university course. Within this university-based website, two separate “courses” were created: Family Empowerment: Mothers’ Discussion Group and Family Empowerment: Fathers’ Discussion Group. Each group was only accessible to the participants (mothers or fathers), the researcher, her advisor, and the university technology support staff. A unique characteristic of Moodle™ is the ability to create threaded discussion forums with participants able to respond to the main topic, to other participant’s postings, and to topics discussed in previous weeks. The administrator (the researcher) of the discussion groups had control over the uploaded materials and the weekly discussion topic forum creation. In addition, the administrator had access to all participation information (e.g., number of postings per participants, last time website was accessed, number of visits without posting per participant). The participants were able to download the materials and respond to postings, but were unable to make changes in the website.

Instruments

There were 3 surveys used in the research study (before, during, and after participating in the online groups). They included the Initial Recruitment Survey Questionnaire (Appendix D),
the Current Services and Supports Survey Questionnaire (Appendix F), and the Post Participation Survey Questionnaire (Appendix G). The Initial Recruitment Survey Questionnaire included child and family demographic information, and topics drawn from the literature on parental stress when raising young children with ASD (Baker-Ericzén, Brookman-Frazee, & Stahmer, 2005; Boyd, 2002; Davis & Carter, 2008; Hastings et al. 2005; Tomanik, Harris, & Hawkins, 2004), as well as items from the Autism Parenting Stress Index developed by Silva and Schalock (2011). Topic choices were presented in a 5 point Likert scale ranging from Highly Unimportant to Highly Important. The survey questionnaire was reviewed, through 1 hour cognitive interviews (Presser et al., 2004; Willis, 1999) for relevance of topics, by two female practitioners in the field of special education who were parents of children with autism.

Questions for the Current Services and Supports Survey Questionnaire were drawn from the literature on the supports and services accessed by families of young children with ASD. Lists of possible therapeutic services accessed by children with ASD and their parents were created. Additionally, open-ended questions requested parents to list general and autism-related websites they visited regularly for information. Dunst, Jenkins, and Trivette (1994) developed the Family Support Scale (FSS) to measure, on a 6 point Likert scale, the degree to which various sources of social support were “helpful” to families, particularly those raising preschoolers with disabilities and the FSS measure was included in its entirety in the Current Services and Supports Survey Questionnaire. Krauss (2000) reported the FSS has internal consistency reliability with a Cronbach’s alpha coefficient of .77. Test-retest reliability over a one month interval was an average of .75 for the 18 scale items and .91 for the total scale score.

Three additional open-ended prompts requested parents to respond to the following: “When I think about raising my child with autism, I am most worried about...”, “I think my child
has the following strengths and talents...”, and “When raising my child with autism, the most difficult thing is...” In addition, parents were asked how they had found out about the online discussion group.

The Post Participation Survey Questionnaire, included questions that examined parents’ perceptions of the benefits of their use of the online discussion groups. Parents were asked to indicate the number of times they visited the group, rank on a 4 point Likert scale the usefulness of the group (ranging from very useful to not useful), rate their participation (high, medium, or low), as well as specify their satisfaction with their participation in the groups. Open-ended questions inquired about reasons the group was useful and not useful, factors that increased or were barriers to participation, suggestions from the parents for the group, as well as reasons for recommending or not recommending the group to others. In addition, parents were asked if they wished to continue participating in the group and the type of format best suited for their participation (e.g., closed online group). Summative evaluation of the online discussion group assisted in determining the usefulness of the format of discussion and the resources provided in meeting the needs of the parent participants.

All three survey questionnaires (Initial Recruitment Survey Questionnaire, Current Services and Supports Survey Questionnaire, and Post Participation Survey Questionnaire) were reviewed by the Survey Research Lab (SRL) at the University of Illinois.

**Procedures**

In keeping with group size recommendations by Yalom and Leszcz (2005), after 12 mothers agreed to participate and had signed voluntary consent, the research study began. At that time, 7 fathers (spouses of participating mothers) agreed to participate. In consultation with the
dissertation committee, the researcher commenced both groups at the same time. Notably, no fathers independently requested to participate, despite targeted invitations to members of fathers’ groups on social media and autism websites. In the interim between completion of the initial survey and the generation of pseudonyms, development of passwords, and determination of parents’ desired initial topic for discussion, three additional mothers requested to join and were added (n =15) to the group. These three mothers completed consent forms and the initial online survey, and joined the mothers’ discussion group within the first two weeks of the 12 week study. No additional fathers requested to participate. Following voluntary consent, the research study began with recruited participants completing the online Initial Recruitment Survey Questionnaire via SurveyMonkey® in order to determine the topic areas of most importance to mothers and fathers raising young children with autism spectrum disorders. Participants received an online $20 Amazon® gift card for completion of the first survey.

Following the development of a Moodle™ page through the College of Education at the University of Illinois, parallel father and mother online discussion groups were created and parents were asked to log-in to the password protected site. On a once-a-week basis, the researcher posted a resource article of interest (based on the topic areas suggested by each online parent group) and posted an initial discussion prompt with follow-up questions. Resources were gathered from research-based organizations with a presence in the field of Autism Spectrum Disorders. These organizations had family-friendly materials focused on parents’ interests.

The researcher was the groups’ facilitator, providing logistical and technical support (e.g., attending to log-in issues). Over the course of 12 weeks, 12 different discussion topics were addressed and an additional discussion forum called “What’s on your mind…?” was added weekly to encourage discussion of immediate concerns that were unrelated to the weekly topic.
The researcher, acting as a facilitator in a resource role, posted pictures of materials or products (e.g., a weighted body suit, a backpack with a leash) mentioned by participants in an effort to encourage further comments and questions. In the first weeks, the facilitator restated one or two unanswered questions posted by participants to draw attention to the need for response by the group. By the fourth week, it was no longer necessary for the facilitator to identify the unanswered postings as the participants responded independently. It was critical in the role as the facilitator to avoid posting solutions to problems and permit the participants to direct the discussions and provide advice to each other. The twelve topics of discussion were chosen from the importance rankings given by the parents in the first online survey. Twelve weeks was chosen as the duration for the discussion groups based on recommended practices for parent education and support programs (Samuelson, 2010; Pillay et al., 2011). All parents were prompted to participate in the weekly discussion by an email from the researcher indicating that a new topic was available on the Moodle™ site. Parents were encouraged to post at least once per week, at a time that was convenient for them. Typically, 20 minutes of participation per week was expected, with an incentive added and email reminders sent at regular intervals. This incentive was the random drawings for four iPod Shuffles® for each group (total of 8) at weeks 3, 6, 9, and 12, with each participant posting counted as an entry in the random drawing. The random number generating feature on Microsoft Excel (2010) was used to select the winner of each drawing. Winners in one week were not able to win again in future drawings but their postings continued to be included in the weekly totals.

The second survey questionnaire on Current Services and Supports was available online at the 4 week time point and each participant received an online $20 Amazon® gift card for its completion. At the end of 12 weeks of online discussion, each participant was given the
opportunity to fill out the final online Post Participation Survey Questionnaire with an online $20 Amazon® gift card given for completion. (Therefore, each participant who completed all 3 surveys received a total of $60 in Amazon® gift cards). Amazon.com® has a simple procedure for online gift cards and the researcher was able to use an Amazon® account to pay for each gift card and Amazon.com® emailed the electronic gift card with an individual code for access to the parent recipient using the email address they provided to the researcher. Because the parents were expected to have Internet access to participate in online discussion, it was expected they would have access to the online receipt of the electronic gift card.

In summary, upon completion of each survey, each participating parent received an online $20 Amazon® gift card for a possible total of $60 per person. Through the initial recruitment survey, the researcher provided an online $20 Amazon® gift card for completion of the online Initial Recruitment Survey Questionnaire (Appendix D). Following a month of participation in the discussion groups, parents were invited to participate in an online Current Services and Supports Survey Questionnaire (Appendix F) regarding the services currently received by their families and the researcher provided an online $20 Amazon® Gift Card for completion of the survey. At the end of 12 weeks, parents were invited to participate in an online Post Participation Survey Questionnaire (Appendix G) regarding participation in the online discussion groups. The researcher provided an online $20 Amazon® gift card for completion of the final survey. An incentive to encourage increased postings on the discussion topics entailed the random drawings for four iPod Shuffles® at weeks 3, 6, 9, and 12, with each participant posting counted as an entry in the drawings.

It should be noted that part of the research study was to explore the use or (lack of use) of the discussion group format over the span of 12 weeks. There was no penalty for not posting on
the discussion group board and the data collected regarding absence of postings was important information for analysis. Parents were reassured via email that participation was at their convenience and was strictly voluntary. The level of participation in the discussion forums had no impact on the invitation to complete the three surveys and the automatic receipt of gift cards for their completion. There was a 100% survey return rate for both fathers and mothers.

Data Collection

Data collection was confidential, but not anonymous, since the researcher had the ability to trace the responses to subject identities. However, this remained the exclusive capability of the researcher and her doctoral advisor. Online survey questionnaire data was collected via SurveyMonkey® and numerical information was entered for analyses into SPSS version 21.0 database (IBM Corp., 2012) by the researcher. Data collected from the online discussion groups was contained on the Learn.ED server which used the Moodle™ Learning Management System administered by the College of Education. A list of email addresses of participating parents, gathered from the consent forms was given to a designated member of the College of Education technology team to set-up access to the password protected Moodle™ site. That one team member was instructed to enter the email addresses, generate pseudonyms, assign passwords, and then return the information to the researcher. All participants’ names, email addresses, consent forms, and other identifying information in the possession of the researcher were stored separately from the de-identified transcripts, which contain pseudonyms in place of participants’ names. There were no audio or video recording of any participating parent in any form. Transcripts were produced only from the written postings on the discussion forums. Only the researcher and doctoral advisor had access to the complete de-identified transcripts and the
online discussion groups. One graduate assistant was trained to assist in coding portions of the de-identified transcripts for themes and received feedback from the researcher and her doctoral advisor.

With many years of professional experience working with families of young children with disabilities and the accompanying challenges to parents, the researcher and her doctoral advisor regularly monitored the online discussions for the need to provide intervention support. The researcher and her doctoral advisor met on a biweekly basis to discuss the transcripts and any area of concern requiring outside assistance or intervention.

Data Analysis

Quantitative analysis. Data collected from the three online survey questionnaires were entered into SPSS version 21.0 database (IBM Corp., 2012) for analyses. Data were used to address research questions 1 and 2, and delved into the kinds of information parents sought following their child’s diagnosis of ASD, as well as the available social supports perceived as helpful by parents. The kinds of information requested by parents were examined for differences and similarities based on factors including parent gender, parent age, child gender, and family SES. In response to research question 4, reports of parent satisfaction and recommendations for online discussion groups were analyzed. Descriptive statistics were calculated (e.g., means, standard deviations, percentages, and response rate) in addition to $t$-tests. Open-ended items on the three survey questionnaires were reviewed and summarized in table format.

Qualitative analysis. A data file of de-identified transcripts from the 12 weeks of the online discussion groups was created. All discussion forum pages were printed in their entirety in order to analyze the parent responses to the weekly forum topic and associated questions, as well
as to analyze the dialogue and discussions between the participants. This view of the order and threaded nature of the discussions provided the contextual framework needed for in-depth analysis of conversation.

In qualitative research, measures of credibility and trustworthiness are key components (Brantlinger et al., 2005). Investigator triangulation, through the use of three trained coders (i.e., the researcher, her advisor, and a trained graduate student), provided one measure of credibility. In addition, the identification of themes deemed inconsistent with the predetermined themes (disconfirming evidence) expanded the ability to identify those unique to the discussion group postings. Member checks were built into the format of the online discussion groups as participants were able to edit and delete statements throughout the duration of the study and discussion postings remained visible, allowing further clarification, if so desired.

**Reflexive statement.** A quality indicator of qualitative research is the self-disclosure by the researcher of assumptions, beliefs, values, and biases (Brantlinger et al., 2005). In my years of working with families in early intervention and early childhood settings, I have developed positions and perspectives on supporting families of young children, particularly those with disabilities. Families of young children with ASD are faced with a wide range of difficulties in their daily lives, with ASD often becoming the central focus of a family. Mothers and fathers experience high levels of stress, and while their children are receiving therapy services, parents’ own needs for support often go unmet. Typical support networks of extended family and friends available to parents of young children are unused or unavailable. Recognition of this understudied need for support had a strong influence on my decision to engage in this research study, which will inform the field while it provides a much-needed forum of support for these families.
**Transcript analysis.** Framework analysis, popular in health-related research and developed by Ritchie and Spencer (1994), is a qualitative analysis that incorporates *a priori* concepts from an existing framework with concepts that emerge from the data. Lacey and Luff (2001) described framework analysis as a thematic analysis that has five key stages: (a) familiarization, (b) identifying a thematic framework, (c) indexing (coding), (e) charting, and (f) mapping and interpretation. Using this method, a systematic analysis of discussion group statements began by reading the data (familiarization), followed by identification of an initial framework with predetermined themes that was refined during subsequent stages. It was important for the researcher to be open-minded and not force the data to fit the *a priori* themes (Lacey & Luff). In the indexing or coding stage, the thematic framework was applied to the data using textual codes to identify statements which corresponded to the themes. Charting was the use of headings from the thematic framework to create charts for each theme across all participants. Mapping and interpretation consisted of searching the data for patterns, associations, and explanations.

In order to address research question 3, “What types of support-intended postings do parents engage in when participating in the online discussion group?” written transcripts were analyzed using the framework of social support behavior code developed by Cutrona and Suhr (1992) for their analysis of marriage partner communication. Coulson and Greenwood (2011) further refined the social support behavior code for use in their analysis of online support groups for families affected by childhood cancer and this version of the code was adapted for the current study. The five main social support typology described in this code included: emotional support (communicating concern, empathy, or encouragement), information support (providing advice or information), esteem support (communicating respect and validation of abilities), network
support (communicating the existence of shared experiences by others in the group), and tangible assistance (offering to provide direct assistance or services). The social support-intended behavior codes are described in Table 3.
Table 3

*Definitions for Coding of Support-Intended Behavior in Mother and Father Discussions*

<table>
<thead>
<tr>
<th>Support Type</th>
<th>Purpose of Communication</th>
</tr>
</thead>
<tbody>
<tr>
<td>Informational Support</td>
<td></td>
</tr>
<tr>
<td>(IS)</td>
<td></td>
</tr>
<tr>
<td>Suggestions/advice</td>
<td>Offers ideas or suggestions for action</td>
</tr>
<tr>
<td>Referral</td>
<td>Refers the recipient to some other source of information or help</td>
</tr>
<tr>
<td>Situation appraisal</td>
<td>Helps reassess or redefine the situation</td>
</tr>
<tr>
<td>Teaching</td>
<td>Provides in-depth information, facts, or news to deal with the situation</td>
</tr>
<tr>
<td>Emotional Support</td>
<td></td>
</tr>
<tr>
<td>(EmS)</td>
<td></td>
</tr>
<tr>
<td>Relationship</td>
<td>Expresses the importance of closeness</td>
</tr>
<tr>
<td>Physical affection</td>
<td>Offers physical contact, such as hugs, kisses, pat on the back</td>
</tr>
<tr>
<td>Confidentiality</td>
<td>Agrees to keep the recipient’s problem in confidence</td>
</tr>
<tr>
<td>Sympathy</td>
<td>Conveys sorrow or regret for the situation faced by the recipient</td>
</tr>
<tr>
<td>Understanding/empathy</td>
<td>Expresses understanding of the situation or discloses similar experience in a way that indicates understanding</td>
</tr>
<tr>
<td>Encouragement</td>
<td>Provides the recipient with hope and confidence</td>
</tr>
<tr>
<td>Prayer</td>
<td>Offers to pray for the recipient</td>
</tr>
<tr>
<td>Esteem Support</td>
<td></td>
</tr>
<tr>
<td>(EsS)</td>
<td></td>
</tr>
<tr>
<td>Compliment</td>
<td>States positive things about the recipient</td>
</tr>
<tr>
<td>Validation</td>
<td>Acknowledges agreement with the views of the recipient</td>
</tr>
<tr>
<td>Relief of blame</td>
<td>Attempts to alleviate any feelings of guilt about the situation</td>
</tr>
<tr>
<td>Network Support</td>
<td></td>
</tr>
<tr>
<td>(NS)</td>
<td></td>
</tr>
<tr>
<td>Access</td>
<td>Provides access to new people for the recipient</td>
</tr>
<tr>
<td>Presence</td>
<td>Offers to be present (“be there”)</td>
</tr>
<tr>
<td>Companions</td>
<td>Reminds the recipient that others share similar experiences and are available</td>
</tr>
<tr>
<td>Support Type</td>
<td>Purpose of Communication</td>
</tr>
<tr>
<td>---------------------------</td>
<td>------------------------------------------------------------------------------------------</td>
</tr>
<tr>
<td>Tangible Assistance (TA)</td>
<td></td>
</tr>
<tr>
<td>Loan</td>
<td>Expresses willingness to lend money to the recipient</td>
</tr>
<tr>
<td>Direct task</td>
<td>Offers to do a direct task for the recipient</td>
</tr>
<tr>
<td>Indirect task</td>
<td>Proposes to take over a task from the recipient while they are stressed</td>
</tr>
<tr>
<td>Active participation</td>
<td>Offers to join the recipient in an activity</td>
</tr>
<tr>
<td>Willingness</td>
<td>Expresses a willingness to help recipient</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Additional Subthemes</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Sharing Statement (SS)</td>
<td></td>
</tr>
<tr>
<td>Information</td>
<td>Provides an explanatory response to discussion topic question, often including a greeting</td>
</tr>
<tr>
<td>Question</td>
<td>Requests information from the group</td>
</tr>
<tr>
<td>Building Relationships (BR)</td>
<td></td>
</tr>
<tr>
<td>Through humor</td>
<td>Uses humorous statement, abbreviations (LOL) and emoticons (�, :P)</td>
</tr>
<tr>
<td>Through inexperience</td>
<td>Expresses a desire to be a part of the discussion although has no personal experience to contribute</td>
</tr>
</tbody>
</table>


Adapted from “Families affected by childhood cancer: An analysis of the provision of social support with online support groups” by N. S. Coulson and N. Greenwood, 2011, *Child: care, health and development, 38*, p. 872. Copyright 2011 by Blackwell Publishing Ltd.
Using a team approach consisting of the researcher and a trained graduate coder, the transcripts were analyzed using coding methods and coder training recommended by Miles and Huberman (1994). Training over several sessions with the graduate coder consisted of an explanatory description of the online discussion groups and topic themes, an overview with definitions of the predetermined support behavior types (subthemes) to be used for coding, partnered coding of example discussions to reach consensus on the predetermined subthemes, and identification of additional subthemes to be used. The first topic discussion postings for the mothers’ and fathers’ group, were independently read and coded by the researcher, her advisor, and the graduate coder and were compared to reach consensus. Then the researcher and graduate coder proceeded to independently read, code, and compare coding of all discussions.

Miles and Huberman (1994) suggested that multiple readings of the texts are needed for the development of matrices to assist in confirming or disconfirming themes, subthemes, and categories. As Santos and McCollum (2007) noted, recurring or emphasized participant statements provide insights into parent ideas and perspectives. First, each week’s transcripts from the fathers’ and mothers’ discussion groups were divided into the broad themes of the key topics for discussion requested by the parents in the initial survey. Second, patterns of support-intended postings (subthemes) based on the social support behavior code (Coulson & Greenwood, 2011) were identified within these broad themes. Third, additional responses and questions generated by parents that did not fit into these predetermined subthemes were analyzed for additional subthemes. The first mother and father discussion group topic (theme) was read and coded for subthemes by the researcher, her doctoral advisor, and a graduate student with expertise in early intervention work with parents of young child with disabilities. Consensus was reached on subtheme categories and additional subtheme categories were added to address postings not
captured by the predetermined subthemes. The researcher and trained graduate coder read all the transcripts independently and then met to gain consensus on the themes, subthemes and categories. The doctoral advisor served as an independent check for the reliability of themes and subthemes, with several randomly chosen discussion postings coded for accuracy. The matrices of the parent participants and their postings coded according to predetermined and emerging subthemes provide a visual summary of support-intended postings. Broad themes and subthemes with 40% or greater of participants in each group contributing a statement were reported. This ensures that themes represented the experience of many of each group’s participants and were not the views of only a few parents (Santos & McCollum, 2007).

**Ethical Considerations**

No ethical concerns developed over the course of recruitment and participation in the online parent discussion groups. In the consent form signed by participants, there was an additional confidentiality agreement that described appropriate conduct (including privacy protection) for the online discussion group. Parents completed and returned consent forms, received pseudonyms and log-in information, and were reminded that all online interactions were voluntary. The researcher and her doctoral advisor were accessible via phone or email to answer questions that any participants had. The only emailed questions to the researcher were challenges associated with accessing the Moodle™ website and participant concerns about absences due to family issues. There was no need to seek outside assistance and intervention for unexpected situations (e.g., referral to resources or therapists). All efforts to maintain confidentiality of participants were made during the course of the study and will continue during any dissemination activities of research findings.
In order to address the unforeseen risk that may occur in online discussion of emotionally charged topics or in discussion of family members, links were posted on the Moodle™ site to Suicide Prevention Lifeline (1-800-273-TALK (8255), www.suicidepreventionlifeline.org) and Childhelp National Child Abuse Hotline (1-800-4-A-CHILD, www.childhelp.org). Both organizations have a long history of supportive assistance and have 24 hours a day, 7 days a week hotlines to crisis counselors. In addition, www.psychology.com/therapist, a national listing of licensed therapists, was available to generate a list of therapists should a parent participant need such. For local participants, the researcher was prepared to seek the assistance of trained counselors in the area, but the need did not arise.
Chapter 4

Results

The results of this mixed methods study are organized around four main research questions with quantitative and qualitative data presented together, as they complement one another. The quantitative results include rankings of desired topics for discussion, percentages and \( t \)-test comparisons of sources of supports reported by parents, levels of satisfaction with participation in the online discussion groups, and tabulation of factors promoting and preventing participation. The qualitative data consist of themes and subthemes of support-intended postings which emerged from multiple readings of the online discussion groups’ transcripts.

Information Parents Seek Following Diagnosis of ASD

The first research question focused on the kinds of information parents seek following their child’s diagnosis of an Autism Spectrum Disorder (ASD) and whether there were differences in the kinds of information requested by parents based on salient factors (e.g., parent gender, parent age, child gender, family SES). As seen in Table 4, a list of choices of discussion topics were drawn from the literature (Baker-Ericzén, Brookman-Frazee, & Stahmer, 2005; Boyd, 2002; Davis & Carter, 2008; Hastings et al. 2005; Tomanik, Harris, & Hawkins, 2004) and the Autism Parenting Stress Index developed by Silva and Schalock (2011). With 16 topics suggested, at least 80% of the mothers (range: 80-100%) chose each topic as important or highly important and at least 43% of the fathers (range: 43-100%) identified each topic as important or highly important. All of the mothers indicated the following topics they considered important or highly important: communication skills, sharing and turn-taking, following directions, making transitions, as well as diet and eating. All of the fathers specified the topics of communication
skills, early reading and literacy, following directions, making transitions, diet and eating, and managing challenging behaviors, as either important or highly important. Both mothers and fathers ranked communication devices as a topic of lower importance. Notably, less than half the fathers (43%) selected sleeping as an important or highly important topic compared to 94% of the mothers. An additional topic of toilet training was added to the final list of 12 topics chosen for the discussion forums based on the recommendation of nine mothers and two fathers who responded to the question “What other topics would you like to see discussed?”
**Table 4**

*Preferred Topics for Discussion as Percentages of Mothers and Fathers*

<table>
<thead>
<tr>
<th>Topic</th>
<th>Mothers (n = 15)</th>
<th>Fathers (n = 7)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Highly</td>
<td>Important</td>
</tr>
<tr>
<td>Communication Skills</td>
<td>73</td>
<td>27</td>
</tr>
<tr>
<td>Peer Friendships</td>
<td>47</td>
<td>47</td>
</tr>
<tr>
<td>Sharing, Turn-Taking</td>
<td>47</td>
<td>53</td>
</tr>
<tr>
<td>Communication Devices</td>
<td>33</td>
<td>47</td>
</tr>
<tr>
<td>School Screenings and Assessment</td>
<td>47</td>
<td>40</td>
</tr>
<tr>
<td>Understanding SpEd Services</td>
<td>80</td>
<td>7</td>
</tr>
<tr>
<td>Early Reading and Literacy Skills</td>
<td>40</td>
<td>53</td>
</tr>
<tr>
<td>Following Directions</td>
<td>80</td>
<td>20</td>
</tr>
<tr>
<td>Moving into Kindergarten</td>
<td>53</td>
<td>27</td>
</tr>
<tr>
<td>Sensory Concerns (e.g., sounds, touch)</td>
<td>67</td>
<td>27</td>
</tr>
<tr>
<td>Making Transitions</td>
<td>60</td>
<td>40</td>
</tr>
<tr>
<td>Diet and Eating</td>
<td>47</td>
<td>53</td>
</tr>
</tbody>
</table>

67
Table 4 (continued)

<table>
<thead>
<tr>
<th>Topic</th>
<th>Mothers (n = 15)</th>
<th>Fathers (n = 7)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Highly Important</td>
<td>Important</td>
</tr>
<tr>
<td>Sleeping</td>
<td>47</td>
<td>47</td>
</tr>
<tr>
<td>Managing Challenging Behavior</td>
<td>80</td>
<td>7</td>
</tr>
<tr>
<td>Working with Therapists/Teachers</td>
<td>53</td>
<td>40</td>
</tr>
<tr>
<td>Interacting with People in Community</td>
<td>47</td>
<td>47</td>
</tr>
</tbody>
</table>
When comparing mothers of girls (n = 5) to mothers of boys (n = 10) on topics chosen for discussion, mothers of girls described all 16 topics as important or highly important. Upon closer inspection, mothers of girls compared to mothers of boys selected the following topics as highly important: communication skills (100% vs. 60%), understanding special education services (100% vs. 70%), and following directions (100% vs. 70%). In addition, 80% of the mothers of boys chose sensory concerns as a highly important topic, compared to 40% of the mothers of girls. Toilet training was a high priority for mothers of girls with 80% requesting it as a topic for discussion.

All of the mothers receiving state or federal assistance (n = 4) indicated the following topics as highly important: understanding special education services, following directions, and managing challenging behaviors. Likewise, all of the mothers over the age of 36 years (n =8) selected communication skills and following directions as highly important compared to mothers aged 36 years and younger (n =7; 100% vs. 43% and 100% vs. 57%, respectively). In addition, 75% of the older mothers chose the topics of diet and eating, and sleeping as highly important compared to 14% of the younger mothers.

Given the similarity in topic choice selections between the mothers and fathers, the same 12 topics were used in the weekly discussions for both online groups. Each week of the study, on Tuesday evening, a new topic for discussion and associated resources were posted and parents in both groups were emailed to alert them to the new posting. Weekly topics for discussion and resources provided are included in Table 5. These resources were selected by the researcher from various relevant, reputable online websites. Additional resources were embedded within discussions, based on parent requests or musings (e.g., sleeping strategies, links to technology apps, sensory activities). Included in the weekly emails, parents were reminded of the iPod
Shuffle® incentive at weeks 3, 6, 9, and 12 when discussion postings were tallied as entries for the random drawing on Sunday evenings. Mothers (n = 15) recorded 435 unique discussion postings across the 12 weeks from which data were analyzed and fathers (n = 6) logged 119 separate postings. It should be noted that each parent discussion group posting often contained more than one support-intended statement and each statement was coded separately in the qualitative analyses.
<table>
<thead>
<tr>
<th>Week</th>
<th>Topic</th>
<th>Resource Links</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Following Directions</td>
<td>Positive Parenting Practices for Young Children with Autism—Parent’s Workbook, Module 2: Teaching Children to Follow Directions, Teacher’s Toolbox (n.d.)&lt;br&gt;<a href="http://www.ttoolbox.com/guides/PosParnt_Trannr_Ch2.pdf">http://www.ttoolbox.com/guides/PosParnt_Trannr_Ch2.pdf</a></td>
</tr>
<tr>
<td>3</td>
<td>Sharing and Turn-taking</td>
<td>Early Childhood Social Skills, autismhelp.info (2008)&lt;br&gt;<a href="http://www.autismhelp.info/App_CmsLib/Media/Lib/1203/M3429_v1_634671616667597895.pdf">http://www.autismhelp.info/App_CmsLib/Media/Lib/1203/M3429_v1_634671616667597895.pdf</a></td>
</tr>
<tr>
<td></td>
<td></td>
<td>Overcoming Feeding Problems in a Child with Autism, an interview with Dr. Kroeger-Geoppinger of Cincinnati Children’s Hospital Medical Center by L. J. Rudy (2010)&lt;br&gt;<a href="http://autism.about.com/od/childrenandautism/ss/howtofeed.htm">http://autism.about.com/od/childrenandautism/ss/howtofeed.htm</a></td>
</tr>
<tr>
<td>Week</td>
<td>Topic</td>
<td>Resource Links</td>
</tr>
<tr>
<td>------</td>
<td>-------------------------------</td>
<td>-----------------------------------------------------------------------------------------------------------------------------------------------</td>
</tr>
</tbody>
</table>
Table 5 (continued)

<table>
<thead>
<tr>
<th>Week</th>
<th>Topic</th>
<th>Resource Links</th>
</tr>
</thead>
</table>
| 11   | Early Reading and Literacy   | Make book time fun and educational for children with autism spectrum disorder (ASD), nonprofit Reach Out & Read (2010)  
http://www.reachoutandread.org/FileRepository/CVSROR_Autism_FINAL_WEB.pdf |
| 12   | Interacting with the Public  | Grocery Shopping with an Autistic Child: Problems & Solutions, by C. Foster (2009)  

A feature of the Moodle™ Learning Management System is access to the data documenting “viewing without posting” behavior (lurking) of online discussion group participants. Over the 12 weeks, mothers (n = 15) viewed the discussions without posting 1157 times and fathers (n = 6) viewed without posting 520 times. Predictably, the highest posting participant in each of the mothers’ and fathers’ online discussion groups was also the highest viewer.

In summary, similarities between the mothers’ and fathers’ discussion groups were apparent in their choices of topics for discussion. Both groups indicated the importance of discussion on the topics of communication skills, following directions, diet and eating, and making transitions. A higher percentage of fathers recorded the importance of discussion on early reading and literacy, and managing challenging behavior. Further, a higher percentage of mothers noted the importance of discussion on sharing and turn-taking. Mothers attached a markedly higher importance to discussion of sleeping compared to fathers and when prompted to provide additional topics for discussion, mothers indicated a markedly high interest in discussion.
in toilet-training. Mothers of girls, older mothers (>36 years), and mothers receiving state or federal assistance indicated following directions were of higher importance as topics for discussion than their respective counterparts. Also, mothers of boys noted sensory concerns were of higher importance for discussion than mothers of girls. The important topics for discussion indicated parents’ desire for supportive information that was directly related to the challenges and concerns they had in raising their young child with ASD. This led to the second research question addressing the sources of support parents were already accessing at the time of entry in the groups.

Sources of Support Already Accessed by Parents

In keeping with the sizable literature focused on social supports and social networks as agents for lessening stress and promoting parent well-being (Dunst, Trivette, & Hamby, 1994), the *Family Support Scale* was used to measure mothers’ and fathers’ perceptions of how helpful 18 different persons, groups, and programs were in raising their young children with ASD. Only one mother opted not to complete this portion of the second survey. When comparing mothers and fathers, a number of similarities were noted, including high levels of helpfulness associated with spouses, early childhood intervention programs, and professional helpers (e.g., social workers, therapists, and teachers). Further, both groups described low levels of helpfulness associated with spouse’s or partner’s friends, other parents, co-workers, social groups and clubs, church members and ministers, and parent groups. Interestingly, mothers and fathers reported statistically significant different levels of helpfulness on two persons and programs. Mothers rated their own friends \(t (19) = 2.23, p = .038\) and professional agencies \(t (19) = 2.25, p = .036\) as more helpful. Table 6 summarizes the results of the *Family Support Scale*. 
Table 6

Summary of Mothers’ and Fathers’ Responses to Family Support Scale (FSS)

<table>
<thead>
<tr>
<th>Scale Items</th>
<th>Mothers (n = 14)</th>
<th>Fathers (n = 7)</th>
<th>t(df)</th>
<th>p</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>How helpful has each of the following been to you in terms of raising your child(ren)?</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>My parents</td>
<td>2.86 (1.88)</td>
<td>2.57 (1.99)</td>
<td>.32(19)</td>
<td>.750</td>
</tr>
<tr>
<td>My spouse or partner’s parents</td>
<td>1.79 (1.67)</td>
<td>3.00 (1.73)</td>
<td>1.55(19)</td>
<td>.137</td>
</tr>
<tr>
<td>My relative/kin</td>
<td>2.29 (1.64)</td>
<td>1.00 (1.73)</td>
<td>1.67(19)</td>
<td>.112</td>
</tr>
<tr>
<td>My spouse or partner’s relative/kin</td>
<td>1.21 (1.53)</td>
<td>1.86 (1.46)</td>
<td>.92(19)</td>
<td>.369</td>
</tr>
<tr>
<td>Spouse or partner</td>
<td>3.93 (1.38)</td>
<td>4.86 (0.38)</td>
<td>1.72(19)</td>
<td>.101</td>
</tr>
<tr>
<td>My friends</td>
<td>2.00 (1.36)</td>
<td>0.71 (0.95)</td>
<td>2.23(19)</td>
<td>.038*</td>
</tr>
<tr>
<td>My spouse or partner’s friends</td>
<td>1.36 (1.93)</td>
<td>1.00 (1.15)</td>
<td>.77(19)</td>
<td>.452</td>
</tr>
<tr>
<td>My own children</td>
<td>2.46 (1.71)</td>
<td>1.43 (1.13)</td>
<td>1.43(18)</td>
<td>.171</td>
</tr>
<tr>
<td>Other parents</td>
<td>1.00 (1.18)</td>
<td>0.71 (0.95)</td>
<td>.56(19)</td>
<td>.585</td>
</tr>
<tr>
<td>Co-workers</td>
<td>1.23 (1.54)</td>
<td>0.29 (0.49)</td>
<td>2.04(16)</td>
<td>.059</td>
</tr>
<tr>
<td>Parent groups</td>
<td>1.93 (2.09)</td>
<td>0.57 (0.98)</td>
<td>2.03(19)</td>
<td>.057</td>
</tr>
<tr>
<td>Social groups/clubs</td>
<td>1.71 (1.59)</td>
<td>1.00 (1.29)</td>
<td>1.03(19)</td>
<td>.317</td>
</tr>
<tr>
<td>Church members/ministers</td>
<td>1.43 (1.70)</td>
<td>0.71 (0.95)</td>
<td>1.23(19)</td>
<td>.232</td>
</tr>
<tr>
<td>My family or child’s physician</td>
<td>3.08 (1.12)</td>
<td>2.71 (0.76)</td>
<td>.77(18)</td>
<td>.454</td>
</tr>
</tbody>
</table>
Table 6 (continued)

<table>
<thead>
<tr>
<th>Scale Items</th>
<th>Mothers (n = 14)</th>
<th>Fathers (n = 7)</th>
<th>t(df)</th>
<th>p</th>
</tr>
</thead>
<tbody>
<tr>
<td>Early childhood intervention program</td>
<td>3.93 (1.27)</td>
<td>2.71 (1.60)</td>
<td>1.90(19)</td>
<td>.073</td>
</tr>
<tr>
<td>School/day-care center</td>
<td>3.14 (1.66)</td>
<td>2.43 (1.99)</td>
<td>.87(19)</td>
<td>.394</td>
</tr>
<tr>
<td>Professional helpers</td>
<td>3.93 (0.92)</td>
<td>3.43 (0.79)</td>
<td>1.23(19)</td>
<td>.234</td>
</tr>
<tr>
<td>Professional agencies</td>
<td>2.29 (1.33)</td>
<td>1.00 (1.00)</td>
<td>2.25(19)</td>
<td>.036*</td>
</tr>
</tbody>
</table>

_How helpful has each of the following been to you in terms of raising your child(ren)?_

Note. _M_ = mean. _SD_ = standard deviation. _t_ = t-score. _df_ = degrees of freedom.
0 = Not Available, 1 = Not at All Helpful, 2 = Sometimes Helpful, 3 = Generally Helpful, 4 = Very Helpful, 5 = Extremely Helpful.

*aOne of the original sample of 15 mothers did not complete the portion of the survey containing the “Family Support Scale.”
* _p_ < .05

In order to analyze the access parents had to online informational support regarding autism, parents were asked to list two autism Internet sites they visited for information about Autism Spectrum Disorder. A majority of the mothers (67%) reported accessing AutismSpeaks.org for information, followed by blogs created by mothers and regionally based autism programs. Fathers (29%) reported visiting AutismSpeaks.org, followed by occasional access to medical-based websites like Easter Seals and a local pediatrician.

Following recognition of the supportive helpfulness of the people and programs in the participating parents’ lives, the research study moved to the analysis of the support-intended nature of the discussion postings recorded in the online discussion groups.
Support-Intended Postings to the Online Discussion Groups

The support-intended behavior codes as developed by Cutrona and Suhr (1992) and refined for online cancer support groups by Coulson and Greenwood (2011) included *Informational Support (IS), Emotional Support (EmS), Esteem Support (EsS), Network Support (NS), and Tangible Assistance (TA).* These behavior codes were used to analyze the predetermined weekly topics of discussion which had been introduced by the posting of a few paragraphs regarding research on the topic, followed by open-ended questions as seen in the example shown in Figure 1.
Reading to our children in the preschool years has several advantages:

1. It helps build a stronger relationship between parent and child—a chance to slow down the day’s activities and provides a moment of nurturing, particularly when it is not seen as a chore.
2. A number of studies have shown that children exposed to reading early in life are more likely to do well in school.
3. Children are not born with the knowledge to read left to right and front to back of a book—sharing the basics of how to read are important pre-reading skills.
4. Young children develop more logical thinking skills as they begin to relate what’s happening in books to their own world.
5. Toddlers and preschoolers initially squirm and become distracted when you are reading but eventually they learn to sit still for the length of the book. You’re building on their attention span and their memory skills.
6. Reading to your child will help to introduce the fundamentals of language.

Some suggestions:

1. Look for books at the library that have photographs of real children and objects.
2. Some children are fascinated by letters of the alphabet and numbers—look for simple alphabet books and easy counting books.
3. Read the same stories over and over – repetition is a language builder.
4. Find books with favorite characters and describe those characters. Encourage your child to point to the character on the page.
5. First look for books with only a few words on the pages – make reading a short time and gradually build up the time.
6. Consider whether cuddling in your lap or sitting side-by-side is better for your child.
7. Let your child choose between books (perhaps between a familiar and a new book)
8. Change your voice to fit the characters or activity in the story.
9. Make reading a daily routine. Look for connections (e.g., Curious George has a yellow shirt and you do too!).

What has been your experience with reading books with your child? Please share your thoughts, questions, and suggestions.
added. Likewise, parents requested information from the group which often elicited the support-intended statements from other participants and these queries were designated as *Sharing Statements-Question* (SS-Q). An additional subtheme emerged and was described as *Building Relationships* (BR) where parents used humor, expressed a desire to participate even though they had no personal experience to contribute, or requested an update for a significant life event (e.g., surgery). The percentages of statements made as a proportion of all statements in both discussion groups are presented in Table 7.

**Table 7**

*Support-Intended Statements in Percentages of Total Statements by Mothers and Fathers*

<table>
<thead>
<tr>
<th>Support Type</th>
<th>Mothers’ Statements (n = 549)</th>
<th>Fathers’ Statements (n = 166)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Informational Support (IS)</td>
<td>17</td>
<td>22</td>
</tr>
<tr>
<td>Emotional Support (EmS)</td>
<td>9</td>
<td>2</td>
</tr>
<tr>
<td>Esteem Support (EsS)</td>
<td>17</td>
<td>11</td>
</tr>
<tr>
<td>Network Support (NS)</td>
<td>10</td>
<td>7</td>
</tr>
<tr>
<td>Tangible Assistance (TA)</td>
<td>&lt;1</td>
<td>0</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Additional Subthemes</th>
<th>Mothers’ Statements (n = 549)</th>
<th>Fathers’ Statements (n = 166)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Sharing Statement (SS)</td>
<td>31</td>
<td>36</td>
</tr>
<tr>
<td>Information Question</td>
<td>11</td>
<td>13</td>
</tr>
<tr>
<td>Building Relationships (BR)</td>
<td>4</td>
<td>8</td>
</tr>
</tbody>
</table>

To ensure subthemes represented the experience of many of each group’s participants and were not the views of only a few parents, subthemes with 40% or more of participants in each group contributing a statement were reported (Santos & McCollum, 2007). As pseudonyms were used in discussion postings, those pseudonyms were continued in the examples presented. A
closer look at the data on parents’ use of Informational Support revealed that 80% of the mothers and 71% of the fathers used Informational Support-Suggestions (IS-Sugg) where a parent offered ideas or suggestions for action, often in response to a question posed by another parent. Other forms of Informational Support (i.e., Appraisal and Teaching) represented only 20% of the mothers and 14% of the fathers. The following are examples of Informational Support-Suggestions:

We use it as a first/then tool. If she is playing with the iPad®, and I tell her it’s time to go potty, she will usually resist. I put my hand on the iPad® (without taking it from her), and I say, “First, potty. Then, Book.” (“Book” is what she calls the iPad®.) If she doesn’t respond, I say it again, and then I take the iPad® from her and walk with it to the bathroom. She almost always follows me—even if she vocalizes displeasure on the way. (Tabatha)

There are quite a few potty training videos out there that show other kids learning and make it look fun to use the potty. Ours is a Blues Clues fanatic so we make it a point to show that episode often. I can’t say it has helped, but it can’t hurt, and these little ones surprise us everyday with what they can do when they want to! (Carlos)

Mothers’ statements of Emotional Support focused on Understanding (EmS-Under) with 67% contributing and Sympathy (EmS-Symp) with 47% contributing, while fathers rarely contributed Emotional Support statements (2%). Understanding (EmS-Under) statements were expressions of empathy and understanding of situations and the writer appeared to be commiserating and sharing feelings. Frustrations in dealing with schools over IEPs, difficulties in toilet-training, and trials faced when family members become ill were some of the many instances that mothers used these Understanding (EmS-Under) statements. Through Sympathy (EmS-Symp) statements, mothers expressed sorrow or regret for the situation described by another. Difficult topics including having more children and frustration with spouses elicited Sympathy statements. Examples of Emotional Support statements included:

(EmS-Under) I think our kids benefit so much from being around peers, they just can’t really show it in conventional ways. I, like you, grapple with the idea of staying home
and trying to engage him myself. (I’m not sure yet, because we haven’t even started in school…so we are going to give it an honest shot.) (Loraine)

(EmS-Symp) I’m sorry your husband is having a hard time coming to terms. I can see how that can make things more difficult and frustrating. But, whatever the label, it doesn’t really matter. What really matters is that he gets services that are specifically where his delays/struggles lie. (Esmeralda)

Esteem Support statements that focused on Validation (EsS Valid) were contributed by 67% of the mothers and 57% of the fathers. These statements were characterized by a parent providing agreement with a previous posting or postings and were directed toward the whole group or a specific person. Examples of Validation (EsS Valid) included:

I hear you about the dietary restrictions. It’s hard. You do wonder if it makes a difference. (Esmeralda)

That’s a good idea Kevin! Maybe even make a game or song of it. Going to give that a shot myself with the bubble pop game app my girl has started to like on the tablet. She loves music and singing! (Carlos)

An additional style of Esteem Support statements, Compliment (EsS Compl) statements, was identified in the discussions. Compliment (EsS Compl) statements were characterized by positive things said about the recipient and 40% of the mothers and none of the fathers posted this type of statement.

You seem to have it together with your little one. (Marcie)
Haha! Marsha! Good one. (Loraine)

Network Support-Companions (NS-Comp) statements were made by 87% of the mothers and 57% of the fathers. These statements sought to remind a previous post writer that other parents were sharing a similar experience and were available. It was through a series of Network Support –Companions statements on the topic of sharing and turn-taking that two of the mothers realized they were in similar situations of raising an elementary age child and 4-year-old fraternal twins, one with and one without autism. In Network-Support Companions statements,
there were no feelings of empathy included and the statements expressed the sentiment of “us too”:

   Like Marcie’s child, my son follows a picture schedule, and his teachers and I have found that this is the best way to convince him to follow directions! (Allyson)

   My son is sensory seeking as well. We have a bean bag in the living room. We’re always playfully throwing him into it. Sometimes it helps him “decompress” from all the demands we put on him throughout the day. (Howard)

   There was only one statement made of Tangible Assistance in both online discussion groups, so no analysis of statements was needed on this type of support. All of the mothers contributed Sharing Statement-Information (SS-Info) and 86% of the fathers posted this style of statement. This was the largest collection of statements posted by both discussion groups and Sharing Statement-Information statements were often used as explanations addressing a topic question or as descriptions of a situation to add to the group’s discussion. The focus was not on offering advice and suggestions, but rather clarifying an experience.

   (on the topic of sharing) We tried buying 2 balls, they weren’t exactly alike but very similar. One was smaller and one was bigger, and they were two different colors. My son picked out the larger one and played with it, but as soon as his sister started to play with hers, even though he was already playing with his, he still went and grabbed hers away from her. (Marcie)

   (on the topic of sharing) This was a really hard thing to teach my son but I believe him starting preschool greatly improved this. When it was just me or my wife, I believe the concept seemed to confuse him. Once other kids were involved, I think he caught on much easier because it was a peer rather than an adult. (John)

   Sharing Statement-Question (SS-Ques) statements were used by 87% of the mothers and 29% of the fathers. Many of the mothers asked questions of the group, particularly in the separate “What’s on your mind…” discussion topic that was posted each week. Mothers used this alternate discussion all twelve weeks while the fathers infrequently posted short discussions on six of the twelve weeks. Examples of the Sharing Statement-Question included:
Anybody have sleep problems? (I mean, I know we mothers do!) Night terrors, waking frequently? Can’t get them to sleep at a certain time? Tried melatonin or Benadryl? What’s the status on sleep for you guys? (Loraine)

Am I the only one who worried about the label? I was puzzled with the label on my daughter. I am afraid that this will follow her in her whole life. I understand we need the label to get the help we need. (Lauren)

But, I can’t get him away from the bottle. Any ideas? I know it’s a comfort thing and it’s safe. But he’s almost 3 years old! (Selena)

Building Relationships through Humor (BR-Hum) statements were used by 47% of the mothers and 43% of the fathers. In addition to the humorous statements counted in this subtheme, the use of emoticons (😊;:P) and acronyms (LOL for “laugh out loud”) were present in both fathers’ and mothers’ discussion group postings. The following are examples of Building Relationships through Humor statements:

- I’m in sensory guessing game mode, constantly. If something upsets him, what could it be? Is the house warm? Am I wearing red? Is my voice annoying? Just kidding, but sort of serious. (Loraine)

- I’m really sorry I haven’t been on discussion this week. It’s been kinda nuts over on my side of autism island. (Rae)

- You must keep two hands on him at all times at a birthday party! And he is like a sneaky ninja and will come from the opposite side of your attention and steal off anyone’s plate. (Paul)

- She must feel the texture of the food and then pick it into little pieces as she eats. If we try to add something new (at least a couple of times a week) she feels it and either pushes to side of tray or it goes flying (future girls’ softball pitcher!) (Carlos)

Although not a separate subtheme, 47% of the mothers and 57% of fathers included a reference to their spouse in their discussion postings. In some instances, frustration with a spouse was expressed, but more often the focus was on the role the spouse played in child-raising. The fathers described the roles their wives had in managing the challenges associated with ASD.

From working with therapists and teachers, to behavior management, to difficult toilet training,
fathers deferred to mothers as the experts on their child. Fathers did mention their own roles as sensory stimulators (e.g., rough-housing play, tossing child in bean bag chair, trampoline jumping), which was often encouraged by their wives. Some mothers described their husbands as less patient with the children at times and conveyed their own frustrations when fathers were out of town for business. Yet, mothers also described the bond their children had with their fathers:

- My son realizes daddy is here and wouldn’t make a move without my husband. (Rae)
- My little guy is SO attached to his daddy during those days. (Selena)
- His Dad doesn’t know too many words but my son likes to show his Daddy the new sign he learned. (Marcie)

To summarize, nine subthemes emerged in the online postings of the discussion groups. *Informational Support-Suggestion* statements were used by mothers and fathers to offer ideas or suggestions of ways to handle concerns expressed by other members of the discussion group. *Emotional Support-Understanding* and *Sympathy* statements were used by mothers but rarely used by fathers. Mothers used these statements to commiserate and convey emotional feelings of sorrow or empathy for situations faced by their peers. Both mothers and fathers acknowledged their agreement with the views of others through *Esteem Support-Validation* statements and at times included short comments of “I agree” and “Good idea”. Mothers used *Esteem Support-Compliment* statements to praise, congratulate, and point out positive things about others. Fathers did not use this style of support statement. *Network Support-Companions* statements were used by both mothers and fathers to remind post writers that companions with shared experiences and similar interests were available, particularly within the online groups. The largest number of postings and the largest number of parents participating were found in the *Sharing Statement-Information* subtheme. These statements were characterized as responses and explanations to the questions posted in the weekly discussions. They consisted of information to aid other participants’ understanding of individual situations and they did not offer advice or suggestions.
to members of the group. Sharing Statement-Questions were used by both mothers and fathers to request information and suggestions from their peers in the discussion groups. These questions were often the impetus for further discussions in the groups. At times, a small number of questions were not direct questions in need of answers but rather were a way of seeking affirmation of the unique realities of raising young children with ASD (e.g., “So how are you guys planning for the holidays? Anyone else dreading this too?” [Bailey]). The final subtheme focused on Building Relationships through Humor and both groups included humorous postings that, at times, lightened the mood from the heavy topic under discussion. In the absence of facial expressions and speech inflection, humor was expressed in discussion statements through unusual turns of phrase, funny analogies, acronyms, and emoticons.

As the online discussion groups came to a close, it was important to assess the success the groups had in addressing the needs of the participants. Mothers had come to the online group to connect with others in similar circumstances:

Hello, all. I’m also excited to be in touch with real people rather than anecdotal stories online! (Loraine)
I’m looking forward to sharing information with everyone :-) (Harriet)

Fathers shared information and suggestions from the outset of the discussion groups but did not express an equivalent excitement in interacting with other fathers. It was critical to evaluate the usefulness of the experience to these unique groups of parents.

Satisfaction with Use of the Online Discussion Groups

A Post Participation Survey (in Appendix G) provided the answers to the final research questions: To what extent are parent participants satisfied with their use of the online discussion groups? What do parents report are the factors that promote participation and prevent
participation in online parent discussion groups? Parents described their weekly habits of visiting the online discussion forums, the usefulness of the discussion group, their perceived level of participation, the ways the group proved useful and not useful to the participant, the incentives and barriers to participation, some suggestions for improvement, and whether they would recommend the group to others. Results of the Post Participation Survey are reported in Table 8.

Table 8

*Post Participation Survey Results in Percentages of Mothers and Fathers*

<table>
<thead>
<tr>
<th>Parent Report of Participation Factors</th>
<th>Mothers (n = 15)</th>
<th>Fathers (n = 7)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Weekly participation</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Less than 1 time</td>
<td>40</td>
<td>43</td>
</tr>
<tr>
<td>1-2 times</td>
<td>33</td>
<td>29</td>
</tr>
<tr>
<td>3-4 times</td>
<td>20</td>
<td>29</td>
</tr>
<tr>
<td>4-5 times</td>
<td>7</td>
<td>0</td>
</tr>
<tr>
<td>Usefulness of discussion group</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Very Useful</td>
<td>20</td>
<td>0</td>
</tr>
<tr>
<td>Useful</td>
<td>27</td>
<td>43</td>
</tr>
<tr>
<td>Somewhat Useful</td>
<td>47</td>
<td>14</td>
</tr>
<tr>
<td>Not Useful</td>
<td>7</td>
<td>43</td>
</tr>
<tr>
<td>Level of participation in discussion group</td>
<td></td>
<td></td>
</tr>
<tr>
<td>High Participation</td>
<td>13</td>
<td>0</td>
</tr>
<tr>
<td>Medium Participation</td>
<td>53</td>
<td>57</td>
</tr>
<tr>
<td>Low Participation</td>
<td>33</td>
<td>43</td>
</tr>
<tr>
<td>Satisfaction with participation</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Satisfied</td>
<td>20</td>
<td>43</td>
</tr>
<tr>
<td>Not Satisfied</td>
<td>80</td>
<td>57</td>
</tr>
<tr>
<td>Recommend this type of group to others</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Would Recommend</td>
<td>93</td>
<td>86</td>
</tr>
<tr>
<td>Would Not Recommend</td>
<td>7</td>
<td>14</td>
</tr>
<tr>
<td>Interest in continuing to participate in group</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Interested</td>
<td>100</td>
<td>57</td>
</tr>
<tr>
<td>Not Interested</td>
<td>0</td>
<td>43</td>
</tr>
</tbody>
</table>
The majority of both mothers and fathers reported they accessed the online discussion groups two or less times per week. The majority of both groups rated their participation level as medium participation with 80% of the mothers and 57% of the fathers not satisfied with their level of participation. Mothers found the online discussion groups more useful than fathers but a high percentage of mothers (93%) and fathers (86%) would recommend online discussion groups such as this one. All of the mothers were interested in continuing to participate in the online discussion group, while 57% of the fathers were interested in continuing.

When asked to list two ways the online groups were useful to the participant, mothers provided 30 statements with 47% of the statements focused on gaining new ideas to help their children, 23% of the statements acknowledged others shared their same situation and they were not alone, and 17% of the statements expressed a sense of belonging to a supportive community. Fathers were asked the same question and provided 11 responses with 27% of the statements focused on accessing others’ experiences and perspectives, and 27% of the statements described contact with others who shared the same challenges. Additional father statements on the usefulness of the group included learning new strategies and encouraging new thought on issues not previously considered.

Due to limited descriptive responses to open-ended questions in the fathers’ group, the responses of both groups were combined to identify incentives and barriers to participation. The online and all-hours nature of the group, the Amazon® gift cards and iPod Shuffles®, the pertinence of topics, access to previous weeks’ discussions, and the weekly reminders were mentioned as factors increasing participation. The most common factor cited for increasing participation was the social interaction with others (e.g., “Others asking questions or posting comments based on what I said or thought.” [father] ). In review of the barriers to participation,
technology difficulties (e.g., inability to log-in) as well as family and work-related issues were cited. The most common barrier for participation was a lack of time in daily life. Interestingly, while it was assumed the asynchronous nature of the online discussion group would facilitate postings at the participants’ preference, time zone differences were cited as barriers due to website maintenance and the large disparity between awake times of some participants. The protective processes put in place (e.g., pseudonyms, counterfeit email addresses) prevented access to other participants but also prevented notification that others had responded to a posting or had posted a new idea. As mentioned previously, 100% of the mothers were interested in continuing participation in an online discussion group. Additionally, a majority of the mothers (69%) specifically recommended the use of a private/closed Facebook™ group as a future forum.

In summary, mothers found the online discussion groups more useful than fathers but both groups were not satisfied with their level of participation at two or less visits to the groups per week. Factors that increased participation included the incentives, the access to new information and ideas, as well as the recognition that parents were not alone and others shared their struggles in similar situations. Barriers to participation included family and work-related issues along with time constraints of daily life. Technology barriers included difficulty accessing through different devices and password challenges. The protective aspects that were necessary for anonymous participation proved to limit integration of the online discussion group into daily life. Notification of postings and responses is a typical feature of online groups and this feature was inoperative for this study. A hallmark question asked of support group participants is whether they would recommend the experience to others. A vast majority (93% of mothers and 86% of fathers) reported they would make that recommendation.
Chapter 5
Discussion

Families of young children newly diagnosed with an autism spectrum disorder (ASD) pursue answers and understanding of the lifelong disability. In their quest for information and support, parents seek others in similar circumstances and are well-suited for support group participation (Mackintosh, Myers, & Goin-Kochel, 2006; Mandell & Salzer, 2007; McCabe, 2008; Murray, Ackerman-Spain, Williams, & Ryley, 2011). Yet there is limited research exploring the use of support groups by parents of young children with ASD, particularly in the stressful time period following diagnosis (Davis & Carter, 2008). Likewise, the literature on parents of children with ASD has not delved into the creation of online supportive networks for families new to the diagnosis.

The primary purpose of this research study was to examine the effectiveness of online discussion forums for parents of young children (prior to entry in kindergarten) recently diagnosed with ASD. The online discussion groups provided a protected setting for parents to share difficulties and delights about parenting their children with ASD and offered reliable information and support to enable parents to address the current challenges they faced. In addition, a major intention of this research study was to identify methods and strategies useful for designing future online parent support groups for families of young children with ASD.

Four research questions were addressed in this study, with a focus on the needs of parents of young children with ASD. First, the study examined the topics of information that parents sought during the preschool years and whether the kinds of information differed based on salient factors (e.g., parent gender, parent age, child gender, and family SES). Of the 16 possible topics for discussion presented, both mothers and fathers indicated communication skills, following directions, making transitions, and diet and eating as important or highly important topics for
discussion. The traits and behaviors exhibited by young children with ASD (e.g., difficulties in communication and social interaction) are a common theme in the literature (Baker-Ericzen, Brookman-Frazee, & Stahmer, 2008; Herring et al., 2006). Paul (2008) described that formal testing of young children with ASD reveals language comprehension skills to be as low as expressive language skills, and that both are significantly delayed relative to chronological and mental age. Parents’ priority of discussion of communication skills in this study’s online forum was expected, given that spoken language deficits, a primary symptom of ASD, was already a focus of therapeutic services being received by all families. Yet the inability of young children with ASD to comprehend the language needed to follow directions and make transitions to new activities may be unexpected. Paul noted that language comprehension is often limited to one or two words per utterance and children in the preschool years have become adept at doing requested actions they were likely do anyway. Out-of-context requests are another matter and safety issues (e.g., not going into the street) become priorities in the mobile and independent preschool years.

Interestingly, mothers and fathers ranked communication devices as a topic of low importance. With all of the children in the study receiving speech therapy services, parents clearly were aware of the speech delays associated with ASD, but may have felt uneasy about discussions focused on augmentative and alternative communication (AAC) devices prior to entry into kindergarten. This reluctance may be based on a fear that the use of an AAC device could impact oral language development. According to Lord and McGee (2001), there is disagreement in the speech and language field whether to use AAC devices to train speech and language in nonverbal young children with ASD. However, both mothers and fathers described
picture communication systems and sign-language woven into their conversations on following directions and making transitions.

When comparing the parents’ survey responses, more mothers than fathers selected the topic of sleeping as important or highly important. Transcripts of the mothers’ discussions indicated the poor sleeping habits of the children in the study had a definite impact on the mothers (“I’m one sleepy mommy!” [Selena]). Hoffman and colleagues (2008) found that the sleep problems of children with autism adversely affected family function and contributed to their mothers’ levels of stress. With mothers as the primary caregiver of young children with ASD, it can be suggested that they are the ones who experience disrupted sleep and have a strong need to talk to others in the same circumstance.

In the open-ended survey question, a discussion on toilet training was requested by nine of the mothers and two of the fathers, confirming the difficulties in this daily living skill for children with ASD, as described by Lord and McGee (2001). Bailey (2008) reported that this skill joins the typical adaptive skill repertoire of feeding, dressing, sleeping, and personal hygiene skills and it can be quite challenging for children with ASD. As mothers are often the primary caregivers of young children with ASD, they are subjected to criticism for their children not reaching developmental milestones at typical times:

This is a sensitive subject for me. My son is going to be 4 on Friday and isn’t potty trained yet. I don’t care that he isn’t, what bothers me is other people who don’t understand WHY he’s not potty trained. (Rae)

In further comparisons based on child gender, mothers of girls placed a higher priority on toilet training, communication skills, understanding special education services, and following directions. Research indicates a prevalence of four boys to every girl with ASD, but a higher impairment in communication skills (Hartley & Sikora, 2009) and cognitive skills for girls (IAN
Community, 2009; Lord & McGee). Perhaps this explains the desire for discussion on understanding special education services and communication skills by mothers of girls. Notably, mothers of boys requested discussion on sensory concerns at a higher rate than mothers of girls. Johnson and colleagues (2007) noted that young children with ASD exhibit sensory symptoms more frequently than their typically developing peers and may demonstrate simultaneous hyposensitivity and hypersensitivity for stimuli in the same sensory modality (e.g., aversion to soft touch or hugs, yet insensitive to pain). Rivet and Matson (2011) noted an absence of research exploring gender differences in core symptoms of ASD, which suggests the need for more study of possible gender links to sensory concerns.

For the mothers receiving state or federal assistance, understanding special education services, following directions, and managing challenging behaviors were ranked as highly important topics for discussion. In their own lives, mothers receiving assistance from state or federal agencies are required to understand these complicated systems of financial and health support and this may be extended to a need to understand the complex system of special education services in order to fully access supports that cannot be personally afforded. Research into the financial effects of raising a child with ASD is sparse, but a recent study indicates that families of children with ASD are at risk for having unmet therapy care needs due to high costs, lack of insurance coverage, or general healthcare plan problems (Chiri & Warfield, 2012). Navigating the world of early childhood special education services for young children, much like government assistance programs, requires persistence and personal motivation (Wessely, Buysse, & Tyndall, 1997). This may be a difficult task when living under the strain of financial hardship.

In an additional analysis, mothers over the age of 36 years ranked communication skills, following directions, diet and eating, and sleeping at a higher level of importance when
compared to younger mothers. The basic life survival skills of eating, sleeping, and communicating wants and needs may be a higher priority to an older mother whose view may be to a future time when she is not present (“Her ability to achieve a level of communication and self-care that will allow her to live independently.” [mother]). Parent priorities should be a guiding force for any online discussion group. Likewise, it is important to recognize that different ages and life stages of both parents and children affect a family’s priorities at any given time point.

Over the course of the research study, mothers averaged 29 unique discussion postings each, while fathers averaged 20 postings each. However, fathers engaged in more “lurking” behavior (viewing without posting) with an average of 86 views as compared to mothers with an average of 77 views. This interesting phenomenon in online discussion groups may allow parents’ feelings to be validated without having to disclose them to others (Mickelson, 1997). Bragadóttir (2008) reported that most fathers never wrote messages to the computer-mediated support group but they found messages, suggestions, and advice from others helpful. It is important to recognize silence does not necessarily mean disengaged. The current study suggests that fathers may be content to observe and process new information instead of actively participating in the conversation.

The second research question regarding current sources of support was addressed by parents in the second online survey. AutismSpeaks.org® was the most often listed website for pertinent information about ASD for both parent groups. In addition, mothers visited blogs created by other mothers and websites of regionally-based autism programs, while fathers visited medical-based websites. AutismSpeaks.org®, self-described as a computer online service, is the world's largest autism advocacy organization supporting efforts in autism research, awareness,
and outreach activities aimed at families, governments, and the general public (Autism Speaks™, 2013). In addition to online support, parents’ perceptions of the extent to which specific persons and programs were helpful were examined using the Family Support Services Scale (FSS; Dunst, Trivette, & Hamby, 1994). While Boyd (2002) described the use of the FSS in a literature review on maternal stress and young children with autism, the current study presented the FSS in an online survey format, the first of its kind. In similar patterns, mothers and fathers described high levels of helpfulness from spouses, early childhood intervention programs, and professional helpers (e.g., social workers, therapists, and teachers). This data provides validation of the usefulness of spousal support in family interventions as well as the effectiveness of professional personnel most versed in the child’s needs associated with ASD. Conversely, both mothers and fathers described low levels of helpfulness associated with their spouse’s or partner’s friends, other parents, co-workers, social groups and clubs, church members and ministers, and parent groups. These sources of high and low levels of helpfulness mirrored findings from a research study by Wang and Michaels (2010) that used a modified version of the FSS survey with Chinese families of children with severe disabilities. The described low levels of helpfulness of other parents and parent groups counters the findings of an online study by Stewart and colleagues (2011) that suggests these are supports most desired by parents of children with asthma and allergies. A closer look into the FSS results in the current study revealed that a number of the mothers and fathers did not have access to other parents (47% and 57%, respectively) or parent groups (47% and 71%, respectively). In this study, a unique finding of statistical significance was that mothers rated both their own friends and professional agencies as more helpful than was reported by fathers. This finding echoes Carpenter and Towers’ (2008) study where they
interviewed fathers of young children with disabilities and found only 14% described a comprehensive network of support that included their own friends.

In answer to the third research question on the types of support-intended postings parents used in online discussions, behavior codes developed by Cutrona and Suhr (1922) and refined by Coulson and Greenwood (2011) were applied. Among the subthemes identified in the current study, the mothers used Emotional Support-Understanding and Sympathy statements to commiserate and convey emotional feelings for situations faced by peers. As King and Moreggi (1998) noted, members of self-help and mutual-aid groups often participate with the expectation of receiving emotional support, in addition to sharing experiences and finding new ways to cope. Likewise, Meadan and colleagues (2010) found support groups were an important source of emotional support for parents of children with ASD. Based on the literature, the question emerges as to why fathers did not engage in emotional support statements in the online discussion group. Perhaps the need for emotional support is not a priority whereas informational support and companionship as in the Network Support-Companions statements are preferred. Conducting online discussion groups requires that the facilitator, particularly when not of the same gender as the participants, recognizes the appropriate style of supportive phrases to meet the needs of the participants.

In a similar vein, Esteem Support-Validation statements were used by both parents to express agreement with the views of others and included short phrases like “I agree.” Yet only mothers used Esteem Support-Compliment statements to congratulate, praise, and point out positive things about other participants. In their study of parents of children with autism in an email group, Huws, Jones and Ingledew (2001) described esteem and emotional support as a sense of concern and caring towards each other conveyed in message postings. Furthermore, they
suggested association with the email group resulted in parents deriving a sense of being cared for, esteemed, and valued. These may be beneficial feelings for a mothers’ online discussion group but may not be in keeping with social interaction behavior expected between fathers who are strangers.

In this study’s new subtheme of Sharing Statement-Information, the largest number of parents participating and the largest number of postings were identified. These statements were informational and explanatory, often occurred in response to the discussion topic, and did not offer advice or suggestions. In a research study of an online group for fathers of children with spina bifida, Nicholas and colleagues (2003) described this statement style as a “story genre.” Fathers expressed themselves through the telling of their personal stories, and seemed to convey a heightened kinship in providing information through this storytelling. Further, Nicholas and colleagues noted that information sharing served as a means of building a foundation for the group. Frequently, in the current father discussion group, the conversation involved sharing concrete or factual information with others in the group. These attempts to give and receive information added to the father’s knowledge and the literature suggests it could ultimately ease a father’s challenge or burden when raising a child with a disability (Nicholas et al.).

Similar to a study by Huws and colleagues (2001), the final subtheme used humor to describe the experiences faced in caring for a young child with ASD. This lightheartedness of humorous messages has been thought to be a factor in people continuing to use the online groups (Fletcher & St. George, 2011; Huws, Jones, & Ingledew). Both mothers and fathers in the current study used Building Relationships through Humor statements to lighten the mood of the heavy topic under discussion. Humor in discussion statements was expressed through unusual turns of phrase, funny analogies, acronyms, and emoticons.
In this study, the communication style, content, and structure of the online discussions provided important clues for effectively facilitating online groups. As suggested by Nicholas and colleagues (2003), inviting stories and humor appears necessary in online groups for men. The use of emotionally-charged or overly complimentary conversations may need to be toned-down or introduced with information-based material. Facilitators might need to model these storytelling or humorous approaches to demonstrate that discussion group participation does not need to be overly emotion-laden.

The final research question was addressed through the use of a post participation survey. Parent participants responded to questions regarding their satisfaction in their use of the online discussion group as well as the factors that promoted and prevented their participation. Mothers and fathers reportedly accessed the online discussion groups two or less times per week and categorized their participation at a medium level. Interestingly, mothers and fathers were not satisfied with their level of participation, citing lack of time, family and work related issues, and technology difficulties as barriers to participation. As Canary (2008) reported, residential location can play a significant role in support groups and a difficulty was noted by one participant who lived multiple time zones away from the majority of the participants. She regularly felt she came to the conversation too late to participate. Likewise, the asynchronous nature of the groups permitted posting at a time convenient for the participant, but questions posted could take a day to receive a response. Mothers found the online discussion groups more useful than fathers, but both indicated they would recommend online discussion groups such as this one. In response to an open-ended question, the access to new ideas, the presence of others in a shared situation, and the sense of belonging to a supportive community were reasons mothers found participation useful. Fathers noted the access to others’ experiences and
perspectives, and the contact with others sharing the same challenges as reasons the online groups were useful. Factors that increased participation, according to the parent participants, included the incentives, the access to new information and ideas, and the recognition that they were not alone and others shared their struggles.

The protective aspects of the online discussion groups (e.g., pseudonyms, password protected site, counterfeit email addresses) were necessary to ensure anonymous participation and permitted participants to speak openly without concern for spousal censure or group criticism of less than perfect English writing skills. Conversely, these same protections limited the integration of the online discussion group into daily life with notification of postings and responses, a typical feature of online forums. Despite these difficulties, parents agreed they would recommend the discussion group experience to others.

Limitations of the Study

This study has several limitations that must be considered when interpreting the results. Caution should be used when interpreting the statistical results of analyzes due to the small sample size. Likewise, the sample size and the homogeneity of race/ethnicity of the participants impact the ability to generalize the results. Further, there are potential biases associated with a purposive sample of parents of young children with ASD who agreed to participate in online discussion groups. These parents may have characteristics different from non-participants who are parenting young children with ASD. This may be especially true for the fathers in this study as they were not self-selected but joined at the recommendation of their wives. While there is a historic challenge in recruiting fathers of children with ASD to research studies (Johnson, Frenn, Feetham, & Simpson, 2011), there is a need to continue efforts to discern ways to provide social
support, including online support, to men (McCabe, 2008). As mentioned previously, fathers of young children with ASD are more likely to report stress when compared to fathers of children with other disabilities and children who are typically developing (Hastings et al., 2005). Results from this study confirm that “even parents of the same child may well have different experiences and views” (Johnson et al., p. 249).

The researcher acknowledges that incentives provided by the $20 Amazon® gift cards received for completion of each of the three online survey questionnaires and the random drawings for iPod Shuffles® may have impacted parent feedback regarding the usefulness of the online discussion groups. However, the survey used to elicit responses on the usefulness of the online discussion groups contained honest comments explaining why participants had not posted often (e.g., “Wish I could have contributed, but it would not have been meaningful.” [dad]). Bronte-Tinkew, Burkhauser, and Metz (2012) reported the use of incentives as a “promising practice” to encourage father participation in support programs.

The use of a protected university website for the online discussion forum had benefits and drawbacks. Parents were able to participate anonymously but were required to enter through a password protected gateway that required remembering pseudonyms and passwords. Technical support was timely (e.g., resetting passwords, log-in assistance) but maintenance on the university website often occurred in late evening hours, limiting access for some parents. Nevertheless, the visual display of threaded discussion conversations, the continued access to previous discussion forums, and the accessibility to posted materials were all beneficial. Parents expressed a desire to have email alerts for posting from other participants typically used in discussion forums but this system was inoperative.
A framework analysis approach supports the use of a predetermined coding system for analyzing themes of support-intended postings, making it convenient and accessible to others for review and replication. However, there is some concern that the constructs defined may not be suitable for the population being studied. For example, *Emotional Support-Understanding (Empathy)* statements were not used by the participating fathers, based on the coding definition. Yet it is difficult to believe fathers do not use this emotion and future research should delve into whether and how this emotion is expressed through the written word. Along a similar line, the Likert scale used to survey parent preferences of topics for discussion included “highly important” and “important” selections. The degree of difference between the two can vary according to who is completing the survey. Combining the two categories to ensure the identification of parent priorities of topics for discussion is warranted.

**Implications for practice**

Following a young child’s diagnosis of ASD, parents seek information and answers. The literature indicates that families of young children with disabilities respond best to support programs that include collaborative relationships between parents and professionals (Canary, 2008). In addition, a facilitator or moderator of discussion is needed to sustain an online support group (Trondsen and Sandaunet, 2009). Parents new to the diagnosis often have not had the opportunity to become involved in autism advocacy organizations, as demonstrated by the absence of families of preschooler with ASD at the local Autism Walk, an initial recruitment strategy. At a time when life is in flux, online parent discussion groups can provide useful information and attentive companions who are experiencing similar challenges. Online recruitment through social media websites, particularly those focused on family support, and one-to-one invitations from teachers and therapists have the highest return.
Parents value the therapists and teachers who work with their children and families. When these professionals are well-versed in child development and the challenges associated with ASD in early childhood years, they provide an invaluable support to parents and families. Collaboration between parents and thoughtful professionals increases the competence and confidence of the caregivers and is critical for optimal outcomes for young children with ASD. In addition, both mothers and fathers depend on their spouses for support in raising their children. Respite care and other strategies used to strengthen the bond between parenting partners should not be overlooked.

In developing online discussion groups, parents need to be able to choose the topics for structured discussion while having an open discussion forum available to converse on current life events and concerns. Traditionally high interest topics should be considered: communication skills, following directions, making transitions, diet and eating. The current study indicates parents are able to generate additional topics in the weeks following the start of the group. Flexible discussion planning to accommodate these new topics should be considered.

It is essential for the discussion group facilitator to frequently visit the conversations and provide the materials and requested research information. Yet, it is equally critical to allow the conversations to evolve and develop with the input from the participants. Difficult topics are discussed in forums such as this and participants often have unique perspectives and suggestions to contribute. Insight gained from the perspectives of others in similar circumstances is the reason parents cite for initially joining the group.

Implications for research

The topics for the online discussion forums were guided by the literature and were successful in encouraging mothers’ conversational postings. The additional “What’s on your
mind…” weekly forum encouraged meaningful discussions for the mothers but did not elicit the same from the fathers. Future research should examine the topics pertinent to fathers’ concerns when raising preschoolers with ASD. Brief conversations on the fathers’ discussion forum revolved around the expenses and insurance coverage of specific behavior therapy interventions, computer applications for iPad® and other touch screen devices, and the use of DAN (Defeat Autism Now!) Doctors for dietary concerns. Perhaps parent participants could be questioned at the midpoint of the online groups for suggestions of additional topics. In addition, a topic expert could be invited to respond online to the questions and discussion, acting as a facilitator on a weekly topic.

Optimal longevity of the online discussion groups is an area for future research. Clearly in this research study, mothers wished to continue to participate. Yet a support group evolves over time and the needs of parents raising young children change as well. Future studies should consider whether a group is most effective when the membership is maintained or when new members are added and families exit as their children transition into school. Experience from this study indicates that 15 participants was a manageable group but further research should explore the ideal group size for sensitive discussions while maintaining a variety of viewpoints. The goal of this online discussion group forum was to address the unique needs and concerns of parents of preschoolers with ASD. While three of the 22 participants were members of minority groups, English was the required language for participation and multicultural perspectives on child-raising were not evident in the discussions. Future research should explore the creation of alternate language discussion groups as well as target recruitment efforts to include more parents from minority groups.
Future research should consider measurement of the effectiveness of the online group discussion. Clearly, parents in the current study would recommend participation in an online discussion group such as this. Yet additional measures of effectiveness could include measures of involvement. For example, some fathers responded that their wives “takes care of that” on topics such as understanding special education services and toilet-training. Likewise, in the final survey one father noted, “The Dads didn’t seem like they spent too much time with their kids and were relating what their wives told them.” Identifying ways to increase parent competence and confidence in their roles as caregivers would be worthwhile.

**Conclusion**

In summary, this investigation of online parent discussion groups was unique in targeting mothers and fathers of preschoolers with ASD. Recruitment challenges and suggested practices were identified for future replication. Identifying discussion topics relevant to parents of young children prior to their entry into kindergarten begins to address the informational needs critical to coping with diagnosis. Materials collected for discussion topics could be downloaded and used in face-to-face parent groups, in addition to the online groups. Mothers and fathers have distinct perspectives and communication styles when participating in supportive online environments and this study provides guidance to practitioners focused on using a family-centered approach in their work. The identification of persons and programs that parents consider helpful through an online version of *Family Support Services Scale* (FSS; Dunst, Trivette, & Hamby, 1994) is new with this study. Service providers can use this information from the FSS to improve partnerships with supports considered useful (e.g., spouses, teachers, and therapists) as well as consider
strengthening and improving supports considered not helpful (e.g., church members and ministers, and parent groups).

It was hoped that individual participants would find benefit from the online discussion forums and that practitioners working with families of young children with autism spectrum disorders would benefit from the information that resulted from this research study. As all mothers indicated a desire to continue meeting as a group, a closed/private Facebook™ group was created and 11 of the mothers have joined. Five self-selected fathers have contacted the researcher for participation in the study, a full year from the initial recruitment effort. This indicates there is interest in this style of online support, but future recruitment of fathers of young children with ASD needs to focus on venues and agencies that already have access to this unique population.

Benefits to the participants of the research study included informal social support gained from a discussion forum with parents sharing similar areas of concern when raising young children with autism spectrum disorders. The literature suggests that discussion groups can have an empowering effect on families during difficult times in their lives (Banach, Iudice, Conway, & Couse, 2010; Baum, 2004; King, Stewart, King, & Law, 2000). The potential benefits of an improved understanding of the concerns and difficulties faced by parents of young children with ASD on a daily basis are important for practitioners who work with these families. Spouses, teachers, and therapists were identified as helpful to parents raising young children with ASD. By identifying the importance of the support-giving role of these people, parents of young children with ASD recognize the value of partnerships when raising their children.
It is hoped that the research study has identified valuable information concerning some of the areas for improving support for parents and will serve as a guide for the development of future online parent discussion groups.
References


Differences among breast and prostate cancer online support groups. *Computers in Human Behavior, 26*, 1400-1404.


Gundersen, T. (2011). ‘One wants to know what a chromosome is’: The Internet as a coping resource when adjusting to life parenting a child with a rate genetic disorder. *Sociology of Health & Illness, 33*(1), 81-95.


van Uden-Kraan, C. F., Dossaert, C. H. C., Taal, E., Lebrun, C. E. I., Drossaers-Bakker, K. W.,


*We are looking for mothers and fathers of a child (not yet in kindergarten) who has an autism spectrum disorder.

*We encourage the participation of fathers and mothers in gender-divided online discussion groups with other parents of young children with an autism spectrum disorder.

*Enrollment in the study is free and Amazon® gift cards are available for participants who complete all the study requirements. 4 iPod Shuffles® will be given away in random drawings throughout the 12 weeks of participation.

If you are interested in participating in this study, please contact:

Laurie Jeans  phone: 217-493-6670  email: ljeans2@illinois.edu
Recruitment Forms

Email invitation to participate:

Dear Parent,
I am a doctoral student in the Department of Special Education at the University of Illinois at Urbana-Champaign. I am recruiting parents, both mothers and fathers, and I would like to invite you to participate in my research study exploring the use of online discussion groups for parents of young children with an autism spectrum disorder.

You may participate if you are a parent of a child with an autism spectrum disorder, who has not yet entered kindergarten.

We will be conducting parallel online discussion groups based on parent gender and both mothers and fathers are encouraged to participate.

Each participant in the online discussion groups will be asked to have access to a computer for approximately 20 minutes per week for 12 weeks to post a message to a discussion board. Names and information gathered throughout the study will be kept confidential and access to the discussion group will be password protected.

Enrollment in the study is free and Amazon® gift cards are available for participants who complete all the study requirements. Four iPod Shuffles® (for each group) will be given away in random drawings throughout the 12 weeks of participation.

If you would like to participate in this research study, please email me at: ljeans2@illinois.edu
If you have any questions, please contact me at ljeans2@illinois.edu or call me at (217) 493-6670.
Or my advisor, Dr. Amy Santos at rsantos@illinois.edu or (217) 333-0260.

Thank you for your consideration,

Laurie Jeans

Sample Newsletter Advertisement

<table>
<thead>
<tr>
<th>Participate in a Parent Research Study</th>
</tr>
</thead>
<tbody>
<tr>
<td>If you are a parent (mother or father) of a young child with an autism spectrum disorder (who has not yet entered kindergarten), you are invited to participate in a research study exploring the use of online discussion groups for parents of young children with an autism spectrum disorder. We will be conducting parallel online discussion groups based on parent gender and encourage fathers and mothers to participate. Parents will be asked to post to the online discussion groups once a week for 12 weeks. Amazon® gift cards are available for each parent who completes the study requirements and 4 iPod Shuffles® (for each group) will be given away in random drawings throughout the 12 weeks. If interested, please contact Laurie Jeans at <a href="mailto:ljeans2@illinois.edu">ljeans2@illinois.edu</a> by (date).</td>
</tr>
</tbody>
</table>
April 20, 2012

In the News

Autism Website Seeks
Transition Success Stories- PRNews

'Seclusion rooms' for autistic students raise questions- USA Today

Insurance coverage for autism is law- Detroit Free Press

Study of Half Siblings Provides Genetic Clues to Autism- University City Patch

About...

TAP Central Office
Noll Medical Pavilion
5220 S. Sixth Street Rd.
Suite 1700
Springfield, IL 62703

Phone: (217) 525-8332
Fax: (217) 789-1420

From the Desk of Bronwyn Rains

"The road of life twists and turns and no two directions are ever the same. Yet our lessons come from the journey, not the destination." - Don Williams, Jr.

Linda Tortorelli, center director at UIUC asked that I speak to a current study that is occurring at UIUC. The Department of Education is looking for male and female parenting partners of a child under the age of 4 years, who has a diagnosis of ASD. The department would like the participation of both parents in online discussion groups with other parents of young children with ASD. Enrollment in the study is free and Amazon gift cards are available for participants who complete all the study requirements. If you are interested please contact: Laura Jeans, 217-493-6670 or ljeans2@illinois.edu. This study appears to focus on building parent networks following the diagnosis of ASD.

This week, Tara Glavin and I were able to observe a 2 hour first responder training offered though CIT in Urbana. Both Karla Doepke and Linda Tortorelli did a great job presenting. Tara and I have some definite ideas of how this training could be improved upon and will move toward a task force later this spring or early summer to get that started.

The new rotation for the center presentations begins this week. We look forward to hearing from the Hope service center this week.

News from the TAP at the Hope Institute

Spring 2012 Social Skills groups are in full swing in our clinic. We are currently running 12 different groups of children and youth aged 3-18. We have had the opportunity to implement the full round of SS Grin curricula and are thankful to have this tool in our belt. We have a large retention rate among our social skills clients and it has been a challenge to create and/or adapt existing materials so that we can teach necessary skills while making the material novel enough to be of interest to group participants. I think that in terms of TAP social skills programming there is never a crowd at the leading edge and all of our centers are blazing trails!
Appendix B

Participant Consent Form

Department of Special Education
College of Education
288 Education Building, MC-708
1310 South Sixth Street
Champaign, IL 61820

Dear Parent,

I am very excited that you have indicated your willingness to participate in the UIUC Online Parent Discussion Groups Research Study for Parents of Young Children with Autism Spectrum Disorders. I appreciate your willingness to contribute your thoughts and concerns about raising young children. I believe you will benefit from the discussion with other parents as we discuss topics of importance and interest in the online father and mother discussion groups. It is my hope that all participants will derive personal benefits from participating in this study.

I have enclosed a participant consent form for you to read and sign. Please return your consent forms to me in the stamped, addressed envelope. These consent forms are required in order to participate in research through the University of Illinois at Urbana-Champaign.

Please call (217) 493-6670 or send me an email at ljeans2@illinois.edu if you have any questions about the consent forms or the research study.

Sincerely,

Laurie Jeans
Laurie Jeans
Dear Parent,

This research study conducted by Dr. Rosa Milagros Santos, Professor in Early Childhood Special Education, and Ms. Laurie Jeans, a doctoral student in the Department of Special Education, is designed to learn about the challenges and concerns of parents who are raising young children with autism spectrum disorders. Dr. Santos has been a member of the University of Illinois faculty for several years. She is engaged in research and teaching activities that focus on supporting parents of young children with disabilities and delays. More information about Dr. Santos is available on her web site: http://education.illinois.edu/frp/s/rsantos

We are inviting you to participate in this particular research project which is part of Ms. Jeans’ doctoral dissertation. In this project, you are asked to participate in all of the following tasks:

1. Complete the online Initial Recruitment Survey Questionnaire on Survey Monkey® prior to participating in the Online Parent Discussion Groups. The survey is expected to take less than 15 minutes.

2. Complete the online Current Services and Supports Survey Questionnaire (including the Family Support Services Scale) on Survey Monkey® after participating for a month in the Online Parent Discussion Groups. The survey is expected to take less than 15 minutes.

3. Complete the online Post Participation Survey Questionnaire on Survey Monkey® following 12 weeks of participation in the Online Parent Discussion Groups. The survey is expected to take less than 15 minutes.

4. Have access to the Internet via computer (personal or public) for each parent participant. Access to one computer is sufficient, since access to the separate online discussion groups will require a password and participation is at a time convenient for the parent. Engaging in the online discussions will require approximately 20 minutes time per week for 12 weeks.

5. Parents will participate in an online (via computer) father or mother discussion group that focuses on topics related to raising young children with autism spectrum disorders. Each week, a new topic will be added to the discussion board via the Internet for a total of 12 weeks. You will be asked to sign a confidentiality agreement describing appropriate conduct for the online discussion group.

6. Parents are expected to post a message on the discussion group at least once a week.

You, as a parent participant, will receive one online $20 Amazon® gift card after completing each of the 3 survey questionnaires listed above (total value--$60). As an added incentive, every 3 weeks of the discussion groups, an iPod Shuffle® (value of $50) will be given away in a random drawing for a total of 4 iPod Shuffles® given away in each discussion group. Each message posting by a parent is equal to one chance to win an iPod Shuffle®. So increased postings will increase chances to win.

August 1, 2012
Participant Consent Form

Although we hope you will be able to participate for 12 weeks, your ongoing participation is strictly voluntary. We do not anticipate any risk greater than what is experienced in normal life. You are free to stop participating at any time and for any reason. You are also free to refuse to answer any questions you do not wish to answer.

The risks associated with participating in our study are no greater than those encountered in daily life. Individual participants may benefit from the discussion activities in this study and others working with families of young children with autism spectrum disorders may benefit from the information that results from this research study. We hope you will enjoy the opportunities for social interaction with other parents raising young children with autism spectrum disorders. If the researchers feel a parent is unusually stressed, we will contact the parent offline and confidentially, to see if they would like immediate access to resources. Additionally, the parent participants can contact the researchers with questions or concerns.

Your name and identifying information will not be used in any publication or presentation of this research. Pseudonyms will be used for any identifying information in the sharing of the research results in an academic paper, journal article and/or conference presentation.

You will receive a copy of the research results after this project is completed, should you request one. All the information obtained from this research project will be kept strictly secure and confidential.

Please indicate below whether you give your consent to participate in this project. Please keep one copy of the consent form for your files and mail the other (with your signed consent) in the enclosed envelope.

If you have any questions about this research project, please contact Ms. Laurie Jeans by telephone (217) 493-6670 or by email at ljeans2@illinois.edu. You may also contact Dr. Santos (217) 333-0260 or by email at rsantos@illinois.edu or Dr. Anne S. Robertson by telephone (217) 333-3023 or by email at arobrtsn@illinois.edu at the Office of School University Research Relations for any questions about your rights as a research participant.

Sincerely,
Laurie Jeans, Ed. M.     Rosa Milagros Santos, Ph.D.

Participant Consent Form (Keep for your records)
I have read the above information and have enough information to make a decision about participating in this study. I consent to participate in this study.

Signature:_____________________________________________________
Email address:__________________________________________________
Date:______________________________

I understand that transcriptions of the online discussion group will be printed only for the purpose of this research study. No identifying information will be used in the sharing of the research results of this project during presentation at professional meetings or in journal articles.

Signature:_____________________________________________________
Date: ______________________________

Please mark below if you would like to receive a written copy of the research results.
________Yes, I would like a written copy of the research results.
________No, I am not interested in receiving a copy of the results.
Participant Consent Form

I have read the above information and have enough information to make a decision about participating in this study. I consent to participate in this study.

Signature:_____________________________________________________

Email address:__________________________________________________

Date:______________________________

I understand that transcriptions of the online discussion group will be printed only for the purpose of this research study. No identifying information will be used in the sharing of the research results of this project during presentation at professional meetings or in journal articles.

Signature:_____________________________________________________

Date: ______________________________

Please mark below if you would like to receive a written copy of the research results.

_______ Yes, I would like a written copy of the research results.

_______ No, I am not interested in receiving a copy of the results.
Appendix C

Online Parent Discussion Group Policies

All members of the Online Parent Discussion Groups Research Study for Parents of Young Children with Autism Spectrum Disorders agree to the policies below. These policies are designed to ensure confidentiality for the families of the discussion group members.

1. To preserve the confidentiality and privacy of group participants, message texts may not be shared or used as documentation for any reason other than for this research. Usernames and passwords are unique and may not be shared. Sharing usernames and passwords violates the privacy of the relationships among project participants. A breach in the security of the online discussion group may result in restricted access to this group.

2. Refrain from posting any personal information about yourself and others. This includes names, addresses, and phone numbers in the messages posted on the website or during the online discussions. Participants are reminded that, although the site is password protected, confidential information should not be shared in this space.

3. With both parents expected to participate, participants are reminded about the need to log out when finished posting on their gender specific online discussion group.

4. Conversations in the online discussion group are accessible to all members. Participants are reminded than any online medium can never be considered completely private. Be certain to logoff the discussion group after each visit.

5. Weekly online discussions will be facilitated by Ms. Jeans, the primary researcher. The views of the facilitator and the participants in the discussion groups do not represent the views of the University of Illinois or any of its partner organizations.

6. Participants take responsibility for what they post to the online discussion group. Users participate at their own risk.

7. Explicit language that is obscene, racist, or sexist is not allowed. The researchers reserve the right to remove any posting that is deemed inappropriate. Online activity interpreted as stalking is prohibited, and such activities will be reported to appropriate authorities.

8. The online discussion texts and postings will be saved and used as data for this research project. Names will not be used in order to preserve confidentiality of participants. Your participation is voluntary and you may withdraw from participating at any time without penalty.

9. The decision to participate, decline, or withdraw from participation in this research project will have no effect on the participant’s grades at, status at, or future relations with the University of Illinois at Urbana-Champaign (e.g., faculty, staff, student, prospective student). If you have questions about your rights as a research participant in this project, please contact the University of Illinois Institutional Review Board at (217) 333-2670 (collect calls are accepted if you identify yourself as a research participant) or via email at irb@illinois.edu.

10. By posting to the online discussion group, you agree to the conditions of the Online Discussion Groups Policies. Enforcement of the terms of use is at the discretion of Dr. Santos and Ms. Jeans.

Please read the following statements and indicate your acceptance by signing below.

I have read and understand the importance of following the Online Parent Discussion Group Policies. This includes the importance of maintaining confidentiality for my family and fellow members of the online discussion group.

I am aware that the weekly online discussion will be saved and printed for use as data in this research project.

Signature:_________________________ Date:______________________
Online Parent Discussion Group Policies

Online Parent Discussion Group Policies (Keep for your records)
Adapted from the Novice Teacher Support Project-Electronic Mentoring User’s Policy, UIUC

All members of the Online Parent Discussion Groups Research Study for Parents of Young Children with Autism Spectrum Disorders agree to the policies below. These policies are designed to ensure confidentiality for the families of the discussion group members.

11. To preserve the confidentiality and privacy of group participants, message texts may not be shared or used as documentation for any reason other than for this research. Usernames and passwords are unique and may not be shared. Sharing usernames and passwords violates the privacy of the relationships among project participants. A breach in the security of the online discussion group may result in restricted access to this group.

12. Refrain from posting any personal information about yourself and others. This includes names, addresses, and phone numbers in the messages posted on the website or during the online discussions. Participants are reminded that, although the site is password protected, confidential information should not be shared in this space.

13. With both parents expected to participate, participants are reminded about the need to log out when finished posting on their gender specific online discussion group.

14. Conversations in the online discussion group are accessible to all members. Participants are reminded that any online medium can never be considered completely private. Be certain to logoff the discussion group after each visit.

15. Weekly online discussions will be facilitated by Ms. Jeans, the primary researcher. The views of the facilitator and the participants in the discussion groups do not represent the views of the University of Illinois or any of its partner organizations.

16. Participants take responsibility for what they post to the online discussion group. Users participate at their own risk.

17. Explicit language that is obscene, racist, or sexist is not allowed. The researchers reserve the right to remove any posting that is deemed inappropriate. Online activity interpreted as stalking is prohibited, and such activities will be reported to appropriate authorities.

18. The online discussion texts and postings will be saved and used as data for this research project. Names will not be used in order to preserve confidentiality of participants. Your participation is voluntary and you may withdraw from participating at any time without penalty.

19. The decision to participate, decline, or withdraw from participation in this research project will have no effect on the participant’s grades at, status at, or future relations with the University of Illinois at Urbana-Champaign (e.g., faculty, staff, student, prospective student). If you have questions about your rights as a research participant in this project, please contact the University of Illinois Institutional Review Board at (217) 333-2670 (collect calls are accepted if you identify yourself as a research participant) or via email at irb@illinois.edu

20. By posting to the online discussion group, you agree to the conditions of the Online Discussion Groups Policies. Enforcement of the terms of use is at the discretion of Dr. Santos and Ms. Jeans.

Please read the following statements and indicate your acceptance by signing below.

I have read and understand the importance of following the Online Parent Discussion Group Policies. This includes the importance of maintaining confidentiality for my family and fellow members of the online discussion group.

I am aware that the weekly online discussion will be saved and printed for use as data in this research project.

Signature: ___________________________________________ Date: ______________________
Appendix D

Initial Recruitment Survey Questionnaire

Initial Survey of Topics for Discussion

Survey Introduction

This survey is designed to gather topic information that parents and caregivers desire when raising young children with autism spectrum disorders. This information will be used to design an online parent/caregiver discussion group.

This survey was designed for parents or caregivers of young children with autism spectrum disorders across the United States. It is a part of a research study conducted by Laurie Jeans, a doctoral student and a Developmental Therapist, under the supervision of Dr. Rosa Milagros Santos, of the Department of Special Education at the University of Illinois at Urbana-Champaign.

In order to participate, you must be a parent or legal caregiver for a child with an autism spectrum disorder, who has not yet entered kindergarten.

We will be conducting parallel online discussion groups based on parent gender and encourage mothers and fathers to participate.

You will be asked some brief questions about yourself, your child, and the information topics you think are important for raising young children with autism spectrum disorder. The survey usually takes about 15 minutes to complete. Of course, you are free to skip any questions or stop taking the survey at any time.

Please be assured that your survey information and your identity will be kept confidential. Thank you for your time and thoughtful responses to the survey!

For further information, please contact:
Laurie Jeans or Dr. Rosa Milagros Santos
Department of Special Education
University of Illinois at Urbana-Champaign
288 Education Bldg.,
1310 South Sixth Street
Champaign, IL
217-333-0260
ljeans2@illinois.edu, rsantos@illinois.edu
## A. Children's Social Areas

Please tell us which topics you think are important for our online discussion group. Please mark one answer for each item:

### 1. Communication Skills

- [ ] Highly Unimportant
- [ ] Unimportant
- [ ] Neither
- [ ] Important
- [ ] Highly Important

### 2. Peer Friendships

- [ ] Highly Unimportant
- [ ] Unimportant
- [ ] Neither
- [ ] Important
- [ ] Highly Important

### 3. Sharing and Turn taking

- [ ] Highly Unimportant
- [ ] Unimportant
- [ ] Neither
- [ ] Important
- [ ] Highly Important

### 4. Communication Devices
(e.g., picture communication, assistive technology)

- [ ] Highly Unimportant
- [ ] Unimportant
- [ ] Neither
- [ ] Important
- [ ] Highly Important
# Initial Survey of Topics for Discussion

## B. Children’s School Readiness Areas

Please tell us which topics you think are important for our online discussion group.

Please mark one answer for each item:

### 5. School Screenings and Assessments
- [ ] Highly Unimportant
- [ ] Unimportant
- [ ] Neither
- [ ] Important
- [ ] Highly Important

### 6. Understanding Special Education Services
- [ ] Highly Unimportant
- [ ] Unimportant
- [ ] Neither
- [ ] Important
- [ ] Highly Important

### 7. Early Reading and Literacy Skills
- [ ] Highly Unimportant
- [ ] Unimportant
- [ ] Neither
- [ ] Important
- [ ] Highly Important

### 8. Following Directions
- [ ] Highly Unimportant
- [ ] Unimportant
- [ ] Neither
- [ ] Important
- [ ] Highly Important

### 9. Moving into Kindergarten
- [ ] Highly Unimportant
- [ ] Unimportant
- [ ] Neither
- [ ] Important
- [ ] Highly Important
### Initial Survey of Topics for Discussion

#### C. Children’s Behavior Areas

Please tell us which topics you think are important for our online discussion group.

Please mark one answer for each item:

<table>
<thead>
<tr>
<th>Topic</th>
<th>Highly Unimportant</th>
<th>Unimportant</th>
<th>Neither</th>
<th>Important</th>
<th>Highly Important</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>10. Sensory Concerns</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><em>(e.g., sensitive to sounds, sight, touch)</em></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>11. Making Transitions</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><em>(e.g., moving between activities, adjusting to changes in routines)</em></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>12. Diet and Eating</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>13. Sleeping</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
## Initial Survey of Topics for Discussion

### D. Parent and Caregiver Involvement Areas

Please tell us which topics you think are important for our online discussion group

Please mark one answer for each item

<table>
<thead>
<tr>
<th></th>
<th>Highly Unimportant</th>
<th>Unimportant</th>
<th>Neither</th>
<th>Important</th>
<th>Highly Important</th>
</tr>
</thead>
<tbody>
<tr>
<td>14. Managing Challenging Behaviors</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>15. Working with Therapists/Teachers</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>16. Interacting with People in the Community</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

17. What other topics would you like to see discussed (e.g., potty-training, tantrums, self-injury)?

### Initial Survey of Topics for Discussion

#### Family Demographics

We would like to get to know a little bit about your family.

**18. Please take a moment and fill out the following information about all of your children.**

**Child 1**
- Child's gender (male/female)
- Child's birthday (mm/dd/yyyy)
- Child's race/ethnicity (White, Black/African American, Hispanic/Latino, Asian, Native American, Other)
- Does Child have a Disability? (Yes/No)
- If so, what? (Name of disability)
- Age at diagnosis of disability (Years)

**Child 2**
- Child's gender (male/female)
- Child's birthday (mm/dd/yyyy)
- Child's race/ethnicity (White, Black/African American, Hispanic/Latino, Asian, Native American, Other)
- Does Child have a Disability? (Yes/No)
- If so, what? (Name of disability)
- Age at diagnosis of disability (Years)

**Child 3**
- Child's gender (male/female)
- Child's birthday (mm/dd/yyyy)
- Child's race/ethnicity (White, Black/African American, Hispanic/Latino, Asian, Native American, Other)
- Does Child have a Disability? (Yes/No)
- If so, what? (Name of disability)
- Age at diagnosis of disability (Years)
## Initial Survey of Topics for Discussion

### Child 4
- **Child's gender (male female):**
- **Child's birthday (mm/dd/yyyy):**
- **Child’s race/ethnicity (White, Black/African American, Hispanic/Latino, Asian, Native American, Other):**
- **Does Child have a Disability? (Yes No):**
- **If so, what? (Name of disability):**
- **Age at diagnosis of disability (Years):**

### Child 5
- **Child's gender (male female):**
- **Child's birthday (mm/dd/yyyy):**
- **Child’s race/ethnicity (White, Black/African American, Hispanic/Latino, Asian, Native American, Other):**
- **Does Child have a Disability? (Yes No):**
- **If so, what? (Name of disability):**
- **Age at diagnosis of disability (Years):**
23. What is your race/ethnicity? Please mark all that apply.

- White
- Black/African American
- Hispanic/Latino
- Asian
- Native American

Other (please specify)

24. What is your gender?

- Female
- Male

25. How many people currently live in your household?

26. What is your marital status?

- Never Married
- Married
- Divorced
- Separated
- Living with Partner

27. What is the highest level of education you have completed?

- Some high school
- High school graduate
- Technical or associate degree
- Bachelor degree
- Graduate/professional degree
Initial Survey of Topics for Discussion

28. Does your family participate in any of the following state or federal assistance programs?
   Please mark all that apply.
   - [] WIC (nutrition supplement for Women, Infants, and Children)
   - [] SNAP (Supplemental Nutritional Assistance Program)
   - [] Food Stamps
   - [] CCAP (Child Care Assistance Programs)
   - [] Subsidized child care
   - [] TANF (Temporary Assistance for Needy Families)
   - [] None
   Other (please specify) _______________________________________________________

29. Do you know another parent of a young child with an autism spectrum disorder who would be interested in participating in our online discussion group?
   - [ ] Yes
   - [ ] No

30. If Yes, please provide contact information for that person.
   Name ____________________________________________
   Email address __________________________________
   or Phone number ________________________________
# Initial Survey of Topics for Discussion

## Thank You!

Thank you for your participation!

Please follow the directions below to register for your free $20 Amazon Gift Card!

### 31. Please enter your email address

**Email Address:** __________
Appendix E

IRB Approval

April 11, 2012

Laurie Jeans
Special Education Department
College of Education
1310 S. Sixth Street
MC-708

Dear Laurie,

On behalf of the College of Education Human Subject Committee, I have reviewed and approved your research project entitled “Family Empowerment: The Use of Online Parent Discussion Groups following Diagnosis of ASD in Young Children”. I find that this project meets the exemption criteria for federal regulation 46.101(b) 2 for research involving normal interviews and observation procedures where the identifying information is protected.

No changes may be made to your procedures without prior Committee review and approval. Your project number is 5077 and projects are typically approved for three years with annual reports required. You are also required to promptly notify the Committee of any problems that arise during the course of the research.

Best regards,

Anne S. Robertson
College of Education Human Subjects Review Committee

Dr. Rosa Milagros Santos
Appendix F

Current Services and Supports Survey Questionnaire

Second Survey: Current Services and Supports

This survey is designed to gather information about the community services and supports used by families of young children with autism spectrum disorders.

You will be asked some brief questions about community services and supports that you, your family, and your child use. The survey usually takes less than 15 minutes to complete. Of course, you are free to skip any questions or stop taking the survey.

Please be assured that your survey information and your identity will be kept confidential. Thank you for your time and thoughtful responses to the survey!

For further information, please contact:
Laurie Jeans or Dr. Rosa Milagros Santos
Department of Special Education
University of Illinois at Urbana-Champaign
288 Education Bldg., 1310 South Sixth Street
Champaign, IL
217-333-0280
ljeans2@illinois.edu; rsantos@illinois.edu
Second Survey: Current Services and Supports

1. Your Gender
   - Male
   - Female

2. Your Age (in years)
   

3. Please mark all that apply

What services, if any, does your child(ren) with autism spectrum disorder receive? (This refers to your child who is the target age of our study--before kindergarten)

- [ ] speech therapy
- [ ] occupational therapy
- [ ] physical therapy
- [ ] developmental therapy
- [ ] behavior therapy (e.g., ABA therapy)
- [ ] nutritionist or dietician services
- [ ] none

Other (please specify)

4. Does your child have an...

- [ ] IFSP (Individualized Family Service Plan)
- [ ] IEP (Individualized Education Program)
Second Survey: Current Services and Supports

Sometimes parents of children with autism spectrum disorder participate in services and supports for themselves.

5. Which of the following services and supports do you participate in?

- [ ] counseling
- [ ] respite care for children with autism
- [ ] face-to-face support groups
- [ ] online support groups (NOT including this online discussion group)
- [ ] community parenting groups
- [ ] religious or prayer groups
- [ ] none

Other (please specify)
Current Services and Supports Survey Questionnaire

Second Survey: Current Services and Supports

Family Support Scale (Dunst, Jenkins, & Trivette, 1994)

Listed below are people and groups that oftentimes are helpful to members of a family raising a young child. This questionnaire asks you to indicate how helpful each source is to your family. Please mark the response that best describes how helpful the sources have been to your family during the past 3 to 6 months. If a source of help has not been available to your family during this period of time, mark Not Available response.

How helpful has each of the following been to you in terms of raising your child(ren)?

6. My parents
   - Not Available
   - Not at All Helpful
   - Sometimes Helpful
   - Generally Helpful
   - Very Helpful
   - Extremely Helpful

7. My spouse or partner’s parents
   - Not Available
   - Not at All Helpful
   - Sometimes Helpful
   - Generally Helpful
   - Very Helpful
   - Extremely Helpful

8. My relative/kin
   - Not Available
   - Not at All Helpful
   - Sometimes Helpful
   - Generally Helpful
   - Very Helpful
   - Extremely Helpful

9. My spouse or partner’s relative/kin
   - Not Available
   - Not at All Helpful
   - Sometimes Helpful
   - Generally Helpful
   - Very Helpful
   - Extremely Helpful

10. Spouse or partner
    - Not Available
    - Not at All Helpful
    - Sometimes Helpful
    - Generally Helpful
    - Very Helpful
    - Extremely Helpful

11. My friends
    - Not Available
    - Not at All Helpful
    - Sometimes Helpful
    - Generally Helpful
    - Very Helpful
    - Extremely Helpful

12. My spouse or partner’s friends
    - Not Available
    - Not at All Helpful
    - Sometimes Helpful
    - Generally Helpful
    - Very Helpful
    - Extremely Helpful

13. My own children
    - Not Available
    - Not at All Helpful
    - Sometimes Helpful
    - Generally Helpful
    - Very Helpful
    - Extremely Helpful

Page 4
### Second Survey: Current Services and Supports

14. **Other parents**  
   - Not Available  
   - Not at All Helpful  
   - Sometimes Helpful  
   - Generally Helpful  
   - Very Helpful  
   - Extremely Helpful

15. **Co-workers**  
   - Not Available  
   - Not at All Helpful  
   - Sometimes Helpful  
   - Generally Helpful  
   - Very Helpful  
   - Extremely Helpful

16. **Parent groups**  
   - Not Available  
   - Not at All Helpful  
   - Sometimes Helpful  
   - Generally Helpful  
   - Very Helpful  
   - Extremely Helpful

17. **Social groups/clubs**  
   - Not Available  
   - Not at All Helpful  
   - Sometimes Helpful  
   - Generally Helpful  
   - Very Helpful  
   - Extremely Helpful

18. **Church members/ministers**  
   - Not Available  
   - Not at All Helpful  
   - Sometimes Helpful  
   - Generally Helpful  
   - Very Helpful  
   - Extremely Helpful

19. **My family or child’s physician**  
   - Not Available  
   - Not at All Helpful  
   - Sometimes Helpful  
   - Generally Helpful  
   - Very Helpful  
   - Extremely Helpful

20. **Early childhood intervention program**  
   - Not Available  
   - Not at All Helpful  
   - Sometimes Helpful  
   - Generally Helpful  
   - Very Helpful  
   - Extremely Helpful

21. **School/day-care center**  
   - Not Available  
   - Not at All Helpful  
   - Sometimes Helpful  
   - Generally Helpful  
   - Very Helpful  
   - Extremely Helpful

22. **Professional helpers (social workers, therapists, teachers, etc.)**  
   - Not Available  
   - Not at All Helpful  
   - Sometimes Helpful  
   - Generally Helpful  
   - Very Helpful  
   - Extremely Helpful

23. **Professional agencies (public health, social services, mental health, etc.)**  
   - Not Available  
   - Not at All Helpful  
   - Sometimes Helpful  
   - Generally Helpful  
   - Very Helpful  
   - Extremely Helpful
<table>
<thead>
<tr>
<th>Question</th>
<th>Options</th>
<th>Other (please specify)</th>
</tr>
</thead>
<tbody>
<tr>
<td>24. Other (please specify below)</td>
<td>Not Available</td>
<td>Not All Helpful</td>
</tr>
<tr>
<td></td>
<td>Sometimes</td>
<td>Helpful</td>
</tr>
<tr>
<td></td>
<td>Generally</td>
<td>Helpful</td>
</tr>
<tr>
<td></td>
<td>Very Helpful</td>
<td>Helpful</td>
</tr>
<tr>
<td></td>
<td>Extremely</td>
<td>Helpful</td>
</tr>
<tr>
<td>25. Other (please specify below)</td>
<td>Not Available</td>
<td>Not All Helpful</td>
</tr>
<tr>
<td></td>
<td>Sometimes</td>
<td>Helpful</td>
</tr>
<tr>
<td></td>
<td>Generally</td>
<td>Helpful</td>
</tr>
<tr>
<td></td>
<td>Very Helpful</td>
<td>Helpful</td>
</tr>
<tr>
<td></td>
<td>Extremely</td>
<td>Helpful</td>
</tr>
</tbody>
</table>
26. When I think about raising my child with autism, I am most worried about...

27. I think my child has the following strengths and talents...

28. When raising my child with autism, the most difficult thing is...

29. Please list 2 Internet sites that you visit regularly for information about raising your child.
   a. 
   b. 
   I do not visit any Internet sites

30. Please list 2 Autism Internet sites that you have visited for information about autism spectrum disorder.
   a. 
   b. 
   I have not visited any Autism Internet sites

31. How did you find out about our Online Parent Discussion Group?
Thank you for your participation!
Please enter your email address below to register for your free $20 Amazon Gift Card.

32. Your email address:
Appendix G

Post Participation Survey Questionnaire

This survey is designed to collect your final thoughts and views about the Online Parent Discussion Groups.

You will be asked some brief questions about your participation in the online discussion group as well as suggestions for future discussion groups. The survey usually takes about 15 minutes to complete. Of course, you are free to skip any questions or stop taking the survey.

Please be assured that your survey information and your identity will be kept confidential. Thank you for your time and thoughtful responses to the survey!

For further information, please contact:
Laurie Jeans or Dr. Rosa Milagros Santos
Department of Special Education
University of Illinois at Urbana-Champaign
288 Education Bldg., 1310 South Sixth Street
Champaign, IL
217-333-0260
ljeans2@illinois.edu; rsantos@illinois.edu
Post Participation Survey Questionnaire

1. Your Gender
   - Male
   - Female

2. Your Age (years)
   

3. Approximately how many times per week did you routinely visit our Online Parent Discussion Group?
   - less than 1 time per week
   - 1-2 times per week
   - 3-4 times per week
   - 4-5 times per week
   - more than 5 times per week

4. Has our Online Parent Discussion Group been useful to you?
   - Very Useful
   - Useful
   - Somewhat Useful
   - Not Useful

5. Please list up to 2 ways that this online discussion group has been useful for you.
   a. 
   b. 

6. Please list up to 2 reasons that this online discussion group has not been useful for you.
   a. 
   b. 
Post Participation Survey Questionnaire

7. Overall, how would you rate your level of participation in the online discussion group?

Please choose one.

- High Participation
- Medium Participation
- Low Participation

8. Were you satisfied with your level of participation?

- Yes
- No

Why or why not?

9. Please list up to 2 factors that helped increase your participation in the online discussion group.

a.

b.

10. Please list up to 2 barriers or difficulties you encountered participating in the online discussion group.

a.

b.
11. What suggestions do you have for improving the online discussion group?

12. Would you recommend this type of online discussion group to other parents?
   - Yes
   - No
   Why or why not?

13. Would you be interested in continuing participation in an online discussion group for parents of young children with an autism spectrum disorder?
   - Yes
   - No
   Do you have suggestions of a format? (e.g., closed group on Facebook, members-only group online, etc.)

14. Please let us know any other comments or suggestions you have.
<table>
<thead>
<tr>
<th>Question</th>
</tr>
</thead>
<tbody>
<tr>
<td>15. Please enter your email address for your free $20 Amazon Gift Card.</td>
</tr>
</tbody>
</table>