

Supporting Parents of Children Diagnosed with Autism Spectrum Disorders

by

Lindsey Grennan

A Graduate Research Project Submitted to the  
University of Alaska Fairbanks  
In Partial Fulfillment of the Requirements of the Degree of  
Masters of Education in Counseling

Christine Cook, Ph.D.

Joanne Healy, Ph.D.

Lynn Harrison, M.Ed.

University of Alaska Fairbanks  
Fairbanks, Alaska  
Spring 2015

### Abstract

According to the Alaska Department of Education and Early Development (ADEED), in the year 2013, 1,110 children with an ASD were enrolled across all the school districts within the state of Alaska (ADEED, 2013). Children with an ASD experience social, behavioral and academic difficulties and parents raising children with an ASD face numerous challenges related to meeting the needs of their child and family (Hall & Graff, 2010; Murphy, Christian, Caplin, & Young, 2007; Solomon & Chung, 2012). This paper reviews current research on experiences of ASD diagnoses for children and parents, and the efficacy of parental engagement with social support and family therapy. The literature review informed the creation of a PowerPoint presentation and a handbook that discuss the experiences of children and parents related to ASDs, describe the research to support the efficacy of local resources, and present the local resources for parents of children with ASDs.

## Table of Contents

	Page
Introduction.....	4
Challenges for Parents of Children with an ASD.....	6
Caregiver health.....	7
Diagnosis.....	8
Marriage quality.....	9
Stress and depression.....	10
Theoretical Foundation.....	11
Literature Review.....	14
Informal and Formal Social Support.....	16
Family Therapy.....	21
Cultural Considerations.....	24
Application.....	25
Intended Audience.....	25
Basic Product.....	25
Conclusion.....	26
References.....	28
Appendix A – Presentation Overview.....	34
Appendix B - Supporting Parents of Children Diagnosed with an ASD Presentation.....	35
Appendix C – Resource Handout.....	62
Appendix D – Application References.....	67

### Supporting Parents of Children with Autism Spectrum Disorders

According to the World Health Organization (2013), the global prevalence of individuals diagnosed with an Autism Spectrum Disorder (ASD) was 1 in 160 in 2013, and the prevalence in low and middle-income countries remains unknown. Children with an ASD comprise one of the largest populations of students receiving special education and related services within the United States (Zablotsky, Boswell, & Smith, 2012). The Autism and Developmental Disabilities Monitoring Network and Surveillance reported about 1 in 68 children within the United States were identified with an ASD in the year 2010 (Autism and Developmental Disabilities Monitoring Network Surveillance Year 2010 Principal Investigators, 2014). According to the Alaska Department of Education and Early Development (ADEED), in the year 2013, 1,110 children with an ASD were enrolled across all the school districts within the state of Alaska (ADEED, 2013). Of those 1,110, 108 children were enrolled in the Fairbanks North Star Borough School district (FNSBSD, 2013).

ASDs are a group of developmental disorders including Autistic Disorder and Pervasive Developmental Disorders-not otherwise specified (Solomon & Chung, 2012; Zablotsky et al., 2012). ASDs are an urgent concern and a dramatic rise in the diagnosis of ASD caused an explosion of research and provided new understandings (Hall & Graff, 2010; Solomon & Chung, 2012; Zablotsky et al., 2012). Kogan et al. (2009) described nationwide statistics of ASD diagnoses in the United States; in the 1980s, 2 to 5 out of 10,000 children received a diagnosis, which contrasts greatly with the year 2007 when 1 in every 91 children received a diagnosis. Challenges across social, communicative and behavioral domains characterize an ASD and are typically present before 3 years of age (Hall & Graff, 2010). Early diagnosis of an ASD is crucial to allow children every opportunity to master adaptive behaviors.



A literature review by Burgess and Gutstein (2007) stated that despite advances in early diagnosis and intervention approaches, quality of life for children with an ASD remains low. Many of these children lack social support, meaningful relationships, future employment opportunities or self-determination. Myers, Ladner and Koger (2011) reviewed existing literature to understand and draw conclusions about the psychological outcomes for children with an ASD. The authors argued that academically, students with an ASD struggle with placement in both special education classrooms and mainstream classrooms. While the majority of students with an ASD are academically appropriate for mainstream classrooms, many struggle to blend in with their neurotypical classmates and experience bullying, social exclusion and social isolation. Children and adolescents, regardless of disability status, are at risk for developing psychological difficulties if they perceive themselves as socially isolated and unaccepted by peers. The social challenges and behavioral expressions inherent in children diagnosed with an ASD increase children's risks of developing low self-esteem. Low levels of self-esteem have been correlated with depression, suicidal tendencies, anxiety, aggression, anti-social behavior, and delinquency. Russell et al. (2012) compared social and behavioral outcomes of 13,944 children in South West England between age 12 to 16 years old formally diagnosed with an ASD and those displaying autistic traits but not formally diagnosed. Social communication skills were significantly worse for those diagnosed than undiagnosed. Children with an ASD reported more bullying and their parents reported difficulty maintaining their child's temper. Overall, Russell et al. (2012) discovered that children with an ASD experienced greater social communication impairments and demonstrated greater restricted interests and ritualistic behaviors than those undiagnosed. Children with an ASD experience social, behavioral and academic difficulties and parents raising children with an ASD face numerous challenges related to meeting the needs of their child and

family (Hall & Graff, 2010; Murphy, Christian, Caplin, & Young, 2007; Solomon & Chung, 2012).

Virtually all aspects of family life may be affected when someone in the family has an ASD (Solomon & Chung, 2012). Research has demonstrated how parenting a child with an ASD may lower marriage quality and satisfaction (Siman-Tov & Kaniel, 2011). Stress and depression rates have been shown to be higher among parents of children with an ASD compared to parents of children without an ASD (Clifford & Minnes, 2013; Neely, Amatea, Echevarria-Doan, & Tannen, 2012; Paster, Brandwein, & Walsh, 2009). There are significant barriers to addressing and improving caregiver health, including lack of time, lack of respite hours, lack of qualified care providers and low prioritization of the need to take care of themselves (Murphy et al., 2007).

Based on the large number of people ASD affects, and the demonstrated need for support for families of children with an ASD, this project will address the following research question: What resources are available in the Fairbanks Alaska community to support parents with children diagnosed with an Autism Spectrum Disorder? The paper will describe the need to support parents of children with an ASD, discuss relevant theory, review the literature regarding the role of social support and family therapy to support parents, and described the intended audience and basic application that results from the literature review.

### **Challenges for Parents of Children with ASD**

As stated previously, parents of children with an ASD face numerous challenges and caregiver burden related to meeting the needs of their child and family (Hall & Graff, 2010; Solomon & Chung, 2012), and may experience chronic stress as a result (Siman-Tov & Kaniel, 2011; Solomon & Chung, 2012). Caregiver burden is defined as parental perceptions of the negative effects of the stress and caregiving responsibilities of parenting (Roper, Allred,

Mandleco, Freeborn, & Dyches, 2014). A child with an ASD presents a range of symptoms that affect the function and quality of family life (Solomon & Chung, 2012). Virtually all aspects of family life may be affected including sleep, meals, toileting, play, travel, education, and work. The following highlights the need to support parents of children with an ASD through providing understanding of caregiver burden, the challenges related to gaining a diagnosis, marital dissatisfaction, and stress and depression.

**Caregiver health.** Murphy et al. (2007) and Whiting (2014) examined the experience of caregivers of children with disabilities. Whiting (2014) investigated how parents of children with disabilities in the United Kingdom experience the need for help and support in caring for their children. The parents of 34 children from 33 families participated in interviews and asked, “how have you experienced the need for help and support in the context of your child’s disability or complex health problem?” (Whiting, 2014, p. 25). Parents identified family, friends, health professionals and social workers as providing considerable support through child care, emotional support, being knowledgeable about disabilities, and navigating the diagnosis process. Parents acknowledged lack of respite care as the largest barrier to supporting the needs of themselves and their family. An implication for professionals is the importance of establishing a trusting relationship with parents and being knowledgeable about disabilities in order to assist them with problem solving and provide emotional and psychological support.

In research by Murphy et al. (2007) caregivers within the United States reported placing a lower priority on their own health relative to that of their child with a disability. Participants included 40 Utah parents/caregivers, of which 33 were mothers, 6 were fathers, and 1 an aunt and legal guardian, of children with a wide range of diagnoses related to disabilities. Participants completed questionnaires and participated in focus groups to explore their current physical and

emotional health needs. The five themes to emerge from participants experience included stress of caregiving, negative impact on caregiver health, sharing the burden, worry about the future, and caregiver coping strategies. Similar to the parents of Whiting (2014), parents in the Murphy et al. study (2007) acknowledged lack of time and lack of respite hours as barriers to adequate support. Parents additionally identified lack of qualified care providers and low prioritization of the need to take care of themselves as barriers to addressing and improving caregiver health (Murphy et al., 2007). Parents expressed concerns related to their own health related limitations as a possible threat to their abilities to provide long-term care for their children. Murphy et al. (2007) postulated worsening caregiver health and lack of options for caregivers as increasing negative outcomes for children. The authors described the results of the study as supporting the development of family centered systems of care to improve parent's emotional well-being, satisfaction with services, and experience of burden. Whiting (2014) and Murphy et al. (2007) acknowledge the importance of services for parents to support their emotional and psychological needs related to parenting children with an ASD.

**Diagnosis.** Obtaining a clear diagnosis can be one of the most significant challenges that a family faces, as second, third, and fourth opinions are often required (Keenan, Dillenburger, Doherty, Byrne, & Gallagher, 2010; Neely et al., 2012). Children displaying severe ASD symptomology in infancy are most often diagnosed by three years of age, while children experiencing less disabling symptoms may not be identified as experiencing an ASD until they are school age (Neely et al., 2012). Disagreements can arise between parents, other family members, and professionals about the existence and severity of possible impairments. While there was an exponential increase in knowledge surrounding ASDs, research by Mansell and Morris (as cited in Neely et al., 2012) uncovered diagnosis as a major source of stress for

parents. Keenan et al. (2010) collected questionnaires and conducted small focus group discussions from a sample of 95 parents and caregivers of children with an ASD in Northern Ireland in order to understand parental perceptions of the process of diagnosis and forward planning (Special Education Needs Statement, Individual Education Plan, and Person Centred Plan) related to children with an ASD. Almost half of parents reported believing the diagnosis process was not completed in a timely or professional manner. Parents described forward planning as time consuming and although reviewed regularly, parental views, monitoring procedures and intervention data were not habitually included. Braiden, Bothwell, and Duffy (2010) also gathered parental insight into parent's experiences of the diagnostic process for an ASD. The authors conducted semi-structured interviews with eleven mothers in Northern Ireland. Parents described negative perceptions and feelings of frustration when dealing with professionals during the diagnosis process. Similar to the parents of Keenan et al. (2010), the parents of Braiden et al. (2010) identified the timing and length of the diagnostic process as a challenge. Specifically, parents desired to know a diagnosis or hunch earlier in the process rather than feel out of touch with the process (Braiden et al., 2010). Delivering a diagnosis of an ASD may never be easy, but family therapy can serve to support families during the diagnosis process, facilitate insight into how an ASD diagnosis is affecting the family and provide a space for decision making (Neely et al., 2012).

**Marriage quality.** Research has demonstrated how parenting a child with an ASD may lower marriage quality and satisfaction and may disrupt familial functioning (Hartley et al., 2010; Siman-Tov & Kaniel, 2011; Solomon & Chung, 2012). Parents of a child with an ASD are nearly twice as likely to divorce as parents without a child with an ASD (Ramisch, 2012; Solomon & Chung, 2012). Hartley et al. (2010) examined the occurrence and timing of divorce

in 391 parents of adult or adolescent children with an ASD. The longitudinal study compared the parents of adult or adolescent children with an ASD to a group of parents of adults or adolescents without a disability. Results demonstrated the prevalence of divorce was significantly higher among the parents of children with an ASD. For parents of children without a disability, the risk of divorce appeared to decrease in the child's late childhood and become extremely low by the time the child reached adulthood. In contrast, for parents of children with an ASD, the risk of divorce remained steep throughout the child's adolescence and early adulthood, and did not decrease until the child reached 30 years old. Hartley et al. (2010) concluded that the heightened risk of divorce in parents of children with an ASD is consistent with findings that families of children with an ASD experience an astonishing level of stress. It is imperative for service providers to be knowledgeable of the increased risk and timing of divorce in families of children with an ASD and service providers are in a role to guide families towards building strategies to improve marital functioning.

**Stress and depression.** Research of parents showed higher self-reports of stress and depression among families of children with disabilities than among families of children developing typically (Bitsika, Sharpley, & Bell, 2013; Clifford & Minnes, 2013; Neely et al., 2012; Paster et al., 2009). Bitsika et al. (2013) investigated stress, anxiety and depression among 73 mothers and 35 fathers of Queensland, Australia who had at least one child with an ASD diagnosis. Results from self-report questionnaires demonstrated that mothers were significantly more anxious and depressed than fathers were. Compared to the average rate of the normal parent population, the mothers and fathers of children with an ASD reported a three to five fold increase of clinically significant anxiety and depression. Previous research by Bitsika and Sharpley (2004, as cited in Bitsika et al., 2013) also demonstrated parental anxiety and

depression rates of parents of children with an ASD elevated above parents of children developing typically. Specifically, Bitsika and Sharpley (2004, as cited in Bitsika et al., 2013) and Bitsika et al. (2013) described parental reports of being stretched beyond their personal limits and feelings of inadequate coping to the demands of their child with an ASD. Bitsika et al. (2013) identified behavior based family interventions, which teach parents techniques to manage ASD symptoms, as highly effective at reducing stress. Further, Bitsika et al. (2013) discovered that it was essential that the social support provided to parents be provided by someone with a high degree of understanding of the behaviors and challenges experienced when raising a child with an ASD.

Families with children with an ASD often have limited contact with the community because family, friends, teachers, and the community do not understand the behavioral characteristics of children with an ASD (Troy, Connolly, & Novak, 2007). The literature stresses the role of social support to mediate the challenges associated with parenting a child with an ASD. Family systems theory and the resiliency model provide a framework for understanding family stress and coping mechanisms.

### **Theoretical Foundation**

The theoretical base influencing this project centers on family systems theory, which views the family's strength as related to the relationship between all members (Troy et al., 2007; Zablotsky, Bradshaw, & Stuart, 2013). Murray Bowen's family system theory outlines the interrelationship between the emotional, intellectual, and feeling systems as related to families (Crossno, 2011). The emotional system includes individuals instinctual and evolutionary functioning, the intellectual system is how individuals think, reason and reflect, and the feelings system serves as the bridge between the emotional and intellectual systems and attaches meaning

to emotional reactions. A counselor operating within family systems theory encourages family members to become experts of their particular family system by increasing awareness of family functioning, patterns and history.

Bowen family systems theory can be applied across a diverse arena of clinical practice (Titelman, 2013). A crucial component of family systems theory is clinical applicability. Bowen therapy aims to increase the capacity of one or more family members to adapt to and deal with the challenges of life. Family systems theory has the potential to inform therapeutic work with families and children for whom behavioral concerns are a significant challenge (O'Gorman, 2012). Within the framework of family systems theory, a child with an ASD diagnosis and the parental effects are referenced within the broader family system. Behavioral concerns are strongly tied to a family's functioning, as a shift in a child's behavior or experience receiving services is likely to impact family functioning such as parental well being and marital satisfaction.

Also prominent in the literature, resiliency models explain an individual's ability to recover or adjust to stressors arising from life events and changes (Twyo et al., 2007). The resiliency model of family stress, adjustment, and adaptation is a strength-based model that emphasizes a family's ability to maintain equilibrium in spite of challenges. According to Twyo et al. (2007), families face an adjustment phase when a stressor is introduced, and with a balance of individual, family and community supports, individuals can make changes to the family system to achieve positive adjustment. A diagnosis of an ASD may be a source of change and stress in a family system. Families are most vulnerable during the adjustment phase following the diagnosis, and the types, patterns, and resources of the family interact with one another to shape the family's level of adjustment. Family resources are considered at the individual, family,



and community levels. Individual resources include intelligence, knowledge and skills, personality traits, and physical and emotional health. Family resources are organizational, decision-making, and conflict resolution skills. Community resources include informal and formal social supports such as personal support from friends and family and institutional supports. Adaptation occurs in the family system when members accept the changes related to a diagnosis of an ASD and understand how the family must function to meet the new and dynamic needs and demands. The level of successful adaptation within a family is dependent on family's utilization of both formal and informal social supports. Family systems theory and resiliency models provide a framework to understand the stress, coping skills, and strengths of parents of children with an ASD (Crossno, 2011; O'Gorman, 2012; Titelman, 2013; Tway et al., 2007; Zablotsky et al., 2013).

Another important consideration to the theoretical foundation of this project is an understanding of group process. As previously introduced, groups are an important formal social support for parents of children with an ASD. In order to effectively lead a group, group facilitators must display courage, a willingness to model, be present, demonstrate genuineness, hold belief in the group process, be open, become aware of subtle culture issues, maintain nondefensiveness when coping with criticism, empathize, and commit to self care (Corey, Corey & Corey, 2014). Theory provides a road map for group practice. Thinking, feeling and behaving models give attention to group members thinking, feeling and doing. Adlerian groups foster social interest and a sense of connectedness with others including a sense of identification and empathy and a sense of belongingness with a group (Corey et al., 2014). A person centered approach to group work provides understanding, support and genuineness while helping members fully accept themselves and decide on ways to change. An understanding and

appreciation of group process is essential to conducting beneficial groups that have the potential to support parents of children with an ASD. The following literature review will discuss the role of informal and formal social supports and family therapy for parents of children diagnosed with an ASD.

### **Literature Review**

Research has shown that when families receive support they are more able to cope with stressors related to parenting a child with an ASD (Hall & Graff, 2010; Siman-Tov & Kaniel, 2011). Social supports are considered one of the most appropriate and essential mechanisms for reducing stress for parents of a child with an ASD (Zablotsky et al., 2013). There are two categories of social support (Boyd, 2002). Formal social support is assistance that is social, psychological, physical or financial that is provided free or in exchange for a fee (Bristol & Schopler as cited in Boyd, 2002). Informal social support is a network including immediate and extended family, friends, neighbors, and other parents of children with disabilities. Informal and formal supports contribute to parental coping among parents of children with disabilities (Benson, 2006; Tehee, Honan, & Hevey, 2009).

Siman-Tov and Kaniel (2011) studied a sample of 176 mothers and fathers of children diagnosed with Pervasive Developmental Disorders living in Israel, and hypothesized that parental resources (sense of coherence, locus of control and social support) would be negatively correlated with parental stress (mental health and quality of marriage). Results demonstrated three main correlations between the variables of parental resources and parental stress. First, there was a positive correlation between parental sense of coherence and the variables mental health and quality of marriage. Secondly, there was a positive correlation between parental external locus of control and stress. Thirdly, there was a negative correlation between parental

formal and informal social support and stress. Therefore, parents who had a sense of coherence perceived a higher quality of marriage, and parents who attributed their circumstances to outside themselves experienced greater stress, while those who had more support felt less stress.

Hall and Graff (2010) studied a support group of 9 parents and 2 grandmothers of children diagnosed with ASD living in a metropolitan area of the southeast United States to investigate parenting views and parental stress related to their children's behaviors, and the availability and accessibility of resources. Results from focus group interviews described parental sources of stress, coping strategies, and resources and supports. Parents identified challenges related to school, caregiver, and medical personnel's lack of knowledge of Autism resources. Parents coping strategies included managing and treating Autism, advocating, planning for the future, accepting reality, hopefulness, humor, and social isolation. Parents identified a need for respite care services in order to decrease social isolation. Regarding availability and access to resources, parents wanted school, caregiver and medical personnel to have greater knowledge of ASDs. The parents involved in professionally led formal social support groups described how important support groups are for sharing information and gaining support.

Parents and family members of children with ASD also display resiliency factors (Solomon & Chung, 2012; Twoy et al., 2007; Zablotsky, et al., 2013). In order to access resilience and cope with stress, parents may benefit from informal and formal social supports and family therapy, which are effective strategies for parents experiencing challenges related to a child's diagnosis of ASD (Hall & Graff, 2010; Neely et al., 2012; Solomon & Chung, 2012).

Parents of children with ASD may benefit from an integrated psychotherapy approach to address the experiences of chronic stress, and family therapists can offer assistance (Ramisch,

2012; Solomon & Chung, 2012). Family therapists are able to help parents identify stressors contributing to the family system and provide strategies to improve communication skills and increase coping skills (Ramisch, 2012).

The literature review supports the need for parents of children with ASD in the Fairbanks region of Alaska to have awareness of the available informal and formal social supports. The creation of a PowerPoint presentation and a handbook discuss the outcomes for children and parents related to ASD, describe the research to support the efficacy of local resources, and present the local resources for parents of children with Autism including individual or family counseling, social support and group support.

### **Informal and Formal Social Support**

Dunst, Trivette, and Cross (as cited in Boyd, 2002) outlined social support as a multidimensional construct including physical assistance, attitude transmission amongst caregivers with shared experiences, resource and information sharing, and emotional and psychological support. As stated previously, there are two categories of social support (Boyd, 2002). Informal social support is a network including immediate and extended family, friends, neighbors, and informal connections with other parents of children with disabilities (Bristol & Schopler as cited in Boyd, 2002). Formal social support is assistance that is social, psychological, physical or financial and provided free or in exchange for a fee.

Research identified both informal and formal supports as factors contributing to adaptive parental coping (Benson, 2006; Tehee et al., 2009). Parents of children with disabilities reported less stress, fewer depressive symptoms, and fewer spousal problems when they had access to social support (Dunn, Burbine, Bowers, & Tantleff-Dunn, 2001; Paster et al., 2009). Benson (2006) used questionnaires to measure the relationship between child symptom severity, stress

proliferation, social support and parent depression within a sample of 60 mothers and 8 fathers of children diagnosed with an ASD within the greater Boston area. Stress proliferation, measured by the stress subscale of the Effects of the Situation Questionnaire (ESQ) was found to be a powerful predictor of parental depression, as measured by the Center for Epidemiologic Studies-Depression Scale (CES-D). Informal social support received from family, friends, parents and non-professionals measured by the Family Support Scale (FFS) was shown to significantly decrease parental depression. However, formal social support by school personnel, public and private agencies and other professionals was not found to be a significant factor in reducing stress or depression. This finding may be related to previous research which outlined parent's negative experiences with professionals surrounding diagnosis and treatment options as related to inadequate information about ASDs. Thus, attention may be warranted in the delivery of effective formal social supports. Parents of children with an ASD are at increased risk for mental health struggles and clinical interventions should address the consequences of an ASD for families, including parental support programs and counseling services.

Social support is an important moderator of stress for parents of children with an ASD, as support can meet parent's emotional, practical and informational needs (Tehee et al., 2009). Tehee et al. (2009) surveyed a sample of 42 parents of children age 3 to 18 diagnosed with an ASD in Ireland for the most salient factors contributing to parental stress relief. The authors examined the influence of parent gender and child age on perceived parental stress, stress and coping related to caregiving, perceived helpfulness of support, child-rearing involvement, and the amount of ASD information/education accessed. Areas of formal and informal supports investigated included school and/or school staff and service, respite services, home help/home tuition, health board/health workers and services, autism society family, spouse, support groups

/other parents, friends, other children, and social life/recreation. Results showed both informal and formal social supports as effective in relieving parental stress. Specifically, formal social supports of school services and staff ranked the highest. Compared with fathers, mothers reported significantly higher levels of stress and more child-rearing involvement. Parents of children age 11 to 14 years old reported the highest levels of stress (Tehee et al., 2009).

Dunn et al. (2001) examined the relationship between stressors, informal and formal social support, locus of control, coping styles, and negative outcomes of social isolation, depression and spousal relationship problems amongst a sample of 39 mothers and 19 fathers of children with an ASD recruited from both the Florida Autism Society and Autism Societies of America. Results supported a correlation between higher levels of social support and fewer spousal problems. There was no direct relationship between social support and isolation, thus Dunn et al. (2001) suggested that parents might feel social isolation despite social support.

The strength of the family is a crucial component of social support, therefore it is important to enhance the relationships among the family (Zablotsky et al., 2013). A weakened family unit is at risk for several negative outcomes including higher stress, low coherence, poor cohesion and adaptability, and less effective coping strategies. Research by Tway et al. (2007) showed that using social support systems was an essential component of family coping strategies. The authors examined coping strategies used by families with children with ASD, and specifically identified which coping strategies offer the most positive outcomes. Coping strategies included acquiring informal social support from family, friends, neighbors and extended family, reframing stressful events in order to make them more manageable, seeking spiritual support through spiritual/religious leaders or church participation, mobilizing family to acquire and accept help, and passive appraisals of problems in an inactive or avoidant manner.

Fifty-five parents of children with an ASD returned questionnaires and results indicated informal social supports as a large part of external family coping strategies. As noted previously, Benson (2006) did not find a relationship between formal social support and a decrease in stress or depression, however the parents in the research of Tway et al. (2007) reported the use of formal supports such as community agencies and medical doctors as effective active coping strategies. Discrepancies in the accessibility and effectiveness of formal social supports arose from a historic lack of best practice guidelines and parents mistrust of education and community providers (Stichter, Crider, Moody, & Kay, 2007). When the incidence of an ASD diagnosis increased nationally, there was extensive information on the disorder and emerging interventions available to parents. As evidenced based interventions had not been solidified, there was professional confusion on implementing interventions and parents began to demand specific interventions and fight for a cure for their child. Currently, social supports are identified as one of the most appropriate and essential mechanisms for reducing stress for parents of a child with an ASD, as research demonstrates formal support groups as positive and stress buffering (Clifford & Minnes, 2013; Tehee et al., 2009; Zablotsky et al., 2013).

Neely et al. (2012) noted that families who perceived themselves as having an adequate amount of informal support experienced less stress than families without support. The authors compiled practical information for family therapists to consider when working with families of children with an ASD, which included the importance of accessing informal and formal support. Bristol and Schopler (as cited in Neely et al., 2012) found that families who perceived higher levels of informal social support experienced less stress. Formal social supports with other parents of children with an ASD are also effective forms of support.

Formal social supports such as psychoeducation and support groups may help parents reshape attitudes and increase the quality of spousal support and caregiving roles within the family (Tehee et al., 2009). In a study by Hall and Graff (2010), parents identified important supports and resources for themselves to include other parents and family members.

Additionally, parents demonstrated a clear need and desire for information about ASDs and showed active participation in acquiring information. Parents specifically identified the need for properly informed professionals to provide accurate and current information of ASD. Parental support groups are cost effective and easy to implement to help parents cope with stress, meet other parents, and develop a sense of belonging (Clifford & Minnes, 2013). Research indicated that professionally led formal social support groups tend to have positive and stress buffering effects for parents of children with an ASD.

The Internet is an increasingly recognized source of social support (Paster et al., 2009). Psychoeducational and support groups are a helpful resource for parents of children with an ASD (Tehee et al., 2009), and have the potential to be available via the Internet (Clifford & Minnes, 2013). For example, in a study by Clifford and Minnes (2013) parents reported being satisfied with the support received from an online support group and identified the connection to other parents as most beneficial. Parents stated concerns of age differences among group members, delay in receiving responses, attendance, and a desire for more resources from the facilitator. Online support groups have the potential to reach parents who would otherwise not participate in traditional support groups because of geographic barriers, lack of childcare, or inconvenience. Online support groups should ensure an experienced and comfortable facilitator, clearly outline the group format and expectations, encourage regular attendance, collaborate with members on the focus and direction, and facilitate relationship development among members. Alongside



informal and formal social supports, family therapy is an effective resource for parents of children with an ASD (Ramisch, 2012; Solomon & Chung, 2012).

### **Family Therapy**

Parents of children with an ASD may benefit from an integrated psychotherapy approach to address the experiences of chronic stress (Solomon & Chung, 2012). Solomon and Chung (2012) aimed to provide family therapists a guide for working with parents of children with an ASD by providing information about autism, identifying parenting challenges, and suggesting comprehensive treatment plans to utilize with families. Family therapists are in a place to offer parents and family members assistance (Ramisch, 2012; Solomon & Chung, 2012). Family therapists should be able to help parents identify stressors contributing to the family system and provide strategies to improve communication skills (Ramisch, 2012). Further, it is important for family therapists to be aware of supports available in the community. Coping skills are essential to address with parents of children with an ASD, and family therapists assist parents to learn adaptive coping skills. Presenting problems and areas of work may include problem solving overwhelming schedules, conflict as a result of exhaustion and grief, and confusion or difficulty accessing treatments and services (Solomon & Chung, 2012).

Overwhelming schedules are of paramount concern for parents. Family therapists can facilitate the creation of new routines and roles, and collaborate with service providers to assist parents to gain access to all applicable resources (Neely et al., 2012). Family therapists also assist parents to make decisions about treatment for their child by providing relevant and thorough psychoeducational information (Hall & Graff, 2010; Neely et al., 2012). Contradictory and controversial treatment options are often confusing and difficult for parents to sort out, and family therapists can provide information about evidence based treatment options. Further,

parents may need to advocate for their child's services, and family therapists assist parents and connect them to appropriate agencies and avenues to advocate effectively (Neely et al., 2012).

Solomon and Chung (2012) described an integrative approach within family therapy that allows therapists to flexibly work with multiple problems or barriers by exploring action, meaning, and emotion. Working within the action domain allows parents to find ways to carry out their daily living tasks as optimally as possible (Solomon & Chung, 2012). Literature described parental stress as strongly correlated to a child's level of negative behaviors (Clifford & Minnes, 2013; Solomon & Chung, 2012). Solomon and Chung (2012) suggested that family therapists collaborate with a behavior technician to help families address negative behaviors. If parents are not able to access a behavior technician, family therapists may introduce and teach behavioral techniques to parents in order to help address children's tantrum and ritual behaviors. Solomon and Chung (2012) contend that the needs of children with an ASD can be overwhelming and demanding, thus requiring parents to develop enhanced structure and routine. Home visits allow a family therapist the opportunity to encourage parent's efforts to create a therapeutic home environment to support the needs of all family members.

Working within the domain of meaning allows parents to understand how their child's diagnosis shapes who their child is, who they are, and cultivate acceptance (Solomon & Chung, 2012). Parental connection and empathy is likely to be impaired when parents have questions of why their child received ASD diagnosis. Gray (2001) described parental narratives as valuable insights into the role of family members experiencing a diagnosis of an ASD. Narratives may include anger at oneself for not doing enough to prevent an ASD (Solomon & Chung, 2012). The family therapist can assist parents to accept the coexistence of multiple personal narratives.

Supporting parents to create and share narratives may foster personality and relational transformations to increase connection and empathy.

The emotional domain allows parents to explore and process complex and intense emotions surrounding their child's diagnosis of an ASD. Woodgate, Ateah, and Secco (2008) used a sample of 16 mothers and 5 fathers of children with an ASD living in Western Canada to collect qualitative data of their experiences parenting. Results described parent's experience of isolation and disconnection from social supports. Solomon and Chung (2012) proposed the role of family therapists to include assisting parents to modify their thinking and feelings surrounding outings with their child and involvement in social supports.

Neely et al. (2012) believe that parent's emotional difficulties related to parenting a child with an ASD should be addressed alongside the logistical challenges of finding treatment for the child. Parents may tirelessly seek internal and external resources to identify or fix the challenges their child is experiencing, and neglect to address personal feelings and reactions. They often experience guilt and blame after their child receives an ASD diagnosis, may feel overwhelmed by these feelings, which may in turn affect their ability to delegate family responsibilities or meet the needs of other children in the family. Family therapists can provide parents the space to grieve or mourn the loss of hopes and dreams for their child. Unacknowledged feelings and reactions have the potential to significantly impact treatment decisions and outcomes. Family therapy can serve as a safe arena for parents to bring up difficulties that are censored in the routines of daily life, such as sibling neglect, financial stress, and lack of emotional and sexual intimacy. The role of culture is an imperative consideration for the effective service delivery of social supports and family therapy.

### **Cultural Considerations**

Across the cultures of the United States (Benson, 2006; Dunn et al., 2001; Neely et al., 2012); Ireland (Keenan et al., 2010; Tehee et al., 2009), Canada (Clifford & Minnes, 2013), and Australia (Bitsika et al., 2013), parents of children with an ASD experience a variety of challenges related to meeting the needs of their children and the above literature review demonstrates formal and informal social supports and family therapy as effective parental coping strategies. Cultural considerations for working alongside families of children diagnosed with an ASD include working with families whose primary language is not English, qualitative differences between parenting and perception of disability across cultures, and patterns of involvement and barriers to participation (Zionts & Zionts, 2003).

Ravindran and Myers (2012) explored the influence of culture in shaping family, professional, and community relationships between developmental disabilities and their treatments. A cultural understanding of the meanings of health, illness, and disability vary greatly. As children with disabilities and their parents are members of families and communities in all parts of the world, the quality and experiences in their lives depends largely on culture. A broad cultural view may assist the understanding and delivery of ASD treatments. Best practice necessitates understanding and respect of families' worldview and collaboration towards mutually agreed upon treatments. Ravindran and Myers (2012) contended the role of culture in the key aspects of ASD treatments as including seeking help, available resources, and the relationship between parents and professionals.

### **Application**

#### **Intended Audience**

As the literature suggested, parents of children with an ASD experience unique challenges (Hall & Graff, 2010; Neely et al., 2012; Solomon & Chung, 2012; Tway et al., 2007)

and utilize different coping mechanisms compared to parents of children without an ASD (Paster et al., 2009; Twoy et al., 2007). Therefore, the target audience of this project is counselors working with parents of children with an ASD and parents themselves living in the region of Fairbanks, Alaska. A presentation including a question and answer segment and a handout of resource information will provide parents of children with an ASD an opportunity to learn experiences of children and parents related to ASDs, understand the research to support the efficacy of local resources, and present local resources available to them in Fairbanks, Alaska. Although the supports identified are specific to Fairbanks, Alaska, much of the presentation may be applicable to counselors and parents across the state of Alaska and the nation at large.

### **Basic Product**

A presentation overview and PowerPoint presentation (see Appendix A and B) and a resource handout (see Appendix C) outline the literature review and present local resources for parents of children with an ASD including individual or family counseling, social support and group support. The presentation discusses the research to support the efficacy of social support and family therapy. The material should be presented in an interactive manner with opportunity for discussion, comments, and questions from audience members. Members may be encouraged to share experiences with agencies and services within Fairbanks. The facilitator will use group counseling skills outlined by Corey et al. (2014) including facilitating, active listening, reflecting, clarifying, empathizing, linking, and supporting.

Resources include the ABEL program, Access Alaska, Alaska Center for Children and Adults, Autism Society of Alaska, Chief Andrew Isaac Health Center, Fairbanks Community Mental Health Services, Fairbanks Counseling and Adoption, Family Centered Services of Alaska, Fairbanks Resource Agency, Hope Counseling Center, Interior Community Health

Center, Resource for Parents and Children, and Step-In Autism Services of Alaska. A brief list of online resources for ASD related information includes the Alaska Department of Health and Social Services, Autism Parents Support, Autism Society, Autism Speaks, Child Parent Autism Café, and Stone Soup Group. The author explored community resources applicable to parents of children with ASD including individual, family, and group therapy and social support groups. Further exploration of effective and applicable online support groups is required before including as a resource for parents, and therefore is not included in this product. The Fairbanks community has resources that rural communities may lack, and counselors in those communities may want to expand their efforts into online and website options.

### **Conclusion**

ASDs are a group of developmental disorders including Autistic Disorder and Pervasive Developmental Disorders-not otherwise specified (Solomon & Chung, 2012; Zablotsky et al., 2012). Children with ASDs comprise one of the largest populations of students receiving special education services in the United States (Zablotsky et al., 2012). In the Fairbanks North Star Borough School district (2013), 108 children with ASD were enrolled in the year 2013. Many aspects of family life are affected by a child's diagnosis of an ASD (Solomon & Chung, 2012) and parents may experience chronic stress and depression as a result (Dunn et al., 2001; Siman-Tov & Kaniel, 2011). Social supports may be one of the most appropriate and essential mechanisms for reducing stress for parents of a child with an ASD (Zablotsky et al., 2013). Research identified both informal and formal social supports as factors in relationship to adaptive parent coping, stress moderation, spousal relationships, and social isolation (Benson, 2006; Dunn et al., 2001; Tehee et al., 2009). Psychoeducation and support groups demonstrate the ability to help parents reshape attitudes and increase the quality of spousal support and

caregiving roles within the family (Tehee et al., 2009). Parental support groups are cost effective and easy to implement to help parents cope with stress, meet other parents, and develop a sense of belonging, and are available online to reach parents who would otherwise not participate in traditional groups (Clifford & Minnes, 2013). Family therapists can offer assistance to parents of children diagnosed with an ASD by the use of integrated psychotherapy approaches to address the experience of stress, conflict, guilt and blame (Neely et al., 2012; Ramisch, 2012; Solomon & Chung, 2012). Family therapists can assist parents to modify thinking and feelings surrounding the challenges related to raising a child diagnosed with an ASD and facilitate involvement in social supports, provide a safe space to grieve or mourn the loss of hopes and dreams for their child, and help parents connect to appropriate agencies for interventions and advocacy (Neely et al., 2012; Solomon & Chung, 2012). As culture influences the family, professional, and community relationships between developmental disabilities and their treatments, a broad cultural view, understanding, and respect may assist the understanding and delivery of ASD treatments (Ravindran & Myers, 2012).

Based on the large number of people ASDs affects, and the demonstrated need for support for families of children with ASDs, this project targets counselors working with parents of children diagnosed with an ASD and parents themselves living in the region of Fairbanks, Alaska. A PowerPoint presentation and a handout were created that discuss the efficacy of resources for parents of children with an ASD including individual or family counseling, social support and group support.

## References

- Alaska Department of Education and Early Development (ADEED). (2013). Special education child count by district - ages 3-21. *Special Education Child Count*. Retrieved from <http://www.eed.state.ak.us/stats/ChildCount/131001ChildCount.pdf>
- Autism and Developmental Disabilities Monitoring Network Surveillance Year 2010 Principal Investigators. (2014). Prevalence of autism spectrum disorder among children aged 8 years - Autism and developmental disabilities monitoring network, 11 sites, United States, 2010. *Morbidity and Mortality Weekly Report: Surveillance Summaries*, 63(2), 1-21. Retrieved from [http://www.cdc.gov/mmwr/preview/mmwrhtml/ss6302a1.htm?s\\_cid=ss6302a1\\_w](http://www.cdc.gov/mmwr/preview/mmwrhtml/ss6302a1.htm?s_cid=ss6302a1_w)
- Benson, P. R. (2006). The impact of child symptom severity on depressed mood among parents of children with ASD: The mediating role of stress proliferation. *Journal Of Autism & Developmental Disorders*, 36(5), 685-695.
- Bitsika, V., Sharpley, C., & Bell, R. (2013). The buffering effect of resilience upon stress, anxiety and depression in parents of a child with an autism spectrum disorder. *Journal Of Developmental & Physical Disabilities*, 25(5), 533-543. doi:10.1007/s10882-013-9333-5
- Boyd, B. A. (2002). Examining the relationship between stress and lack of social support in mothers of children with autism. *Focus On Autism & Other Developmental Disabilities*, 17(4), 208. doi:10.1177/10883576020170040301
- Braiden, H., Bothwell, J., & Duffy, J. (2010). Parents' experience of the diagnostic process for autistic spectrum disorders. *Child Care In Practice*, 16(4), 377-389. doi:10.1080/13575279.2010.498415



- Burgess, A. F., & Gutstein, S. E. (2007). Quality of life for people with autism: Raising the standard for evaluating successful outcomes. *Child & Adolescent Mental Health, 12*(2), 80-86. doi:10.1111/j.1475-3588.2006.00432.x
- Clifford, T. T., & Minnes, P. (2013). Logging on: Evaluating an online support group for parents of children with autism spectrum disorders. *Journal Of Autism & Developmental Disorders, 43*(7), 1662-1675.
- Corey, M.S., Corey, G., & Corey, C. (2014). *Groups: Process and practice* (9<sup>th</sup> ed.). Pacific Grove, CA: Brooks/Cole Publishing Company.
- Crossno, M. A. (2011). Bowen family systems theory. In L. Metcalf (Ed.), *Marriage and family therapy: A practice-oriented approach* (pp. 39-64). New York, NY: Springer.
- Dunn, M. E., Burbine, T., Bowers, C. A., & Tantleff-Dunn, S. (2001). Moderators of stress in parents of children with autism. *Community Mental Health Journal, 37*(1), 39.
- Fairbanks North Star Borough School District [FNSBSD]. (2013). *Enrollment and ethnicity report*. Retrieved from [http://www.k12northstar.org/sites/default/files/enrollment-ethnicity-report\\_oct1-2013.pdf](http://www.k12northstar.org/sites/default/files/enrollment-ethnicity-report_oct1-2013.pdf)
- Gray, D. E. (2001). Accommodation, resistance and transcendence: Three narratives of autism. *Social Science & Medicine, 53*(9), 1247. Retrieved from [web.hszg.de/~wirsing/ASH%20Sozialmedizin09/AAErfasst/GRAY.pdf](http://web.hszg.de/~wirsing/ASH%20Sozialmedizin09/AAErfasst/GRAY.pdf)
- Hall, H., & Graff, J. (2010). Parenting challenges in families of children with autism: A pilot study. *Issues in Comprehensive Pediatric Nursing, 33*(4), 187-204. doi:10.3109/01460862.2010.528644

- Hartley, S. L., Barker, E. T., Seltzer, M. M., Greenberg, J., Bolt, D., Floyd, F., & Orsmond, G. (2010). The relative risk and timing of divorce in families of children with an autism spectrum disorder. *Journal of Family Psychology, 24*(4), 449-457. doi:10.1037/a0019847
- Keenan, M., Dillenburger, K., Doherty, A., Byrne, T., & Gallagher, S. (2010). The experiences of parents during diagnosis and forward planning for children with autism spectrum disorder. *Journal Of Applied Research In Intellectual Disabilities, 23*(4), 390-397.
- Kogan, M. D., Blumberg, S. J., Schieve, L. A., Boyle, C. A., Perrin, J. M., Ghandour, R. M., ... van Dyck, P. C. (2009). Prevalence of parent-reported diagnosis of autism spectrum disorder among children in the U.S., 2007. *Pediatrics, 124*(5), 1395-1403. doi:10.1542/peds.2009-1522
- Murphy, N. A., Christian, B., Caplin, D. A., & Young, P. C. (2007). The health of caregivers for children with disabilities: Caregiver perspectives. *Child: Care, Health & Development, 33*(2), 180-187. doi:10.1111/j.1365-2214.2006.00644.x
- Myers, J., Ladner, J., & Koger, S. (2011). More than a passing grade: Fostering positive psychological outcomes for mainstreamed students with autism. *Journal of Developmental & Physical Disabilities, 23*(6), 515-526. doi:10.1007/s10882-011-9242-4
- Neely, J., Amatea, E. S., Echevarria-Doan, S., & Tannen, T. (2012). Working with families living with Autism: Potential contributions of marriage and family therapists. *Journal Of Marital & Family Therapy, 38*(1), 211-226. doi:10.1111/j.1752-0606.2011.00265.x
- O'Gorman, S. (2012). Attachment theory, family system theory, and the child presenting with significant behavioral concerns. *Journal Of Systemic Therapies, 31*(3), 1-16. doi:10.1521/jsyt.2012.31.3.1

- Paster, A., Brandwein, D., & Walsh, J. (2009). A comparison of coping strategies used by parents of children with disabilities and parents of children without disabilities. *Research In Developmental Disabilities: A Multidisciplinary Journal*, 30(6), 1337-1342. doi: 10.1016/j.ridd.2009.05.010
- Ramisch, J. (2012). Marriage and family therapists working with couples who have children with autism. *Journal Of Marital And Family Therapy*, 38(2), 305-316. doi: 10.1111/j.1752-0606.2010.00210.x
- Ravindran, N., & Myers, B. (2012). Cultural influences on perceptions of health, illness, and disability: A review and focus on autism. *Journal Of Child & Family Studies*, 21(2), 311-319. doi:10.1007/s10826-011-9477-9
- Roper, S. O., Allred, D. W., Mandleco, B., Freeborn, D., & Dyches, T. (2014). Caregiver burden and sibling relationships in families raising children with disabilities and typically developing children. *Families, Systems, & Health*, 32(2), 241-246. doi:10.1037/fsh0000047
- Russell, G., Golding, J., Norwich, B., Emond, A., Ford, T., & Steer, C. (2012). Social and behavioural outcomes in children diagnosed with autism spectrum disorders: A longitudinal cohort study. *Journal of Child Psychology & Psychiatry*, 53(7), 735-744. doi:10.1111/j.1469-7610.2011.02490.x
- Siman-Tov, A., & Kaniel, S. (2011). Stress and personal resource as predictors of the adjustment of parents to autistic children: A multivariate model. *Journal of Autism and Developmental Disorders*, 41(7), 879-890.

- Solomon, A. H., & Chung, B. (2012). Understanding autism: How family therapists can support parents of children with autism spectrum disorders. *Family Process, 51*(2), 250-264.  
doi:10.1111/j.1545-5300.2012.01399.x
- Stichter, J. P., Crider, G., Moody, M., & Kay, D. (2007). Developing an outcome-based curricular framework for employing evidence-based practices in autism. *Beyond Behavior, 16*(2), 3-17.
- Tehee, E., Honan, R., & Hevey, D. (2009). Factors contributing to stress in parents of individuals with autistic spectrum disorders. *Journal Of Applied Research In Intellectual Disabilities, 22*(1), 34-42. doi:10.1111/j.1468-3148.2008.00437.x
- Titelman, P. (Ed). (2013). *Clinical application of bowen family systems theory*. New York, NY: Routledge.
- Twoy, R., Connolly, P. M., & Novak, J. M. (2007). Coping strategies used by parents of children with autism. *Journal Of The American Academy Of Nurse Practitioners, 19*(5), 251-260.  
doi:10.1111/j.1745-7599.2007.00222.x
- Whiting, M. (2014). Support requirements of parents caring for a child with disability and complex health needs. *Nursing Children & Young People, 26*(4), 24-27.
- Woodgate, R. L., Ateah, C., & Secco, L. (2008). Living in a world of our own: The experience of parents who have a child with autism. *Qualitative Health Research, 18*(8), 1075-1083.  
doi:10.1177/1049732308320112
- World Health Organization. (2013). Autism spectrum disorders and other developmental disorders: From raising awareness to building capacity. In *Mental health*. Retrieved from [http://www.who.int/mental\\_health/maternal-child/autism\\_report/en/](http://www.who.int/mental_health/maternal-child/autism_report/en/)
- Zablotsky, B., Boswell, K., & Smith, C. (2012). An evaluation of school involvement and

satisfaction of parents of children with ASD. *American Journal on Intellectual and Developmental Disabilities*, 117(4), 316-330.

Zablotsky, B., Bradshaw, C. P., & Stuart, E. A. (2013). The association between mental health, stress, and coping supports in mothers of children with autism spectrum disorders. *Journal Of Autism And Developmental Disorders*, 43(6), 1380-1393.

Zionts, L. T., & Zionts, P. (2003). Multicultural aspects in the education of children and youth with autism and other developmental disabilities. *Focus On Autism & Other Developmental Disabilities*, 18(1), 2.

## **Appendix A**

### **Presentation Overview**

The following is a presentation for counselors working with parents of children diagnosed with an ASD and parents themselves living in the region of Fairbanks, Alaska. The presentation is approximately 75 minutes in length, allowing time for questions and answers from participants.

#### **Goals for presentation:**

Foster awareness of the parental challenges related to raising children with an ASD diagnosis and highlight the research to support providing the resources of social support and family therapy.

#### **Objectives to achieve goal:**

- Introduce the outcomes for children and parents related to ASDs
- Highlight the research to support the efficacy of local resources
- Present the local resources for parents of children with an ASD including individual or family counseling, and social support.

#### **Note for facilitators:**

This presentation is intended for audiences that have knowledge of ASDs and introductory experience in the ASD community. The material may require adaptations for audiences who are new to the ASD community. Therefore, it may be important to survey the audience's knowledge before the presentation. For example, the age of the child/children diagnosed with an ASD, the year of diagnosis, agency involvement, the professional's knowledge of ASDs, the professional's history serving families of children with ASDs, etc.

**Appendix B**

**Supporting Parents of Children Diagnosed with Autism Spectrum Disorders**

Supporting Parents of Children  
Diagnosed with Autism  
Spectrum Disorders

By Lindsey Grennan, B.S.

*Presenter notes:*

The presenter should introduce themselves and provide information regarding their connection with ASDs (professional and/or personal).

The term ASD will be used throughout the presentation to refer to an Autism Spectrum Disorder.

## Presentation Goals

- Foster awareness of the parental challenges related to raising children with an ASD diagnosis
- Highlight the research to support providing the resources of social support and family therapy.



# Presentation Agenda

- Introduce the outcomes for children and parents related to ASDs
- Highlight the research to support the efficacy of local resources
- Present the local resources for parents of children with an ASD including individual or family counseling, and social support.

## ASD Prevalence

- Globally: 1 in 160 individuals in 2013
- United States: 1 in 68 children in 2010
- Alaska: 1,100 enrolled in school districts in 2013
- Fairbanks, Alaska: 108 enrolled in public school district in 2013

*Presenter notes:*

According to the World Health Organization (2013), the global prevalence of individuals diagnosed with an Autism Spectrum Disorder (ASD) was 1 in 160 in 2013

Children with ASDs comprise one of the largest populations of students receiving special education and related services within the United States (Zablotsky, Boswell, & Smith, 2012).

The Autism and Developmental Disabilities Monitoring Network and Surveillance reported about 1 in 68 children within the United States were identified with an ASD in the year 2010 (Autism and Developmental Disabilities Monitoring Network Surveillance Year 2010 Principal Investigators, 2014).

According to the Alaska Department of Education and Early development, in the year 2013, 1,110 children with an ASD were enrolled across all the school districts within the state of Alaska (Alaska Department of Education and Early Development, 2013).

In the Fairbanks North Star Borough School district, 108 children with an ASD were enrolled in the year 2013.

# Experiences Related to ASDs

Quality of life for many children with an ASD

remains low and children may lack:

- Social support
- Meaningful relationships
- Future employment opportunities
- Self determination

(Burgess & Gutstein, 2007)

*Presenter notes:*

While majorities of students with an ASD are academically appropriate for mainstream classrooms, many struggle to blend in with their neurotypical classmates and experience bullying, social exclusion and social isolation (Burgess & Gutstein, 2007)

Children and adolescents, regardless of disability status, are at risk for developing psychological difficulties if they perceive themselves as socially isolated and unaccepted by peers.

The social challenges and behavior expressions inherent in children diagnosed with an ASD increase children's risks of developing low self-esteem.

Low levels of self-esteem have been correlated with depression, suicidal tendencies, anxiety, aggression, anti-social behavior, and delinquency.

# Experiences Related to ASDs

Comparisons between children age 12 to 16 years old *formally diagnosed with an ASD* and those *not formally diagnosed but displaying autistic traits*

- Social communication impairments
- Greater restricted interest
- Greater ritualistic behaviors

(Russell et al., 2012)

## *Presenter notes:*

Russell et al. (2012) compared social and behavioral outcomes between children age 12 to 16 years old formally diagnosed with an ASD and those displaying autistic traits but not formally diagnosed.

Social communication skills were significantly worse for those diagnosed than undiagnosed.

Children with an ASD diagnosis reported more bullying and their parents reported difficulty responding to their child's temper.

Overall, Russell et al. (2012) discovered that children with an ASD diagnosis experienced greater social communication impairments and demonstrated greater restricted interests and ritualistic behaviors than those undiagnosed.

# Parental Challenges

- Virtually all aspects of family life may be affected
- Stress and depression
- Barriers to addressing and improving caregiver health

(Clifford & Minnes, 2013; Murphy et al., 2007; Neely, Amatea, Echevarria-Doan, & Tannen, 2012; Paster, Brandwein, & Walsh, 2009; Siman-Tov & Kaniel, 2011)

## *Presenter notes:*

Ask parents to share challenges they have experienced related to raising a child with an ASD

Ask professionals to share challenges they have assisted parents to navigate.

Allow approximately 15 minutes for discussion.

Research has demonstrated how parenting a child with an ASD may lower marriage quality and satisfaction (Siman-Tov & Kaniel, 2011).

Stress and depression rates have been shown to be higher among parents of children with an ASD compared to parents of children without ASD (Clifford & Minnes, 2013; Neely, Amatea, Echevarria-Doan, & Tannen, 2012; Paster, Brandwein, & Walsh, 2009).

There are significant barriers to addressing and improving caregiver health, including lack of time, lack of respite hours, lack of qualified care providers and low prioritization of the need to take care of themselves (Murphy et al., 2007).

# Meeting Parental Needs

- What is caregiver burden?
- How do ASDs contribute?
- Specific challenges
  - Caregiver health, diagnosis, marriage quality, stress and depression

(Roper, Allred, Mandleco, Freeborn, & Dyches, 2014; Solomon & Chung, 2012)

## *Presenter notes:*

Caregiver burden is defined as parental perceptions of the negative effects of the stress and caregiving responsibilities of parenting (Roper, Allred, Mandleco, Freeborn, & Dyches, 2014)

A child with an ASD presents a range of symptoms that affect the function and quality of family life (Solomon & Chung, 2012).

Virtually all aspects of family life may be affected including sleep, meals, toileting, play, travel, education, and work.

Specific challenges included issues related to gaining a diagnosis, marital dissatisfaction, and stress and depression.

# Caregiver Health

- Low priority on personal health
- Parental experiences
- Barriers to addressing and improving health
- Parental concerns

(Murphy et al., 2007)

## *Presenter notes:*

Murphy et al. (2007) found caregivers reported placing a lower priority on their own health relative to that of their child with a disability.

Participants included forty Utah parents/caregivers, of which thirty three were mothers, six were fathers, and an Aunt and legal guardian, of children with a wide range of diagnoses related to disabilities.

Participants completed questionnaires and participated in focus groups to explore their current physical and emotional health needs.

The five themes to emerge from participants experience included **stress of caregiving, negative impact on caregiver health, sharing the burden, worry about the future, and caregiver coping strategies.**

Barriers to addressing and improving caregiver health included **lack of time, lack of respite hours, lack of qualified care providers and low prioritization of the need to take care of themselves.**

Parents expressed concerns related to their own health related limitations as a possible threat to their abilities to provide long-term care for their children.

Murphy et al. (2007) postulated worsening caregiver health and lack of options for caregivers as increasing negative outcomes for children. Family centered systems of care are needed to improve parent's emotional well-being, satisfaction with services, and experience of burden.

# Diagnosis

- Gaining a clear diagnosis
- Parental, familial, and professional disagreements
- Parental perceptions
- Family therapy

(Keenan et al., 2010; Neely et al., 2012)

## *Presenter notes:*

Keenan et al. (2010) collected **questionnaires and conducted small focus group** discussions from a sample of 95 parents and caregivers of children with an ASD in Northern Ireland in order to understand parental perceptions of the process of diagnosis and forward planning (Special Education Needs Statement, Individual Education Plan, and Person Centred Plan) related to children with an ASD.

Almost half of parents reported believing the diagnosis process was not completed in a timely or professional manner.

Parents described forward planning as time consuming and although reviewed regularly, parental views, monitoring procedures and intervention data were not habitually included.

Family therapy can serve to support families during the diagnosis process, facilitate insight into how an ASD diagnosis is affecting the family and provide a space for decision making (Neely et al., 2012).



# Marriage Quality

- Lower marriage quality and satisfaction
- Family disruption
- Stress
- Timing of divorce

(Hartley et al., 2010; Siman-Tov & Kaniel, 2011; Solomon & Chung, 2012)

## *Presenter notes:*

Research found parents of children with an ASD had lower marriage quality and satisfaction and the ASD may disrupt familial functioning (Hartley et al., 2010; Siman-Tov & Kaniel, 2011; Solomon & Chung, 2012).

Hartley et al. (2010) examined the occurrence and timing of divorce in 391 parents of adult or adolescent children with an ASD.

The longitudinal study compared the parents of adult or adolescent children with an ASD to a group of parents of adults or adolescents without a disability.

Results demonstrated the prevalence of divorce was significantly higher among the parents of children with an ASD.

For parents of children without a disability, the risk of divorce appeared to decrease in the child's late childhood and become extremely low by the time the child reached adulthood.

It is imperative for service providers to be knowledgeable of the increased risk and timing of divorce in families of children with an ASD, and service providers are in a role to guide families towards building strategies to improve marital functioning.

# Stress and Depression

- Higher self-reports of stress and depression
  - 3-5x increase of clinically significant anxiety and depression
- Behavior based family interventions
- Social support

(Bitsika et al., 2013; Tzoy, Connolly, & Novak, 2007)

## *Presenter notes:*

Bitsika et al. (2013) looked at the variables of stress, anxiety and depression among 73 mothers and 35 fathers of Queensland, Australia who had at least one child with an ASD.

Results from self-report questionnaires demonstrated that mothers were significantly more anxious and depressed than fathers were.

Parents of a child with an ASD reported a three to five times increase of clinically significant anxiety and depression.

Further, Bitsika et al. (2013) revealed parent's identification of social support as requiring a high degree of understanding and of the behaviors and challenges experienced when raising a child with an ASD.

Families with children with an ASD often have limited contact with the community because family, friends, teachers, and the community at large do not understand the behavioral characteristics of children with an ASD (Tzoy, Connolly, & Novak, 2007).

# Interventions

When families receive support they are more able to cope with stressors related to parenting a child with an ASD

(Hall & Graff, 2010; Siman-Tov & Kaniel, 2011)

*Presenter notes:*

Ask parents to share current supports.

Allow approximately 5 minutes for sharing.

# Interventions

- What do parents identify needing from providers?
- What interventions are available to support parents of children with an ASD?

*Presenter notes:*

Parents indicated resources for themselves as other parents and family members (Hall & Graff, 2010).

Parents noted a clear need and desire for information about ASDs and showed active participation in acquiring information.

Parents specifically identified the need for properly informed professionals to provide accurate and current information of ASDs.

Ask parents if they identify with the needs that research highlighted;  
Allow approximately 10 minutes for discussion.

# Social Support

- Informal social supports
  - Family, friends, neighbors, and information connections with parents of other children with disabilities
- Formal social supports
  - Social, psychological, physical or financial provided free or in exchange for a fee

(Bristol & Schopler as cited in Boyd, 2002).

## *Presenter notes:*

Dunst, Trivette, and Cross (as cited in Boyd, 2002) outlined social support as a multidimensional construct including physical assistance, attitude transmission amongst caregivers with shared experiences, resource and information sharing, and emotional and psychological support.

Formal social support is assistance that is social, psychological, physical or financial that is provided free or in exchange for a fee (Bristol & Schopler as cited in Boyd, 2002).

Informal social support is a network including immediate and extended family, friends, neighbors, and other parents of children with disabilities.

Family therapists are able to help parents identify stressors contributing to the family system and provide strategies to improve communication skills and increase coping skills (Ramisch, 2012).

# Social Support

## Outcomes:

- Informal social support was shown to significantly decrease parental depression
- Social support was shown to relieve parental stress

(Benson, 2006; Tehee et al., 2009)

### *Presenter notes:*

Parents of children with disabilities reported less stress, fewer depressive symptoms, and fewer spousal problems when they had access to social support (Dunn et al., 2001; Paster et al., 2009).

Benson (2006) used questionnaires to measure the relationship between child symptom severity, stress proliferation, social support and parent depression within a sample of 60 mothers and 8 fathers of children diagnosed with an ASD within the United States.

Stress proliferation was found to be a powerful predictor of parental depression, and informal social support was shown to significantly decrease parental depression.

Formal social support was not found to be a significant factor in reducing stress or depression.

Tehee et al. (2009) surveyed a sample of 42 parents of children diagnosed with an ASD in Ireland for the most salient factors contributing to parental stress relief.

Areas of formal and informal supports investigated included school and/or school staff and service, respite services, home help/home tuition, health board/health workers and services, autism society family, spouse, support groups/other parents, friends, other children, and social life/recreation.

Results showed both informal and formal social supports as relieving parental stress. Formal social supports of school services and staff ranked the highest.

# Social Support

## Outcomes

- Correlation between higher levels of social support and fewer spousal problems
- Informal social supports were found to be a large part of external family coping strategies

(Dunn et al., 2001; Twoy et al., 2007)

### *Presenter notes:*

Dunn et al. (2001) examined the relationship between stressors, informal and formal social support, locus of control, coping styles, and negative outcomes of social isolation, depression and spousal relationship problems amongst a sample of 39 mothers and 19 fathers of children with an ASD living in the United States.

Results supported a correlation between higher levels of social support and fewer spousal problems.

There was no direct relationship between social support and isolation, thus Dun et al. (2001) suggested that parents might feel social isolation despite social support.

Twoy et al. (2007) identified the coping strategies used by families with children with an ASD, specifically, which coping strategies offer the most positive outcomes.

Coping strategies included acquiring social support, reframing, seeking spiritual support, mobilizing family to acquire and accept help, and passive appraisals.

Fifty-five parents of children with an ASD returned questionnaires and results indicated informal social supports as a large part of external family coping strategies.

# Social Support

## What about the Internet?

- Parents reported being satisfied with the support received from an online support group and identified the connection to other parents as most beneficial

(Clifford & Minnes, 2013)

### *Presenter notes:*

Clifford and Minnes (2013) described online support groups as having the potential to reach parents who would otherwise not participate in traditional support groups because of geographic barriers, lack of childcare, or inconvenience.

Online support groups should ensure an experienced and comfortable facilitator, clearly outline the group format and expectations, encourage regular attendance, collaborate with members on the focus and direction, and facilitate relationship development among members.



# Family Therapy

- Place to offer parents and family members assistance
- Identify stressors and provide strategies to improve communication skills

(Ramisch, 2012; Solomon & Chung, 2012)

*Presenter notes:*

Family therapists are in a place to offer parents and family members assistance (Ramisch, 2012; Solomon & Chung, 2012).

Therapists can identify stressors contributing to the family system and provide strategies to improve communication skills (Ramisch, 2012).

Family therapists should be aware of supports available in the community.

Coping skills are essential to address with parents of children with an ASD, and family therapists assist parents to learn adaptive coping skills.

Presenting problems and areas of work may include problem solving overwhelming schedules, conflict as a result of exhaustion and grief, and confusion or difficulty accessing treatments and services (Solomon & Chung, 2012).

# Family Therapy

- Creating new routines and roles
- Collaboration with service providers
- Treatment decisions through relevant and thorough psychoeducational information
- Advocacy

(Hall & Graff; Neely et al., 2012)

## *Presenter notes:*

Family therapists can:

- facilitate the creation of new routines and roles, and collaborate with service providers to assist parents to gain access to all applicable resources (Neely et al., 2012);
- assist parents to make decisions about treatment for their child by providing relevant and thorough psychoeducational information (Hall & Graff, 2010; Neely et al., 2012);
- provide information about evidence based treatment options;
- assist parents and connect them to appropriate agencies and avenues to advocate effectively (Neely et al., 2012).

# Family Therapy

An integrative approach within family therapy allows therapists to flexibly work with multiple problems or barriers by exploring **action**, **meaning**, and **emotion**

(Solomon & Chung, 2012)

*Presenter notes:*

Working within the action domain allows parents to find ways to carry out their daily living tasks as optimally as possible (Solomon & Chung, 2012).

Working within the domain of meaning allows parents to understand how their child's diagnosis shapes who their child is, who they are, and cultivate acceptance.

The emotional domain allows parents to explore and process complex and intense emotions surrounding their child's diagnosis of an ASD.

# Family Therapy

Unacknowledged feelings and reactions have the potential to significantly impact treatment decisions and outcomes for parents of children with an ASD.

(Neely et al., 2012)

## *Presenter notes:*

Parent's emotional difficulties related to parenting a child with an ASD should be addressed alongside the logistical challenges of finding treatment for the child (Neely et al., 2012).

Parents may feel guilt and blame after their child receives an ASD diagnosis, may feel overwhelmed by these feelings, which may in turn affect their ability to delegate family responsibilities or meet the needs of other children in the family.

Family therapists can provide parents the space to grieve or mourn the loss of hopes and dreams for their child.

Unacknowledged feelings and reactions have the potential to significantly impact treatment decisions and outcomes.

Family therapy can serve as a safe arena for parents to bring up difficulties that are censored in the routines of daily life, such as sibling neglect, financial stress, and lack of emotional and sexual intimacy.

## Cultural Considerations

- Across cultures parents of children with an ASD experience a variety of challenges
- Culture shapes family, professional, and community relationships
- Understanding and respect of families' worldview and collaboration is needed

(Ravindran & Myers, 2012)

### *Presenter notes:*

Ravindran and Myers (2012) explored the influence of culture in shaping family, professional, and community relationships between developmental disabilities and their treatments.

Cultures understanding of the meanings of health, illness, and disability vary greatly.

A broad cultural view may assist the understanding and delivery of ASD treatments.

Best practice necessitates understanding and respect of families' worldview and collaboration towards mutually agreed upon treatments.

Ravindran and Myers (2012) contended the role of culture in the key aspects of ASD treatments as including seeking help, available resources, and the relationship between parents and professionals.

## Conclusion

- Children with an ASD and their parents face numerous challenges
- Social supports and family therapy can provide support
- There are valuable resources in the Fairbanks community for professionals and parents

### *Presenter notes:*

In conclusion, this presentation described that children with an ASD experience social, behavioral and academic difficulties and parents raising children with an ASD face numerous challenges related to meeting the needs of their child and family (Benson, 2006; Clifford & Minnes, 2013; Dunn et al., 2001; Hall & Graff, 2010; Murphy et al., 2007; Neely et al., 2012; Ramisch, 2012; Solomon & Chung, 2012; Tehee et al., 2009; Zablotsky et al., 2013).

The literature identified social supports and family therapy as ways to provide support to parents to alleviate the experience of poor caregiver health, depression, stress, and marital dissatisfaction.

There are valuable resources in the Fairbanks community for professionals and parents.

## Available Resources

- Review Resource Handout
- Questions or Comments?

# References

- Alaska Department of Education and Early Development (ADEED). (2013). Special education child count by district - ages 3-21. *Special Education Child Count*. Retrieved from <http://www.eed.state.ak.us/stats/ChildCount/131001ChildCount.pdf>
- Autism and Developmental Disabilities Monitoring Network Surveillance Year 2010 Principal Investigators. (2014). Prevalence of autism spectrum disorder among children aged 8 years - Autism and developmental disabilities monitoring network, 11 sites, United States, 2010. *Morbidity and Mortality Weekly Report Surveillance Summaries*, 63(2), 1-21. Retrieved from [http://www.cdc.gov/mmwr/preview/mmwrhtml/ss6302a1.htm?s\\_cid=ss6302a1\\_v](http://www.cdc.gov/mmwr/preview/mmwrhtml/ss6302a1.htm?s_cid=ss6302a1_v)
- Benson, P. R. (2006). The impact of child symptom severity on depressed mood among parents of children with ASD: The mediating role of stress proliferation. *Journal Of Autism & Developmental Disorders*, 36(5), 685-695.
- Bitsika, V., Sharpley, C., & Bell, R. (2013). The buffering effect of resilience upon stress, anxiety and depression in parents of a child with an autism spectrum disorder. *Journal Of Developmental & Physical Disabilities*, 25(5), 533-543. doi:10.1007/s10882-013-9333-5
- Boyd, B. A. (2002). Examining the relationship between stress and lack of social support in mothers of children with autism. *Focus On Autism & Other Developmental Disabilities*, 17(4), 208. doi:10.1177/10883576020170040301
- Burgess, A. F., & Gutstein, S. E. (2007). Quality of life for people with autism: Raising the standard for evaluating successful outcomes. *Child & Adolescent Mental Health*, 12(2), 80-86. doi:10.1111/j.1475-3588.2006.00432.x
- Clifford, T. T., & Minnes, P. (2013). Logging on: Evaluating an online support group for parents of children with autism spectrum disorders. *Journal Of Autism & Developmental Disorders*, 43(7), 1662-1675.
- Dunn, M. E., Burbine, T., Bowers, C. A., & Tantleff-Dunn, S. (2001). Moderators of stress in parents of children with autism. *Community Mental Health Journal*, 37(1), 39.
- Hall, H., & Graff, J. (2010). Parenting challenges in families of children with autism: A pilot study. *Issues in Comprehensive Pediatric Nursing*, 33(4), 187-204. doi: 10.3109/01460862.2010.528644
- Hartley, S. L., Barker, E. T., Seltzer, M. M., Greenberg, J., Bolt, D., Floyd, F., & Orsmond, G. (2010). The relative risk and timing of divorce in families of children with an autism spectrum disorder. *Journal of Family Psychology*, 24(4), 449-457. doi:10.1037/a0019847
- Keenan, M., Dillenburger, K., Doherty, A., Byrne, T., & Gallagher, S. (2010). The experiences of parents during diagnosis and forward planning for children with autism spectrum disorder. *Journal Of Applied Research In Intellectual Disabilities*, 23(4), 390-397.



# References

- Murphy, N. A., Christian, B., Caplin, D. A., & Young, P. C. (2007). The health of caregivers for children with disabilities: Caregiver perspectives. *Child: Care, Health & Development, 33*(2), 180-187. doi:10.1111/j.1365-2214.2006.00644.x
- Neely, J., Amatea, E. S., Echevarria-Doan, S., & Tannen, T. (2012). Working with families living with Autism: Potential contributions of marriage and family therapists. *Journal Of Marital & Family Therapy, 38*(1), 211-226. doi:10.1111/j.1752-0606.2011.00265.x
- Paster, A., Brandwein, D., & Walsh, J. (2009). A comparison of coping strategies used by parents of children with disabilities and parents of children without disabilities. *Research In Developmental Disabilities: A Multidisciplinary Journal, 30*(6), 1337-1342. doi: 10.1016/j.ridd.2009.05.010
- Ramisch, J. (2012). Marriage and family therapists working with couples who have children with autism. *Journal Of Marital And Family Therapy, 38*(2), 305-316. doi: 10.1111/j.1752-0606.2010.00210.x
- Ravindran, N., & Myers, B. (2012). Cultural influences on perceptions of health, illness, and disability: A review and focus on autism. *Journal Of Child & Family Studies, 21*(2), 311-319. doi: 10.1007/s10826-011-9477-9
- Roper, S. O., Allred, D. W., Mandleco, B., Freeborn, D., & Dyches, T. (2014). Caregiver burden and sibling relationships in families raising children with disabilities and typically developing children. *Families, Systems & Health, 32*(2), 241-246. doi:10.1037/fsh0000047
- Russell, G., Golding, J., Norwich, B., Emond, A., Ford, T., & Steer, C. (2012). Social and behavioural outcomes in children diagnosed with autism spectrum disorders: a longitudinal cohort study. *Journal of Child Psychology & Psychiatry, 53*(7), 735-744. doi:10.1111/j.1469-7610.2011.02490.x
- Siman-Tov, A., & Kaniel, S. (2011). Stress and personal resource as predictors of the adjustment of parents to autistic children: A multivariate model. *Journal of Autism and Developmental Disorders, 41*(7), 879-890.
- Solomon, A. H., & Chung, B. (2012). Understanding autism: How family therapists can support parents of children with autism spectrum disorders. *Family Process, 51*(2), 250-264. doi:10.1111/j.1545-5300.2012.01399.x
- Tehee, E., Honan, R., & Hevey, D. (2009). Factors contributing to stress in parents of individuals with autistic spectrum disorders. *Journal Of Applied Research In Intellectual Disabilities, 22*(1), 34-42. doi:10.1111/j.1468-3148.2008.00437.x
- Twoy, R., Connolly, P. M., & Novak, J. M. (2007). Coping strategies used by parents of children with autism. *Journal Of The American Academy Of Nurse Practitioners, 19*(5), 251-260. doi:10.1111/j.1745-7599.2007.00222.x
- World Health Organization. (2013). Autism spectrum disorders and other developmental disorders: From raising awareness to building capacity. In *Mental health*. Retrieved from [http://www.who.int/mental\\_health/maternal-child/autism\\_report/en/](http://www.who.int/mental_health/maternal-child/autism_report/en/)
- Zablotsky, B., Boswell, K., & Smith, C. (2012). An evaluation of school involvement and satisfaction of parents of children with ASD. *American Journal on Intellectual and Developmental Disabilities, 117*(4), 316-330.

## Appendix C

### Resources for Caregivers of Children with an ASD

Resource names, phone numbers, and website addresses may change, but these are current as of April, 2015.

#### **Autism & Behavior Educational Liaisons (ABEL) Program** - Fairbanks North Star Borough School District

- Training for parents and families

907-451-0573

512 12th Ave (corner of Lacey & 12th), Fairbanks, AK 99701

<http://www.k12northstar.org/departments/sped/abel-program>

#### **Access Alaska**

- Community and Individualized Advocacy
- Parent Advocacy Support Group  
Third Tuesday of each month, 5:30 to 7 PM at Access Alaska – Fairbanks  
Call Ann at 479-7940 for more information.

907-479-7940

526 Gaffney Rd, Suite 100, Fairbanks, AK 99701

<http://accessalaska.org>

#### **Alaska Center for Children and Adults**

- Infant Learning Program  
Includes family directed services to support caregivers

907-456-4003

1020 Barnette Street

Fairbanks, AK 99701

<http://alaskacenter.org>

#### **Autism Society of Alaska**

- Psychoeducation
- BeSafe law enforcement interaction training
- Parent Coffee Talk
- Annual Alaska Walk for Autism

1-877-374-4421

1024 Barnette Street

Fairbanks, AK 99701

<http://www.asagoldenheart.org>

**Chief Andrew Isaac Health Center**

- Individual, family and group therapy

907-451-6682

1717 West Cowles Street

Fairbanks, AK 99701

<https://www.tananachiefs.org/patients/caihc/>

**Fairbanks Community Mental Health Services**

- Individual, group, and family therapy
- Skill development
- Psychoeducation
- Parenting with Love and Limits

907-371-1300

3830 South Cushman Street

Fairbanks, Alaska 99701

<http://www.acmhs.com/programs-services/child-family-services>

**Fairbanks Counseling and Adoption**

- Individual, family, marital and pre-marital therapy
- Parent advocacy
- Parent support and educational groups

907-456-4729

912 Barnette St.

Fairbanks, AK 99701

<http://www.fcaalaska.org/copy-of-services>

**Family Centered Services of Alaska**

- Individual therapy
- Youth Education Support Services
- REACH Respite Home

907-474-0890

1825 Marika Road

Fairbanks, AK 99709

<http://www.familycenteredservices.com>

**Fairbanks Resource Agency**

- In-home support
- Respite care
- Supported Parenting Program

907-456-8901

805 Airport Way

Fairbanks, AK 99701

<https://fairbanksresourceagency.wordpress.com>

**Hope Counseling Center**

- Individual, couple and family therapy
- Specialties include parenting, self esteem, and relationship challenges

907-451-8208

926 Aspen St, Fairbanks, AK 99709

<http://www.hopecounselingcenter.org/>

**Interior Community Health Center**

- Programs for parents to:
  - Develop self-management skills
  - Reduce stress
  - Create a healthy lifestyle

907-455-4567

1606 23<sup>rd</sup> Ave, Fairbanks, AK 99701

<http://www.myhealthclinic.org>

**Resource Center for Parents and Children**

- Parenting education classes
- Groups and workshops

907-456-2866

726 26<sup>th</sup> Ave

Fairbanks, AK 99701

<http://www.rcpcfairbanks.org>

**Step-In Autism Services of Alaska**

- Applied Behavior Analysis for children experiencing disabilities
- Parental psychoeducational information

907-374-7001

3550 Airport Way #208

Fairbanks, AK 99708

<http://stepinautism.com>

## **Online Resources**

### **Alaska Department of Health and Social Services: Autism**

This website provides information on what ASDs are, how to learn more about ASDs, and state and nation wide resources. There is a link to upcoming events and contact information for Alaska's Autism Program.

<http://dhss.alaska.gov/dph/wcfh/Pages/autism/default.aspx>

### **Autism Parents Support**

This online support is designed by parents and caregivers to provide useful information and stress relief to parents and caregivers of children with ASDs using humor and providing a sense of togetherness.

<http://www.autismparentssupport.org/index.html>

### **Autism Society**

The Autism Society supplies resources about ASDs, how to live with ASDs, ways to get involved, current research, news, and resources near you.

<http://www.autism-society.org>

### **Autism Speaks**

Autism Speaks has grown into the world's leading autism science and advocacy organization, dedicated to funding research into the causes, prevention, treatments and a cure for autism; increasing awareness of autism spectrum disorders; and advocating for the needs of individuals with autism and their families.

<https://www.autismspeaks.org>

### **Autism Support Network**

The mission of Autism Support Network is to short-cut the uphill battle individuals and families undertake when faced with autism – whether that means the initial diagnosis, the day-to-day living and coping needed, relationship and therapeutic strategies and the latest information. Their support community is intended to further reduce the need to “reinvent the wheel” and collectively pool global knowledge and support from all those touched by ASD wherever they might live.

<http://www.autismsupportnetwork.com>

### **Child Autism Parent Café**

This online resource provides parent/sibling support, information, resources and practical strategies to help manage day-to-day living with autism, by way of informative web sites and community outreach.

<http://www.child-autism-parent-cafe.com>

**Stone Soup Group**

This family resource guide is packed with information, tips, and contacts for a vast array of different issues facing families caring for children with special needs. It includes information and resources on education, medical needs, transitions, financial programs, and planning for the future.

Family Resource Guide

<http://www.stonesoupgroup.org/Guide.html>

## Appendix D

### Application References

- Alaska Department of Education and Early Development (ADEED). (2013). Special education child count by district - ages 3-21. *Special Education Child Count*. Retrieved from <http://www.eed.state.ak.us/stats/ChildCount/131001ChildCount.pdf>
- Autism and Developmental Disabilities Monitoring Network Surveillance Year 2010 Principal Investigators. (2014). Prevalence of autism spectrum disorder among children aged 8 years - Autism and developmental disabilities monitoring network, 11 sites, United States, 2010. *Morbidity and Mortality Weekly Report: Surveillance Summaries*, 63(2), 1-21. Retrieved from [http://www.cdc.gov/mmwr/preview/mmwrhtml/ss6302a1.htm?s\\_cid=ss6302a1\\_w](http://www.cdc.gov/mmwr/preview/mmwrhtml/ss6302a1.htm?s_cid=ss6302a1_w)
- Benson, P. R. (2006). The impact of child symptom severity on depressed mood among parents of children with ASD: The mediating role of stress proliferation. *Journal Of Autism & Developmental Disorders*, 36(5), 685-695.
- Bitsika, V., Sharpley, C., & Bell, R. (2013). The buffering effect of resilience upon stress, anxiety and depression in parents of a child with an autism spectrum disorder. *Journal Of Developmental & Physical Disabilities*, 25(5), 533-543. doi:10.1007/s10882-013-9333-5
- Boyd, B. A. (2002). Examining the relationship between stress and lack of social support in mothers of children with autism. *Focus On Autism & Other Developmental Disabilities*, 17(4), 208. doi:10.1177/10883576020170040301
- Burgess, A. F., & Gutstein, S. E. (2007). Quality of life for people with autism: Raising the standard for evaluating successful outcomes. *Child & Adolescent Mental Health*, 12(2), 80-86. doi:10.1111/j.1475-3588.2006.00432.x

- Clifford, T. T., & Minnes, P. (2013). Logging on: Evaluating an online support group for parents of children with autism spectrum disorders. *Journal Of Autism & Developmental Disorders, 43*(7), 1662-1675.
- Dunn, M. E., Burbine, T., Bowers, C. A., & Tantleff-Dunn, S. (2001). Moderators of stress in parents of children with autism. *Community Mental Health Journal, 37*(1), 39.
- Hall, H., & Graff, J. (2010). Parenting challenges in families of children with autism: A pilot study. *Issues in Comprehensive Pediatric Nursing, 33*(4), 187-204. doi:10.3109/01460862.2010.528644
- Hartley, S. L., Barker, E. T., Seltzer, M. M., Greenberg, J., Bolt, D., Floyd, F., & Orsmond, G. (2010). The relative risk and timing of divorce in families of children with an autism spectrum disorder. *Journal of Family Psychology, 24*(4), 449-457. doi:10.1037/a0019847
- Keenan, M., Dillenburger, K., Doherty, A., Byrne, T., & Gallagher, S. (2010). The experiences of parents during diagnosis and forward planning for children with autism spectrum disorder. *Journal Of Applied Research In Intellectual Disabilities, 23*(4), 390-397.
- Murphy, N. A., Christian, B., Caplin, D. A., & Young, P. C. (2007). The health of caregivers for children with disabilities: Caregiver perspectives. *Child: Care, Health & Development, 33*(2), 180-187. doi:10.1111/j.1365-2214.2006.00644.x
- Neely, J., Amatea, E. S., Echevarria-Doan, S., & Tannen, T. (2012). Working with families living with Autism: Potential contributions of marriage and family therapists. *Journal Of Marital & Family Therapy, 38*(1), 211-226. doi:10.1111/j.1752-0606.2011.00265.x
- Paster, A., Brandwein, D., & Walsh, J. (2009). A comparison of coping strategies used by parents of children with disabilities and parents of children without disabilities. *Research*



- In Developmental Disabilities: A Multidisciplinary Journal*, 30(6), 1337-1342. doi: 10.1016/j.ridd.2009.05.010
- Ramisch, J. (2012). Marriage and family therapists working with couples who have children with autism. *Journal Of Marital And Family Therapy*, 38(2), 305-316. doi: 10.1111/j.1752-0606.2010.00210.x
- Ravindran, N., & Myers, B. (2012). Cultural influences on perceptions of health, illness, and disability: A review and focus on autism. *Journal Of Child & Family Studies*, 21(2), 311-319. doi:10.1007/s10826-011-9477-9
- Roper, S. O., Allred, D. W., Mandelco, B., Freeborn, D., & Dyches, T. (2014). Caregiver burden and sibling relationships in families raising children with disabilities and typically developing children. *Families, Systems, & Health*, 32(2), 241-246. doi:10.1037/fsh0000047
- Russell, G., Golding, J., Norwich, B., Emond, A., Ford, T., & Steer, C. (2012). Social and behavioural outcomes in children diagnosed with autism spectrum disorders: a longitudinal cohort study. *Journal of Child Psychology & Psychiatry*, 53(7), 735-744. doi:10.1111/j.1469-7610.2011.02490.x
- Siman-Tov, A., & Kaniel, S. (2011). Stress and personal resource as predictors of the adjustment of parents to autistic children: A multivariate model. *Journal of Autism and Developmental Disorders*, 41(7), 879-890.
- Solomon, A. H., & Chung, B. (2012). Understanding autism: How family therapists can support parents of children with autism spectrum disorders. *Family Process*, 51(2), 250-264. doi:10.1111/j.1545-5300.2012.01399.x

- Tehee, E., Honan, R., & Hevey, D. (2009). Factors contributing to stress in parents of individuals with autistic spectrum disorders. *Journal Of Applied Research In Intellectual Disabilities*, 22(1), 34-42. doi:10.1111/j.1468-3148.2008.00437.x
- Twoy, R., Connolly, P. M., & Novak, J. M. (2007). Coping strategies used by parents of children with autism. *Journal Of The American Academy Of Nurse Practitioners*, 19(5), 251-260. doi:10.1111/j.1745-7599.2007.00222.x
- Zablotsky, B., Boswell, K., & Smith, C. (2012). An evaluation of school involvement and satisfaction of parents of children with ASD. *American Journal on Intellectual and Developmental Disabilities*, 117(4), 316-330.