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Family Predictors of Quality of Life and Child Problem Behavior in Families of Young Children with Autism Spectrum Disorders

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Abstract of the Dissertation

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Previous research on young children with Autism Spectrum Disorders (ASD) has primarily focused on the affected child, while often overlooking the family of the child with ASD. Multiple child-related variables have been linked with quality of life and problem behavior; however the role of family variables has not yet been evaluated in a systematic way. The purpose of the present study was to evaluate the association between (a) variables within the family system (i.e. relationship discord, social isolation, parental depression, and elevated parental stress) and (b) quality of life and problem behavior. One hundred and one mothers of 2-8 year old children with ASD participated. Assessment of problem behavior, quality of life, maternal depression, relationship discord, parental stress, and social support

was conducted. Bivariate correlations and multiple regression analyses were used to evaluate the association among these variables. Relationship discord, maternal depression, and parental stress were associated with (a) high levels of problem behavior in young children with ASDs and (b) poor quality of life for both the child and the family. The role of the family in ASDs and implications for future intervention research is discussed.

Dedication

This dissertation is dedicated to Dr. Edward (Ted) Carr. Ted was a brilliant thinker and researcher, whose work forever changed the lives of those with autism and their families. Ted encouraged change by questioning the status quo and broadened the definition of successful intervention by focusing not only on child problem behavior, but overall quality of life. Ted's guidance led to me to seek out a greater understanding of the family system and the relationship between family difficulties and both problem behavior and quality of life in children with ASD. Ted taught me that if you think outside the box and stay true to what you believe in, you will make a positive impact on others.

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I. Introduction

Research has documented the role of child-related variables, such as language abilities and intellectual skills in contributing to family quality of life and child problem behavior (Koegel, 2000; Hieneman & Dunlap, 2000; Hieneman & Dunlap, 2001). However, little research has examined the role of family-related variables. Not all families are the same; families with a child (or children) with an ASD experience varying difficulties that influence how well they can implement intervention strategies and their ability to cope with the burden of intensive treatments. This, in turn may impact child problem behavior and family quality of life. Quality of life has multiple aspects including social relationships, personal satisfaction, employment, self-determination, recreation and leisure, community adjustment, and community integration (Carr, 2007). Problem behavior, such as aggression, property destruction, self-injurious behaviors, and tantrums, has the potential to negatively impact quality of life by limiting opportunities in the community for education, socialization, and employment (Koegel, Koegel, & Dunlap, 1996).

Research on families of young children with ASDs have centered on the family as a facilitator of intervention. Many interventions for young children with ASDs involve families and are considered best practice as they are strongly associated with a number of desired outcomes relevant to child development and family functioning (Harris, 1982; Koegel, 2000; Lucyshyn, Horner, Dunlap,

Albin, & Ben, 2002). This includes increased language production, appropriate social and pragmatic use of language, increased overall quality of life, increased community integration and decreased problem behavior. These interventions frequently focus on training parents to implement behavioral programs at home to treat difficulties such as self-injury and aggression as well as to teach new adaptive skills, such as eating, dressing, and communication (Harris, 1984). These interventions are not intended to cure ASD, but are rather considered approaches to assist both the child and his or her family to develop skills, adapt and cope with the challenges posed by the disorder.

Research in other child clinical populations, reviewed below, supports the influence of family variables on problem behavior and family quality of life (Reyno & McGrath, 2006; Webster-Stratton & Hammond, 1990). This literature base has identified several core variables as highly linked to problem behavior and quality of life. These include: (a) relationship discord, (b) maternal insularity (social isolation), (c) parental depression, and (d) elevated parental stress. The aim of the current study is to extend this research by testing if these four variables predict quality of life and child problem behavior in families of young children with ASDs. It is predicted that a high level of relationship discord, social isolation, parental depression and parental stress will be associated with poor quality of life and a high level of problem behavior.

Relationship discord

Relationship discord frequently occurs in parents of children with ASD. In comparing parents of children with and without disabilities, researchers have found that parents of children with disabilities are more likely to report relationship adjustment problems (Bristol, Gallagher, & Schopler, 1988). Further, when compared with parents of children with a variety of developmental disabilities, parents of children with ASDs report more relationship difficulties. For example, compared to mothers of children with Down syndrome and parents of children with no developmental disorders, mothers of children with ASD report less relationship satisfaction (Rodrigue, Morgan, & Gefken, 1990). Additionally, in an interview study involving 33 parents of children with ASD (21 mothers and 12 fathers), 55% of parents reported that having a child with ASD added stress to their marriage (Blair, Block, Chambliss, Hobbs, & Urgarte, 1996). A recent meta-analysis, based on 13 studies found that parents of children with disabilities (ASD and other developmental disorders) report poorer relationship adjustment (overall effect size d = .21; Risdal & Singer, 2004). Overall, these studies indicate the presence of relationship discord and conflict in families of children with ASD.

Outcomes associated with relationship discord

The presence of relationship discord suggests an inability of couples to resolve problems collaboratively (Floyd & Zmich, 1991). That is, a discordant couple is less likely to work together effectively when faced with a problem and is more likely to engage in blaming, verbal abuse, and other forms of conflict.

Relationship discord may be associated with inconsistent discipline (Stoneman, Brody, & Burke, 1989). Additionally, relationship turmoil is associated with inconsistencies in child rearing practices (Downey & Coyne, 1990). Not only are individual parents inconsistent in their parenting practices, but the two parents are also likely to display inconsistencies between them. Inconsistent parenting as the result of relationship discord has not been studied in families of children with ASDs. However, inconsistency may be highly deleterious for children with ASDs as inconsistency between parents is likely to lead to increased child problem behavior as procedures that reduce or eliminate problem behavior, such as response cost or time out, require consistency in how they are implemented (Cooper, Heron, & Heward, 1987). Inconsistent use of such procedures prevents a child from learning which behaviors are and are not acceptable and therefore will likely lead to an increase in the level of problem behavior.

Relationship discord and conflict often involve a lack of spousal support. Downey and Coyne (1990) found that relationship conflict disrupted mutual support within the context of parenting. In the absence of mutual support, there is a lack of overall coordinated teamwork. This leads to a decreased ability to handle behavior problems as they arise, making long term behavioral difficulties more likely to arise. Additionally, without coordination between parents, community integration and quality of life for the family are likely to suffer. Coordination and mutual support has not been studied specifically within the context of families of

children with ASDs. However, this may be extremely pertinent for families of children with ASDs. Community integration for a child with ASD, such as participation in a local community group or attending a community religious service, often involves a coordinated effort and thoughtful planning. For example, for a child with an ASD to participate successfully on a local Little League baseball team, coordination and planning are necessary to increase the likelihood of a successful experience for both the child and his or her family. This will likely require connecting with various coaches and game officials for support and collaboration as well as the support of teammates and their parents.

The negative impact of relationship discord and conflict on child behavior has been documented in several clinical populations. Relationship discord predicts more problem behavior and higher child deviance and aggression, as observed and reported by both teachers and parents, in children with oppositional behavior (Webster-Stratton & Hammond, 1990). Significantly, it is also correlated with a failure to maintain intervention effects over time. In the ASD literature, there is, at present, only limited evidence suggesting that relationship discord and conflict predicts child problem behavior and quality of life. Thus, Singer, Goldberg-Hamblin, Peckham-Hardin, Barry and Santarelli (2002) suggested that relationship discord interferes with successful behavioral parent training with respect to the issue of challenging behavior. One study examined the effects of relationship discord on intervention outcomes in families of children with

developmental disabilities, including some with ASD (Baker, Landen, & Kashima, 1991). Relationship discord predicted significantly poorer parent training outcome.

Social Isolation

The levels of social support available to mothers of children with ASD differ from those of mothers of children without ASD. Mothers of children with ASD perceive less availability of emotional support and friendships than both mothers of typically developing children and children with mental retardation (Weiss, 2002). Parents of children with developmental disabilities, including ASD, have lower rates of social participation than do parents who do not have a child with a disability (Seltzer, Greenberg, Floyd, Pettee, & Hong, 2001). Measures of social participation have included the number of social organizations that parents participated in, such as charity organizations and sports teams, as well as the number of times the parents had visited with relatives in the past week. Additionally, when a child with disabilities exhibits problem behaviors, both the child and the rest of the family may become isolated from their extended family and friends and limit their community involvement (Lucyshyn, Horner et al., 2002).

Outcomes associated with social isolation

The relationship between social isolation and problem behavior has been documented in children with externalizing behavior disorders. Socially isolated

mothers display an increased level of aversive responses to both aversive and non-aversive child behaviors (Dumas & Wahler, 1983). Therefore, they fail to develop a consistent response style to their children's behaviors and tend to reward and punish their children indiscriminately. For example, the socially isolated mother may punish her child for cursing today, but ignore the behavior tomorrow; this pattern of parenting will likely lead to higher levels of problem behavior.

It has been suggested that social isolation of the family predicts family quality of life in families of children with ASDs (Singer et al., 2002). One intervention technique, the Parent to Parent mutual aid program, specifically targets social isolation by providing experienced parent "mentors' (Santelli, Ginsberg, Sullivan, & Niederhauser, 2002). Parent to Parent programs have been noted to increase parents' acceptance of their children's disability, the amount of perceived progress related to getting their family's needs met, their ability to cope with their children's disability, and their ability to problem solve, all important aspects of quality of life.

Parental depression

Depression frequently occurs in parents of children with ASD. In general, mothers of children with intellectual disabilities, including ASD, are significantly more likely to report that their children's problems have made them depressed than are mothers of children without disabilities (44% as compared to 9%; Emerson, 2003). Further, mothers of children with ASD are significantly more

likely to be depressed than are mothers of typically developing children, and children with mental retardation, spina bifida, or Down syndrome (Abbeduto, Seltzer, Shattuck, Krauss, Orsmond, & Murphy, 2004; Singer, 2006; Weiss, 2002). In a study of 120 mothers (40 of children with ASD, 40 of children with mental retardation, and 40 of typically developing children), mothers of children with ASD reported more symptoms of depression than both mothers of children with mental retardation and mothers of typically developing children (Weiss, 2002). In an additional study of 235 mothers of children with developmental disabilities (fragile X syndrome, Down syndrome, and ASD), mothers of children with ASD had significantly more depressive symptoms than mothers in each of the other groups (Abbeduto et al., 2004). Finally, a meta-analysis of 18 studies concluded that parents of children with developmental disabilities, in general, are at an elevated risk for depression as compared to parents of typically developing children (effect size of .39; Singer, 2006). It has been suggested that parental depression can predict child problem behavior in families of children with ASD (Harris, 1984). However, this has not been studied systematically.

Outcomes associated with parental depression

The relationship between maternal depression and problem behavior has previously been documented. Lovejoy, Graczyk, O'Hare, and Neuman (2000) found that mothers who were depressed, compared with those who were not depressed, were more likely to disengage from their children. Disengagement

manifested as ignoring, lack of responsivity, and low level of involvement with the child, all of which can lead to increased levels of problem behavior. Additionally, individuals with depression tend to attend more to negative behaviors in others, which may influence parents' perceptions of their children's behavior (Reyno & McGrath, 2006). Depressed mothers perceive their children as more disturbed than non-depressed mothers (Webster-Stratton & Hammond, 1990). Additionally, maternal ratings of child problem behavior are correlated more highly with maternal self-report of depression than with direct observations of child problem behavior (Griest, Forehand, & Wells, 1981). These associations have not been studied in families of children with ASDs.

Mothers experiencing depression respond less positively, less frequently, and less quickly to their children than do mothers who are not depressed, which in turn leads to higher levels of problem behavior (Downey & Coyne, 1990). Additionally, a meta-analysis of 30 studies found that mothers experiencing depression showed higher rates of negative maternal behavior such as negative feedback to the child, rejection, and use of coercive control (Lovejoy et. al, 2000). Overall, parents with depression show an increased level of negative interactions with their children, which is associated with higher problem behavior and poor quality of life. This pattern of an increased level of negative interactions in mothers experiencing depression has not been studied in families of children with ASDs.

Elevated parental stress

High levels of parental stress are frequently observed in parents of children with ASD. In a study of 60 mothers of children with ASD, Tomanik, Harris, & Hawkins (2005) concluded that having a child with ASD is a significant source of stress. Mothers of children with ASD had an average total stress score in the clinically significant range on the Parenting Stress Inventory (PSI; Abidin, 1995). Furthermore, parents of children with developmental disabilities, including ASD, reported more disruptions in daily family routines than did parents of children without disabilities (Bristol et al., 1988).

Parental stress is more prevalent in parents of children with ASD than other developmental disabilities. Interviews of 120 mothers revealed that mothers of children with ASD experienced significantly more emotional exhaustion than both mothers of children with mental retardation and mothers of typically developing children, as reported on the emotional exhaustion subscale of the Maslach Burnout Inventory (Weiss, 2002). Additionally, stress-related somatic complaints (e.g., sweaty hands, tachycardia (racing heart beat), and shortness of breath) were assessed in this set of mothers. Mothers of children with ASD reported significantly more somatic complaints than both mothers of children with mental retardation and typically developing children.

Outcomes associated with parental stress

Elevated parental stress may interfere with a parent's ability to provide appropriate positive reinforcement. It has been suggested that the coercive process (e.g., Patterson, 1982) may underlie the difficulties faced by parents who report high levels of stress. Parents who undergo many negative life experiences are likely to engage in coercive process with respect to relationships outside the parent-child dyad. Coercive process can occur in two ways. First, the parent can place an aversive demand on the child and in response to that demand, the child engages in problem behavior (Patterson, 1980). The parent then removes the demand, thus negatively reinforcing the child's problem behavior. Alternatively, the child may engage in problem behavior when the parent is not attending to him or her. The parent is reinforced by the cessation of the child's problem behavior, increasing the likelihood that, in the future, the parent will continue to perpetuate this coercive process, further strengthening problem behavior.

The negative impact of parental stress on child problem behavior has been documented in child clinical populations. Thus, parental stress significantly predicted problem behavior for children with aggressive, antisocial, and oppositional behavior (Kazdin, 1995). Parents who reported that their children were functioning within the "normal" range of aberrant behavior following treatment had a lower mean score on the Parenting Stress Inventory (PSI) than parents who did not report their children functioning within the "normal" range.

Additionally, those parents who reported their children as functioning within the "normal" range had fewer negative life events.

The present study

The present study evaluated the relationship between variables within the family system (relationship discord, social support, parental depression, and parental stress) and child problem behavior and quality of life (of both children with ASD and their parents). It was hypothesized that the family variables would influence problem behavior and quality of life, as they are associated with increased problem behavior and poorer quality of life within families with other childhood psychological disorders.

Although these associations have been studied at length in families of children with oppositional behavior and attentional difficulties, the association between family variables and child problem behavior and quality of life has not yet been systematically studied in children with ASDs. Results from other populations cannot automatically be extended to ASDs due to inherent deficits present in individuals with ASDs in the social domain. For example, children with ASDs have difficulty learning through social modeling and most social behavior needs to be explicitly taught. However, children, including those with behavior difficulties, are excellent at copying the behavior of adults who surround them. Therefore, the association between relationship discord and problem behavior may be due to social imitation. If this was the sole force driving the association,

the same association may be diminished, if not eliminated, in families of children with ASDs. It is important to study these associations specifically in families of children with ASDs.

II. Method

Participants

Participants were 101 mothers of children with ASD. The inclusion criteria were as follows: (a) the mother must have had a child living at home with an ASD, (b) the child must have been between 2 and 8 years of age, (c) the mother must have been in a romantic relationship (either married or living together for 2 years), (d) the family must have resided in North America.

The mean age of mothers completing the study was 37.97 (*SD* = 4.78; range 28-51). The mean age of their children was 5.02 years (*SD* = 1.74; range 2-8). Primary diagnoses of the children in the sample were Autistic Disorder (62.4%), Pervasive Developmental Disorder- Not Otherwise Specified (PDD-NOS; 32.7%), and Aspergers Disorder (5.0%). The majority of participants self-identified as Caucasian (86.1%), followed by African American (5.0%), Asian (3.0%), Hispanic (3.0%), or more than one ethnicity (3.0%). A significant majority also reported English as the primary language spoken at home (98%). Participants were well educated; 68.3% had completed college and 34.6% had completed an advanced degree. Notably, 52.6% of participants reported that they are full-time homemakers, not currently working outside the home.

Procedure

Participants were recruited (a) through schools and clinics specializing in ASDs, (b) on listserves which target parents of children with ASDs, and (c) at a series of free workshops provided by the researchers on positive behavior supports. Once contacted by an interested family, the researcher verified that the family met the inclusion criteria for the study and sent the survey packet to the family via mail. The survey packet comprised multiple measures assessing family variables, child problem behavior, quality of life, and child demographic variables. After receipt of the completed survey packet, participants received a $10 Target gift card.

Measures

Relationship discord. Relationship discord was measured using the Couples Satisfaction Index (CSI; Funk & Rogge, 2007, Appendix A). The CSI was developed utilizing item response theory and has been shown to demonstrate excellent internal consistency as well as convergent validity with other measures of relationship discord. The scale also demonstrates strong reliability in this sample, $\alpha = .98$. The Marital Status Inventory (MSI; Weiss & Cerreto, 1980, Appendix B) was also used as a measure of relationship discord. The scale contains 14 true/false response items that assess behavioral steps taken toward divorce. The scale demonstrates strong discriminative validity. Reliability in this sample was low, $\alpha = .47$, and was not strengthened by removal of a single item.

Parental depression. Parental depression was measured using the Center for Epidemiological Studies Depression Scale (CES-D; Radloff, 1977, Appendix C). The scale comprises 25 self-report items intended to measure symptoms of depression in the general population. The CES-D has been shown to demonstrate excellent internal consistency (Cronbach's alpha = .85) and test-retest reliability (r = .45 – .70 for between 2 weeks and 12 months). For the current sample, the scale was reliable, α = .75. CES-D self-reports are associated with nurse-clinician ratings (r = .56) and with other self-report measures of depression (r = .51 – .61).

Social Support. Social support was measured using the Family Support Scale (Dunst, Trivette, & Hamby, 1999; Appendix D). The scale consists of 18 likert scale self-report items. The scale shows internal consistency, coefficient alpha for the scale is .79. Test-retest reliability has been evaluated for both the individual items (average r = .75) and the entire scale (r = .91). For this sample the scale was reliable, α = .79. Criterion validity has also been assessed. Scores on the Family Support Scale are correlated with scores on the Questionnaire of Resources and Stress. Higher levels of support are correlated with lower levels of personal and family problems (r = -.17 through -.25, $p \leq .025$, dependent on subscale).

Parental stress. Parental stress was measured using the Parenting Stress Inventory- Short Form (PSI/SF) developed by Abidin (1995; Appendix E). The scale contains 36 self-report items that produces three factors: Parental Distress

(PD), Parent-Child Dysfunctional Interaction (PCDI), and Difficult Child (DC). The scale is highly correlated with the longer version of the scale (Abidin, 1997). Test-retest reliability has been assessed through correlation between scores at a 1 year follow-up ($r = .75$, $p < .001$) (Haskett, Ahern, Ward, & Allaire, 2006). Reliability for this sample was high, $\alpha = .92$. Criterion validity has been assessed as well. Scores on the PSI were significantly related to Global Severity Index scores on the SCL–90–R, $r(185) = .56$, $p < .001$.

Extraneous variables.

Extraneous variables are those factors that have been previously documented to influence quality of life and child problem behavior but are not related to the family variables under consideration. Previous studies have identified child variables that are also associated with quality of life and child problem behavior (Koegel, 2000). Information on these additional child variables, namely diagnosis, autism symptoms and any additional medical problems was gathered through a series of questions (Appendix F) and the Social Responsiveness Scale (SRS; Appendix G). The SRS consists of 65 likert scale items (Constantino, 2005). It is a parent report measure of the severity of autism spectrum symptoms. In this sample, $\alpha = .89$, indicating a reliable measure.

Outcome variables

Problem behavior. Problem behavior was assessed by the Irritability subscale of the Aberrant Behavior Checklist (ABC; Aman, Singh, Stewart, &

Field, 1985; Appendix H). This subscale consists of 15 Likert scale items. The scale demonstrates internal consistency as demonstrated by a coefficient alpha of .92. Interrater reliability of the subscale, analyzed with Spearman correlation coefficients, ranges from .39 to .70 dependent on rater pairings. Test-retest reliability was also analyzed with a Spearman correlation and was .98. Reliability for the sample was high, $\alpha = .92$, The subscale also demonstrated concurrent validity with the Withdrawal, Stereotyped Behavior, and Self Abusive Behavior domains of the Adaptive Behavior Scale (Spearman correlations of .40, .54, and.59, respectively).

Quality of Life. Quality of life (QOL) was measured through three scales that tap into different aspects of QOL. The Beach Center Family Quality of Life Survey is a 25 item Likert scale self-report measure composed of subscales aimed at assessing Family Interaction, Parenting, Emotional Well-Being, Physical/Material Well-Being, and Disability-Related Support (Appendix I). For each of the subscales, test-retest reliability was assessed and the correlations between time points for each subscale ranged from .41 to .82 (Park et. al, 2003). Reliability for this sample was high, $\alpha = .93$. Convergent validity was assessed for two of the subscales (Family Interaction and Physical/Material Well-being). The Family APGAR, a 5-item measure of family functioning, was significantly correlated with the satisfaction mean for the Family Interaction subscale, $r(87) = .68$, $p < .001$. Similarly, the Family Resource Scale, a 30-item measure of family

resources, was significantly correlated with the mean of the five items on the Physical/Material Well-Being subscale, $r(58) = .60$, $p < .001$.

Subjective well being, another component of QOL, was measured using the Satisfaction with Life scale (Diener, Emmons, Larsen, & Griffin, 1985) (Appendix J). This self-report scale contains 5 Likert items. The scale has shown strong internal reliability and moderate temporal stability with a coefficient alpha of .87 for the scale and a 2-month test-retest stability coefficient of .82. Reliability for this sample was high, $\alpha = .90$.

An additional aspect of QOL, community integration, was measured with a quality of life scale developed by the River Street Autism Program (Dyer, Martino, & Parvenski, 2006) (Appendix K). Although no psychometric data are available for this scale, it has good face validity and taps areas of QOL that are not measured by the other two scales (i.e., community integration for both the child and the family). The scale consists of 6 Likert scale items. Reliability was assessed for this sample, $\alpha = .57$. The removal of any single item did not improve reliability.

III. Results

Descriptive statistics for problem behavior, overall family quality of life, satisfaction with life, community integration, maternal depression, relationship satisfaction, relationship discord, level of social support, and parental stress are listed in Table 1 in addition to bivariate correlations among these variables. The

highest associations were between scales that assessed similar constructs, such as the two relationship discord measures (r = .65, p <.001) and overall family quality of life and satisfaction with life (r = .71, p <.001). However, there were also many moderate to large correlations between other variables, such as the relationship between overall quality of life and relationship satisfaction (r = .64, p <.001), parental depression (r = -.61 p <.001), and parental stress (r = -.55 p <.001).

A series of multiple regression analyses was conducted each looking at an individual criterion variable to determine the unique variance accounted for by each family system variable. Relationship satisfaction, parental stress, maternal depression, and social support were entered simultaneously as there was no a priori theoretical reason to believe that any one variable would be a stronger predictor than another. Relationship discord, as measured by the Marital Status Inventory, however, was entered a second step in the multiple regression equation. The measure provides a good descriptor how people are coping in their marriage in a clinically significant way beyond the information offered by measuring relationship satisfaction alone. However, the measure is more challenging in terms of client acceptability and may be difficult to include in normal clinical usage. Therefore, it was entered as a second step in all the multiple regression equations to see whether it added additional information over and above other variables.

In the first set of analyses, two separate analyses were conducted using two aspects of quality of life as the criterion variables, overall family quality of life and community integration. In the second set of analyses problem behavior was the criterion variable. A multiple regression analyses was not conducted for satisfaction with life as it was highly correlated with overall family quality of life (r = .71, p <.001). The satisfaction with life measure was originally included as it was thought to measure a unique aspect of quality of life. However, as the two measures were highly correlated they appear to measure the same construct. The overall family quality of life measure had stronger psychometric properties; therefore regression analyses were only conducted for that measure. For both analyses, maternal depression, relationship satisfaction, level of social support and parental stress were the predictor variables. For each criterion variable, a secondary analysis was conducted which added autism severity as an additional predictor variable to the regression analysis; previous research had established that autism severity was a predictor of both problem behavior and quality of life (Koegel, 2000).

Quality of life analyses

In the first analysis, a multiple regression analysis was conducted with overall family quality of life as the criterion variable. The overall R^2 was .63, $F(4, 96) = 40.06$, $p < .001$. The standardized regression coefficients (betas) were .39 for relationship satisfaction, -.23 for parental depression, .20 for social support,

and -.29 for parental stress. The association between relationship satisfaction and quality of life remained significant, $t(96) = 5.15$, $p < .001$, although it was reduced from a bivariate r of .64 to a partial r of .47. The association between parental stress and quality of life remained significant, $t(96) = -4.13$, $p < .001$, although it was reduced from a bivariate r of -.55 to a partial r of -.39. The association between social support and quality of life remained significant, $t(96) = 3.02$, $p = .003$, although it was reduced from a bivariate r of .41 to a partial r of .30. In addition, the association between parental depression and quality of life remained significant $t(96)= 2.83$, $p = .006$, although it was reduced from a bivariate r of -.61 to a partial r of -.28.

As a secondary analysis, autism severity was added as a predictor variable of quality of life. Autism severity offered no additional level of prediction to the model, and the overall R^2 remained at .62, $F(5, 95) = 32.25$, $p < .001$. The association between autism severity and quality of life was largely eliminated (bivariate r of -.22 to a partial r of -.10).

As an additional analysis, a multiple regression analysis was conducted with community integration as the criterion variable. The overall R^2 was .09, $F(4, 96) = 2.34$, $p = .061$. None of the predictor variables offered any significant unique prediction to community integration. The association between relationship satisfaction, maternal depression, parental stress and social support with community integration was largely eliminated. When autism severity was added a

predictor variable of community integration the model continued to lack significant prediction. The overall R^2 was .12, $F(5, 95) = 2.6$, $p = .03$.

Problem behavior analyses

A regression analysis examined child problem behavior as the criterion variable and maternal depression, relationship satisfaction, level of social support and parental stress as the predictor variables. The overall R^2 was .26, $F(4, 96) = 8.34$, $p < .001$. The standardized regression coefficients (betas) were -.09 for relationship satisfaction, .02 for depression, .09 for social support, and .48 for parental stress. Only the coefficient for parental stress was significant, $t(96) = 4.85$, $p < .001$. Note the substantial discrepancy between problem behavior's bivariate correlations with relationship satisfaction (-.23) and parental depression (.25) and the unique associations in the context of the regression equation (partial r = -.09 and .02, respectively), indicating that neither offered significant unique prediction. The association of parental stress with problem behavior, on the other hand, was only slightly reduced when removing the variance accounted for by relationship satisfaction, parental depression and social support (from a bivariate r of .49 to a partial r of .44). Social support, even after partialing out relationship satisfaction, depression, and parental stress, still failed to have any significant correlation with child problem behavior.

As a secondary analysis, autism severity was added as a predictor variable of problem behavior. The addition of autism severity increased the level of

prediction of the model, and increased the overall R^2 from .26 to .39, $F(5, 95) = 12.33$, $p < .001$. The coefficient for autism severity was significant, $t(96) = 4.61$, $p < .001$. The coefficient for parental stress remained significant and the coefficients for relationship satisfaction, parental depression, and social support continued to lack significance.

Marital Status Inventory analyses

For each multiple regression analysis, Marital Status Inventory (MSI) scores were added after the other predictor variables. For all three criterion variables, overall family quality of life, community integration, and problem behavior, the MSI did not add significant unique prediction. The correlation for the MSI and overall family quality of life was reduced from a bivariate *r* of -.40 to a partial .06 and the coefficient was not significant, $t(95) = .61$, $p = .542$. Secondly, the correlation for the MSI and community integration was reduced from a bivariate *r* of .22 to a partial .15 and the coefficient was not significant, $t(95) = 1.5$, $p = .137$. Additionally, the correlation for the MSI and problem behavior was reduced from a bivariate *r* of .26 to a partial -.10 and the coefficient was not significant, $t(95) = -.98$, $p = .33$.

IV. Discussion

Within a national convenience sample of mothers of young children with ASDs, quality of life and child problem behavior were significantly associated with relationship discord, maternal depression, and parental stress. Additionally,

quality of life was significantly associated with level of social support. Although autism severity was bivariately related to quality of life and child problem behavior, it did not account for unique variance in predicting family quality of life when included in a multiple regression analysis with other predictors. Thus, mothers' reports of their own level of stress were significantly associated with family quality of life, whereas their reports of their children's level of autism symptoms were not significantly associated. Similarly, relationship discord, parental stress, maternal depressive symptoms, and level of social support were all significantly associated with family quality of life whereas autism severity was not. However, autism severity did have a significant unique contribution to the model for prediction of problem behavior.

Autism severity had the highest level of association with problem behavior in this study. However, this association may be partially inflated due to method of measurement used for both problem behavior and autism severity. Autism severity was measured using the SRS, which correlates highly with DSM-IV diagnostic categories as measured by the Autism Diagnostic Interview-Revised (Constantino et al., 2003). The SRS is most highly correlated with the stereotyped behavior and restricted interests domain of the ADI-R. The questions on the SRS that measure this domain may overlap with several of the questions on the ABC, possibly accounting for the high association between these two variables. For example, an item on the SRS is "Becomes upset in situations with lots of things

going on." This may overlap with several of the items on the ABC, dependent on how the child shows that he or she is upset. It is recommended that future research investigate multiple methods to determine autism severity, such as the Autism Diagnostic Observation Schedule (ADOS) and the ADI to allow for a more comprehensive measure of autism severity.

None of the measured predictor variables were significantly associated with community integration in the multiple regression equation. The measure used for community integration lacked strong psychometric properties and had been used in one previous study. The measure was chosen for its high face validity and because no other measure of community integration could be found in a review of existing literature. A stronger measure may have led to different results. It is recommended that future research focus on the development of a valid and reliable measure of community integration as it is an important component of quality of life.

All of the family variables measured including relationship satisfaction, maternal depression, parental stress, and social support were strongly associated with quality of life, both in the bivariate correlations and the multiple regression analyses. However, not all of the family variables measured were uniquely associated with problem behavior when regression analyses were conducted. Problem behavior leads to poor quality of life. In this sample, they were moderately correlated (r = -.34, p <.001). However, multiple families with

reported high levels of problem behavior reported good quality of life. Family systems difficulties may interfere with quality of life independent of the level of problem behavior exhibited by the child. For a family with a high level of family systems difficulties, quality of life may be poor independent of level of problem behavior. Conversely, a family with a low level of family systems difficulties may have a greater ability to cope with problem behavior therefore buffering the deleterious effects of problem behavior on quality of life.

Relationship satisfaction was significantly correlated to both problem behavior and all three indicators of quality of life. This supports previous research on the association between relationship satisfaction and problem behavior and quality of life in both the autism and general child clinical populations. Families who reported low levels of relationship satisfaction are likely to have significantly higher levels of problem behavior and fewer gains in child development, following intervention (Baker et. al, 1991). Additionally, family conflict, including arguments between family members, is significantly associated with autism severity in children (Kelly, Garnett, Atwood, & Peterson, 2008).

Relationship discord leads to inconsistency in parenting practices (Downey & Coyne, 1990). Consistency is vital for individuals with ASDs. One of the core features of ASD is inflexible adherence to specific routines and rituals (DSM-IV). This can take the form of intolerance for change ("preservation of sameness") that often results in severe distress and behavioral problems (Howlin,

1998). Best practices for children with ASD incorporate consistent and predictable systems of scheduling, where the child can know what activities to expect and when in their day they will occur (Horner, Carr, Strain, Todd, & Reed, 2002). Additionally, consistency is critical when providing reinforcement for successive attempts at learning a new skill, such as functional communication training (Carr, Levin, McConnachie, Carlson, Kemp, & Smith, 1997). By creating inconsistency, relationship discord may prevent gains in child development as well as interfere with establishing effective behavioral strategies, thereby decreasing quality of life and increasing problem behavior.

Maternal depression was significantly correlated with both high problem behavior and all three indicators of poor quality of life. This supports previous literature suggesting that maternal depression predicts child problem behavior in children with ASDs (Harris, 1984). This also coincides with findings from a study investigating general child behavioral difficulties, whereby maternal depression was highly correlated with child problem behavior (Griest et. al, 1981)

Mothers experiencing depression provide higher rates of negative feedback to their children (Lovejoy et.al, 2000). They also show more rejection toward their children and have more negative interactions with their children. Additionally, they respond less positively, less quickly, and less frequently to their children. Positive attention and reinforcement are essential components of many strategies and interventions for children with ASDs. A key aspect of

interventions for children with ASDs is to prevent reinforcement of problem behavior and to provide reinforcement of adaptive behaviors (Horner et al., 2002). Depressive symptoms may prevent parents from identifying and reinforcing their children's positive behavior. By increasing a mother's likelihood to engage in negativity, maternal depression may decrease intervention effectiveness thereby decreasing quality of life and increasing problem behavior.

Parental stress was significantly correlated with both high problem behavior and all three indicators of poor quality of life. This supports previous research that demonstrated that parenting stress is associated with high levels of problem behavior and fewer gains in child development in children with ASDs (Osborne, McHugh, Saunders, & Reed, 2008). Additionally, this finding is consistent with research in children with aggressive, antisocial, and oppositional behavior whereby parental stress was a significant predictor of problem behavior (Kazdin, 1995).

Parental stress also interferes with a parent's ability to provide appropriate positive reinforcement in response to their children's behavior (Webster-Stratton, 1985). This is, as previously mentioned, essential for the development of children with ASDs. By interfering with the ability to provide appropriate positive reinforcement, parental stress may decrease the effectiveness of interventions, thereby decreasing quality of life and increasing problem behavior. Additionally, in a study of parents of young children with ASDs, level of parenting stress was

highly associated with their reported level of parenting competency (Osborne & Reed, 2010), including lower levels of parental involvement and less communication. These variables may also be mechanisms involved in the association between parental stress and poor quality of life and high levels of problem behavior.

Social support was significantly correlated with quality of life but not with problem behavior. This supports prior literature on the provision on social support as a means of increasing quality of life through the Parent to Parent Program (Santelli et. al, 2002). In a study comparing parents who participated in a Parent to Parent Program to waitlist controls, those who participated reported increased emotional and informational support. The association with problem behavior, however, was not supported. Prior research has divided social support into emotional and instrumental support (Wills & Shinar, 2000). This study only measured instrumental support using the Family Support Scale, which primarily measures instrumental. In parents of children with ASDs, instrumental support actually led to increased negative mood of parents and increased stress (Pottie, Cohen, & Ingram, 2009). The authors hypothesized this may be due to additional demands often required to access support services, such as organizing schedules and bringing their children to appointments). This could negate any effects social support may have on child problem behavior. Future research should look at both emotional and instrumental support.

Socially isolated mothers display an inconsistent response style and pattern of reinforcement to their children's behaviors (Dumas & Wahler, 1983). Consistent reinforcement is necessary to produce gains across a wide variety of behaviors and it is needed to facilitate skill development in children with ASD (Cooper et al., 1987). By interfering with consistent use of positive reinforcement, low levels of social support may decrease the likelihood of intervention success, which may thereby lead to increased problem behavior and decreased quality of life.

Limitations of the current study

As the current study was a single time point design, the directionality of the relationship between family variables and quality of life and child problem behavior was not explored. The question of whether poor quality of life and problem behavior cause family difficulties or whether family difficulties cause poor quality of life and problem behavior still remains. Future studies will be needed to assess families whose children receive the initial ASD diagnosis and follow the families prospectively over a period of several years to allow a better understanding of the pathways between these variables.

Furthermore, the current study only looked at mothers who were currently in romantic relationships. Those families with the most discordant relationships (i.e. families who had already divorced) were excluded from the study. Several disqualified participants reported that they felt that their difficulties with their

children led to the demise of their marriages. By enrolling families immediately after diagnosis and re-evaluating the families on a yearly basis, these families could be included and more information about the influence of child's ASD diagnosis and the trajectory of their parent's relationship could be evaluated. Additionally, only mothers were enrolled in the study and therefore the unique perspective of fathers was not taken into account. Future studies will be necessary to assess the role of fathers in the family system as it relates to family quality of life and child problem behavior.

An additional limitation of the current study was that the sample, although from varying geographical areas, was relatively homogenous. The majority of the sample were highly educated (68.3% had completed college). Additionally, the sample was not racially diverse (86.1% reported they were Caucasian). This sample, although not highly diverse, may be representative of which families are most likely to participate in research. Research conducted by the Interactive Autism Network, a large autism research database, has found that African-American, Hispanic, and Asian families are less likely to participate in autism research (Interactive Autism Network, 2007). Additionally, parents participating in autism research are more likely to be highly educated. Future studies may want to focus recruitment efforts on underrepresented groups to get a more representative sample of the families of children with ASDs. The current sample may actually be an underrepresentation of difficulties experienced by families of

children with ASDs. The families assessed report a high number of resources, both financial and intellectual, that may serve as buffer. However, despite their resources, the families in this study still report significant difficulties in quality of life, problem behavior, relationship discord, parenting stress, and maternal depression.

Future directions

Traditionally, interventions for children with ASD focus solely on intervening with the child. However, these interventions overlook the importance of the family system in which the child functions. By taking into account the entire family system, interventions can become more comprehensive and individualized to the needs of each family. The route to more effective intervention may lie in addressing factors such as parental depression and relationship discord prior to or concurrently with child-focused intervention. A model of intervention that includes a focus on family's unique needs could serve as a useful heuristic for constructing new and more effective interventions for children with ASD.

Some interventions have been developed which incorporate techniques aimed specifically at assisting parents of children with ASDs. For example, a treatment program was recently developed which incorporates positive behaviors support and optimism training (Durand & Hieneman, 2010). Not only are parents trained on how to identify problem behaviors, assess their function, utilize

prevention strategies and manage consequences, they are also trained to become more optimistic about their own parenting skills and their children's ability to make positive changes. Parents are encouraged to not only explore the function of their children's problem behavior, a core component of traditional positive behavior support techniques, but they are also encouraged to explore their own thoughts and feelings in relation to their children. By adding the additional optimistic parenting component to the traditional intervention, parents reported improvements in both problem behavior and quality of life.

The family system is an important component when working with children with ASDs. Parental depression, parental stress, relationship discord, and lack of social support influence the level of problem behavior and decrease quality of life for both the child and his or her family. The current study provides evidence that supports expanding the focus of intervention from the affected child alone to the child and his or her entire family system. Future research will be needed to explore the pathways of the association between family variables and problem behavior and quality of life. However, by tailoring interventions to meet the particular needs of the family of a child with ASD, more positive outcomes are likely.

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Table 1

Correlations Among Study Variables

Variable	Problem Behavior	Quality of Life	Sat. with Life	Com. Int.	Rel. Sat	MSI	Mat. Dep.	Soc. Supp.	Parent. Stress
Problem Behavior	–	-.34**	-.22*	-.26**	-.23*	.26**	.25*	-.04	.49**
Quality of Life		–	.71**	.32**	.64**	-.40**	-.61**	.41**	-.55**
Satisfaction with Life			–	.27**	.60**	-.34**	-.63**	.29**	-.46**
Community Integration				–	.22*	-.22*	-.25*	.14	-.23*
Relationship Satisfaction					–	-.65**	-.54**	.21*	-.32**
Marital Status Inventory						–	.34**	-.17	.26**
Maternal Depression							–	-.29**	.43**
Social Support								–	-.22*
Parenting Stress									–
M	12.87	92.90	20.36	18.50	51.03	2.61	17.49	36.11	102.20
SD	8.88	16.15	7.36	4.21	19.97	3.20	10.12	12.50	21.62

*p <.01; **p<.001

APPENDIX A

Couples Satisfaction Index

Please answer the following questions regarding your relationship with your romantic partner.

1. Please indicate the degree of happiness, all things considered, of your relationship.

Extremely Unhappy	Fairly Unhappy	A Little Unhappy	Happy	Very Happy	Extremely Happy	Perfect
0	1	2	3	4	5	6

2. In general, how often do you think that things between you and your partner are going well?

All the time	Most of the time	More often than not	Occasionally	Rarely	Never
5	4	3	2	1	0

Please indicate the extent you agree with the following statements.

	Not at all True	A little True	Somewhat True	Mostly True	Almost Completely True	Completely True
3. Our relationship is strong	0	1	2	3	4	5
4. My relationship with my partner makes me happy	0	1	2	3	4	5
5. I have a warm and comfortable relationship with my partner	0	1	2	3	4	5
6. I really feel like part of a team with my partner	0	1	2	3	4	5

	Not at all	A little	Somewhat	Mostly	Almost Completely	Completely
7. How rewarding is your relationship with your partner?	0	1	2	3	4	5
8. How well does your partner meet your needs?	0	1	2	3	4	5
9. To what extent has your relationship met your original expectations?	0	1	2	3	4	5
10. In general, how satisfied are you with your relationship?	0	1	2	3	4	5

For each of the following items, select the answer that best describes *how you feel about your relationship.* Base your
responses on your first impressions and immediate feelings about the item.

11.	INTERESTING	5	4	3	2	1	0	BORING
12.	BAD	0	1	2	3	4	5	GOOD
13.	FULL	5	4	3	2	1	0	EMPTY
14.	STURDY	5	4	3	2	1	0	FRAGILE
15.	DISCOURAGING	0	1	2	3	4	5	HOPEFUL
16.	ENJOYABLE	5	4	3	2	1	0	MISERABLE

APPENDIX B

Marital Status Inventory

We would like to get an idea of how your marriage stands right now. Please answer the following by circling true or false for each item.

T F 1. I have occasionally thought of divorce or wished that we were separated, usually after an argument or other incident.

T F 2. I have considered divorce or separation a few times other than during or shortly after a fight, although only in vague terms.

T F 3. I have thought specifically about separation or divorce. I have considered who would get the kids, how things would be divided, pros and cons of such actions, etc.

T F 4. I have discussed the question of my divorce or separation with someone other than my spouse (trusted friend, psychologist, minister, etc.)

T F 5. I have not suggested to my spouse that I wished to be divorced, separated or rid of him/her.

T F 6. I have not made any specific plans to discuss separation or divorce with my spouse. I have not considered what I would say, etc.

T F 7. I have not discussed the issue seriously or at length with my spouse.

T F 8. My spouse and I have separated. [This is a (a) trial separation or (b) permanent separation, circle one]

T F 9. Thoughts of separation or divorce occur to me very frequently, as often as once a week or more.

T F 10. I have made no inquiries from nonprofessionals as to how long it takes to get a divorce, grounds for divorce, costs involved in such actions, etc.

T F 11. I have not consulted a lawyer or other legal aid about the matter.

T F 12. I have set up an independent bank account in my name as a measure of protecting my own interests.

T F 13. I have not contacted a lawyer to make preliminary plans for a divorce.

T F 14. I have filed for divorce or we are divorced.

APPENDIX C

Centers for Epidemiological Studies Depression Scale (CES-D)

Below is a list of some of the ways you may have felt or behaved. Please indicate how often you have felt this way during the **past week**: (circle **one** number on each line)

	Rarely or none of the time (<1 day)	Some or a little of the time (1-2 days)	Occasionally or a moderate amount of time (3-4 days)	All of the time (5-7days)
1. I was bothered by things that usually don't bother me.....	0	1	2	3
2. I did not feel like eating; my appetite was poor.....	0	1	2	3
3. I felt that I could not shake off the blues even with help from my family...	0	1	2	3
4. I felt that I was just as good as other people..... ……	0	1	2	3
5. I had trouble keeping my mind on what I was doing.....	0	1	2	3
6. I felt depressed.....	0	1	2	3
7. I felt that everything I did was an effort.....	0	1	2	3
8. I felt hopeful about the future.....	0	1	2	3
9. I thought my life had been a failure.	0	1	2	3
10. I felt fearful.....	0	1	2	3
11. My sleep was restless.....	0	1	2	3
12. I was happy.....	0	1	2	3
13. I talked less than usual.....	0	1	2	3
14. I felt lonely.....	0	1	2	3
15. People were unfriendly.....	0	1	2	3
16. I enjoyed life.....	0	1	2	3
17. I had crying spells.....	0	1	2	3
18. I felt sad.....	0	1	2	3

19. I felt that people disliked me.....0	1	2	3
20. I could not "get going"..... 0	1	2	3

APPENDIX D
Family Support Scale
© Dunst, Trivette, & Hamby, 1999

Instructions: Listed below are people and groups that oftentimes are helpful to members of a family raising a young child. This questionnaire asks you to indicate how helpful each source is to your family.

Please circle the response that best describes how helpful the sources have been to your family during the past 3 to 6 months. If a source off help has not been available to your family during this period of time, circle NA (Not Available) response.

How helpful has each of the following been to you in terms of raising your child(ren):	Not Available	Not at All Helpful	Sometimes Helpful	Generally Helpful	Very Helpful	Extremely Helpful
1. My parents	NA	1	2	3	4	5
2. My spouse or partner's parents	NA	1	2	3	4	5
3. My relatives/kin	NA	1	2	3	4	5
4. My spouse or partner's relatives/kin	NA	1	2	3	4	5
5. Spouse or partner	NA	1	2	3	4	5
6. My friends	NA	1	2	3	4	5
7. My spouse or partner's friends	NA	1	2	3	4	5
8. My own children	NA	1	2	3	4	5
9. Other parents	NA	1	2	3	4	5
10. Co-workers	NA	1	2	3	4	5
11. Parent groups	NA	1	2	3	4	5
12. Social groups/clubs	NA	1	2	3	4	5
13. Church members/minister	NA	1	2	3	4	5
14. My family or child's physician	NA	1	2	3	4	5
15. Early intervention programs	NA	1	2	3	4	5
16. School or day care	NA	1	2	3	4	5
17. Professional helpers	NA	1	2	3	4	5
18. Professional agencies	NA	1	2	3	4	5

APPENDIX E
Parenting Stress Index
© Abidin, 1995

Instructions
Read each statement carefully. For each statement, please focus on the child you are most concerned about, and circle the response that best represents your opinion.

Circle the SA if you strongly agree with the statement.
Circle the A if you agree with the statement.
Circle the NS if you are not sure.
Circle the D if you disagree with the statement.
Circle the SD if you strongly disagree with the statement.

For example, if you sometimes enjoy going to the movies, you would circle A in response to the following statement:

I enjoy going to the movies. SA (A) NS D SD

While you may not find a response that exactly states your feelings, please circle the response that comes closest to describing how you feel. YOUR FIRST REACTION TO EACH QUESTION SHOULD BE YOUR ANSWER. Circle only one response for each statement.

SA = Strongly Agree A=Agree NS=Not Sure D=Disagree SD=Strongly Disagree

1. I often have the feeling that I cannot handle things very well	SA	A	NS	D	SD
2. I find myself giving up more of my life to meet my children's needs than I ever expected	SA	A	NS	D	SD
3. I feel trapped by my responsibilities as a parent	SA	A	NS	D	SD
4. Since having this child, I have been unable to do new and different things	SA	A	NS	D	SD
5. Since having a child, I feel that I am almost never able to do things that I like to do	SA	A	NS	D	SD
6. I am unhappy with the last purchase of clothing I made for myself	SA	A	NS	D	SD
7. There are quite a few things that bother me about my life	SA	A	NS	D	SD
8. Having a child has caused more problems that I expected in my relationship with my spouse (or male/female friend)	SA	A	NS	D	SD
9. I feel alone and without friends	SA	A	NS	D	SD
10. When I go to a party, I usually expect not to enjoy myself	SA	A	NS	D	SD

11. I am not as interested in people as I used to be	SA	A	NS	D	SD
12. I don't enjoy things as I used to	SA	A	NS	D	SD
13. My child rarely does things for me that make me feel good	SA	A	NS	D	SD
14. Sometimes I feel my child doesn't like me and doesn't want to be close to me	SA	A	NS	D	SD
15. My child smiles at me much less than I expected	SA	A	NS	D	SD
16. When I do things for my child, I get the feeling that my efforts are not appreciated very much	SA	A	NS	D	SD
17. When playing, my child doesn't often giggle or laugh	SA	A	NS	D	SD
18. My child doesn't seem to learn as quickly as most children	SA	A	NS	D	SD
19. My child doesn't seem to smile as much as most children	SA	A	NS	D	SD
20. My child is not able to do as much as I expected	SA	A	NS	D	SD
21. It takes a long time and it is very hard for my child to get used to new things	SA	A	NS	D	SD

For the next statement, choose your response from the choices "1" to "5" below:

22. I feel that I am: 1. not very good at being a parent 2. a person who has some trouble being a parent 3. an average parent 4. a better than average parent 5. a very good parent	1	2	3	4	5	
23. I expected to have closer and warmer feelings for my child than I do and this bothers me	SA	A	NS	D	SD	
24. Sometimes my child does things that bother me just to be mean	SA	A	NS	D	SD	
25. My child seems to cry or fuss more often than most children	SA	A	NS	D	SD	
26. My child generally wakes up in a bad mood	SA	A	NS	D	SD	
27. I feel that my child is very moody and easily upset	SA	A	NS	D	SD	
28. My child does a few things which bother me a great deal	SA	A	NS	D	SD	
29. My child reacts very strongly when something happens that my child doesn't like	SA	A	NS	D	SD	

30. My child gets upset easily over the smallest thing	SA	A	NS	D	SD
31. My child's sleeping or eating schedule was much harder to establish than I expected	SA	A	NS	D	SD

For the next statement, choose your response from the choices "1" to "5" below:

32. I have found that getting my child to do something or stop doing something is:	1	2	3	4	5

1. much harder than I expected
2. somewhat harder than I expected
3. about as hard as I expected
4. somewhat easier than I expected
5. much easier than I expected

For the next statement, choose your response from the choices "10+" to "1-3"

33. Think carefully and count the number of things which your child does that bothers you	10+	8-9	6-7	4-5	1-3
34. There are some things that my child does that really bother me a lot	SA	A	NS	D	SD
35. My child turned out to be more of a problem than I expected	SA	A	NS	D	SD
36. My child makes more demands on me than most children	SA	A	NS	D	SD

APPENDIX F
Child Demographic Information

1. How old is your child? _____years

2. What is your child's IQ? _____

3. Please list any diagnoses your child may have, including *psychological diagnoses* such as autism or ADHD *and* *medical diagnoses* such as asthma or gastric reflux.

_____

_____

_____

APPENDIX G

Social Responsiveness Scale

© Constantino, 2005

For each question, circle the number that best describes your child's behavior over the past 6 months.

1 = NOT TRUE 2 = SOMETIMES TRUE 3 = OFTEN TRUE 4 = ALMOST ALWAYS TRUE

1. Seems much more fidgety in social situations than when alone……..…….....1 2 3 4
2. Expressions on his or her face don't match what he or she is saying…….…….....1 2 3 4
3. Seems self-confident when interacting with others…..……...1 2 3 4
4. When under stress, he or she shows rigid or inflexible patterns of behavior that seem odd……..1 2 3 4
5. Doesn't recognize when others are trying to take advantage of him or her…….……...…1 2 3 4
6. Would rather be alone than with others……..……...……...1 2 3 4
7. Is aware of what others are thinking or feeling…..……..1 2 3 4
8. Behaves in ways that seem strange or bizarre...……...1 2 3 4
9. Clings to adults, seems too dependent on them……....1 2 3 4
10. Takes things too literally and doesn't get the real meaning of a conversation……...1 2 3 4
11. Has good self-confidence……..…….....1 2 3 4
12. Is able to communicate his or her feelings to others…….……..1 2 3 4
13. Is awkward in turn-taking interactions with peers (e.g., doesn't seem to understand the give-and-take of conversations)…….……1 2 3 4
14. Is not well coordinated…….……....1 2 3 4
15. Is able to understand the meaning of other people's tone of voice and facial expression…….1 2 3 4
16. Avoids eye contact of has unusual eye contact……..……..1 2 3 4
17. Recognizes when something is unfair……..1 2 3 4
18. Has difficulty making friends, even when trying his or her best…….……1 2 3 4
19. Gets frustrated trying to get ideas across in conversations.…….1 2 3 4
20. Shows unusual sensory interests (e.g., mouthing or spinning objects) or strange ways of playing with toys……...……1 2 3 4
21. Is able to imitate others' actions…….……..1 2 3 4
22. Plays appropriately with children his or her age…..……1 2 3 4
23. Does not join group activities unless told to do so……..……1 2 3 4
24. Has more difficulty than other children with changes in his or her routine….1 2 3 4
25. Doesn't seem to mind being out of step with or "not on the same wavelength" as others……...….1 2 3 4
26. Offers comfort to others when they are sad……..……1 2 3 4
27. Avoids starting social interactions with peers or adults.……..1 2 3 4
28. Thinks or talks about the same thing over and over.……1 2 3 4
29. Is regarded by other children as odd or weird…….……1 2 3 4

1 = NOT TRUE 2 = SOMETIMES TRUE 3 = OFTEN TRUE 4 = ALMOST ALWAYS TRUE

30. Becomes upset in a situations with lots of things going on……1 2 3 4
31. Can't get his or her mind off something once he or she starts thinking about it……..….1 2 3 4
32. Has good personal hygiene……..1 2 3 4
33. Is socially awkward, even when he or she is trying to be polite.……1 2 3 4
34. Avoids people who want to be emotionally close to him or her…….….1 2 3 4
35. Has trouble keeping up with the flow of a normal conversation…….…….1 2 3 4
36. Has difficulty relating to adults…….……...1 2 3 4
37. Has difficulty relating to peers…….……1 2 3 4
38. Responds appropriately to mood changes in others (e.g., when a friend's or playmate's mood changes from happy to sad)…….1 2 3 4
39. Has an unusually narrow range of interests……..……1 2 3 4
40. Is imaginative, good at pretending (without losing touch with reality)……1 2 3 4
41. Wanders aimlessly from one activity to another……...1 2 3 4
42. Seems overly sensitive to sounds, textures, or smells……...1 2 3 4
43. Separates easily from caregivers……...1 2 3 4
44. Doesn't understand how events relate to one another (cause and effect) the way other children his or her age do…….….1 2 3 4
45. Focuses his or her attention to where others are looking or listening……1 2 3 4
46. Has overly serious facial expressions…… 1 2 3 4
47. Is too silly or laughs inappropriately……..1 2 3 4
48. Has a sense of humor, understands jokes……...1 2 3 4
49. Does extremely well at a few tasks, but does not do as well at most other tasks…….…...1 2 3 4
50. Has repetitive, odd behaviors such as hand flapping or rocking…….....1 2 3 4
51. Has difficulty answering questions directly and ends up talking around the subject……...1 2 3 4
52. Know when he or she is talking too loud or making too much noise.……1 2 3 4
53. Talks to people with an unusual tone of voice (e.g. talks like a robot or like he or she is giving a lecture……..……...1 2 3 4
54. Seems to react to people as if they are objects……...1 2 3 4
55. Knows when he or she is too close to someone or is invading someone's space……..1 2 3 4
56. Walks in between two people who are talking…..……...1 2 3 4
57. Gets teased a lot……..……1 2 3 4
58. Concentrates too much on parts of things rather than seeing the whole picture. (e.g., If asked to describe what happened in a story he or she may talk only about the kind of clothing the characters were wearing……1 2 3 4
59. Is overly suspicious……..……1 2 3 4
60. Is emotionally distant, doesn't show his or her feelings……..…1 2 3 4
61. Is inflexible, has a hard time changing his or her mind……...1 2 3 4
62. Gives unusual or illogical reasons for doing things……..……...1 2 3 4

1 = NOT TRUE 2 = SOMETIMES TRUE 3 = OFTEN TRUE 4 = ALMOST ALWAYS TRUE

63. Touches others in an unusual way (e.g., he or she may touch someone just to make contact and then walk away without saying anything)……..1 2 3 4
64. Is too tense in social settings……..……..1 2 3 4
65. Stares or gazes off into space……..……1 2 3 4

APPENDIX H
Aberrant Behavior Checklist – Irritability Subscale

This set of questions refers to your child's behavior over the PAST MONTH.

Please rate your child's behavior for the last four weeks when they're not in school. For each item, decide whether the behavior is a problem and circle the appropriate number:

0 = not at all a problem
1 = the behavior is a problem but slight in degree
2 = the problem is moderately serious
3 = the problem is severe in degree

When judging your child's behavior, please keep the following points in mind:

(a) Take the relative *frequency* into account for each behavior specified. For example, if your child averages more temper outbursts than most other children with autism you know, it is probably moderately serious (2) or severe (3) even if these occur only once or twice a week. Other behaviors, such as noncompliance, would probably have to occur more frequently to merit an extreme rating.

(b) If you have access to this information, consider the experiences of other adults with this child. If the child has problems with others but not with you, try to take the whole picture into account.

(c) Try to consider whether a given behavior interferes with his/her development, functioning, or relationships. For example, body rocking or social withdrawal may not disrupt other children or adults, but it almost certainly hinders individual development or functioning.

Do not spend too much time on each item – your first reaction is usually the right one.

1. Injures self on purpose	0	1	2	3
2. Aggressive to other children or adults (verbally or physically)	0	1	2	3
3. Screams inappropriately	0	1	2	3
4. Temper tantrums/outbursts	0	1	2	3
5. Irritable and whiny	0	1	2	3
6. Yells at inappropriate times	0	1	2	3
7. Depressed mood	0	1	2	3
8. Demands must be met immediately	0	1	2	3
9. Cries over minor annoyances and hurts	0	1	2	3
10. Mood changes quickly	0	1	2	3

11. Cries and screams inappropriately	0	1	2	3
12. Stamps feet or bangs objects or slams doors	0	1	2	3
13. Deliberately hurts himself/herself	0	1	2	3
14. Does physical violence to self	0	1	2	3
15. Has temper outbursts or tantrums when he/she does not get own way	0	1	2	3

APPENDIX I

The Beach Center Family Quality of Life Survey

All the information you give us is confidential. Your name will not be attached to any of the information you give us. It is important that you answer as many questions as you can, but please feel free to skip those questions that make you feel uncomfortable.

How satisfied am I that…	*Very Dissatisfied*	*Dissatisfied*	*Neither*	*Satisfied*	*Very Satisfied*
1. My family enjoys spending time together.					
2. My family members help the children learn to be independent.					
3. My family has the support we need to relieve stress.					
4. My family members have friends or others who provide support.					
5. My family members help the children with schoolwork and activities.					
6. My family members have transportation to get to the places they need to be.					
7. My family members talk openly with each other.					
8. My family members teach the children how to get along with others.					
9. My family members have some time to pursue our own interests.					
10. Our family solves problems together.					

How satisfied am I that…	*Very Dissatisfied*	*Dissatisfied*	*Neither*	*Satisfied*	*Very Satisfied*
11. My family members support each other to accomplish goals.					
12. My family members show that they love and care for each other.					
13. My family has outside help available to us to take care of special needs of all family members.					
14. Adults in our family teach the children to make good decisions.					
15. My family gets medical care when needed.					
16. My family has a way to take care of our expenses.					
17. Adults in my family know other people in the children's lives (friends, teachers, etc.).					
18. My family is able to handle life's ups and downs.					
19. Adults in my family have time to take care of the individual needs of every child.					
20. My family gets dental care when needed.					

How satisfied am I that…	*Very Dissatisfied*	*Dissatisfied*	*Neither*	*Satisfied*	*Very Satisfied*
21. My family feels safe at home, work, school, and in our neighborhood.					
22. My family member with a disability has support to accomplish goals at school or at workplace.					
23. My family member with a disability has support to accomplish goals at home.					
24. My family member with a disability has support to make friends.					
25. My family has good relationships with the service providers who provide services and support to our family member with a disability.					

APPENDIX J

Satisfaction with Life Scale

Below are five statements that you may agree or disagree with. Using the 1-7 scale below indicate your agreement with each item by placing the appropriate number on the line preceding that item. Please be open and honest in your responding.

- 7 - Strongly agree
- 6 - Agree
- 5 - Slightly agree
- 4 - Neither agree nor disgree
- 3 - Slightly disagree
- 2 - Disgree
- 1 - Strongly disgree

____ In most ways my life is close to my ideal.

____ The conditions of my life are excellent.

____ I am satisfied with my life.

____ So far I have gotten the important things I want in life.

____ If I could live my life over, I would change almost nothing.

APPENDIX K
Community Integration Scale

	Never	Monthly or Less	A Few Times a Month	About Once a Week	2-3 Times a Week or More
How often does your child interact with peers/friends?	1	2	3	4	5
How often does your child participate in extracurricular activities?	1	2	3	4	5
How often do you participate in leisure/recreational activities (without your child)?	1	2	3	4	5
How often does your child participate in leisure/ recreational activities with the family?	1	2	3	4	5
How many days are you on (or did you) vacation this year?	0	1-3	3-5	6-14	15+
	Always	*Often*	*Sometimes*	*Rarely*	*Never*
Does problem behavior ever prevent you or restrict you from going into public as much as you would like?	1	2	3	4	5