

# Focus on Autism and Other Developmental Disabilities

<http://foa.sagepub.com/>

---

## Examining the Relationship Between Stress and Lack of Social Support in Mothers of Children With Autism

Brian A. Boyd

*Focus Autism Other Dev Disabl* 2002 17: 208

DOI: 10.1177/10883576020170040301

The online version of this article can be found at:

<http://foa.sagepub.com/content/17/4/208>

---

Published by:

Hammill Institute on Disabilities



and



<http://www.sagepublications.com>

Additional services and information for *Focus on Autism and Other Developmental Disabilities* can be found at:

**Email Alerts:** <http://foa.sagepub.com/cgi/alerts>

**Subscriptions:** <http://foa.sagepub.com/subscriptions>

**Reprints:** <http://www.sagepub.com/journalsReprints.nav>

**Permissions:** <http://www.sagepub.com/journalsPermissions.nav>

# Examining the Relationship Between Stress and Lack of Social Support in Mothers of Children with Autism

Brian A. Boyd

A selective, critical literature review is presented on the relationship between stress and the paucity of social supports for mothers of children with autism. The published literature reviewed reveals an association between challenging child characteristics and a mother's inclination to seek social support, with mothers under greater stress being more prone to pursue social support. For mothers of children with autism, informal support appeared to be a more effective stress-buffer than formal support. The cumulative results of several studies illustrated that parents who received support related better emotionally to their children. Furthermore, low levels of social support were the most powerful predictors of depression and anxiety in mothers.

Parenting a child with a disability can produce great stress and a sense of imbalance in the family system (Burrell, Thompson, & Sexton, 1994). It is important that parents have a means to cope with such stress, and one factor that has been shown to alleviate parental stress is social support (Bristol, 1984; Dyson, 1997; Sharpley, Bitsika, & Efreimidis, 1997). However, the ability of social support to serve as a stress mediator has been found to be related to the parent's gender. For example, Krauss (1993) found that social support contributed to lower maternal stress, yet for fathers it was not a significant contributor to lower stress levels. Such findings may reflect the fact that typically the majority of caregiver demands are placed on mothers of children with disabilities (McLinden, 1990).

As a group, mothers of children with autism appear to be the most adversely

affected by the stress-related factors that result from rearing a child with a disability. Sanders and Morgan (1997) reported higher levels of stress in mothers of children with autism when compared to mothers of children with other developmental disabilities (e.g., Down syndrome). According to Sharpley et al. (1997), the three most stressful factors associated with parenting a child with autism are (a) concern over the permanency of the condition; (b) poor acceptance of autistic behaviors by society and, often, by other family members; and (c) the very low levels of social support received by parents.

Dunst, Trivette, and Cross (1986) defined social support as a multidimensional construct that includes physical and instrumental assistance, attitude transmission, resource and information sharing, and emotional and psychological support. Social support may also refer to

formal services one receives from professional-based organizations, and/or services from more loosely structured organizations (e.g., social clubs, churches) that the family deems important to their lifestyle. This literature review will examine four aspects of social support, which fall into one of two categories: precursors that lead mothers to seek out social support and the actual use of social support to alleviate stress. First, the review will investigate the characteristics of users of social support and the characteristics of their children that lead parents to seek that support. Second, the review will look at the stress that mothers experience due to a lack of social support. Third, the review will consider the positive effects of social support (informal or formal) on maternal stress. Finally, the literature review will examine the effects of social support on parenting children with disabilities.

This article reviews research from professional peer-reviewed journals and two edited books (Schopler & Mesibov, 1983, 1984) concerning the use of social support to alleviate stress in mothers of children with autism. All reviewed literature was found by conducting a search on the ERIC database using the keywords *social support*, *autism*, *mothers*, *parents*, and *developmental disabilities*. This is not an exhaustive review; the ar-

ticles span 20 years (from 1979 to 1999). No articles related to the use of social support by mothers of children with autism were found past 1999. The articles that will be reviewed used a variety of research methods, including parent questionnaires, self-report measures, and analytic research designs to obtain their findings.

## Measures

Three self-report instruments were commonly used to measure the magnitude of stress experienced by parents of children with autism, and the social supports (formal or informal) available to them.

### Parenting Stress

Two stress measures were routinely used in the reviewed literature: the *Parenting Stress Index* (PSI; Abidin, 1983) and the *Questionnaire on Resources and Stress* (QRS; Holyroyd, 1974). Other less commonly used stress measures are mentioned in the review. The PSI is a self-report measure designed to determine the degree of stress in the parent-child system. The stress index is divided into two domains: child characteristics and parent characteristics. The division of the domains permits the differentiation of stress that is primarily child related from that which is related to other aspects of parenting (Robbins, Dunlap, & Plienis, 1991). The QRS is a 285-item true-false measure designed to assess the possible pattern of parental stress.

### Family Support

The most routinely used measure of family support was the *Family Support Scale* (Dunst, Jenkins, & Trivette, 1984). Again, less frequently reported measures of family support are referred to within the review. The *Family Support Scale* is an 18-item self-report scale measuring different sources of support (e.g., spouses, friends) that parents have found useful in rearing the young child with a disability (Dyson, 1997).

## Precursors to Seeking Social Support

This section will address three topics related to mothers' inclination to pursue social support. First, it will examine the particular characteristics mothers possess that lead them to seek social support. Second, it will concentrate on how the characteristics of the child with autism interact with those of the mother to further influence her decision to obtain social support (and perhaps further limit her choices). Last, it will look at the negative effects that can accrue when social support is unavailable.

### User Characteristics

*User characteristics* refers to those inherent qualities or external factors that persuade the mother to locate social support. One of the main precursors that lead mothers of children with autism to seek social support is the amount of stress they are experiencing as a result of rearing their child (Sharpley et al., 1997). A high level of stress in mothers of children with autism has been well documented (Bristol & Schopler, 1983; Koegel et al., 1992). Five studies were found that examined the characteristics of mothers of children with autism. Koegel et al. proposed that they have a "consistent stress profile" associated with rearing the child. This conclusion was based on a study that involved 50 mothers across cultural and geographic environments who had children of different ages and functioning levels. All mothers in the study were found to be stressed according to the QRS. Elevated stress levels due to the cognitive impairments of the child, and the potential long-term dependency of the child on the parents because of those impairments were also found in a study by Robbins et al. (1991).

Robbins et al. (1991) carried out a yearlong early intervention program for 12 children with autism ranging in age from 29 to 52 months. Eight of the children had a formal diagnosis of autism, and the remaining were described as having autistic tendencies. Mothers actively

participated in the intervention plan and received individualized programming for their child 5 hours each week over approximately a 3-month period. The program consisted of teaching the mothers techniques to facilitate their children's learning and to address behavior management issues. Even after intervention, all of the mothers reported on the PSI that their children were significant sources of stress. However, the stress scores of the parents whose children made the least amount of progress (low-improvement group) were significantly higher than those who made the greatest gains (high-improvement group).

Robbins et al.'s (1991) finding that all 12 mothers felt their child was a significant source of stress is alarming, given that such high stress levels are not found when mothers of children with other developmental disabilities are studied. For example, Wolf, Noh, Fisman, and Speechley (1989) conducted a survey study composed of parents of 124 children (31 with autism, 31 with Down syndrome, 62 with no disabilities) who were statistically matched on gender and age. The parents completed three questionnaires related to measures of stress, depression, and social support. Numerous phone calls from the investigators led to a 100% response rate from the parents. The study found that both mothers and fathers of children with autism were significantly more stressed than parents of children from the two other groups, and that mothers of children with autism were at an increased risk for depression. However, symptoms of depression in mothers who believed that social support was readily available were suppressed.

Still, the characteristics of the child appeared to exacerbate the stress levels and the display of depressive symptoms in the mother (Dumas, Wolf, Fisman, & Culligan, 1991). Dumas and colleagues compared the level of parenting stress, child behavior problems, and depression in parents who had children with autism, Down syndrome, behavior disorders, or normal development. The PSI was used to measure parent's stress level, and the *Beck Depression Inventory* (BDI; Beck,

Ward, Mendelson, Mock, & Erbaugh, 1988) was used to measure depression in 149 mothers and 123 fathers. The BDI is a 21-item instrument designed to measure depressive symptomatology. The study revealed that parents of children with autism and behavior disorders had the highest levels of stress and that those higher levels were reflected on the child domain section of the PSI, which suggests that the child's characteristics affected the parents' stress level. Parents of children with behavior disorders reported the most numerous and most intense behavioral difficulties. This in itself is not surprising; however, according to the BDI, mothers of children with autism and behavior disorders experienced higher levels of depression than the other two groups. Both the stress and the depression appeared to be related to rearing an exceptional child. However, not all mothers of children with autism in the study experienced clinically elevated stress scores. Some mothers seem to possess characteristics or traits that shield them from the psychological manifestation of stress and depression that can accompany rearing a child with autism (Gill & Harris, 1991).

Gill and Harris (1991) examined the personalities of mothers of children with autism to determine if there were innate characteristics that buffered them from experiencing high stress levels. The study involved 60 mothers and measured the effects of social support and hardiness on the women's responses to the stressful demands of rearing a child with autism. Individuals with "hardy" personalities were defined as those who remain emotionally and physiologically healthy even after experiencing high degrees of stress, due to certain inherent characteristics, such as control, commitment, and embrace of challenges. Hardiness was measured using the *Hardiness Test* (see Maddi, Kobasa, & Hoover, 1979), a 50-item self-report measure that provides both a total score and individual scores on the characteristics associated with hardy personalities. The results showed that individuals with hardy personalities reported the fewest somatic complaints. Also, mothers who reported

having social support had fewer depressive and somatic symptoms related to stress or depression. Gill and Harris concluded that social support may not be the causal or only factor in determining ability to cope or remain emotionally healthy in the face of parenting stress; rather, it is likely correlated with inherent individual personality traits.

Given that it is some mothers' personality traits, rather than social support, that buffer them from experiencing elevated stress levels as a result of rearing an exceptional child, mothers of children with autism who use social support not only may have more stress-inducing variables in their lives, such as the characteristics of the child's disability, but also may be more vulnerable to the effects of that stress because certain intrinsic personality traits are not present.

### **Child Characteristics**

Some mothers' ability to cope with the stress that results from raising a child with a disability may be related to particular characteristics of their children (Norton & Drew, 1994). Child characteristics are those qualities that the child possesses (e.g., temperament, cognitive abilities) that further sway the parent's decision to seek or not to seek social support. A pilot study by Bristol (1979) that involved 40 mothers of children with autism found that the number of coping problems reported by the mother was significantly related to both child characteristics and the adequacy of programming available to them. The best predictors of parent and family problems in families of children with autism were the children's difficult management problems, their degree of dependency on caregivers, and their need for assistance with self-help skills. These characteristics led parents to seek out social support to relieve some of the stress associated with rearing the child. The use of respite care services in families who have children with autism with more difficult child characteristics was examined in a study of 36 two-parent families in which the child with autism was between 7 and 17 years of age (Factor, Perry, & Freeman, 1990). Nine-

teen of the 36 families in the study used respite care and 17 did not. Users of respite care reported that their children had more difficult child characteristics and significantly more physical incapacitation than nonusers. The results suggested that the characteristics of the child influenced the mother's decision to seek out and use social supports.

Salisbury (1990) investigated the characteristics of users and nonusers of respite care in 105 mothers of children showing mild/moderate or severe/profound disabilities. Children in the study were referred to as "developmentally disabled" and although Salisbury mentioned that they all had mental retardation, there is no mention of whether any of the children had dual diagnoses. She found that the child's level of functioning was significantly related to the mother's reported level of stress. Higher levels of stress were reported by mothers of children with severe/profound disabilities. Mothers who actually used respite care reported higher levels of stress at the point of enrollment into respite care services than did nonusers on items associated with their child's cognitive development. The study also found that the size of the mother's social support network was negatively correlated with self-reports of stress: Mothers with larger support networks reported lower levels of stress. Similarly, Bristol and Schopler (1983) found that mothers with few supports had higher levels of stress than mothers with many supports. It seems that two of the most significant child characteristics that lead mothers of children with autism to seek social support are behavior management concerns and cognitive limitations. Having children with challenging characteristics leads mothers to seek formal supports, such as respite services, especially if there are few supportive members in the mother's current social network.

### **Lack of Social Supports**

Three studies were found that examined the effects on mothers of a scarcity of social support. One study looked at the lack of support provided by formal agencies

(Sanders & Morgan, 1997), another investigated the lack of support provided by spouses (Konstantareas & Homatidis, 1989), and Gray and Holden (1992) studied the effects of limited social support on both parents. Sanders and Morgan interviewed 54 families who represented three populations of children (those with autism, Down syndrome, and no disabilities) to examine stress and parental adjustment to a child with disabilities. The results of the study showed that mothers of children with autism reported more parent and family problems (e.g., time demands), were slightly more pessimistic about the prospect of their child being self-sufficient, and perceived more negative child characteristics when compared with mothers and fathers of children with Down syndrome and parents of typical children. Time demands reported by these mothers related to difficulty finding baby-sitters or other respite services due to their children's severe problem behavior (e.g., self-injurious behavior, physical aggression, unusual sleep patterns).

Furthermore, mothers of children with autism and those of children with Down syndrome reported significantly less family participation in recreational and sporting activities than did mothers of typical children. Both groups of mothers also reported less involvement in political, social, intellectual, and cultural activities, which often serve as stress-reducers to typical mothers. Sanders and Morgan (1997) demonstrated that a lack of social support can lead parents to withdraw from the larger community because of the negative characteristics they associate with their child's disability—which in turn exacerbates their stress level. It is not surprising, then, that the study also found that mothers of children with autism were the most stressed of the three groups and that they had more difficulty obtaining community-based social support.

When mothers first seek support, they often turn to more informal sources—in particular, their spouses (Konstantareas & Homatidis, 1989). Konstantareas and Homatidis investigated the effects of spousal support on maternal stress in a

study of 44 parents of children with autism ranging in age from 2 to 7 years. Mothers rated their levels of stress on an adapted version of the *Childhood Autism Rating Scale* (CARS; see Schopler, Reichler, DeVellis, & Daly, 1980), a 14-item scale that measures the severity of autistic symptomatology. In the study, parents and clinicians also used the scale to independently rate the severity of the child's symptoms. They found that mothers who rated their children as more severely disabled also had higher stress scores than their husbands. Mothers' stress scores were negatively correlated with the degree of support they received, whereas fathers' stress scores were negatively correlated with both the number and the degree of supports. Thus, for mothers, the extent to which support services were *useful* was a better indicator of low maternal stress than simply having a great number of resources available. This finding differs from that of Salisbury (1990), who found that mothers' stress levels were reduced by having large social support networks. Perhaps Konstantareas and Homatidis' findings are a more refined analysis of those by Salisbury, as they specifically examined spousal support.

Twenty-four of the mothers in the Konstantareas and Homatidis (1989) study, but only three of the fathers, expressed the need for additional support from their spouses. Specifically, mothers wanted the husband to (a) provide them with some relief from caring for the child with autism, (b) play more of a part in disciplining the child, and (c) provide help spontaneously with daily chores, instead of having to be asked. Mothers also reported more aggravations with the support agencies they were currently using than did fathers. This finding may be related to the fact that mothers are typically the ones who are in direct contact with the support agencies because they are often responsible for the caretaking demands of the child. The fact that mothers spend more time with the child could also explain why the mothers' ratings of the disability's severity were closer to the clinical ratings than the fathers'. Still, the child with autism was a

source of stress for both parents; thus, the effects of limited support networks on the well-being of both parents is of concern.

Gray and Holden (1992) examined factors that contributed to the psychosocial well-being of parents of children with autism. One hundred seventy-two parents responded to questionnaires sent by the researchers. The questionnaires were used to gather background and demographic information and to measure the families' coping skills and their use of social support. Social support was measured using the *Social Support Index* (SSI; McCubbin et al., 1983), a 25-item scale designed to measure social support from the family and community. The study showed that parents who received more social support scored lower on measures of depression, anxiety, and anger. In fact, the most powerful predictor of depression and anxiety in parents was lower levels of social support.

Mothers who received less social support were also *angrier*. Limited social support may produce such negative effects in mothers because it forces them to withdraw from community-based events, which are potentially stress-reducing. And for mothers, as opposed to fathers, the perceived usefulness and availability of the social support network may play a more vital role in alleviating stress than its actual size. In fact, mothers most often want, and first seek, support from their spouses.

Mothers' and children's characteristics often interact to influence the mother's decision to seek and use social support. If the mother is unable to locate such support, it can further affect her emotional well-being. Next I will review literature that has examined how the actual use of social support affects the mother and her relationship with the child.

## Use of Social Support

### *Effects of Social Support*

Research addressing the effects of social support on family stress can be grouped into two categories: (a) research assessing

the effects of informal support and (b) research assessing the effects of formal support. Bristol and Schopler (1983) defined *formal support* as assistance that is social, psychological, physical, or financial and is provided either for free or in exchange for a fee through an organized group or agency. They defined *informal support* as a network that may include the immediate and extended family, friends, neighbors, and other parents of children with disabilities. Two studies have examined the effects of informal support on maternal stress.

**Informal Support.** Bristol (1984) studied the psychosocial environment of families of children with autism to determine which family characteristics helped them to adapt to and cope with the child. Forty-five mothers were recruited from consecutive referrals to Division TEACCH, a statewide program for individuals with autism in North Carolina. In the study, 27 of the 45 children had formal diagnoses of autism, and 18 had significant communication and/or behavioral problems. The study found that mothers in the low-stress group reported greater perceived support. The study also found that for all mothers, the most important sources of support that led to lower stress levels were spouses, the mothers' relatives, and other parents of children with disabilities. Mothers who perceived greater support also reported significantly fewer depressive symptoms and happier marriages.

Similar reactions to informal supports were found by Herman and Thompson (1995) when they looked at factors related to families' perceptions of "internal resources" in rearing a child with a developmental disability. Similar to Bristol's (1984) use of "informal supports," "internal resources" was defined as resources that were within the family unit and did not need to be provided by external agents (e.g., special needs-related agencies). Participants were 415 families enrolled in the Cash Subsidy Program in Michigan for children with developmental disabilities (mental retardation, cerebral palsy, autism, and epilepsy). Both mothers and fathers felt that their part-

ner—an internal resource—was the most helpful in providing social support, and more than half of the respondents reported that social support from more formal sources, such as parent groups, social clubs, and day care centers, was unavailable.

**Formal Support.** Peck (1998) evaluated the effects of a multicomponent intervention for families of young children with autism that was designed to reduce the families' stress. The intervention program applied a family systems model that targeted three goals: to increase families' (a) factual knowledge about autism, (b) knowledge of stress and mechanisms for coping with stress, and (c) awareness of social support and advocacy issues. Nineteen parents of children with autism ranging in age from 2 to 6 years were enrolled in the intervention program. However, only the nine parents who completed the program and provided the most data were included in the treatment group. The results of the study revealed that parents showed only a modest non-significant increase in factual knowledge, and the intervention was even less successful at increasing knowledge about stress management. Still the majority of parents reported positive experiences of attending the parent support group, which entailed meeting other parents of children with autism, discussing common concerns, and increasing the size of their support network. Bristol (1984) reported similar findings in regard to parent support groups in her study of the support needs of parents.

Krauss, Upshur, Shonkoff, and Hauser-Cram (1993) examined the effects of professionally organized parent support groups for 150 mothers of infants and toddlers with disabilities (Down syndrome, motor impairment, and developmental delay of unknown origin). The results of the study revealed both positive and negative effects of parent support groups. On the positive side, the intensity of participation by mothers in the parent support group was associated with significant gains in perceived support from other mothers in the group. Thus, the more the mothers attended, the

more apt they were to perceive the support of other parents in the group as beneficial. On the negative side, greater intensity in attendance was also associated with mothers' elevated reports of the personal strain that the child placed on the family. Krauss and colleagues suspected that these results were due to group meetings' functioning as a place parents could go to discuss common concerns, one of which was the significant impact the child had on the family.

Bailey et al. (1999) examined the support needs of 200 Latino parents of children with developmental disabilities, living in diverse parts of the United States, to determine their needs and the social supports currently available to meet those needs. The results revealed that parents needed information, specifically, about the child's condition, how to obtain services for the child, and how to cope with the child's behavior. Mothers and fathers reported that they received the highest levels of support from family and formal support sources. Both were rated as being significantly more supportive than friends or other sources of informal support (e.g., churches, neighbors).

Overall, informal support appears to be a more effective stress buffer than formal support. One of the findings that pervaded the literature on both informal and formal supports was the benefit mothers derived from joining parent support groups. At group meetings they were able to freely share their concerns about their child. This finding leads to the necessary examination of how the use of social support then affects parenting.

### ***Influence of Support on Parenting***

Three studies examined the combined effects of maternal stress and the lack of social support on parenting behavior. Again, there is a severe lack of research addressing these variables in relation to parents of children with autism. Yet, these variables are important because they can aid professionals in developing more effective interventions to help parents cope with rearing a child with disabilities; thus,

they have been included in the present review. Hadadian (1994) studied 15 families with children ages 15 to 20 months with diagnoses of developmental delay or physical or sensory impairment, and 15 families with children having no known disabilities. Parents completed a set of measures that included the PSI. The study found that mothers who received support from their spouses related better emotionally to their children. Negative correlations were found for both fathers and mothers in regard to perceived stress and actual support. Thus, as the amount of actual support from family and friends decreased, the amount of perceived stress levels increased. A negative correlation was also found between mothers' perceived stress levels and the amount of community support.

Dunst, Trivette, and Cross (1986) investigated the mediating influences of social support for 137 parents of children with mental retardation, children with physical impairments, and those developmentally at risk for cognitive disabilities. They found that parental satisfaction with social support networks was associated with better personal well-being, more positive attitudes about the child, more positive interactions in parent-child play opportunities, and higher scores of their children on developmental tests. The study by Dunst et al. demonstrated the positive effects social support networks can have on the parent-child dyad. However, when such support is lacking or unavailable, it can cause parents to take drastic measures for the well-being of the family unit, for example, placing the child with disabilities in an out-of-home setting (Raif & Rimmerman, 1993).

Raif and Rimmerman (1993) examined factors related to parental inclination to apply for out-of-home placement for young children with developmental disabilities. Sixty-one parents from the central-western part of Israel participated in the study. The parents' sense of coherence and their use of social supports (formal and informal) were the variables investigated to assess their relationship to parental stress. *Sense of coherence* was defined as a core personality component af-

fecting a person's ability to cope. This trait comprises (a) comprehensibility (the cognitive dimension representing the person's perception of the world as structured and consistent), (b) manageability (the reflection of the person's view about his or her available and attainable resources), and (c) meaningfulness (the reflection of the person's sense of his or her life).

Raif and Rimmerman (1993) found that parents with a high sense of coherence had lower stress values on the QRS and a reduced inclination to apply for out-of-home placement for their children. Informal social support reported on the *Family Support Scale*, but not formal social support, was found to be associated with parental stress and with parents' inclination to apply for out-of-home placement for their child with disabilities—parents who received support from their extended families and friends had low stress levels and a low inclination to apply. Formal organizations were not found to be stress-reducing, nor did they reduce the parents' inclination to apply. The child's level of functioning was also related to parental application rates, with parents of children who had more severe disabilities having a higher tendency to apply than parents of children with mild to moderate disabilities. This study demonstrated how the child's characteristics can interact with a lack of social support and adversely affect both parents and child. Parents who receive social support relate better emotionally to their children and engage in more positive interactions with them. If social support is not available, parents may be forced to place their child outside of the home to restore family functioning.

Informal support, particularly spousal support, seems to be a more effective stress buffer for mothers of children with autism than formal support. The most beneficial form of formal support for mothers is the parent support group, where parents who have children with similar disabilities can go to share their concerns. Parents who receive support are less stressed and relate more positively to their children; parents who fail to receive social support may be put in

the unfortunate position of having to place their child out of home.

## Discussion

On the basis of the reviewed literature, it appears that both parent and child characteristics play a role in parents' decision to seek social support. Two of the most significant child characteristics that lead mothers to pursue social support are cognitive limitations and behavior problems (Bristol, 1979; Salisbury, 1990). Children with autism who have more severe cognitive limitations place a greater degree of stress on their mothers because of their potential for long-term dependency. Robbins et al. (1991) found that even with intervention, mothers of children with significant cognitive limitations were more stressed than mothers whose children had less severe cognitive impairments. Behavior issues may present even more of a challenge than cognitive ones because of the potential public scrutiny parents face from society, and perhaps from family and friends as well (Sharpley et al., 1997). This may place external pressure on families to seek social support to help them address the child's behavior problems. Unfortunately, these child characteristics may also further limit the mothers' social support choices and force them to withdraw from potentially stress-reducing activities because of the time demands the child places on the family. Such dramatic situations often lead to higher levels of stress and depression in mothers.

Stress and depression are two of the main factors that lead mothers of children with autism to obtain social support. As a result of such stress, mothers first seek support from their family (in particular, their spouses). In general, informal support sources are more effective at reducing stress in mothers than formal support. The most useful source of formal support for mothers seems to be parent support groups, where they feel free to discuss their concerns about rearing a child with autism without fear of being scrutinized (Krauss et al., 1993). Mothers who receive social support relate bet-

ter emotionally to their children and have more positive interactions with them (Dunst et al., 1986). When such support is not available, the result is often higher levels of stress and depression.

Still, the majority of studies reviewed in this article used parental self-reports to measure stress and parents' perception, and/or actual use, of social support. More objective research is needed to determine how specific child and parent characteristics interact to influence parents' decision to seek social support. For example, Bristol (1984) found that parents in the low-stressed group of her study had children who were perceived by their mothers to have less difficult personality characteristics and to be less socially obtrusive. In Bristol's study, the child's temperament and the mother's stress level interacted to influence the mother's decision to seek social support. Those mothers who believed their child was not temperamentally difficult also perceived greater support from informal sources. To provide more effective intervention services for parents of children with autism, professionals in the field must better understand how parent and child variables interact to affect parents' ability to seek out and obtain needed social support.

Researchers must further examine what types of social support would be most beneficial to parents. There is a paucity of research studies addressing the use of social support by parents of children with autism, which is reflected in the fact that no research was found for review after the year 1999. Research should also be conducted on the needs of fathers, so interventionists can better address their concerns as well. It is important to examine the needs of both parents because they are part of a family system, and often the actions of one parent affect those of the other. Dyson (1997) found that when fathers reported having more social support, a positive family relationship, and greater family emphasis on the personal growth of individual family members, mothers reported lower levels of stress.

Research is also needed to address the benefits of formal support for parents of

children with autism. Current studies on formal support have produced mixed results (Krauss et al., 1993). Professionals in the field must understand how both informal and formal supports can be used to alleviate the consistent stress associated with parenting a child with autism. Finally, future studies should examine how the use of social support by parents translates into positive parenting behavior, increased knowledge of the child's condition, and improved family functioning. Through this knowledge the field will be better able to meet the needs of the family and help them cope with, accept, and adapt to parenting a child with autism.

### **Implications for Practice**

**Parent- and Child-Related Interventions.** Stress and depression are two of the critical variables that lead mothers of children with autism to seek social support (Sharpley et al., 1997; Wolf et al., 1989). Effective interventions should both remediate the characteristics of autism in the child and alleviate the stress level of the parent by providing them access to sources of social support and parent training programs. Training is needed to help parents cope with the child's challenging characteristics. Behavior management issues and cognitive limitations are among the greatest stress-inducing child variables for the parent (Bristol, 1979; Salisbury, 1990); therefore, interventions geared toward the child should also help the parent address behavior management concerns in the home and community, and ways to cope with children who possess uneven patterns of cognitive development.

**Continuum of Supports.** Herman and Thompson (1995) found that husbands provide some of the most beneficial support to mothers. However, because society has become so much more diverse and the definition of family so much broader, service providers should help mothers identify alternative types of informal support when there is no spouse present. So far service providers have a limited knowledge base of how to best

support these parents. Parent support groups are an effective means of formal support for mothers of children with developmental disabilities, but even they have their flaws (Krauss et al., 1993; Peck, 1998). Service providers must be able to provide a continuum of support services to families, much like educators currently provide a continuum of alternative placements for their children. By providing parents with choices, it is more likely that they will find a support system that best meets their unique and diverse needs.

There are a number of reasons why professionals in the field must find more effective methods of supporting families of children with autism. For one, helping parents obtain needed social support may help to curtail the unnecessary institutionalization of countless children. Raif and Rimmerman (1993) demonstrated that high-stressed parents are more inclined to place their children out of home. Also, mothers of children with autism are one of the most stressed parental groups, and consistent and pervasive stress makes it even more difficult to parent. Future research must continue to investigate why this particular group of parents is so stressed and what types of social support best alleviate that stress. Professionals have a responsibility to help these mothers better cope with an already difficult, and potentially lifelong, situation.

### **ABOUT THE AUTHOR**

*Brian A. Boyd, MEd, is a doctoral student in the Department of Special Education at the University of Florida. His research interests include early intervention and autism spectrum disorders. Address: Brian A. Boyd, University of Florida, Department of Special Education, G-315 Norman Hall, PO Box 1107050, Gainesville, FL 32611-7050; e-mail: bb129@hotmail.com*

### **AUTHOR'S NOTES**

1. *This article was written as part of the author's master's project.*
2. *I would like to thank Martha Snell and Paige Pullen, of the Department of Special Education at the University of Virginia, for*



their thoughtful and critical reviews of this article. Their continuous guidance and encouragement throughout this process allowed me to complete this manuscript.

## REFERENCES

- Abidin, R. R. (1983). *Parenting stress index manual*. Charlottesville, VA: Pediatric Psychology Press.
- Bailey, D. B., Skinner, D., Correa, V., Arcia, E., Reyes-Blanes, M. E., Rodriguez, P., et al. (1999). Needs and supports reported by Latino families of young children with developmental disabilities. *American Journal of Mental Retardation, 104*, 437-451.
- Beck, A. T., Ward, C. H., Mendelson, M., Mock, J., & Erbaugh, J. (1988). An inventory for measuring depression. *Archives of General Psychiatry, 45*, 561-571.
- Bristol, M. M. (1979). *Maternal coping with autistic children: Adequacy of interpersonal support and effects of child's characteristics*. Unpublished doctoral dissertation, University of North Carolina, Chapel Hill.
- Bristol, M. M. (1984). Family resources and successful adaptation to autistic children. In E. Schopler & G. B. Mesibov (Eds.), *The effects of autism on the family* (pp. 290-308). New York: Plenum Press.
- Bristol, M. M., & Schopler, E. (1983). Stress and coping in families of autistic adolescents. In E. Schopler & G. B. Mesibov (Eds.), *Autism in adolescents and adults* (pp. 251-276). New York: Plenum Press.
- Burrell, B., Thompson, B., & Sexton, D. (1994). Predicting child abuse potential across family types. *Child Abuse and Neglect, 18*, 1039-1049.
- Dumas, J. E., Wolf, L. C., Fisman, S. N., & Culligan, A. (1991). Parenting stress, child behavior problems, and dysphoria in parents of children with autism, Down syndrome, behavior disorders, and normal development. *Exceptionality, 2*, 97-110.
- Dunst, C. J., Jenkins, V., & Trivette, C. M. (1984). Family Support Scale: Reliability and validity. *Journal of Individual, Family and Community Wellness, 1*, 45-52.
- Dunst, C. J., Trivette, C. M., & Cross, A. H. (1986). Mediating influences of social support: Personal, family, and child outcomes. *American Journal of Mental Deficiency, 90*, 403-417.
- Dyson, L. I. (1997). Fathers and mothers of school-age children with developmental disabilities: Parental stress, family functioning, and social support. *American Journal of Mental Retardation, 102*, 267-279.
- Factor, D. C., Perry, A., & Freeman, N. (1990). Brief report: Stress, social support, and respite care use in families with autistic children. *Journal of Autism and Developmental Disorders, 20*, 139-146.
- Gill, M. J., & Harris, S. L. (1991). Hardiness and social support as predictors of psychological discomfort in mothers of children with autism. *Journal of Autism and Developmental Disorders, 21*, 407-416.
- Gray, D. E., & Holden, W. J. (1992). Psychosocial well-being among the parents of children with autism. *Australia and New Zealand Journal of Developmental Disabilities, 18*, 83-93.
- Hadadian, A. (1994). Stress and social support in fathers and mothers of young children with and without disabilities. *Early Education and Development, 5*, 226-235.
- Herman, S. E., & Thompson, L. (1995). Families' perception of their resources for caring for children with developmental disabilities. *Mental Retardation, 33*, 73-83.
- Holyroyd, J. (1974). The questionnaire on resources and stress: An instrument to measure family response to a handicapped member. *Journal of Humanistic Psychology, 37*, 1-11.
- Koegel, R. L., Schreibman, L., Loos, L. M., Dunlap, G., Robbins, F. R., & Plienias, A. J. (1992). Consistent stress profiles in mothers of children with autism. *Journal of Autism and Developmental Disorders, 22*, 205-216.
- Konstantareas, M., & Homatidis, S. (1989). Assessing child symptom severity and stress in parents of autistic children. *Journal of Child Psychology and Psychiatry and Allied Disciplines, 30*, 459-470.
- Krauss, M. W. (1993). Child-related and parenting stress: Similarities and differences between mothers and fathers of children with disabilities. *American Journal of Mental Retardation, 97*, 393-404.
- Krauss, M. W., Upshur, C. C., Shonkoff, J. P., & Hauser-Cram, P. (1993). The impact of parent groups on mothers of infants with disabilities. *Journal of Early Intervention, 17*, 8-20.
- Maddi, S. R., Kobasa, S. C., & Hoover, M. (1979). An alienation test. *Journal of Humanistic Psychology, 37*, 1-11.
- McCubbin, H. I., McCubbin, M. A., Patterson, J. M., Cauble, H. E., Wilson, L. R., & Warwick, W. (1983). CHIP—Coping Health Inventory for Parents: An assessment of parental coping patterns in the case of the chronically ill child. *Journal of Marriage and the Family, 45*, 359-370.
- McLinden, S. E. (1990). Mothers' and fathers' reports of the effects of a young child with special needs on the family. *Journal of Early Intervention, 14*, 249-259.
- Norton, P., & Drew, C. (1994). Autism and potential family stressors. *The American Journal of Family Therapy, 22*, 67-76.
- Peck, C. Z. (1998). Program evaluation of a family systems model of service delivery for parents of children with autism: Promoting adaptation to family stress. *Special Services in the Schools, 14*, 127-145.
- Raif, R., & Rimmerman, A. (1993). Parental attitudes to out-of-home placement of young children with developmental disabilities. *International Journal of Rehabilitation Research, 16*, 97-105.
- Robbins, F. R., Dunlap, G., & Plienias, A. J. (1991). Family characteristics, family training, and the progress of young children with autism. *Journal of Early Intervention, 15*, 173-184.
- Salisbury, C. L. (1990). Characteristics of users and nonusers of respite care. *Mental Retardation, 28*, 291-297.
- Sanders, J. L., & Morgan, S. B. (1997). Family stress and management as perceived by parents of children with autism or Down syndrome: Implications for intervention. *Child and Family Behavior Therapy, 19*, 15-32.
- Schopler, E., & Mesibov, G. B. (Eds.). (1983). *Autism in adolescents and adults*. New York: Plenum Press.
- Schopler, E., & Mesibov, G. B. (Eds.). (1984). *The effects of autism on the family*. New York: Plenum Press.
- Schopler, E., Reichler, R. J., DeVellis, R. F., & Daly, K. (1980). Toward the objective classification of childhood autism: Childhood Autism Rating Scale (CARS). *Journal of Autism and Developmental Disorders, 10*, 91-103.
- Sharpley, C. F., Bitsika, V., & Efremidis, B. (1997). Influence of gender, parental health, and perceived expertise of assistance upon stress, anxiety, and depression among parents of children with autism. *Journal of Intellectual and Developmental Disability, 22*, 19-28.
- Wolf, L. C., Noh, S., Fisman, S. N., & Speechley, M. (1989). Brief report: Psychological effects of parenting stress on parents of autistic children. *Journal of Autism and Developmental Disorders, 19*, 157-166.