Running Head: Maternal Stress and Support and Sibling Relationships

Maternal stress and support in light of sibling relationships for families of developmentally

disabled children

By

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ABSTRACT

JOYCE, OLIVIA The role of sibling relationship on maternal stress and support levels for mothers of developmentally disabled children. Department of Psychology, June 2013.

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In the current research the role of sibling relationship in relation to caregivers' stress and support levels in families of developmentally disabled children was investigated. Previous research has demonstrated the stresses and benefits both mothers and siblings of special needs children confront in raising and interacting with their child or sibling. Typically developing siblings have been shown to attenuate the disabled siblings' problematic behaviors—the same behaviors that increase mothers' stress levels the most (Rodrigue, Geffken, & Morgan, 1990). However, research regarding the effects of disabled siblings on typically developing siblings remains conflicted, such that both highly positive and highly negative outcomes have been found (Cicirelli, 1985; Harvey & Greenway, 1984). The present study closely examined maternal stress and support levels for mothers of special needs children; specifically, maternal stress levels of mothers of only developmentally disabled children were compared to mothers of both typically developing and developmentally disabled children. For the latter, problematic sibling behaviors and positive interactions between the disabled and nondisabled siblings were additionally assessed. The innovative findings of the current research suggest that positive sibling relationships beget enhancing, developmental circumstances for developmentally disabled siblings and are associated with diminished problematic behaviors in the disabled siblings. Further, for all mothers of special needs children, reduced numbers of problematic behaviors in the developmentally disabled children were associated with lessened maternal stress and heightened maternal support. These relationships should be further

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investigated to better understand the complexities of the familial relationships in these exceptional families and how sibling relationship is associated with maternal well-being.

Introduction

Families grow and thrive in an intertwined way and they must be understood as systems. Children with developmental disabilities not only develop with, but also nourish, their families; caregivers, siblings, and developmentally disabled children affect and respond to one another. The well-being of mothers of special needs children cannot be separated from the well-being of their disabled children or other family members. The present research examined the role of sibling interaction and the problematic behaviors associated with pervasive developmental disorders. This relationship was analyzed in light of maternal stress and support in mothers of special needs children.

A mother is one of the most influential supports in a child's life. Mothers are the primary caregivers and the people responsible for the children's daily needs, health, and development in over 95% of family situations (Lach, Kohen, Garner, Brehaut, Miller, Klassen & Rosenbaum, 2009; Crowe & Florez, 2006). Most mothers of special needs children provide specialized care and developmental opportunities to encourage their children's growth and inclusion with their families and community beginning in their children's infancy. However, while these duties require the highest level of strength and perseverance, research has consistently shown that many of these mothers in fact have poor mental health and high stress (Rodrigue, Geffken, & Morgan, 1990). While these findings are robust, implicit in these results is the fact that some mothers are able to stay healthy and do not experience high levels of stress. Therefore, research that creates better understanding as to why some mothers excel, while others do not, can assist in the development of strategies to help mothers of special needs children.

While the spectrum of developmental disabilities ranges in severity and impact on family life, a multitude of research has focused on the effects of autism on family life (Gold, 1993; Hastings, 2003; Knott, Lewis, & Williams, 2007; Macks & Reeve, 2007). The development and emergence of autism is enigmatic, and is the source of much research and debate. The prevalence of autism has increased so dramatically that autism spectrum disorders affect nearly 1 out of every 110 children and are even more prevalent among male children (Schaaf, Toth-Cohen, Johnson, Outten, & Benevides, 2011).

The behaviors of developmentally disabled children often impede the everyday functioning of the mothers and families of the children. The mother especially, carrying most of the childcare burden, is often faced with life-altering and stressful changes. The nature of autism, and the behaviors associated with it, often create special and trying demands for the entire family. Disabled children tends to display inappropriate behaviors, act aggressively toward themselves or other people, engage in repetitive actions and self-stimulation, 'tune out' authoritative or parental figures, and show delays in language, communication, eye contact and affection (Schaaf et al., 2011). Many of these behaviors are considered "sensoryseeking" or "sensory-avoiding" behaviors, and often hinder the children's play, self-care and learning activities. The sensory aspect of autism is a prominent facet of the disorder, and the need for constant attention and supervision is exhausting and time consuming for the primary caregivers.

Children with autism in particular show considerable difficulties in their social functioning. Although they develop attachment relationships, their ability to initiate and sustain reciprocal interactions is almost always limited (Knott et al., 2007). In comparison to typically developing children, children with autism show less attention when interacting with

another person, less social referencing in ambiguous situations, lower levels of positive affect in social situations, and less attention to another's distress (Schaaf et al., 2011). Additionally, they demonstrate less responsiveness to their parents during play interactions and are less involved in the interactions compared to typically developing children (Knott et al., 2007).

In previous research, elevated maternal stress has been repeatedly and robustly demonstrated in mothers of children with autism (Baker-Ericzen, Brookman-Frazee, & Stahmer, 2005; Crnic, Friedrich, & Greenberg, 1983; Eisenhower, Baker, & Blacher, 2005; Pottie & Ingram, 2008, Schaaf et al., 2011). Eisenhower et al. (2005) found in observational testing that the difficulties of the disorder, specifically deficits in the children's social relatedness and regulatory problems, combined with the lessening or lack of time for personal needs, were associated with increased maternal stress. Additionally, the elevation in maternal stress was linked with maternal depressive symptoms. Clearly, research must not only focus on treating and diagnosing children with autism, but also address ways to improve in the wellbeing of mothers of children with autism.

Children with autism are often reported as having more behavior problems than children with mixed etiology intellectual disabilities (Kasari & Sigman, 1997) and children with Down syndrome (Eisenhower et al. 2005; Sanders and Morgan, 1997). In contrast, children with Down syndrome are reported as having fewer behavior problems than other children with intellectual disabilities (Dykens & Kasari 1997; Ricci & Hodapp 2003). Blacher and McIntyre (2006) used self report measures to compare behavior problems in children with autism, Down syndrome, and mixed etiology intellectual disability and found that children with autism had the most problem behaviors, and children with Down syndrome the least.

Mothering a child with Down syndrome has been described as a mosaic of experiences

and emotions (Pillay, Girdler, Collins, & Leonard, 2012). Parents of children with Down's syndrome or those of mixed etiologies report higher life satisfaction and lower levels of stress than parents of children with autism (Holroyd & McArthur, 1976). The significant difference between the stress levels mothers of children with autism and mothers of children with Down syndrome has been attributed to the specific, and difficult, behaviors related to autism that are not present in other pervasive disabilities (Sanders & Morgan, 1997). More recently, Pisula (2006) analyzed maternal stress in mothers of autistic children and mothers of children with Down syndrome and found that mothers of children with autism showed higher stress levels than those of children with Down's syndrome on seven of the 15 stress scales. Most significantly were the scales of "Overprotection/Dependency" and "Difficult Personality Characteristics" such that mothers of children with autism reported greater difficulty in dealing with the intense and prolonged dependency of their child and their difficult behaviors.

Parenting a developmentally disabled child can put strains on finances, leisure time, marital relations, and the parenting of additional children. Individuals with pervasive developmental disorders (such as Autism and Down Syndrome) often exhibit deficits in communication, mood swings, social interaction, speech, and difficulties in making transitions (Schaaf et al., 2011). Sensory-related behaviors, (e.g. repetition or anxiety) and social deficits are related to the highest levels of maternal stress (Baker-Ericzen et. al, 2005). The difficulties mothers face in assisting their developmentally disabled children often create social anxiety and unparalleled stresses (Davis & Carter, 2008). Furthermore, the stress attributed to the child often reflects the deep stresses of the entire family (Baxter, Cummins, & Yoilitis, 2000). Therefore, it is imperative to analyze the well-being of family systems to better understand the full effects of special needs on mothers. A number of caregiving responsibilities increase the sources of stress for parents of developmentally challenged children—particularly for mothers who are most often the primary caregivers (Brehaut, Kohen, Raina, Walter, Russell, Swinton, O'Donnell, & Rosenbaum, 2004). Significant sources of stress often include parental concerns about interacting with professionals and difficulties obtaining helpful services (Todis & Singer, 1991). Families are required to make sense of significant amounts of information about the diagnosis and recommended intervention methods. The time and energy needed to identify the most helpful interventions, and provide care for the children and siblings, as well as the financial stresses from loss of time at work and/or the cost of additional therapies puts stress on family resources (Birenbaum, Guyot, & Cohen, 1990). In addition, parents often experience stress related to the prospect of providing long-term care for their children and the associated limits on family opportunities (Gallagher & Bristol, 1989).

The functionality of a family system and the quality of a marriage or partnership has been shown to relate to maternal stress in families of developmentally disabled children (Pottie & Ingram, 2008). In a longitudinal study, couples with higher levels of positive daily moods utilized "problem focused, social support, positive reframing, emotional regulation, and compromise" coping in their daily lives (Pottie & Ingram, 2008, p. 861). Unfortunately, a cyclical effect often occurs within maternal stress; maternal stress emerges from poor situational factors (e.g. stresses with the developmentally disabled child), but then fosters and enables worse familial situations and functioning (Eisenhower et al., 2005). However, we can assume that in the same fashion, a supportive, well-running family system could ameliorate the mother's stress. When we consider the effects of having a special needs child on the mother, we also must consider her environment. Factors affecting parents' abilities to successfully adapt to having a child with special needs have been the focus of numerous studies over the last three decades (Bristol, 1984; Bristol, Gallagher, & Schopler, 1988; Tunali & Power, 1993; Crnic, Friedrich, & Greenberg, 2002; Baker-Ericzen et al., 2005; Siklos & Kerns, 2006; Davis & Carter, 2008). The positive influence of social support on the adaptation of families with specials needs children has been well documented (Hill, 1949; McCubbin & Patterson, 1983; Siklos & Kerns, 2006). Social support has been defined as ''information leading the person to believe that he is cared for and loved, valued and esteemed, and is important in a network of mutual obligation and communication'' (Cobb, 1976, p. 300). Social support includes support from one's spouse, extended family and friends, as well as support from community programs, professional help, and the availability of services and programs geared toward families with a disabled child. Families that receive these supports exhibit healthier adaptations to having children with pervasive developmental disorders (Bristol, 1984, Donovan, 1988; Sanders & Morgan, 1997; Siklos & Kerns, 2006).

The relationship between two parents is pivotal and influential in the upbringing of a child. A good quality relationship may help the parents individually cope and deal with the stresses of the disorder. The transactional model of stress and coping, as proposed by Lazarus and Folkman (1984), has led much of the research on the coping process. The transactional model conceptualizes coping as a dynamic process involving a parent's appraisal of an event, personal and family resources, contextual or situational factors, and cognitive or behavioral responses. The effectiveness of one's coping is determined by the match between a particular stressor (e.g., a difficult child behavior) and the coping responses (e.g., ignoring the behavior) used to manage that stressor, and evaluated by examining the resulting emotions (Pottie &

Ingram, 2008). The quality of coping method has been linked to parents' psychological health and well-being. A mediating factor in this coping process may be the quality of the parenting partnership; a dependable, resilient relationship gives needed support and understanding in the rearing of a developmentally disabled child.

Tunali & Power (2002) studied different dimensions of coping among mothers of toddler-aged children with autism by measures of self-report. This study found that mothers of special needs children who placed a greater emphasis on spousal support and parental roles in their discussions of marriage had greater life satisfaction than mothers who did not. Mothers with greater life satisfaction were also lower in maternal stress (as stress is associated with depressive behaviors). These findings suggest that the functionality of a family unit may be influential in life satisfaction for a mother and ameliorating for maternal stress.

Parents' beliefs about receiving adequate social support for themselves and their children with autism have been shown to be very important for successful family adaptation (Bristol, 1984; Donovan, 1988). Bristol (1984) found that the strongest indicator of healthy adaptation and coping in the family was the amount of perceived support the mother received from her spouse; parents reported that their most important coping strategy was the belief that their child's program had the family's best interests in mind, indicating that the belief that their child is receiving appropriate services is vital for parents to cope with the ongoing stresses related to having a child with special needs (Bristol, 1984). In mothers of adolescent children with autism, self report measures revealed that increased perception of social support is also related to decreased perception of stress in mothers, indicating that social support plays an important role in maintaining good mental health for these parents (Donovan, 1988). The overwhelming evidence suggests that formal services and programs are imperative for the

successful adaptation of the family of a child with special needs. Mothers of children with autism who perceive supports to be helpful have been shown to cope more successfully than mothers who perceive their supports to be unhelpful (Donovan, 1988).

Outside help is often subsidized by local school districts, but when families are in lowincome communities, and have fewer funds themselves, assistance is often sparse and out of reach. Therefore, as would be expected, maternal education and family income appear to be correlated with maternal stress such that higher levels of education and income are related lower maternal stress (Phetrasuwan & Mile, 2008). The level of financial stability and additional funds is related to stress in families of children with autism; special programs, tutors, aides and assistance are often deemed necessary for the child's development and the mother's psychological stability. The research by Phetrasuwan & Mile (2008) also suggests that the mothers' education levels and incomes are often related to availability of programs and assistance, such that low-income families are more often based in communities with fewer educational programs and support groups for developmentally disabled children and their families.

In addition to social support, the caregiver must have familial support to maintain good mental health and confidence. Sharpley, Bitsika, & Efremidis (1997) demonstrated a significant effect between the level of understanding which mothers felt that their immediate family members had of their children's problems and their stress levels. That is, parents who believed that the family members giving assistance had a clear understanding of the child's difficulties and needs were also less anxious, depressed and had higher levels of confidence in their own abilities to handle their children's major difficulties. The perceived expertise (by the assisting family member) in handling the children's problems generalized to the parents' own beliefs in their abilities to similarly deal with those problems. Self-efficacy (or belief in one's ability to perform a task successfully) is the major predictor of future successful performance of that task (Bandura, 1986). If parental confidence in their abilities to handle their children's major problems is directly influenced by their confidence in other family members' understanding of their children's problems, then this raises an important issue for training parents and care-givers in how to deal effectively with children with disabilities. Clearly, while it is vital to train parents in behavior management of their children with developmental disabilities, it appears to be similarly important to train those immediate family members in the same skills, thus contributing to the parents' well-being and their confidence, self-efficacy, and future ability to deal effectively with the demands of parenting a child with developmental disabilities.

Belsky's (1984) model of "the determinants of parenting" suggests that the parents' characteristics, the child's characteristics and the environment in which the interaction is taking place—such as the relationship between the parents and the social system—directly affect the interaction between parents and their children. Therefore, the first year is likely more difficult and stressful because as the parents begin to parent using previous parenting schemas, the child reacts to the poorly fitting parenting style with more stress-inducing behaviors. Additionally, if the family already has healthy children, then these children's reactions to the disabled sibling, and their reaction to the parents' adaptive shift in parenting style, also influence both the disabled sibling's behaviors and the parents' stress. It is therefore imperative that the relationships within the family be further studied to clarify and explain family dynamics.

While maintaining strong partnerships and methods of coping are important for maintaining low levels of maternal stress levels, ameliorating the behaviors of the special needs child is still most salient and stressful. Eisenhower et al. (2005) found that managing the demanding behaviors and upset feelings, disciplining, and managing behavior in public places were the highest sources of overall parenting stress for all participating mothers of preschool aged children who had cerebral palsy, autism, or Down Syndrome. Symptom-related stressors that were found to be most salient were the children's emotional responses, expressions of fear or nervousness, verbal communication issues, and ability to relate to people. Mothers reported stress related to not having time for their own activities and needs and difficulties in giving themselves permission for such needs (Eisenhower et al., 2005).

Tomanik, Harris & Hawkins (2004) found that the aberrant and adaptive behaviors of children aged 2-7 with pervasive developmental disorders were some of the most salient factors in the emergence of maternal stress. In self-report measures, mothers answered that the combination of high aberrant behavior, (defined as disruptive behavior, isolation and inactivity, stereotypic behavior, hyperactivity, non-compliance and inappropriate speech), and low adaptive behavior, (defined as a disabled child's inability to cope with his environment), was related to high parental distress. The mothers' inability to alleviate the intensified reactions or behaviors of their autistic children or manage these behaviors in public places seems to intensify their stress levels (Eisenhower et al., 2005). In the families of special needs children the burden of managing the children's behaviors is associated with increased maternal stress levels (Rodrigue et al., 1990), therefore interventions and interactions that alleviate or control such behaviors might also ameliorate the elevated maternal stress levels.

Sibling interactions between a typically developing child and a child with a

developmental disability can be powerful instruments in the disabled child's socialization; the interactions foster the development of important instrumental and affective relationship skills (Cicirelli, 1985). What developmentally disabled children learn from relating to their siblings can potentially assist in cognitive, affective, and social skills development. For developmentally disabled children, positive and frequent sibling interactions provide important sources of emotional support (Dunn, 1988), whereas negative and infrequent sibling interactions may disrupt the psychological adaptation process (Knott et. al, 2007).

Research regarding the effects of disabled siblings on typically developing siblings has expanded our view of these exceptional families (Moore, Howard, & McLaughlin, 2002). It has been reported that siblings of children with mixed disabilities (ages 7-25) are at risk for lower self-concept, low self-esteem, and greater anxiety (Harvey & Greenway, 1984) than siblings of children without disabilities. Typically developing siblings may also experience additional caregiving responsibilities (Cuskelly & Gunn, 2003), which suggests that these children may experience some stress related to family dynamics. Later in life, these siblings may become sole caretakers of their siblings into their adulthood (Dew, Balandin, & Llewellyn, 2008).

Typically developing siblings may experience numerous stressors, including loss of parental attention, changes in family roles and activities, feelings of guilt and shame, and the negative reactions of others outside of the family (Rodrigue & Geffken, 1993). Adjustment difficulties may be even more pronounced in small families, as the burden of care cannot be easily shared and attention from other siblings is not available to compensate for the reduction in parental attention. Furthermore, increases in parental stress may have residual effects on siblings in the family (Morgan, 1988).

Grossman (1972) reported that 45% of college-aged siblings of children with mixed etiology had negative feelings, such as shame regarding their siblings—although the social stigma associated with having a child with a disability was likely more prominent at the time the study was conducted compared to current culture. More recently, Pit-Ten Cate and Loots (2000) examined issues related to peers and society and concluded that there were no complications in peer relationships associated with having a sibling with a physical disability, but nearly 20% of their sample (siblings aged 10-18) chose not to tell some people about their siblings with disabilities out of shame. In addition, Powell and Gallagher (1993) noted that school-age children experienced conflicted feelings of wishing to be accepted by their peers, but wanting to defend their siblings with a disability.

Some studies have shown no significant differences in the self-concept, social competence, and behavior adjustment of siblings of developmentally disabled children compared to siblings of typically developing children (Dyson, 1999), while others reported positive effects of having a sibling with special needs (Pit-Ten Cate & Loots, 2000). Dyson (1999) demonstrated that in the presence of socioeconomic advantage and early intervention, children of siblings with mixed etiologies showed no maladjustments in self-concept, behavior adjustment, and social competence. Furthermore, this study's findings suggest that a family's psychological functioning—such as parents' emotional adjustment, availability of social support to the family, family relationships, and the family's emphasis on personal growth—can influence a child's psychosocial functioning more than having a sibling with a disability (Dyson, 1999). Grossman (1972) also found that 45% of the siblings believed they had benefited from having a sibling with cognitive disabilities; they reported increased

understanding of other people, more tolerance and compassion, and a greater appreciation of their own good health and intelligence.

Pit-Ten Cate & Loots (2000) demonstrated that typically developing school-aged children with special needs siblings showed no difference in the measures of peer relationships and trust in parents in comparison to children without special needs siblings. Stainton & Besser (1998) actually found that families with disabled children actually benefitted from their presence, and identified nine recurring themes: "source of joy and happiness; increased sense of purpose and priorities; expanded personal and social networks and community involvement; increased spirituality; source of family unity and closeness; increased tolerance and understanding; personal growth and strength; positive impacts on others/ community" (p. 68).

Kaminsky and Dewey (2002) further studied the role of healthy siblings in these unique family systems and found that these children must often carry an adult-like burden in assistance and care. However, despite the burden, their relationships with their disabled siblings during childhood are often healthy and promote needed growth for the disabled sibling. Research suggests that healthy, positive sibling relationships foster unparalleled social development for autistic siblings (Knott et al., 2007).

While research regarding the experience of having siblings with mixed etiologies is inconclusive, specifically siblings of children with Down syndrome tend to cope remarkably well. A hallmark finding from these studies involves the so-called "Down syndrome advantage" (Seltzer & Ryff, 1994). Many studies have found that families of children with Down syndrome cope better than families of children with other disability conditions. Families seem to be warmer and more harmonious (Mink, Nihira, & Meyers, 1983), mothers experience less stress (Hodapp & Freeman, 2003), and close, harmonious relationships with their offspring are reported by fathers (Hornby, 1996) and by adult siblings of persons with Down syndrome compared with other disabilities (Orsmond & Seltzer, 2006). Examining 41 siblings of children with Down syndrome, Van Riper (2000) found that the typically developing siblings helped increase the social competence of their developmentally disabled siblings.

Compared to siblings of children with autism, siblings of children with Down syndrome show fewer externalizing and internalizing problems (Fisman, Ellison, & Freeman, 2000; Kaminski and Dewey, 2002). Having a sibling with Down syndrome may also produce such positive effects as increased levels of empathy or appreciation for individual differences (Cuskelly and Gunn, 2006). Overall, "being the sibling of a child with Down syndrome does not appear to have a negative impact on either problem behaviors or self-perceptions of competence and these brothers and sisters of a child with Down syndrome do not seem to be penalized in their opportunities to participate in a normal childhood" (Cuskelly and Gunn, 2006, p 924).

Few studies have been able to find significant improvements in social behavior when children with autism interact with peers. However, through naturalistic observation of preschool aged autistic children, Knott et al. (2007) was able to find that sibling interactions fostered growth over twelve months in the number prosocial initiations and agonistic interactions for the disabled child. The agonistic interactions, while not typically desirable, were considered 'normal' development and are encouraged in the development of autistic children. This study conceptualized that the healthy sibling led the interaction and provided a model for behavior for the sibling with autism. These findings suggest that the autistic child's social development has a somewhat 'normal' pattern of growth, albeit at a slower rate. Social interaction and imitation in children with autism is especially cultivated in the special relationship the child has with a healthy sibling and suggests unparalleled improvements.

Despite the ameliorating developmental effects of having a healthy sibling for a child with autism, it seems as though the effects of having a sibling with autism for a healthy child are less clear (Kaminsky & Dewey, 2002; Christensen, Hutman, Rozga, Young, Ozonoff, Rogers, Baker, & Sigma, 2010). Some research suggests that the siblings of children with autism, aged young adolescent to young adult, were quite well adjusted and had low levels of loneliness (Kaminsky & Dewey, 2002). However, other reports suggest that siblings (assessed during their infancy) were less engaged in age appropriate play behavior in peer interactions than children with siblings with autism (Christensen, et al., 2010). These discrepancies could be due to the wide age differences in the siblings in the studies, or it may call attention to the need for better, more in-depth research. A compilation of research further reveals that sibling adjustment is often inconsistent, especially when looking into later years of life (Smith & Elder, 2010). One prominent, and fairly consistent finding is the positive correlation between the use of peer group therapy for siblings and the increased life satisfaction the siblings report (Kaminsky & Dewey, 2002; Smith & Elder, 2010). This finding suggests the powerful influence of peer relationships on the healthy siblings and suggests moves to mandate and subsidize this type of care.

Additionally, research has assessed the benefits of having a healthy sibling present during group therapy for a sibling with Asperger syndrome (Castorina & Negri, 2010). This approach combines the benefitting effects of having a healthy sibling for a child with autism as well as the benefitting effects for a healthy sibling of going to group therapy with other siblings of disabled children. This study found that there were significant improvements in the disabled siblings' abilities to read non-verbal social cues and emotions. The present study hoped to extend this finding—that relationships with typically developing siblings enhance the disabled sibling's social and cognitive abilities—by examining positive sibling interaction and problematic child behaviors.

Taken together, these studies suggest that having a sibling with a disability may be associated with some positive benefits as well as stress and may require coping strategies for children to adjust to the family dynamics. In these circumstances, while parents may benefit from siblings assisting with the care of the child with a disability, any difficulties experienced by siblings are likely to contribute to the overall level of parental stress.

The current research surveyed mothers of special needs children. The surveys assessed the mothers' maternal stress and perceived support levels, the developmentally disabled children's problematic behaviors, the behaviors of any additional children in the family, and the relationships between the typically developing siblings and the developmentally disabled children. From these data we began to ascertain whether having a sibling is associated with less maternal stress and enhanced support.

In the present research the role of the sibling relationship in relation to caregivers' stress levels and perceived support in families of developmentally disabled children was investigated. Previous research has shown that the added aspects of parenting a child with special needs often result in elevated maternal stress in eighty percent of mothers (Davis & Carter, 2008). These stresses are linked to the social deficits and inabilities children with developmental disorders often display. Some studies suggest that typically developing siblings can attenuate the disabled siblings' problematic behaviors (Knott et al., 2007)—the

same behaviors that often increase mothers' stress levels (Rodrigue et al., 1990). Research has also focused on both the benefits of sibling relationships on children with special needs as well as the benefits and maladjustments a healthy child develops when having a sibling with special needs. However, little or no research has examined the possible connection between the quality of sibling relationships between typically developing children and their developmentally disabled siblings with maternal stress and support.

In the current study, I hypothesized that in special needs families of multiple children, increased amounts of positive sibling interaction would be associated with fewer problematic behaviors in the developmentally disabled siblings. I further suggested that in relation to these weakened problematic child behaviors, mothers of both developmentally disabled and typically developing children would report higher perceived social support and lower stress levels than mothers of only developmentally disabled children.

Method

Participants

Participants were the mothers of 68 developmentally disabled children. The mothers' ages varied between 25 and 65 (M=39.5 years), and their developmentally disabled children's ages varied between 1 and 30 years old (M=10.34). The target children were diagnosed with either Autism (n=24), Asperger's syndrome (n=3), Down syndrome (n=19), Cerebral Palsy (n=4), intellectual disabilities (n=13), or learning disabilities (n=5). Forty-seven children were male, and 21 were female.

Seventeen of the developmentally disabled children had no sibling, 23 had only one sibling, 21 had only two siblings, 6 had only three siblings, and 1 had four siblings. Forty-two of the siblings were female, and 37 were male. The siblings ranged in age from 1 to 40

(M=19.1 years).

Materials

Maternal Measures. The Perceived Stress Scale (PSS) is a widely used psychological self-report instrument for measuring the perception of stress (Cohen, Karmarck, & Mermelstein, 1983). It measures the degree to which situations in one's life are appraised as stressful, such that a summed high score indicates a high perception of stressful events. The 10 items were designed to determine how overloaded respondents found their lives by asking about their thoughts and feelings during the last month, (e.g. "In the last month, how often have you been upset because of something that happened unexpectedly?"). In each case, respondents are asked how often they felt a certain way (Never/Almost Never/ Sometimes/ Fairly Often/Very Often), with four items reversely phrased. The PSS has good concurrent validity with social anxiety and symptomatology, and has a good test-retest correlation of .85 (Cohen et al., 1983). PSS scores are not related to participant age or gender, and the questions are of a general nature and are relatively free of content specific to any sub-population group (Cohen et al., 1983). In our sample the stress scale had a Chronbach's alpha of .85.

The Social Support Index is a self-report instrument designed to measure the degree to which respondents find their communities supportive (McCubbin, Patterson, & Glynn, 1983). This 17-item index assesses perceived support by asking questions regarding the mother's community, (e.g., "If I had an emergency, even people I do not know in this community would be willing to help."), and to what degree she felt supported, (Strongly Disagree/ Disagree/ Neutral /Agree/ Strongly Agree), with six items reversely phrased. High scores on this index indicate high perceptions of social support. The SSI has good concurrent validity with family well-being and is a good predictor of family resilience (McCubbin et al., 1983). In the current study, SSI scores had a Chronbach's alpha of .90.

A 7-item demographics questionnaire was also included in the survey to assess the mothers' education levels, number of children, marital status, household income, employment, ethnicity, and age.

Child Measures. The Short Form of the Developmental Behavior Checklist (DBC-P24) is a short derivative of the widely used Developmental Behavior Checklist (DBC), (Taffe, Gray, Einfeld, Dekker, Koot, Emerson, Koskentausta, & Tonge, 2007). The DBC-P24 is a 24-item assessment of behavioral and emotional disturbance in individuals with intellectual disability. Each item indicated a different behavior, (e.g. "Becomes overexcited"), and a check indicated that the child demonstrated such behavior. A high summed score on the checklist indicates a high number of problematic behaviors in the developmentally disabled child of the participant. The checklist is designed for the parents of the developmentally disabled child (ages 4-18) to complete. As with the original form, this shortened version has low bias (less than .01) across different disorders and syndromes (Taffe, et al., 2007).

Sibling Measures. A slightly modified four-item version of the Strengths and Difficulties Questionnaire (SDQ) was included to better understand the parents' perspectives of their typically developing children's behaviors (Goodman, 1997). The original questionnaire is a brief measure of the adjustment and psychopathology of children and adolescents (ages 4-16) and is designed for parents to complete. The SDQ poses questions on a five-factor structure of emotional, conduct, hyperactivity-inattention, peer, and prosocial behaviors (e.g. "Overall, do you think that this sibling has difficulties regulating emotions?") and to what degree mothers believed their child demonstrated such difficulties (No Difficulties/Yes, Minor Difficulties/Yes, More Serious Difficulties/Yes, Severe Difficulties). For data analysis, summed scores for each typically developing children were averaged together. A high score indicates high levels, on average, of difficult behaviors for the typically developing children in a family. The SDQ can identify individuals with adjustment issues with a specificity of 94.6% (Goodman, 1997).

Based on the research of Schaaf et al. (2011) and Knott et al. (2007) we included an additional item to assess the extent of interaction between each sibling with their developmentally disabled sibling. This 5-item question was developed to incorporate the most salient interactions between siblings (e.g. "How often does this sibling interact with your child with disabilities in the follows ways: Playful activities (games, sports, crafts, etc)"), (Knott et al, 2007). Each question was answered on a four-item scale (Not at all/ Only a Little/ Quite a Lot/ A Great Deal), with one question reversely coded. For data analysis, summed scores for each typically developing children's interactions were averaged together. A high score indicates, on average, high levels of positive interaction between the typically developing siblings and the sibling with developmental disabilities.

Procedure

I contacted a Massachusetts special needs center and a New York special needs center to recruit participants. Upon consent, the centers forwarded an email to the mothers of their students. The email included a description of the study, consent form and the link to the anonymous survey via Survey Monkey. Participation was additionally recruited through three online parenting forums. A brief description of the survey along with the survey link and consent form were posted on each of the forums. A donation of \$3 per participant was made to each of the respective centers for each participant recruited from either site. Participants recruited through the Internet were not compensated.

Results

Table 1 presents the means and standard deviations of the main variables: mothers' stress levels (PSS), mothers' perceived support levels (SSI), developmentally disabled children's problematic behavior scores (DBC-P24), siblings' problematic behavior scores (SDQ), levels of sibling interaction, and child's age. The data for each of these variables are presented separately for mothers with only developmentally disabled children, and for mothers with both developmentally disabled children and typically developing children.

There were no differences in the number of problematic behaviors, (t (62) = -.32, p = .73), child's age (t (65) = .70, p = .48), or number of siblings (t (66) = .32, p = .25) between male and female children.

Maternal stress levels

My first hypothesis asked whether there were significant differences in the stress levels of mothers of only developmentally disabled children compared to the stress levels of mothers of both developmentally disabled and typically developing children. Although a t-test for the maternal stress levels of both groups was not significant (t (66) = .96, p = .34), a correlation between the number of children in a family and maternal stress level was significant, r = -.24, p = .047, such that mothers with more children reported lower stress levels. Table 2 contains correlations.

As predicted, maternal stress was further correlated with maternal support (r = -.67, p = .00), such that increased maternal stress was associated with decreased maternal support. Additionally, maternal stress was correlated with problematic child behaviors (r = .66, p = .00), such that increased problematic child behaviors were associated with increased maternal support. I further explored maternal stress by running a linear regression predicting mothers' stress levels using the predictors of number of problematic child behaviors, mothers' perceived support, and the number of children in a family. The regression was significant, F (3,60) = 29.21, p = .00. R² = .594, indicating that 59.4% of variance in maternal stress scores was accounted for in this regression. Individual t-tests showed two significant predictors of mothers' stress level: mothers' support levels, (t = -4.33, p = .00), and disabled children's problematic behaviors, t = -4.32, p = .00. The number of children was not a significant predictor of maternal stress, t = -1.20, p = .23. That is, when taken together, maternal support levels and problematic behaviors predicted maternal support levels, but the number of children in a family did not add to the prediction.

Problematic behaviors of developmentally disabled children

I further hypothesized that the number of problematic behaviors would be significantly higher for developmentally disabled children without any typically developing siblings than for developmentally disabled children with typically developing siblings. An independent samples t-test revealed that number of problematic behaviors exhibited by the developmentally disabled children trended in the predicted direction, such that children with no siblings (M = 8.08, SD = 4.01) had greater numbers of problematic behaviors than children with typically developing siblings (M = 6.27, SD = 3.66) but was not significant, t (62) =1.56, p = .12. Upon further analysis, the number of children in a family was correlated with the number of problematic behaviors, (r = -.28, p = .02), such that the more siblings the developmentally disabled children had, the fewer problematic behaviors they demonstrated.

For the sample of all mothers combined, problematic child behaviors were additionally correlated with maternal stress (r = .67, p = .00), and maternal support (r = -.50, p

= .00), such that greater amounts of problematic child behaviors were associated with heighted maternal stress and weakened support. In the subset of mothers with multiple children, problematic behaviors of the developmentally disabled child were correlated with average problematic sibling behaviors (r = .39, p = .00), such that more problematic behaviors demonstrated by the developmentally disabled child were associated with increased average problematic sibling behaviors.

In this subset of mothers with multiple children, a linear regression predicting the number of problematic behaviors demonstrated by developmentally disabled children using the predictors of the number of siblings, the amount of positive sibling interaction, and the developmentally disabled child's age was significant F(3,46) = 3.35, p = .03. The number of siblings (t = -1.95, p = .05) and positive sibling interaction (t = -2.05, p = .05) were significant, such that a greater number of siblings and greater amounts of positive sibling interaction predicted fewer problematic behaviors in the developmentally disabled child. The child's age was only borderline significant in predicting problematic behaviors, t = 1.54, p = .12. $R^2 = .423$, indicating that 42.3% of the variance in problematic behavior scores were predicted by positive sibling interaction, the number of siblings, and the child's age.

Sibling interaction as a mediator of problematic behaviors

In the current study, I hypothesized that in special needs families of multiple children increased positive sibling interaction would be associated with decreased maternal stress and decreased problematic behaviors. I analyzed this hypothesis by running a correlation between the average amounts of positive sibling interaction with the number of problematic child behaviors in a subset of mothers with both typically developing and developmentally disabled children. This analysis revealed a significant correlation (r = -.33, p = .02) such that higher

amounts of positive sibling interactions within families of multiple children are associated with lessened amounts of problematic behaviors of the developmentally disabled child. The correlations among the major variables for mothers of multiple children can be found in Table 3.

Data analysis revealed a significant correlation between the average number of positive interactions with the nondisabled siblings and the ages of the developmentally disabled children (r = -.29, p = .04), such that older disabled children had fewer positive interactions with their nondisabled siblings than younger disabled children. Additionally, an independent t-test revealed that gender and positive sibling interaction were related (t (49) = - 1.99, p = .05), such that female developmentally disabled children were reported to have more positive sibling interactions than male children.

Maternal Support

The final hypothesis of the current research, that mothers of both developmentally disabled and typically developing children would report higher amounts of support (M = 3.61, SD = .63) than mothers of only developmentally disabled children (M = 3.27, SD = .72), was marginally supported in an independent t-test t (64) = -1.77, p = .08. Additionally the correlations between the amount of maternal support and the number of children in a family (r = .30, p = .01) and the amount of maternal support and the number of problematic behaviors in the developmentally disabled child (r = .50, p = .00) were significant, such that greater amounts of maternal support were associated with more children in a family and fewer problematic child behaviors.

Although I proposed that maternal support would not only be correlated with the number of children, but also the quality of their children's relationship, a correlation between

the amount of positive sibling interaction and maternal support was not significant (r = .16, p = .28). However, maternal support was marginally correlated to the average sibling problems (r = .26, p = .07), such that when typically developing children demonstrated higher amounts of problematic behaviors the mothers reported lower perceived support.

Discussion

The current research examined the relationships among the number of typically developing children in a special needs family and the problematic behaviors of their developmentally disabled siblings, as well as the maternal stress and perceived support levels of their mothers. Mothers of children with autism, Down syndrome and mixed etiologies reported less stress and higher support when they had greater numbers of typically developing children. Furthermore, higher numbers of typically developing siblings in families were associated with fewer problematic behaviors of developmentally disabled. While the paucity of research on sibling relations and maternal stress and support levels inhibits the strength of the findings, the effects warrant further analysis.

Mothers of children with developmental disabilities have reported the greatest stress when there are deficits in the children's social relatedness and regulatory problems (Eisenhower et al., 2005), and when their children are hyperactive, unable to take of themselves, and unable to communicate or interact with others (Tomanik et al., 2004). Additional research has reported that similar characteristics of developmentally disabled children—prosocial and reciprocal interaction—are increased when sibling interaction is increased (Knott et al., 2007). The current research extended these findings to explore whether developmentally disabled children with siblings are reported to display fewer problematic behaviors than developmentally disabled children without siblings. I predicted that higher amounts of positive sibling interaction would attenuate such maladjustments, and the amelioration would be associated with lessened maternal stress in mothers of multiple children.

In the current study, I found a significant relationship between decreased maternal stress and increased number of children in the family. Further analysis showed additional links between an increased number of children in a family with increased maternal support, and increased support with decreased maternal stress. Furthermore, as predicted, lower amounts of problematic behaviors in the disabled children were associated with diminished maternal stress. As a linear regression suggested, the combination of high maternal support and low problematic child behaviors significantly predicted diminished maternal stress.

Maternal support has been extensively studied and declared a well-steeped "protector" in shielding mothers from grief, mental illness, and physical recovery (Cobb, 1976). In exceptional families of special needs children, maternal support may also shield mothers from experiencing maternal stress (Siklos & Kerns, 2006). However, the development of maternal support may be contingent on the number of supportive family members, including children, and the extent of these children's positive interactions with the disabled children. The idea that maternal support is influenced by not only the quantity, but also the quality of familial relations, was supported by the finding that maternal support was correlated with both the number of family members, and the number problematic child behaviors and marginally correlated with sibling behaviors as well.

As predicted, the problematic behaviors of children with developmental disabilities appeared to be related to the number of typically developing siblings they have, such that children with more siblings demonstrated fewer problematic behaviors. I hypothesized that this association would be related to the effect of increased prosocial and reciprocal interactions for developmentally disabled children with typically developing siblings compared to developmentally disable children without siblings (Knott et al., 2007). The developmentally disabled children's abilities to engage in collaborative interactions appear to be uniquely enhanced by the role reciprocity inherent in the sibling relationship—peer interactions do not suffice (Knott et al., 2007).

I further hypothesized that not only the number of siblings, but also the quality of sibling relationships would be associated with problematic child behaviors. In support of this hypothesis, the current research found that the amount of positive sibling interactions was significantly correlated with the number of problematic child behaviors, such that greater amounts of positive sibling interaction were associated with diminished problematic child behaviors.

To answer the question regarding maternal support, such that maternal support can be predicted by not only the quantity, but also the quality of familial relations, I examined the relationship between the number of siblings and amount of positive interaction, in relation to perceived maternal support. Interestingly, while I found that the number of siblings, the amount of problematic child behaviors, and the amount of sibling problematic behaviors were significantly related to the amount of perceived support, I did not find that the amount of positive interaction was related to maternal support.

Taken together, these findings suggested that while increased amounts of positive sibling interactions were related to fewer problematic child and sibling behaviors, maternal support seems to be predicted by these outcomes, (lessened problematic behaviors), rather than the process (positive sibling interaction). For families of multiple children, the combined increase in maternal support and decrease in the number of problematic predicted a decrease in maternal stress.

Limitations

In drawing conclusions about the meaning of the results presented here, certain limitations must be addressed. While the sample size of the present research was small (n=68), specifically the numbers of mothers with only a developmentally disabled child (n=17) and with more than one typically developing child (n=28) were small. Additionally, the current study is limited by the wide range of siblings' and children's ages (1-40 and 1-30, respectively). Additionally, the measures of children's behaviors and sibling's behaviors were developed for children aged 4-18 years old. Future research that is able to recruit more mothers of developmentally disabled children without siblings, whose ages are in a smaller, more appropriate range will find more profound differences in the stress and support levels of such mothers, and will be able to extend their findings further.

The sample of mothers of children with developmental disabilities was primarily obtained through educational centers, and therefore, it is likely that this was not a random sample of parents but rather a group that shares certain common characteristics. Consequently, the sample may represent a sample of parents who are more highly stressed due to their children's disorders and are reaching out to the community for help. On the other hand, these may be families who are somewhat less stressed, because these parents could find the time to participate in the survey. It is unclear which hypothesis is true of the group.

Furthermore, given the correlational nature of many of the findings, the direction of effect in my findings remains unclear. Therefore it is imperative to consider alternative explanations. Firstly, although I proposed that the relationship between greater number of

children in a family and lessened number of problematic child behaviors suggests that the presence of siblings may ameliorate problematic behaviors, it may also suggest that mothers of developmentally disabled children with fewer problematic behaviors are more willing to have more children—mothers of children with more severe disabilities may feel too burdened to have more children. Similarly, the associations between the number of children in a family and the amount of maternal stress and support may suggest that more children ameliorate stress and enhance support. However, it is possible that mothers of special needs children who perceive lower stress levels and higher support levels feel more capable of having additional children. Lastly, while the data suggest that their problematic behaviors are lessened, the correlation could also suggest that developmentally disabled children with fewer problematic behaviors are easier playmates and naturally encourage greater amounts of positive sibling interaction.

Given the limitations noted above, several conclusions can still be drawn from the present study. For mothers of developmentally disabled children, an increased number of children was related decreased maternal stress and increased perceived support. Further, maternal stress and maternal support were negatively associated with each other, such that higher stress was related to lower support. Maternal support was additionally related to decreased problematic child and sibling behaviors. I understand these original findings to suggest that sibling relationships encourage unique interaction opportunities that enhance the development of developmentally disabled children. These relationships may not only decrease problematic child behaviors, but also increase maternal support; this increase in maternal support may ameliorate maternal stress.

While the paucity of such findings limits the conclusions, the novelty of the results is noteworthy. Future research should further examine these exceptional families with more focused sampling, and smaller age ranges for the children and siblings. To better examine the main variables of maternal stress and support, problematic child behaviors, and positive sibling interaction, additional research may want to consider the differences in these effects in longitudinal studies. Examining families of only developmentally disabled children over time, matched for behaviors, may reveal how problematic behaviors develop. Further more, the behaviors of children whose parents have additional, typically developing children, in relation to their sibling relationships, would shed light on this interesting phenomenon.

While the current research found innovative findings, further research is imperative in clarifying and extending the implications. Future research should analyze the complex relationship between developmentally disabled children and their typically developing siblings, in light of problematic child behaviors and maternal stress and support with greater participation, more refined measures, and with longitudinal and more in-depth design

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| | Mothers of only disabled children | developmentally (N=17) | Mothers with both developmentally disabled children and typically developing children (<i>N</i> =51) | | |
|---|-----------------------------------|---------------------------|--|--------------------|--|
| Variables | Mean | Standard Deviation | Mean | Standard Deviation | |
| Mother's Stress (PSS) | 1.98 | .71 | 1.82 | .52 | |
| Mother's Support (SSI) | 3.27 | .72 | 3.61 | .63 | |
| Child's Problematic Behavior Score (DBC-P24) | 8.08 | 4.01 | 6.28 | 3.66 | |
| Child's Age | 10.17 | 5.59 | 10.41 | 6.97 | |
| Average Sibling Problematic Behavior Score (SDQ) | _ | _ | 14.24 | 4.29 | |
| Average Sibling Interaction Score | — | — | 2.50 | .66 | |

Table 1Mean and Standard Deviations of Major Variables

| <u>Variables</u> | Stress | Support | Child Problem Behavior | Number of Siblings | Child's Age | | |
|--|--------|---------|------------------------------|-----------------------|-------------|--|--|
| Mother's Stress (PSS) | | 67*** | .66*** | 24** | .07 | | |
| Mother's Support (SSI) | | — | 50*** | .30** | .00 | | |
| Child's Problematic Behavior Score (DBC-P24) | | | — | 28** | .20 | | |
| Number of Siblings | | | | _ | .01 | | |
| Child's Age | | | | | | | |
| * $p \le .10, **p \le .05, ***p \le .01$ | | | | | | | |

Table 2Correlations for all mothers (N=68)

Table 3

Correlations for mothers of both developmentally disabled and typically developing children (N = 51)

| <u>Variables</u> | Stress | Support | Child Problem Behaviors | Avg. Sibling Problem Behaviors | Avg. Amount of Positive Sibling Interaction | Child's Age | Number of Siblings |
|---|--------|---------|-------------------------------|---|---|----------------|--------------------------|
| Mother's Stress (PSS) | | 64*** | .64*** | .15 | 098 | 03 | 29** |
| Mother's Support (SSI) | | | 50*** | 26* | .16 | .00 | .26* |
| Child's Problematic Behavior Score (DBC-P24) | | | _ | .39*** | 33*** | .20 | 24* |
| Average Sibling Problematic Behavior Score | | | | _ | 82*** | .25* | 09 |
| Average amount of Positive Sibling Interaction Score | | | | | | 29** | 05 |
| Child's Age | | | | | | _ | 01 |
| Number of Siblings | | | | | | | _ |

* $p \le .10$, ** $p \le .05$, *** $p \le .01$