

A CROSS-SECTIONAL STUDY OF PATTERNS OF RENEWED STRESS AMONG
PARENTS OF CHILDREN WITH AUTISM

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A Dissertation submitted to the
Graduate School-New Brunswick
Rutgers, The State University of New Jersey

In partial fulfillment of the requirements

For the degree of

Doctor of Philosophy

Graduate Program in Clinical Psychology

written under the direction of

Sandra L. Harris

And approved by

New Brunswick, New Jersey

May, 2009

ABSTRACT OF THE DISSERTATION

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Parents of children with autism report levels of stress higher than that reported by parents of children with other developmental disabilities and typically developing children (Donovan, 1988). Though a considerable amount of research has focused on the identification of variables, specific to autism, that increase parent stress, little attention has been given to shifts in parenting stress over time. Parents may be especially susceptible to increased stress during times characterized by transitions in their child's educational, vocational, or residential placement and at times when they are reminded of the effects of the long-term nature of their child's diagnosis. Children's developmental transitions into school-age, adolescence, and adulthood are times during which parents are often faced with decisions about their child's placement and may be more likely to experience "transition" and "reminder" events that increase parent stress.

The current study compared the stress of parents (67 mothers and 39 fathers) whose children were currently aging into a developmental transition and those whose children were not. Parents completed questionnaires regarding their current level of stress, recent experiences raising their child with autism, child behavior, and social support. Contrary to expectations, parents of children in developmental transition groups did not report higher stress levels than did other parents. Additionally, parents of children in developmental transition and non-developmental transition groups were equally likely to report considering a transition in their child's placement or being reminded of their child's long-term diagnosis. However, child problem behavior significantly predicted parenting stress for mothers and fathers, and the number of reported reminders of their child's long-term diagnosis significantly predicted increased parenting and general life stress for fathers, but not for mothers.

Though replication and a larger sample size are necessary to validate the findings in the current study, these initial results suggest that mothers' and fathers' stress levels are differentially affected by their experiences with their child with autism. Implications of this research include tailoring parent support to address concerns about child problem behavior and, for fathers, addressing the perceived impact of their child's long-term disability on the goals they held for themselves and their child prior to diagnosis.

Acknowledgement

The completion of this project would not have been possible without the help and support of many. First and foremost, thank you to the parents who participated in this study and shared their experiences in raising a child with autism. I was touched to have you share such personal memories and moments and I appreciate your support for my continued work in the field. This research was supported by the Organization for Autism Research, and I am grateful to be funded by an organization that sponsors important and groundbreaking research in the assessment and treatment of children with autism and their families. Much appreciation goes to the staff of the New Jersey Center for Outreach and Services for the Autism Community for their help in disseminating recruitment fliers to the autism community. Special thanks go to Barbara Wells, Ian Wells, and Ian's job skills classmates for assembling the recruitment fliers. Many people gave input on early drafts of the measures, methods, and statistics used in this dissertation, including Richard Ashmore, Douglas Penfield, John Lazarus, Michael Greenberg, Lucila Ohno, and Ruy Machado. Thank you for pointing me in the right direction. Additionally, many thanks to Takehiko Nakama for his help conceptualizing the statistical analyses for my data set.

I am grateful for the invaluable encouragement and resources offered by the faculty and staff at the Douglass Developmental Disabilities Center. Special thanks to Meredith Bamond, Suzannah Ferraioli, Megan Martins, and Sharon Grant for their unconditional willingness to help me navigate this process. My undergraduate researchers, Melissa Dackis, Mina Kim, Lynn Henke, and Johanna Lima earn accolades for the hours they spent assembling questionnaire packets and entering data. Most notably, thank you to Robert LaRue, Mary Jane Weiss, Jan Handleman, and Lara

Delmolino for your guidance not only in this project but also throughout the course of my graduate program.

I would like to express my gratitude to my committee members, Danielle McCarthy, George Wagner, Becky MacDonald, and Sandra Harris for their input on early drafts of the proposal and dissertation, and for taking the time to provide constructive feedback on the project. Sandy, you are the quintessential mentor, and I treasure the time that I have spent with you on both an academic and a personal level. Your sense of humor and unwavering concern for my professional and personal development are the essential ingredients for a successful—and dare I say it, pleasurable—graduate school experience. Thank you for everything.

Finally, thank you to my closest friends and family who have seen me through this process. Amanda, Naomi, the Masseys, Mom, Dad, Ben, Allie, and Sean, you have been unfailing in your support of my work in this field, and I thank you all for your encouragement.

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A Cross-Sectional Study of Patterns of Renewed Stress Among Parents of Children With Autism

Parents of children with autism experience a level of stress unique to their situation, related to the long-term disability and myriad symptoms exhibited by their children. Children with autism often demonstrate behavior that poses challenges to the parents, including a lack of meaningful communication between parent and child and, in many cases, the absence of a positive affective relationship (Donovan, 1988). High rates of aberrant behavior (e.g., tantrums, aggressions, disruptions) may also contribute to the high level of parent stress (Baker et al., 2003; Olsson & Hwang, 2001).

While parents of children with autism may experience a high level of stress relative to that experienced by other parents, this stress may increase and decrease during important phases and transitions throughout the child's life. Identification of these time periods is crucial so that school personnel, therapists, and other professionals may help prepare parents for these events and provide adequate support. Many programs for individuals with autism offer parent training or parent support groups, acknowledging that the stress of raising a child with autism can be overwhelming for parents. While these services may help decrease parent stress, program awareness of the triggers for high parent stress may make these services more effective.

Although many professionals in the field provide anecdotal reports about the periods of life that are most stressful for parents of children with autism (e.g., Hanline, 1991), little research has empirically investigated the events, transitions, and parent cognitions that impact parent stress most significantly. The proposed study is designed to identify these periods of increased stress through the examination of self-reported stress

and stressors experienced by parents raising a child, aged infancy to adulthood, with autism. To provide a rationale for the current research, I will first review the current body of literature regarding parent stress in raising a child with autism as well as past research hypotheses regarding events during which parent stress might increase. I will also summarize what is currently known about protective factors against stress among parents of children with autism. Following this, I will detail the hypotheses of my study, which examines the patterns of stress among parents of children with autism using a cross-sectional questionnaire design.

Stress among Parents of Children with Autism

Psychological stress is defined as “a particular relationship between the person and the environment that is appraised by the person as taxing or exceeding his or her resources and endangering his or her well-being” (Lazarus & Folkman, 1984, p. 19). Four types of stressors are discussed in the literature. The first, acute, time-limited stressors, are those that are transient in nature, and result in instantaneous but fleeting stress, such as that experienced when one is startled by a snake. Stressor sequences are those that occur over a longer period of time in response to an initiating event such as the death of a loved one or a job loss. Chronic intermittent stressors are those that increase stress but on a variable schedule (e.g., weekly, monthly). Chronic stressors are those that may have been initiated by a discrete event and persist continuously over time. (Elliott & Eisdorfer, 1982; Glasberg, Martins, & Harris, 2006).

Parents of children with autism likely experience chronic psychological stress, due to the unremitting challenges of raising a child with a lifetime diagnosis. This level of strain on parents may increase or decrease with the occurrence of specific events or

transitions but, on the whole, persists at a level higher than that of other parents. Parents of children with autism experience a greater level of stress than do parents of typically developing children, and even experience more stress than do parents of children with other disabilities such as Down syndrome and mental retardation (Donovan, 1988) or parents of children with fatal or chronic illnesses (Bouma & Schweitzer, 1990). Stress experienced by parents of children with autism may be indexed in part by the mental health observed in these parents. A few studies indicate that mothers (Olsson & Hwang, 2001; Moes, Koegel, Schreibman & Loos, 1992) and fathers (Olsson & Hwang, 2001) of children with disabilities, including autism, experience higher rates of depression than do other parents. However, research has not investigated whether parents of children with autism are more vulnerable to depression than parents of children without autism prior to their child's birth. Consistent with the prevalence rates of depression rates among men and women in the general population (e.g., Maier et al., 1999), mothers of children with autism tend to experience twice the rate of depression than do fathers (Moes et al., 1992). The combined effect on parents of children with autism, however, is staggering. Olsson and Hwang (2001) found that, among families raising a child with autism, 50% of mothers and 21% of fathers experienced elevated levels of dysphoria or depression. This is in sharp contrast to the lower rates among families of typical children: 17% of mothers and 15% of fathers reported elevated scores (Olsson & Hwang, 2001).

The higher rate of depression—as an index of stress—among mothers of children with autism may be due to the fact that the mother frequently serves as the primary caregiver for the child with autism. She often takes on more child and house care responsibilities than the father (Bristol et al., 1988), commonly sacrificing her career for

the needs and demands of her child (Olsson & Hwang, 2001; Seltzer, Greenberg, Floyd, Pettee, & Hong, 2001). Seltzer et al. (2001) report that parents of children with developmental disabilities work fewer weeks per year than parents of children with mental health (e.g., bipolar disorder, major depression, schizophrenia) problems or typical children. This finding is especially prominent among mothers of children with developmental disabilities, who work an average of 8 weeks fewer per year than do parents of children with mental health problems or typical children. As mothers of children with autism take on more childcare than do fathers, they may be at a greater risk of depression and high levels of stress than are fathers of children with autism.

Parent stress—and concomitant increases in psychological distress—among parents of children with autism may be related to the high level of child care and responsibility required of many parents. In addition, the symptoms characteristic of children with autism may rob parents of a positive affective relationship with their child. Autism is a developmental disorder marked by significant impairments in language, social skills, and a pattern of restricted repetitive and stereotyped behaviors (American Psychiatric Association, 2000). Many children with autism demonstrate an absence of appropriate emotion and a low desire for social interaction. This perceived indifference, combined with the child's inability to effectively communicate with parents, may generate high levels of stress for parents (Donovan, 1988; Olsson & Hwang, 2001).

Moreover, caring for a child with autism is a lifelong responsibility that stands in contrast to that taken on by other parents. While all parents expect to provide childcare for their son or daughter through childhood and often into late adolescence, many parents are relieved of intensive childcare as the child leaves the home and attends college or

seeks employment. Parents are then able to watch their child develop a career, explore romantic relationships, and raise children of their own.

Parents of children with autism, however, recognize that the care they provide for their child is unlikely to remit in adulthood, and that their child will not reach the milestones achieved by most typical children. For example, parents of children with developmental disabilities are significantly more likely to have their child live with them into adulthood. Seltzer et al. (2001) report, among parents in their 50s, 57% of parents of children with developmental disabilities still lived with their affected child, compared to 41% of parents of children with other severe mental health disorders and only 16% of parents with typical children. The cognitive, affective, and physical limitations exhibited by children with autism often result in long-term dependency on their parents. As a result, parents of children with autism report limited aspirations for their child's future—in contrast to parents of typical children who look forward to the promising accomplishments of their adult child—which may contribute to their overall level of chronic stress (Donovan, 1988). Returning to Lazarus and Folkman's (1984) definition of psychological stress, this prolonged required care may seem in excess of what parents feel they are able to provide given their mental, emotional, physical, or in some cases, financial resources and therefore contribute to elevated parent stress.

While most research on parent stress has focused on the effects of the global stressor of raising a child with autism on stress, no research has assessed the possible individual events within a child's life that might further increase parent stress beyond the normative elevated stress level. Each year of a child's life, events, transitions, and parent cognitions will take place that have the potential to increase parent stress. Identifying

these individual stressors, as well as potential protective factors will be paramount to implementing effective support programs for parents of children with autism.

Life Events among Parents of Children with Autism

While chronic stress will be experienced by many parents of children with autism, transitions and events specific to the developing child with autism may further increase this level of stress. These events may, in a sense, layer an acute episode of increased stress onto an already elevated level of chronic stress. All families, including those of typical children, experience stressor sequences that elevate psychological stress. Such events may include the death of a family member or a move to a new home. These events often result in increases in stress that, while initially intense, decrease over time as the event passes into history or the family learns to adjust to the change incurred by the event.

Families of children with autism experience these normative stressful family events, but they also experience events that are unique to the individual with autism. These events may include the time of diagnosis, transitions to a new school or residential placement, or the child's inability to reach developmental milestones typical of other children. Researchers have suggested that the events that increase parent stress are those that remind the parent of the child's diagnosis and the lifelong care that is required for the child (Blacher, 1984; Hanline, 1991; Wikler, 1986). Many researchers posit that emotions first experienced by parents at diagnosis may be re-experienced when events or transitions remind parents of their child's disorder and they again must face their loss of a typical, healthy child. These transitions serve as reminders of "what might have been" and may cause increases in parent stress beyond the normative, chronic level experienced

by parents of children with autism (Hanline, 1991; Wikler, 1986). A review of events that have been hypothesized by researchers to result in increased parent stress follows.

Diagnosis. The period of time during which a child approaches diagnosis or is diagnosed is a time ridden with complex emotions for parents. To begin, parents may recognize that their child is not developing typically and grow concerned about potential illness. Parents have retrospectively reported on this concern, and the worry that took place when their child developed differently or more slowly than expected (Midence & O'Neill, 1999). If parents do not recognize the signs of early disability, perhaps because of lack of familiarity with the developmental milestones of typical children, other family members or friends may recognize signs of trouble and approach the parents about their child's delayed development. This confrontation may lead to increased confusion and concern among parents, as well as resentment toward those who are suggesting that their child is delayed.

Seeking medical opinion for their child's delay, parents respond to their child's diagnosis of autism with a number of varied emotions. Many parents may experience feelings of shock, denial, disbelief, and confusion. Some parents may disagree with the initial diagnosis and seek several medical opinions to confirm the diagnosis (Blacher, 1984; Midence & O'Neill, 1999). Parents during this time might begin to mourn the loss of the child that they expected to have, and become increasingly saddened as they recognize symptoms characteristic of individuals with autism: low desire for social interaction and relationships, inappropriate affect, poor communication skills, and maladaptive behavior (Blacher, 1984).

Regardless of how parents first react to their child's diagnosis, all stand to experience an increased level of stress. How the stress experienced by parents during this time compares to that experienced by parents at later times in life, however, is not currently known. Researchers suggest that the level of stress experienced by parents at the time of diagnosis is renewed during events of early childhood, adolescence, and adulthood that remind a parent of the long-term nature of his or her child's diagnosis. A summary of these events follows.

Early Childhood. A period of parenting that has received surprisingly little focus among parents of children with autism is that of their son or daughter's early childhood, before the age of 4 years. This is likely because children are often diagnosed during this time, but recently early detection of autism has become more sophisticated, identifying children who receive a diagnosis of autism by age 2 in some cases (e.g., Bryson et al., 2007; Chawarska et al., 2007; Richler, Bishop, Kleinke, & Lord, 2007; Sullivan et al., 2007).

Given the number of decisions required of parents and the critical developmental milestones their child should reach during early childhood, the lack of consideration of this time period in empirical research on parent stress is unexpected. During their child's early years, parents must seek and acquire appropriate treatment services; though as parents newly exposed to raising a child with autism they know little about the disorder and effective treatments. At this time, parents may feel confused about how best to acquire treatment for their child and, with many marketed—though often questionable—programs for children with autism, they may feel overwhelmed by the decisions they must make regarding their child's future.

As mentioned, events that may be especially stressful for parents of children with autism during their child's early development include those that remind the parents of the child's disability (Hanline, 1991; Wikler, 1986). Developmental milestones that are not reached may cause the parents significant despair, such as when the child reaches the age at which he or she should be able to talk, but the child remains nonverbal. Social milestones, such as the age at which the child should start kindergarten, may also upset the parent if the child does not accomplish them. At this age, parents may also observe younger siblings developmentally surpassing the child with autism, again reminding the parent of the child's disability (Hanline, 1991).

In the past few decades, increased emphasis has been placed on the use of early intervention in improving the prognosis of children with autism (e.g., Lovaas, 1987; Smith, 1999). The ultimate goal of many early intervention programs is to transition a child into a general education setting. As a result, parents also hold this as a goal for their child, and the effectiveness of many early intervention programs may heighten parents' hope for this goal. Early intervention, therefore, sets parents up for many transition stressors that they may experience as their child reaches school-age.

School-Age. Many parents of children with autism experience what is termed "the courageous paradox" (Hartshorne, 2002, p. 268) in which they tell themselves that, if their child never makes progress, they will accept him or her as she is; at the same time, however, they never give up hope that their child will improve beyond all expectations. This paradox is heightened by the constant barrage of stories parents face in which children diagnosed with autism, upon receiving early intervention services, seem to miraculously develop the requisite skills needed to lead a normal life (e.g., Adams, 2005).

Some children seem to thrive in early intervention services, initially appearing extremely low functioning and improving to a level at which they are able to be mainstreamed into general education classrooms. Having heard these stories, many parents may hope for such an outcome for their child, wishing for their child's inclusion in a general education setting and the resulting possibility that their child may lead the life of a typical child.

Parents who are told that their child will not be able to be included in a general education setting because of a lack of requisite skills may experience what could be termed a "second diagnosis." At this time they may realize—perhaps for the first time—that their child is incapable of full inclusion and will likely receive special education services throughout his or her school years. This realization may bring a relapse of grief, sorrow, anger, and resentment for the parents, resulting in increases in parent stress.

Parents whose children are successfully included in a general education setting may grapple with different stressors, such as understanding the treatment delivery system of the general education setting as well advocating for their child's legal rights to special education services in this setting (Hanline, 1991). In addition, social concerns for parents may arise, such as how to integrate children in extracurricular and social activities (Hanline, 1991), and how to manage situations in which their child may be teased or bullied.

Inclusion presents parents with a number of concerns that must be faced on a daily basis. As early intervention services become more effective and as general education settings become more capable of including children with autism, the parents' expectation that their child enter a general education setting and the stressors that accompany the ultimate placement may be increased from what it was a few decades ago.

Accordingly, this area may not have received the research attention that it currently requires.

Adolescence and Adulthood. Some transitions that may increase stress levels among parents are naturally occurring life events, such as transitions into adolescence or adulthood. Again, the onset of adolescence and adulthood may remind parents of their child's long-term diagnosis as they consider the events typical of these ages that their child will not experience (e.g., entry into high school or college, marriage, etc.). Wikler (1986) examined the stresses of families of older children by longitudinally evaluating the stresses of parents as their children transitioned into adolescence and adulthood. In comparing parents of children with mental retardation aged 7 to 25 years, the author found that parents whose children were experiencing the onset of adolescence or adulthood (i.e., ages 11 to 15 and ages 20 to 21) exhibited the highest level of stress among parents. While Wikler points out that a lack of control group limits the ability of the reader to discriminate normal parent stress at this time from the unique stress experienced by parents of children with disabilities, it provides a nice example of empirical evidence for the increased stress experienced by parents during times of transition.

Additional reasons for increased parent stress during this time include the decisions required of parents during these times regarding their child's future. Adolescence and adulthood require parents to consider options for their child's academic setting, vocational career, residence, and guardianship (Baker & Blacher, 2002; Hanline, 1991). Of these, decisions regarding the child's long-term residence have received the most attention in research. Residential placement may have been considered earlier in the

child's life if he or she exhibited significant behavior problems that made it difficult for parents to care for the child in their home, but many families will consider placement as the child grows older and they look for more long-term care options as the child's parents age.

Coping and Protective Factors among Parents of Children with Autism

The periods of a child's life from diagnosis to adulthood present parents with a series of challenges that may further elevate their chronic level of stress. Though stress levels among parents of children with autism are generally higher than that of other parents, some factors may moderate the effects of raising a child with autism on the psychological health of the parent, and as a result may serve as protective factors for parents. Hill (1949) described a model of stress that he termed the "ABCX" model, in which the effects of a stressor (A) interact with crisis-meeting resources (B) and the definition of the event (C) to contribute to the development of and family response to a crisis (X). According to this model, parents' resources and the way in which they perceive their child and the events in their lives will affect the ultimate intensity of a stressful event (Hill, 1949; Lazarus & Folkman, 1984). In examining the effects of stressor events on parents of children with autism, we must be sure to consider the impact of the "Bs and Cs" of the event—or the parents' coping resources—on parent stress.

Much research has examined the effects of coping resources and protective factors on parent stress, and knowledge of such factors requires careful consideration of these variables when assessing parent stress. While the present study sought to identify the specific events that may trigger increased parent stress, coping strategies and protective factors that may protect parents against increase in stress should be controlled

for, or even examined as variables of interest in their own right. To that end, the current study assessed the effects of specific coping strategies and protective factors, including child characteristics, personal resources, and social support, on parent stress. A review of coping resources and protective factors that were assessed in the current study follows.

Child characteristics. Several child characteristics can contribute to the overall level of stress experienced by parents. Gender, for instance, is one variable that may contribute to the stress experienced by parents in response to their child's disability. Parents appear to exhibit greater parental adjustment—and thus experience less stress—to a female child who has been diagnosed with a disability, as opposed to a male son. Some parents, especially fathers, have higher expectations for sons and as a result experience more stress in recognizing the child's skill deficits (Frey, Fewell, & Vadasy, 1989; Krauss, 1993; Scorgie, Wilgosh, & McDonald, 1998). Child age may also affect parent stress, in that as children age, parents may grow more pessimistic about their life outcome and possibilities for growth and development (Scorgie et al., 1998; Donovan, 1988). Parents of older children, therefore, may experience more stress than parents of younger children.

The symptoms exhibited by the child with autism may also significantly affect the stress experienced by parents. For instance, children who are able to communicate effectively with parents may reduce the amount of stress exhibited by their parents as compared to parents whose children are nonverbal or poor communicators (Frey et al., 1989). Parents whose children are emotionally responsive may experience lower levels of stress than parents of children who do not respond emotionally (Krauss, 1993). The severity of a child's maladaptive behavior may also affect parents' ability to cope with

their child's disability. Baker et al. (2003) found that child behavior problems predicted parent stress among parents of individuals with developmental delays, even after accounting for prior stress levels. Additionally, parent stress predicted future child behavior problems, suggesting that parents may find themselves in a cycle in which their increasing levels of stress further exacerbate the source of stress.

Personal resources. A number of parent psychological resources may also impact the level of stress they experience in raising a child with autism. Demographic variables, such as parent age, education, finances, and religious faith are significantly related to psychological distress among parents of children with autism. Specifically, parents with higher education, greater financial resources, and stronger religious faith experience significantly less stress in raising their child with autism than do other parents (e.g., see review by Yau & Li-Tsang, 1999), and older parents experience greater stress than younger parents (Minnes & Woodford, 2005). Additionally, parenting and coping skills such as problem solving ability and feelings of self-efficacy in parenting are also related to parent stress. Hastings & Brown (2002) found that mothers who reported high feelings of self-efficacy in raising their child with autism experienced lower levels of depression, while fathers who reported high self-efficacy experienced lower anxiety if their child with autism exhibited high rates of problem behavior.

Parent resiliency also appears to be affected by the way in which parents perceive their child's disability and the coping strategies that they implement. The stress exhibited by parents of children with disabilities appears to be moderated by the parents' level of optimism, such that parents with greater optimism experience lower levels of stress in response to their child's disability (Baker, Blacher, & Olsson, 2005). Parents who exhibit

“hardiness,” in which they see their child’s disability as an opportunity rather than an obstacle, persevere in the face of challenge, and maintain a sense of control over events experience significantly less stress, anxiety and depression than other parents (Gill & Harris, 1991; Weiss, 2002). Weiss (2002) reports, however, that mothers of individuals with autism are significantly less hardy than mothers of children with mental retardation or typical children and are thus at a disadvantage when responding to environmental stressors.

Social support. Resources provided by family and other social relationships can significantly improve parent coping skills. The parents’ access to a support network is crucial to their adjustment to raising a child with autism. More important than the availability of this social network, however, is the satisfaction with the amount of social support received from the social network (Yau & Li-Tsang, 1999). While a parent may be surrounded by friends and family, it is his or her satisfaction with the support that ultimately affects the level of parental stress. Boyd (2002) reports that mothers who exhibit low stress levels in raising children with autism report more perceived support than do mothers who exhibit high stress levels.

Reportedly the best predictor of coping success among parents of children with autism is the quality of the parents’ marital relationship (Boyd, 2002; Kersh, Hedvat, Hauser-Cram, & Warfield, 2006; Yau & Li-Tsang, 1999). High marital strength is often considered necessary for a parents’ healthy adaptation to crisis. Given that each is experiencing the same events and few can empathize with the parent to the extent of a spouse, the superior level of protection afforded by a sound marital relationship is not surprising.

Parents may receive additional social support from agencies structured to support families of children with autism. For example, support groups for parents of children with autism may be beneficial for parents. These groups are often structured to allow discussion of experiences common to the parents attending the group and to provide resources for parents during difficult time periods (Hartman, Radin, & McConnell, 1992). Parents are able to share their concerns with others who have had similar experiences, which may decrease their stress regarding the situations and provide them with useful information regarding decisions they must make for their child's future (Yau & Li-Tsang, 1999).

Summary

Researchers have extensively hypothesized that events specific to raising a child with autism increase parent stress and renew the emotions experienced by parents at the time of their child's diagnosis. These events, which are strewn throughout childhood, adolescence, and adulthood, remind the parents of the child's diagnosis and of the long-term challenges that the child and the parents will face. Professionals suggest that parents will require additional support during these times, indicating that parents need increased resources to help them navigate the turmoil they experience during these transitions and events.

Although Wikler (1986) did empirically investigate the levels of stress experienced among parents of children with mental retardation, she did not sample parents of children younger than the age of 7, and her sample did not include individuals with autism. This did not allow for comparison between levels of stress and the stress experienced at diagnosis, and also does not encompass the stress experienced by parents

prior to possible educational inclusion. In the two decades that have passed following the publication of Wikler's research, advances have been made in the treatment of autism specifically, and as a result the patterns of stress among parents, including those of young children, should be reassessed.

To that end, the current study asked parents of children with autism to report on the stress they have experienced during recent events in their child's life. Parents' accounts allowed a comparison of stress experienced by parents who are raising children in different stages of development, such as early childhood, school-age, adolescence, and adulthood. Of particular interest were parents whose children were currently transitioning into a developmental stage, as these children were hypothesized to experience many of the life events that researchers have indicated may increase parent stress. This cross-sectional comparison allowed the examination of patterns of parent stress over time in response to specific transitions and events in their child's life. Identification of the events that contribute to the highest levels of stress will be crucial to the development of support groups and parent trainings that will most effectively protect parents from psychological distress in raising their child with autism.

Research Questions and Hypotheses

I examined the patterns of parent stress through cross-sectional analysis of responses from parents of children in different developmental stages. The stages of development used in this study were similar to those described by Wikler (1986) with the addition of an early childhood stage, onset of school-age stage, and adulthood stage. That is, child age stages were comprised of *early childhood* (under the age of 4;0), *developmental transition to school-age* (4;0 to 6;11), *school-age* (7;0 to 10;11 years),

developmental transition to adolescence (11;0 to 14;11 years), *adolescence* (15;0 to 18;11 years), *developmental transition to adulthood* (19;0 to 21;11 years), and *adulthood* (older than 22;0). Parents of children in developmental transition groups will be compared to children in non-developmental transition groups. Notably, these groups are based on the chronological age of the child and are not based on whether the child has *actually* experienced a transition (e.g., a change in placement) in recent months. That is, a child may be placed in a developmental transition group because his age falls into a range verging on the onset of school-age, adolescence, or adulthood; however, he may not have experienced any transitions, such as a change in school placement, in recent months. Conversely, a child in a non-developmental transition group may have experienced several transitions recently. Specific hypotheses regarding these groups follow.

Do parents whose children are currently aging into a new developmental stage (e.g., school-age, adolescence, adulthood) experience more stress than parents whose children are not aging into a new developmental stage?

Based on Wikler's (1986) early research and qualitative research on parents' reactions to diagnosis, I expect to find a main effect of child group membership on parent stress. I hypothesize that cross-sectional analysis of the parents' reports of current stress will show that parents whose children are in the developmental transition age groups report higher current stress than parents of children who are not in a developmental transition group.

What events occur during the onset of a new developmental stage that may contribute to higher levels of parent stress during these times? Researchers and professionals have frequently suggested that parents experience renewal of stress when

transitions or events remind them of the long-term effects of their child's diagnosis and they again mourn the loss of the typical child they had expected to raise (Hanline, 1991; Wikler, 1986). To explain the higher levels of stress experienced by parents of children in developmental transition groups, I expect a significantly greater percentage of parents in these groups to have recently considered or experienced a transition in their child's educational, residential, or vocational placement and to report being reminded of the long-term nature of their child's disability in the past 6 months.

Method

Participants

Parents of children with autism were recruited for this study through fliers and announcements distributed by agencies in support of parents with autism (e.g., New Jersey Center for Outreach and Services for the Autism Community [COSAC]) and schools and programs specializing in the treatment of individuals with autism (e.g., Douglass Developmental Disabilities Center). The fliers, which explained the purpose of the current study and encouraged parents to contact the primary investigator to participate (see Appendix A), were distributed to families directly by these agencies and programs to protect the confidentiality of the families served.

The recruitment fliers targeted parents of children who had been diagnosed with Autistic Disorder. To sample the effects of raising a child with autism throughout development, the children with autism ranged in age from birth to adulthood. A “parent” was defined as a biological parent, step-parent, or adoptive parent for the child with autism. If only one parent currently cared for the individual with autism (e.g., divorced or single parents), that parent was the sole reporter for the family. Otherwise, parent dyads were recruited for this study and each parent was asked to respond individually. Parent dyads could be comprised of married or cohabitating couples, either heterosexual or homosexual.

Approximately 1,500 recruitment fliers were distributed to parents of children who attended the Douglass Developmental Disabilities Center or who were currently included on the COSAC mailing list. The total number of families that received the flier could not be obtained due to the recruiting procedure used (e.g., multiple families could

have viewed a flier distributed by COSAC), but a total of 146 families contacted the primary investigator and expressed interest in receiving a questionnaire packet for the purposes of this study. Of these, 112 families (76.7%) returned completed questionnaires. Seven of these families (6.3%) had two children with autism and were excluded from analyses because of concerns that raising multiple children with autism may affect parent stress differently from raising only one child with autism. Of the remaining families, 71 (67.6%) included a child diagnosed with Autistic Disorder, 24 (22.9%) included a child diagnosed with Pervasive Developmental Disorder, Not Otherwise Specified, and 10 families (9.5%) included a child diagnosed with Asperger's Disorder. Only children with Autistic Disorder were eligible for participation in this study, and as a result the final sample of families was comprised of the 71 families raising a child with autism.

Data Collection Procedures

Once parents contacted the primary investigator by phone, e-mail, or mail regarding their interest in participating in the study, the primary investigator sent a questionnaire packet to their home using the address provided by the family. Prior to distributing the questionnaire, the primary investigator determined whether one or two parents would participate in the study by noting the contacting parents' response to the recruitment flier question, "Will a second parent also participate?" and sent out the appropriate number of questionnaires per packet.

The packet sent to parents included a cover letter and two copies of the consent form for participation in the proposed study (Appendix B), in which the purpose of the research as well as the risks and benefits of participation in the research was explicitly described. In addition to the primary consent form, parents were also asked if they would

be willing to be contacted in the future for a follow-up to the proposed study. While the current study focused on cross-sectional analysis of parent stress, future research in this area may require longitudinal measures. Parent permission for future contact was ascertained in this round of data collection to permit this follow-up. If parents were willing to participate in this research in the future, they were asked to sign a consent form for future contact by the primary investigator as well as to provide the names of two contacts (e.g., family members or friends) who might be able to provide their current address if, at the time of follow-up, they have relocated. They were also asked to fill in a letter to these contacts which, in the event that the primary investigator is unable to contact the family, notifies the contact person that the family has given their permission for the contact person to release their personal information. These follow-up data, however, were not included in the current dissertation. Parents were asked to return one, signed copy of the consent form and to retain the second copy for their records.

Upon completion of the consent forms, parents completed a series of questionnaires that assessed demographic and background information for the parents and child, the child's adaptive and maladaptive skills, current parent stress, stress during life events frequently experienced when raising a child with autism, normative stressful life experiences, and the quality of parents' relationship, social support, and coping strategies. These measures are described below. The entire packet of questionnaires was expected to take parents approximately 60 minutes to complete.

Upon completion of the questionnaires, parents returned the packet to the primary investigator in a self-addressed, stamped envelope. If parents had not returned the questionnaire within 1 month of mailing, the primary investigator contacted the family by

either phone or e-mail to ask if they planned to return the questionnaire. The family was contacted using the contact information provided by families when they originally contacted the primary investigator.

Instruments and Measures

Parent and child background and demographic information. Each parent was asked to complete a *Primary Caregiver Background Information* form (Appendix C), an 11-item questionnaire in which they provided information about their current marital status, age, background information, education, and employment. This form was designed to be completed in less than 5 minutes. Parents were also asked to complete one copy of the *Child and Family Background Information* form (Appendix D), a 20-item questionnaire in which they provided information about the gender, age, and diagnosis for their child. They also indicated their child's current educational and residential placements, as well as the current family composition. If the child was currently living at home, the parents were asked to indicate the number of people currently living at home with the child and to indicate the number of individuals who acted as caregivers for the child. Finally, the parents were asked to indicate the ethnicity of the child, the current language spoken in the home environment, and the family's income. This form was designed to be completed in less than 10 minutes.

Child's adaptive and maladaptive behavior. To assess the adaptive skills and maladaptive behavior exhibited by the child with autism, parents were asked to complete two clusters within the *Scales of Independent Living - Revised (SIB-R)*: Bruininks, Woodcock, Weatherman, & Hill, 1996). Parents should have been able to complete the two clusters of the *SIB-R* in 10 minutes. The Social Interaction and Communication Skills

cluster (56 items) assessed the child's performance through parent ratings in social interaction, language comprehension, and language expression. Parents rated their child's ability to perform each social interaction and communication skill completely without help or supervision on a 4-point Likert scale (0 = "Never or rarely," 3 = "Always or almost always"), and the ratings in each cluster are summed into a raw score. The measure provides an age equivalence score based on raw scores (*SIB-R* Standard Score, *SIB-R* SS), with older ages indicating greater child adaptive skills. The Problem Behavior Scale provided a summary of child problem behavior in eight areas: hurtful to self, unusual or repetitive habits, withdrawal or inattentive behavior, socially offensive behavior, uncooperative behavior, hurtful to others, destructive to property, and disruptive behavior. Parents rated the frequency of occurrence for each problem behavior using a 6-point Likert scale (0 = "Never," 5 = "One or more times an hour") and rated the severity of each problem behavior on a 5-point Likert scale (0 = "Not serious," 4 = "Extremely serious"). Frequency and severity scores for all problem behavior were summed in a General Maladaptive Index (*SIB-R* GMI). Lower scores on this index indicated more frequent, severe problem behavior.

Past research reports that the split-half reliability and test-retest reliability correlations for the Social Interaction and Communication Skills cluster indicate high reliability, with correlations of 0.90 and 0.96, respectively (Bruininks et al., 1996). Test-retest for the General Maladaptive Index is high, with a correlation of 0.83 and interrater reliability correlations for both clusters surpass 0.80 (Bruininks et al., 1996). Scores on the *SIB-R* also evidence strong correlations with the Vineland Adaptive Behavior Scales (Roberts, McCoy, Reidy, & Crucitti, 1993) and community adjustment (McGrew,

Bruininks, Thurlow, & Lewis, 1992) for individuals with developmental disabilities, suggesting high criterion validity for the measure as well.

Parenting stress. Current levels of parent stress were measured using the *Parenting Stress Index-Short Form (PSI-SF*; Abidin, 1990b), a 36-item measure on which parents used a 5-point Likert scale to indicate the extent to which they agree or disagree with various statements about their parenting skills and their relationship with their child. Possible scores ranged from 36 to 180, with higher scores indicating a greater level of parenting stress. Test-retest measures for the *PSI-SF* indicate a high reliability of 0.84. The short form is highly correlated with the *PSI* long form (*PSI*; Abidin, 1990a), with a correlation of 0.94. The long form of the *PSI* possesses moderate to high concurrent, construct, predictive, and discriminative validity (see review in Abidin, 1990a). The *PSI-SF* can be completed by parents in 10 minutes.

In addition, parents were asked to respond to two questions regarding their overall level of stress: One question (Parenting Stress 1, PS 1) assessed their level of stress, taking into account all areas of their life (e.g., family, finances, employment, personal events), and the second question (Parenting Stress 2, PS 2) assessed their level of stress taking into account only the stress experienced in raising their child with autism (Appendix E). Parents were asked to respond to these questions on a 9-point Likert scale in which 0 is “Not Stressful at All” and 8 is “Extremely Stressful.” These questions could be completed in less than 5 minutes.

Each parent’s stress in response to recent transitions, events, and parent cognitions specific to raising a child with autism was measured using the *Parenting Life Experiences Questionnaire (PLEQ*; Appendix F), a measure authored by the primary

investigator for the purposes of this study. This form was designed to be completed by parents within 15 minutes. The 42-item questionnaire lists transitions or events that are tailored to parents of children with autism, and asks the parents to indicate whether the event has happened or they have thought about the event in the past 6 months. The measure is comprised of 21 transition events, in which the parent has prepared for or undergone a transition with their child (e.g., “I searched for appropriate initial services for my child,” “My child entered a vocational placement”); 6 reminder events, in which the parent has thought about the long-term nature of their child’s diagnosis and its impact on their own long-term goals or their goals for their child (e.g., “I realized that my child will require long-term care and supervision,” “I thought about how I will not be able to reach the dreams and goals I had for myself prior to having my child diagnosed with autism”); 6 diagnosis events, in which the parent had experiences related to their child receiving a diagnosis of autism (e.g., “I noticed early signs that my child was not developing as s/he should”); and 6 other events that do not describe either a transition or a reminder event (e.g., “I noticed that my child’s siblings were affected by his/her disability”). If an event had taken place, parents were asked to report the perceived level of stress they experienced at the time of the event. If parents had thought about this event occurring in the future, they were asked to indicate the level of stress they experienced when they thought about this event occurring in the future.

Parents indicated the stress they experienced either during the event or while thinking about the event using a Likert scale on which 0 was “Not Stressful at All” and 5 was “Extremely Stressful.” Higher scores indicated more significant stress during the

time of the event or while thinking about the event. Parents were also asked to respond to questions specific to the event to further clarify the parents' experiences.

Parent resources. To assess and control for the effects of social support and coping strategies on parent stress, a number of short questionnaires assessed parents' resources in these areas. The seven-item short form of the *Dyadic Adjustment Scale* (DAS-7; Hunsley, Best, Lefebvre, & Vito, 2001; Appendix G) asked parents to rate the quality of their relationship with their partner in seven different areas, including the frequency with which they spend time together, calmly discuss things together, and the overall happiness in the relationship. Parents used a 6-point Likert scale to rate six items and a 7-point Likert scale to rate a seventh item, and scores ranged from 0 to 36, with higher scores indicating greater relationship adjustment. The DAS-7 has high internal consistency when administered as a separate scale (Cronbach's $\alpha = 0.78$ for both clinical and community samples), high correlation with other relationship satisfaction measures (*Kansas Marital Satisfaction Scale*, $r = .69$; *Emotional Self-Disclosure Scale*, $r = .43$), and high criterion validity, differentiating between distressed and non-distressed couples as identified by the *Dyadic Adjustment Scale* (DAS; Spanier, 1976). This form can be completed by parents in less than 5 minutes, and was only to be completed by a parent if they indicated that they were currently in a relationship.

The social support received by parents was measured using a social support scale developed for use with parents of chronically ill children (Ferrari, 1982; Appendix H). The 10-item social support scale is a modified version of the 40-item *Inventory of Socially Supportive Behavior* (ISSB; Barrera, Sandler, & Ramsay, 1981) on which parents indicated the actual receipt of social support by rating on a 5-point Likert scale the

frequency with which they had received forms of support over the past month (0 = “Not at all,” 5 = “About every day”). Scores on the measure range from 10 to 50, with higher scores indicating greater receipt of social support. This modified version of the *ISSB* has a test-retest reliability of 0.64. This form can be completed by parents in less than 5 minutes.

Finally, the *Coping Health Inventory for Parents (CHIP*: McCubbin et al., 1983; Appendix I) is a 45-item measure on which parents indicate 1) whether they utilize a variety of coping strategies in caring for their chronically ill child, such as talking with medical personnel, developing personal interests, and sharing concerns with family and friends; and 2) the extent to which the coping strategies are beneficial on a 4-point Likert scale (0 = “Not helpful,” 3 = “Extremely helpful”). Scores on the measure are calculated by summing the rated benefit of all endorsed items and range from 0 to 135, with higher scores indicating greater coping health. This form could be completed by parents in 10 minutes. The *CHIP* was modified for use in this study by making some items more applicable to children with autism (e.g., “Taking good care of all the medical equipment [or my child’s educational materials] at home” and “Talking with medical staff [or teachers and administrators] when we visit the medical center [or my child’s educational program]”).

Factor analyses indicate that the 45-item questionnaire provides three subscales of coping strategies, Maintaining Family Integration, Cooperation and an Optimistic Definition of the Situation (19 items), Maintaining Social Support, Self-Esteem (17 items), and Psychological Stability, and Understanding the Medical Situation through Communication with Other Parents and Consultation with the Medical Staff (8 items).

The internal consistency of these three scales is adequate, with Cronbach alpha scores ranging from 0.71 to 0.79 (McCubbin et al., 1983).

Other stressful events. To control for the potential confound that normative stressful events might impact parent stress levels, parents were asked to complete the *Social Readjustment Rating Scale (SRRS)*: Hobson et al., 1998, Appendix J, an update of the original by Holmes & Rahe, 1967). The 51-item checklist asked each parent to indicate whether the events have occurred in the past 6 months. The events were weighted according to the social adjustment required following exposure to the event, and the total score indicated the total amount of social readjustment required during the previous 6 months. Higher scores indicate higher levels of social readjustment. The *SRRS* could be completed by parents in 5 minutes.

Missing Data

Though the first page of the questionnaire packet reminded parents to carefully check over their packets for missed items, in some cases parents skipped individual questions or full pages. If a parent skipped an entire page or more of the packet, the missed pages or portions were copied and mailed to the parent's home asking him or her to complete the missing items and return the pages to the first author. For those items that remained incomplete on the Primary Caregiver Questionnaire, Child and Family Background Questionnaire, and the PLEQ, they were coded as "missing" in the data file. Because complete responses were necessary on the *PSI-SF*, *CHIP*, *DAS-7*, *ISSB*, and *SRRS* to calculate the parents' scores for the measures, a person-mean substitution method (Hawthorne & Elliott, 2005; Downey & King, 1998; Roth, Switzer, & Switzer, 1999) was used to fill in missing data. If a participant skipped an item on one of these

measures, the average of that participant's completed responses on the measure or, if the measure was comprised of subscales, on the subscale was used to substitute missing responses on a measure. Past research indicates that this method is most accurate when the amount of missing data is 20% or less of the total measure (Downey & King, 1998), and so the cases in which the amount of missing data on a measure or subscale surpassed 20%, a score for the measure was not attained and the participant's responses were not included in subsequent analyses that included that measure.

Missing responses on the *SIB-R* Social Interaction and Communication Skills cluster were substituted using the method described in the *SIB-R* manual by using the lower score of the two items immediately before and after the missing response. Unfortunately, no substitution method exists for the Problem Behavior Scale, and responses cannot be accurately substituted for using the person-mean substitution method. As a result, parents who were missing responses on this scale were removed from subsequent analyses that included this scale. Table 1 represents the percentage of mothers and fathers who missed one or more items on each measure that required complete responses to generate the measure score, as well as the percentage of parents whose measure scores were invalidated by missing data.

Results

Demographics

Seventy-one families of children with autism returned completed questionnaires and met criteria for inclusion in this study. Of these respondents, 35 (49.3%) comprised couples in which two heterosexual, married parents each returned a completed questionnaire packet. In 32 families (45.1%), only the mother of the child with autism responded, and in 4 families (5.6%), only the father responded. As a result, a total of 67 mothers and 39 fathers completed questionnaires for participation in this study. Because the responses of mothers and fathers in married couples were non-independent, mothers' and fathers' responses to the questionnaires were analyzed separately.

The average age of responding mothers was 44.99 years ($n = 67$, $SD = 8.41$), and the average age of fathers was 48.08 years ($n = 39$, $SD = 10.07$). Demographic information for mothers and fathers is included in Table 2. A majority of mothers and fathers were born in the United States and identified themselves as white or Caucasian, had completed college, and held either a part- or full-time job. Of the mothers who currently held a job, the average number of hours worked outside the home was 39.86 ($n = 43$, $SD = 14.54$), and among fathers who held a job, the average number of hours worked outside the home was 44.71 ($n = 35$, $SD = 13.45$). Over 75% of mothers ($n = 56$) and 85% of fathers ($n = 33$) reported that their family income was more than \$80,000. Additional information about the children with autism's family structure and current educational or vocational placement is reported in Table 3.

Summary Scores on Questionnaire Measures

Parents' scores on the *PSI-SF*, *DAS-7*, *ISSB*, *CHIP*, *SRRS*, *SIB-R* SS and *SIB-R* GMI are reported in Table 4. More than half—53.7% ($n = 46$)—of mothers reported stress levels above the 95th percentile, and more than a third (35.8%, $n = 24$) of mothers scored above the 99th percentile. Similarly, 53.8% ($n = 21$) of fathers' *PSI-SF* scores fell above the 95th percentile, and 25.6% ($n = 10$) of fathers scored above the 99th percentile on the *PSI-SF*.

On average, mothers reported experiencing 3.01 transition events ($SD = 2.62$, Median = 2.00, Min = 0, Max = 12) and 2.67 reminder events ($SD = 1.71$, Median = 3.00, Min = 0, Max = 6) in the past 6 months. Similarly, fathers reported experiencing an average of 2.28 transition events ($SD = 2.16$, Median = 2.00, Min = 0, Max = 8) and 1.74 reminder events ($SD = 1.57$, Median = 1.00, Min = 0, Max = 5).

The skill levels of the children with autism, as measured by the *SIB-R*, covered a large range, from Age-Appropriate to Negligible, with problem behavior ranging from Normal to Very Severe. The percentage of children who fell within each skill level and maladaptive behavior range on the *SIB-R* is reported in Table 5. Nearly three-quarters of mothers ($n = 49$) and more than three-quarters of fathers ($n = 20$) had children whose scores placed them in the Limited skill level or lower, and the children whose maladaptive behavior index placed them in the Normal range accounted for the largest proportion of the sample ($n_{\text{mothers}} = 22$, $n_{\text{fathers}} = 19$).

Age Groups

The ages of the children with autism included in the sample of responding mothers ranged from 2.96 years to 38.57 years ($M = 11.70$, $SD = 7.76$) and the ages of the

children with autism included in the sample of fathers ranged from 2.96 years to 42.62 years ($M = 12.98$, $SD = 2.29$). Table 6 includes the number of children with autism who fell into each age group included in my hypotheses. No parents reported that their child had received a diagnosis of autism within the past 6 months, and as a result no mothers or fathers were included in the diagnosis group.

Because the size of these age groups was unequal and some age groups—notably children under the age of 4 and over the age of 19—comprised a small number of parents and children, analyses were not conducted with these smaller groups. The groups were instead combined into the “developmental transition” group (ages 4;0-6;11, 11;0-14;11, 19;0-21;11) and the “non-developmental transition” (ages 0;0-4;0, 7;0-10;11, 15;0-18;11, 22;0 and up) group. Thirty mothers were included in the “developmental transition” group (44.8%) and 37 mothers comprised the “non-developmental transition” group (55.2%). Seventeen fathers (43.6%) had children in the onset group, and 22 fathers (56.4%) had children with autism in the non-developmental transition group.

Additionally, because Wikler (1986) found compellingly different stress levels among parents in developmental transition and non-developmental transition groups, I regrouped the mothers and fathers into the original age groups used by Wikler to clarify my findings. Wikler only included children between the ages of 7 and 25 in her sample, and so the children in my sample under the age of 7 years ($n_{\text{mothers}} = 19$, $n_{\text{fathers}} = 12$) and over the age of 25 years ($n_{\text{mothers}} = 4$, $n_{\text{fathers}} = 3$) were removed from this analysis. Table 7 represents the number of parents’ children with autism who fell into each of Wikler’s (1986) age groups.

Parent Stress by Developmental Transition Group

My first hypothesis was that parents in the developmental transition-group would experience more stress than parents in the non-developmental transition group. To test this hypothesis, a series of two-tailed *t*-tests was conducted to compare levels of stress between parents in the developmental transition group and the non-developmental transition group. Because parent responses to PS 1 (stress in response to all areas of general life) were highly correlated with the *PSI-SF* for mothers, $r = .57, p < .001$, but not for fathers, $r = .29, p = .08$, and PS 2 (stress in response to parenting a child with autism) was highly correlated with the *PSI-SF* for mothers, $r = .61, p < .01$, and fathers, $r = .45, p < .01$, the *PSI-SF* was used as the dependent variable for mothers, and the *PSI-SF* and PS 1 were used as the dependent variables for fathers. The PS 2 was omitted from subsequent analyses because of its high correlation with the *PSI-SF* for mothers and fathers.

A summary of mothers' and father's average *PSI-SF* and PS 1 scores in the developmental transition groups and in the groups reformed using Wikler's onset groups are found in Table 8. The difference in scores on the *PSI-SF* between developmental transition groups and non-developmental transition groups was not significant for either mothers, $t(65) = .25, p = .80, d = .06$, or fathers, $t(37) = -.62, p = .54, d = .20$. Additionally, fathers' average responses on the PS 1 were not statistically different in the developmental transition group and the non-developmental transition group, $t(37) = .17, p = .87, d = .06$. My hypothesis that the stress of parents whose children were currently in a developmental transition age group would be higher than that of parents who were in a non-developmental transition age group was not supported. Findings were the same when

using Wikler's onset and non-onset age groups. Again, the *PSI-SF* scores did not differ significantly for either mothers in the developmental transition group and non-developmental transition group, $t(36) = .14, p = .89, d = .05$, or fathers in these groups, $t(22) = -.05, p = .96, d = .02$. When considering fathers' responses to the PS 1, the responses in Wikler's onset group and non-onset group was again non-significant, $t(22) = 1.23, p = .23, d = .52$.

Transition and Reminder Events by Developmental Transition Group

I expected that, if parents experienced more stress in developmental transition groups than in non-developmental transition groups, that this stress could be attributed to a greater number of parents in the developmental transition group who had experienced a transition or reminder event with their child in the past 6 months than in the non-developmental transition group. Though my hypothesis that parent stress in developmental transition and non-developmental transition groups would differ was not supported, I explored whether more parents in the developmental transition group reported a reminder or transition event than parents in the non-developmental transition group, and also whether parents in the developmental transition group reported *more* reminder or transition events than parents in the non-developmental transition group.

My hypothesis that more parents in the developmental transition group would report having experienced a transition or reminder event in the past 6 months than non-developmental transition parents was not supported. An overwhelming majority of mothers in the developmental transition group had experienced a transition ($n = 26$, 86.7%) or reminder ($n = 27$, 90%) in the past 6 months, but an equally overwhelming majority of mothers in the non-developmental transition groups had also experienced a

transition ($n = 32, 86.5\%$) or reminder ($n = 30, 81.1\%$) in the past 6 months. These distributions were not significantly different as a function of either transitions, $\chi^2(1, 67) = .00, p = .98$, or reminders, $\chi^2(1, 67) = 1.04, p = .31$. The average number of mothers' reported transition and reminder events is reported in Table 9. The number of reported events was not significantly different for either transitions, $t(65) = .52, p = .61, d = .12$, or reminders, $t(65) = 1.28, p = .21, d = .32$.

The majority of fathers in the developmental transition group reported experiencing a transition ($n = 14, 82.4\%$) or reminder ($n = 12, 70.6\%$) in the past 6 months, and a majority of fathers in the non-developmental transition group also responded that they had experienced a transition ($n = 15, 68.2\%$) or reminder ($n = 15, 68.2\%$) in the past 6 months. No significant difference was found between the number of fathers in each group who reported experiencing a transition event, $\chi^2(1, 39) = 1.01, p = .32$, or a reminder event, $\chi^2(1, 39) = .03, p = .87$, in the past 6 months. Additionally, there was no significant difference in the number of transition events reported by fathers in the developmental transition and non-developmental transition groups, $t(37) = 1.08, p = .29, d = .35$, or between the number of reminder events reported by fathers in the two groups, $t(37) = .69, p = .50, d = .22$. The average number of transition and reminder events reported by fathers in the PLEQ is reported in Table 9. Parents in the non-developmental transition groups were just as likely to report a transition or reminder event, and to report as many transition and reminder events, as were parents in the developmental transition group.

Parenting Stress Models

Though parent stress was not related to the child's inclusion in developmental transition or non-developmental transition groups and the child's inclusion in these groups was not related to the number of transition and reminder events experienced by parents, I further explored the possibility that the number of transition events and reminder events may impact the levels of parent stress. Consistent with my original hypotheses, I expected that parents who experienced a greater number of transition events and reminder events would also experience more stress than other parents. As a first step in this analysis, I entered each possible covariate (scores on all measures in the questionnaire packet along with sociodemographic variables) into separate univariate regression analyses with each dependent variable: *PSI-SF* as the dependent variable for mothers and fathers and the PS 1 as a second dependent variable for fathers only. In 5 analyses of the set of 20 analyses run for each dependent variable, the predictor variable was entered into the analyses as a categorical variable. These predictor variables were Marital Status (married/partnered, divorced/separated), Ethnicity (Caucasian/white, Non-White), Education (achieved college degree or higher, achieved less than college degree), Employment (employed outside of the home, not employed outside of the home), Child First-Born (child with autism first-born in family, child with autism not first-born in family). In all other analyses for each dependent variable, the predictor variable was entered into the analysis as a continuous variable. Tables 10 and 11 include the results of the univariate analyses for mothers and fathers with *PSI-SF* as the dependent variable, and Table 12 reports the results of the univariate analysis for fathers with the PS 1 as the dependent variable.

Mothers' parenting stress was significantly related to the quality of their relationship with their significant other, such that higher relationship quality predicted decreased parent stress. Fathers' parenting stress was significantly related to their scores on the *CHIP*, with lower scores (fewer or less effective coping skills) predicting higher parenting stress. Additionally, mothers' and fathers' parenting stress was significantly related to their child's scores on the *SIB-R* for both adaptive level and general maladaptive index. Lower scores on both indices, indicating fewer age-appropriate adaptive skills and more problem behavior, predicted higher stress levels in mothers and fathers. Finally, fathers' overall life stress as measured using the PS 1 was significantly related to child age, scores on the *SRRS*, and fathers' employment status, with younger children with autism, higher scores on the *SRRS* (indicating more stressful recent life events), and current full- or part-time employment predicting higher stress levels.

Importantly, the overall number of transition and reminder events reported by mothers on the PLEQ also significantly predicted parenting stress. For fathers, the overall number of reminder events reported by fathers on the PLEQ predicted fathers' scores on the *PSI-SF* and PS 1, with increases in the number of transition events predicting higher levels of stress. For mothers, increases in the number of reminder events *and* the number of transition events predicted higher levels of stress in these initial univariate analyses.

The variables that were not found to be significant in these univariate analyses at a $p < .25$ level were removed from subsequent analyses. Significant covariates at the $p < .25$ level were then entered into a subsequent hierarchical linear regression to examine the unique variance predicted by parents' reports of the transition events and reminder events

reported in the past 6 months. The results of these analyses are found in Tables 13, 14, and 15.

When all covariates were entered into the models for mothers, only their child's score on the maladaptive behavior index accounted for a significant percentage of the variance in mothers' *PSI-SF* scores (Table 13, Table 14). More child problem behavior predicted higher parenting stress for mothers. The addition of the number of transition and reminder events mothers had experienced in the past 6 months did not strengthen the models. In contrast, while fathers' reports of their child's maladaptive behavior accounted for a significant percentage of the variance in their *PSI-SF* scores, the addition of the number of reminder events that fathers had experienced in the past 6 months accounted for an additional 12% of the variance in fathers' *PSI-SF* scores, with greater numbers of reminder events predicting higher parenting stress for fathers (Table 15). The effect size attributable to the addition of the reminder variable to this model is large, $f^2 = 0.38$.

The addition of the reminder variable to the model for father's scores on the PS 1 had a similar effect: Although fathers' scores on the *SRRS* and the *DAS-7* accounted for a significant proportion of the variance in fathers' scores on the PS 1, the addition of the number of reminder events fathers had experienced in the past 6 months accounted for an additional 19% of the variance in PS 1 scores (Table 17). Greater numbers of reminder events had the most significant predictive value of fathers' overall life stress. The effect size attributable to the addition of the reminder variable to this model is moderate, $f^2 = .30$.

Discussion

The group of parents that participated in this study was characterized by high levels of parenting stress. More than half of mothers and fathers included in the sample had scores on the *PSI-SF* that placed them in the 95th percentile for parenting stress and, even more alarmingly, a third of mothers and a quarter of fathers had scores that placed them in the 99th percentile for parenting stress. On the whole, this group of parents reported extremely high levels of stress in parenting their child with autism. This elevation in stress fits with the portrait of parent stress presented in earlier research that indicates that parents raising children with autism experience stress exceeding that of other parents, even those raising children with other mental and physical disabilities (e.g., Bouma & Schweitzer, 1990; Donovan, 1988). Though no comparison group was used in this study, the parents' placement in the highest percentiles of parent stress indicates a clinical level of parenting stress that one might expect to exceed that of many of their peers.

Contrary to expectations, however, parents of children in developmental transition groups did not experience significantly higher levels of parenting stress than did parents who were not in developmental transition groups. The results of the current study suggest that raising a child who is currently aging into a developmental transition stage does not elevate parent stress beyond levels experienced by parents whose children are not in a developmental transition stage. Despite hypotheses that developmental transition stages based on age would be characterized by an increased likelihood that parents would experience transitions in their child's placement and report being reminded of the long-term nature of their child's diagnosis, in actuality parents in the developmental transition

group and non-developmental transition group were roughly equally likely to have reported a transition or reminder event, and on average reported experiencing a similar number of transition and reminder events in the past 6 months. The age groups used in the current study as the basis for developmental transition stages were, in actuality, no more likely to be characterized by transitions than were non-developmental transition age groups. This finding leads us to conclude that, based on the variables used in this study, child age provides us with little information about the transitions that a child with autism experiences, the reminders of the child's long-term diagnosis parents experience, or related parent stress.

Notably, however, all analyses comparing the parent stress and number of reminder and transition evidenced small to moderate effect sizes. These results stand in contrast to the moderate to large effects of Wikler's (1986) findings that parents of children experiencing developmental transitions reported more stress than parents of children who were not experiencing developmental transitions. While the sample size of the current study may have had the power to detect a finding of Wikler's magnitude, it was limited given the small to moderate effect sizes of the current study and left the analyses underpowered and non-significant. A larger sample size may have identified significant differences in parenting stress and the number of transitions and reminders reported by parents in the two groups.

Because of the limited power in the analyses, the results should be interpreted cautiously. However, when assessing the similarity of stress levels among parents of children in developmental transition groups and those of children in non-developmental transition groups, a few explanations may be considered. Notably, a majority of mothers'

and fathers' children were placed in private day schools or residential facilities where, potentially, decisions about transitions are less dependent upon child age and more dependent upon child functioning level or the program's arbitrary age criteria for transitions. Additionally, recent focus has been placed on preparing parents for their child's transitions long before transitions take place. For example, agencies have begun to emphasize the importance of encouraging parents to plan for their child's adult life—guardianship, work placement, home placement—long before their child reaches adulthood (Organization for Autism Research, 2006). As a result, parents may begin to think about these transition events and be reminded of the effects of their child's diagnosis on their long-term goals during times unsynchronized with developmental transitions.

The development in programming and long-term planning may help explain the current study's failure to replicate Wikler's (1986) findings that parents of children in "onset" groups experience more stress than parents of children in "non-onset" groups. Wikler conducted this study over 20 years ago, and over the past two decades services available to children with disabilities, as well as the emphasis on planning for the child's future in advance, have shifted considerably. Transitions for children may now be occurring based on functional skills rather than on age and parents may be considering options for their child long before developmental transitions actually occur.

Another reason for the similar levels of reported stress among parents of children in developmental and non-developmental transitions groups is the potentially poor validity of the use of age as a proxy for developmental stages. The age groups used in this study were based in part on Wikler's (1986) age groups and, for the younger ages, on

expected ages of typical children as they transition to school. Parents' experiences in raising their child with autism, however, may be more influenced by the events that occur within developmental stages than by the chronological age of their children. For example, a child's transition to adolescence is biologically marked by puberty, which may trigger parents' thoughts about transitions and their child's long-term diagnosis more than does the age at which their child might be expected to experience puberty. The removal of age as a proxy for a developmental transition and a focus on the effects of specific events characteristic of developmental transitions (e.g., onset of puberty, considering new school placements) on parent stress is a worthy next step in this line of research.

One cannot ignore the noticeable absence of parents' experiences of transition events as significant, consistent predictors in the parenting and general life stress models, especially given the attention that has been given to the impact of transitions on parents' stress in the literature. This unexpected finding may be due, in part, to the vast majority of parents who reported that they had experienced a transition event with their child with autism in the past 6 months. Over 80% of mothers and fathers reported that they had experienced a transition event in the past 6 months. Given the field's current focus on anticipating and preparing for significant transitions in advance of when a transition is actually to take place (e.g., Organization for Autism Research, 2006), parents' consideration of and engagement in transitions may actually characterize their experiences with their child for much of their life. Lazarus and Folkman (1984) point out that ambiguity in a given situation, for example, not knowing when an event will occur, how long it will last, the likelihood it will happen, and what will happen, is a source of stress for individuals.

In truth, ambiguity colors much of a parents' life with their child with autism, as the events that will occur and the outcome of those events often cannot be predicted. Transitions are merely discrete uncertain events in a lifetime of uncertainty for parents of children with autism. As a result, parents may either habituate over time to the stresses caused by these time-limited transitions or, alternatively, experience a chronic elevated level of stress in response to the overarching ambiguity in their lives to which the effects of time-limited stressor events contribute little. One might consider that the act of raising a child with autism may impose a ceiling effect on parent stress, such that parents' experiences of individual transitions add little variance to the pre-existing elevated level of parenting stress. Closer examination of fluctuations in parents stress in response to acute events in their child's life is necessary to fully appreciate the impact of these transient events on the chronic stress that parents experience.

A finding that deserves considerable emphasis, despite the fact that it was not a focus of the hypotheses, is the powerful influence of problem behavior on parent stress in the current study. For both mothers and fathers, child problem behavior predicted significant proportions of variance in both mothers' and fathers' parenting stress, even when all stressors were taken into account. Past research indicates that child maladaptive behavior predicts parenting stress (Baker et al., 2003), and the current study has replicated this finding and shown problem behavior to be one of the most powerful variables in predicting parenting stress. Because research has not indicated and one might not expect problem behavior to be associated with aging into a developmental transition group, the fact that parenting stress is so highly predicted by problem behavior may

partially explain the null findings regarding stress of parents in developmental transition and non-developmental transition groups.

The powerful impact of child problem behavior is not surprising given the toll maladaptive behavior can take on the family. For instance, parents of children with problem behavior may spend more time trying to manage their child than other parents, leaving less time for other activities that may reduce their stress (e.g., completing work, spending time with friends). Additionally, parents may be concerned about the effect increased maladaptive behavior has on their own safety and well-being as well as that of other children in the house, especially if the maladaptive behavior is aggressive in nature. Finally, increases in problem behavior may reduce parents' expectations of a positive outcome for their child with autism. Not only may problem behavior be potentially dangerous for the child with autism (e.g., self-injurious behavior), but high levels of problem behavior will limit social interaction and educational effectiveness (Horner, Demier, & Brazeau, 1992) as well as prevent the child from being easily included in community and in educational settings (Sprague & Rian, 1993, as cited in Horner, Carr, Strain, Todd, & Reed, 2002). Even children with high levels of social and communication skills may be prevented from full inclusion by engaging in maladaptive behavior that will be disruptive or dangerous in a school or community setting. The impact that problem behavior has on family, as well as the potential effect it can have on the child's current placement and future outcome, places it in the forefront of parents' concerns regarding their child.

For mothers, problem behavior was the most influential variable in predicting parent stress. Initial results indicated that increased quality of their relationship as well as

lower child functioning and higher problem behavior were related to higher levels of parent stress. However, when all variables were entered into a parenting stress model, only mothers' reports of their child's problem behavior accounted for a significant proportion of the variance in their stress, with increased problem behavior predicting higher levels of parenting stress. The remaining factors did not contribute significantly to mothers' stress, indicating that only current child problem behavior was associated with the level of stress experienced by mothers.

A different picture emerged for fathers. Both parenting stress and general life stress were assessed for fathers. Coping health, child functioning level and problem behavior, and reminder events impacted parenting stress in initial univariate analyses, with decreased coping health and child functioning and increased child problem behavior and reminder events contributing to increases in parenting stress. When all related variables were entered into the parenting stress model for fathers, however the predictive strength of coping health dropped out and child problem behavior remained a significant predictor of problem stress. In contrast to mothers, however, fathers' parenting stress was also significantly predicted by the total number of reminder events fathers reported. Increases in the number of reminder events predicted concomitant increases in parenting stress. Additionally, reminder events had a significant impact on fathers' general life stress. Decreased marital quality, increased child age, and high social readjustment scores predicted higher general life stress in initial univariate analyses. Although fathers' social readjustment scores as well as decreases in the quality of their marital relationship both remained significant predictors in the model for general life stress, fathers' report of the

number of reminder events in the past 6 months predicted significant increases in fathers' general life stress.

The discriminative findings regarding the variables that contribute to the stress of mothers and fathers of children with autism are intriguing and should be explored further. Before this exploration can occur, however, one should note the limitations of the analyses used in the current study. First, the power of the analyses for both mothers and fathers—given the small sample size and the large number of predictors—may have been insufficient to detect even moderate effect sizes in some cases. For fathers, though a moderate effect size was detected with the addition of reminders to the model, the small sample size may have made the test especially susceptible to influence from outliers. As a result, a replication with a larger sample size may mitigate the striking difference between mothers and fathers with regard to significant predictors of parenting stress. Moreover, the transition and reminder count variables are both non-normal in distribution, and the use of a model specifying a Poisson distribution rather than a normal distribution for the dependent variable may be better suited to the variables used in this study. Replication of the current study, along with these additional analyses, would be necessary to ascertain whether the current findings truly characterize the experiences of mothers and fathers raising a child with autism. That noted, we can begin to speculate possible explanations for the differences found between mothers and fathers in this initial study.

For both mothers and fathers, child problem behavior appears an important predictor of concomitant parenting stress. Parent reports of reminder events—those that remind parents of their child's diagnosis and the lifelong care required for the child—

were also hypothesized to have an impact on parent stress, as has been speculated by past researchers (Blacher, 1984; Hanline, 1991; Wikler, 1986). The differential effect on mothers and fathers, however, is unexpected. For fathers, the experience of reminder events predicts additional significant proportion of variance in both parenting and general life stress. This finding regarding the impact of reminders on stress, however, is not true of mothers.

Mothers of children with autism frequently take on the role of primary caregiver for their child (Bristol et al., 1988; Olsson & Hwang, 2001; Seltzer et al., 2001), and it appears that this sample was no exception. Over half of the mothers included in this sample were either not employed or employed only part-time, compared to less than 10% of fathers. Also in contrast to fathers, mothers' general life stress was highly correlated with parenting life stress, indicating that their role as parent may take primacy when considering the stress they experience overall. In the role of primary caregiver—especially as a stay-at-home primary caregiver—mothers may be especially focused on their child's daily problem behavior and the potential adverse effects on the problem behavior on the child, family, and themselves. Child problem behavior has an impact on fathers' parenting stress, and likely for the same reasons as it does for mothers; the resulting impact on child, parent, and family. But mothers' role as primary caregiver and the consequential focus on the impact of problem behavior on the child's short-term and long-term potential may wash out the effects of transitions and reminders on mothers' parenting stress.

Mothers and fathers both report experiencing reminders of their child's long-term diagnosis and realizing that they and their child will not accomplish all that they had

hoped for. In fact, mothers report more reminder events on average than do fathers. However, the report of reminder events may have a more deleterious effect on fathers' stress than it does on mothers. The reason that fathers—but not mothers—are so seriously impacted by reminders of their child's long-term diagnosis has many possible sources. Important to note, however, all of these explanations are purely speculative and require further replication to certify their role in fostering the differential effects of reminders on mothers and fathers.

As a first explanation, one must consider that the majority of fathers in this sample—over 90%—worked full-time to provide for their families. By taking on the role as providers, they may feel a sense of failure not experienced by mothers regarding their inability to protect their child and provide their child with the life they had expected for him or her, and thoughts such as “Some of the dreams and goals I had for my child will not be reached” may impact fathers' stress differently than mothers'. Additionally, while many mothers in this sample appear to fill the role of primary caregiver and thus may have restructured their goals for their lives around their role as parent, fathers' goals may remain focused around their careers. As such, fathers may more readily recognize and acknowledge the impact their child has on the long-term goals and dreams they had for themselves as well as the sacrifices they may have to make to provide continual care for their child. As a result, fathers' endorsement of statements such as, “I thought about how I will not be able to reach the dreams and goals I had for myself prior to having my child diagnosed with autism” may have a greater impact on fathers' stress than mothers' endorsement has on mothers' stress.

As is accounted for in the ABCX model (Hill, 1949), the ways in which parents' define a situation—in this case, the way in which they view their child's potential—will have an effect on their stress in response to their child's diagnosis. Research indicates that mothers frequently hold the role as primary caregiver for the child with autism. While mothers, in this role, may acknowledge that they are often reminded of what their child may have accomplished had he or she not been diagnosed with autism, their involvement in their child's daily accomplishments may help them refocus on their child's current trajectory and re-establish appropriate goals more easily than can fathers. For fathers, parenting life stress and general life stress were uncorrelated and predicted in part by different variables. This difference in predictor variables may indicate that fathers compartmentalize areas of their lives (e.g., parenting, career, relationship), an indication that fathers' focus on parenting is more diverted than mothers. This split in focus may prevent fathers from being as involved in their child's daily life as are mothers, and limit their recognition of daily gains and developments in child skill and behavior. As a result, when faced with the reminder that their child has not accomplished what was once imagined for him or her, fathers may be less able to establish new, appropriate goals for their child than mothers and may instead focus more on what has been lost than rather than on what is still to be gained. This focus on loss may heighten father's stress in response to the reminder.

Finally, researchers have posited that fathers hold especially high expectations of male children (Frey et al., 1989; Krauss, 1993; Scorgie et al., 1998). Consistent with reports among the autism population (American Psychiatric Association, 2000), over 80% of the fathers' children in the current sample were male. As a result, the fathers in

this sample may have held higher expectations of their male children than did mothers and be especially affected by reminders of their child's long-term disability and resulting inability to accomplish dreams and goals held by their fathers.

One limitation of the current study, however, is the inability of the analyses to determine direction of effect between variables. While the explanations offered in this paper support the effect that problem behavior and reminders of the child's diagnosis have on the stress experienced by parents of children with autism, one must also consider that the stress experienced by parents of children with autism may alter their reports of their child's problem behavior and of being reminded of their child's long-term disability. That is, a father who is experiencing higher levels of parenting stress may be more likely to rate problem behavior as more interfering in the family's life, and may also more readily report being reminded of the effect of the autism diagnosis on the child and parent. Continued research in this area, especially longitudinal research examining the effects of early child behavior and parent cognitions on later parent stress, will help illuminate the causal relation between problem behavior, reminders, and parent stress.

Although a replication of the current study is needed to strengthen the impact of the findings, the initial results of this line of research have potential implications for understanding the sources of parent stress among parents of children with autism, as well as providing support for these parents. The original hypotheses of this study, if supported, would have suggested that providing support for families of children with autism would be especially crucial as the child aged into a developmental transition group. Instead, it appears that parents of children with autism experience elevated parenting stress throughout the course of their child's life and will need continued and consistent support.

That said, the focus of this support may need to be tailored, not dependent upon the age of the child, but upon the perceptions and cognitions of the parent regarding their child and his or her symptoms and diagnosis.

For both mothers and fathers, emphasis should be placed on recognizing the toll that child problem behavior has on parent stress. Importantly, in this study, the scores of problem behavior on the *SIB-R* are not based on actual occurrence of child problem behavior, but rather on parents' *perceptions* of the child's problem behavior. As a result, therapists should be especially careful to ascertain parents' views of their child's problem behavior and to fully understand how much parents feel like the problem behavior interferes with their child's life and with their own life.

Furthermore, parent training in strategies to decrease problem behavior may be crucial to reducing parent stress. As was noted by Baker et al. (2003), child behavior predicts parent stress and, in turn, parent stress predicts future child behavior. As a result, training parents to reduce their child's behavior and to develop a sense of efficacy in controlling their child's behavior may be paramount in reducing parent stress and thereby reducing the likelihood of increased maladaptive behavior in the future. Tonge et al. (2006) reported that parents of children with autism who received a behavior management intervention experienced greater alleviation of mental health symptoms such as anxiety, insomnia, somatic symptoms and family dysfunction at 6-month follow-up than did those who had received counseling alone. Parent training may increase parents' sense of self-efficacy, which has been demonstrated to protect mothers and fathers from the effects of child problem behavior on stress-related disorders such as depression and anxiety (Hastings & Brown, 2002). These findings indicate that parent training may be

beneficial in reducing parent stress and mental health risks over time. Parent support groups that place a significant focus on managing problem behavior will be especially helpful in this effort, as will programs that help generalize treatment strategies for reducing problem behavior to home settings.

When working with parents of children with autism, understanding and recognizing the emotions parents might experience in being reminded of their child's long-term diagnosis is a skill that could only be helpful in providing support to parents. An intense focus on the impact of these reminders on fathers' stress may be especially helpful in preserving fathers' well-being. Importantly, however, therapists must identify the mechanisms by which experiencing these reminders impacts parent stress. As has been mentioned, these reminders may heighten fathers' concern for the family's future security, exacerbate feelings of failure over not being able to provide and protect their child and family, raise awareness of the sacrifices they have made in their own life for the development of their child, or increase feelings of the loss of a child with whom they connect and pass on their legacy. In fact, all of these concerns may play a role in elevating parent stress. Cognitive approaches may be useful in restructuring fathers' goals for themselves and their family and focusing on their child's current development. For example, by reminding fathers of the ways in which they can create a meaningful relationship with their child and help their child grow to accomplish goals appropriate for their own developmental level, the therapist may lessen the impact reminders of the child's long-term diagnosis have on fathers' stress in all areas of their life.

The limitations of the current study should be considered when considering the implications of this study. As has been previously mentioned, the sample size limited the

power of the analyses as well as the conclusions that could be drawn. An increased sample size would allow for more viable research findings as well as for additional analyses that could not be run in the current study. For example, analyses of parent stress levels within each of the different age groups may have revealed patterns of parent stress that were not discernable in the larger developmental transition and non-developmental transition groups. Additionally, removing age as a proxy for development may help elucidate the effects of developmental stages on parenting stress.

One should also consider the homogeneity of the sample when assessing the generalizability of the findings. A majority of both mothers and fathers were white, highly educated, and from middle-class to upper-class families. Despite recruiting through a statewide agency, the interested families who contacted the primary investigator fell within a specific demographic and the results of the study may not be generalized to more diverse populations. Furthermore, the sampling method used may have attracted parents with lower stress levels than parents who did not respond to the recruitment flier or, conversely, parents who were so stressed that they were seeking an outlet through which to convey their experiences. Although the parents in the current sample evidenced elevated levels of parenting stress, they may have had more time or resources to respond to the recruitment flier and participate in the study than did parents who did not participate.

The use of unstandardized, unvalidated instruments in the current study should also be acknowledged when considering the results of this study. For example, the Parenting Stress questions (PS 1 and PS 2) that assessed stress in parenting a child with autism as well as stress in all areas of life are not validated instruments and may not have

been valid measurements of parenting stress and life stress. However, responses to the question on stress experienced in parenting a child with autism were highly correlated with the *PSI-SF* (a validated measure of parenting stress), indicating that this question did indeed measure parenting stress. Additionally, the question on stress experienced in all areas of a parents' life was, for fathers, related to variables one would expect to effect general life stress such as significant life events and marital quality. Regardless, one should consider this limitation and future research should include a validated measure of general life stress.

The PLEQ was an instrument developed by the primary investigator for the purposes of this study and, like the PS 1 and PS 2, unvalidated. The transition and reminder events within the PLEQ were those identified as such by the primary investigator, and additional events within the PLEQ may be considered transitions or reminders by parents and impact parent stress in ways not assessed in the current study. Further research to validate the use of this instrument, as well as factor analyses of the items within the measure may prove to increase the utility of this instrument in clinical research.

This current study reveals previously unstudied variables that impact mothers' and fathers' stress in raising a child with autism and begins to identify the patterns of stress parents experience while raising their child. Further research, however, will help elucidate the answers to questions posed by the current research. By increasing the sample size and thus the number of parents with children in each age group, the pattern of parent stress over time may be more highly defined than was possible in the current study. An increased sample size will also allow the analysis of specific events that may

characterize the experiences of parents within developmental stages and increase parent stress during those stages. Alternatively, such analyses will help identify events that may occur in any developmental stage but, regardless of timing, inevitably increase parent stress. By including parents of children who have recently received a diagnosis of autism in the sample, comparisons of parents of children in specific age groups, or whose children are currently experiencing a specific event, to parents of children who have recently received diagnosis, may help address researchers' hypothesis that parents re-experience the stress first experienced at diagnosis when their child undergoes specific transitions (Hanline, 1991; Wikler, 1986).

Perhaps most intriguing however, is the line of research encouraged by the findings regarding the impact of reminder events on fathers of children with autism. In addition to a much-needed replication of the current study, future research should investigate the events that trigger these reminder cognitions in fathers, to identify whether fathers experience these cognitions in response to specific events in their child's life or whether they are unchanging cognitions that persist from diagnosis throughout the child's life. For example, fathers may be reminded of their child's long-term disability by specific events in their child's life, such as when their child has not achieved a benchmark skill, or their reports of being reminded of their child's long-term disability and related losses may be pervasive, enduring thoughts and beliefs that are not triggered by acute events but instead serve as a marker of a characteristic that makes one susceptible to stress. Further, research should examine the mechanisms by which these cognitions impact fathers' stress, whether because these reminders increase fathers'

concern about future security, feelings of failure, or loss of their expected typical child and legacy.

Finally, a logical extension of the current study and related research is the examination of support systems for parents that will be most effective in decreasing parent stress. Developing both behavioral and cognitive behavioral therapies for parents that will increase their efficacy in managing their child's problem behavior as well as decrease their focus on the long-term nature of their child's diagnosis and the resulting loss of dreams they had prior to their child's diagnosis may be paramount to reducing parent stress.

Much research has focused on the positive impact of reducing parent stress on both parents' well-being as well as the well-being and skill development of their child. Consequently, identifying predictors of parent stress, as well as patterns of parent stress over time, will build inroads into improving the overall health of parents and their children with autism. The results of this current study indicate that parent stress is unrelated to children's progression into developmental stages but is instead driven by the problem behavior exhibited by the child. Additionally, fathers appear especially susceptible to the effects of being reminded of their child's long-term diagnosis and the feeling that they and their children will not achieve what had been imagined by parents prior to diagnosis. The implications of this study suggest tailoring parent support groups to the parent perceptions and cognitions of their child's behavior and the goals they held for themselves and for their child to maximize the effectiveness of the groups in reducing parent stress. This study provides an excellent springboard for further research on the impact of child behavior and parent cognitions on parent stress, and on its own it has

provided insight into the development of parent stress during the challenging experience of raising a child with autism.

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Table 1

Frequency and Percentage of Mothers and Fathers Missing Items and Receiving Invalidated Scores on Questionnaire Measures

Measure	Mothers				Fathers			
	Missing ≥ 1 Item		No Score		Missing ≥ 1 Item		No Score	
	<i>n</i>	%	<i>n</i>	%	<i>n</i>	%	<i>n</i>	%
<i>PSI-SF</i>	9	13.4	0	0	3	7.7	0	0
<i>CHIP</i>	19	28.4	1	1.5	7	18.0	1	2.6
<i>DAS-7</i>	3	4.5	1	1.5	2	5.1	1	2.6
<i>SRRS</i>	0	0	0	0	0	0	0	0
<i>ISSB</i>	0	0	0	0	2	5.1	2	5.1
<i>SIB-R SS</i>	9	13.4	0	0	6	15.4	1	2.6
<i>SIB-R GMI</i>	12	17.9	12	17.9	6	15.4	6	15.4

Table 2

Ethnicity, Education, and Employment Demographics for Mothers and Fathers

	Mothers		Fathers	
	<i>n</i>	%	<i>n</i>	%
Marital Status				
Married/Partnered	58	86.6	38	97.4
Divorced/Separated	9	13.4	1	2.6
Ethnicity				
American Indian/Alaskan Native	0	0	0	0
Asian/Pacific Islander	3	4.5	0	0
Black/African-American	4	6.0	1	2.6
White	56	83.6	37	94.9
Hispanic/Latino	3	4.5	0	0
Biracial	1	1.5	0	0
Other	0	0	1	2.6
Education				
High School Grad/GED	4	6.0	1	2.6
Business/trade/vocational	4	6.0	4	10.3
College, did not graduate	4	6.0	3	7.7
Graduated from College	21	31.3	13	33.3
Professional Training	34	50.7	18	46.2
Employment				
Not Employed	23	34.3	3	7.7
Part-Time	14	20.9	0	0
Full-Time	29	43.3	35	89.7

Table 3

Family Structure and School Placement of Mothers' and Fathers' Children with Autism

	Mothers		Fathers	
	<i>n</i>	%	<i>n</i>	%
Parent Relationship to Child				
Biological Parent	63	94.0	36	92.3
Step-Parent	1	1.5	1	2.6
Adoptive Parent	3	4.5	2	5.1
Child's Sex				
Male	59	88.1	33	84.6
Female	8	11.9	6	15.4
Child First-Born				
Yes	30	44.8	20	51.3
No	37	55.2	19	48.7
Child has Sibling(s)				
Yes	32	82.1	32	82.1
No	12	17.9	7	17.9
Sibling(s) with Disabilities				
Yes	11	16.4	4	10.3
No	49	73.1	30	76.9
School Placement				
Private Day School	30	44.8	16	41.0
Special Needs Classroom	15	22.4	8	20.5
General Education Classroom	7	10.4	5	12.8
Residential Placement	6	9.0	4	10.3
Vocational Placement	1	1.5	1	2.6
Other	8	11.9	5	12.8

Table 4

Summary of Mothers' and Fathers' Scores on Questionnaire Measures

Measure	Mothers					Fathers				
	<i>n</i>	Min	Max	<i>M</i>	<i>SD</i>	<i>n</i>	Min	Max	<i>M</i>	<i>SD</i>
<i>PSI-SF</i>	67	55	147	102.52	22.64	39	59	147	100.03	20.84
PS 1	67	2	8	5.90	1.46	39	1	8	5.54	1.59
PS 2	67	1	8	5.33	1.44	39	2	8	4.82	1.48
<i>SRRS</i>	67	0	682	159.43	140.23	39	0	485	122.56	120.00
<i>CHIP</i>	66	20	129	67.39	23.23	38	19	97	49.55	21.35
<i>DAS-7</i>	59	7	35	21.61	21.61	38	5	36	23.58	5.91
<i>ISSB</i>	67	11	48	26.33	8.69	37	10	47	22.70	10.28
<i>SIB-R SS</i>	67	0	122	42.51	36.87	37	0	140	43.59	38.36
<i>SIB-R GMI</i>	55	-45	3	-15.84	12.30	33	-42	3	-12.03	12.67

Table 5

Distribution of Mothers' and Fathers' Children across SIB-R Adaptive Behavior Skill

Levels and Maladaptive Behavior Index Levels

	Mothers' Children		Fathers' Children	
	<i>n</i>	%	<i>n</i>	%
Adaptive Behavior Skill Level				
Advanced	0	0	1	2.6
Age-Appropriate to Advanced	2	3.0	2	5.1
Age-Appropriate	8	11.9	1	2.6
Limited to Age-Appropriate	8	11.9	3	7.7
Limited	10	14.9	8	20.5
Limited to Very Limited	4	6.0	4	10.3
Very Limited	12	17.9	4	10.3
Very Limited to Negligible	23	34.3	14	35.9
Maladaptive Behavior Index Seriousness Level				
Normal	22	32.8	19	48.7
Marginally Serious	15	22.4	4	10.3
Moderately Serious	12	17.9	6	15.4
Serious	2	3.0	3	7.7
Very Serious	16	23.9	7	17.9

Table 6

Distribution of Mothers' and Fathers' Children with Autism across Hypothesis Age Groups

Age Group	Age	Mothers		Fathers	
		<i>n</i>	%	<i>n</i>	%
Early Childhood	0;0 - 4;0	6	9.0	2	5.1
Transition to School-Age	4;0 to 6;11	19	28.4	10	25.6
School-Age	7;0 - 10;11	13	19.4	7	17.9
Transition to Adolescence	11;0 - 14;11	8	11.9	6	15.4
Adolescence	15;0 - 18;11	12	17.9	8	20.5
Transition to Adulthood	19;0 - 21;11	3	4.5	1	2.6
Adulthood	22;0 and up	6	9.0	5	12.8

Table 7

Distribution of Mothers' and Fathers' Children with Autism across Wikler Age Groups

Group	Mothers		Fathers	
	<i>n</i>	%	<i>n</i>	%
Onset	15	22.4	11	28.2
11-15	14	20.9	11	28.2
20-21	1	1.5	0	0
Non-Onset	23	34.3	13	33.3
7-10	13	19.4	7	17.9
16-19	8	11.9	4	10.3
22-25	2	3.0	2	5.1

Table 8

Summary of Mothers' and Fathers' PSI-SF and PS 1 Scores across Hypothesis and Wikler Groups

Group	<i>PSI-SF</i>		PS 1	
	<i>M</i>	<i>SD</i>	<i>M</i>	<i>SD</i>
Mothers				
Hypothesis Groups				
Developmental Transition	103.30	23.23	N/A	N/A
Non-Developmental Transition	101.89	22.45	N/A	N/A
Wikler Groups				
Onset	101.67	21.67	N/A	N/A
Non-Onset	100.57	24.52	N/A	N/A
Fathers				
Hypothesis Groups				
Developmental Transition	97.65	23.73	5.59	1.37
Non-Developmental Transition	101.86	18.67	5.50	1.77
Wikler Groups				
Wikler Onset	102.00	19.79	5.82	.75
Wikler Non-Onset	102.38	21.62	5.23	1.42

Table 9

Mothers' and Fathers' Reported Transition and Reminder Events on PLEQ across Developmental Transition Groups

	Transition Events		Reminder Events	
	<i>M</i>	<i>SD</i>	<i>M</i>	<i>SD</i>
Mothers				
Developmental Transition	3.20	2.54	2.97	1.67
Non-Developmental Transition	2.86	2.71	2.43	1.72
Fathers				
Developmental Transition	2.71	2.34	1.94	1.68
Non-Developmental Transition	1.95	2.01	1.59	1.50

Table 10

Summary of Univariate Regression Analyses for Variables Predicting Mothers' PSI-SF Score

Predictor	<i>n</i>	<i>B</i>	<i>SE B</i>	β	R^2	<i>p</i>
Child Age	67	-.19	.36	-.06	.00	.61
Parent Age	67	-.31	.33	-.11	.01	.36
Marital	67	.17	8.17	.00	.00	.98
Ethnicity	67	-3.24	7.51	-.05	.00	.67
Education	67	7.84	7.20	0.13	.02	.28
Income	64	-1.07	1.92	-.07	.01	.58
Employed	67	-4.30	5.85	-.09	.01	.46
Hours Worked/Week	42	-.17	.26	-.10	.01	.52
Child First-Born	67	-5.29	5.57	-.12	.01	.35
Number of Siblings	67	-.66	2.25	-.04	.00	.77
<i>SRRS</i>	67	.03	.02	.18	.03	.15
<i>CHIP</i>	66	-.18	.12	-.19	.04	.13
<i>DAS-7</i>	59	-1.19	.47	-.32	.10	.01
<i>ISSB</i>	67	-.01	.32	.00	.00	.99
<i>SIB-R SS</i>	67	-.27	.07	-.44	.20	.00
<i>SIB-R GMI</i>	55	-1.21	.20	-.64	.41	.00
# Transition Events	67	2.12	1.04	.25	.06	.05
# Reminder Events	67	5.28	1.51	.40	.16	.00

Table 11

Summary of Univariate Regression Analyses for Variables Predicting Fathers' PSI-SF Score

Variable	<i>n</i>	<i>B</i>	<i>SE B</i>	β	R^2	<i>p</i>
Child Age	39	.30	.39	.13	.02	.45
Parent Age	39	.48	.33	.23	.05	.16
Marital	39	24.61	21.01	.19	.04	.25
Ethnicity	39	-8.99	15.26	-.10	.01	.56
Education	39	11.51	8.16	.23	.05	.17
Income	37	3.50	2.65	.22	.05	.20
Employed	39	11.58	12.55	.15	.02	.36
Hours Worked/Week	35	.53	.26	.33	.11	.05
Child First-Born	39	-9.19	6.59	-.22	.05	.17
Number of Siblings	39	1.71	2.48	.11	.01	.50
<i>SRRS</i>	39	-.01	.03	-.07	.00	.69
<i>CHIP</i>	38	-.37	.15	-.37	.14	.02
<i>DAS-7</i>	38	-.85	.57	-.24	.05	.15
<i>ISSB</i>	37	-.03	.35	-.02	.00	.92
<i>SIB-R SS</i>	37	-.21	.08	-.40	.16	.01
<i>SIB-R GMI</i>	33	-.92	.26	-.54	.29	.00
# Transition Events	39	1.48	1.57	.15	.02	.35
# Reminder Events	39	7.79	1.77	.59	.33	.00

Table 12

Summary of Univariate Regression Analyses for Variables Predicting Fathers' PS I Score

Variable	<i>n</i>	<i>B</i>	<i>SE B</i>	β	R^2	<i>p</i>
Child Age	39	-.06	.03	-.32	.10	.05
Parent Age	39	-.02	.03	-.15	.02	.36
Marital	39	1.50	1.61	.15	.02	.36
Ethnicity	39	-.04	1.17	-.01	.00	.97
Education	39	.52	.63	.13	.02	.42
Income	37	.14	.21	.12	.01	.49
Employed	39	2.03	.91	.35	.12	.03
Hours Worked/Week	35	.00	.02	.01	.00	.95
Child First-Born	39	-.49	.51	-0.16	.02	.34
Number of Siblings	39	-.14	.19	-.12	.01	.48
<i>SRRS</i>	39	.01	.00	.35	.12	.53
<i>CHIP</i>	38	-.01	.01	-.13	.02	.42
<i>DAS-7</i>	38	-.09	.04	-.31	.10	.06
<i>ISSB</i>	37	.02	.03	.11	.01	.53
<i>SIB-R SS</i>	37	.00	.01	.00	.00	.99
<i>SIB-R GMI</i>	33	-.02	.02	-.13	.02	.48
# Transition Events	39	.11	.12	.15	.02	.35
# Reminder Events	39	.42	.15	.42	.17	.01

Table 13

Summary of Hierarchical Regression Analysis for Variables Predicting Mothers' PSI-SF Scores (N = 47)

Variable	Model 1			Model 2		
	<i>B</i>	<i>SE B</i>	β	<i>B</i>	<i>SE B</i>	β
<i>SIB-R SS</i>	-.07	.08	-.12	-.09	.09	-.15
<i>SIB-R GMI</i>	-1.01	.26	-.50**	-.92	.30	-.46**
<i>DAS-7</i>	-.53	.49	-.15	-.45	.50	-.13
<i>CHIP</i>	-.07	.13	-.08	-.08	.13	-.08
<i>SRRS</i>	.01	.02	.06	.00	.02	.01
# Transition Events				.96	1.38	.11
# Reminder Events				.38	2.37	.03
R^2		.40			.41	
F for change in R^2		5.49**			.38	

* $p < .05$. ** $p < .01$.

Table 14

Summary of Hierarchical Regression Analysis for Variables Predicting Fathers' PSI-SF Scores (N = 28)

Variable	Model 1			Model 2		
	<i>B</i>	<i>SE B</i>	β	<i>B</i>	<i>SE B</i>	β
<i>SIB-R SS</i>	-.03	.13	-.06	.03	.12	.05
<i>SIB-R GMI</i>	-.74	.32	-.45*	-.82	.29	-.50*
<i>CHIP</i>	-.33	.22	-.31	-.21	.20	-.20
Hours Worked/Week	.38	.27	.25	.15	.26	.10
<i>DAS-7</i>	-.57	.85	-.13	-.52	.75	-.12
Parent Age	-.59	.66	-.22	-.10	.62	-.04
Education	-4.21	9.21	-.08	2.56	8.61	.05
First-born Child	-6.38	8.38	-.15	-.70	7.77	-.02
Income	1.30	3.81	.07	1.81	3.37	.10
Marital Status	21.67	20.52	.19	-1.04	20.43	.01
# Reminder Events				6.41	2.66	.48*
R^2		.56			.68	
F for change in R^2		2.16			5.79*	

* $p < .05$. ** $p < .01$.

Table 15

Summary of Hierarchical Regression Analysis for Variables Predicting Fathers' PS I Scores using Continuous Reminder Variable (N = 34)

Variable	Model 1			Model 2		
	<i>B</i>	<i>SE B</i>	β	<i>B</i>	<i>SE B</i>	β
<i>SRRS</i>	.01	.00	.37*	.00	.00	.35*
Hours Worked/Week	-.01	.02	-.10	-.03	.02	-.26
Child Age	-.01	.04	-.04	-.01	.04	-.03
<i>DAS-7</i>	-.09	.05	-.29	-.11	.05	-.35*
# Reminder Events				.44	.15	.47**
R^2		.18			.37	
F for change in R^2		1.56			8.43**	

* $p < .05$. ** $p < .01$.

Appendix A

Dear Parent/Guardian,

Hello! I am a doctoral student at Rutgers University, and I work as a research coordinator at the Douglass Developmental Disabilities Center. I am currently conducting research on the **patterns of stress experienced by parents of children with autism**, and would like to know if you are interested in participating in this research. Participation is open to all parents (biological, step, adoptive parents; married or unmarried) raising children, infants through adults, diagnosed with autism.

Participation requires completion of a series of questionnaires about your child with autism and your experiences in raising your child. These questionnaires will be sent to your home. **No travel is required for this study, and participation requires little more than an hour of your time.** This research is being conducted for my doctoral dissertation under the supervision of Dr. Sandra Harris.

Your participation in this research may help us develop a **greater understanding of the unique experiences of parents of children with autism**. This will be helpful in the future development of effective trainings and support groups for parents of children with autism.

I am eager to hear about your experiences in raising your child. **To learn more about this project or to participate in this study, please contact Kate Fiske at 732-932-3017 x161 or at kfiske@rci.rutgers.edu.** You may also complete the bottom portion of this flier and return it to Kate Fiske at the DDDC, 151 Ryders Lane, New Brunswick, NJ 08901. Thank you for your time and consideration. I hope to hear from you.

Sincerely,
Kate Fiske, M.S.
Research Coordinator
Douglass Developmental Disabilities Center

Yes, I am interested in participating in this study! Please contact me using this information:

1st Parent Name

2nd Parent Name (if applicable)

Address

Phone Number

E-mail Address

Appendix B

Dear Parent/Guardian,

Thank you for agreeing to participate in my research study on the stress experienced by parents raising a child with autism. I am interested in identifying the patterns of stress that parents experience when raising a child with autism, especially in response to events unique to raising a child with autism. Identification of these events is important to the development of effective support groups and trainings for parents. Your help with this research is greatly appreciated.

I am currently a doctoral student at Rutgers University, and I work as a research coordinator at the Douglass Developmental Disabilities Center. I have previously provided behavioral consultation to the students, teachers, and parents of the Douglass School and co-lead a sibling support group. This research study is my doctoral dissertation, as supervised by Dr. Sandra Harris.

I have enclosed with this letter a consent form for your participation in this study. Please read the consent form carefully. Each parent should sign the consent form only if you agree with all of the statements in the form. Once you have completed the consent form, I would also like to know if you would allow me to contact you in the future for further participation in this area of research. Please fill out the *Consent for Future Contact* form if you are interested in future participation.

Once you have completed the consent forms, please complete the questionnaires provided. A packet of questionnaires has been provided for each parent in the household. In addition to these questionnaires, one parent (in consultation with a second parent, if necessary) should also fill out the *Child and Family Background Questionnaire*. All questionnaires should be filled out completely and returned to Kate Fiske using the self-addressed, stamped envelope provided.

If you have any questions regarding this information, please feel free to contact Kate Fiske at 732-932-3017 x161 or at kfiske@rci.rutgers.edu. Dr. Sandra Harris may be contacted at 732-932-3017 x155 or at sharris@rci.rutgers.edu. The Rutgers University Institutional Review Board may be contacted at 732-932-0150, at humansubjects@orsp.rutgers.edu, or at 3 Rutgers Plaza, New Brunswick, NJ 08901.

Thank you,

Kate E. Fiske, M.S.
Research Coordinator
Douglass Developmental Disabilities Center

Informed Consent for Research Participation

This form requests your consent for your participation in a research study on the patterns of stress experienced by parents raising a child with autism. The project is being conducted by Kate Fiske; I am a doctoral student in clinical psychology at Rutgers University and a research coordinator at the Douglass Developmental Disabilities Center. I am doing this project for my doctoral dissertation under the supervision of Dr. Sandra Harris.

Your participation in this study is completely voluntary, and your family is one of approximately 100 families whom I am inviting to participate. The research requires you to complete a series of questionnaires regarding you and your child's demographic information, your child's adaptive skills and maladaptive behavior, your coping behaviors and the social support you receive, and the stress you currently experience and that you have experienced in the past in response to specific events. Participation in this study requires the completion of all questionnaires by the parent(s) in the household. The questionnaires should take approximately 1 hour to complete.

Potential benefits of this study include parents' identification of their own and their child's strengths in a variety of areas through their responses to these questionnaires. More broadly, parent participation may contribute to a greater understanding of the patterns of stress among parents of children with autism. This understanding may allow professionals to design more effective trainings and support groups for parents of children with autism in the future. I am also required to inform you of the risks of this study. Some questionnaires may contain items that may be difficult for you to answer or that may upset you. In addition, you may grow tired of responding to the items on the questionnaires. While these questions have been carefully chosen to identify areas of potential difficulty for parents, at any time you may choose not to answer a question if it causes distress.

While I am required to inform you that Rutgers University will not be responsible for compensation or treatment in the event of research-related adverse experiences, the procedure for this research study poses no foreseeable risks to your child and minimal risk to you. Distress that you may experience in the completion of this study is not expected to exceed that experienced in daily life. Should you find yourself upset by the completion of these questionnaires, however, please do not hesitate to contact me using the contact information provided below so that I may help you find appropriate resources.

The data collected during this study will be used only in the research study evaluating patterns of parent stress and will be viewed only by me (Kate Fiske) and my advisor, Sandra Harris, and research assistants whom I have hired. To preserve the confidentiality of questionnaire responses, any identifying information about you or your child (i.e., consent forms and contact information) will be kept separate from your responses to questionnaires. I will be the only person who can link your responses to your identity. To maintain security and confidentiality, I will store and maintain all information in a locked cabinet. When the material loses its scientific value, it will be destroyed (e.g., erased/shredded) to ensure no one else gains access to it. This study may evolve into a longitudinal research, or research that spans several years. I may be contacting families in future years if they provide consent for this contact. Because of this, I will not be sending individual or group results directly to the families who have

completed these questionnaires. Families may read results from this study published in professional journals, and at some point in the future I may be able to send you the longitudinal results of my findings.

If at any time you wish to decline participation in this study, you may do so without penalty and without any impact on the treatment or services delivered to you or your child by the agency or program that initially sent you the description of this research project. In addition, your decision not to participate will also not impact any future services you may receive from the Douglass Developmental Disabilities Center.

If you have any questions regarding this information please feel free to contact Kate Fiske at 732-932-3017 x161 or at kfiske@rci.rutgers.edu. Dr. Sandra Harris may be contacted at 732-932-3017 x155 or at sharris@rci.rutgers.edu. The Rutgers University Institutional Review Board may be contacted at 732-932-0150, at humansubjects@orsp.rutgers.edu, or at 3 Rutgers Plaza, New Brunswick, NJ 08901.

Thank you for your time and consideration of a study that could provide information to help parents of children with autism in the future.

Sincerely,

(Principal Investigator) Kate Fiske
Behavioral Consultant, Douglass Developmental Disabilities Center

_____ I/we understand the terms of this consent and agree to participate in this study and for the responses I/we provide to be confidentially used for research purposes.
Please initial bottom of first page if you consent to participation.

_____ I/we decline to participate in this study.

First Parent:

Second Parent, if applicable:

_____ 1st Parent/Guardian Name (please print)

_____ 2nd Parent/Guardian Name (please print)

_____ 1st Parent/Guardian Signature

_____ 2nd Parent/Guardian Signature

_____ Date

_____ Date

Please return all pages of this consent form with your questionnaire responses in the self-addressed, stamped envelope provided. A copy of the consent form will be returned to you.

Consent for Future Contact

I may like to contact you again in the future to participate in additional research on parent experiences in raising a child with autism. Please indicate below whether you consent for me to contact you in the future about additional research in this area. This consent form only gives me permission to contact you. It does not commit you to participation in future research. If I do contact you, you will be able to accept or decline participation at that time.

When contacting you in the future, I will make every effort to contact you directly, but sometimes families move and change contact information, and I may have difficulty contacting them. If you consent to future contact and participation, I ask that you supply contact information for two other people who would know how to contact you if I cannot. Please also sign the attached Release of Information Forms for each family contact.

Thank you for your consideration,

(Principal Investigator)

Kate Fiske

Research Coordinator, Douglass Developmental Disabilities Center

_____ I/we consent to being contacted by Kate Fiske about future possibilities for participation in this research area. I/we understand that this consent does not commit us to future participation.

_____ I/we decline to be contacted about future possibilities for participation in this research area.

First Parent:

Second Parent, if applicable:

1st Parent/Guardian Name (please print)

2nd Parent/Guardian Name (please print)

1st Parent/Guardian Signature

2nd Parent/Guardian Signature

Date

Date

Family Contact Information

1. Your current family contact information:

Name:	
Relation:	
Phone #:	
Other Phone #:	
Address:	

Follow-Up Contacts

(used only if primary investigator cannot contact family directly)

2. First friend or family member (outside of your immediate family) to contact:

Name:	
Relation:	
Phone #:	
Other Phone #:	
Address:	

3. Second friend or family member (outside of your immediate family) to contact:

Name:	
Relation:	
Phone #:	
Other Phone #:	
Address:	

Re: Release of Information: Follow-up Contact

Dear _____ :
(Family Contact #1)

Our family is participating in a project at the Douglass Developmental Disabilities Center (DDDC) of Rutgers, the State University of New Jersey that may require follow-up over a period of several years. I have given permission to the DDDC staff to contact you for information in the event that they have difficulty locating our family. I consent to your disclosure of our most current contact information to Ms. Kate Fiske and her staff at Rutgers. Ms. Fiske is the principal investigator of this study and Dr. Sandra Harris is her faculty supervisor. Your assistance in helping them locate me and my family is deeply appreciated. If you have any questions regarding this authorization, please contact me. You can also contact the Sponsored Programs Administrator at Rutgers University at (732) 932-0150, extension 2104 if you have questions about the study.

To contact Kate Fiske to provide our family's current contact information, please call her at 732-932-3017 x161 or e-mail her at kfiske@rci.rutgers.edu.

Thank you,

Parent/Guardian Signature

Date

Parent/Guardian Name

Appendix C

Primary Caregiver Background Information

A primary caregiver (e.g., biological parent, step-parent, adoptive parent) should complete this form. Please tell us more about yourself.

1. Who is filling out this form? What is your relationship to the child with autism?

- a) _____ Biological Mother
- b) _____ Biological Father
- c) _____ Other, please specify: _____

2. What is your current marital status?

- a) _____ Single, or Never Married
- b) _____ Married
- c) _____ Widowed
- d) _____ Divorced
- e) _____ Separated
- f) _____ Partnered

3. When is your birthday?

_____/_____/_____
MONTH DAY YEAR

4. How old are you?

YEARS

5. In what country were you born? _____

6. If you were born outside of the United States:

- a) How long have you lived in the United States altogether?

YEARS

7. Which of the following best describes your ethnicity? Please check all that apply:

- a)____ American Indian/Alaskan Native
- b)____ Asian/Pacific Islander
- c)____ Black/African-American
- d)____ White
- e)____ Hispanic/Latino(a)
- e)____ If Other, Please Specify:

8. How far did you go in school?

- a)____ 8th grade or less Which grade? _____
- b)____ more than 8th grade, but did not graduate from High School.
Which grade? _____
- c)____ went to a business, trade, or vocational school instead of High School
- d)____ High School graduate/GED
- f)____ went to a business, trade, or vocational school after high school
- g)____ went to college, but did not graduate
- h)____ graduated from a college or university
- i)____ professional training beyond a 4-year college or university
- j)____ never went to school
- k)____ don't know

9. Are you employed?

NO PART-TIME FULL-TIME

10. If employed, what is your occupation? _____

11. If employed, indicate the number of hours per week you spend working outside of the home:

HOURS

Appendix D

Child and Family Background Information

A primary caregiver (e.g., biological parent, adoptive parent) should complete this form. Please tell us more about your family and the individual with autism. The word “child” will consistently refer to the individual with autism, regardless of his or her age.

1. Who is filling out this form? What is your relationship to the child with autism?

- a) _____ Biological Mother
 b) _____ Biological Father
 c) _____ Other, please specify: _____

2. Please specify today's date:

_____/_____/_____
 MONTH DAY YEAR

3. Specify the child's sex (CIRCLE ONE):

MALE FEMALE

4. When is the child's birthday?

_____/_____/_____
 MONTH DAY YEAR

5. What is the child's diagnosis (check one)?

- a) _____ Autistic Disorder
 b) _____ Pervasive Developmental Disorder, Not Otherwise Specified
 c) _____ Asperger's Disorder
 d) _____ Other; Please specify _____

6. At what age was the child first diagnosed?

_____, _____
 YEARS MONTHS

7. Who provided the child's first diagnosis (check all that apply)?

- a) _____ Psychologist
- b) _____ Psychiatrist
- c) _____ Developmental pediatrician
- d) _____ Neurologist
- e) _____ Other medical professional, please specify: _____
- f) _____ Other, please specify: _____

8. This child's current placement is a:

- a) _____ Private day school for children with special needs
- b) _____ Special needs classroom within a general education school
- c) _____ General education classroom
- d) _____ Residential facility
- e) _____ Vocational placement
- f) _____ Other; Please specify: _____

9. If the child is attending a general education school, what grade is s/he currently in (or going into)?

GRADE

10. If the child is currently living in a residential facility, how often do you see him or her (check one)?

- a) _____ Every Day
- b) _____ Bi-Weekly
- c) _____ Weekly
- d) _____ Bi-Monthly
- e) _____ Monthly
- f) _____ Bi-Annually
- g) _____ Annually
- h) _____ Other, please specify: _____

**IF THE CHILD IS CURRENTLY LIVING IN A RESIDENTIAL FACILITY,
PLEASE SKIP TO QUESTION 14. IF THE CHILD IS LIVING AT HOME,
PLEASE CONTINUE ON TO QUESTION 11.**

11. Please list the people who have lived with the child with autism in the past year. Indicate the relation of each person to the child (e.g., mother, sibling, aunt, grandfather, etc.), the sex and age of each person, and whether the person has had a significant role in caring for the child in the past year.

<u>Relation to Child</u>	<u>Sex (circle one)</u>	<u>Age in Years</u>	<u>Significant Caregiver?</u>
a)	MALE FEMALE		YES NO
b)	MALE FEMALE		YES NO
c)	MALE FEMALE		YES NO
d)	MALE FEMALE		YES NO
e)	MALE FEMALE		YES NO
f)	MALE FEMALE		YES NO
g)	MALE FEMALE		YES NO
h)	MALE FEMALE		YES NO
i)	MALE FEMALE		YES NO

12. How many adults, 18 years and older, including yourself but NOT including the child with autism, live in the child's home?

ADULTS: _____

13. How many total children, less than 18 years old, NOT including the child with autism, live in the home?

CHILDREN: _____

14. What is the relationship status of the child's biological parents?

- a) _____ No contact with each other
- b) _____ Parents have contact, but not living together
- c) _____ Cohabiting, but not married
- d) _____ Married
- e) _____ Separated

15. How many siblings does the child have (include full, partial, and step-siblings)?

16. Are any siblings diagnosed with a developmental disability other than autism?

NO YES

If YES, what is his/her/their diagnosis? _____

17. Was this your first-born child? NO YES

If NO, how many other children did you have when this child was born? _____

18. Which of the following best describes the child's ethnicity? Check all that apply:

a) _____ American Indian/Alaskan Native

b) _____ Asian/Pacific Islander

c) _____ Black/African-American

d) _____ White

e) _____ Hispanic/Latino(a)

e) _____ If Other, Please Specify:

19. Is there another language spoken in the home (circle one)? NO YES

If YES, which languages? _____

20. About how much total income, before taxes, has your family received in the last twelve months? Include all those contributing to the household. Include your own income, the income of everyone else in your household, and income from welfare benefits, dividends, and all other sources.

a) _____ under \$5,000

g) _____ \$50,001 to \$60,000

b) _____ \$5,000 to \$10,000

h) _____ \$60,001 to \$80,000

c) _____ \$10,001 to \$20,000

h) _____ \$80,001 to \$100,000

d) _____ \$20,001 to \$30,000

i) _____ \$100,001 to \$150,000

e) _____ \$30,001 to \$40,000

j) _____ over \$150,001

f) _____ \$40,001 to \$50,000

a. How many people altogether live off this income? _____

Appendix E

Parent Stress

1. If I consider the stress in all areas of my life, including family matters, finances, employment, and personal events, the stress level I currently experience is (circle one):

0	1	2	3	4	5	6	7	8
No Stress		A Little Stress		Some Stress		A Lot of Stress		Extreme Stress

2. If I consider only the stress in raising my child with autism, the current level of parenting stress I experience is (circle one):

0	1	2	3	4	5	6	7	8
No Stress		A Little Stress		Some Stress		A Lot of Stress		Extreme Stress

Appendix F

Parenting Life Experiences Questionnaire

Directions: A primary caregiver (e.g., biological parent, step-parent, adoptive parent) should complete this form. For each event, indicate whether the event occurred in your family in the past 6 months, did not occur in the past 6 months but you thought about it happening in the future, or it did not occur and you did not think about it. If the event occurred in the past 6 months, indicate how stressful the event was for you, where "0" is "Not Stressful at All" and "5" is "Extremely Stressful." If the event has not yet occurred but you have thought about it happening in the future, please indicate how stressful it is for you to think about this event occurring in the future, where "0" is "Not Stressful at All" and "5" is "Extremely Stressful." Finally, answer any follow-up questions for the event as indicated.

Who is completing this form? What is your relation to the child with autism (e.g., biological mother/father, step-mother/father, etc.)?

Event	Has this event occurred or have you thought about it in the past 6 months? (Please check one)	If "YES", how stressful was this event for you? If "NOT YET", how stressful is it to think about this event occurring in the future?	Additional Questions: Please Complete if Indicated
SAMPLE) My child was admitted to the hospital.	<input type="checkbox"/> Yes: This happened in the past 6 months <input type="checkbox"/> Not Yet: This did not happen in the past 6 months, but during that time I thought about it happening in the future <input type="checkbox"/> No: This did not happen in the past 6 months and I did not think about it	0 1 2 3 4 5 Not Stress- Extremely ful at All Stressful	If "YES," why was your child admitted?
1) I noticed early signs that my child was not developing as s/he should.	<input type="checkbox"/> Yes: This happened in the past 6 months <input type="checkbox"/> Not Yet: This did not happen in the past 6 months, but during that time I thought about it happening in the future <input type="checkbox"/> No: This did not happen in the past 6 months and I did not think about it	0 1 2 3 4 5 Not Stress- Extremely ful at All Stressful	If "YES," list early signs:
2) Other people suggested something might be wrong with my child.	<input type="checkbox"/> Yes: This happened in the past 6 months <input type="checkbox"/> Not Yet: This did not happen in the past 6 months, but during that time I thought about it happening in the future <input type="checkbox"/> No: This did not happen in the past 6 months and I did not think about it	0 1 2 3 4 5 Not Stress- Extremely ful at All Stressful	If "YES," list early signs noticed by other people:
3) I tried to find a diagnosis for my child (e.g., looked for a doctor who could provide accurate diagnosis).	<input type="checkbox"/> Yes: This happened in the past 6 months <input type="checkbox"/> Not Yet: This did not happen in the past 6 months, but during that time I thought about it happening in the future <input type="checkbox"/> No: This did not happen in the past 6 months and I did not think about it	0 1 2 3 4 5 Not Stress- Extremely ful at All Stressful	If "YES," how long did it take to find a diagnosis after you realized something might be wrong?

4) My child was misdiagnosed with an illness or disorder other than autism.	<input type="checkbox"/> Yes: This happened in the past 6 months <input type="checkbox"/> Not Yet: This did not happen in the past 6 months, but during that time I thought about it happening in the future <input type="checkbox"/> No: This did not happen in the past 6 months and I did not think about it	0 1 2 3 4 5 Not Stress- Extremely ful at All Stressful	If "YES," what was your child diagnosed with?
5) I received a professional diagnosis for my child.	<input type="checkbox"/> Yes: This happened in the past 6 months <input type="checkbox"/> Not Yet: This did not happen in the past 6 months, but during that time I thought about it happening in the future <input type="checkbox"/> No: This did not happen in the past 6 months and I did not think about it	0 1 2 3 4 5 Not Stress- Extremely ful at All Stressful	
6) I debated whether specialized services (e.g., early intervention, center-based program, special needs program) were appropriate for my child.	<input type="checkbox"/> Yes: This happened in the past 6 months <input type="checkbox"/> Not Yet: This did not happen in the past 6 months, but during that time I thought about it happening in the future <input type="checkbox"/> No: This did not happen in the past 6 months and I did not think about it	0 1 2 3 4 5 Not Stress- Extremely ful at All Stressful	
7) I searched for appropriate initial services for my child.	<input type="checkbox"/> Yes: This happened in the past 6 months <input type="checkbox"/> Not Yet: This did not happen in the past 6 months, but during that time I thought about it happening in the future <input type="checkbox"/> No: This did not happen in the past 6 months and I did not think about it	0 1 2 3 4 5 Not Stress- Extremely ful at All Stressful	If "YES," how long did it take to locate appropriate services?
8) I enrolled my child into initial services.	<input type="checkbox"/> Yes: This happened in the past 6 months <input type="checkbox"/> Not Yet: This did not happen in the past 6 months, but during that time I thought about it happening in the future <input type="checkbox"/> No: This did not happen in the past 6 months and I did not think about it	0 1 2 3 4 5 Not Stress- Extremely ful at All Stressful	If "YES," what initial services did your child receive?
9) My child reached an age when s/he should have achieved developmental milestones, but had not (e.g., learning to talk).	<input type="checkbox"/> Yes: This happened in the past 6 months <input type="checkbox"/> Not Yet: This did not happen in the past 6 months, but during that time I thought about it happening in the future <input type="checkbox"/> No: This did not happen in the past 6 months and I did not think about it	0 1 2 3 4 5 Not Stress- Extremely ful at All Stressful	
10) A younger sibling/cousin/peer developmentally surpassed my child with autism.	<input type="checkbox"/> Yes: This happened in the past 6 months <input type="checkbox"/> Not Yet: This did not happen in the past 6 months, but during that time I thought about it happening in the future <input type="checkbox"/> No: This did not happen in the past 6 months and I did not think about it	0 1 2 3 4 5 Not Stress- Extremely ful at All Stressful	

11) I noticed that my child's siblings were affected by his/her disability.	<input type="checkbox"/> Yes: This happened in the past 6 months <input type="checkbox"/> Not Yet: This did not happen in the past 6 months, but during that time I thought about it happening in the future <input type="checkbox"/> No: This did not happen in the past 6 months and I did not think about it	0 1 2 3 4 5 Not Stress-ful at All Extremely Stressful	If "YES," how were they affected?
12) An expected change in educational placement occurred (e.g., transition from one school or classroom to another after reaching a specified age).	<input type="checkbox"/> Yes: This happened in the past 6 months <input type="checkbox"/> Not Yet: This did not happen in the past 6 months, but during that time I thought about it happening in the future <input type="checkbox"/> No: This did not happen in the past 6 months and I did not think about it	0 1 2 3 4 5 Not Stress-ful at All Extremely Stressful	If "YES," describe the change:
13) An unexpected change in educational placement occurred (e.g., losing funding for child's placement, placement changed by district).	<input type="checkbox"/> Yes: This happened in the past 6 months <input type="checkbox"/> Not Yet: This did not happen in the past 6 months, but during that time I thought about it happening in the future <input type="checkbox"/> No: This did not happen in the past 6 months and I did not think about it	0 1 2 3 4 5 Not Stress-ful at All Extremely Stressful	If "YES," describe the change:
14) Following disagreements about my child's IEP with our school district, I had to seek legal counseling and/or go through legal mediation and hearings.	<input type="checkbox"/> Yes: This happened in the past 6 months <input type="checkbox"/> Not Yet: This did not happen in the past 6 months, but during that time I thought about it happening in the future <input type="checkbox"/> No: This did not happen in the past 6 months and I did not think about it	0 1 2 3 4 5 Not Stress-ful at All Extremely Stressful	
15) I debated whether an inclusion setting would be appropriate for my child.	<input type="checkbox"/> Yes: This happened in the past 6 months <input type="checkbox"/> Not Yet: This did not happen in the past 6 months, but during that time I thought about it happening in the future <input type="checkbox"/> No: This did not happen in the past 6 months and I did not think about it	0 1 2 3 4 5 Not Stress-ful at All Extremely Stressful	If "NOT YET," do you think inclusion will be appropriate for your child? Yes No Unsure
16) I searched for a placement in an inclusion setting for my child (e.g., inclusion preschool or general education classroom).	<input type="checkbox"/> Yes: This happened in the past 6 months <input type="checkbox"/> Not Yet: This did not happen in the past 6 months, but during that time I thought about it happening in the future <input type="checkbox"/> No: This did not happen in the past 6 months and I did not think about it	0 1 2 3 4 5 Not Stress-ful at All Extremely Stressful	
17) My child entered an inclusion setting (e.g., inclusion preschool or general education classroom).	<input type="checkbox"/> Yes: This happened in the past 6 months <input type="checkbox"/> Not Yet: This did not happen in the past 6 months, but during that time I thought about it happening in the future <input type="checkbox"/> No: This did not happen in the past 6 months and I did not think about it	0 1 2 3 4 5 Not Stress-ful at All Extremely Stressful	

24) My child experienced onset of puberty (e.g., menstruation, facial hair).	<input type="checkbox"/> Yes: This happened in the past 6 months <input type="checkbox"/> Not Yet: This did not happen in the past 6 months, but during that time I thought about it happening in the future <input type="checkbox"/> No: This did not happen in the past 6 months and I did not think about it	0 1 2 3 4 5 Not Stress-ful at All Extremely Stressful	
25) My child experienced onset of sexual behavior (e.g., masturbation).	<input type="checkbox"/> Yes: This happened in the past 6 months <input type="checkbox"/> Not Yet: This did not happen in the past 6 months, but during that time I thought about it happening in the future <input type="checkbox"/> No: This did not happen in the past 6 months and I did not think about it	0 1 2 3 4 5 Not Stress-ful at All Extremely Stressful	
26) I realized that my child will require long-term care and supervision.	<input type="checkbox"/> Yes: This happened in the past 6 months <input type="checkbox"/> Not Yet: This did not happen in the past 6 months, but during that time I thought about it happening in the future <input type="checkbox"/> No: This did not happen in the past 6 months and I did not think about it	0 1 2 3 4 5 Not Stress-ful at All Extremely Stressful	If "YES": How frequently did you think of this during the past 6 months? (circle one) Once or twice Every month Every week Every day
27) I debated whether a vocational placement would be appropriate for my child.	<input type="checkbox"/> Yes: This happened in the past 6 months <input type="checkbox"/> Not Yet: This did not happen in the past 6 months, but during that time I thought about it happening in the future <input type="checkbox"/> No: This did not happen in the past 6 months and I did not think about it	0 1 2 3 4 5 Not Stress-ful at All Extremely Stressful	If "NOT YET," do you think a vocational placement will be appropriate in the future? Yes No Unsure
28) I searched for a vocational placement (e.g., job site) for my child.	<input type="checkbox"/> Yes: This happened in the past 6 months <input type="checkbox"/> Not Yet: This did not happen in the past 6 months, but during that time I thought about it happening in the future <input type="checkbox"/> No: This did not happen in the past 6 months and I did not think about it	0 1 2 3 4 5 Not Stress-ful at All Extremely Stressful	
29) My child entered a vocational placement.	<input type="checkbox"/> Yes: This happened in the past 6 months <input type="checkbox"/> Not Yet: This did not happen in the past 6 months, but during that time I thought about it happening in the future <input type="checkbox"/> No: This did not happen in the past 6 months and I did not think about it	0 1 2 3 4 5 Not Stress-ful at All Extremely Stressful	
30) I thought about how I will not be able to reach the dreams and goals I had for myself prior to having my child diagnosed with autism.	<input type="checkbox"/> Yes: This happened in the past 6 months <input type="checkbox"/> Not Yet: This did not happen in the past 6 months, but during that time I thought about it happening in the future <input type="checkbox"/> No: This did not happen in the past 6 months and I did not think about it	0 1 2 3 4 5 Not Stress-ful at All Extremely Stressful	If "YES": How frequently did you think of this during the past 6 months? (circle one) Once or twice Every month Every week Every day

31) I debated whether a post-secondary education (e.g., college) would be appropriate for my child.	<input type="checkbox"/> Yes: This happened in the past 6 months <input type="checkbox"/> Not Yet: This did not happen in the past 6 months, but during that time I thought about it happening in the future <input type="checkbox"/> No: This did not happen in the past 6 months and I did not think about it	0 1 2 3 4 5 Not Stress-ful at All Extremely Stressful	If "NOT YET," do you think post-secondary education will be appropriate in the future? Yes No Unsure
32) I searched for a post-secondary education (e.g., college) placement for my child.	<input type="checkbox"/> Yes: This happened in the past 6 months <input type="checkbox"/> Not Yet: This did not happen in the past 6 months, but during that time I thought about it happening in the future <input type="checkbox"/> No: This did not happen in the past 6 months and I did not think about it	0 1 2 3 4 5 Not Stress-ful at All Extremely Stressful	
33) My child began post-secondary education.	<input type="checkbox"/> Yes: This happened in the past 6 months <input type="checkbox"/> Not Yet: This did not happen in the past 6 months, but during that time I thought about it happening in the future <input type="checkbox"/> No: This did not happen in the past 6 months and I did not think about it	0 1 2 3 4 5 Not Stress-ful at All Extremely Stressful	
34) I debated whether a residential facility would be appropriate for my child.	<input type="checkbox"/> Yes: This happened in the past 6 months <input type="checkbox"/> Not Yet: This did not happen in the past 6 months, but during that time I thought about it happening in the future <input type="checkbox"/> No: This did not happen in the past 6 months and I did not think about it	0 1 2 3 4 5 Not Stress-ful at All Extremely Stressful	If "NOT YET," do you think a residential facility will be appropriate in the future? Yes No Unsure
35) I searched for a residential facility placement for my child.	<input type="checkbox"/> Yes: This happened in the past 6 months <input type="checkbox"/> Not Yet: This did not happen in the past 6 months, but during that time I thought about it happening in the future <input type="checkbox"/> No: This did not happen in the past 6 months and I did not think about it	0 1 2 3 4 5 Not Stress-ful at All Extremely Stressful	
36) My child entered a residential facility.	<input type="checkbox"/> Yes: This happened in the past 6 months <input type="checkbox"/> Not Yet: This did not happen in the past 6 months, but during that time I thought about it happening in the future <input type="checkbox"/> No: This did not happen in the past 6 months and I did not think about it	0 1 2 3 4 5 Not Stress-ful at All Extremely Stressful	
37) I thought about what my child might have accomplished if s/he had not been diagnosed with autism.	<input type="checkbox"/> Yes: This happened in the past 6 months <input type="checkbox"/> Not Yet: This did not happen in the past 6 months, but during that time I thought about it happening in the future <input type="checkbox"/> No: This did not happen in the past 6 months and I did not think about it	0 1 2 3 4 5 Not Stress-ful at All Extremely Stressful	If "YES": How frequently did you think of this during the past 6 months? (circle one) Once or twice Every month Every week Every day

38) My child exhibited a significant increase in inappropriate behavior (e.g., aggressions, stereotypy, self-injurious behavior, non-compliance)	<input type="checkbox"/> Yes: This happened in the past 6 months <input type="checkbox"/> Not Yet: This did not happen in the past 6 months, but during that time I thought about it happening in the future <input type="checkbox"/> No: This did not happen in the past 6 months and I did not think about it	0 1 2 3 4 5 Not Stress- Extremely ful at All Stressful	
39) I made legal decisions regarding my child's future guardianship and care after my death.	<input type="checkbox"/> Yes: This happened in the past 6 months <input type="checkbox"/> Not Yet: This did not happen in the past 6 months, but during that time I thought about it happening in the future <input type="checkbox"/> No: This did not happen in the past 6 months and I did not think about it	0 1 2 3 4 5 Not Stress- Extremely ful at All Stressful	
40) The most stressful event that occurred in the past 6 months that involved my child was: _____	<input type="checkbox"/> Yes: This happened in the past 6 months <input type="checkbox"/> Not Yet: This did not happen in the past 6 months, but during that time I thought about it happening in the future <input type="checkbox"/> No: This did not happen in the past 6 months and I did not think about it	0 1 2 3 4 5 Not Stress- Extremely ful at All Stressful	
41) The most joyful event that occurred in the past 6 months that involved my child was: _____	<input type="checkbox"/> Yes: This happened in the past 6 months <input type="checkbox"/> Not Yet: This did not happen in the past 6 months, but during that time I thought about it happening in the future <input type="checkbox"/> No: This did not happen in the past 6 months and I did not think about it	0 1 2 3 4 5 Not Stress- Extremely ful at All Stressful	
42) One thing that parents who have a newly diagnosed child with autism should know about the future with their child is:	Fill in response here:		

Appendix G

Couple's Questionnaire

Most persons have disagreements in their relationships. Using the scale below, please indicate the approximate extent of agreement or disagreement between you and your partner on each item on the following list.

1. Philosophy of (the way we think about and approach) life _____
2. Aims, goals, and things believed important _____
3. Amount of time spent together _____

5	4	3	2	1	0
Always	Almost	Occasionally	Frequently	Almost	Always
Agree	Always	Disagree	Disagree	Always	Disagree
	Agree			Disagree	

Using the scale below, how often would you say the following events occur between you and your mate?

4. Have a stimulating exchange of ideas _____
5. Calmly discuss something together _____
6. Work together on a project _____

0	1	2	3	4	5
Never	Less	Once or	Once or	Once a	More
	than once	twice a	twice a	day	often
	a month	month	week		

7. The dots on the following line represent degrees of happiness in your relationship. The middle point, "happy," represents the degree of happiness of most relationships. Please circle the dot which describes the degree of happiness, all things considered, of your relationship.

0	1	2	3	4	5	6
•	•	•	•	•	•	•

Extremely	Fairly	A Little	Happy	Very	Extremely	Perfect
Unhappy	Unhappy	Unhappy		Happy	Happy	

Appendix H

Social Support Questionnaire

Instructions: The purpose of this scale is to assess the type and amount of support that you receive from other individuals. To complete this scale, fill in the number representing how often each of the ten items occurred **during the preceding month** using the following 5-point scale:

- 1 = Not at all
- 2 = Once or twice
- 3 = About once a week
- 4 = Several times a week
- 5 = About every day

In the past month, how often has someone:

- 1) Comforted you by showing you some physical affection? _____
- 2) Checked back with you to see if you had followed the advice you were given? _____
- 3) Listened to you talk about your private feelings? _____
- 4) Said things that made your situation clearer and easier to understand? _____
- 5) Told you how he/she felt in a situation that was similar to yours? _____
- 6) Expressed interest and concern for your well-being? _____
- 7) Let you know that he/she will always be around if you need assistance? _____
- 8) Told you that he/she feels very close to you? _____
- 9) Joked and kidded to try to cheer you up? _____
- 10) Pitched in to help you do something that needed to get done? _____

Appendix I

Coping Health Inventory for Parents

Parents may use different strategies to help them cope with the challenges of raising a child with autism. For each item on the list below, indicate whether you use the strategy to cope and, if yes, how helpful the strategy is.

Item	Coping Strategy	Do you use this strategy? (Circle one)	If Yes, How helpful is this strategy? (Circle one)			
			Not Helpful	Minimally Helpful	Moderately Helpful	Extremely Helpful
1	Believing that my child(ren) will get better.	Yes No Not Possible	0	1	2	3
2	Investing myself in my children.	Yes No Not Possible	0	1	2	3
3	Doing things with my children.	Yes No Not Possible	0	1	2	3
4	Believing that things will always work out.	Yes No Not Possible	0	1	2	3
5	Telling myself that I have many things I should be thankful for.	Yes No Not Possible	0	1	2	3
6	Building a closer relationship with my spouse.	Yes No Not Possible	0	1	2	3
7	Talking over personal feelings and concerns with a spouse.	Yes No Not Possible	0	1	2	3
8	Doing things with family relatives.	Yes No Not Possible	0	1	2	3
9	Believing in God.	Yes No Not Possible	0	1	2	3
10	Taking good care of all the medical equipment [or educational materials] at home.	Yes No Not Possible	0	1	2	3
11	Believing that my child is getting the best medical [or educational] care possible.	Yes No Not Possible	0	1	2	3
12	Trying to maintain family stability.	Yes No Not Possible	0	1	2	3
13	Doing things together as a family (involving all members of the family).	Yes No Not Possible	0	1	2	3
14	Trusting my spouse (or former spouse) to help support me and my child(ren).	Yes No Not Possible	0	1	2	3

15	Showing that I am strong.	Yes	No	Not Possible	0	1	2	3
16	Getting other members of the family to help with chores and tasks at home.	Yes	No	Not Possible	0	1	2	3
17	Having my child with the medical condition seen at the clinic/hospital on a regular basis.	Yes	No	Not Possible	0	1	2	3
18	Believing that the medical center/hospital has my family's best interest in mind.	Yes	No	Not Possible	0	1	2	3
19	Encouraging child(ren) with medical condition to be more independent.	Yes	No	Not Possible	0	1	2	3
20	Involvement in social activities (parties, etc.) with friends.	Yes	No	Not Possible	0	1	2	3
21	Being able to get away from the home care tasks and responsibilities for some relief.	Yes	No	Not Possible	0	1	2	3
22	Getting away by myself.	Yes	No	Not Possible	0	1	2	3
23	Eating.	Yes	No	Not Possible	0	1	2	3
24	Sleeping.	Yes	No	Not Possible	0	1	2	3
25	Allowing myself to get angry.	Yes	No	Not Possible	0	1	2	3
26	Purchasing gifts for myself and/or other family members.	Yes	No	Not Possible	0	1	2	3
27	Concentrating on hobbies (art, music, jogging, etc.).	Yes	No	Not Possible	0	1	2	3
28	Working, outside employment.	Yes	No	Not Possible	0	1	2	3
29	Becoming more self-reliant and independent.	Yes	No	Not Possible	0	1	2	3
30	Keeping myself in shape and well-groomed.	Yes	No	Not Possible	0	1	2	3
31	Talking to someone (not professional counselor/doctor) about how I feel.	Yes	No	Not Possible	0	1	2	3
32	Engaging in relationships and friendships which help me to feel important and appreciated.	Yes	No	Not Possible	0	1	2	3
33	Entertaining friends in our home.	Yes	No	Not Possible	0	1	2	3
34	Investing time and energy in my job.	Yes	No	Not Possible	0	1	2	3
35	Going out with my spouse on a regular basis.	Yes	No	Not Possible	0	1	2	3
36	Building close relationships with people.	Yes	No	Not Possible	0	1	2	3
37	Developing myself as a person.	Yes	No	Not Possible	0	1	2	3

38	Talking with other parents in the same type of situation and learning about their experiences.	Yes No Not Possible	0	1	2	3
39	Talking with the medical staff [or educational staff] when we visit the medical center [or school].	Yes No Not Possible	0	1	2	3
40	Reading about how other persons in my situation handle things.	Yes No Not Possible	0	1	2	3
41	Reading more about the medical problem [or developmental disability] which concerns me.	Yes No Not Possible	0	1	2	3
42	Explaining our family situation to friends and neighbors so they will understand.	Yes No Not Possible	0	1	2	3
43	Being sure prescribed medical or [educational/behavior] treatments for child(ren) are carried out at home on a daily basis.	Yes No Not Possible	0	1	2	3
44	Talking with other individuals/parents in my same situation.	Yes No Not Possible	0	1	2	3
45	Talking with the doctor about my concerns about my child(ren) with the medical condition [or developmental disability].	Yes No Not Possible	0	1	2	3

Appendix J

Recent Life Events Checklist

Listed below are a number of events which sometimes bring about change in the lives of those who experience them. Please check those events which you have experienced *in the past 6 months*. Be sure that all check marks are directly across from the items they correspond to.

Check (✓) if event occurred in the past 6 months	Event
	1. Death of spouse/mate
	2. Death of close family member
	3. Major injury/illness to self
	4. Detention in jail or other institution
	5. Major injury/illness to close family member
	6. Foreclosure on loan/mortgage
	7. Divorce
	8. Being a victim of crime
	9. Being the victim of police brutality
	10. Infidelity
	11. Experiencing domestic violence/sexual abuse
	12. Separation or reconciliation with spouse/mate
	13. Being fired/laid-off/unemployed
	14. Experiencing financial problems/difficulties
	15. Death of close friend
	16. Surviving a disaster
	17. Becoming a single parent
	18. Assuming responsibility for sick or elderly loved one
	19. Loss of or major reduction in health insurance/benefits
	20. Self/close family member being arrested for violating the law
	21. Major disagreement over child support/custody/visitation
	22. Experiencing/involved in auto accident
	23. Being disciplined at work/demoted
	24. Dealing with unwanted pregnancy
	25. Adult child moving in with parent/parent moving in with adult child
	26. Child [not child with autism] develops behavior or learning problem
	27. Experiencing employment discrimination/ sexual harassment
	28. Attempting to modify addictive behavior of self
	29. Discovering/attempting to modify addictive behavior of close family member
	30. Employer reorganization/downsizing
	31. Dealing with infertility/miscarriage
	32. Getting married/remarried
	33. Changing employers/careers
	34. Failure to obtain/qualify for a mortgage

	35. Pregnancy of self/spouse/mate
	36. Experiencing discrimination/harassment outside the workplace
	37. Release from jail
	38. Spouse/mate begins/ceases work outside the home
	39. Major disagreement with boss/co-worker
	40. Change in residence
	41. Finding appropriate child care/day care [for child other than child with autism]
	42. Experiencing a large unexpected monetary gain
	43. Changing positions (transfer, promotion)
	44. Gaining a new family member [through birth, adoption, etc.]
	45. Changing work responsibilities
	46. Child leaving home
	47. Obtaining a home mortgage
	48. Obtaining a major loan other than home mortgage
	49. Retirement
	50. Beginning/ceasing formal education
	51. Receiving a ticket for violating the law

Curriculum Vita

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