THE IMPACT OF ACCESS TO SERVICES AND SYMPTOM SEVERITY ON PARENTING STRESS AND STRESS-RELATED GROWTH IN PARENTS OF CHILDREN WITH AUTISM

by

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Dedicated to Matthew David Spannagel
For You were Fearfully and Wonderfully Made
# Table of Contents

Table of Contents ........................................ 4
List of Tables .................................................. 6
List of Figures .................................................. 7
Acknowledgements ............................................ 8
Abstract .......................................................... 9
Introduction ..................................................... 10
  Autism .......................................................... 11
  Severity of Autism ........................................ 12
  Access to Services ....................................... 13
  Hopefulness ............................................... 24
  Familial Coping and Stress ............................. 25
  Stress Related Growth ................................ 29
  Summary and Hypotheses ................................ 32
Method .......................................................... 33
  Participants ................................................. 33
  Procedure .................................................. 34
  Measures .................................................... 35
Specific hypotheses ........................................... 41
Results .......................................................... 43
  Descriptive Statistics and Missing Data ............. 43
  Primary Analyses ......................................... 44
  Secondary Analyses ..................................... 47
Discussion 48
Autism Severity 48
Service Needs 49
Hopefulness 51
Limitations and Future Directions 52
Implications 54
Tables and Figure 57
References 63
List of Tables

Table 1 Variables and Measures 57
Table 2 Mean, Standard Deviation, Minimum, and Maximum of Variables 58
Table 3 Spearman rho correlations Among Predictor and Criteria Variables 59
Table 4 Testing Coping as a Mediator between Met Service Needs and Parenting Stress 60
Table 4 Testing Coping as a Mediator between Met Service Needs and Stress-Related Growth 61
List of Figures

Figure 1  Theoretical Model  62
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The Impact of Access to Services and Symptom Severity on Parenting Stress and Stress-Related Growth in Parents of Children with Autism

Abstract

by

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Research has consistently demonstrated that parenting a child with autism can lead to increased perceived stress for parents. This stress may be affected by a number of variables such as the severity of the child’s autism symptoms and the difficulty accessing essential services. There may also exist a complex pattern of interaction among these variables. Parental coping and level of hopefulness may mitigate this stress in some way. Furthermore, some parents may actually demonstrate personal growth as a result of parenting for a child with a pervasive and chronic condition such as autism.

The current study investigated several questions: (1) Is symptom severity associated with parenting stress? 2) Is access to services related to child clinical outcomes, parenting stress, and parental stress-related growth? 3) Do hopefulness and coping ability function as mediators of these relationships?

Thirty-eight parents of children with autism were obtained from a Cleveland Clinic autism patient registry. Parents were asked to complete several questionnaires related to access to services, specifically met and unmet service needs (Family Support Index; Heller and Factor, 1993), level of hopefulness (Adult Trait Hope Scale; Synder, 1991), coping (Coping Health Inventory for Parents; McCubbin et al., 1983), parenting stress (Parenting Stress Index-Short Form; Abidin, 1995), stress-related growth (Stress Related Growth Scale; Park et al., 1996), and child outcomes (Ohio Autism Clinical Impression Scale; Butter and Mulik, 2006)

Main results were that autism severity at diagnosis was not related to any variables. Current severity was related to parenting stress. As predicted, met service needs was significantly negatively related to child’s current level of severity. Results were that met service needs was significantly negatively related to parenting stress and significantly positively related to parental coping. Coping and met service needs were both significantly positively related to stress-related growth. This study did not find that coping and hopefulness functioned as mediators. This study is the first to examine the relationships among these variables with this population, and the findings have important implications for professionals serving these families.
The Impact of Access to Services and Symptom Severity on Parenting Stress and Stress-Related Growth in Parents of Children with Autism

Research has consistently demonstrated that parents of children with developmental disabilities experience greater stress than parents of children without developmental disabilities (Konstantareas, 1991; Hastings, 2002). Research studies have also shown that being a parent of a child with autism can be more stressful than parenting a child with a chronic physical illness or other developmental disability (Tunali and Powers, 2002; Sounders, DePaul, Freeman, and Levy, 2002; Luther, Canham, and Cureton, 2005). Several negative effects of this stress have been documented such as familial discord (Sobsey, 2004), and parental depression (Little, 2002). Some families, however, cope positively and seem to adapt to this stress without such fallout (Sobsey, 2004; Luther, Canham, and Cureton, 2005), demonstrating that family outcomes can vary from healthy to unhealthy. Numerous factors have been associated with parental and family adjustment such as family response style (Jones and Passey, 2005), amount of social support (Park, Turnbull and Rutherford, 2002), and parental perceptions of the child’s disability (Grant and Whittell, 2000).

Autism is a specific neurodevelopmental/neurobehavioral disorder characterized by the onset in early childhood of significantly impaired social reciprocity/interaction, disordered communication, and/or patterns of restricted and/or repetitive behaviors (American Psychiatric Association [APA], 2000). Children with autism require access to and utilization of extensive health care resources across their lifespan. Parents assume the multi-faceted task of caring for the child across systems in addition to their typical parenting and family responsibilities. Research has shown that the provision of such care
can prove detrimental to the psychological well-being of these parents and impact family functioning. Also, the child’s presentation and symptom severity can add to the parenting stress (Raina et al., 2005). The degree of severity may alter the service needs of the family, making more extensive care necessary and research has shown that symptom severity is related to reduced treatment effects (Eaves and Ho, 2004). Yet there is a dearth of research examining how access to and provision of services, specifically unmet service needs, impacts child clinical outcomes and parenting stress.

Research with other chronically ill populations has demonstrated that caregivers can experience stress-related growth such as meaning-making, increased social bonds, and an increased sense of mastery (Aldwin, 1994). Stress-related growth has not yet been examined in parents of children with autism. It is possible that parenting a child with autism may also lead to growth.

This study examined whether symptom severity at diagnosis and service access is associated with child clinical outcomes, perceived parenting stress, and parental growth. It also investigated whether hopefulness and coping ability mediate the relationships between the predictors and criteria.

Autism

According to the American Psychiatric Association (2000), autism is a complex, developmental, neurobiological disorder that typically lasts throughout a person's lifetime. The disorder is characterized by the childhood onset of qualitative impairments in social interaction and communication, affecting the way a child perceives the world and making communication and social interaction difficult. These impairments are typically accompanied by restricted repetitive and stereotyped patterns of behaviors,
interests, and activities. Autism is a general term used to describe a group of complex developmental brain disorders known as Pervasive Developmental Disorders (PDD). The other pervasive developmental disorders are PDD-NOS (Pervasive Developmental Disorder – Not Otherwise Specified), Asperger's Syndrome, Rett Syndrome and Childhood Disintegrative Disorder. Many parents and professionals refer to this group as Autism Spectrum Disorders (ASDs). Current nomenclature describes children according to their level of functioning from low to high functioning autism.

According the National Institute of Mental Health ([NIMH], 2009), most children with autism have difficulty learning to engage in the give-and-take of everyday human interactions. Children with autism may have difficulty with maintaining eye contact in a normal way, understanding social cues and nuances, and emotion regulation. Establishing and maintaining social relationships proves difficult for children with autism. Although children with autism usually appear physically typical, odd repetitive movements may set them apart from other children. These behaviors might be extreme and highly apparent or more subtle. Repetitive behavior sometimes takes the form of a persistent, intense preoccupation. These strong interests may be unusual because of their content or intensity. Overall symptoms, across all affected areas, can range from very mild to quite severe and symptom presentation can vary greatly between individuals (APA, 2000).

Recent Center for Disease Control and Prevention reports estimates that 1 in 110 individuals is diagnosed with autism, making it more common than pediatric cancer, diabetes, and AIDS combined (Center for Disease Control and Prevention [CDC], 2010). It occurs in all racial, ethnic, and social groups and is four times more likely to strike boys than girls.
Etiology can be defined as the cause or origin of a disease or condition. For many psychological disorders, etiology is known and that knowledge guides optimal prevention and treatment endeavors. Unfortunately, autism is a disorder where the precise causes are unknown (APA, 2000). Former etiological theories have focused on maternal rejection, childhood vaccinations, and other fallacies. Autism has increasingly come to be recognized as a biologically based, lifelong, developmental disability. Recent empirical research highlights the importance of genetic factors and early environmental insults (Folstein, 1999; Trottier, Srivastava and Walker, 1999; Larrson, et al., 2005). However, no specific biological cause or sets of causes have emerged that can account for more than a minority of cases. Overall research suggests a specific genetic finding that could be reasonably linked to the autism population has been located in approximately 10 to 40% of cases (Cohen, et al, 2005; Shen et al, 2010). Many neuropathologic and neuroimaging studies report abnormalities in certain areas of the brain, including the cerebellum, mesial temporal structures, brainstem, basal ganglia, and corpus collosum (Aylward, Minshew, Field, Sparks, and Singh, 2002). These reports also included findings of increased head circumference, increased midsagittal brain area, and increased brain volume (Akshoomoff, Pierce, and Courchesne, 2002; Aylward, Minshew, Field, Sparks, and Singh, 2002; Bartholomeusz, Courchesne, and Karns, 2002; Piven, et al, 1992).

Autism, often broadly considered as a “spectrum” of related disorders, is chronic and pervasive, thus necessitating all-encompassing management. As such, intervention is often accessed through multiple broad disciplines, including medicine, psychology/behavior analysis, and education, as well as various specific therapies (e.g.,
behavioral, speech/language, occupational, physical) often in various settings. Effective treatments largely focus on minimizing core impairments and deficits while maximizing functional independence by supporting development and learning, teaching socialization and communication skills, and reducing maladaptive behaviors (Myers, Plauche Johnson, and the Council on Children with Disabilities, 2007). Medical services can be key to identifying and managing comorbid or related conditions (e.g., seizures, metabolic disorders) and/or to providing psychopharmacological treatment for specific symptoms or behaviors. Within this complex web, parents are often central in identifying, evaluating, determining access to, locating and coordinating funding for, and continually monitoring the implementation of and effectiveness of care, especially if striving for integrated services. This task becomes increasingly complicated in the midst of a conflicting and constantly changing knowledge base regarding autism and the current fiscal reality of the high cost of effective treatment. Thus, access to services is seemingly a very important variable in determining various outcomes.

Severity of Autism

Several studies have examined the relationship between symptom severity at diagnosis and child clinical outcomes. Gabriels and colleagues (2001) completed a study in which they examined predictors of developmental outcomes in 17 children diagnosed with autism or PDD-NOS, who received generic treatment over an average of three years. Results indicated that developmental IQ scores at initial diagnosis were predictive of functioning at follow-up, and specifically, were more predictive than baseline language ability. Ben-Itzchak and Zachor (2007) examined the relationship between cognitive and socio-communication levels in 25 children with autism who were to receive intensive
behavioral intervention. Results indicated that children with higher initial cognitive
levels and fewer socio-communicative delays showed better skill acquisition for receptive
and expressive language as well as improvement in play skills. Eaves and Ho (2004)
followed forty-nine 2 year olds with suspected autism over a 3 year period. These
investigators found that younger, higher functioning children with milder autism (as
indicated by the overall Childhood Autism Rating Scale) were the most improved.

Access to services

Autism pervades all ecological domains in terms of the effects on an individual,
the family, and the broader community. The child and their families, their diagnosis and
treatment, are all encased in contexts of media and public policy. Surrounding the rapidly
developing neurobiological/neurogenetic core of autism lies the variable developmental
course and behavioral expression of the disorder, with increases in functioning and/or
decreases in impairment primarily impacted through behavioral and educational
interventions. Whether a child with this specific neurobiological disorder receives the
recommended array of interventions, however, varies based on another layer of factors
far from professional recommendations or research support. These layers include
historical and legislative precedent which often places autism treatment as “educationally
related” rather than “medically necessary”. Therefore, it becomes a question as to which
institution pays for the treatment as it is unclear if the treatment should be covered under
medical insurance or part of the educational system. It then becomes a very real
economic issue as well. Children and their families often face significant barriers such as
cost or availability of providers in accessing services across educational, medical and
behavioral services. Therefore, it is important to understand each grouping of services, accompanying legislation, and cost.

*Educational Interventions*

Outside of the general role of the education system for children, The Committee on Educational Interventions for Children with Autism of the National Research Council (2001) delineated the following principles and components of effective early interventions for children with ASD: (1) Provision of intensive intervention, 25 hours/week, year round, in systematically planned, and developmentally appropriate educational activities designed to address identified objectives, (2) Low student: teacher ratio (3) Promotion of social opportunities, social skills instruction, (4) Incorporation of structure and ongoing measurement (5) Use of assessment-based curricula, and the (6) Use of Functional Behavior Analysis. Although schooling may not officially start until the pre-school time, educational systems and school districts serve children from birth when identified with a disability of some kind (Turnbull, Wilcox, and Stowe, 2002).

Typically, early intervention services span the ages of birth through three years and the services are based in a designated state agency. Children with special needs then transition from this system to the public school system at three years of age. The Special Education Law, historically known as Individuals with Disabilities Education Improvement Act (IDEA), governs special education in the public education systems. This Law mandates that public education systems provide appropriate intervention services and educational programming, including auxiliary services, to eligible children (Turnbull, Wilcox, and Stowe, 2002). Autism is mentioned specifically in the IDEA as a condition that constitutes a disability. Notably, there is great variability by state as to
which children are eligible and what exactly constitutes “appropriate” and “effective” intervention services. According to Wise and colleagues (2010), most education programs remain untailored to a child’s specific needs. This research also found that while many states report that they offer at least some autism-specific services, including behavioral interventions, most states report using a variety of generic interventions for approximately five or fewer hours per week (Wise, et al, 2010). Given the spectrum of presentations for children with autism and the necessity of intense intervention, the education system may not in fact be providing the recommended and optimal level of services (Jensen and Cain Spannagel, 2011).

There is a disconnect between the legislation and actual implementation. Broad stroke “legalese” can create various loopholes, and quality assurance is conducted at the local level. Additionally, funding varies by state thus creating geographical disparities. It is also important to consider that if autism treatment remains situated as an “educational” issue, many health insurance companies may not be required to pay for treatment which puts the cost onto individual families. The IDEA legislation calls for “seamless” implantation within the school system yet there is nothing to require continuous treatment across a child’s ecology. The disorder is pervasive, yet there is a fiscal and responsibility disconnect.

Medical Management

In addition to general health care and prevention, children with autism may also have unique health care needs that relate to underlying etiologies such as Fragile X syndrome, Tuberous Sclerosis, specific chromosomal deletions or duplications, or other medical conditions such as epilepsy or cerebral palsy that are associated with autism.
Children with autism tend to have increased gastrointestinal problems, sleep disturbance, comorbid depression/anxiety, and maladaptive behaviors such as aggression, self-injurious behaviors, repetitive behaviors, etc (Bauman, 2010; Croen, Najjar, Ray, Lotspeich, and Bernal, 2006). Pharmacological interventions are often used to target comorbidities and/or specific maladaptive behaviors. Recent surveys indicate that although there is currently insufficient literature to establish consensus regarding evidence-based approach to pharmacological management, approximately 45% of children and adolescents are treated with psychotropic medication (Myers, et al., 2007). Overall, health care utilization and costs are substantially higher for children with autism and mortality rates are increased (Croen, et al., 2006).

Recently, national mental health parity legislation has passed which requires insurance companies to provide more generous coverage for treatment of mental illnesses, comparable to what is provided for physical illnesses. This legislation, however, does not currently guarantee coverage for autism and its treatments. While some states have passed similar “autism parity” bills, there is no required private insurance coverage for the diagnosis or treatment of autism in Ohio. The State of Ohio, through different Medicaid waivers and services, pays for certain autism services although there are long waiting lists for these waivers. Services for children ages 0-3 are covered through the Ohio Department of Health “Help Me Grow” Program and Ohio Department of Mental Retardation and Developmental Disabilities Early Intervention Services. Services for children ages 3+ and adults are delivered through ODMRDD. Limited services are covered through the Ohio Department of Health, Bureau of Services for Children with Medical Handicaps (BCMH) including services for children with
medical conditions that are “medically eligible”. That is, children with autism who have other medically eligible conditions like seizures, hearing loss, and gastrointestinal problems may be covered by BCMH. Parents can obtain a time-limited diagnostic enrollment that will pay for autism testing and assessment services, although since autism per se, is not a covered diagnosis, treatment is not included.

**Behavioral Interventions**

Applied Behavior Analysis (ABA) is the science of applying what is learned from the analysis of behavior toward the goal of meaningful change and Ivar Lovaas applied this science to children with developmental disabilities (Lovaas, 1987). Early Intensive Behavioral Intervention (EIBI) is a technically more accurate label for intensive and data-driven ABA-based intervention programs designed for young children with autism. EIBI is a coordinated, programmatic treatment for autism that is based upon the ABA principles, with specialized curriculum, techniques and instructional methods that make use of what is known about learning, behavior, and the brain.

EIBI, as provided in research and organized clinical settings, has consistently resulted in significant positive benefit for young children with autism, with increased functional skills, increased cognitive performance, and decreased autistic symptoms (New York State Department of Health Early Intervention Program 1999; Harris and Handleman, 2000). According to Lovaas (1987), nearly 50% of treated subjects achieved “near-normal” functioning, that is indistinguishable from typical peers, after 2-3 years of intervention with maintenance of gains at follow-up 7 years later. Clinical research to date supports that EIBI, specifically utilizing ABA-based intervention for 25-40 hours per week, incorporated throughout the child’s total day (New York State Department of
Health Early Intervention Program 1999; Harris and Handleman, 2000) is effective for a significant number of young children with autism and is likely more effective than community options, less intensive treatment, regular education, or the simple passage of time (Jensen and Sinclair, 2002).

Despite data demonstrating this efficacy and cost-effectiveness, EIBI for children with autism is laden with implementation barriers, including parent and professional misinformation and mistrust of behavioral technology and lack of standardization in training and service delivery (Jacobson and Mulick, 2000). This treatment is not traditionally covered by Medicaid or more private insurance carriers. As a result, the majority of children do not receive services that are empirically based and provided by appropriately trained professionals in a well-managed program that is designed in such a way as to be reasonably likely to result in successful outcome.

Differential Access and Cost

Research has shown that children with autism receive more medical and health-related services than children without autism, and more money is spent on these services (Leslie 2007; Liptak 2008). As reviewed by Liptak (2008), research has shown that children with autism often have difficulty accessing essential and appropriate services. Krauss, Gulley, Sciegaj, and Wells (2003) examined access to specialty medical care among children with mental retardation, autism, and other health care needs. Results indicated that over a third of children with autism had difficulty obtaining needed care from specialty doctors, compared with one fifth of children with mental retardation. Approximately 25% of the children with autism in this sample were reported to have had both health plan-based and provider-based access problems such as difficulty getting
referrals for services and finding specialists. Additionally, children with autism reported more difficulty with coordination and collaboration of care between specialty doctors and other providers. This difficulty proves detrimental given the pervasiveness of autism.

Gurney, McPheeters, and Davis (2005) compared parent-report prevalence of health conditions and health care use between children with and without autism using a cross-sectional analysis of the 2003 to 2004 National Survey of Children’s Health. They found that parents with a child with autism were more likely to report their child’s health as fair or poor. The results indicated that children with autism were far more likely than children without autism to receive auxiliary services such as physical, occupational, or speech therapy and these children were also found to use both behavioral and psychiatric services. On average, parents reported significantly more visits for their children with autism over 12 months for each type of physician visit than did parents of children without autism. The adjusted mean number of nonemergent care visits was 2.80 for children with autism compared with 1.56 for children without autism (Gurney, McPheeters, and Davis, 2005).

Krauss and colleagues (2003) found that parents who had primary Medicaid coverage for their children reported less difficulty accessing specialty care than those parents with private insurance. However, this finding needs to be examined in light of Ruble, Heflinger, Renfrew, and Saunders’ research (2005) indicating that between 1995 and 2000 the number of children who received services over time increased significantly, yet the rate of service use was still only one tenth of what should be expected based on prevalence rates. Furthermore, the mean number of services provided per child decreased and the range of services narrowed. Results indicated that children began receiving more
case management services and medication treatment, but that the use of other psychological or behavioral services decreased. This finding is striking given that research support for behavioral interventions as the primary, effective, treatment (Lovaas, 1987, Smith, 2001, McEachin, Smith, Lovaas, 1993). Furthermore, access does not necessarily imply effective care or improved clinical outcomes.

Liptak (2008) examined disparities in access to health services for children with autism using data from the National Survey of Children’s Health. Their work indicated economic and racial/ethnic disparities in access to and use of mental health services even when controlling for age, insurance, and parent-reported severity of symptoms. For example, Latinos and children of low socioeconomic status had more difficulty getting specialty care than non-Latinos and children from wealthier families. Also, families who rated their children’s autism as most severe had the most difficulty getting a referral to a specialist. These findings are alarming given the importance of early diagnosis (Stone, Coonrod, and Ousley, 2000). and the implementation of an intervention plan which are typically done by a specialist.

Kohler (1999) found that even when families can access care, they often find the treatment to be ineffective stating the care is “too little”, “too late”, or simply “wrong”. For example, 44% of parents complained about delay in receiving a diagnosis, 64% of parents reported that at least one service that was utilized was ineffective, and numerous families reported lack of coordination or collaboration among involved professionals.

Effective intervention programs are time and labor intensive and therefore extremely costly to implement. Using even conservative estimates of gains in functioning, however, the cost-benefit is dramatic when considering potential savings to
Given the pervasive and chronic nature of autism, the unknown etiology and the lack of “specific” medical “cure”, clinical interventions and educational programming are especially essential. Yet, the severity and complexity often leads to a difference in conceptualizing the overall care for individuals with autism, with a diffusion of responsibility and accountability in assuring access to and appropriate funding of care. The cost of financing intensive programs is a critical issue to all facets of the ecological system—individuals, families, school systems and communities. These factors, especially combined, can prove stressful for families. Thus, an important question remains: what might help parents manage and mitigate their own stress? Two
characteristics emerge in the broader literature as potentially important—hopefulness and coping.

**Hopefulness**

Snyder and colleagues (1996) defined hope as “a cognitive set involving the belief in one’s capabilities to produce workable routes to goals (the pathways component), as well as the self-related beliefs about initiating and sustaining movement toward those goals (the agency component) (p. 401).” According to this definition, hope has three components. The first component of hope involves having specific goals. The second component is pathways thinking, which pertains to a person’s belief that s/he can come up with multiple paths to reach that goal. The third component is agency, which involves a person’s beliefs that it is possible to reach his/her goal. Synder and colleagues (1991) stated that hope is guided by the perception of successful agency related to goals, and that hope is influenced by the perceived availability of successful pathways related to goals. Synder et al. (1991) have found that individuals who are more hopeful set higher goals for themselves, tend to perceive that they will be more successful at attaining these higher goals, and actually obtain these goals more often in the face of obstacles or adversity.

Hopefulness has been found to lead to lower levels of depression and anxiety (Arnau, Rosen, Finch, Rhudy, and Fortunato, 2007) and better overall mental and physical health (Magaletta and Oliver, 1999). Hopefulness has also been shown to be associated with better coping abilities and reduced burnout (Synder, et al. 1991, 1996).

Individual dispositional factors, such as hope, may explain or impact how parents react to having a child with autism. In the absence of studies of hope in parents of children with autism, related literature must be examined although the research is still
sparse. Horton and Wallander (2001) studied 111 mothers of children with Type I diabetes, spina bifida, and/or cerebral palsy. They hypothesized that maternal perceptions of hope and social support act as resilience factors against distress in mothers of children with chronic physical conditions. Their results indicated that hope was found to be negatively associated with maternal distress and hope accounted for a significant amount of the variance beyond that accounted for by the disability-related stress. In high stress conditions, mothers reporting higher levels of hope exhibit less distress than those reporting a low level of hope. Mednick and colleagues (2007) further explored hope as a potential resilience factor in mothers of children with chronic illness. The study focused on the relationship between hope and anxiety in mothers of young children with Type I diabetes. Results indicated that mothers reporting high levels of hope reported lower levels of anxiety.

Horton and Wallander (2001) as well as Mednick and colleagues’ (2007) findings are consistent with research indicating that individuals reporting higher levels of hope are more adaptive and better able to cope with distress when compared to individuals reporting lower levels of hope. Additionally, it appears that hopefulness may serve as a protective factor against psychological distress in mothers who care for children with chronic health conditions.

Familial Coping and Stress

According to a review by Blount and colleagues (2007), stress and coping are often studied in relation to one another. Stress can be defined as the balance between external environmental demands and the perceived internal ability to respond (Raina et
al., 2005). Stress can take on many forms such as the observable distressing event (e.g. chronic illness) and subjective dimensions (e.g. perceived threat) (Blount et al., 2007).

Families most certainly experience stress when caring for a child with chronic illness or disability, and the family can be negatively affected (Sobsey, 2004; Tunali and Powers, 2002).

The life-time management of a child with autism ideally involves complementary relationships among multiple service providers and the child’s family. Given this need, the symptomatology of autism, and the pervasiveness of the disorder, the family often feels the fiscal and emotional impact of autism. The emotional and social stresses can result in deprivations in other family relationships and activities. Breakdowns in communication can occur within immediate family members and between extended family. There is often inadequate time for leisure activities and far less energy for marital relationships with a resulting high divorce rate among parents (Sobsey, 2004; Luther, Canham, and Cureton, 2005).

Caregiver stress may be modified by certain characteristics of the caregiver such as age, marital status, and coping ability (Luther, Canham, and Cureton, 2005). The child’s symptom presentation and severity may also impact the caregivers’ stress (Raina, 2005). Economic factors such as social economic status and access to care (Jarbink, Fombonne, and Knapp, 2003) also influence parenting outcomes. Keller and Honig (2004) examined stress factors in families with a school-aged child with a disability and found that overall parents scored in the 90th percentile on the child domain of the parenting stress scale indicating that child characteristics were major contributors to overall stress in the parent-child relationship. Family demographics have been linked to
stress outcomes for families of children with disabilities (Keller and Honig, 2004) in that low socioeconomic status families may be less likely to receive family support, and may experience increased stress and emotional problems in raising children with disabilities than high socioeconomic status families. Jarbrink, Fombonne, and Knapp (2003) estimated that the cost of raising a child with a disability is approximately three times greater than the cost of raising a nondisabled child. The mere nature of autism—poor social reciprocity, language delays/impairments, and atypical behaviors—can in itself be stressful. Thus, as research suggests (Tunali and Powers, 2002; Luther, Canham, and Cureton, 2005; Sounders, DePaul, Freeman, and Levy, 2002) parenting a child with autism can be more stressful than parenting a typical child or a child with another type of developmental delay or chronic illness.

Estes and colleagues (2009) investigated parenting stress and psychological functioning among mothers of preschool children with autism and developmental delay. Specifically, they examined how child characteristics influenced maternal parenting stress and psychological distress. Mothers of children with autism demonstrated higher mean levels of parenting stress and psychological distress than the comparison mothers, particularly for mothers who reported high levels of child problem behaviors.

Research studies have shown the psychosocial effects of autism for the family. For example, Gray and Holden (1992) found high levels of emotional distress for parents of children with autism including significantly higher rates of depression, anxiety, and anger. Also, parents reported career problems including the lack of opportunity for outside employment for mothers. In examining longitudinal data, Gray (2002) found that while reported levels of distress were less after 10 years, over half the parents still
reported significant amounts of depression and anxiety, and approximately a third were receiving psychotherapy or pharmacological treatment themselves in attempts to cope with the situation.

There is some evidence to suggest that parenting stress reduces the effectiveness of interventions for children with autism. Using a community-based sample of 65 children with autism, Osbourne, McHugh, Saunders, and Reed (2008) examined the contribution of parental stress on the intervention outcomes for children with autism. Overall, the study indicated the effectiveness of an early teaching intervention for children with autism. Children demonstrated gains in intellectual, educational, and adaptive behavioral and social skills especially for the children who received more time-intensive interventions. However, results demonstrated that the effects were negatively impacted by high levels of parenting stress especially for time-intensive interventions. Early teaching interventions produced fewer gains when parents reported higher levels of stress, suggesting a relationship between parent stress and child outcomes. The investigators posited that parenting stress may influence parenting style and the implementation of the home intervention. Other coping strategies were reported such as religion, social support, and various hobbies.

From a risk and resiliency framework, stress increases risk for adverse outcomes while effective coping functions as a mitigating effect on negative outcomes and can potentially promote growth (McCubbin, 1987). Research has asserted that many families positively cope and adapt to stress. Coping can be defined as a dynamic process that changes in response to the ongoing demands of the stressor (Blount, et al., 2007). Jones and Passey (2005) explored the impact of the level of coping resources and
strategies on parental stress using a sample of primary caregivers of children with developmental delays and behavior problems. Results showed that coping strategies involving the maintenance of family cohesion was strongly associated with reduced stress. Bristol (1987) found that coping was related to healthier adaptation. Coping can be influenced by interpersonal and environmental factors. According to McCubbin and colleagues’ Resiliency Model of Family Stress (1997), families that adapt successfully tend to have traits of resiliency, good coping skills, and informal and formal social support from the community.

Tunali and Powers (2002) found that the beliefs and attitudes of mother of a child with autism are related to successful coping. Mothers who coped more successfully reported cognitive and lifestyle changes that emphasized their role as caregivers more so than focusing on their careers. These mothers also reportedly placed less importance on others’ opinions of their child’s behaviors and reported a higher tolerance for the uncertainty regarding their child’s progress and outcome.

Stress Related Growth

Caring for a child with autism is often lifelong with potential additive and chronic stresses. This extensive process can lead to effects of chronic stress. While there is documentation of the negative effects of caregiving stress (Keller and Honig, 2004), recent efforts have highlighted the potential positive effects of this caregiving process.

Dealing with stress and trauma can provide a person with information regarding themselves and innate abilities, a changed sense of relationships with others, and a changed philosophy on life (Tedeschi and Calhoun, 1996). Linley and Joseph (2004) who refer to this phenomenon as, “adversarial growth” state that the process of struggling
through adversity may result in changes that propel the individual to a higher level of
functioning than that which existed prior to the event. This stress-related growth
paradigm involves coping styles, belief systems and cognitive mechanisms, and social
support systems.

Park and Fenster (2004) have conjectured that stress-related growth can occur in
three ways. One, growth can result from the individual reconstructing a personal
worldview to incorporate the knowledge gained from experiencing the stressor. Two,
stress-related growth can be achieved through cognitive processing, or meaning-making.
Thus, instead of reconstructing an entire worldview, the individual revises their existing
schema to include information about the stressful experience. With chronic stress, the
individual may gradually integrate new information into a pre-existing world view.
Three, Park and Fenster (2004) hypothesized that individuals achieve stress-related
growth through conscious coping processes such as religious participation (Tedeschi and
Calhoun, 1996), personal resources, and cognitive appraisals. Such mechanisms may act
as mediators between the stressful life experience and outcomes. Aldwin (1994) has
postulated that stress-related growth can occur as a result of gaining mastery and the
improvement of social bonds. Stressful experience can lead to an increase in positive
personal traits or positive interpersonal change that increases overall resiliency and
coping ability (McCallum and Yarry, in press).

Very few studies examine stress-related growth in parents of children with
disabilities. King and Patterson (2000) conducted a study in which parents of children
with Down Syndrome wrote about current goals and goals they had before they learned
their child had Down Syndrome. These parents completed measures of salience of the
narrative subjective-well-being and stress-related growth. Results demonstrated a positive relationship between investment in current goals and higher levels of stress-related growth. Two years later investigators reexamined the parents’ subjective well-being and stress-related growth, and found an association between investing in “lost goals” and increased stress-related growth. That is, the degree to which individuals were able to explore and think about their previously cherished life goals correlated with reported experienced growth. King and Patterson articulated that perhaps individuals who have the capacity to admit to the legitimate loss may be more likely to report experiencing growth than are those individuals who do not acknowledge such loss, suggesting that considering loss and lost goals may be related to feelings of personal growth. The investigators noted that that the passage of time may be necessary for the individual to feel this growth as it may not occur concurrently with the actual loss.

Singer and colleagues (2010) evaluated longitudinal outcomes and factors affecting parental stress and coping in mothers of high-risk low-birth weight children with bronchopulmonary dysplasia. These investigators compared three groups—high-risk very low birth weight children with bronchopulmonary dysplasia, low risk very low birth weight children with bronchopulmonary dysplasia, and term infants over a 14 year period. While isolating factors of social support, findings were congruent with above mentioned studies in regards to parental stress. Findings indicated that mothers of high-risk very low birth weight children reported more personal stress, more child-related stress, and more family-related stress when compared to term mothers. Interestingly, despite greater perceived stress, mothers of these children also reported higher levels of parenting satisfaction at 14 years. Singer and colleagues states that these results suggest
that mothers experience posttraumatic growth and resilience after significant distress early on (Singer, et al, 2010).

Summary and Hypotheses

Research has consistently demonstrated that parenting a child with autism can lead to increased perceived parental stress (Konstantareas, 1991; Hastings, 2002; Sounders, DePaul, Freeman, and Levy, 2002; Tunali and Powers, 2002; Luther, Canham, and Cureton, 2005;), potentially arising from a number of factors such as child’s autism severity and/or the difficulty accessing essential services. There may also exist a complex pattern of interaction among these variables. It is possible that a parental coping and/or their level of hopefulness mitigate this stress in some way. Further, some parents may demonstrate personal growth through parenting a child with a pervasive and chronic condition such as autism. As the literature has shown the negative impact of parenting stress on child outcomes, parental hopefulness and coping may not only influence level of parenting stress but, in turn, influence the child’s functioning.

The current study investigated several questions: (1) Is symptom severity at diagnosis associated with parenting stress? 2) Is access to services related to child clinical outcomes, parenting stress, and parental stress-related growth? 3) Do hopefulness and coping function as mediators of these relationships?

It was hypothesized that symptom severity would be significantly positively related to parenting stress. Met service needs would also be significantly related to current ratings of severity and improvement. Additionally, met service needs would be significantly negatively related to parenting stress and significantly positively related to
stress-related growth. It was also hypothesized that coping ability and hopefulness mediate these relationships. See Figure 1.

Method

Participants

Participants were thirty-eight parents of children who had been previously diagnosed with autism (32 biological mothers, 6 biological fathers). Participants were selected from a pool of 635 children from a registry with children who were diagnosed with an autism spectrum disorder.

Inclusion criteria were as follows: children who were diagnosed at least six months prior but within the last five years; the sample included only children currently under twelve years of age due to measurement constraints; children had to have a Childhood Autism Rating Scale (CARS) available; and only children undergoing an initial diagnostic evaluation were utilized (i.e., children who were previously diagnosed with autism and seeking a second opinion were excluded). Once inclusion criteria were applied, 165 children were eligible for this study.

The registry was initially established in order to follow patients that have an active diagnosis of autism and/or other pervasive developmental disorders. Registry information is used to identify trends in diagnosis, symptom presentation, and development of autistic spectrum disorders within this patient group. All children in the registry were diagnosed by the same expert pediatric psychologist in autism using similar diagnostic procedures and criteria. As part of the assessment, the Childhood Autism Rating Scale (CARS) was used to determine if the child met diagnostic criteria for autism and to obtain a level of severity. The following information was drawn from the registry for this study: demographic information (e.g. date at diagnosis, date of birth, sex), total
CARS score, Full Scale IQ if available (IQ was either established at time of diagnosis or provided from outside source. Very few children had the IQ at baseline (N=5), therefore IQ was not controlled for in analyses.

Consistent with approved IRB protocol, parents were contacted by mail or email and invited to participate through patient letter and waiver of consent materials. Of the 165 parents contacted, the investigator was notified that only 120 participants had current mailing addresses and were actually obtainable (i.e., 45 families did not have current contact information on file at The Cleveland Clinic). Therefore, from the pool of 120 contacted parents, 38 parents participated which yielded a participation rate of 32%. Each parent was asked to complete the survey for the child specified on the mailing, resulting in 38 parents reporting on one child each. Consenting participants either completed the survey online (N=36) or through mailed forms (N=2).

The mean age for parents was 38 years of age (SD= 8.07) and the mean age for the children was 7 years of age (SD=2.6). The sample included parents of 34 boys and 4 girls. The racial-ethnic composition of the sample was as follows: 92% Caucasian, 3% African American, and 3% as multiracial, and 2% self-identified as other. Seventy-six of the parents reported being currently married to the child’s biological parent and 50% reported having at least a college education. Eighty-two percent of parents reported private insurance coverage with the remaining 18% reporting Medicaid coverage. Current diagnoses of children were as follows: 58% Autism, 16% Asperger, 16% PDDNOS. Median household income was $60,000. Of the participating parents, 21 of their children were categorized as having mild-moderate symptomatology at baseline and 17 were categorized as having severe symptomatology at baseline. There were no significant
differences between those parents who participated and those parents who chose not to participate on the CARS scores or time since diagnosis (M=2.89 years and M=3.02 years, respectively).

For this study, power analyses indicate that to detect a significant effect an appropriate sample should include 116 participants. The current sample is small, and results should therefore be interpreted with caution.

**Procedure**

Parents completed relevant measures either online (N=36) or by mail (N=2). Study data was collected and managed using Research Electronic Data Capture ([REDCap], Harris et al., 2009). REDCap is a secure, web application designed to support data capture for research studies, providing user-friendly web-based case report forms, real-time data entry validation (e.g. for data types and range checks), audit trails and a de-identified data export mechanism to common statistical packages (e.g. SPSS). The system was developed by a multi-institutional consortium which includes Cleveland Clinic and was initiated at Vanderbilt University. The database is hosted at the Cleveland Clinic Research Datacenter and managed by Quantitative Health Sciences. The system is protected behind a login and Secure Sockets Layer (SSL) encryption. Data collection is customized for each study or clinical trial based on a study-specific data dictionary defined by the research team with guidance from the REDCap administrator in Quantitative Health Sciences at the Cleveland Clinic.

The protocol included: the modified Family Support Index (Heller and Factor, 1993), Parenting Stress Index-SF, (Abidin, 1995), Stress Related Growth Scale (Park et al., 2006), Adult Trait Hope Scale (Synder et al., 1991), and the Coping Health Inventory
for Parents (McCubbin et al., 1983), and The Ohio Autism Clinical Impression Scale (Butter and Mulik, 2006). Parents reported that the survey took approximately one half hour to complete. See Figure 1 for overall model and Table 1 for measures and scores.

Measures

Predictors

Autism Severity

Children’s Autism Rating Scale (CARS). The CARS (Schopler, Reichler, and Ro, 1993) is designed for clinicians to recognize and classify children with autism. After observing the child and examining relevant information from parent reports and other records, the clinician rates the child on each item covering a particular characteristic, ability, or behavior. Using a 7 point scale, the clinician indicates the degree to which the child’s behavior deviates from that of a typical child of the same age. After the child has been rated on each of the 15 items, a total score is computed by summing the individual ratings. Children who score above a given point are considered as showing symptoms consistent with autism. In addition, scores falling within the autistic range can be divided into two categories—mild to moderate autism and severe autism. Scores from 30 to 36 indicate mild to moderate autism, scores between 37 and 60 indicate severe autism. The CARS is typically utilized as a component of a larger diagnostic battery and can be used to assess the level of severity. For the purpose of this study, the CARS was the only measured used to establish symptom severity of children at baseline.

Most studies report acceptable internal consistency with alpha coefficients often at or exceeding .85 and a test-retest coefficient of .88 on a child sample evaluated twice within one year (Saemundsen et al., 2003; Sturmey, Matson, and Sevin, 1992). Interrater
agreement data are less favorable with Pearson correlations for the Total Score at or below .71 (Schopler et al., 1988).

Several studies reported data attesting to the CARS’ validity. Data generally support the CARS ability to discriminate between autistic and non-autistic samples (Eaves and Milner, 1993; Sponheim, 1996). Although data are mixed as to whether the CARS can accurately discriminate among the ASDs (Nordin et al., 1998; Sponheim, 1996), the instrument correlates with clinician ratings and clinical classifications based on DSM-IV criteria (Schopler et al., 1988; Sponheim, 1996). Pilowsky, Yirmiya, Shulman, and Dover (1998) reported 91.8% agreement in diagnostic classification for positive cases of autism and 44.4% agreement for negative cases, with an overall kappa of .36. Saemundsen et al (2003) reported strong relationships between the CARS and Autism Diagnostic Interview-Revised subscales. Most diagnostic classification studies support the CARS’ utility in diagnostic decision-making.

Access to Services

*Family Support Index.* The Family Support Index (Heller and Factor, 1993; Heller, Miller, and Hsieh, 1999, Caldwell and Heller, 2007) is comprised of a list of 28 common types of services used by individuals with disabilities. For this study, the investigator modified a version of this measure to identify access to services and usage patterns for families with autism. Questions focused on whether or not families used each service and who provided the services. If they were not using the service, parents were then asked if they perceived a need for the service or not. Barriers to treatment (e.g., cost, lack of providers) were also assessed. Met and unmet service needs for each service are totaled.
The FSI was developed in order to measure support and service use for families with members with developmental disabilities. This measure appears to be the only published self-report measure addressing these issues. Heller, Miller, Hsieh (1999) utilized this measure to examine the impact of a consumer-directed family support program on family caregivers and their relatives with a developmental disability. Caldwell and Heller (2007) used the Family Support Index to investigate the longitudinal outcomes of the consumer-directed program. Both studies reported that the measure adequately captured service use and level of satisfaction.

Outcome Criteria

Child Clinical Functioning

*The Ohio Autism Clinical Impressions Scale* (OACIS; Butter and Mulik, 2006)

The OACIS is a 20-item, clinician or teacher completed measure based upon interview and/or observation that rates both current severity and improvement. Initial findings suggest that the OACIS has strong internal and test-retest reliability, though inter-rater reliability is only moderately strong. Research indicated both convergent and divergent validity, and this measure has evidence as a measure of improvement related to an empirically validated treatment. The OACIS is currently being used in five studies across the country and it was recently adopted by the Autism Speaks Autism Treatment Network’s recommended treatment measures (Butter and Mulik, 2011). It should be noted that while parents completed this measure for our study, there are no validation studies in which parents are the raters.

The OACIS is an efficient, brief measure of the core symptoms of autism that would be sensitive to intervention effects, both pharmacological and psychosocial. The
OACIS was based upon the structure and format of the widely used Clinical Global Impressions (CGI) scale (Guy 1976). While the CGI is a “global” impressions scale, the OACIS was designed to be a measure of “specific symptom” impressions regarding social interaction, aberrant behaviors, repetitive behaviors, verbal communication, nonverbal communication, hyperactivity, anxiety, sensory sensitivity, and restricted, narrow interests.

Each of 9 items on the OACIS represents a rating of the severity of a specific symptom associated with Autism Spectrum Disorders, while 1 item is a global rating of autism severity. Each item is rated on a 7-point scale, with higher numbers representing greater symptom severity. The OACIS also has an improvement scale in which raters indicate improvement across each domain using the same scaling as the severity scale. For this study, the severity and improvement scales were used.

Parenting Stress

Parenting Stress Index-Short Form. The PSI-SF (Abidin, 1995) is a tool designed to determine the amount of stress in the parent-child system. The PSI-Short Form is a direct derivative of the Parenting Stress Index (PSI) full-length test. All 36 items on the Short Form are contained on the Long Form with identical wording for parents of children 12 years and younger. The PSI-SF yields a Total Stress score from three scales: parental distress, parent-child dysfunctional interaction, and difficult child. The questionnaire uses a Likert scale ranging from strongly agree to strongly disagree. Higher scores indicate a higher amount of stress. For the purpose of this study, the total stress score was utilized.
According to Reitman, Currier, and Stickle (2002), internal consistencies for the PSI-SF were very good to excellent. The PSI-SF Difficult Child subscale was most strongly associated with a measure of child oppositionality, and the Parental Distress subscale was most highly associated with self-reported psychological symptoms and low income. Parent-Child Dysfunctional Interaction was associated with parent reports of psychological symptoms as well as low income and education. Haskett, Ahern, Ward, and Allaire (2006) found that the measure was correlated with measures of parent psychopathology, parental perceptions of child adjustment, and observed parent and child behavior. According to Abidin (1995), while the PSI-SF has not been as utilized as the PSI due to its more recent development, it is believed that it shares the same validity of the full-length PSI because it is a direct derivative of the full-length PSI, a well-developed and widely used measure of parenting stress. Numerous studies have shown a strong factor structure and strong validity (Haskett, 2006; McKelvey, 2009).

Stress Related Growth.

Stress Related Growth Scale. The Stress-related Growth Scale (Park et al., 1996) consists of 50 items which assesses positive changes that the respondent has experienced because of or following a particular stressor. Each item is scored as a 0 (not at all), 1 (somewhat), and 2 (a great deal). A total SRGS score is calculated. The SRGS has demonstrated good internal consistency (r=.88) and test-retest reliabilities. According to Part et al. 1996, the SRGS was positively related to residual change in optimism, positive affectivity, number of socially supportive others, and social support satisfaction.

Roesch, Rowley, and Vaughn (2004) have concluded that stress related growth, as measured by the SRGS, is best conceptualized as a multidimensional construct. The three
factor model is comprised of the following: rational/mature thinking, affective/emotional
growth, and religious spiritual growth. The total SRGS score was used for this study.

**Mediators**

**Hopefulness**

*The Adult Trait Hope Scale.* The Hope Scale was developed and validated by
The four pathway items reflect cognitive appraisals of one’s ability to generate routes for
reaching goals under both unimpeded and impeded circumstances. The four agency items
aim to tap the sense of motivational determination in using one’s pathways to desired
goals. The Hope Scale has consistently demonstrated acceptable internal consistencies
($r=.74$ and .88) across several studies and reliable test-retest reliabilities over 3-, 8- and
10-week intervals ($r=.73$ to .85; Synder et al., 1991). Convergent validity has been
documented as the Hope Scale has been predictive of goal-related activities and coping
strategies beyond other self-report measures (Synder et al., 1991). For the purpose of this
study, a total hopefulness score was utilized.

**Coping**

*The Coping Health Inventory for Parents.* The Coping Health Inventory (CHIP;
McCubbin et al., 1983) is a parent self-report inventory including 45 specific behaviors in
which one might engage to cope with having a child with a serious illness. There are 3
coping factors: 1) family integration, cooperation and optimistic definition of the
situation, 2) maintaining social support, self-esteem, and psychological stability 3)
understanding the health care situation through communication with other parents and
consultation with the health care team. According to McCubbin 1983, the scale has the
following internal consistencies: Subscale \(= .79\), Subscale 2\(= .79\), and Subscale 3\(= .71\).

This measure has been used with parents of children with various serious illnesses (Alderfer, et al., 2007). For the purpose of this study, the total CHIP score was used with a higher CHIP total score indicating more “helpful coping”.

As mentioned earlier, Full-Scale IQs were not available for the majority of the children so therefore it could not be analyzed or controlled for. Amount of time since diagnosis and child age were calculated and used as covariates in the analyses.

**Specific Hypotheses**

(See Table 1 for measures and specific scores)

*It was hypothesized that:*

1. autism severity at diagnosis (CARS) would be significantly positively related to parenting stress on the Parenting Stress Index-SF.

2. met service needs (FSI) would be significantly related to outcome scores.
   a. Specifically, met service needs would be significantly negatively related to the OACIS current severity scores.
   b. met service needs would be significantly positively related to current improvement scores on the OACIS.
   c. met service needs would be significantly negatively related to parenting stress.
   d. met service needs would be significantly positively related to stress-related growth (SRG).

3. hopefulness (Adult Trait Hope Scale) would mediate the relationships between predictors and outcomes.
a. Specifically, hopefulness would mediate the relationship between met service needs and stress-related growth.

b. hopefulness would function as a mediator between severity at diagnosis and improvement ratings.

c. hopefulness would mediate the relationship between autism severity and parenting stress.

4. coping would mediate the relationships between predictors and outcomes.

   a. coping would mediate the relationship between unmet service needs and parenting stress. Coping would mediate the relationship between unmet service needs and stress-related growth.

   b. coping would also mediate the relationship between severity at diagnosis and parenting stress.

Results

Descriptive Statistics and Missing Data

Preliminary analyses included descriptive statistics (including skewness and kurtosis) and graphical examination of distributions for outliers (histograms, box and whisker plots) to evaluate the assumptions for correlation and regression analyses. Means and standard deviations were obtained (see Table 2). These means did not significantly depart from normal distribution and clinical populations. Skewness and kurtosis were used to determine that distributions did not depart substantially from an approximately normal distribution and from clinical populations. Minimum and maximum values of each variable were obtained in order to confirm that these values were within the possible
range of scores. It is important to interpret the results below with caution given the small sample size and low power.

There was a very small amount of missing data throughout the overall sample of 38 participants. Although the datum missing appeared to be random, dummy codes were created to indicate the presence or absence of data, and correlations between variables and missing data indicators were analyzed for patterns or associations with demographics, diagnosis, or other key outcome variables. Analyses (e.g. Chi-square, t-test) revealed no statistically significant relationships between variables and missing data, suggesting that the data were missing at random. Additionally, primary analyses were initially conducted with missing data excluded listwise, which provides less bias than pairwise deletion and is a recommended approach if the actual amount of data missing is small (Allison, 2002). Missing data was then substituted by the procedures listed below and the results remained unchanged. Therefore, in order to utilize all participant responses given the small sample, all statistical analyses were run on all participants data which included substitutions when necessary.

Missing data was handled via the recommended procedure for the specific measures. For the Adult Hope Trait Scale, Parenting Stress Index-Short Form, and the Stress Related Growth, scores were calculated if not more than one item is missing from any subscale. When that criterion was met, the missing data convention was to a) identify the subscale from which the item was missing; b) compute the average score for the completed items within the subscale and round the average to the nearest whole number; and c) and sum the subscale score as directed.

*Primary Analyses*
Spearman Rank Order Correlations ($r, \rho$) were used to determine the linear association among variables. Because there were strong directional predictions, significance was compared to an alpha level of $p < .05$, one-tailed. See Table 3 for correlations.

First, we examined the relationship between autism severity at baseline and parenting stress. Autism severity at baseline (as measured by the CARS) was not significantly related to parenting stress (PSI-SF) at outcome ($r(38)=.03$). Autism severity did not correlate with any other studied variable except current severity ($r(38)=.36$) and improvement ($r(38)=-.34$) on the OACIS. That is, the children with more autism severe symptomatology at baseline showed less improvement at outcome.

Second, we examined the relationship between service needs (as measured by the FSI) and outcome measures. As hypothesized, met service needs was significantly negatively related to stress ($r(38)=-.60, p<.01$) and was significantly positively related to stress-related growth ($r(38)=.30$). These results demonstrated that parents who reported that their child’s needs were being met were reporting less stress than those families who reported lower levels of met needs. Also, these families reported more stress-related growth. Additionally, met service needs was significantly negatively related to current severity level ($r(38)=-.40$). That is, parents who reported more met needs for their child also reported less severe autistic symptom presentation at present.

Third, we examined the relationship between our mediators and other variables. Coping was significantly positively related to met service needs ($r(38)=.48, p<.01$). Coping was significantly negatively related to parenting stress ($r(38)=-.43, p<.01$) and significantly positively related to stress related growth ($r(38)=.34$). That is, parents who
reported helpful coping reported more met needs, less stress, and more stress-related growth. Our second proposed mediator, hopefulness, was not significantly related to any variables. Therefore, only mediation hypotheses involving coping as a variable were conducted and presented below.

Fourth, we examined the relationships among our outcome variables. Parenting stress was significantly positively related to current severity ($r(38)=.68, p<.01$). Results therefore suggest that the more severe autism presentation relates to higher levels of perceived stress. Therefore, it should be noted that partial correlations, controlling for current severity, were conducted on all significant relationships involving parenting stress, coping, and service needs. In doing this, relationships remained significant. Thus, it appears that coping and met service needs are important variables for parent outcomes, regardless of current severity levels.

The above correlations represent moderate to large effect sizes (Cohen, 1988).

*Linear Regression*

As outlined by Baron and Kenny (1986), multiple regression analyses were used to assess the predictive power of the two main predictors (autism severity and unmet service needs) and to test whether coping is functioning as a mediator for hypothesized relationships.

If significant relationships were established between the predictor and outcome variables as outlined above, significant relationships were also found between the predictor variables and the mediators as outlined above, and significant relationships were also found between the proposed mediator variables and the dependent variables, multiple regression analyses were then also used to investigate whether coping was
functioning as a mediator. These conditions were tested using three multiple regression analyses for each mediation hypotheses. The significance of the relationship between the predictor and the mediator was examined in the first regression. The significance of the predictors and the outcome variables were examined in the second regression, while not controlling for the specified mediator. The third regression equation tested the relationship between the independent variables and the mediator as predictors of the outcome. Baron and Kenny (1986) recommend simultaneous entry in this third equation. The Sobell Formula was used to estimate any indirect effects (Holmbeck, 1997; Mackinnon, et al., 2002; Mackinnon, Fairchild, and Fritz, 2007).

Because coping demonstrated a robust pattern of relationships with service needs parenting stress and stress-related growth, we computed regression analyses to determine its contribution and to evaluate its role as a mediator. For all analyses, including coping in the model failed to change the significance of met service needs as a predictor of parenting stress or stress-related growth. See Tables 4 and 5 for raw regression weights, standard errors, and associated tests of significance. These findings may be an artifact of low power for such statistical analyses.

While these regression models did not indicate that coping was functioning as a mediator or that coping was a significant predictor of these outcome variables, we did examine the amount of unique variance accounted for by these models. In multiple regression equation, when both unmet service needs and coping are entered as independent variables, they account for 41% ($R^2=.41, p<.01$) of the variance when predicting parenting stress.

Secondary Analyses
Spearman rho correlations (significance was compared to an alpha level of \( p < .05 \), two-tailed) were used to determine if the time passed since initial evaluation or the current age of the child were related to any variables. Results indicated that neither time nor current age were significantly related to any variable and therefore they were not investigated further.

We explored the relationships among our descriptive variables (e.g. race, income, insurance status) and the other main variables. Results indicated that current reported income was significantly positively related to met service needs \((r(38)=.50)\). That is, parents reporting higher household incomes reported more met service needs. Interestingly, insurance coverage was not significantly related to any variable. Having another child with developmental disability was significantly negatively related to coping \((r(38)= -.37, \ p<.01)\). It is important to note that above mentioned correlations were not altered when controlling for reported income or having another child with a developmental disability.

Several measures (e.g. Adult Hope Trait Scale, CHIP, SRG, PSI-SF) have subscales. Other primary analyses used only main scores, spearman rho correlations were used to analyze any relationships between the subscales and other variables. No significant relationships were found.

Discussion

This study investigated three main questions: (1) Is symptom severity at diagnosis associated with parenting stress? 2) Is access to services related to child clinical outcomes, parenting stress, and parental stress-related growth? 3) Do hopefulness and coping function as mediators of these relationships? Results from this study indicated
that autism severity at time of diagnosis was not related to parenting stress. Met services needs emerged as an important predictor in that it was related to parental coping, less stress, and more stress related growth. Coping was related to several variables, such as parenting stress and stress related growth, but it did not appear to function as a mediator. Hopefulness was not significantly related to any variable.

**Autism Severity**

It was hypothesized that severity of autism at baseline would be related to more parenting stress at outcome, however, results did not indicate any relationship between these variables. Interestingly, while baseline severity was not related to parenting stress, current severity was significantly positively related to parenting stress. That is, the more severe autism presentation at outcome was related to higher levels of perceived stress. It is possible that the importance of service access is at play here, mitigating the stress resulting from baseline severity in some way, making current severity a more important factor. Access to services appears to be significantly related to parenting stress. It appears that the current emotional, social, and fiscal stressors may be playing a bigger part of parenting stress than severity at baseline.

**Service Needs**

Families often face numerous barriers in accessing timely and effective services to address the broad spectrum of autism. Results from this study indicated that parents who could actually access services, reporting more met needs for their child, also reported less severe autism symptomatology at present. Children accessing services appears to be related to better child outcomes. This crucial finding speaks to the
importance of families accessing services across delivery systems (e.g., schools, medical settings, behavioral interventions).

Results also indicated that met service needs was significantly negatively related to stress and significantly positively related to coping. These findings indicate that parents who obtain essential services experience less stress. In addition, these results demonstrated that parents who reported that their child’s needs were being met perceived their coping strategies were helpful.

It is possible that the act of coordinating services is inherently stressful but actually obtaining services results in lower stress. The coordination of services may be in itself an active coping behavior. Furthermore, met service needs was significantly negatively related to current autism severity. It makes logical and theoretical sense that decreased symptom severity would be related to decreased stress and perhaps makes psychological resources more available for parental coping. These findings highlight the importance of accessing appropriate services for both children and their parents.

Parents who were reporting met service needs were also reporting stress-related growth. This finding is particularly important as this study was the first to examine stress-related growth with this population. The sample size was too small to determine by which mechanism the growth was occurring—by reconstructing world view, meaning making, or conscious coping processes. From clinical experience with these families and the demonstrated role of coping with this sample, it is conjectured that conscious coping such as joining parent groups or seeking religious support, may be promoting this stress-related growth. Parents may be finding gratification, purpose, and growth in their advocacy efforts to obtain essential services, and this may result in positive feelings of
self-efficacy. This finding is consistent with Singer and colleagues research with the low birth weight population which found that despite initial stress, parents reported stress-related growth over time (Singer, 2010). As stress-related growth was significantly positively related to coping in this current study, coping may play an integral role in mitigating the stress in obtaining services and actually promote feelings of growth and satisfaction in this process.

While multiple regression analyses did not indicate that coping was functioning as a mediator, perhaps due to measurement and/or power issues, coping did emerge as a very important variable in this study. Parents who reported helpful coping strategies were reporting decreased stress. This finding is important especially given the research that demonstrates that stress can be related to decreased treatment effects and lack of improvement for the child with autism (Osbourne, McHugh, Saunders, and Reed 2008). Parents reporting helpful coping also appear to be reporting higher levels of stress-related growth from their parenting experience. These findings underscore the clinical importance of focusing on coping and parental gains in the course of treatment. In doing so, targeting these factors could work to improve the psychological well-being of the parent and also lead to increased gains for the child. Given the interrelatedness of these variables, family functioning and course of the disorder could be positively impacted.

Hopefulness

It was hypothesized that hopefulness would function as a mediator between autism severity at baseline and parenting stress, and would also mediate the relationship between met service needs and stress-related growth. Results were that hopefulness did not relate to any variable, obviating its potential to function as a mediator. The absence
of relationships with hopefulness is in itself an interesting finding. While it is possible that there were problems with the measure, means and standard deviations for hopefulness as measured by the Adult Trait Hope Scale were comparable to that of the college population on which the measure was normed. Synder et al (1996) conceptualized hope as both a ‘state’ and a ‘trait’. It is possible that hopefulness as a trait is not exceptionally important for these parents of children with autism; perhaps, hopefulness as a ‘state’ may be more important in the same way that current severity level was related to parenting stress more so than initial severity level.

Limitations and Future Directions

Some limitations with this study should be noted. These results are based on a small sample size and power was limited. Because we computed a large number of correlations, interpretations should be made with some caution. As only correlational analyses were used, data is suggestive of relationships among these variables and does not imply causation. It should be noted, however, that significant findings formed a consistent pattern as hypothesized and effect sizes were medium to large. Given the findings and the importance of this research, efforts should focus on increasing the sample size for future research.

Method variance, that is variance attributed to the measurement method rather than the constructs of interest, may have caused systematic measurement error and further bias the estimates of the true relationship among theoretical constructs. Method variance could have either inflated or deflated observed relationships between constructs, thus leading to both Type I and Type II errors. Because the majority of the measures were
completed by parents, method variance could account for some of the relationships among the met services, parenting stress, coping, and stress-related growth measures.

Outside of autism severity level at baseline, all measures were completed by parents. Using only parent-report is a main limitation to this study especially for the OACIS which was validated for clinician and teacher ratings but not for parents. It is possible that parents are inaccurate reporters for child’s current severity and improvement. Future studies should use clinician-ratings of current severity and improvement.

Other potential measurement issues should also be addressed. Initial diagnosis was based on only one clinician’s diagnosis which included their individual ratings on the CARS as well as other assessment methods. There were no inter-reliability data on the specific CARS score at baseline or to confirm the overall diagnosis of autism. Also, the Family Support Index was modified to assess the needs for this specific autism population and thus validity could have been affected.

As the CHIP measure assesses current coping strategies and their perceived helpfulness, future research may utilize additional coping measures such as the COPE (Carver, Scheier, and Weintraub, 1989) to better understand different facets of coping. As conjectured above, state hopefulness may be a more salient construct for these parents so utilizing Synder’s ‘state’ hopefulness measure (Synder, et al, 1996) may yield different results. Given lack of results in this study for hopefulness, but the interest in parent’s hopefulness when dealing with treatment barriers with a chronic condition like autism and the importance of hopefulness in other studies, other ways to study this variable may be warranted.
Although there were no significant differences for CARS scores or time since diagnosis between those contacted individuals who participated in this study and those who chose not to participate, it is possible that there is some volunteer bias. It is possible that the participating parents were more motivated to participate. Also, the participants could have differed based on marital status, socioeconomic and insurance coverage factors, or available support networks allowing time to complete this survey.

In the future, in addition to these potential methodological changes, completing this study at a different time point may impact results. The country’s health care policy has changed significantly from the conception of the project to present and will continue to evolve as mental health parity, autism specific parity, a socialized health care, and “medical home” models are instituted (Brachlow, et al, 2007; Carbone, et al, 2010). This study should be conducted several years in the future to assess this potential impact on service needs and access.

It may also be interesting to conduct this study at various settings including those that serve low income families, specifically or Medicaid-only clinics. Sample characteristics indicated the majority of our parents were still married to the other biological parent which is discrepant from the overall literature (Luther, Canham, and Cureton, 2005.) They also report higher median incomes than typical households (United States Census Bureau, 2010) and the majority of participants were Caucasian. As this sample was fairly homogenous, it limits the ability to generalize these results across populations. Efforts should be made to include a more ethnically and economically diverse group. Also, the majority of the respondents for this study were mothers. Future
research should attempt to increase the participation of fathers in the research as they may endorse different coping, stress, and growth responses than the mothers.

Nevertheless, even with these limitations, these findings suggest that access to services is a critical factor for parents of children with autism, and access may even impact child outcome. Coping appears to be a key factor for these families as well.

*Implications*

This research highlights how access to services, specifically met service needs, relates to child clinical outcomes and parenting stress. This study addresses the impact that disparities in service access can have on a child with autism and their families. It highlights the impact of interconnected ecological systems, and the unfortunate diffusion of responsibility and fiscal disconnect across these systems, on a child with autism. The findings have clinical implications for both intervention and prevention. They highlight the necessity for clinicians and professionals working with these families to educate families regarding essential empirically supported services. Professionals then can act as a connecting link, providing concrete instruction regarding their rights as parents and the availability of quality service providers in the area.

This study highlights the importance of focusing on systemic and parental factors such as parenting stress when working with a child with autism. These results demonstrate the role of coping for families for both the parent and child. Professionals working with these families should spend considerable time identifying coping strategies, and then intervening to increase positive coping strategies. Coping could lead to decreased parental stress and in turn lead to treatment gains for the child. Professionals should provide both psychological coping strategies as well as offer lists of local support
resources. Professionals should also emphasize stress-related growth for parents by drawing attention to the parent’s micro- and macro-level advocacy work as well as the positive changes they have witnessed in themselves throughout the process of having a child with autism. Even though hopefulness did not emerge as a significant variable in this study, research on hopefulness with other populations does speak to the importance of instilling hope for these parents.

It appears that ensuring that the child’s treatment needs are met is related to decreased stress and improvement for the child. This study demonstrates the importance of coping for these families and that these parents are reporting stress-related growth as they parent a child with autism. This study underscored the importance of systemically serving children with autism and their parents.
Table 1

*Variables and Measures*

<table>
<thead>
<tr>
<th>Predictor Variables</th>
<th>Mediator Variables</th>
<th>Outcome Variables</th>
</tr>
</thead>
<tbody>
<tr>
<td>Autism Severity</td>
<td>Hopefulness</td>
<td>Parenting Stress</td>
</tr>
<tr>
<td>Childhood Autism Rating Scale: Total Score</td>
<td>Adult Hope Scale: Total Score</td>
<td>Parenting Stress Index-Short Form: Total Stress</td>
</tr>
<tr>
<td>Access to Services</td>
<td>Coping</td>
<td>Stress-Related Growth</td>
</tr>
<tr>
<td>Family Support Index: Total Met/Unmet Needs</td>
<td>Coping Health Inventory for Parents: Total Score</td>
<td>Stress Related Growth Scale: Total Score</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Clinical Outcome</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Ohio Autism Clinical Impression Scale:</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Severity and Improvement Score</td>
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</table>
Table 2

*Mean, Standard Deviation, Minimum, and Maximum of Variables*

<table>
<thead>
<tr>
<th>Measure</th>
<th>$M$</th>
<th>$SD$</th>
<th>Minimum</th>
<th>Maximum</th>
</tr>
</thead>
<tbody>
<tr>
<td>Childhood Autism Rating Scale</td>
<td>36.047</td>
<td>3.85</td>
<td>30.5</td>
<td>44.0</td>
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<tr>
<td>Family Support Index (Met Needs)</td>
<td>4.35</td>
<td>2.15</td>
<td>1.00</td>
<td>7.00</td>
</tr>
<tr>
<td>Hopefulness</td>
<td>51.44</td>
<td>7.83</td>
<td>25.00</td>
<td>64.00</td>
</tr>
<tr>
<td>Coping</td>
<td>81.68</td>
<td>17.52</td>
<td>41.00</td>
<td>117.00</td>
</tr>
<tr>
<td>Parenting Stress</td>
<td>96.59</td>
<td>23.77</td>
<td>46.00</td>
<td>146.00</td>
</tr>
<tr>
<td>Stress-Related Growth</td>
<td>25.30</td>
<td>5.76</td>
<td>10.00</td>
<td>32.00</td>
</tr>
</tbody>
</table>
Table 3

*Spearman rho correlations Among Predictor and Criteria Variables*

<table>
<thead>
<tr>
<th></th>
<th>CARS</th>
<th>Service</th>
<th>Coping</th>
<th>Hope</th>
<th>SRG</th>
<th>Stress</th>
<th>Curr Sever</th>
<th>Improv</th>
</tr>
</thead>
<tbody>
<tr>
<td>CARS</td>
<td>-</td>
<td>-.05</td>
<td>.07</td>
<td>.16</td>
<td>-.06</td>
<td>-.03</td>
<td>.36*</td>
<td>-.34*</td>
</tr>
<tr>
<td>Service</td>
<td>-</td>
<td></td>
<td>.48**</td>
<td>.14</td>
<td>.30*</td>
<td>-.60**</td>
<td>-.40*</td>
<td>-.02</td>
</tr>
<tr>
<td>Coping</td>
<td>-</td>
<td></td>
<td></td>
<td>.13</td>
<td>.34*</td>
<td>-.43**</td>
<td>-.20</td>
<td>-.08</td>
</tr>
<tr>
<td>Hope</td>
<td>-</td>
<td></td>
<td></td>
<td></td>
<td>.09</td>
<td>-.06</td>
<td>-.06</td>
<td>-.13</td>
</tr>
<tr>
<td>SRG</td>
<td>-</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>-.16</td>
<td>.08</td>
<td>.07</td>
</tr>
<tr>
<td>Stress</td>
<td>-</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>.68**</td>
<td>.25</td>
</tr>
<tr>
<td>Curr Sever</td>
<td>-</td>
<td></td>
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<td></td>
<td></td>
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</tbody>
</table>

*N (38)*

*Note: CARS=Childhood Autism Rating Scale; Service=Family Support Index; Coping=Coping Health Inventory for Parents; Hope=Adult Trait Hopefulness Scale; SRG=Stress-Related Growth; Stress=Parenting Stress Index-Short Form; Curr Sever=Current Severity on OACIS; Improv=OACIS Improvement score*

*p<.05, ** p<.01*
Table 4

*Testing Coping as a Mediator between Met Service Needs and Parenting Stress*

<table>
<thead>
<tr>
<th>Testing Steps in Mediation Model</th>
<th>β</th>
<th>SE β</th>
<th>p</th>
</tr>
</thead>
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<tr>
<td>Step 1:</td>
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<td></td>
</tr>
<tr>
<td>Outcome: coping</td>
<td>3.77</td>
<td>1.22</td>
<td>.004*</td>
</tr>
<tr>
<td>Predictor: met needs</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Step 2:</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Outcome: stress</td>
<td>-6.83</td>
<td>1.50</td>
<td>.000*</td>
</tr>
<tr>
<td>Predictor: met needs</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Step 3:</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Outcome: stress</td>
<td>-5.69</td>
<td>1.68</td>
<td>.002*</td>
</tr>
<tr>
<td>Predictor: met needs</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Mediator: coping</td>
<td>-0.28</td>
<td>0.20</td>
<td>.164</td>
</tr>
</tbody>
</table>

*p<.05, ** p<.01
### Table 5

**Testing Coping as a Mediator between Met Service Needs and Stress-Related Growth**

<table>
<thead>
<tr>
<th>Testing Steps in Mediation Model</th>
<th>$\beta$</th>
<th>SE $\beta$</th>
<th>$p$</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Step 1:</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Outcome: coping</td>
<td>3.77</td>
<td>1.22</td>
<td>.004*</td>
</tr>
<tr>
<td>Predictor: met needs</td>
<td></td>
<td></td>
<td></td>
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<tr>
<td><strong>Step 2:</strong></td>
<td>-.829</td>
<td>.441</td>
<td>.047*</td>
</tr>
<tr>
<td>Outcome: stress-gr</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Predictor: met needs</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Step 3:</strong></td>
<td>.559</td>
<td>.502</td>
<td>.241</td>
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<tr>
<td>Outcome: stress-gr</td>
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<td></td>
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<tr>
<td>Predictor: met needs</td>
<td>.058</td>
<td>.60</td>
<td>.343</td>
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<tr>
<td>Mediator: coping</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

*Note: stress-gr = stress-related growth*

*p<.05, **p<.01
Figure 1. Theoretical Model
References


U.S. Census Bureau: State and County QuickFacts. (2010). Data derived from Population Estimates, Census of Population and Housing, Small Area Income and Poverty Estimates, State and County Housing Unit Estimates, County Business Patterns,