STRUCTURAL EQUATION MODEL OF VARIABLES ASSOCIATED WITH FAMILY FUNCTIONING AMONG A NATIONALLY REPRESENTATIVE SAMPLE OF FAMILIES WITH A CHILD WITH AUTISM

Stephanie K. Bezner, M.S.

Dissertation Prepared for the Degree of

DOCTOR OF PHILOSOPHY

UNIVERSITY OF NORTH TEXAS

August 2009

APPROVED:

Kenneth W. Sewell, Major Professor
Craig S. Neumann, Committee Member
Amy R. Murrell, Committee Member
Linda L. Marshall, Chair of the Department of Psychology
Michael Monticino, Dean of the Robert B. Toulouse School of Graduate Studies
Bezner, Stephanie K. *Structural Equation Model of Variables Associated with Family Functioning among a Nationally Representative Sample of Families with a Child with Autism*. Doctor of Philosophy (Clinical Psychology), August 2009, 69 pp., 12 tables, 7 figures, references, 67 titles.

Previous research indicates that stressors experienced by a family, the perceived level of burden assigned by the family to the stressor, and the utilization of resources predict family functioning. The current study utilized a nationally representative sample of families of children with autistic disorder to determine if previously proposed models of family functioning accurately conceptualized family functioning within a representative sample. Structural equation modeling was utilized to test the double ABCX and the linear ACBX models of family functioning. With slight modifications, the double ABCX model was supported, thus indicating that pileup of stressors, perception of burden, and utilization of resources each have unique predictive ability for family functioning, with perception of burden demonstrating the highest amount of predictive ability. Results, implications, and limitations of the study are discussed.
Copyright 2009

by

Stephanie K. Bezner
# TABLE OF CONTENTS

<table>
<thead>
<tr>
<th>Section</th>
<th>Page</th>
</tr>
</thead>
<tbody>
<tr>
<td>LIST OF TABLES</td>
<td>v</td>
</tr>
<tr>
<td>LIST OF FIGURES</td>
<td>vi</td>
</tr>
<tr>
<td>INTRODUCTION</td>
<td>1</td>
</tr>
<tr>
<td>Clinical Presentation of Autism</td>
<td>1</td>
</tr>
<tr>
<td>Prevalence of Autism</td>
<td>4</td>
</tr>
<tr>
<td>Correlates of Autism</td>
<td>5</td>
</tr>
<tr>
<td>Increased Psychopathology and Sleep Difficulties Among Family Members</td>
<td>6</td>
</tr>
<tr>
<td>Higher Prevalence of Behavior Problems</td>
<td>7</td>
</tr>
<tr>
<td>Increased Parental Stress</td>
<td>8</td>
</tr>
<tr>
<td>Financial and Employment Difficulties</td>
<td>12</td>
</tr>
<tr>
<td>Family Functioning</td>
<td>13</td>
</tr>
<tr>
<td>Severity of Condition, Parental Stress, and Coping</td>
<td>17</td>
</tr>
<tr>
<td>Social Support</td>
<td>19</td>
</tr>
<tr>
<td>Proposed Models</td>
<td>20</td>
</tr>
<tr>
<td>ABCX Model</td>
<td>20</td>
</tr>
<tr>
<td>Double ABCX Model</td>
<td>21</td>
</tr>
<tr>
<td>ACBX Model</td>
<td>26</td>
</tr>
<tr>
<td>Rationale for Current Study</td>
<td>27</td>
</tr>
<tr>
<td>METHODS</td>
<td>30</td>
</tr>
</tbody>
</table>
LIST OF TABLES

<table>
<thead>
<tr>
<th>No.</th>
<th>Table Title</th>
<th>Page</th>
</tr>
</thead>
<tbody>
<tr>
<td>1.</td>
<td>Questions Included in Indicators</td>
<td>40</td>
</tr>
<tr>
<td>2.</td>
<td>Indicator Means, Standard Deviations, and Ranges</td>
<td>40</td>
</tr>
<tr>
<td>3.</td>
<td>Intercorrelations among Indicators for Pileup of Stressors</td>
<td>41</td>
</tr>
<tr>
<td>4.</td>
<td>Intercorrelations between Questions for Perceived Burden</td>
<td>42</td>
</tr>
<tr>
<td>5.</td>
<td>Intercorrelations among Indicators for Utilization of Resources</td>
<td>42</td>
</tr>
<tr>
<td>6.</td>
<td>Intercorrelations among Indicators for Family Functioning</td>
<td>42</td>
</tr>
<tr>
<td>7.</td>
<td>Factor Loadings of Indicators on Pileup of Stressors</td>
<td>45</td>
</tr>
<tr>
<td>8.</td>
<td>Factor Loadings of Indicators on Perceived Burden</td>
<td>45</td>
</tr>
<tr>
<td>9.</td>
<td>Factor Loadings of Indicators on Family Functioning</td>
<td>46</td>
</tr>
<tr>
<td>10.</td>
<td>Standardized Coefficients (StdYX) Matrix for Latent Variables</td>
<td>47</td>
</tr>
<tr>
<td>11.</td>
<td>Standardized Coefficients (StdYX) for Family Functioning on Latent Variables</td>
<td>47</td>
</tr>
<tr>
<td>12.</td>
<td>Comparison of Goodness-of-Fit Indices for the Two Proposed Models</td>
<td>50</td>
</tr>
</tbody>
</table>
LIST OF FIGURES

<table>
<thead>
<tr>
<th>Figure</th>
<th>Description</th>
<th>Page</th>
</tr>
</thead>
<tbody>
<tr>
<td>1.</td>
<td>ABCX Model (Hill, 1949)</td>
<td>21</td>
</tr>
<tr>
<td>2.</td>
<td>Double ABCX Model (McCubbin &amp; Patterson, 1983)</td>
<td>22</td>
</tr>
<tr>
<td>3.</td>
<td>Linear ACBX Model (Orr et al., 1991)</td>
<td>26</td>
</tr>
<tr>
<td>4.</td>
<td>Double ABCX Model for the Current Study</td>
<td>28</td>
</tr>
<tr>
<td>5.</td>
<td>Linear ACBX Model for the Current Study</td>
<td>30</td>
</tr>
<tr>
<td>6.</td>
<td>Adjusted Double ABCX Model with Standardized Coefficients (StdYX)</td>
<td>49</td>
</tr>
<tr>
<td>7.</td>
<td>Modified Double ABCX Model</td>
<td>52</td>
</tr>
</tbody>
</table>
INTRODUCTION

Previous research has assessed the relation between a variety of variables, such as behavior problems, parental stress level, and family functioning among families with children diagnosed with autistic disorder. Other studies have considered models in order to concurrently assess variables related to family functioning and adaptation. The current study aimed to assess the utility of the double ABCX model on a nationally representative sample of families with children with autism. The study considered the role of stressors experienced by the family, utilization of resources, parental perception of the burden placed on the family, and the resulting level of family functioning.

In this introduction, the associated symptoms and prevalence of autistic disorder are considered, followed by a review of correlates associated with autism. Previous models are also considered. These models have been proposed to conceptualize family functioning in relation to stressors, perception of stressors, and utilization of resources. The current study tested two previously observed models to determine which model better conceptualizes family functioning within a nationally representative sample of families with children with autistic disorder.

Clinical Presentation of Autism

Autistic disorder, commonly referred to as autism, is characterized by disruption of both language and interpersonal development, as well as stereotyped patterns of behaviors and interests. The diagnostic criteria for autistic disorder are delineated in the Diagnostic and Statistical Manual of Mental Disorders, Fourth Edition Text Revision (DSM-IV-TR; American Psychiatric Association [APA], 2000). Autism includes impairment in social interaction, as demonstrated by considerable difficulty with developing interpersonal relationships, utilizing
nonverbal behaviors, engaging in social and emotional reciprocity, and engaging in behaviors to share experiences with others.

Impairment in communication is also a defining feature of autism. Communication difficulties can be seen through a delay in or complete absence of language development, substantial difficulty in maintaining interpersonal dialogue, repetitive or idiosyncratic language usage, and deficits in imaginative behavior (DSM-IV-TR; APA, 2000, p. 75). Diagnostic criteria also include behaviors and interests that are stereotyped and repeatedly demonstrated. This criterion is demonstrated through overly intense interest in parts of objects and areas of concentration. Rigid observance of routine behaviors and repeated motoric gesture, such as flapping ones hands, are also demonstrated in autistic disorder. To be diagnosed with autistic disorder, an individual must demonstrate symptomology from each category of behaviors (APA, 2000, p. 75).

In addition to the behaviors specifically outlined in the diagnostic criteria, individuals with autistic disorder often demonstrate a multitude of maladaptive behaviors including, “hyperactivity, short attention span, impulsivity, aggressiveness, self-injurious behaviors, and particularly in young children, temper tantrums” (APA, 2000, p. 72). Individuals diagnosed with autistic disorder often demonstrate peculiarities in sensory experiences, irregularity in eating and sleeping patterns, and idiosyncratic expression of affect. The majority of those diagnosed with autistic disorder also demonstrate deficits in cognitive development, often meeting criteria for mental retardation (APA, 2000, p. 71).

Soucy (2000) employed structural equation models to conceptualize the symptoms experienced by individuals with autism in order to gain greater understanding of autistic disorder. Exploratory, confirmatory, and hierarchical factor analyses were conducted on data
from 109 children diagnosed with autism. Results emphasized the heterogeneity found among children with autism. When using a model consisting of three first-order latent variables which load onto one second-order latent variable, a comparative fit index (CFI) of .91 was obtained. The author conceptualized the three first order variables to be communication, level of adaptive functioning, and cognition, and suggests that the second-order variable may represent the autism’s biological character.

Autism is one of the specific disorders found within the diagnostic class of pervasive developmental disorders, also referred to as autism spectrum disorders. The class is characterized by developmental delays in interpersonal interaction and communication, as well as stereotyped areas of interest and behaviors. Autistic disorder, Rett’s disorder, childhood disintegrative disorder, Asperger’s disorder, and pervasive developmental disorder not otherwise specified are all included within the diagnostic class (APA, 2000, p. 69). Previous studies have varied in their utilization of the overall class and the use of autistic disorder specifically. The present study will utilize participants who have been specifically diagnosed with autistic disorder. However, given that the underlying symptom presentation is similar between the diagnoses, it is appropriate to consider previous research related to both pervasive developmental disorders in general, as well as autistic disorder specifically. Additionally, research related to parental stress and family functioning levels among families with a child with cognitive delay, such as mental retardation, will be considered due to the high prevalence of cognitive delays in autistic disorder (APA, 2000, p. 71).
Prevalence of Autism

The DSM-IV-TR reports the median prevalence rates of autistic disorder to be 5 in 10,000; however, prevalence rates range from 2 to 20 individuals in every 10,000 (APA, 2000, p. 73). Estimates from the French morbidity register of children with disabilities were used to determine the prevalence of pervasive developmental disorders between the years of 1980 to 1993. Overall, 22.2 individuals out of every 10,000 met diagnostic criteria for a pervasive developmental disorder. However, during the span of the study, the prevalence rate increased from 14.7 out of every 10,000, to 30.8 individuals out of every 10,000 individuals surveyed despite the use of consistent definitions and geographic location throughout the study (Guillem, Cans, Guinchat, Ratel, & Jouk, 2006).

Montes and Halterman (2006) conducted a study utilizing the National Household Education Before and After School Survey to determine the prevalence of autism. Parental report of either presence of absence of autism yielded a prevalence rate of 66 children having autistic disorder out of every 10,000 children. Presence of autism was not shown to be related to geographic location, with equal representation of autism across geographic regions.

Through the use of a population cohort of children ages 9-10, Baird et al. (2006) ascertained a prevalence estimate of children with autism spectrum disorders. The estimate was made through the special needs and autism program. Results yielded a prevalence rate of 39.9 per 10,000 children meeting criteria for autism, and 77.2 children per 10,000 being diagnosed with other autism spectrum disorders. Overall, the prevalence of children with autism spectrum disorders was 116.1 per 10,000 children.

Reading (2006) addressed prevalence rates of autism, specifically those determined through The Special Needs and Autism Project. He asserted that prevalence studies may
underestimate the prevalence of autism by using criteria that are too stringent, and thus eliminating children with mild symptomology that may be enrolled in mainstream classes and children with social communication disorders. Reading’s proposition (2006) may explain the discrepancies found between the various prevalence studies. The studies have varied in the determination of what symptoms warrant the diagnosis of autistic disorder, with lower prevalence found in studies with more stringent diagnostic criteria. Additionally, studies have varied in their inclusion of individuals not meeting criteria for autistic disorder, but meeting criteria for other pervasive developmental disorders. With the inclusion of other pervasive developmental disorders, prevalence rates significantly increase. In consideration of family functioning among families with children with autism, research relating to those specifically diagnosed with autism, those diagnosed with a pervasive developmental disorder, and those with other developmental delays, such as mental retardation, will be reviewed. For the current study, those specifically diagnosed with autism will be considered. However, in reviewing previous studies, the language of the individual authors will be adopted in describing the target populations.

Correlates of Autism

*Increased Psychopathology and Sleep Difficulties Among Family Members*

Research has consistently shown increased prevalence of psychopathology among family members of individuals with autistic disorder. Smalley, McCracken, and Tanguay (1995) examined the prevalence of mood and anxiety disorders within 36 families of children with autistic disorder. Among the first degree relatives, 64% met criteria for major depressive disorder, and 39% demonstrated symptomology consistent with Social Phobia. The prevalence of
these disorders was significantly higher than the prevalence found within families of children with other genetic conditions, such as seizure disorders and tuberous sclerosis complex, as well as among the control group. Interestingly, the onset of the major depressive disorder occurred prior to the autistic child’s birth in 64% of the parents, and the onset in all of the parents diagnosed as having a Social Phobia occurred prior to the birth of the child with autism.

These results were further supported by Bolton, Pickles, Murphy, and Rutter (1998). First-degree relatives of an individual with autism experienced higher levels of mood disorders, particularly major depressive disorder. In addition to mood disorders, motor ticks and obsessive-compulsive disorder were significantly more prevalent within families with an autistic child than in families with a child with Down syndrome. Furthermore, those individuals identified as having obsessive-compulsive disorder demonstrated interpersonal and communication difficulties similar to those demonstrated in autism. Results also demonstrated that the onset of the mood disorders were not restricted to the timeframe following the birth of a child with autism.

Dor-Shav and Horowitz (1984) explored possible parental differences in parents with a child diagnosed as autistic. Fathers of children diagnosed with autistic disorder obtained considerably higher IQ scores, whereas mothers of autistic children demonstrated higher levels of neuroticism and introversion as compared to parents without a child with autism.

Mouridsen, Rich, Isager, and Nedergaard (2007) considered both psychiatric and personality disorders among parents of autistic children. The study surveyed families of autistic children from a 25-year time-frame who had been treated in in-patient treatment facilities. Compared to the 8.2% of psychiatric disorders found among mothers in the control group, 15.7% of mothers of an autistic child met criteria for a psychiatric disorder. Criteria for a personality
disorder was met in 7.8% of mothers of an autistic child, whereas only 2.1% of mothers met criteria in the control group. However, results could be inflated due to the severity of the autism within the study. Those included demonstrated symptomology severe enough to been seen in an inpatient unit.

In addition to increased psychopathology, parents of children with autism have also been shown to demonstrate increased levels of sleep related difficulties. In a study conducted by Lopez-Wagner, Hoffman, Sweney, and Hodge (2008), parental reports of sleep were compared between those with and without a child with autism. Parents of a child with autism significantly reported higher levels of sleep related difficulties than the comparison group, though both groups showed relations between parent and child sleep problems.

**Higher Prevalence of Behavior Problems**

Baker, Blacher, Crnic, and Edelbrock (2002) found that children with mental retardation demonstrated greater levels of behavior problems than children without cognitive delays. Problematic behaviors were assessed through the use of the Child Behavior Checklists (CBCL) and the Bayley Behavior Scales. Children with cognitive delays demonstrated 3 to 4 times greater likelihood of behavior problems in the clinical range on the CBCL, as compared to children without cognitive delay.

**Increased Parental Stress**

The behavior problems exhibited by children with autism appear to lead to increased levels of parental stress. Baker, Blancher, Crnic, and Edelbrock (2002) found that parenting stress levels were significantly higher in parents of children with cognitive delays; however, results indicate that that the behavior difficulties accounted for more variance in parental stress levels than did the cognitive delays.
Baker et al. (2003) explored the role of cognitive delays, such as mental retardation, on behavior problems and subsequent parental stress levels. They found parental stress levels were significantly higher among those whose children had cognitive delays, compared to a control group. However, the higher parental stress appeared to be accounted for by the level of behavior problems and not the delay in development itself. Hierarchical regression analysis identified a cyclical pattern to child behavior and stress. Child behaviors appear to increase parental stress levels. As parental stress levels increase, the behavior problems subsequently increase, and the pattern continues.

Abbeduto et al. (2004) explored the relation between behavior problems and parental well-being and coping. The study included mothers of adolescents and young adults who had been diagnosed as having autistic disorder, Down syndrome, or fragile X syndrome. Behavioral problems demonstrated by the children were the most consistent predictor of maternal well-being. Group differences were also explored, and indicated that mothers of children with autism experienced the lowest levels of well-being, whereas mothers of children with Down syndrome experienced the highest levels out of the three groups.

Through the use of a sample of children and adolescents diagnosed as having Attention Deficit/Hyperactivity Disorder, Kendall, Leo, Perrin, and Hatton (2005) considered the relations between problematic behaviors demonstrated by children, level of maternal distress, and family functioning. Results from the study indicate that the relation between behavioral difficulties and family functioning may be mediated by maternal distress levels.

Through the use of a community sample, Baker-Ericzen, Brookman-Frazee, and Stahmer (2005) further explored parental stress levels among parents of children with autism spectrum disorders. When compared to parents of children with autistic disorder, parents of children with
developmental delays endorsed significantly higher levels of both child-related stress and parent-related stress on the Parenting Stress Index. Parenting stress levels were assessed both before and following the involvement of the child in an inclusive program for toddlers. After the child’s participation in the program, maternal reports of child-related stress were significantly diminished. However, there was no control group of children in a self-contained setting that was not specific to their current program. Therefore, it is impossible to determine if improvements were related to the program specifically, or involvement in a general self-contained environment. Maternal reports of parent-related stress, and paternal reports of both child-related and parent-related stress remained consistently elevated. Among mothers, decreased social skill abilities significantly predicted increased child-related stress.

Herring et al. (2006) assessed parental psychopathology, and family functioning in relation to behavior and emotional problems experienced by children with pervasive developmental disorders. Results yielded relations between the child’s behavioral and emotional difficulties, parental psychopathology and stress level, and family functioning. The diagnosis of a pervasive developmental disorder did not account for as much variability as did the child’s behavioral and emotional symptomology. Additionally, mothers reported experiencing higher stress levels regarding their children than did fathers.

Everett (2001) explored the level of parental stress in relation to child and family features, as well as type of treatment received. Results indicated that among parents with children with a pervasive developmental disorder, the child’s adaptive abilities and the family functioning strengths were related to the level of stress experienced by the parents. However, an alliance between health professionals and the child’s family that addresses family and child needs was shown to moderate the relation between the child’s adaptive abilities and parental
stress. This study provided evidence for the beneficial effects experienced by both the child and family when treatment is focused on the family unit rather than focusing solely on the child.

Vitanza and Guarnaccia (1999) assessed underlying latent variables affecting parental psychological symptomology among mothers of children diagnosed with attention-deficit hyperactivity disorder. Parenting stress level, parental characteristics, and characteristics of the environment were hypothesized to affect parental symptomology. Structural equation modeling supported the influence of the parent’s stress level and characteristics; however, results provided support for overall life stress opposed to specific environmental variables.

Dyson (1997) also conducted a study considering parental stress, family functioning, and social support among families with and without children with developmental delays, such as mental retardation and physical impairments. When families with children with developmental delays were compared to those without, no significant differences were found in family functioning, or social support. There were, however, significant differences found in stress levels. Parents of children with a developmental delay experienced higher levels of stress. The study did not find any differences between stress levels experienced by mothers and fathers of children with delays.

The relation between parental stress and developmental progress of children with autism was explored by Robbins, Dunlap, and Plienis (1991). The study included only children with autism classified as having either moderate or severe symptomology. They found a relation between maternal stress level, as demonstrated on the Parenting Stress Index, and the progress exhibited by the child, measured by the Learning Accomplishment Profile. As the child progressed and demonstrated improvements, the parent’s level of reported stress decreased.
These findings are consistent with higher stress levels among children with greater developmental delays, as compared to those with fewer developmental delays.

Jones and Passey (2005) explored potential factors affecting parental stress levels. They included families of children with pervasive developmental disorders and behavior problems. They found that the family’s coping style as well as internal locus of control maintained by the parents produced stronger predictions of parental stress than did characteristics of the child or family resources. The parents reporting the lowest stress levels were optimistic, viewed themselves as being in control of their life (as opposed to their child’s disability controlling their life), and focused on cooperation and integration within the family.

Pottie and Ingram (2008) also considered coping style differences in parental stress levels and mood among parents with children diagnosed with an autism spectrum disorder. Five coping styles (support seeking, problem focused, positive reframing, emotional regulation, and compromising) were found to relate to increased parental mood, whereas escape, blaming, withdrawal, and helpless coping styles were associated with decreased parental mood level. Additionally, emotion regulation, support seeking, and worrying coping styles were moderating variables in the stress-mood relationship.

Financial and Employment Difficulties

Viner-Brown and Kim (2005) examined the relations among child health problems, family financial status, and parental employment status through the use of the 2001 National Survey of Children with Special Health Care Needs. Families with incomes that were significantly below the federal poverty level, families with young children, and families with children whose health problems consistently impacted their ability to participate in activities, experienced significantly greater levels of employment and financial difficulties. The families
who experienced employment and financial difficulties expressed lower levels satisfaction with
the health services they received, and viewed decisions about health as less of a partnership
between themselves and health professionals. In addition, these families were less likely to
acquire or have sufficient health insurance or receive comprehensive care from a primary care
physician. However given the small sample size of children who were uninsured in the study,
generalizations regarding health insurance should be made with caution.

Family Functioning

Relations between autistic disorder and family functioning status have also been
explored. In 2002, McIntyre, Blacher, and Baker considered the impact of adolescents and young
adults meeting criteria for both a developmental delay (autism, mental retardation, Down
syndrome, or cerebral palsy) and behavior problems. There was a relation found between the
behavioral and mental health problems and maternal reports of negative effect on family
functioning. However, the study lacked variance in functional level demonstrated by the child,
which likely masked a relation between functional level and parental stress. They assessed
family functioning with the Family Impact Questionnaire, which measures both negative
evaluation regarding parenting and effect on familial relationships.

Child characteristics, such as gender, severity of the condition, or temperament, were not
found to relate to family functioning by Trute (1990). The study utilized a cross-sectional,
randomly selected group of families with a child who had a pervasive developmental disorder.
Interestingly, parents of a child with a developmental delay demonstrated greater frequency of
disagreements, but showed higher levels of marital cohesiveness than the norms for the scales.
This may be indicative of the greater need for parents of a child with a pervasive developmental
disorder to better coordinate parenting in order to meet the needs of the child. Education
attainment of the father was also shown to relate positively to reported overall family functioning levels.

Morgan (1988) explored family functioning among families with children diagnosed with autistic disorder. Specifically, concepts within the family systems framework were considered. Expressiveness, family cohesiveness, continuation of outside social connections, and maintenance of active recreation were related to improved levels of family functioning. Altiere and Kluge (2009) also considered family cohesion and family functioning among those with a child diagnosed with an autism spectrum disorder. Families who demonstrated an enmeshed relational style also exhibited improved coping, suggesting that the closeness – even associated with enmeshment - may help the family better cope with intense difficulties.

Failla (1991) explored the relations among family functioning and coping, social support, stressors, and family hardiness. Family hardiness has been defined as “the internal strengths and durabilities of a family unit which provide a sense of control over stressful situations which allow for responding in an active rather than passive manner” (Stevenson, Henry, & Robinson, 1996, p. 61). Failla (1991) demonstrated that higher satisfaction with family functioning was related to higher levels of family hardiness, coping, and social support. Lower satisfaction with family functioning was associated with higher stress levels, the loss of social support, and increased age of parent. The variables of family hardiness, functional support, stressors within the family, and the age of the parent accounted for 42% of the overall variance found within family functioning.

Higgins, Bailey, and Pearce (2005) also studied the effects of having a child with a pervasive developmental disorder on family functioning, marital satisfaction experienced by the child’s parents, parental self-esteem, and coping techniques. When compared to a comparison
group of parents without a child with autism, parents of children with autism spectrum disorders did not demonstrate any significant differences in self-esteem. However, they did report significantly lower levels of marital satisfaction, cohesiveness within the family, and adaptability of the family.

Rodrigue, Morgan, and Geffken (1992) investigated differences between families of children with autism or Down syndrome and children without any developmental delays. Family functioning and coping strategies used by the child’s father were considered. Fathers of children with autism or Down syndrome utilized coping strategies including seeking information and having wish-fulfilling fantasies more frequently than fathers of children without developmental delay. The fathers of the children with developmental delays also indicated that they experienced higher levels of financial strain as well as increased disturbance in family centered activities. Few differences were found between families with a child with autism, and families with a child with Down syndrome.

Hall (1995) considered the role of parental characteristics and beliefs in relation to family functioning through the use of a sample including families with children diagnosed with autistic disorder or cerebral palsy. Family functioning was predicted by parental attributes and tendencies (such as parental self-esteem, maintaining an internal locus of control, and having fewer irrational beliefs), as well as coping abilities and social support. Combined, these variables accounted for 88% of the total variance within family functioning. A direct relationship between socio-economic status and family functioning was also observed. No group differences were found in any variables between autistic disorder and the physical developmental delays associated with Cerebral Palsy.
Willoughby and Glidden (1995) considered the role of cognitive delays, such as mental retardation, on parental marital satisfaction. Fathers’ active participation in child care was related to greater marital satisfaction for both parents. Increased levels of marital satisfaction was also related to higher income levels.

In addition to overall family functioning, some studies have examined the impact that having a sibling with a pervasive developmental disorder has on the siblings’ functioning. Schubert (1995) assessed sibling adjustment, sibling relationships, and family functioning within families of children with autistic disorder, mental retardation, and a control group, through the use of both observational and informant data. Informant data from parents and teachers did not yield any significant differences between the different groups. However, observational data did indicate a difference between those families with children diagnosed as having mental retardation, with this group demonstrating statistically higher (but not clinically significant) levels of depressive symptomology than siblings of autistic children, or those without any developmental delays.

Hastings (2003) found significant differences between siblings of children with autism and normative data. Levels of behavior adjustment problems among siblings of autistic children were not significantly different from normative data overall. In families with children with less severe autism, higher social support was related to lower levels of adjustment difficulties demonstrated by the sibling. In families of children with more severe autism, social support was not related to adjustment difficulties experienced by the sibling. It is possible that these results are not indicative of all siblings of children with autism due to the high socioeconomic status of the majority of the participants. Greater difficulties may be seen in siblings when the socioeconomic advantages are not present.
To summarize, previous research has demonstrated relations between autism and a variety of correlates. Relations have been found between autism and increased psychopathology among family members, increased levels of problematic behaviors demonstrated in those with the diagnosis of autistic disorder, and increased parental stress. Relations have also been found between the diagnosis of autism and poorer family functioning. Models have been proposed to integrate the various correlates of autism, and to consider how stressors, utilization of resources, and parental perceptions affect family functioning.

Severity of Condition, Parental Stress, and Coping

Research has shown that the severity of a child’s condition contributes to family outcomes, in particular parental stress and coping. Cameron and Orr (1989) examined parental stress levels on the Parenting Stress Index among parents of children with cognitive delays, such as mental retardation. They utilized a median split to categorize levels of stress among the families. Significant differences in the child’s level of independence, required assistance, behavioral difficulties, and number of developmental delays were found between those with high levels of parental stress and those with low to moderate levels of parental stress, with behavioral difficulties and the number of developmental delays accounting for the most variability in parental stress. The study employed a median split in considering levels of stress experienced by parents. This statistical method equates differences experienced by two individuals near the midpoint with two individuals at endpoints. Strength of relation observed in the study could be impacted by the limitation of variability of parental stress due to the median split; however, it is likely that the direction of the results was not affected.

Margalit, Shulman, and Stuchiner (1989) assessed the relation between children’s behavior problems and parental stress in a study of families with children diagnosed with
moderate mental retardation. Group differences were assessed between children who
demonstrated behavior problems, and those who did not. Results indicated that the severity of the
child’s behavior problems was related to increased stress experienced by the parent. When
considering family climate (cohesiveness, conflict, independence, achievement, etc.), fathers
demonstrated a positive relation between perceptions of restricted opportunities for personal
growth and increased stress, whereas mothers experienced lower levels of stress with perception
of greater familial support. Differences in family climate, as measured by the Family
Environment Scale, were not found between families of children demonstrating behavior
difficulties and those who were not.

Mulvihill (2005) utilized data from the 2001 National Survey of Children with Special
Health Care Needs to explore the relations between the severity of the child’s condition with
family functioning and the quality of relationship with health professionals. There was an
indirect relation between the severity of the child’s health condition and family functioning, with
families experiencing negative impact on family functioning as condition severity increased.
There were also elevated levels of unmet healthcare needs within the relationship between the
family and the health care professional as the level of severity increased. Families with a child
with severe health conditions demonstrated a greater need for health care coordination,
experienced their health care providers as being less sensitive, and expended greater levels of
temporal and financial resources. Though the study was able to obtain a fairly representative
sample of the population, some problems were demonstrated. For instance, the study used
information subjectively given by the parent, such as severity of the condition, which may not be
an accurate account of the child’s condition. Additionally, all of the items in the questionnaire
were assumed to be weighted equally, which may not be representative of the variables
considered.

Social Support

The impact of social support among parents of children with autism has been broadly explored. Boyd (2002) conducted a literature review of studies that considered the relation between parental stress levels and social support among parents of children with autism. Of the studies reviewed, several common themes emerged. Mothers of children with more severe symptoms were more likely to seek social support. Informal social support was shown to be a greater buffer against parental stress than formal social support, and those receiving social support indicated that they were better able to relate to their children emotionally. In addition, parental depression and anxiety was best predicted by levels of social support among mothers with an autistic child. Mothers who experienced less social support demonstrated higher levels of depression and anxiety than those who received increased levels of social support.

Bishop, Richler, Cain, and Lord (2007) also found social support impacts outcome variables. This study, including children diagnosed with autism spectrum disorders, considered the impact of perceived social support, frequency of repetitive behaviors, and adaptive behaviors on the perception of negative impact of having a child with autism. Lower levels of social support and adaptive behaviors, as well as increased repetitive behaviors were all shown to relate to increased perception of burden.

Respite care can be one form of social support experienced by parents and families. Abelson (1999) assessed the availability of respite care to families who had children with a range of disabilities, such as autistic disorder, cerebral palsy, and mental retardation. Although the families indicated that respite care would be beneficial to family functioning, the results
indicated that there was a general lack of accessibility to respite care. The limitation of access to respite care was not found to be associated with demographic factors, financial factors, or the severity of the child’s disability.

Herman and Marcenko (1997) conducted a study to assess the perception of available resources and the utilization of respite care through the use of path analysis. Among families with children diagnosed with mental retardation, both the quantity and quality of available respite care indirectly influenced levels of parental depressive symptomology. Time resources, which were related to availability of child care and financial ability to afford childcare, were shown to be the strongest predictors of the level of depressive symptomology among parents.

Proposed Models

*ABCX Model*

Hill (1949) proposed the ABCX model to explain difficulties in family functioning among families dealing with stresses and crises. The model postulates that a stressor, family level of resources, and the family’s perception of the stressor affect family functioning. Within the model, “A” represents a stressor on the family, such as the child’s disorder, severity of the child’s disorder, and related demographic factors, such as the age of the child. The “B” signifies the existing resources for the family, such as parental employment status, education level, psychological support, and respite care. The family’s perception of the stressor is denoted as “C.” These factors lead to the family adaptation, represented by “X.” Hill’s model has since been modified, and revised models have been applied specifically to families with children with autistic disorder.
The double ABCX model of family outcomes conceptualized by McCubbin and Patterson (1983) is a modification of Hill’s earlier ABCX model. The model considers a pile-up of stressors (aA) instead of one single stressor within a family, as well as both previously existing resources as well as those newly attained resources that address the stressors (bB). The manner in which the family interprets the stressors and assigns meaning within the family is denoted by “cC.” The model suggests that stressors (aA) affect both family resources (bB), and family assignment of meaning (cC). Available family resources (bB) and family definition of the stressors (cC) are also thought to be related. The model proposes that all three factors affect family adaptation (xX). 

Figure 1. ABCX model (Hill, 1949).
Figure 2. Double ABCX model (McCubbin & Patterson, 1983).

Patterson and McCubbin (1983) first assessed the double ABCX model through the use of a sample of families with children diagnosed with cystic fibrosis. Significant changes during a six month period on the Family Life Change Instrument were summed in order to determine the cumulative stressor levels. Through the use of Pearson product moment correlations, they demonstrated an association between increased levels of family changes within family relationships, management within the family, and the financial status and a decline in pulmonary functioning. This provides support for studying cumulative levels of family stressors, instead of a sole stressor event, in order to fully assess family adaptation to stressors.

The applicability of the double ABCX model to families with children diagnosed as having autism or communication disorders was assessed through the use of canonical correlation analyses by Bristol (1987). Parental marital satisfaction, maternal depressive symptoms, and
reported levels of family functioning were assessed to demonstrate level of family adjustment. The double ABCX model was shown to accurately predict family adjustment within families of children with autistic disorder and communication disorders.

Family adaptation of families in the Army who relocated oversees was examined through the use of structural equation modeling by Lavee, McCubbin, and Patterson (1985) to assess the applicability of the double ABCX model. Three analyses were conducted with differing specifications through the use of structural equation modeling, which allowed for the double ABCX model’s variables to be analyzed holistically. Results supported the model, indicating that previous stressors as well as the current crisis act as a pile-up of demands. Family adaptation was affected by both family system resources as well as social support. Family system resources were shown to directly affect family adaptation. Social support for the family acted as a buffer, which reduced strain experienced by the families following their relocation.

Parkenham, Samios, and Sofrenoff (2005) studied a convenience sample from a university clinic of families of children with Asperger Disorder. They used correlation and hierarchical regression analyses, and found support for the use of the double ABCX model when considering parental adjustment. Specifically, the severity of the stressor, the combination of current and previous stressors, and coping levels were related to parental adjustment.

Bayat (2005) explored relations between parental perceptions of autism and quality of life within the family. The study utilized structural equation modeling on a sample of families of children with autism spectrum disorders. Those reporting positive contributions from the autistic disorder also reported higher levels of quality of life within the family. Qualitative analyses revealed positive outcomes, such as increased closeness within the family, compassion, sense of empowerment, and patience among parent of children with an autism spectrum disorder.
Negative outcomes included negative effects on family functioning, interpersonal relationships, and increased levels of parental depression.

Pakenham, Sofronoff, and Samios (2004) considered two different aspects of family assignment of meaning to a crisis. The first conceptualization of meaning was finding benefits from the stressor, and the second was attempting to make sense of the stressor. Content analysis was utilized to assess the two conceptualizations. Parents’ answers yielded 12 themes that focused on making sense of the stressor, and 8 themes that were related to perceived benefits of the stressor. These themes were related to parental adjustment predictors, increased social support, parental sense of self-efficacy, and more adaptive coping strategies, thus providing additional support for the double ABCX model.

Shin and Crittenden (2003) found only partial support for the double ABCX model. They utilized samples of families with children with mental retardation in both the United States and in Korea. The two different cultures yielded different models of the effects of stress on family outcome. Among American mothers, the role of attitudes had a mediating effect on the relation between behavior problems and stress experienced by the mother. Additionally, social support did not directly affect stress, but did so indirectly through parental attitudes. Parental attitudes acted as a mediator between perceived social support and parental stress level. Parents with negative attitudes had increased stress levels, which led to lower levels of perceived social support. Among the Korean sample, lower social support and negative parental attitudes were related to higher stress levels, whereas maladaptive behaviors did not lead to higher levels of stress.

Tobing (2005) also found only partial support for the double ABCX model. The study consisted of families with children diagnosed with autism spectrum disorders. Parental stress and
the level of the child’s functional impairment were both directly related to distress experienced by the mother. Satisfaction with available social support systems and parenting competency level were inversely related to the level of distress experienced by the mother. Neither the availability of social support systems nor the number of coping strategies employed by the parent significantly related to maternal distress levels.

A recent study by Manning (2008) assessed the applicability of the double ABCX model within school aged children with autism. Hierarchical regression analyses were utilized. Findings showed a strong relation between the associated behavior problems and the perception of the situation and resulting outcomes. Interestingly, results revealed that the families, though experiencing high levels of stress, still fell within healthy levels of family functioning.

*ACBX Model*

When considering causal ordering of factors affecting family adjustment and functioning, some studies have provided support for modifications of the ABCX model. Orr, Cameron, and Day (1991) assessed factors affecting families of children with mental retardation through the use of path analysis. Results did not support the ABCX model, but instead supported a linear ACBX model, with the family’s perception of the stressors affecting the utilization or resources, then followed by the family’s experience of stress.
Nachshen and Minners (2005) explored empowerment, or the attitudes, knowledge, and behaviors to adeptly handle daily challenges, among parents with children with and without developmental disabilities. Structural equation modeling was used to determine if the double ABCX model or the linear ACBX model accurately reflected stressors and their relation to family empowerment. As with previous studies, parents of children with developmental disabilities reported higher levels of behavior problems, and they experienced higher stress levels, and lower levels of social support. Results supported the linear ACBX model, with parental well-being and availability of resources mediating the relation between the experienced stressor and subsequent levels of empowerment.
Rationale for Current Study

Previous studies have primarily utilized convenience samples. For instance, Mouridsen, Rich, Isager, and Nedergaard (2007) used participants who had been seen in an inpatient facility. Therefore, the results may not generalize to all families of children with autism within the United States due to the severity of symptoms required to necessitate inpatient hospitalization. Due to the use of relatively small convenience samples, the results may not be representative of demographics of all families of children with autism across the country. The present study utilized a large, nationally representative sample of families with autistic children, allowing for results to be generalized to families with children with autism from across the country.

The present study aimed to investigate relations between stressor variables, perception of the child’s diagnosis as a burden on the family, utilization of resources, and resulting family functioning among families of children diagnosed specifically with autistic disorder. The current study assessed the applicability of the double ABCX model on the nationally representative sample of families of children with autism. The model for this study is presented in Figure 4.
Figure 4. Double ABCX model for the current study.

It was hypothesized that a pile-up of family stressors would predict utilization of resources as well as the perceived burden of the disorder on the family, as indicated by the parent. It was also hypothesized that there would be a relation between perceived burden and the family’s utilization of resources. All three, pile-up of stressors, utilization of resources, and perceived burden on the family, were hypothesized to predict family functioning.

To test the proposed models, the pile-up of stressors experienced by the family was indicated by the severity of the child’s condition, services required by the child due to the disorder, required medications, functional limitations the child experiences, concerns the parent has, and the family’s socio-economic status. These were conceptualized as causal indicators (i.e., as indicators caused by the latent variable). Whether they are better understood as causal indicators or as effect indicators (i.e., that the latent variable is caused by the indicators) is conceptual in nature and perhaps debatable. However, for the current study, it was presumed
that they were better conceptualized as causal indicators. The utilization of resources by the family was indicated by the level of physician’s care, social support, and health insurance utilization. The family’s level of functioning was indicated by the family’s engagement in family activities, maternal level of health, paternal health level, parental coping, and familial disagreements.

The current study also assessed the applicability of the ACBX model to determine if it better conceptualized the current data. The model for the ACBX model is presented in Figure 5. For this model was hypothesized that, as in the ABCX model, the pile-up of family stressors would predict utilization of resources and perceived burden on the family. It was further hypothesized that the perceived burden within the family would predict utilization of resources. Additionally, in accordance with the ACBX model, it was hypothesized that the pile-up of stressors and the utilization of resources would predict family functioning.

Figure 5. Linear ACBX model for the Current Study.
METHODS

Participants

Information regarding participants, materials, and procedures for the current study was obtained from the Design and Operation of National Survey of Children’s Health, 2003 (Blumberg, Olson, Frankel, Osborn, Srinath, & Giambo, 2005). Participants for this study were obtained through a larger survey, the National Survey of Children’s Health, which was collected through the State and Local Area Integrated Telephone Survey. The survey was conducted by the Maternal and Child Health Bureau of the Health Resources and Services Administration.

Surveys were conducted regarding 102,353 children. Of the surveys completed, 495 respondents (0.48%) reported that the child’s doctor or health care professional had informed them that the child had autism. One hundred twenty-two respondents (0.12%) reported that they did not know if they had been told that the child had autism, and 7 respondents (0.01%) refused to answer. The remaining 101,726 respondents (99.39%) indicated that they had not been told by a health care provider that the child had autism. The 495 children who had received the diagnosis of autism were included in the present study.

Materials

Participants in this study were administered the National Survey of Children’s Health (NSCH) questionnaire (Appendix A). The survey was compiled by Maternal and Child Health Bureau directors, children’s health researchers, representatives from family organizations, and survey design specialists. The survey covers eight primary domains including: demographic factors, mental and physical health status of the child, health insurance, access to and utilization
of health care, presence of a primary healthcare provider, family functioning, parental health concerns, and characteristics of the children’s neighborhoods. Age specific questions were also included in the survey to assess for developmental concerns. Portions of the survey were derived from previous surveys, such as the National Health Interview Survey (NHIS) (National Center for Health Statistics, 2002) and the National Survey of Children with Special Health Care Needs (NCHS) (Blumberg et al., 2003). The compiled items for the survey were divided into 11 sections.

The first section of the questionnaire includes questions to determine if an eligible child lives within the household, and requests information regarding the respondent’s relationship to the child. The second section ascertains information regarding the child’s health status, such as the presence of any physical, mental, or developmental conditions, and their impact on the child. A question assessing for possible emotional and behavioral difficulties is also included.

Section 3 of the NSCH questionnaire questions whether the child has health insurance coverage, and section four assess the utilization the child’s access to and utilization of health care services. The fifth section includes questions to determine if the child has a primary care physician, and the quality of the service they receive from their physician. Another question assesses for the use of specialized services, such as physical therapy or counseling.

Section 6 was administered to respondents for children ages 0 to 5 years old, and includes questions to assess for difficulties in learning, problematic behavior, developmental level, and the current arrangements for child care. The respondents with children and adolescents age 6 to 17 were administered Section 7. This section included questions to determine the child or adolescent’s school functioning, extracurricular activities, and behaviors. Questions assessing
interpersonal competence, problematic behaviors, and depressive symptomology were drawn from the Behavior Problems Index (Zill, 1990).

Family functioning is assessed in section 8, which includes questions relating to recreational outings, religious involvement, and familial stress levels, and the manner through which the family settles disagreements. Questions regarding parental aggravation level were compiled from the Parenting Stress Index (Abidin, 1997), and the Parental Attitudes about Childrearing scale (Easterbrooks & Goldberg, 1984).

The ninth section of the questionnaire ascertains information relating to the physical, mental, and emotional health status of the child’s parents, followed by the tenth section which obtains information about the child’s neighborhood. The last section of the NSCH questionnaire obtains additional demographic information, such as ethnicity, family income, and the use of welfare programs.

Procedure

Participants for this study were obtained through a larger survey, the National Survey of Children’s Health. Interviews were contacted via random-digit-dialing through The National Immunization Survey Sampling Plan, which samples from 78 distinct geographic areas encompassing the entire United States. Phone interviews were conducted between January 2003 and July 2004. A total of 102,353 interviews were conducted.

When an address could be identified for a telephone number, an advance letter was mailed to the respondent prior to the phone interview being conducted. Letters were sent to 67.4% of telephone numbers included in the sample. The letter included a brief description of the purpose of the survey, and informed recipients that their number had been randomly selected to
be included in the study. Letter recipients were asked to participate, and given contact information for questions regarding the survey.

A toll-free telephone number was left on answering machines of those telephone numbers selected when a respondent did not answer the phone. Respondents could use this number to indicate that there were no children living in the household, ask questions regarding the study, or to complete the survey.

Interviews for the NSCH were completed by Abt Associates Incorporated and their subcontractors. Interviewers were trained through education regarding the survey, mock interviews, and exposure to refusal aversion techniques. Interviewers were evaluated following their training, and were required to successfully fulfill the evaluation requirements prior to conducting interviews.

The NSCH was conducted utilizing a computer data collection software program, the computer-assisted telephone interviewing (CATI) system. The software program allows for the interviewer to maneuver through the questionnaire based upon the answers given to the questions. As the interviewer recorded information, the CATI system automatically presented relevant questions based upon previous answers. In addition to routing interviewers to appropriate questions, the software program also determined if responses were in an allowable range, assessed the consistency of responses within the survey, and recorded information within a data file.

Once an individual was contacted by phone, the interviewer introduced the interview and asked if there were any children age 19 to 35 months old living within the household. If there was a child within this age range, the National Immunization Survey (NIS) was completed to ascertain information regarding immunization levels within this age group. Answers to relevant
questions in the NIS survey were automatically transferred to the NSCH survey so that respondents were not asked duplicate questions. Following the NIS survey, the NSCH was administered when there was a child less than 18 years of age living within the household. The interviewer completed the survey with the individual living in the household who had the most knowledge regarding the child’s health status and care. The child’s mother or female guardian completed the survey 78% of the time, and their father or male guardian completed the survey 17% of the time. Grandparents or other relatives completed the remaining surveys (4%).

Following the determination that there was a child under the age of 18 living in the household, informed consent was obtained. The voluntary nature of the survey, the authorizing legislation, the confidentiality of the data, the nature of the survey content, and the expected time for completion of the survey were discussed. Once informed consent had been obtained, the remainder of the survey was conducted.

Information concerning the number of children living within the household and their respective ages was gathered. From the list of children living in the household, one child was randomly sampled. The survey data were then collected regarding the health of this child. Informants were also questioned about their relationship to the child being considered.

Spanish speaking respondents were interviewed in Spanish by a Spanish speaking interviewer, through the use of a Spanish language version of the questionnaire. The Spanish translation of the questionnaire was reviewed and assessed for accuracy. Of the interviews completed, 5.9% were conducted in Spanish.

Given that some respondents completed both the NIS survey and the NSCH survey, whereas others completed only the NSCH survey, the completion time of the interviews varied. The average completion time for respondents not completing the NIS survey was 28 minutes, 53
seconds. For those completing both, relevant data were automatically transferred from the NIS survey to the NSCH survey, yielding a shorter completion time averaging 23 minutes and 25 seconds.

On average, a telephone number was called eight times (median = 5) in order to make contact with a respondent. Some respondents chose not to complete the survey. Of those contacted and determined to have a child living in the household, 43,552 interviews were not completed. Discontinuation of the survey occurred at various points during the survey, such as following the NIS interview, following the informed consent, or when the respondent was asked if she/he was the most knowledgeable adult in the household regarding the child’s health.

The percentage of successful screening calls to determine if a child lived in the household was 87.8%, and the percentage of completed interviews for households containing at least one child was 68.8%. Overall, the response rate was 55.3%.

Initially, the response rates for the NSCH were lower than earlier projects. It was determined that financial incentives could be awarded for completion of the survey in order to increase response rates among those who initially declined to participate. Advance letters included statements regarding the incentives such as, “When you complete the interview, we will send you $15.00 in appreciation for your participation.”

The various datasets compiled by the State and Local Area Integrated Telephone Survey have led to a broad range of published research articles. The National Survey of Children’s Health, 2003, has been used by researchers as well. For instance, Blackman and Gurka (2007) explored the correlation between asthma and developmental and behavioral problems, finding a higher prevalence of behavioral, emotional, and developmental problems among children with asthma.
For the present study, those who responded yes to the question, “Has a doctor or health professional ever told you that (child’s name) has autism,” were included in the study.
RESULTS

Descriptive Statistics

Data were analyzed using SPSS 12.0 for Windows (SPSS Inc., 2003) and MPlus4 Editor (Muthen & Muthen, 2001). Of the 102,353 individuals surveyed, 495 respondents stated that they had been informed by a health care professional or doctor that the child in consideration had autism. This represents 0.48 percent of the overall sample. Of these individuals, 438 cases had complete data on all of the study variables. Those with missing data on the variable composites were deleted listwise from the study. Descriptive analyses were used to summarize demographic data of those included in the statistical analyses.

Ages of children ranged from 1 to 17, with a mean of 9.76 (SD = 4.19). Three hundred forty-one were male (77.9%), and 71 were female (22.1%). Biological, step, foster, and adoptive mothers of the child in consideration comprised 358 (81.7%) of those surveyed, whereas 75 (17.1%) were biological, step, foster, or adoptive fathers. Five sisters or brothers completed the surveys of those included in the data analyses. Every state was represented among those included. Sixty-six (15.1%) of those included lived in single adult households, 303 (69.2%) lived in a two adult household, and 69 (15.8%) lived with three adults. Ethnicity was ascertained through two different questions. The first asked if the individual was of Hispanic or Latino origin. Thirty-eight (8.7%) participants represented a Hispanic or Latino background. A second question asked about white (352 participants, 80.4%), black (41 participants, 9.4%), multiracial (17 participants, 3.9%), and “other” (13 participants, 3.0%) racial identities.

Indicators were derived from the survey questions usually by averaging a set of responses to create a composite. Prior to developing the indicators, questions were coded with reverse scoring where appropriate. Cases where the individual refused to answer or responded
that they did not know the information were coded as a 0 in order not to skew the means with a higher number. In the survey, parental concerns about their child reaching their developmental milestones and/or age appropriate difficulties were specific to the age range of the individual being considered. Each of these separate ranges was converted into a unified indicator of parental concern by ascertaining the mean of the questions that were asked. Due to the lack of data for some participants regarding both parents, maternal and paternal health factors were averaged to determine a parental health indicator. Socioeconomic status was conceptualized as financial difficulties due to limited information regarding parental educational attainment.

Perceived burden was indicated by two specific questions, as opposed to multiple indicator variables. Question S8Q07 asked, “During the past month, how often have you felt (child’s name) is much harder to care for than most children (his/her) age? Would you say never, sometimes, usually, or always?” and Question S8Q09 inquired, “During the past month, how often have you felt you are giving up more of your life to meet (child’s name)’s needs than you ever expected? Would you say never, sometimes, usually, or always?” These questions were considered independently within the model because when combined, goodness of fit estimates decreased (CFI = .606, TLI = .650). Specific questions for each of the indicators are included in Table 1.
### Table 1

*Questions Included in Indicators*

<table>
<thead>
<tr>
<th>Indicator</th>
<th>Questionnaire Questions Included</th>
</tr>
</thead>
<tbody>
<tr>
<td>Severity</td>
<td>S2Q09, S2Q17, S2Q47, S2Q60</td>
</tr>
<tr>
<td>Required Services</td>
<td>S2Q07, S2Q13, S2Q16, S4Q23, S5Q09, S5Q10, S5Q10A, S6Q55</td>
</tr>
<tr>
<td>Medications</td>
<td>S2Q04, S2Q05, S4Q15</td>
</tr>
<tr>
<td>Functional Limitations</td>
<td>S2Q10, S2Q59, S7Q04, S7Q09</td>
</tr>
<tr>
<td>Parental Concerns*</td>
<td>S6Q08, S6Q13, S6Q14, S6Q15, S6Q16, S6Q17, S6Q18, S6Q19, S6Q20, S6Q21, S6Q22, S6Q23, S6Q24, S6Q25, S6Q26, S6Q27, S7Q30, S7Q31, S7Q32, S7Q33, S7Q34, S7Q35, S7Q36, S7Q37, S7Q38, S7Q39, S7Q40</td>
</tr>
<tr>
<td>Financial Difficulties</td>
<td>Poverty level R</td>
</tr>
<tr>
<td>Perceived Burden (Latent Variable)**</td>
<td>S8Q07, S8Q09</td>
</tr>
<tr>
<td>Physician Care</td>
<td>S4Q03R, S4Q06, S4Q07, S5Q01, S5Q02, S5Q04, S5Q06A, S5Q08A, S5Q09A</td>
</tr>
<tr>
<td>Health Insurance</td>
<td>S3Q01, S3Q04, S3Q05</td>
</tr>
<tr>
<td>Social Support</td>
<td>S6Q48, S6Q49, S6Q50, S8Q11, S10Q01, S10Q02, S10Q03</td>
</tr>
<tr>
<td>Family Activities</td>
<td>S6Q62, S7Q13, S8Q01R, S8Q03, S8Q05</td>
</tr>
<tr>
<td>Parental Health</td>
<td>S9Q08, S9Q09, S9Q15, S9Q15A, S9Q18, S9Q19</td>
</tr>
<tr>
<td>Parental Coping</td>
<td>S8Q06</td>
</tr>
<tr>
<td>Disagreements</td>
<td>S8Q08, S8Q10, S8Q12, S8Q13, S8Q14, S8Q15</td>
</tr>
</tbody>
</table>

Note: * Parental Concerns is comprised of only those questions that are applicable to the child in consideration’s age.

**Perceived Burden is a latent variable comprised without composite indicators. Individual questions were considered separately in the analyses.

Means, standard deviations, and ranges of the indicators are displayed in Table 2.
Table 2

*Indicator Means, Standard Deviations, and Ranges*

<table>
<thead>
<tr>
<th>Indicator</th>
<th>Mean</th>
<th>Standard Deviation</th>
<th>Minimum</th>
<th>Maximum</th>
</tr>
</thead>
<tbody>
<tr>
<td>Severity</td>
<td>1.49</td>
<td>0.37</td>
<td>0.0</td>
<td>3.00</td>
</tr>
<tr>
<td>Required Services</td>
<td>0.79</td>
<td>0.33</td>
<td>0.0</td>
<td>1.43</td>
</tr>
<tr>
<td>Medications</td>
<td>1.31</td>
<td>0.82</td>
<td>0.0</td>
<td>2.00</td>
</tr>
<tr>
<td>Functional Limitations</td>
<td>0.80</td>
<td>0.32</td>
<td>0.0</td>
<td>1.25</td>
</tr>
<tr>
<td>Parental Concerns</td>
<td>1.08</td>
<td>0.55</td>
<td>0.0</td>
<td>3.00</td>
</tr>
<tr>
<td>Financial Difficulties</td>
<td>3.37</td>
<td>2.52</td>
<td>1.00</td>
<td>8.00</td>
</tr>
<tr>
<td>S8Q07 (Perceived Burden)</td>
<td>2.66</td>
<td>1.10</td>
<td>0.0</td>
<td>4.00</td>
</tr>
<tr>
<td>S8Q09 (Perceived Burden)</td>
<td>2.27</td>
<td>1.16</td>
<td>0.0</td>
<td>4.00</td>
</tr>
<tr>
<td>Physician Care</td>
<td>2.28</td>
<td>0.93</td>
<td>0.0</td>
<td>6.56</td>
</tr>
<tr>
<td>Health Insurance</td>
<td>1.87</td>
<td>0.38</td>
<td>0.0</td>
<td>2.00</td>
</tr>
<tr>
<td>Social Support</td>
<td>2.38</td>
<td>0.77</td>
<td>0.0</td>
<td>3.25</td>
</tr>
<tr>
<td>Family Activities</td>
<td>2.24</td>
<td>1.44</td>
<td>0.0</td>
<td>8.33</td>
</tr>
<tr>
<td>Parental Health</td>
<td>1.62</td>
<td>0.60</td>
<td>0.67</td>
<td>3.33</td>
</tr>
<tr>
<td>Parental Coping</td>
<td>1.58</td>
<td>0.60</td>
<td>1.0</td>
<td>4.00</td>
</tr>
<tr>
<td>Disagreements</td>
<td>1.92</td>
<td>0.41</td>
<td>0.67</td>
<td>3.33</td>
</tr>
</tbody>
</table>

Correlations between the measured indicators loading on the same latent variables are presented in Tables 3 through 6. The correlation between the two questions used to comprise the latent variable of perception of burden is found in Table 4.
### Table 3

*Intercorrelations Among Indicators for Pileup of Stressors*

<table>
<thead>
<tr>
<th></th>
<th>Severity</th>
<th>Required Services</th>
<th>Medications</th>
<th>Functional Limitations</th>
<th>Parental Concerns</th>
<th>Financial Difficulties</th>
</tr>
</thead>
<tbody>
<tr>
<td>Severity</td>
<td>1.00</td>
<td>.292**</td>
<td>.230**</td>
<td>.324**</td>
<td>.139**</td>
<td>.063</td>
</tr>
<tr>
<td>Required Services</td>
<td></td>
<td>1.00</td>
<td>.375**</td>
<td>.443**</td>
<td>.203**</td>
<td>.063</td>
</tr>
<tr>
<td>Medications</td>
<td></td>
<td></td>
<td>1.00</td>
<td>.230**</td>
<td>.066</td>
<td>.004</td>
</tr>
<tr>
<td>Functional Limitations</td>
<td></td>
<td></td>
<td></td>
<td>1.00</td>
<td>.246**</td>
<td>.033</td>
</tr>
<tr>
<td>Parental Concerns</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>1.00</td>
<td>.114*</td>
</tr>
<tr>
<td>Financial Difficulties</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>1.00</td>
</tr>
</tbody>
</table>

Note: **Correlation is significant at the .01 level (2-tailed). *Correlation is significant at the .05 level (2-tailed).

### Table 4

*Intercorrelations Between Questions for Perceived Burden*

<table>
<thead>
<tr>
<th>Question S8Q07</th>
<th>S8Q07</th>
<th>S8Q09</th>
</tr>
</thead>
<tbody>
<tr>
<td>Question S8Q07</td>
<td>1.00</td>
<td>.503**</td>
</tr>
<tr>
<td>Question S8Q09</td>
<td></td>
<td>1.00</td>
</tr>
</tbody>
</table>

Note: **Correlation is significant at the .01 level (2-tailed).

### Table 5

*Intercorrelations Among Indicators for Utilization of Resources*

<table>
<thead>
<tr>
<th></th>
<th>Physician Care</th>
<th>Health Insurance</th>
<th>Social Support</th>
</tr>
</thead>
<tbody>
<tr>
<td>Physician Care</td>
<td>1.00</td>
<td>.113*</td>
<td>.067</td>
</tr>
<tr>
<td>Health Insurance</td>
<td>1.00</td>
<td></td>
<td>.110*</td>
</tr>
<tr>
<td>Social Support</td>
<td></td>
<td></td>
<td>1.00</td>
</tr>
</tbody>
</table>

Note: *Correlation is significant at the .05 level (2-tailed).
Table 6

*Intercorrelations Among Indicators for Family Functioning*

<table>
<thead>
<tr>
<th></th>
<th>Family Activities</th>
<th>Parental Health</th>
<th>Parental Coping</th>
<th>Disagreements</th>
</tr>
</thead>
<tbody>
<tr>
<td>Family Activities</td>
<td>1.00</td>
<td>.202**</td>
<td>.079</td>
<td>.091</td>
</tr>
<tr>
<td>Parental Health</td>
<td></td>
<td>1.00</td>
<td>.334**</td>
<td>.332**</td>
</tr>
<tr>
<td>Parental Coping</td>
<td></td>
<td></td>
<td>1.00</td>
<td>.349**</td>
</tr>
<tr>
<td>Disagreements</td>
<td></td>
<td></td>
<td></td>
<td>1.00</td>
</tr>
</tbody>
</table>

Note: **Correlation is significant at the .01 level (2-tailed).

**Confirmatory Factor Analysis**

Confirmatory factor analysis (CFA) was utilized to assess the fit of the measurement model. Latent variables were comprised of their respective indicator variables, and latent variables were freely correlated. Specific variables were denoted as ordinal when appropriate, and the composites for medications and health insurance were recoded in order to eliminate non-integer data. Though the data were ordinal in nature, the indicator representing health insurance had to be coded as a continuous variable to meet the demands of the statistical procedures. As a result, covariance between other variables and health insurance will likely be slightly underestimated. The initial CFA goodness of fit indicators were not adequate to accurately conceptualize the data within a measurement model (CFI = .769, TLI = .794, RMSEA = .097, SRMR = 1.628). Physician care, health insurance, and social support did not demonstrate strong factor loadings on the latent variable, utilization of resources, with StdYX values of .302, .052, and .211 respectively. As a result, the latent variable, utilization of resources, was removed from the model, and physician care, health insurance, and social support were considered to be independent variables directly predicting family functioning.
Despite this correction, the CFA continued to yield sub-optimal goodness-of-fit estimates (CFI = .787, TLI = .810, RMSEA = .094, SRMR = 1.534). Though these estimates were improved from the initial CFA, further modifications were needed. The indicator representing financial difficulties did not account for a significant amount of variance within the pile-up of stressors, and was therefore removed (StdYX = .016). Additionally, due to the low amount of variance accounted for, the relation between health insurance and pile up of stressors (StdYX = .030), health insurance and perceived burden (StdYX = .097), and physician care and family functioning (StdYX = .048) were set to zero. Given the initial non-significant relations between these variables, setting them to zero allows for improved estimates of the model, as opposed to estimating non-significant correlations in the overall model.

With these alterations, the goodness-of-fit estimates improve, but continued to fall short of accepted standards (CFI = .869, TLI = .882, RMSEA = .078, SRMR = 1.354). To further improve the measurement model, the family activities indicator was removed from family functioning due to the limited factor loading on the latent variable (StdXY = .267). Following this adjustment, the CFA reached accepted standards for goodness-of-fit estimates (CFI = .893, TLI = .902, RMSEA = .075, SRMR = 1.276).

Structural Equation Models

Following the confirmatory factor analysis, structural equation models were utilized to examine the two alternative hypothesized models. The double ABCX model was tested, using the modifications determined from the CFA analyses. It was hypothesized that the severity of the child’s condition, services required by the child due to the disorder, required medications, functional limitations the child experiences, concerns the parent has, and the financial difficulties
would indicate the pile-up of stressors experienced by the family. However, the use of financial difficulties as a factor in determining pile-up of stressors was not supported by the CFA; therefore, it was removed for the structural equation models. Factor loadings of the indicator variables and the pileup of stressors are included in Table 7.

Table 7

*Factor Loadings of Indicators on Pileup of Stressors*

<table>
<thead>
<tr>
<th>Indicator</th>
<th>StdYX</th>
</tr>
</thead>
<tbody>
<tr>
<td>Severity</td>
<td>.504</td>
</tr>
<tr>
<td>Required Services</td>
<td>.642</td>
</tr>
<tr>
<td>Medications</td>
<td>.508</td>
</tr>
<tr>
<td>Functional Limitations</td>
<td>.579</td>
</tr>
<tr>
<td>Parental Concern</td>
<td>.388</td>
</tr>
</tbody>
</table>

Level of physician’s care, social support, and health insurance utilization were hypothesized to indicate the factor related to utilization of resources. However, given the low factor loadings found in the CFA, the latent variable was removed for further analyses. It was hypothesized that perceived burden on the family would be indicated by questions asking the caretaker about burdens placed on the family related to the child’s condition. Factor loadings of the indicator variables and the perception of burden are recorded in Table 8.
Table 8

*Factor Loadings of Indicators on Perceived Burden*

<table>
<thead>
<tr>
<th>StdYX</th>
</tr>
</thead>
<tbody>
<tr>
<td>Question S8Q07</td>
</tr>
<tr>
<td>Question S8Q09</td>
</tr>
</tbody>
</table>

The family’s engagement in family activities, parental level of health, parental coping, and familial disagreements were hypothesized to indicate the factor of family functioning. However, due to the low factor loading found for family activities on family functioning, this indicator was removed for these statistical analyses. Factor loadings of the indicator variables and family functioning are found in Table 9.

Table 9

*Factor Loadings of Indicators on Family Functioning*

<table>
<thead>
<tr>
<th>StdYX</th>
</tr>
</thead>
<tbody>
<tr>
<td>Parental Health</td>
</tr>
<tr>
<td>Parental Coping</td>
</tr>
<tr>
<td>Disagreements</td>
</tr>
</tbody>
</table>

The factor loadings found between the indicators and the latent variables in tables 7 through 9 are consistent with the determination that the indicators accurately represent the underlying construct.

It was further hypothesized that stressors would predict perceived burden and utilization of resources. It was also hypothesized that there would be a relation between the parent’s
perception of burden on the family and use of resources. Additionally, the current study suggested that the stressors, utilization of resources, and perceived burden on the family would all predict family functioning.

To assess these hypotheses, covariance was assessed between pileup of stressors and perception of burden within the family with physician care and social support. Relations between both pileup of stressors and perceived burden and health insurance were set to zero. The relation between physician care and family functioning was also set to zero due to findings from the CFA. Family functioning was regressed on the pileup of stressors, perception of burden, physician care, health insurance, and social support. A matrix of the standardized coefficients (StdYX) values for the independent variables is included in Table 10.

Table 10

*Standardized Coefficients (StdYX) Matrix for Latent Variables*

<table>
<thead>
<tr>
<th></th>
<th>Pileup of Stressors</th>
<th>Perceived Burden</th>
<th>Physician Care</th>
<th>Social Support</th>
<th>Health Insurance</th>
</tr>
</thead>
<tbody>
<tr>
<td>Pileup of Stressors</td>
<td>.814</td>
<td>.374</td>
<td>.195</td>
<td></td>
<td>Set to Zero</td>
</tr>
<tr>
<td>Perceived Burden</td>
<td>.234</td>
<td>.105</td>
<td></td>
<td></td>
<td>Set to Zero</td>
</tr>
<tr>
<td>Physician Care</td>
<td></td>
<td></td>
<td>.067</td>
<td>.113</td>
<td></td>
</tr>
<tr>
<td>Social Support</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>.110</td>
</tr>
</tbody>
</table>

StdYX values for the regression of family functioning onto the other latent variables are found in Table 11.
Table 11

*Standardized Coefficients (StdYX) for Family Functioning on Latent Variables*

<table>
<thead>
<tr>
<th>Family Functioning</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Pileup of Stressors</td>
<td>.049</td>
</tr>
<tr>
<td>Perceived Burden</td>
<td>.549</td>
</tr>
<tr>
<td>Physician Care</td>
<td>.065</td>
</tr>
<tr>
<td>Health Insurance</td>
<td>.123</td>
</tr>
<tr>
<td>Social Support</td>
<td>.163</td>
</tr>
</tbody>
</table>

These findings indicate that each latent variable shows unique effects above that found from the general factor. The pileup of stressors and perception of burden showed high covariance, thus indicating that the two may not represent distinct entities. Surprisingly, the pileup of stressors did not account for a substantial proportion of the family functioning outcome when compared to the perception of burden within the family. Thus, even though pileup of stressors does demonstrate unique effects in the prediction of family functioning, the perception of burden is a much stronger indicator of familial outcome.

The hypothesized double ABCX model, once corrected for low covariance among the indicators associated with utilization of resources and nonsignificant relation between financial difficulties and pile-up of stressors, was tested and supported by the Tucker Lewis index, as well as the comparative fit index. Both the Tucker Lewis index (TLI) and the comparative fit index (CFI) equaled 0.901. For these indices, values near .90 or higher reflect a good model fit. These two indicators of model fit support that the model is a good fit with the data and preclude the need for model modifications.
The value for the root mean square error of approximations (RMSEA) was 0.075. For the RMSEA, a value close to .06 or less is considered to be a good indicator of fit, which was not attained by the current model. The chi-square value equaled 108.33 (31, \(N = 438\)), and the weighed root mean square residual equaled 1.205. The model, with standardized coefficients, is illustrated in Figure 6.

![Adjusted Double ABCX model with standardized coefficients](image)

**Figure 6.** Adjusted Double ABCX model with standardized coefficients (StdYX).

A structural equation model was also utilized to consider the proposed alternative linear ACBX Model. To assess this model, family functioning was regressed on pileup of stressors, physician care, health insurance, and social support. Physician care, health insurance, and social support were regressed on perceived burden, and perceived burden was regressed on pileup of stressors. Adjustments were made to the proposed model to account for the nonsignificant relation found between financial difficulties and pileup of stressors and between the indicators thought to be associated with the latent variable representing utilization of resources. The indicator of financial difficulties was removed as an indicator, and the utilization of resources
was moved as a latent variable. Physician care, health insurance, and social support were then considered to be independent variables.

This model was not supported by statistical findings. The indices of goodness of fit did not meet accepted criterion. The Comparative Fit Index was 0.846, and the Tucker Lewis Index was 0.874. As with the adjusted double ABCX model, the value for the Root Mean Square Error of Approximations (RMSEA) did not support a good fit (RMSEA = 0.085). This value demonstrates less accuracy in fit of the data to the linear ACBX Model than the modified ABCX model discussed previously. For the modified linear ACBX model, the Chi-square value equaled 157.726 (38, N = 438), and the Weighed Root Mean Square Residual equaled 1.354.

When compared to each other, the modified linear ACBX model showed a significant drop in the Tucker Lewis Index, as well as a decrease in the Root Mean Square Error of Approximations. Given the intercorrelations above and beyond the effects found from the general factor as well as the goodness-of-fit estimates, the modified double ABCX model is the better model to conceptualize the variable relations. Comparison of goodness-of-fit indices between the modified double ABCX model and the modified linear ACBX model are provided in Table 12.

Table 12

Comparison of Goodness-of-Fit Indices for the Two Proposed Models

<table>
<thead>
<tr>
<th>Goodness-of-Fit Indices</th>
<th>Modified Double ABCX Model</th>
<th>Linear ACBX Model</th>
</tr>
</thead>
<tbody>
<tr>
<td>$X^2$</td>
<td>108.330</td>
<td>157.726</td>
</tr>
<tr>
<td>$Df$</td>
<td>31</td>
<td>38</td>
</tr>
<tr>
<td>$p$ value</td>
<td>0.000</td>
<td>0.00</td>
</tr>
<tr>
<td>CFI</td>
<td>0.901</td>
<td>0.846</td>
</tr>
<tr>
<td>TLI</td>
<td>0.901</td>
<td>0.874</td>
</tr>
<tr>
<td>RMSEA</td>
<td>0.075</td>
<td>0.085</td>
</tr>
<tr>
<td>WRMR</td>
<td>1.205</td>
<td>1.354</td>
</tr>
</tbody>
</table>
A pictorial representation of the modified ABCX Model supported by the present data is presented in Figure 7. The variable width of the arrows represents the strength of relation, with thicker arrows representing stronger relations and thinner arrows representing weaker relations.

Figure 7. Modified Double ABCX model.
DISCUSSION

The current study hypothesized that the indicator variables would accurately comprise the latent variables. The pile-up of stressors experienced by a family was conceptualized to include the severity of the child’s condition, services required by the child due to their diagnosis, required medications, functional limitations the child experiences, parental concerns the parent has, and the financial difficulties. All of these factors (severity, required services, medications, functional limitations, and parental concerns), with the exception of financial difficulties, were shown to account for variance within the stressors experience by the family. Surprisingly, financial difficulties were not found to be a significant factor in the assessment of pileup of stressors. This may be due to limited information obtained regarding financial difficulties. Participants were asked about their income level, but were not asked about their expenses or their experience of financial difficulties. It may also be that financial status and difficulties do not impact family functioning within this population as anticipated. Previously, a study conducted by Beckman (1983) found that in families with a child with a disability, socioeconomic status was not significantly correlated with maternal stress level. Instead, Beckman’s study found that the mother being a single parent was correlated with maternal stress levels.

Level of physician’s care, social support, and health insurance utilization were hypothesized to indicate the latent variable related to utilization of resources. However, results did not provide support for a unified construct of resource use. It appears that utilization of resources is not a unified underlying construct. Instead, there appear to be different relations between the use of various types of resources and resulting family functioning. Each of the resources assessed: physician care, health insurance, and social support, all showed unique variance within the resulting familial outcome when considered as separate entities.
It was hypothesized that perceived burden on the family would be indicated by questions relating to burden placed on the family as a result of the child’s condition. As predicted, both of the questions ascertaining information about burden accounted for high levels of variance within the construct of perception of burden, and appeared to adequately assess for the underlying concept. They were considered independently within the model due to decreased goodness of fit estimates when combined.

The level of functioning within the family was conceptualized to include the family’s engagement in family activities, parental health factors, parental coping, and familial disagreements. As hypothesized, parental health factors, parental coping, and family disagreements represented the level of family functioning. However, family activity level did not account for a significant amount of variance within the latent variable. Therefore, it appears that parental health and coping, as well as familial discord and disagreements are better indicators of the family’s health than how often they are participating in shared activities.

For this study, it was hypothesized that the data would support the double ABCX model of family functioning among families with children diagnosed with autism. Specifically, it was hypothesized that pileup of stressors would predict perceived burden and utilization of resources, and that there would be a relation between the parent’s perception of burden on the family and use of resources. Additionally, the current study predicted that the stressors, utilization of resources, and perceived burden on the family would all predict family functioning. With slight modifications, the double ABCX model was supported by the current study. The unified latent variable representing resource use was removed, and physician care, use of health insurance, and utilization of social support were each considered as separate independent variables. Each was shown to be predictive to varying extents of family functioning, with social support affecting
family functioning the most and physician care impacting it the least of the three. There were relations between pileup of stressors, perception of burden, physician care, use of resources, and social support. Interestingly, the pileup of stressors and perception of burden showed high covariance, indicating that the two may represent the same or highly similar underlying concept. However, when the perception of burden was conceptualized as an indicator of pileup of stressors, the model did not account for as much variance as when it was conceptualized as a distinct factor.

Stressors, perception of burden, physician care, health insurance, and social support were all shown to relate to family functioning above and beyond the general factor of the model. This demonstrates the importance of considering each of these factors independently, as well as holistically. The perception of burden represented the strongest effect on family functioning, particularly when compared to the effects accounted for by pileup of stressors. This highlights the importance of perception of the stressors, as opposed to the mere presence of stressors within a family, to determine the likely familial outcome.

These findings are consistent with previous research (Patterson & McCubbin, 1983; Bristol, 1987; Lavee, McCubbin, Patterson, 1985). However, the current study highlighted the importance of the family’s perception of the stressors as being an integral factor in resulting family functioning. This is in contrast to findings by Parkenham, Samios, and Sofrenoff (2005) which showed no relation between perception and outcome, but is consistent with the findings of Manning (2008). Manning found that perception of burden and behavior problems demonstrated by the child were most closely associated with family functioning outcomes.

The hypothesized linear ACBX model was also examined for the current study. For this model it was hypothesized that the pile-up of family stressors would predict utilization of
resources and perceived burden on the family. It was further hypothesized that the perceived burden would also predict use of resources in a linear fashion. Additionally, in accordance with the linear ACBX model, it was hypothesized that the pile-up of stressors and the utilization of resources would predict family functioning.

Results revealed that this measurement model was not adequate in explaining family functioning, even when corrected for low variances found in the confirmatory factor analysis. This does not support findings by Orr, Cameron, and Day (1991) or by Nachshen and Minners (2005).

Therefore, when the two models are compared, the modified double ABCX model appears to be the more viable model to conceptualize the prediction of family functioning from between pileup of stressors, perception of burden from the stressors, and utilization of physician care, health insurance, and social support among families with children diagnosed with autism. Perception of burden appears to be the strongest predictor of family functioning.

Whereas previous studies have primarily utilized convenience samples, such as Mouridsen, Rich, Isager, and Nedergaard (2007), the findings of the current study are particularly significant in that it utilizes a nationally representative sample of families reporting to have a child diagnosed with autism. This greatly improves generalizability of the modified ABCX model to families with children diagnosed with autism residing in the United States.

The current study also highlights the importance of considering the various types of available resources and their use as distinct facets relating to family functioning. When conceptualizing the implementation of resources, it is important to consider differences that may be found depending upon the type of resources available and how each type may impact the overall functioning of the family differentially. For instance, of the three types considered for the
current study, it appears that social support has the greatest effect on family functioning, whereas physician care demonstrated the least. Nonetheless, each was predictive of level of functioning.

Additionally, the study finds that when considering family functioning, it is important to include parental health, parental coping, and familial disagreements, but that number of family activities does not appear to be a strong indicator of the level of functioning.

Clinical Implications

The findings of the current study have clear implications for clinicians. Given the size and demographic representation of the sample, the findings have strong generalizability to families with children diagnosed with autism within the United States. Clinicians should be aware of how all of the various family and lifestyle factors effect family functioning, particularly the importance of assessing how the family perceives the stressors.

The current study demonstrated that pileup of stressors, perception of burden, and utilization of physician care, health insurance, and social support all impact family functioning, with the perception of the child’s difficulties as being a burden being the strongest indicator of family functioning. When working with families who have children with autism, it would be important to ascertain information regarding each of these factors, particularly the family’s perception of the disorder and its effect on the family. In therapeutic interactions, improvements could likely be made in level of family functioning with the use of cognitive restructuring techniques addressing the family’s perception of burden. Stressors could be reframed from being negative in nature, to either being neutral or positive. Psychoeducation could be used to provide information relating to the stressors, and therapy could focus on the positive aspects of their child’s difficulties. Sandler and Mistretta (1998) found that parents of those with mental
retardation often reported significant personal growth from their parenting experiences, such as increased levels of compassion and sympathy, greater tolerance, and increased selflessness. These growth opportunities could be highlighted within a therapeutic context to help those with children with autism to view their stressors in a positive manner.

The present research demonstrated that utilization of resources is not a unified concept, but instead different resources impact family functioning differently. Within clinical settings, it is important to consider the different resources that are available to a family, as well as how these resources may differentially impact the family. For instance, the resource showing the greatest effect on functioning was social support. Thus, it would be important to assess for social support availability and utilization by the family. Clinicians could ascertain information relating to social support resources upon making a diagnosis of autism, or whenever a child or family seeks treatment. Families could be encouraged to increase social support networks, and limitations or difficulties with social support could be addressed. Additionally, information and referrals could be provided for other types of resources, such as financial assistance, child care, and medical care.

The finding that the number of family activities was not indicative of overall family functioning also has clinical implications. When assessing the level of family functioning, it is more important to consider relational factors, such a family discord and disagreements, as well as parental health and coping than how often the family is interacting. Despite a family being involved in a considerable level of activity, the family may demonstrate difficulties in overall functioning. In family therapy, it would be important to focus on underlying relational factors and difficulties, as opposed to simply encouraging the family to engage in more activities.
Limitations

There were several limitations to the current study. First due to the self-report nature of the questionnaire, information provided by the respondent cannot be independently verified. This may account for the high number of respondents reporting they had been informed that the child in consideration had autism. Of the 102,353 individuals surveyed, 495 (.48%) cases were considered to have autism. Prevalence estimates of autism vary significantly depending upon sampling method and inclusion criteria employed. The current study shows prevalence rates significantly higher than those reported in the DSM-IV-TR (5 in 10,000). However, prevalence for the present research was similar to that found by Montes and Halterman (2006) from the National Household Education Survey, which was based on parental report of either presence of absence of autism and yielded a prevalence rate of 66 children out of every 10,000 with autistic disorder.

Additionally, the inclusion criterion for the study was based on one question specific to autism. Not only could the diagnosis of autism not be independently verified, but the question did not consider other pervasive developmental disorders related to autism, such as Asperger’s disorder. Therefore, results are limited to the diagnosis of autism. With such high numbers of those surveyed reporting to have a child with autism, as well as the lack of independent verification of, results in the current study may be impacted. It is possible that many of those reporting a diagnosis of autism did not actually meet diagnostic criteria for autism. Participants may have also endorsed having a child with autism if their child had been diagnosed with another autism spectrum disorder. Given the potential over reporting, it is possible that participants also over reported on other questions, leading to increased error variance. This could have led to results that are not truly representative of an autistic population. Given that an over-
reporting scenario would likely introduce more error variance into the relations, the actual
strength of relations between the study variables in an autistic population could be higher than
observed in the present study. However, given that the percentages reporting a diagnosis of
autism is consistent with the upper range of prevalence rates, it is likely that the sample is
representative of those with autism.

Although the present study had a large sample compared to previous studies, the current
study did not allow for the analysis of ethnic or subculture differences due to the power
requirements of the structural equation model. It is possible that different ethnicities and
subcultures demonstrate different relations between the variables assessed and family
functioning. The model from the current study may be a confluence of the various cultures
represented, and may not specifically represent any particular subgroup. For instance, Bishop,
Richler, Cain, and Lord (2007) found that African American mothers experienced lower levels of
perceived burden related to their child having an autism spectrum disorder than did Caucasian
mothers. These differences could lead to different model specifications within the various
ethnicities.

Another possible limitation of the present study is the nature of the measure used to
ascertain information relevant to the study constructs. The questionnaire was not developed to
measure the study variables, and therefore, may lack some reliability and/or validity in the
concepts measured. However, given that the majority of indicator variables demonstrated
adequate factor loadings onto their latent variables, and the latent variables demonstrated
expected relations, it is likely that the measure provided adequate information regarding the
researched variables. With more reliable measures, error variance would likely be reduced;
therefore, the supported model within the current study would likely account for even greater levels of variance.

One limitation of the measure itself was its lack of information regarding perception of the stressors as being positive factors in the parent’s life and/or family functioning. Instead, the questions relating to perception of burden only provided options for the respondent to provide negative or neutral reactions. This artificially limits the actual variance found within the perceptions families can have of their child’s diagnosis. With this limited variance, relations between perception of burden and pile up of stressors, utilization or resources, and family functioning are potentially underestimated in the current study.

Directions for Future Research

Future research is warranted to further investigate the relations between the stressors a family experiences, their perception of the stressors, their utilization of various resources, and how each of these impacts the family. Specifically, given that perception of burden was the strongest indicator of family outcome, research should investigate perception of burden further. Positive, neutral, and negative perceptions should be considered, and implications of each should be explored. Research could assess growth experiences individuals and families have from the stressors they experience, and consider how these positive experiences could impact outcome variables.

Additional research could also consider factors associated with family functioning, and how best to conceptualize the functioning of a family. In the present study, family activities were not found to be a good indicator of the family’s level of functioning. It may be helpful to
delineate specific factors that impact this functioning, as well as why these factors are considered to be more significant indicators than others.

To minimize any diagnostic confusion and to better assess underlying constructs, measures specific to diagnosing autism and ascertaining information relating to family perceptions and functioning might be used to gain improved understanding of these factors. Additionally, it may be helpful to further differentiate various resources used by families. The current study only considered physician care, insurance, and social support; however, assessment of other resources may help to better conceptualize how varying resource access and utilization patterns impact familial outcomes.

Beneficial future research could also further consider how the perception of burden, once addressed in psychotherapy, could alter the family outcomes. Families could be recruited once their child is diagnosed with autism, and could be involved in psychotherapy as they adapt to the diagnosis. It would be important implement validated and reliable assessments to determine if the child meets criteria for autism to avoid any discrepancies there may be between diagnoses made by different care givers, such as psychologists, psychiatrists, and general practitioners. Participants could be given initial measurements of stressors, perceptions of the stressors, current use of resources, and family functioning, and could be assigned to either a control group or a treatment group. The treatment group could participate in therapy aimed at providing psychoeducation and helping them to reframe any negative reactions or perceptions of burden they have toward the diagnosis. Additionally, therapy could address the concepts shown to best indicate family functioning in the current study. Difficulties with parental coping, parental health, and family discord and disagreements could be addressed within the psychotherapy.
Following the treatment, families could then be reassessed with the same measures from the initial assessments. Results from initial assessments could be compared with post-treatment assessments, and results could be compared between the control group and treatment group. It is likely that therapy focused on perception of burden as well as on relational difficulties within the family would greatly improve the level of functioning within the families of children diagnosed with autism.

Conclusions

The present study provided support of a slightly modified double ABCX model of family functioning within a nationally representative sample of families of children with autistic disorder, thus increasing the generalizability of the model to a broader population within the United States. Pileup of stressors, perception of burden, and utilization of resources each have unique predictive ability for family functioning, with perception of burden demonstrating the highest amount of predictive ability. Therefore, lessening the family’s perception of burden within clinical settings will be important in improving family functioning. Additionally, resources utilized by a family can impact the familial outcome. Availability and utilization of a range of resources should be assessed and encouraged within this population to improve overall family functioning. Finally, family relational variables appear to be the best indicators of family functioning, and therefore, should be at the forefront when assessing and treating families.
REFERENCES


