# Factors Associated with Individual, Familial, and Community Well-Being of Youth with Autism Spectrum Disorder

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## Project Overview

Autism spectrum disorder (ASD) is characterized by difficulties with social communication and interaction and the presence of restricted, repetitive behaviors (American Psychiatric Association, 2013). Social communication and interaction encompass the appropriate use of verbal and nonverbal behaviors in a social context. Restricted, repetitive patterns of behavior or activities may be evidenced by stereotyped motor movements, challenges with transitions, and adverse responses to specific sounds. Children and adolescents with ASD can present with a broad spectrum of autism symptoms. The Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition (American Psychiatric Association, 2013) conceptualizes severity of autism symptoms as the amount of support required for each of the two ASD symptom domains (e.g., requiring very substantial support for deficits in social communication and requiring support for restricted, repetitive behaviors). Although symptom profiles vary, to receive a diagnosis of ASD, a child’s autism symptoms must have a significant negative impact on daily living and functioning. For example, youth with ASD have difficulty with developing and maintaining friendships. In addition, children and adolescents with ASD have difficulty adjusting to changes in routine or expectations. Together, these core symptoms have a negative impact on overall adaptive functioning or everyday skills needed to function independently (Bertollo et al., 2020; Kanne et al. 2011; Klin et al. 2007).

Additionally, autistic youth often have co-occurring physical (e.g., sleep and gastrointestinal problems), mental health (e.g., anxiety and depression), and neurodevelopmental conditions (e.g., language disorder and intellectual disability [ID]) which further impact their functioning (American Psychiatric Association, 2013; Bauman, 2010; Simonoff et al., 2008; Soke et al., 2018). For example, children and adolescents with autism and co-occurring attention-deficit/hyperactivity disorder (ADHD) experience poorer physical functioning, emotional functioning, school functioning, and social functioning than youth with ASD without ADHD (Sikora et al., 2012). This may be due to the addition of ADHD symptoms (e.g., inattention, hyperactivity, and impulsivity) further impeding the appropriate attention and response to social and nonsocial environmental cues. For example, youth with ASD and ADHD would likely have more difficulty sitting and actively engaging during classroom lessons than youth with ASD without ADHD. Similarly, children with ASD and co-occurring language disorder or ID would likely be more challenged to communicate effectively than children with ASD alone. Difficulties with effective communication impair one's ability to interact with others and meet one's needs (American Psychiatric Association, 2013; Liss et al., 2001). In sum, youth with ASD are challenged by the core symptoms of autism, as well as commonly co-occurring conditions.

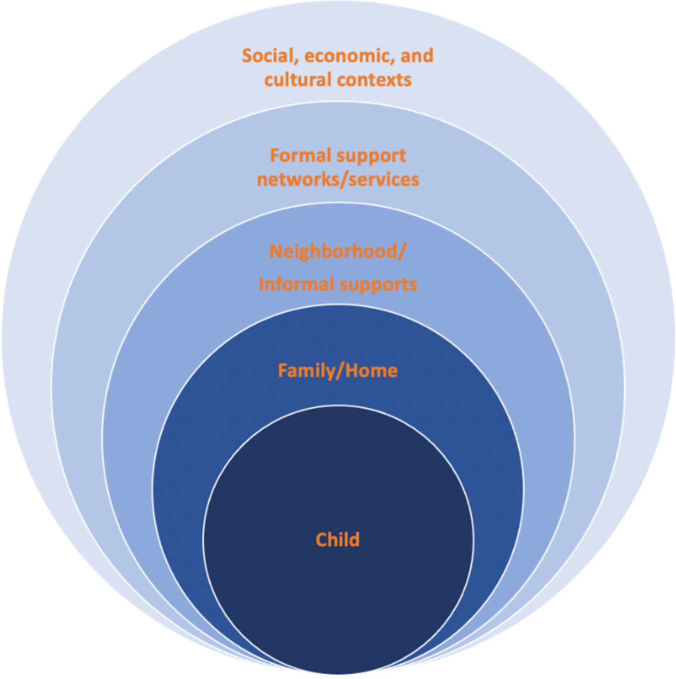
Despite these myriad challenges, youth with ASD also possess significant strengths (American Psychiatric Association, 2013; Bayat, 2007; Carter et al., 2015; Dawson et al., 2007; Urbanowicz et al., 2019). Parents of autistic youth have described their children as courageous, empathetic, and kind (Carter et al., 2015). Children and adolescents with ASD may demonstrate exceptional cognitive abilities and knowledge and skills in domains of special interest (Dawson et al., 2007; de Schipper et al., 2016; Kirchner & Dziobek, 2014; Urbanowicz et al., 2019). A worldwide survey of autism experts found that 92% of experts observed skills related to ASD in individuals on the autism spectrum (de Schipper et al., 2016). The experts indicated that individuals with ASD possess creative talents, artistic skills, good memory, and strong mathematical and technical abilities. The experts further remarked that these skills need to be actively recognized and nurtured so that autistic persons can maximize their potential. As children and adolescents with ASD have notable strengths and challenges, the construct of well-being is a fitting means of holistically describing their health.

Quality of life and well-being are often used interchangeably in the literature; they are multidimensional concepts that describe one's functioning and life satisfaction (Skevington & Bohnke, 2018). The construct of well-being incorporates an individual's physical health, psychological state, perceptions/beliefs, independence, and interactions with their social and nonsocial environment (WHOQOL Group, 1994). Assessment of well-being includes subjective (e.g., feeling angry or sad) and objective (e.g., grooming and participation in exercise) indicators of mental and physical condition (Varni et al., 2001; WHOQOL Group, 1994, 1995).

Studies have found that children and adolescents with autism experience worse well-being than the general pediatric population (Kamp-Becker et al., 2011; Shipman et al., 2011). Furthermore, research demonstrates that autistic youth have poorer well-being than youth with other diagnoses (Bastiaansen et al., 2004; Kuhlthau et al., 2010). Bastiaansen and colleagues (2004) found that children with ASD had poorer parent- and clinician-reported well-being than children with mood disorders, anxiety disorders, and attention-deficit and disruptive behavior disorders. Potential reasons for disparities in well-being experienced by autistic youth warrant further research.

Various models for human development and the development of well-being have been proposed. Biopsychosocial (Engel, 1980), bioecological (Bronfenbrenner, 1977), contextual (Lerner & Kauffman, 1985), and transactional systems theories (Sameroff, 1983) are several well-known human development models (Cuvo & Vallelunga, 2007). All these models theorize that individuals develop through multiple simultaneous and continuous transactions between the person and their environment, thereby causing both to change reciprocally over time. The

Figure 1. Figure depicting the dynamic and reciprocal associations among youth with ASD and their environments.



theoretical framework for this dissertation series is informed by the aforementioned commonality among models of development and hypothesizes that associations among youth with ASD and their environments are dynamic and reciprocal (see Figure 1). The strengths and challenges of autistic youth impact their functioning and the functioning of others in their ecology; and the well-being of youth with ASD is influenced by the characteristics of the individuals and systems with which they interact, as well as the larger social, economic, and cultural contexts in which they live.

Investigations into child-level, family-level, community-level, and policy-level factors associated with the well-being of autistic children and adolescents are worthy of further study. Such investigations could inform the development and implementation of interventions aimed at promoting wellness in youth with ASD and their families and communities. Therefore, the three papers in this dissertation series explore the interactions among the different levels of the ecology of autistic youth and well-being.

## Paper 1: Associations Between Domains of Health-Related Quality of Life and Co-occurring Emotional and Behavioral Problems in Youth with Autism Spectrum Disorder

Paper 1 in this dissertation series examined child-level factors within the theoretical framework (see Figure 1). More specifically, Paper 1 investigated relations between co-occurring emotional and behavioral problems (i.e., irritability, social withdrawal, stereotypic behavior, hyperactivity/noncompliance, and inappropriate speech) and varied domains of health-related quality of life (HRQoL; i.e., school functioning, physical functioning, social functioning, and emotional functioning) in children with ASD. Data for this project were previously collected as part of a study of a treatment-outcome tool for children with ASD (Mazurek et al., 2020). Five two-step hierarchical multiple regressions were conducted. Dependent variables were Pediatric Quality of Life Inventory 4.0 (PedsQL; Varni et al., 2001) HRQoL domains of physical functioning, emotional functioning, school functioning, and social functioning. Covariates (i.e., age, gender, IQ, and autism symptom severity) were entered at step 1. Entered at step 2 were the independent variables of interest: Aberrant Behavior Checklist (ABC; Aman & Singh, 1986) subscales of irritability, social withdrawal, stereotypic behavior, hyperactivity/noncompliance, and inappropriate speech. The study found that increased irritability was associated with poorer emotional and physical functioning in youth with autism. In addition, findings showed that greater social withdrawal was associated with worse social functioning. Furthermore, the study demonstrated that more hyperactivity/noncompliance was related to worse school functioning. Findings from Paper 1 indicate that co-occurring emotional and behavioral problems strongly relate to day-to-day well-being in autistic youth and should be considered when assessing HRQoL and well-being in this group.

In sum, Paper 1 examined associations between child-level factors (i.e., co-occurring emotional and behavioral problems) and well-being in youth with ASD. Paper 1 found that child-level factors were associated with well-being in children and adolescents with autism. However, examining only child-level factors in the theoretical framework would lead to an incomplete understanding of well-being in autistic youth by omitting potentially clinically relevant contextual information. As such, further investigations were needed to investigate relations among other factors in the ecology of autistic youth (e.g., family/home) and their well-being. Paper 2 was designed to address this gap.

## Paper 2: Relations among Co-occurring Psychopathology in Youth with Autism Spectrum Disorder, Family Resilience, and Caregiver Coping

Paper 2 in this dissertation series examined family-level factors within the theoretical framework (see Figure 1). More specifically, Paper 2 in this dissertation series investigated relations among commonly co-occurring mental health conditions (i.e., anxiety, depression, ADHD, and conduct/behavioral problems) in children and adolescents with ASD and caregiver coping (i.e., managing daily child-rearing demands). In addition, Paper 2 examined whether family resilience functions as a compensatory or protective factor in the associations among co-occurring psychopathology in autistic youth and the coping of their caregivers.

Data for this study were obtained from several waves of the National Survey of Children's Health (NSCH; United States Census Bureau, 2016, 2017, 2018). The NSCH is a nationally distributed caregiver report survey focused on the physical and emotional health of American youth and their families. For the NSCH, caregiver coping was operationalized as how well the caregiver was "handling the day-to-day demands of raising children (United States Census Bureau, 2016, 2017, 2018)." The NSCH family resilience variable was a composite measure based on caregivers' responses to four survey items. The first analysis conducted was a binary multiple logistic regression with caregiver coping as the dependent variable. Independent variables of interest were co-occurring anxiety, depression, ADHD, and behavioral/conduct problems in youth with ASD. The second analysis conducted was a binary multiple logistic regression to examine possible interactions between co-occurring mental health conditions in children with ASD and family resilience. All other included variables remained the same. As no significant interactions were found, the final model conducted was a binary multiple logistic regression with family resilience as an independent predictor of caregiver coping. Again, all other model variables were retained.

The study found that children and adolescents with ASD and co-occurring conduct problems or depression were significantly more likely to be cared for by adults who were not coping well with the daily demands of raising children. Additionally, results showed that high family resilience was an independent predictor or compensatory factor of caregiver coping. Nonetheless, the study further demonstrated that co-occurring conduct problems or depression in autistic youth were associated with worse caregiver coping even after accounting for the positive relationship between family resilience and caregiver coping. Findings from this investigation suggest that co-occurring conduct problems and depression in youth with ASD may overwhelm their caregiver’s ability to cope, and that family resilience interventions may improve the coping of adults caring for children and adolescents with autism.

In sum, Paper 2 examined relations among the family/home environment and the child with ASD. Aligned with the theoretical framework of this dissertation series (see Figure 1), Paper 2 found an association between autistic child-level factors and family-level factors. The functioning of youth with ASD, their parents, and their families were interconnected. Nonetheless, a third paper in this dissertation series was required to investigate the potential relationships between youth with ASD and their broader communities.

## Paper 3: Association Between Neighborhood Support and Family Resilience in Households with Children with Autism

As evidenced by Paper 2, families with children with ASD are able to demonstrate resilience in response to the myriad stressors they experience. However,  resilience among families of children with ASD has received little attention in the literature. Of note, no quantitative research has investigated predictors of resilience in families with autistic children and adolescents. A potential predictor of family resilience in households with autistic youth is neighborhood support. Therefore, Paper 3 of this dissertation series examined the potential association between neighborhood support and family resilience in households with children and adolescents with ASD. Analyses were completed using data from several waves of the NSCH (United States Census Bureau 2016, 2017, 2018, 2019). Several indicators of neighborhood support were utilized to create a composite (or latent) construct in a structural equation model (SEM). Included indicators were identified by the NSCH as measures of neighborhood support/neighborhood cohesion/social capital. Similarly, family resilience was a composite variable composed of indicators identified by the NSCH as aspects of family resilience. The study found a significant positive relationship between neighborhood support and family resilience. This suggests that interventions to promote informal support systems (e.g., neighborhood support) for families of children and adolescents with autism may improve these families' ability to demonstrate resilience and respond effectively to stressors.

In sum, Paper 3 investigated the relationship between the home environment/family functioning of autistic youth, and the neighborhoods in which youth with ASD live and the informal support systems with which their families engage. Paper 3 investigated neighborhood-level factors within the theoretical framework (see Figure 1) and indicated that neighborhood-level factors relate to the well-being of families with autistic children.

## Implications

This dissertation series is broadly focused on individual, familial, and community factors associated with well-being of autistic children and adolescents. Paper 1 studied the association between child-level factors and individual well-being in children and adolescents with autism. Paper 2 investigated associations among child-level, parent-level, and family-level characteristics in the functioning of households with ASD youth. Paper 3 examined the association between neighborhoods or informal support systems and well-being in families of youth with autism. Several theories of child development and well-being hypothesize that the interactions between youth and their environments are continuous and reciprocal (Bronfenbrenner, 1977; Lerner & Kauffman, 1985; Sameroff, 1983); through these transactions between the child and their environment/ecology, both change over time. Therefore, the functioning of children with ASD impacts and is impacted by their families, informal support systems, formal support systems and services, and their broader cultural contexts. Intervention to improve wellness at any level of the ecology of ASD youth will likely have further reaching positive results. For example, if policies are enacted that ensure the availability of evidence-based services, children and adolescents with autism, their families, and their communities may benefit. In sum, this dissertation series asserts that the associations among ASD child-level factors, home-level factors, community-level factors, and societal-level factors are dynamic and reciprocal. As such, these interconnections have implications for ASD supports, services, and policies.

## Limitations & Future Directions

Although this dissertation series contributes to the literature on well-being in youth with ASD, their families, and communities, it is limited by several factors. Most measures were parent-report; therefore, a risk of bias exists. Parents may intentionally (e.g., because of social desirability) or unintentionally (e.g., due to confabulation) deviate their report from direct assessment measures (Suchman, 1962). Direct assessments of child functioning were only available for Paper 1. Direct assessments of autistic child development and well-being were not accessible for Paper 2 and 3. Similarly, direct measures of family and neighborhood/community functioning were not available for Paper 2 and Paper 3. Future research would benefit from data obtained by directly observing interactions among youth with ASD, their families, and members of their informal support systems (e.g., neighbors, extended family members). Future research would additionally benefit from multi-rater (i.e., self, parent, teacher, neighbor, etc.) approaches and multi-method approaches, such as the combination of self-report and direct observation of functioning. This would reduce the risk of bias inherent to survey research (Suchman, 1962). Additionally, this dissertation series relied exclusively on cross-sectional data. Therefore, the bidirectional associations among child-level, family-level, community-level, and policy-level factors are hypotheses based on the theoretical framework; however, directionality/causality could not be tested. More research with longitudinal data is necessary to determine whether relations among the levels of the ecology of autistic youth are reciprocal. Furthermore, Paper 1 and Paper 2 did not investigate potential measurement issues. Only Paper 3 included measurement invariance analyses. As such, results of Paper 1 and Paper 2 may be confounded by differences in assessment/scale properties. Finally, this dissertation did not examine the potential impact of formal support systems/services and social, economic, and cultural contexts on the well-being of youth with ASD, their families, and their communities. One might test the full theoretical model by integrating measures of each level (i.e., child, family, informal support system, formal support system, and cultural context) into a single SEM. Future research in this area is warranted as the services and accommodations available to children and adolescents with ASD and their supporters is quite likely related to well-being in this population.

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# PAPER 1

## Associations between Domains of Health-Related Quality of Life and Co-occurring Emotional and Behavioral Problems in Youth with Autism Spectrum Disorder

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## Abstract

**Background**: Health-related quality of life (HRQoL) can be used as a measure of the impact of a particular disorder on one's daily functioning. Previous studies have found that co-occurring psychiatric disorders in children and adolescents with autism spectrum disorder (ASD) are associated with poorer HRQoL than ASD alone. Less is known about potential associations between specific symptoms of co-occurring psychopathology (i.e., emotional and behavioral problems) and domains of functioning or HRQoL in youth with ASD.

**Method**: Participants were 470 children with ASD 2-14 years old recruited from one of three sites. Hierarchical multiple regressions were conducted with Pediatric Quality of Life Inventory 4.0 (PedsQL; Varni et al., 2001) HRQoL domains of physical functioning, emotional functioning, school functioning, and social functioning as the dependent variables. Covariates were entered at step 1, followed by the independent variables of interest at step 2: irritability, social withdrawal, stereotypic behavior, hyperactivity/noncompliance, and inappropriate speech.

**Results**: The study found that increased irritability was associated with poorer emotional and physical functioning and that greater social withdrawal was associated with worse social functioning. Furthermore, findings showed that more hyperactivity/noncompliance was associated with worse school functioning.

**Conclusions**: Results demonstrated that certain emotional and behavioral symptoms are differentially associated with domains of HRQoL. This indicates that co-occurring emotional and behavioral problems should be considered when measuring HRQoL in children with ASD. It also

suggests that treating co-occurring emotional/behavioral problems could improve HRQoL and functioning in certain domains for this population.

## Introduction

Quality of life (QoL) is a comprehensive, multidimensional approach to subjectively evaluating psychosocial and physical well-being; it is an individual's perception of their well-being given their physical, psychological, and social context (WHOQOL Group, 1995). As health measurement has been broadened to include more than indicators of morbidity and mortality, the construct of QoL serves as a guiding framework for assessing overall well-being and life satisfaction (WHOQOL Group, 1994). Typically, QoL assessments incorporate indicators of physical, social, and emotional well-being; however, as a construct, QoL is an organizing concept rather than an objective index (Wallander, Schmitt, & Koot, 2001). Operationalization of QoL may vary across studies, and therefore must be clearly defined by the research team.

Although used interchangeably with the construct of quality of life in some publications, health-related quality of life (HRQoL) is more specific to the impact of a particular disease or disorder and its treatment on the daily functioning of an individual (Dey, Landolt, & Mohler-Kuo, 2012; Drotar, 2004). By contrast, QoL is a broader concept that can be applied to all children regardless of diagnostic classification and disease burden (Wallander et al., 2001). Specific definitions of HRQoL may differ; however, there is widespread agreement that HRQoL is a multidimensional construct with several domains. In the pediatric HRQoL literature, a number of domains have been studied including physical functioning, emotional functioning, social functioning, and school functioning (Bastiaansen, Koot, Ferdinand, & Verhulst, 2004; Dey et al., 2012; Ikeda, Hinckson, & Krägeloh, 2014; Wallander et al., 2001). Each domain consists of subjective and objective indicators of HRQoL, which are the factors measured. For example, physical functioning can include indicators of energy level and walking ability (Varni, Seid, & Kurtin, 2001).

Assessment of HRQoL is particularly well-suited to conditions that have a significant negative impact on multiple domains of everyday functioning, such as autism spectrum disorder (ASD), which is a pervasive developmental disorder characterized by impairment in social communication and a pattern of restricted and repetitive behaviors (American Psychiatric Association, 2013). Appropriately describing HRQoL and factors that influence HRQoL in individuals with ASD could improve subjective and objective outcomes in this population (Burgess & Gutstein, 2007). For individuals with ASD and their families, HRQoL is a meaningful measure of overall well-being.

A number of measures have been utilized to examine HRQoL as a multidimensional construct in children and adolescents with autism (Ikeda et al., 2014). In their review of the literature, Ikeda and colleagues (2014) determined that the Pediatric Quality of Life Inventory 4.0 (PedsQL; Varni et al., 2001) had been used the most frequently to investigate HRQoL in this population. In addition, the PedsQL was the only measure with established reliability and validity in youth with ASD (Kuhlthau et al., 2010; Shipman, Sheldrick, & Perrin, 2011).

Given their myriad of challenges, it is unsurprising that children and adolescents with ASD experience poorer HRQoL than the general pediatric population (Kamp-Becker et al., 2011; Kuhlthau et al., 2010, 2013; Shipman et al., 2011). Youth with ASD also experience poorer HRQoL than youth with other physical health conditions (Kuhlthau et al., 2010, 2013) and mental health conditions (Bastiaansen et al., 2004). Bastiaansen and colleagues (2004) found that children with a pervasive developmental disorder had poorer parent- and clinician-reported quality of life than children with diagnoses from other groups of psychiatric disorders including mood, anxiety, attention-deficit, and disruptive behavior disorders.

Research indicates that the severity of core symptoms of ASD is associated with measures of HRQoL (Kuhlthau et al., 2010, 2013). Kuhlthau and colleagues (2010) found an association between HRQoL and social responsiveness and repetitive behaviors in a sample of children and adolescents with autism. Parents of 286 youth (2-17 years old) with ASD completed the PedsQL (Varni et al., 2001), Social Responsiveness Scale (SRS; Constantino, 2005), and Repetitive Behavior Scale-Revised (RBS-R; Bodfish, Symons, & Lewis, 1999). There were significant negative correlations between the SRS and all areas of functioning measured by the PedsQL: physical functioning, emotional functioning, social functioning, and school functioning. Also, there were significant negative correlations between the RBS-R and PedsQL for all scales except school functioning. Findings indicate that increased problems with social responsiveness and repetitive behaviors are associated with poorer HRQoL in youth with ASD.

Several investigations have also found a significant correlation between HRQoL and psychiatric co-occurrence in youth with ASD (Kuhlthau, McDonnell, Coury, Payakachat, & Macklin, 2018; Kuhlthau et al., 2010, 2013). These studies indicate that more severe internalizing and externalizing symptomatology is associated with poorer HRQoL in a variety of domains (Kuhlthau et al., 2013), including physical functioning, emotional functioning, social functioning, and school functioning (Kuhlthau et al., 2010). Studies of the HRQoL of youth with ASD and specific psychiatric comorbidities, such as attention-deficit/hyperactivity disorder (ADHD; Sikora, Vora, Coury, & Rosenberg, 2012) and obsessive-compulsive disorder (OCD; Kuhlthau et al., 2018) have found similar results. Children with ASD and a co-occurring mental illness experienced worse HRQoL than those with ASD alone (Kuhlthau et al., 2018; Sikora et al., 2012).

Less is known about potential associations between specific symptoms of co-occurring psychopathology (i.e., emotional and behavioral problems) and domains of HRQoL in young people with ASD. Kuhlthau and colleagues (2013) found significant associations between parent-reported problem behavior, as measured by the Aberrant Behavior Checklist (ABC; Aman & Singh, 1986), and parents' assessment of their child's satisfaction and achievement, as measured by the Child Health and Illness Profile-Child Edition (CHIP-CE; Riley et al., 2004). It was found that specific emotional and behavioral problems were differentially associated with CHIP-CE subscale scores. For example, the stereotypic behavior subscale of the ABC had a significant negative association with the satisfaction and achievement subscales of the CHIP-CE. More severe stereotypic behavior, as measured by the ABC, was associated with poorer life satisfaction and achievement, as measured by the CHIP-CE. Nonetheless, this investigation had several limitations. The sample size was only 71 youth with autism; and the potential confound of intellectual functioning was not accounted for in statistical models. In addition, the CHIP-CE has not been validated in youth with ASD (Ikeda et al., 2014).

The present study aimed to examine potential associations between emotional and behavioral problems (i.e., irritability, social withdrawal, stereotypic behavior, hyperactivity/noncompliance, and inappropriate speech) and varied domains of HRQoL (i.e., school functioning, physical functioning, social functioning, and emotional functioning) in a large sample of youth with ASD. The PedsQL was used to assess HRQoL as it is the only measure of HRQoL with evidence of validity and reliability in youth with ASD (Bastiaansen et al., 2004; Limbers, Heffer, & Varni, 2009; Ikeda et al., 2014). It was hypothesized that greater hyperactivity/noncompliance would be associated with poorer school functioning as the ability to remain seated and attentive is a necessary skill to learn in the classroom. It was also hypothesized that higher social withdrawal and hyperactivity/noncompliance would be associated with poorer social functioning as children with ASD who are overactive may be more likely to engage in socially impulsive or intrusive behavior, while those who are withdrawn and aloof may have fewer opportunities for peer engagement. Finally, it was theorized that more irritability would be associated with poorer emotional functioning as irritability is predominantly an affective experience.

# Methods

## Participants

Data for this analysis were previously collected as part of a larger study focused on the psychometric properties of a treatment-outcome tool for autism, the results of which have been reported on by Mazurek and colleagues (2020). Participants were 470 youth 2-14 years of age (*M* = 6.80) recruited from one of three sites: (1) University of Missouri, (2) Rady Children's Hospital San Diego, and (3) Nationwide Children's Hospital. All participants were diagnosed with ASD according to Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition (DSM-5; American Psychiatric Association, 2013) criteria and met or exceeded clinical cut-off scores on the Autism Diagnostic Observation Schedule, Second Edition (ADOS-2; Lord et al., 2012).

## Measures

**Demographic characteristics.** Primary caregivers completed a demographic questionnaire designed for the original study, which included information about child age and gender.

**Intellectual ability.** Intelligence was assessed with either the Differential Ability Scales, Second Edition (DAS-II; Elliot, 2007) General Conceptual Ability score or the Mullen Scales of Early Learning (MSEL; Mullen, 1995) Early Learning Composite score depending on child age and ability. The DAS-II measures the cognitive abilities of youth across a range of developmental levels from 2 years, 6 months through 17 years, 11 months. The MSEL measures the cognitive and developmental functioning of children from birth to 68 months of age.

**Autism symptom severity.** The Social Responsiveness Scale, Second Edition (SRS-2; Constantino & Gruber, 2012) was utilized as a measure of autism symptoms. The SRS-2 is a 65-item caregiver-report assessment of ASD symptomatology, including social-communication impairment and stereotyped behaviors; and can be used as a continuous measure of overall ASD traits. The SRS-2 has demonstrated good validity (Constantino et al., 2003) and reliability (Constantino & Gruber, 2005).

**Co-occurring emotional and behavioral problems.** The Aberrant Behavior Checklist (ABC; Aman & Singh, 1986) was used to measure co-occurring emotional and behavioral symptoms. The ABC is a 58-item parent-report assessment of problem behavior among individuals with developmental disabilities. It comprises five subscales: irritability, social withdrawal, stereotypic behavior, hyperactivity/noncompliance, and inappropriate speech; and it has shown strong psychometric properties (Aman, Burrow, & Wolford, 1995).

**Health-related quality of life.** The Pediatric Quality of Life Inventory 4.0 (PedsQL; Varni et al., 2001) is a 23-item questionnaire designed to assess the HRQoL of children and adolescents 2-18 years old. It includes four age-appropriate versions (2-4 years old, 5-7 years old, 8-12 years old, and 13-18 years old) and takes approximately 5-10 minutes to complete. All versions use a 5-point rating scale for respondents to assess HRQoL over the previous month.

Scores are converted to a 0-100 scale with higher scores indicating better HRQoL. The PedsQL evaluates four distinct areas of health-related functioning: physical functioning, emotional functioning, school functioning, and social functioning. Due to the age and developmental ability of the sample, the caregiver-report version of the PedsQL was used in this study. The PedsQL is the only measure of HRQoL with established reliability and validity in youth with ASD (Ikeda et al., 2014).

## Data Analysis

Sample characteristics and means and standard deviations for ABC and PedsQL scales were generated (see Table 1). Five two-step hierarchical multiple regressions were conducted with PedsQL physical functioning, emotional functioning, school functioning, and social functioning as the dependent variables. Entered at step 1 were the covariates of age, gender, IQ, and SRS-2 T-score. Entered at step 2 were the independent variables of interest: ABC irritability, social withdrawal, stereotypic behavior, hyperactivity/noncompliance, and inappropriate speech. Shapiro-Wilk tests were utilized to examine the distribution of model residuals. If necessary, an outcome variable was transformed such that model residuals met the assumption of normality. Standardized beta coefficients, $R^2$, $\Delta R^2$, and p-values were reported.

Table 1. Sample characteristics (*N* = 470) and means and standard deviations for ABC and PedsQL

| | *M* (*SD*)/Frequency |
|---|---|
| Age | 6.80 (3.79) |
| Gender | |
| Male | 82.13% |
| Female | 17.87% |
| Race/Ethnicity | |
| White | 64.68% |
| Black | 5.32% |
| American Indian and Alaska Native | 0.21% |
| Asian | 4.04% |
| Native Hawaiian and Other Pacific Islander | 0.64% |
| Hispanic | 2.77% |
| Other | 1.91% |
| 2+ Race/Ethnicity | 18.94% |
| Not Reported | 1.49% |
| IQ | 84.56 (23.48) |
| IQ < 70 | 26.67% |
| IQ ≥ 70 | 73.33% |
| Vocabulary Size | |
| No Words | 4.89% |
| 1-5 Words | 5.53% |
| 6-25 Words | 6.60% |
| 26-100 Words | 9.36% |
| More Than 100 Words | 72.34% |
| Not Reported | 1.28% |

| | |
|---|---|
| SRS-2 Total T-score | 71.73 (12.21) |
| ABC | |
| Hyperactivity/Noncompliance | 18.64 (10.70) |
| Inappropriate Speech | 3.37 (2.82) |
| Irritability | 12.07 (9.43) |
| Social Withdrawal | 10.02 (7.55) |
| Stereotypic Behavior | 4.48 (4.37) |
| PedsQL | |
| Emotional Functioning | 65.09 (18.77) |
| Social Functioning | 53.71 (21.00) |
| School Functioning | 62.90 (19.42) |
| Physical Functioning | 73.99 (19.36) |

SRS-2: Social Responsiveness Scale-Second Edition, ABC: Aberrant Behavior Checklist, PedsQL: Pediatric Quality of Life Inventory 4.0

# Results

## Emotional Functioning

The hierarchical multiple regression revealed that at step 1, age, gender, IQ, and SRS-2 contributed significantly to the model, $F(4, 372) = 34.39$, $p < .001$, and accounted for 26.99% of the variance in PedsQL emotional functioning (see Table 2). Introducing ABC subscales (i.e., irritability, social withdrawal, stereotypic behavior, hyperactivity/noncompliance, and inappropriate speech) explained an additional 13.46% of the variance in emotional functioning; and this $\Delta R^2$ was significant, $F(5, 367) = 16.59$, $p < .001$. Of the independent variables of interest, ABC irritability was significantly associated with emotional functioning on the PedsQL ($\beta = -.36$, $p < .001$). Shapiro-Wilk test indicated that model residuals were normally distributed.

Table 2. Hierarchical multiple regression examining associations between co-occurring emotional and behavioral problems in youth with ASD and emotional functioning

| | *B* (*SE*) | β | $R^2$ | $\Delta R^2$ | *p* | $\eta_p^2$ |
|---|---|---|---|---|---|---|
| Step 1 | | | 0.27 | | < 0.001 | |
| Age | -0.01 (0.23) | 0.00 | | | 0.956 | |
| Gender | 2.88 (2.18) | 0.06 | | | 0.188 | |
| IQ | -0.23 (0.04) | -0.29 | | | < 0.001 | |
| SRS-2 Total T-Score | -0.83 (0.08) | -0.48 | | | < 0.001 | |
| Step 2 | | | | 0.13 | < 0.001 | |
| Age | -0.23 (0.22) | -0.05 | | | 0.299 | |
| Gender | 2.49 (2.00) | 0.05 | | | 0.214 | |
| IQ | -0.21 (0.03) | -0.27 | | | < 0.001 | |
| SRS-2 Total T-Score | -0.44 (0.10) | -0.25 | | | < 0.001 | |
| ABC Hyperactivity/Noncompliance | -0.01 (0.11) | -0.01 | | | 0.918 | .00 |
| ABC Inappropriate Speech | -0.56 (0.33) | -0.08 | | | 0.092 | .01 |
| ABC Irritability | -0.74 (0.12) | -0.36 | | | < 0.001 | .09 |
| ABC Social Withdrawal | -0.01 (0.14) | 0.00 | | | 0.953 | .00 |
| ABC Stereotypic Behavior | -0.12 (0.23) | -0.03 | | | 0.592 | .00 |

SRS-2: Social Responsiveness Scale-Second Edition, ABC: Aberrant Behavior Checklist, PedsQL: Pediatric Quality of Life Inventory 4.0

*B* (*SE*): unstandardized beta (standard error for the unstandardized beta), β: standardized beta, $R^2$: coefficient of determination, $\Delta R^2$: change in the coefficient of determination, *p*: probability value, $\eta_p^2$: partial eta squared

## Social Functioning

The hierarchical multiple regression revealed that at step 1, age, gender, IQ, and SRS-2 contributed significantly to the model, $F(4, 373) = 28.67$, $p < .001$, and accounted for 23.51% of the variance in PedsQL social functioning (see Table 3). Introducing ABC subscales (i.e., irritability, social withdrawal, stereotypic behavior, hyperactivity/noncompliance, and inappropriate speech) explained an additional 3.32% of the variance in social functioning; and this $\Delta R^2$ was significant, $F(5, 368) = 3.34$, $p = .006$. ABC social withdrawal was significantly associated with social functioning on the PedsQL (β = -.22, $p < .001$). Shapiro-Wilk test indicated that model residuals were normally distributed.

Table 3. Hierarchical multiple regression examining associations between co-occurring emotional and behavioral problems in youth with ASD and social functioning

| | *B* (*SE*) | β | $R^2$ | $\Delta R^2$ | *p* | $\eta_p^2$ |
|---|---|---|---|---|---|---|
| Step 1 | | | 0.24 | | < 0.001 | |
| Age | -0.27 (0.27) | -0.05 | | | 0.333 | |
| Gender | -0.73 (2.57) | -0.01 | | | 0.775 | |
| IQ | -0.03 (0.04) | -0.03 | | | 0.513 | |
| SRS-2 Total T-Score | -0.95 (0.10) | -0.47 | | | < 0.001 | |
| Step 2 | | | | 0.03 | 0.006 | |
| Age | -0.16 (0.28) | -0.03 | | | 0.576 | |
| Gender | -0.06 (2.55) | 0.00 | | | 0.981 | |
| IQ | -0.06 (0.04) | -0.07 | | | 0.166 | |
| SRS-2 Total T-Score | -0.70 (0.13) | -0.35 | | | < 0.001 | |
| ABC Hyperactivity/Noncompliance | 0.10 (0.14) | 0.05 | | | 0.486 | .00 |
| ABC Inappropriate Speech | -0.09 (0.43) | -0.01 | | | 0.836 | .00 |
| ABC Irritability | 0.07 (0.15) | 0.03 | | | 0.623 | .00 |
| ABC Social Withdrawal | -0.63 (0.18) | -0.22 | | | < 0.001 | .03 |
| ABC Stereotypic Behavior | -0.37 (0.29) | -0.07 | | | 0.203 | .00 |

SRS-2: Social Responsiveness Scale-Second Edition, ABC: Aberrant Behavior Checklist, PedsQL: Pediatric Quality of Life Inventory 4.0

*B* (*SE*): unstandardized beta (standard error for the unstandardized beta), β: standardized beta, $R^2$: coefficient of determination, $\Delta R^2$: change in the coefficient of determination, *p*: probability value, $\eta_p^2$: partial eta squared

## School Functioning

The hierarchical multiple regression revealed that at step 1, age, gender, IQ, and SRS-2 contributed significantly to the model, $F(4, 353) = 52.03$, $p < .001$, and accounted for 37.09% of the variance in PedsQL school functioning (see Table 4). Introducing ABC subscales explained an additional 2.81% of the variance and this $\Delta R^2$ was significant, $F(5, 348) = 3.25$, $p = .007$.

ABC hyperactivity/noncompliance was significantly associated with school functioning on the PedsQL (β = -.15, *p* = .022). Shapiro-Wilk test indicated that model residuals were normally distributed.

Table 4. Hierarchical multiple regression examining associations between co-occurring emotional and behavioral problems in youth with ASD and school functioning

| | *B* (*SE*) | β | $R^2$ | $\Delta R^2$ | *p* | $\eta_p^2$ |
|---|---|---|---|---|---|---|
| Step 1 | | | 0.37 | | < 0.001 | |
| Age | -1.98 (0.23) | -0.40 | | | < 0.001 | |
| Gender | 3.96 (2.19) | 0.08 | | | 0.071 | |
| IQ | 0.00 (0.04) | -0.01 | | | 0.903 | |
| SRS-2 Total T-Score | -0.70 (0.08) | -0.39 | | | < 0.001 | |
| Step 2 | | | | 0.03 | 0.007 | |
| Age | -2.17 (0.23) | -0.44 | | | < 0.001 | |
| Gender | 3.15 (2.17) | 0.06 | | | 0.148 | |
| IQ | 0.01 (0.04) | 0.01 | | | 0.898 | |
| SRS-2 Total T-Score | -0.54 (0.11) | -0.30 | | | < 0.001 | |
| ABC Hyperactivity/Noncompliance | -0.27 (0.12) | -0.15 | | | 0.022 | .01 |
| ABC Inappropriate Speech | 0.05 (0.35) | 0.01 | | | 0.896 | .00 |
| ABC Irritability | -0.16 (0.13) | -0.08 | | | 0.214 | .00 |
| ABC Social Withdrawal | 0.06 (0.14) | 0.02 | | | 0.686 | .00 |
| ABC Stereotypic Behavior | 0.09 (0.24) | 0.02 | | | 0.705 | .00 |

SRS-2: Social Responsiveness Scale-Second Edition, ABC: Aberrant Behavior Checklist, PedsQL: Pediatric Quality of Life Inventory 4.0

*B* (*SE*): unstandardized beta (standard error for the unstandardized beta), β: standardized beta, $R^2$: coefficient of determination, $\Delta R^2$: change in the coefficient of determination, *p*: probability value, $\eta_p^2$: partial eta squared

## Physical Functioning

Shapiro-Wilk test indicated that model residuals were not normally distributed; therefore, PedsQL physical functioning was squared and the hierarchical regression rerun. After transformation, model residuals followed the normal distribution. Hierarchical multiple regression found that at step 1, age, gender, IQ, and SRS-2 contributed significantly to the model, *F*(4, 373) = 24.57, $p < .001$, and accounted for 20.86% of the variance in physical functioning (see Table 5). Introducing ABC irritability, social withdrawal, stereotypic behavior, hyperactivity/noncompliance, and inappropriate speech explained an additional 3.61% of the variance; and this $\Delta R^2$ was significant, *F*(5, 368) = 3.52, $p = .004$. ABC irritability was significantly associated with physical functioning on the PedsQL ($\beta = -.19$, $p = .003$).

Table 5. Hierarchical multiple regression examining associations between co-occurring emotional and behavioral problems in youth with ASD and physical functioning[a]

| | *B* (*SE*) | β | $R^2$ | $\Delta R^2$ | *p* | $\eta_p^2$ |
|---|---|---|---|---|---|---|
| Step 1 | | | 0.21 | | < 0.001 | |
| Age | -93.78 (34.43) | -0.14 | | | 0.007 | |
| Gender | 258.83 (323.53) | 0.04 | | | 0.424 | |
| IQ | -9.90 (5.48) | -0.09 | | | 0.071 | |
| SRS-2 Total T-Score | -101.20 (12.16) | -0.41 | | | < 0.001 | |
| Step 2 | | | | 0.04 | 0.004 | |
| Age | -90.43 (34.90) | -0.13 | | | 0.01 | |
| Gender | 314.15 (320.64) | 0.05 | | | 0.328 | |
| IQ | -9.65 (5.56) | -0.09 | | | 0.083 | |
| SRS-2 Total T-Score | -72.63 (16.12) | -0.29 | | | < 0.001 | |
| ABC Hyperactivity/Noncompliance | 24.91 (17.45) | 0.10 | | | 0.154 | .01 |
| ABC Inappropriate Speech | -53.99 (53.50) | -0.06 | | | 0.313 | .00 |
| ABC Irritability | -55.99 (19.01) | -0.19 | | | 0.003 | .02 |
| ABC Social Withdrawal | -40.33 (22.04) | -0.11 | | | 0.068 | .01 |
| ABC Stereotypic Behavior | 15.89 (36.69) | 0.03 | | | 0.665 | .00 |

[a]Physical functioning (i.e., outcome variable) squared so that model residuals would follow the normal distribution

SRS-2: Social Responsiveness Scale-Second Edition, ABC: Aberrant Behavior Checklist, PedsQL: Pediatric Quality of Life Inventory 4.0

*B* (*SE*): unstandardized beta (standard error for the unstandardized beta), β: standardized beta, $R^2$: coefficient of determination, $\Delta R^2$: change in the coefficient of determination, *p*: probability value, $\eta_p^2$: partial eta squared

## Discussion & Implications

The current study sought to examine relationships between emotional and behavioral problems (i.e., irritability, social withdrawal, stereotypic behavior, hyperactivity/noncompliance, and inappropriate speech) and different domains of HRQoL (i.e., school functioning, physical functioning, social functioning, and emotional functioning) in a large sample of children with ASD. Results indicated that increased irritability was associated with poorer emotional and physical functioning. Not surprisingly, the study also found that greater social withdrawal was associated with worse social functioning. Furthermore, findings showed that more hyperactivity/noncompliance was associated with poorer school functioning.

As hypothesized, significant associations were found between irritability and emotional functioning in children and adolescents with ASD. Youth with autism who exhibited more irritability also demonstrated worse general emotional functioning. As irritability is often conceptualized as a predominately affective experience (Stringaris, 2011), this does not seem surprising. Nonetheless, formal definitions of *irritability* are scarce in the literature. Snaith and Taylor (1985) define *irritability* as a mood state characterized by reduced control over anger, which typically results in verbal and/or behavioral outbursts. In individuals with ASD, irritability is often associated with externalizing behaviors, such as tantrums and aggression (Fung et al., 2016; Owen et al., 2009); and these externalizing behaviors are commonly viewed as having a significant negative impact on others (Oldehinkel, Hartman, De Winter, Veenstra, & Ormel, 2004). However, the relationship between irritability and emotional functioning in youth with ASD suggests that irritability can be an outward behavioral manifestation of a negative internal feeling state; irritability may be an indicator of poor emotional well-being in young people with autism. It could also be that the emotional functioning subscale of the PedsQL (Varni et al.,

2001) and the irritability subscale of the ABC (Aman & Singh, 1986) are not measuring entirely distinct constructs. Both subscales include indicators of negative mood states (e.g., sad or depressed mood). As such, there is likely some overlap in the symptoms and behaviors assessed by the subscales.

The current results also demonstrated that greater irritability was associated with poorer physical functioning among children with ASD. Although this finding was not predicted, there is a well-established relationship between irritability and physical illness in individuals without autism (Cohen-Mansfield & Billig, 1986; Fava, 1987; Klein, Ziering, Girsh, & Miller, 1985; Mangelli et al., 2006). For example, studies have found an association between irritability and gastrointestinal disorders, endocrine disorders, and cardiovascular disorders (Fava, 1987; Mangelli et al., 2006). In persons with ASD, a relationship has been found between irritability and gastrointestinal symptoms (Chaidez, Hansen, & Hertz-Picciotto, 2014). This study did not examine the directionality of relationships between emotional and behavioral problems and HRQoL; thus, it is not known whether physical symptoms play a causal role in the development of irritability or whether irritability contributes to the occurrence of physical symptoms in children with ASD. Nonetheless, this investigation highlights the importance of health care providers assessing for medical conditions and physical impairment if youth with autism present with irritability.

As predicted increased hyperactivity/noncompliance was associated with worse school functioning in children and adolescents with ASD. In youth without ASD, hyperactivity and noncompliance have been found to have a significant negative impact on academic performance; hyperactivity and noncompliance can contribute to poorer task efficiency, assignment completion, and work accuracy (Austin & Agar, 2005; Greenwood, Horton, & Utley, 2002). In youth with ASD, Sikora and colleagues (2012) found that co-occurring ADHD, which is characterized by symptoms of hyperactivity and noncompliance, was associated with worse school, physical, emotional, and social functioning, as well as poorer overall HRQoL. Results from this study suggest that symptoms of hyperactivity and noncompliance in children with autism may not need to reach clinically significant levels to have a negative impact on school functioning. Health care providers and educators should collaborate to address hyperactive and noncompliant behaviors in school-age youth with ASD to support school and academic performance in this population.

Furthermore, as predicted, it was found that increased social withdrawal was associated with worse social functioning. While all children with ASD demonstrate social-communication challenges, their patterns of social behavior may vary; some children with autism actively attempt to engage socially, and some children with autism seek to avoid social engagement (Volkmar, Carter, Grossman, & Klin, 1997). When children with ASD are withdrawn and isolate themselves from peers, they have fewer opportunities to practice their social skills and learn through social reinforcement (e.g., attention, approval, and affection from others) (Katz, Conway, Hammen, Brennan, & Najman, 2011; Skinner, 1965). Social withdrawal is associated with myriad negative social consequences, including peer victimization (Dill, Vernberg, Fonagy, Twemlow, & Gamm, 2004) and lower quality friendships (Rubin, Wojslawowicz, Rose-Krasnor, Booth-LaForce, & Burgess, 2006). Therefore, social withdrawal is a worthwhile therapeutic target. Results from this investigation suggest that decreasing social withdrawal may improve social functioning and quality of life in youth with ASD.

It was also predicted that increased hyperactivity/noncompliance would be associated with worse social functioning in children with ASD; however, this study did not find a significant relationship between symptoms of hyperactivity and noncompliance and social functioning. This may be because the children with ASD in this study were relatively young overall (*M* = 6.80 years) and there may be fewer peer and social expectations for behavioral regulation at younger ages. There is positive growth in children's social skills from school-entry to the late-elementary years and into adolescence (Berry & O'Connor, 2010; Klimes-Dougan & Zeman, 2007). Social skills allow one to successfully initiate and maintain social interactions and relationships, and include such abilities as impulse control and interpersonal conflict resolution (Berry & O'Connor, 2010; Gresham & Elliott, 1990). Hyperactivity and noncompliance may have less impact on social functioning in younger children with autism as these behaviors are more normative early in social development. As children with ASD grow older and social expectations increase in complexity, it is possible that hyperactivity/noncompliance may have a greater impact on social performance.

The results of this study add to previous literature on HRQoL in autism by highlighting the additional burden of co-occurring emotional and behavioral symptoms and the negative associations between certain emotional/behavioral problems and domains of functioning. Nonetheless, this investigation did have several limitations. Participants were recruited from a small number of autism clinics; and, therefore, may not be representative of all children and adolescents with ASD. In addition, emotional and behavioral problems and HRQoL of youth with ASD were based on parent-report. However, it would not have been possible for all participants to provide self-report due to the inclusion of very young children and those with limited cognitive functioning.

In summary, this investigation examined relationships between several emotional and behavioral problems (i.e., irritability, social withdrawal, stereotypic behavior, hyperactivity/noncompliance, and inappropriate speech) and varied domains of HRQoL (i.e., school functioning, physical functioning, social functioning, and emotional functioning) in a large sample of young people with ASD. The results showed that certain emotional and behavioral symptoms are differentially associated with domains of HRQoL. This indicates that co-occurring emotional and behavioral problems should be considered when measuring HRQoL in children with ASD; and it also suggests that treatment of co-occurring emotional and behavioral problems may improve functioning in certain domains and HRQoL in children with ASD. As this study was cross-sectional, directionality could not be determined. Longitudinal studies of co-occurring symptoms and HRQoL in youth with autism would provide a better understanding of causality. Additionally, investigations of relationships between treatment of co-occurring emotional and behavioral symptoms and HRQoL in children and adolescents with ASD would further the field.

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# PAPER 2

# Relations Among Co-occurring Psychopathology in Youth with Autism Spectrum Disorder, Family Resilience, and Caregiver Coping

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## Abstract

**Background**: Co-occurring mental health problems are common in youth with autism spectrum disorder (ASD) and are associated with greater caregiver stress; however, it is not known whether such challenges overwhelm caregivers' ability to cope. Research has demonstrated that families of children with ASD are able to demonstrate resilience; yet, whether family resilience functions as a compensatory or protective factor in ASD families has not been investigated. This study aimed to examine the relations among family resilience, co-occurring psychopathology in youth with ASD, and caregiver coping.

**Method**: Data from this study were obtained from the 2016-2018 National Survey of Children's Health (NSCH). Multiple binary logistic regression was run to examine the associations among commonly co-occurring psychiatric disorders in youth with ASD (i.e., anxiety, depression, attention-deficit/hyperactivity disorder, and behavioral/conduct problems) and caregiver coping. Another multiple binary logistic regression was run to examine whether family resilience moderates the aforementioned relationships.

**Results**: Youth with ASD and co-occurring conduct problems or depression were significantly more likely to be cared for by adults who were not coping well. High family resilience was directly associated with lower odds of poor parental coping; nonetheless, co-occurring conduct problems and depression were still associated with worse coping of caregivers after accounting for family resilience.

**Conclusions**: Findings indicate that co-occurring depression and conduct problems in ASD youth may overwhelm their caregivers' coping resources. Results also suggest that interventions targeting family resilience may improve the coping of adults caring for children and adolescents with ASD.

## Introduction

Autism spectrum disorder (ASD) is a neurodevelopmental disorder characterized by significant social-communication deficits and repetitive, stereotyped behaviors (American Psychiatric Association, 2013). Youth with autism have difficulty in a number of areas including with play (Williams et al., 2001; Wing, 1996), processing of emotions and sensory input (Baron-Cohen et al., 2001; Philip et al., 2010), and developing and maintaining relationships (Bauminger & Kasari, 2000; Bauminger & Shulman, 2003). These challenges often require that caregivers provide additional support and scaffolding of skills for their children with ASD; and these increased child-rearing demands elevate risk for high levels of stress among caregivers (Hayes & Watson, 2013; Schieve et al., 2007).

Compounding the challenges of autism's core features, youth with ASD often exhibit significant symptoms of other physical and mental health disorders (Bauman, 2010; Leyfer et al., 2006; Simonoff et al., 2008). Over 95% of youth with ASD have at least one co-occurring condition (Soke et al., 2018). Anxiety and attention-deficit/hyperactivity disorder (ADHD) are among the most common co-occurring disorders in children and adolescents with autism. Anxiety affects between 11% and 84% of youth with ASD (van Steensel et al., 2011; White et al., 2009), and ADHD affects between 22% and 83% of youth with ASD (Sokolova et al., 2017). Depression and behavioral or conduct problems are also common in young people with ASD with prevalence estimates of 17% to 44% (Santomauro et al., 2016) and approximately 25% (Hill et al., 2014; Kaat & Lecavalier, 2013), respectively. Research indicates that co-occurring mental health problems in children and adolescents with ASD are associated with greater caregiver stress (Kring et al., 2009; Theule et al., 2010).

*Caregiver stress* can be defined as the experience of caregivers when addressing a situation appraised as threatening or demanding, particularly when a coping response is insufficient to decrease distress (Plant & Saunders, 2007). Previous research has indicated an association between elevated parental stress and negative parenting practices including decreased responsiveness and involvement with children (Ponnet, 2013), and child physical abuse (Mash et al., 1983). In addition, studies suggest a relation between greater caregiver stress and higher rates of psychiatric disorders (e.g., anxiety and depression) in caregivers (Gray, 2002; Vitaliano et al., 2003). Factors commonly associated with greater caregiver stress include household income (Smith et al., 2001) and single parent household status (Cairney et al., 2003; Weinraub & Wolf, 1983), as well as a variety of child characteristics (e.g., age, special health care need, and problem behavior [Anderson, 2008; Hayes & Watson, 2013]). Parents of children with autism report higher levels of caregiver stress than parents of typically developing children (Hayes & Watson, 2013; Woodman et al., 2015). In addition, caregivers of children with ASD report greater parenting stress than caregivers of children with other developmental conditions (e.g., Down syndrome and cerebral palsy) (Hayes & Watson, 2013). Studies have found that the severity of impairments in social communication and restricted/repetitive behaviors in youth with ASD is strongly associated with parental stress in caregivers (Davis & Carter, 2008; Estes et al., 2009; Gabriels et al., 2005; Lecavalier et al., 2006). Research has also indicated that the severity of co-occurring challenging behavior in children and adolescents with ASD is a significant stressor for caregivers (Estes et al., 2009, 2013).

Although caregivers of children and adolescents with ASD experience significant challenges and stressors, studies have found that they can also demonstrate effective coping in response to these stressors (Hall & Graff, 2011; Lai & Oei, 2014; Smith et al., 2008). For example, several studies have indicated that caregivers utilize social support (e.g., extended family and friends) (e.g., Lee, 2009; Lin et al., 2008; Mandell & Salzer, 2007) and cognitive reframing/reappraisal (i.e., modification of maladaptive thoughts) (e.g., Hall, 2012; Lee, 2009) to cope with stressors and the challenges associated with raising youth with ASD.

*Coping* refers to the use of thoughts and behaviors to respond to the demands of a situation that is perceived as stressful (Folkman & Moskowitz, 2004). For parents and guardians of youth, *caregiver coping* is more specific to managing the stress associated with the day-to-day demands of child-rearing (United States Census Bureau, 2016, 2017, 2018); these demands are substantial and include meeting basic survival (e.g., food, shelter, and medical care) and more complex social-emotional (e.g., emotional support) needs.

For caregivers of young people with autism, coping resources could be further strained by increased demands for support in child daily functioning necessitated by the core features of ASD and other frequently co-occurring symptoms (Lai & Oei, 2014). Research has indicated a relationship between child characteristics and parent coping approaches. Child age (Mandell & Salzer, 2007; Smith et al., 2008), gender (Mandell & Salzer, 2007), severity of ASD (Abbeduto et al., 2004; Lai & Oei, 2014), level of cognitive functioning (Boyd, 2002), and behavior problems (Boyd, 2002; Gray, 2006) have been found to be associated with caregiver coping styles or strategies. Previous studies have not, however, investigated whether the demographic and/or clinical characteristics of youth with autism influence their parents' ability to cope effectively. Therefore, it is not known if some child factors overwhelm caregivers' coping resources. As such, this study aimed to examine the association between commonly co-occurring mental health conditions (i.e., anxiety, depression, ADHD, and conduct/behavioral problems) in children and adolescents with ASD and caregiver coping. Additionally, this study sought to investigate the function of family resilience in the relationship between co-occurring psychiatric disorders in youth with ASD and the coping of their caregivers.

Living with a young person with ASD poses challenges for individuals other than primary caregivers (e.g., siblings), as the core and associated symptoms of ASD can disrupt multiple domains of family functioning and impact all individuals living in the home (Kapp & Brown, 2011). Despite these difficulties, research has shown that many families with children with ASD are able to demonstrate resilience (Bayat, 2007). Resilience can be defined as "a dynamic process encompassing positive adaptation within the context of significant adversity" (Luthar et al., 2000, p. 545), and it is applicable to both individuals and systems, such as families (Masten, 2014; Patterson, 2002). While family resilience is not a static trait and its demonstration may differ based on specific family and contextual factors, it can broadly be understood as the process of leveraging collective strengths in times of particular stress and ultimately, achieving some metric of success. Walsh (2003) highlights a few family factors that are hypothesized to promote the demonstration of resilience, including family belief systems (e.g., appraising challenges as manageable or choosing a hopeful outlook), organizational patterns (e.g., remaining connected within the family unit or drawing on other social networks), and communication/problem-solving (e.g., working through problems collaboratively or sharing personal emotional experiences with others in the family). Families who engage in processes that facilitate adaptive belief systems, organizational patterns, and collaboration/problem solving are more likely to be able to demonstrate resilience in response to a stressor (Walsh, 2003). Further, families who are able to demonstrate resilience often emerge from the stressor stronger and better able to handle future difficulties (Cowan et al., 1996). As an illustrative example, in a study of resilience in families of youth with ASD, Bayat (2007) found that 62% of families defined themselves as being closer due to having a child on the autism spectrum. One parent stated, “Through working together, we all learned how to help my son together. In some sense, this also makes our family closer, because an individual cannot handle the toughness alone” (Bayat, 2007, p. 709).

The question remains whether family resilience functions as an independent predictor (i.e., a compensatory factor) or a moderating variable (i.e., a protective factor) of coping in caregivers of youth with ASD. If family resilience serves as a compensatory factor, the capacity to demonstrate resilience, as evidenced by the leveraging of family strengths to achieve success in spite of a significant stressor, will directly relate to parent coping regardless of child co-occurring psychopathology diagnosis. Alternatively, if family resilience fits a protective factor model, it would differentially affect caregiver coping based on whether a child has a co-occurring psychiatric disorder. For example, the ability to demonstrate family resilience may only enhance coping of parents who have a child with co-occurring behavior problems.

No study has examined the potential relationship between resilience measured at the family level and caregiver outcomes in ASD families. Results from a study conducted by Halstead et al. (2018) suggest that resilience may be an independent predictor of caregiver coping in families with children and adolescents with ASD. Halstead and colleagues (2018) found that maternal resilience functioned as a compensatory factor of well-being in mothers of children with developmental disability and autism; maternal resilience had a significant main effect relationship with maternal well-being outcomes. Mothers who were more resilient exhibited more positive coping, as evidenced by fewer symptoms of stress, anxiety, and depression.

The relations among caregiver coping, psychiatric co-occurrence in youth with ASD, and family resilience have not yet been studied and warrant investigation. This study aimed to examine the association between commonly co-occurring mental health conditions (i.e., anxiety, depression, ADHD, and conduct/behavioral problems) in youth with ASD and caregiver coping. This investigation also sought to clarify whether family resilience functions as a compensatory or protective factor in the relationship between co-occurring psychiatric disorders in children and adolescents with ASD and the coping of their caregivers. As previous research has suggested that several parent, child, and family factors may be related to caregiver coping in this population, the following covariates were included in all models: child age, child race, child sex, child co-occurring intellectual disability (ID), caregiver age, caregiver sex, single parent household status, and household income. It was hypothesized that co-occurring psychopathology (i.e., anxiety, depression, ADHD, and behavior problems) in youth with ASD would be associated with poorer caregiver coping and, based on caregiver resilience literature, that family resilience would be a compensatory factor in this relationship.

# Methods

## Participants and Procedures

Data from this study were obtained from three waves of the National Survey of Children's Health (NSCH) – 2016, 2017, and 2018 (United States Census Bureau, 2016, 2017, 2018). The NSCH is a nationally distributed caregiver survey focused on the physical and emotional health of American children and adolescents. Of note, data from the NSCH are cross-sectional.

Households were mailed invitations for an adult in the household to go online to complete a short screener. This screener assessed the presence and number of children birth to age 17 living in the home, as well as child basic demographic characteristics and special health care needs. If a child or children lived in the household, caregivers were immediately directed to a more detailed, age-specific questionnaire. For households with more than one child, one was randomly selected to be the subject of this questionnaire; youth with special health care needs were oversampled to increase the sample size of these groups. All non-responding households received a reminder in the mail, and a mailed paper-and-pencil screener was provided if the household did not respond to two web survey invitations. In addition, caregivers could request a mailed copy of the screener and main questionnaire.

Analyses for this study were limited to children and adolescents 6-17 years of age (*M* = 12.22) with a current diagnosis of autism spectrum disorder. Individuals younger than 6 years were excluded as co-occurring psychopathology is less common in young children (Mayes et al., 2011). Participants included 2,173 children and adolescents from varied racial/ethnic and socioeconomic backgrounds (see Table 1).

Table 1. Sample characteristics

| | Total sample<br>M (SD)/Frequency | *Good Coping* group<br>M (SD)/Frequency | *Poor Coping* group<br>M (SD)/Frequency |
|---|---|---|---|
| n | 2,173 | 994 | 1,179 |
| Child age | 12.22 (3.32) | 12.25 (3.32) | 12.19 (3.33) |
| Child sex | | | |
| Male | 79.52% | 78.87% | 80.07% |
| Female | 20.48% | 21.13% | 19.93% |
| Child race | | | |
| White | 77.31% | 78.37% | 76.42% |

| | | | |
|---|---|---|---|
| Black/African American | 6.86% | 8.05% | 5.85% |
| American Indian/Alaska Native | 1.10% | 1.41% | .85% |
| Asian | 4.28% | 2.92% | 5.43% |
| Native Hawaiian/Other Pacific Islander | .23% | .30% | .17% |
| Some other race | 2.30% | 2.31% | 2.29% |
| Two or more races | 7.92% | 6.64% | 8.99% |
| Child ID | 18.05% | 15.69% | 20.03% |
| Caregiver age | 45.29 (8.89) | 45.09 (8.92) | 45.46 (8.86) |
| Caregiver sex | | | |
| Male | 26.93% | 26.50% | 27.30% |
| Female | 73.07% | 73.50% | 72.70% |
| Single parent | 17.09% | 17.03% | 17.14% |
| Family poverty ratio[a] | 267.36 (128.42) | 258.96 (130.76) | 274.44 (126.04) |

[a] Income of household as percentage of federal poverty level

## Measures

### *Demographic Information*

The NSCH gathered information on child, caregiver, and family/household demographics, including child age, child race, child sex, caregiver age, caregiver sex, single parent household, and household income.

### *Autism Diagnosis*

On the NSCH, respondents were asked whether they have ever been told by a health care professional that a child has autism, Asperger's Disorder, pervasive developmental disorder, or another autism spectrum disorder, and whether the child currently has the condition. Participants for this study were limited to youth who were reported by a caregiver to currently have the condition.

### ***Co-occurring Psychopathology and Intellectual Disability Diagnosis***

Similarly, co-occurring psychopathology and ID diagnosis were based on whether the caregiver responded to the NSCH that the child had ever been diagnosed by a health care provider with anxiety, depression, ADHD, behavioral/conduct problems, and/or ID, and that they currently had the condition.

### ***Caregiver Coping***

Caregiver coping was operationalized by the NSCH as how well the caregiver was “handling the day-to-day demands of raising children.” Categorical response options were “very well,” “somewhat well,” “not very well,” and “not very well at all.” For analysis, response categories were dichotomized to create groups of roughly equal size. Caregivers with *Good Coping* responded that they were handling daily child-rearing demands “very well.” Caregivers with *Poor Coping* responded that they were handling the daily demands of child-rearing “somewhat well,” “not very well,” or “not very well at all.”

### ***Family Resilience***

On the NSCH, family resilience was a composite measure based on respondents’ answers to the following four survey items: “When your family faces problems, how often are you likely to do each of the following?” (1) “talk together about what to do,” (2) “work together to solve our problems,” (3) “know we have strengths to draw on,” and (4) “stay hopeful even in difficult times.” Categorical response options were (a) “none of the time,” (b) “some of the time,” (c) “most of the time,” or (d) “all of the time.” In the NSCH data set, the family resilience composite variable had three levels: *Low Resilience*/0 = all or most of the time to 0-1 items; *Moderate Resilience*/1 = all or most of the time to 2-3 items; *High Resilience*/2 = all or most of the time to all 4 items.

## Data Analytic Plan

Descriptive statistics were generated for the total sample, as well as *Good Coping* and *Poor Coping* groups. Differences between *Good Coping* and *Poor Coping* groups in child co-occurring psychopathology were examined with chi-square tests.

To examine the relation between co-occurring psychopathology in youth with ASD and caregiver coping, a binary multiple logistic regression was run. Independent variables of interest were child anxiety, depression, ADHD, and behavioral/conduct problems. Based on theory and previous research, covariates were child age, child race, child sex, child ID, caregiver age, caregiver sex, single parent household, and household income. The dependent variable was caregiver coping, which was operationally defined as a respondent handling daily child-rearing demands "very well" vs. "somewhat well," "not very well," or "not very well at all." Pearson $\chi^2$ goodness-of-fit test was run to investigate model fit.

To investigate whether family resilience functions as a compensatory or protective factor in the association between co-occurring psychiatric disorders in youth with ASD and caregiver coping, a second binary multiple logistic regression model was run. In this model, possible interactions between co-occurring psychopathology (i.e., anxiety, depression, ADHD, and behavioral/conduct problems) and family resilience were examined. Caregiver coping was maintained as the outcome; and the same model covariates were utilized (i.e., child age, child race, child sex, child ID, caregiver age, caregiver sex, single parent household, and household income). Pearson $\chi^2$ goodness-of-fit test was run to investigate model fit. All analyses were completed with STATA I/C v. 16.

## Results

### Differences in Co-occurring Psychopathology in Youth with ASD Between Caregivers with *Good Coping* and *Poor Coping*

Chi-square tests indicated that the frequency of child anxiety ($\chi^2(1) = 20.49$, $p < .001$), depression ($\chi^2(1) = 22.26$, $p < .001$), ADHD ($\chi^2(1) = 9.05$, $p = .003$), and conduct problems ($\chi^2(1) = 49.62$, $p < .001$), were significantly greater in the *Poor Coping* group compared to the *Good Coping* group (see Table 2).

Table 2. Frequency of co-occurring psychopathology in youth with ASD for *Good Coping* and *Poor Coping* caregiver groups

| | *Good Coping* Frequency | *Poor Coping* Frequency |
|---|---|---|
| Anxiety | 40.88% | 59.12% |
| Depression | 34.82% | 65.18% |
| Conduct problems | 38.94% | 61.06% |
| ADHD | 42.48% | 57.52% |

### Associations Between Co-occurring Psychopathology in Youth with ASD and Caregiver Coping

Binary multiple logistic regression indicated that, accounting for child anxiety, child depression, child ADHD, child age, child race, child sex, child ID, caregiver age, caregiver sex, single parent household, and household income, conduct problems in a child with ASD was significantly associated with caregiver coping (B = .53, $p < .001$) (see Table 3). Child conduct problems was associated with 1.69 times greater odds that the caregiver was in the *Poor Coping* group (i.e., coping “somewhat well,” “not very well,” or “not very well at all” with daily demands of raising children). It was also found that child depression was significantly associated with caregiver coping (B = .47 , $p = .001$), after controlling for all other model predictors. Child depression was associated with 1.60 times greater odds that the caregiver was coping poorly. By contrast, anxiety and ADHD in a child with ASD were not significantly associated with caregiver coping over and above the effects of other considered variables. In addition, the covariates significantly associated with caregiver coping were household income (B = .001, $p = .012$), child ID (B = .28, $p = .023$), and child race, specifically Asian as compared to White (B = .77, $p = .002$). Pearson $\chi^2$ goodness-of-fit test indicated acceptable model fit ($\chi^2(1963) = 1981.89$, $p = .378$).

Table 3. Binary multiple logistic regression results examining the associations among co-occurring psychopathology in youth with ASD and caregiver coping

| | B (SE) | OR (95% CI) | *p* |
|---|---|---|---|
| Child anxiety | .17 (.11) | 1.19 (.96-1.46) | .105 |
| Child depression | .47 (.14) | 1.60 (1.22-2.11) | .001 |
| Child conduct problems | .53 (.10) | 1.69 (1.39-2.06) | <.001 |
| Child ADHD | .06 (.10) | 1.06 (.87-1.29) | .543 |
| Child age | -.01 (.02) | .99 (.96-1.02) | .442 |
| Child sex[a] | -.14 (.12) | .87 (.70-1.09) | .237 |
| Child race[b] | | | |
| Black | -.28 (.19) | .76 (.52-1.11) | .150 |

| | | | |
|---|---|---|---|
| American Indian/Alaska Native | -.53 (.45) | .59 (.24-1.42) | .236 |
| Asian | .77 (.25) | 2.16 (1.33-3.51) | .002 |
| Native Hawaiian/Other Pacific Islander | -.34 (.94) | .71 (.11-4.52) | .721 |
| Some other race | .15 (.30) | 1.17 (.64-2.11) | .612 |
| Two or more races | .33 (.17) | 1.39 (.98-1.95) | .061 |
| Child ID | .28 (.12) | 1.33 (1.04-1.70) | .023 |
| Caregiver age | .01 (.01) | 1.01 (.99-1.02) | .910 |
| Caregiver sex[c] | .00 (.11) | 1.00 (.81-1.24) | .987 |
| Single parent | -.02 (.13) | .98 (.76-1.26) | .854 |
| Family poverty ratio[d] | .00 (.00) | 1.00 (1.00-1.00) | .012 |

[a] Reference category = male

[b] Reference category = White

[c] Reference category = male

[d] Income of household as percentage of federal poverty level

### Associations Between Co-occurring Psychopathology in Youth with ASD and Caregiver Coping: The Effect of Family's Ability to Demonstrate Resilience

A binary multiple logistic regression was run with family resilience moderating the relationship between child conduct problems and caregiver coping, child depression and caregiver coping, child anxiety and caregiver coping, and child ADHD and caregiver coping (maintaining previous model covariates [i.e., child age, child race, child sex, child ID, caregiver age, caregiver sex, single parent household, and household income]); main effects of family resilience, child depression, child conduct problems, child anxiety, and child ADHD on caregiver coping were also examined. As no interaction terms (e.g., family resilience x child conduct problems) were significant, the interaction terms were removed; and the model was rerun. Binary multiple logistic regression indicated that, accounting for model covariates (i.e., child age, child race, child sex, child ID, caregiver age, caregiver sex, single parent household, and household income), child depression, child conduct problems, child ADHD, and child anxiety, family resilience was significantly associated with caregiver coping. A family that demonstrated *High Resilience* had 79% lower odds of a caregiver not coping well with the daily demands of raising children (i.e., being in the *Poor Coping* group) than a family that demonstrated *Low Resilience*. A family that demonstrated *Moderate Resilience* had 55% lower odds of a caregiver coping not well than a family that demonstrated *Low Resilience*. In addition, controlling for other model predictors, child conduct problems ($B = .46, p < .001$) and child depression ($B = .40, p = .005$) were significantly associated with caregiver coping. Child conduct problems was associated with 1.59 times greater odds that the caregiver was in the *Poor Coping* group (i.e., coping "somewhat well," "not very well," or "not very well at all" with daily demands of raising children). Child depression was associated with 1.50 times greater odds that the caregiver was not coping well. Anxiety and ADHD in a child with ASD were not significantly associated with caregiver coping over and above the effects of other considered variables. The covariates significantly associated with caregiver coping were household income ($B = .001, p = .007$), child ID ($B = .32, p = .014$), and child race, specifically Asian ($B = .74, p = .004$) and Black ($B = -.43, p = .033$) as compared to White. Pearson $\chi^2$ goodness-of-fit test indicated acceptable model fit ($\chi^2(1964) = 1986.52, p = .356$).

Table 4. Binary multiple logistic regression results examining the associations among co-occurring psychopathology in youth with ASD, caregiver coping, and family's ability to demonstrate resilience

| | B (SE) | OR (95% CI) | *p* |
|---|---|---|---|
| *High Resilience*[a] | -1.57 (.17) | .21 (.15-.29) | <.001 |
| *Moderate Resilience*[a] | -.79 (.20) | .45 (.31-.67) | <.001 |
| Child depression | .40 (.14) | 1.50 (1.13-1.99) | .005 |
| Child conduct problems | .46 (.10) | 1.59 (1.29-1.94) | <.001 |
| Child anxiety | .17 (.11) | 1.18 (.96-1.46) | .121 |
| Child ADHD | .04 (.10) | 1.04 (.85-1.27) | .711 |
| Child age | -.02 (.02) | .98 (.95-1.01) | .171 |
| Child sex[b] | -.17 (.12) | .84 (.67-1.06) | .143 |
| Child race[c] | | | |
| Black | -.43 (.20) | .65 (.44-.97) | .033 |
| American Indian/Alaska Native | -.63 (.47) | .53 (.21-1.35) | .183 |
| Asian | .74 (.25) | 2.10 (1.28-3.45) | .004 |
| Native Hawaiian/Other Pacific Islander | -.08 (.94) | .92 (.15-5.87) | .934 |
| Some other race | .11 (.32) | 1.12 (.60-2.10) | .712 |
| Two or more races | .32 (.18) | 1.37 (.97-1.95) | .078 |
| Child ID | .32 (.13) | 1.37 (1.07-1.77) | .014 |
| Caregiver age | .00 (.01) | 1.00 (.99-1.01) | .597 |
| Caregiver sex[b] | -.02 (.11) | .98 (.78-1.22) | .827 |
| Single parent | -.09 (.14) | .92 (.70-1.19) | .518 |
| Family poverty ratio[d] | .00 (.00) | 1.00 (1.00-1.00) | .007 |

[a] Reference category = *Low Resilience*

[b] Reference category = male

[c]Reference category = White

[d]Income of household as percentage of federal poverty level

## Discussion and Implications

This study aimed to understand the relationship between commonly co-occurring psychiatric conditions (i.e., anxiety, depression, ADHD, and conduct/behavioral problems) in youth with ASD and their caregivers' coping. In a large, national sample, results indicated that children and adolescents with autism and co-occurring conduct problems or depression were significantly more likely to be cared for by adults who were not coping very well with the daily demands of childrearing. This study also sought to determine whether family resilience functions as a compensatory (i.e., independent predictor) or protective factor (i.e., moderator) in the association between co-occurring mental health problems in youth with ASD and caregiver coping. Results revealed that family's ability to demonstrate resilience was a compensatory factor and directly associated with lower odds of worse caregiver coping. These results highlight the importance of understanding the impact of caring for a child with ASD and a co-occurring psychiatric disorder on parents' capacity to best raise all children in the home, and indicate that family resilience may be a valuable intervention target to improve ASD caregivers' ability to handle the day-to-day demands of raising children.

As hypothesized, co-occurring behavior problems in ASD youth was significantly associated with worse caregiver coping. Much research has indicated that the extent of problem behaviors exhibited by children and adolescents with autism is one of the most significant stressors for caregivers (e.g., Estes et al., 2009, 2013; Koegel et al., 1992; Lai & Oei, 2014). Behavioral and conduct problems can be so severe that a child with ASD and/or family members are at significant risk of harm. Even in the absence of dangerous challenging behaviors, parents may adapt their family's life to avoid triggering their child's problem behavior (Doubet & Ostrosky, 2015; Fox et al., 1997). For example, they may avoid leaving home due to frequent tantrums when in public. In addition, it is quite difficult for caregivers to obtain childcare if their child exhibits significant behavior problems (DeVore & Bowers, 2006). Reliable childcare and/or respite services reduce strain by providing temporary relief of caregiving burden (Botuck & Winsberg, 1991; Cowen & Reed, 2002). It may be that the significant stress and social isolation associated with caring for a child with ASD and co-occurring conduct problems overwhelms parents' ability to cope with childrearing demands. Alternatively, it could be that poor parental coping may exacerbate child behavior problems. The aforementioned relationships may also have bidirectional effects.

Findings also indicated that co-occurring depression in youth with ASD was related to poorer coping in caregivers. It may be that the symptoms of child depression are quite troubling for parents. Symptoms of pediatric depression may include feelings of sadness and worthlessness, as well as decreased energy and social responsiveness (American Psychiatric Association, 2013). A child or adolescent expressing self-deprecating thoughts and/or exhibiting social withdrawal may be quite distressing for parents. A further source of strain may be the dearth of evidence-based treatment options for depression co-occurring with ASD (Menezes et al., 2018; Menezes et al., 2020), particularly as compared to other commonly co-occurring mental health conditions in this population (e.g., anxiety and ADHD; Davis & Kollins, 2012; Ung et al., 2015; Vasa et al., 2014). As such, it is likely quite difficult for caregivers to locate providers who can deliver effective mental health services to their children with ASD and depressive symptoms. Research has demonstrated that decreased treatment access is associated with increased parental distress in caregivers of youth with autism (Iadarola et al., 2019; Zamora et al., 2014). Increased distress associated with difficulty obtaining services for depression co-occurring with ASD could have a significant negative impact on caregiver coping. Alternatively, parental distress and poor coping may result in negative effects on child mood. The relationship between poor caregiver coping and child depression may also be bidirectional.

Contrary to predictions, anxiety and ADHD co-occurring with ASD were not associated with worse caregiver coping. It is possible that these conditions do not interfere with family functioning over and above other common challenges associated with ASD. It could also be the case that families are able to access treatment options for these co-occurring conditions in their communities (Davis & Kollins, 2012; Storch et al., 2013; Ung et al., 2015; Vasa et al., 2014). For example, cognitive-behavioral therapy has demonstrated efficacy in treating anxiety co-occurring with autism (Storch et al., 2013; Ung et al., 2015), and psychostimulant medication has demonstrated efficacy in treating ADHD co-occurring with autism (Davis & Kollins, 2012; Santosh et al., 2006).

Findings supported the hypothesis that family's capacity to demonstrate resilience is an independent predictor (i.e., compensatory factor) of caregiver coping. Caregivers who endorsed that their families frequently use strategies associated with resilience were better able to cope with childrearing demands regardless of whether their child with ASD had co-occurring conduct problems or depression. Family resilience enables the family system to adapt successfully to conditions that threaten system function (Luthar et al., 2000; Matsen, 2014). If the family system is functioning well, caregivers may be better able to cope with their responsibilities. These findings indicate future directions for research on targeted intervention and critical support for families of youth with ASD and other co-occurring diagnoses. Building family resilience could be considered as a target for future intervention studies. Although resilience was once considered a static trait, research suggests that resilience can be developed (Bayat, 2007; Matsen, 2014).

Nonetheless, findings indicated that co-occurring depression and behavioral concerns in youth with ASD were associated with worse caregiver coping, even after accounting for the positive relationship between family resilience and the coping of caregiving adults. This suggests that co-occurring depression and behavior problems in children and adolescents with ASD may place such an additional burden to caregiving demands that the conditions overwhelm the coping resources of parents. Alternatively, there may be complex and potentially bidirectional relations among child, caregiver, and family behaviors and functioning. Longitudinal research is needed to better understand how these variables interact over time. Regardless of the timing or directionality of these associations, the current results highlight the importance of the accessibility of high-quality intervention services for depression and behavior problems in children with autism. The effective treatment of co-occurring depression and conduct problems in youth with ASD may improve parents' ability to cope and care for all their children. Future intervention studies targeting co-occurring depression and challenging behavior in youth with autism should consider measuring family- and caregiver-level outcomes. Similarly, caregiver- and family-level interventions to improve resilience and coping should assess potential improvements in child mood and behavior.

This study adds to the literature by examining the relationships among caregiver coping, psychiatric co-occurrence in youth with ASD, and family resilience. Nonetheless, it was limited by several factors. Although the study benefitted from a large and nationally derived sample, due to the nature of nationwide survey research, all diagnoses were caregiver-reported. Direct assessments or diagnostic verification of ASD and co-occurring mental health conditions were not available. In addition, caregiver coping was indicated by a single question with few categorical response options; however, this question was a direct and likely valid assessment of caregiver’s perception of their coping. Similarly, assessment of family resilience was categorical rather than continuous. Finally, this investigation was cross-sectional; as such, the causal direction of observed relations among variables cannot be determined. Future longitudinal research is needed to thoroughly examine the complex relations among co-occurring psychopathology in children and adolescents with ASD and caregiver and family functioning.

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## PAPER 3

# Association Between Neighborhood Support and Family Resilience in Households with Children with Autism

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# Abstract

The capacity of ASD families to demonstrate resilience is a notable strength that has received little attention in the literature. A potential predictor of family resilience in households with youth with ASD is neighborhood support. This study examined the relationship between neighborhood support and family resilience in households with ASD youth utilizing data from the National Survey of Children's Health. A structural equation model was constructed as neighborhood support and family resilience were latent variables. Findings demonstrated that neighborhood support significantly predicts family resilience. This study contributes to the literature as the first quantitative investigation of predictors of ASD family resilience. Strengths in youth with ASD, their families, and their communities can be and should be leveraged to address challenges.

Children and adolescents with autism spectrum disorder (ASD) have difficulties with social communication and behavioral rigidity (American Psychiatric Association, 2013), and often experience symptoms of commonly co-occurring physical and mental health conditions (Matson & Goldin, 2013). Given these various difficulties, it is unsurprising that youth with ASD often experience worse quality of life than the general pediatric population (Kuhlthau et al., 2010, 2013). Studies have also found that youth with autism experience worse objective and subjective well-being than youth with other diagnoses (e.g., diabetes, anxiety) (Bastiaansen et al., 2004; Cottenceau et al., 2012; Ikeda et al., 2014).

In addition, the symptoms associated with ASD impact the daily lives and functioning of all individuals in the home (Bayat, 2007; Hayes & Watson, 2013; Menezes et al., 2021; Shivers et al., 2019). Research has found that parents and siblings of young people with autism report stressful life conditions (Bayat, 2007; Benderix & Sivberg, 2007; Hayes & Watson, 2013; Shivers et al., 2019). The need to provide additional supports and accommodations for the individual with ASD due to their social-emotional and behavioral challenges can be emotionally and financially taxing for family members (Bayat, 2007).

Research indicates that some specific behavioral characteristics of youth with ASD are associated with well-being in their family members (Estes et al., 2009; Ross & Cuskelly, 2006). For example, more severe impairments in social communication and restricted/repetitive behaviors in children and adolescents with ASD are associated with poorer caregiver mental health and sibling adjustment (Benson & Karlof, 2008; Davis & Carter, 2008; Estes et al., 2009; Pilowsky et al., 2004). Research has also shown that lower cognitive functioning and more severe challenging behavior in youth with ASD are associated with increased stress in their parents and siblings (Estes et al., 2009, 2013; Mascha & Boucher, 2006; Ross & Cuskelly, 2006). However, despite significant stressors and challenges, youth with ASD and their family members often thrive (Bayat, 2007; Lai & Szatmari, 2019).

Many individuals with ASD live fulfilling lives (Lai & Szatmari, 2019). Siblings and parents of youth with autism are often well-adjusted (Bayat, 2007). Research suggests that having a brother or sister with ASD enhances empathy and prosocial behavior in siblings without ASD (Orm et al., 2021). In addition, many parents believe having a child with ASD brings their family closer (Bayat, 2007). Families of children with ASD often work together and utilize their strengths during difficult times; they demonstrate resilience.

Much research on youth with ASD and their families has focused on stressors (e.g., Bouma & Schweitzer, 1990; Griffith et al., 2010; Lee et al., 2009; Rao & Beidel, 2009; Wolf et al., 1989); far fewer studies have explored resilience processes and positive adaptations to challenges in this population (Riosa et al., 2017). There has been a limited focus on assessing and intervening to promote strengths in individuals with autism and their families (Urbanowicz et al., 2019); however, autistic advocates and scholars contend that individuals with autism and their families have not only limitations, but also strengths (Bayat, 2007; Pellicano & Stears, 2011; Urbanowicz et al., 2019). If these strengths are identified, they can be utilized to address difficulties. A family's ability to demonstrate resilience is one strength that is worthy of further investigation and is an area of research aligned with the priorities of the autistic community (Pellicano & Stears, 2011; Urbanowicz et al., 2019).

Family resilience refers to a family's capacity to cope with challenges and flourish despite adversity (Patterson, 2002). The family resilience framework proposed by Walsh (2003) suggested that several factors promote a family's ability to demonstrate resilience: communication (e.g., collaborative problem-solving), shared belief systems (e.g., positive outlook), and organizational patterns (e.g., connectedness). Utilizing qualitative methods, Bayat (2007) surveyed parents and other primary caregivers of youth with autism and found strong evidence of family resilience. Families of children and adolescents with ASD pooled their resources and worked together to solve problems; they made positive meaning out of adverse situations; and they defined themselves as being closer due to having a child with ASD. Bayat (2007) also found that family resilience improved over time as family members adjusted to the child's unique needs. In addition, Kapp and Brown (2011) similarly used qualitative methods and surveyed mothers of youth with ASD on their perception of their family's resilience. Findings indicated that family time, the spousal relationship, and social support (e.g., from extended family members, support groups) were significant resilience resources.

To date, no quantitative research has investigated predictors of family resilience in households of children with ASD, which is a notable gap in the literature. Studies of families in the general population indicate that several factors are associated with family resilience. Family racial/ethnic background, physical and/or mental health condition(s) in a family member, socioeconomic status, and having a two-parent versus single-parent household are well-established predictors of family resilience in households without youth with ASD (Goldstein et al., 2021; Ungar, 2013; Walsh, 2016). As such, these factors may also be associated with resilience among families of children with ASD.

A potential predictor of family resilience that has received little attention in the literature is neighborhood support. Neighborhood support may improve family resilience by ensuring safety of family members in the neighborhood through shared expectations for supervision and monitoring. Neighborhood cohesion likely minimizes community violence, which is a well-known family stressor (e.g., Margolin & Gordis, 2000).

Studies have investigated the relationship between neighborhood cohesion and other aspects of family functioning. Using structural equation modeling (SEM), Fan and Chen (2012) examined associations between neighborhood conditions and family factors in a sample of over 50,000 youth with data from the 2007 National Survey of Children's Health (NSCH). Neighborhood support was a composite variable of several survey items that assessed the perceived availability of informal social support. Family functioning was also a composite variable and was indicated by items assessing parenting issues (e.g., coping with parenting demands) and family activities (e.g., eating meals together). The results indicated that neighborhood support/social cohesion was significantly associated with improved family functioning.

In households with children and adolescents with ASD, the social networks in supportive neighborhoods may offer opportunities for social participation and the transmission of information about services available in the community. As such, neighborhood support and cohesion would likely be associated with aspects of family functioning in households of youth with ASD. Whitehead (2017) investigated the association between neighborhood support and family functioning in this population utilizing data from the 2007 and 2011-2012 NSCH. Mothers of children with ASD who perceived their neighborhood as supportive reported better family functioning. The operationalizations of neighborhood support and family functioning were similar to that of Fan and Chen (2012). Of note, the alpha coefficient for the family functioning index utilized by Whitehead (2017) did not meet the minimally reliable cutoff; therefore, Whitehead (2017) asserted that results should be interpreted with caution.

The potential relationship between neighborhood support and family functioning in households with youth with ASD has not been sufficiently studied. Only one study has examined the association between neighborhood cohesion and family functioning in this group, and the results were of questionable reliability. The potential association between neighborhood support and resilience in families with children and adolescents with ASD has yet to be investigated, and the study of family resilience is a strengths-based research-practice perspective aligned with the priorities of the autistic community. Therefore, this study utilized SEM to examine the potential association between neighborhood support and family resilience in households of youth with ASD. Given that previous research has found that social support promotes resilience in families with children and adolescents with autism, it was hypothesized that neighborhood support would be associated with greater resilience among families (Kapp & Brown, 2011).

## Methods

### Participants and Procedures

Secondary data analysis was conducted utilizing data from the 2016, 2017, 2018, and 2019 NSCH (United States Census Bureau 2016, 2017, 2018, 2019), a nationally distributed caregiver-report survey of the physical and mental health of American youth and their families. Data are cross-sectional as information was not obtained about the same children and adolescents across the four waves of data collection.

For each wave of the NSCH, invitations were mailed for an adult in the household to complete a short online screener. The screener assessed the number of children and adolescents in the home (i.e., individuals under the age of 18), as well as child demographic characteristics and special health care needs. If youth lived in the home, caregivers were immediately directed to a more detailed questionnaire. For households with more than one child, one was randomly selected to be the target of the survey; however, youth with special health care needs (including

ASD) were oversampled to increase the sample size of these groups (NSCH; United States Census Bureau 2016, 2017, 2018, 2019).

Analyses for this study were limited to families in which the subject of the questionnaire was a child or adolescent with ASD. The sample included 3,247 youth and their families, who were representative of diverse racial/ethnic and socioeconomic backgrounds (see Table 1).

Table 1. Sample characteristics

| | M (SD)/Frequency |
|---|---|
| Child age | 11.32 (4.08) |
| Child gender | |
| Male | 80.14% |
| Female | 19.86% |
| Child race | |
| White | 76.84% |
| Black | 7.67% |
| American Indian/Alaska Native | 1.05% |
| Asian | 4.03% |
| Native Hawaiian/Other Pacific Islander | .28% |
| Some other race | 1.85% |
| Two or more races | 8.28% |
| Autism symptom severity | |
| Mild | 51.09% |
| Moderate/Severe | 48.91% |
| Co-occurring intellectual disability | 16.68% |
| Co-occurring conduct problems | 54.59% |

| | |
|---|---|
| Parent/Respondent gender | |
| Male | 27.38% |
| Female | 72.62% |
| Single parent household | 16.60% |
| Family poverty ratio[a] | 263.01 (128.98) |

[a] Income of household as percentage of federal poverty threshold

## Measures

### *Demographic Information*

The NSCH gathered information on youth and family/household demographics, including child age, child race, child sex, single parent household, and household income.

### *Diagnostic Information*

Caregivers were asked whether they had ever been told by a qualified health care provider that the child had specific conditions, including autism, intellectual disability (ID), behavioral/conduct problems, and a range of other diagnoses. If a history of a specific diagnosis was endorsed, respondents were also asked whether the child currently had the condition. The current analysis was limited to families who had a child or adolescent with a current diagnosis of autism who was the target of the 2016-2019 NSCH.

### *Autism Symptom Severity*

Respondents were asked to rate the severity of their child's autism on the NSCH. The two response options were *mild* and *moderate/severe*.

### *Neighborhood Support*

Several indicators of neighborhood support were used to create a composite (or latent) variable using SEM (see Figure 1). Included indicators were identified by the NSCH as measures of neighborhood support/neighborhood cohesion/social capital. The latent variable for neighborhood support was estimated based on self-reported levels of agreement with three statements (items): (1) *People in this neighborhood help each other out*, (2) *We watch out for each other's children in this neighborhood*, and (3) *When we encounter difficulties, we know where to go for help in our community*. Respondents were asked whether they definitely agree, somewhat agree, somewhat disagree, or definitely disagree with each statement (see Appendix A).

### ***Family Resilience***

Family resilience was also treated as a latent variable estimated based on several indicators from the NSCH (see Figure 1). Indicators were items identified by the NSCH as assessing family resilience. The family resilience latent variable was estimated based on responses to the following four survey items: “When your family faces problems, how often are you likely to do each of the following?” (1) *Talk together about what to do*, (2) *Work together to solve our problems*, (3) *Know we have strengths to draw on*, and (4) *Stay hopeful even in difficult times*. Response options to the four items were none of the time/some of the time, most of the time, or all of the time (see Appendix A).

## **Data Analytic Plan**

An SEM was constructed given neighborhood support and family resilience were treated as latent variables (see Figure 1). SEM was performed in Mplus (version 8.3) with weighted least squares means and variance adjusted (WLSMV) estimation. WLSMV is a robust estimator and is well-suited to modeling categorical data (Brown, 2006).

In the measurement model, two latent variables (i.e., neighborhood support and family resilience) were created. Neighborhood support was based on three indicators (i.e., survey items) and family resilience was based on four indicators (i.e., survey items) described in the Measures section. Measurement invariance was tested by family household income (i.e., top versus bottom halves of the income distribution). The item parameters associated with neighborhood support and family resilience showed evidence of invariance (see Appendix B).

Treating neighborhood support and family resilience as latent variables has several benefits, including that such an approach helps account for measurement error, does not necessarily assume all items should be weighted equally when situating individuals on the latent continuum, and allows one to include participants in the model even if not all items were completed (McNeish & Wolf, 2020). Research further shows that producing scores outside a latent variable framework, and in particular by simply adding up item responses, often makes untenable assumptions about the nature of the construct that can bias estimates of interest (McNeish & Wolf, 2020; Soland, 2022).

As shown in Figure 1, latent variables were utilized as part of a structural model to examine the relationship between family resilience and neighborhood support. Based on theory and research, we fit a model in which neighborhood support predicted family resilience. Though not included in the path diagram, child age, child sex, child race, autism symptom severity, co-occurring ID, co-occurring conduct problems, single parent household, and family household income were included as covariates in the prediction of family resilience. Model fit was assessed with Comparative Fit Index (CFI), Root Mean Square Error of Approximation (RMSEA), and Standardized Root Mean Square Residual (SRMR). CFI >0.95, RMSEA <0.06 and SRMR <0.08 are indicative of good overall fit (Hu & Bentler, 1999; Steiger, 1990; West et al., 2012).[1]

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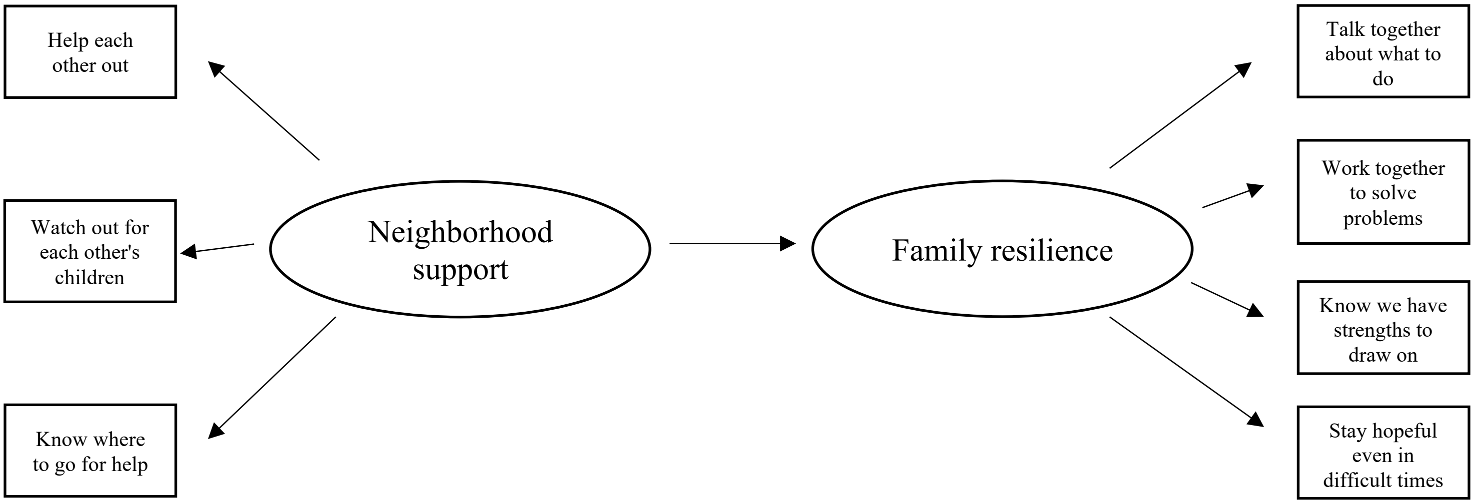
[1] We utilized these fit statistic cutoffs bearing in mind that they are not universally applicable, and they should be adjusted based on the nature of the model being fit (McNeish & Wolf, 2021).

Figure 1. Path diagram for association between neighborhood support and family resilience in households with children with autism. Model covariates and residuals are not depicted for parsimony[a].



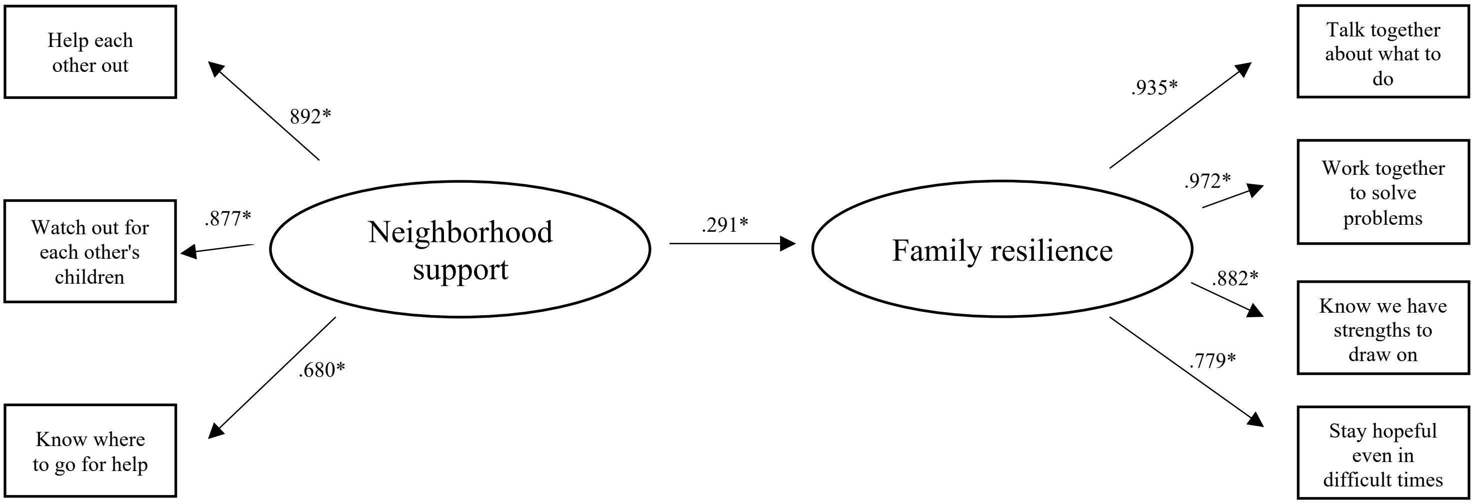
[a]Child age, child sex, child race, autism symptom severity, co-occurring ID, co-occurring conduct problems, single parent household, and family household income were included as covariates in the prediction of family resilience.

## Results

Figure 2 replicates Figure 1, but includes Mplus's fully standardized version of the estimates (that is, the total variance [residual plus explained] of both the indicators and latent variables is rescaled to have a variance of 1). Standardized factor loadings on neighborhood support ranged from .680 to .892. Standardized factor loadings on family resilience ranged from .779 to .972. This demonstrates that the latent variables explained between 46% and 94% of the variance in the observed item responses, with only one item explaining less than 60% of the variance. Overall model-fitting criteria for the SEM were additionally indicative of good fit: CFI = .990; RMSEA = .048; SRMR = .051 (Hu & Bentler, 1999; Steiger, 1990; West, Taylor, & Wu, 2012).

Returning to Figure 2, in households with children and adolescents with ASD, neighborhood support was significantly associated with family resilience (β = .291, *p* < .001) accounting for covariates. More specifically, every one standard deviation increase in neighborhood support was associated with a .291 standard deviation increase in family resilience.

Figure 2. Structural equation model for association between neighborhood support and family resilience in households with children with autism. Model covariates and residuals are not depicted for parsimony[a].



[a]Child age, child sex, child race, autism symptom severity, co-occurring ID, co-occurring conduct problems, single parent household, and family household income were included as covariates in the prediction of family resilience.

$^{*}p < .001$

## Discussion

This study sought to understand whether neighborhood support was associated with family resilience among households of youth with ASD. In a large national sample, the results indicated that greater neighborhood support related to better family resilience in households with children and adolescents with autism. These findings highlight the importance of informal support systems for the well-being of families of children with ASD.

As hypothesized, the SEM results indicated that neighborhood support significantly predicted family resilience. In households of youth with ASD, resilient families may obtain social support from their neighborhoods/communities. Extended kin and social networks in families' communities may provide information about services and supports, companionship, and respite for parents from caregiving demands (Luthar et al., 2000). Supportive neighborhoods can mitigate stressors for families of youth with ASD and may help them better respond to adversity (i.e., demonstrate resilience). As directionality and causality cannot be determined from this cross-sectional analysis, it is also possible that families with a stronger capacity for resilience may also give back to their communities and actively contribute to the strength of their neighborhoods. There may further be a complex interaction between neighborhood support/neighborhood cohesion/social capital and a family's capacity to demonstrate resilience. Community connectedness is a function of the relations among individual residents and collective cohesion and efficacy (e.g., shared expectations for socially altruistic behaviors; Sampson, 2013).

Particularly for families who experience myriad challenges, such as families of youth with ASD, the capacity to respond adaptively to adverse experiences and demonstrate resilience is valuable. This study suggests that interventions to improve neighborhood support could promote resilience processes in families of children with ASD. Although not specific to autism, neighborhood-level interventions have demonstrated efficacy in improving neighborhood closeness and trust (Shen et al., 2017), suggesting that this may be a particularly promising area for future autism research. All families benefit from community support and resources, but those with exceptional stressors can especially benefit from external support (Black & Lobo, 2008; Sampson, 2013). A lack of social support can erode family resilience, particularly under stressful conditions (Luthar, 1999). Future research should investigate whether neighborhood and community interventions improve functioning of families with children and adolescents with autism.

This study adds to the literature as the first quantitative investigation of predictors of family resilience in households of children with ASD. Although individuals with ASD and their families experience difficulties, they also possess strengths; these strengths, such as a family's capacity to demonstrate resilience, can and should be leveraged to address adversity. Although this investigation contributes to the limited autism-focused strengths-based literature base and is well-aligned with the research priorities of autistic community (Pellicano & Stears, 2011; Urbanowicz et al., 2019), it is limited by several factors. The study benefited from a large sample; nonetheless, due to the nature survey research, all measures were parent-report and therefore a risk of bias exists. Direct assessments of child development (e.g., autism symptom severity, cognitive ability), family functioning, and neighborhood social networks were unavailable. Neighborhood and community social network analysis could have provided further information about the relations among neighborhood-level and family-level factors for this population and warrants investigation in future research. Additionally, this study was cross-sectional and causality/directionality could not be determined. More research with longitudinal data is needed to elucidate the causal direction of associations among neighborhood support and family resilience in households of youth with ASD. Overall, the results of this investigation indicate that neighborhoods and communities may be a meaningful source of support for families of children and adolescents with autism, and these informal social support networks should be valued and leveraged to support families.

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# Appendix A

Table 1. Response frequencies for neighborhood support indicators

| | Definitely agree | Somewhat agree | Somewhat disagree | Definitely disagree |
|---|---|---|---|---|
| Help each other out | 30.47% | 49.18% | 13.29% | 7.05% |
| Watch out for each other's children | 35.54% | 42.90% | 12.97% | 8.59% |
| Know where to go for help | 40.25% | 40.09% | 12.67% | 7.00% |

Table 2. Response frequencies for family resilience indicators

| | All of the time | Most of the time | Some/None of the time |
|---|---|---|---|
| Talk together about what to do | 39.49% | 42.52% | 17.98% |
| Work together to solve our problems | 39.19% | 42.22% | 18.59% |
| Know we have strengths to draw on | 42.49% | 40.67% | 16.84% |
| Stay hopeful even in difficult times | 40.30% | 46.36% | 13.34% |

# Appendix B

Table 1. Measurement invariance tests for neighborhood support construct

| | Chi-Square | *p* |
|---|---|---|
| Metric against Configural | 3.60 | 0.165 |
| Scalar against Metric | 7.50 | 0.186 |

Table 2. Measurement invariance tests for family resilience construct

| | Chi-Square | *p* |
|---|---|---|
| Metric against Configural | 7.20 | 0.066 |
| Scalar against Metric | 1.83 | 0.608 |