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**Boston University** 

# Adult siblings who have a brother or sister with autism: Between-family and within-family variations in sibling relationships

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### **Abstract**

Prior research on the sibling relationship in the context of autism spectrum disorder (ASD) has included only one sibling per family. We used multi-level modeling to examine aspects of the sibling relationship in 207 adults who have a brother or sister with ASD from 125 families, investigating variability in sibling relationship quality and pessimism within and between families. We found that there was greater variability in aspects of the sibling relationship with the brother or sister with ASD within families than between families. Sibling individual-level factors were associated with positive affect in the sibling relationship, while family-level factors were associated with the sibling's pessimism about their brother or sister's future. The findings illustrate the unique experiences of siblings within families.

**Keywords** Adulthood · Sibling relationship · Autism spectrum disorder

### Introduction

Researchers have examined sibling relationships when one sibling has an intellectual or developmental disability (Davys et al., 2011; Greenberg, Seltzer, Orsmond, & Krauss, 1999; Orsmond & Seltzer, 2000; Orsmond & Seltzer, 2007a), but relatively less research has focused on sibling relationships during adulthood when one sibling has autism spectrum disorder (ASD) (Orsmond & Seltzer, 2007a). Autism is a relatively recently identified disorder, with the first cohort diagnosed in the 1940's now reaching middle and later adulthood. Autism is also unique in that social impairments are a core feature and may specifically affect sibling relationships. Understanding adult sibling relationships in the context of ASD is important because of the long-term caregiving implications. Siblings often become the guardians or primary caregivers for their brother or sister with a disability once their parents are no longer able to do so (Bigby, 1997; Heller & Arnold, 2010). Thus, research findings will have relevance to the development of supports and policies affecting these families (Arnold, Heller, & Kramer, 2012).

The sibling relationship has unique salience in

adulthood in the context of illness or disability.

Sibling relationships in adulthood have been characterized along a number of dimensions, including warmth, conflict, and rivalry (Stocker, Lanthier, & Furman, 1997). Most research with the general population of adults has focused on feelings of warmth and closeness and has reported that while adult siblings may have less contact due to geographic distance or life circumstances, many adults report increased feelings of closeness to their siblings throughout adulthood (Bedford, 1989; Cicirelli, 1991; Dew, Llewellyn, & Balandin, 2004; Gold, 1989). In times of family crisis, especially in the context of declining parental health and eventual death, the sibling relationship is often reactivated and becomes a source of support (Goetting, 1986). When one sibling has a disability such mutual support may be less available, and the parental decline and death likely has caregiving implications for the sibling without a disability.

The research on siblings of individuals with ASD has focused on siblings in childhood, and primarily on behavioral adjustment in the sibling without a disability, rather than on the qualities of the sibling relationship (Orsmond & Seltzer, 2007a). Limited research on sibling relationships in adulthood when one sibling has ASD has indicated

that although siblings may have less direct contact with their brother or sister with ASD, they generally rate the sibling relationship relatively high in positive affect (Hodapp & Urbano, 2007; Orsmond, Kuo, & Seltzer, 2009). However, siblings with a brother or sister with ASD appear to experience less emotional closeness in the sibling relationship and have less direct contact with their brother or sister than adult siblings who have a brother or sister with other types of developmental disabilities, such as Down syndrome (Hodapp & Urbano, 2007; Orsmond & Seltzer, 2007b; Tozer, Atkin, & Wenham, 2013). Qualitative research suggests that the sibling relationship is conditioned by past experiences, that siblings feel a sense of responsibility and commitment to their brother or sister and value the sibling relationship, yet sometimes express frustration with maintaining a reciprocal relationship (Tozer et al., 2013).

Research on siblings of individuals with disability has been methodologically challenged by the selection of one sibling per family so that data points are independent (Hodapp, Glidden, & Kaiser, 2005; Krull, 2007). Prior research examining siblings who have a brother or sister with a developmental disability has examined one sibling dyad per family (one sibling and the brother or sister with disability). Recently, researchers have used multilevel modeling statistical techniques to examine the within and between family processes that affect sibling relationships in the general population (Gilligan, Suitor, & Nam, 2015; Jenkins, Rasbash, Leckie, Gass, & Dunn, 2012; Jenkins, Dunn, O'Connor, Rasbash, & Behnke, 2005; Marciniak, 2017) and to understand family processes in parent-child relationships (O'Connor, Dunn, Jenkins, & Rasbash, 2006). No prior research has used such methods to examine sibling relationships in the context of disability. In the current study, we used multi-level modeling to examine variability in aspects of the sibling relationship within and between families in adults who have a brother or sister with ASD. Both individual-level and family-level covariates were examined as predictors of positive affect in the relationship and pessimism about the brother or sister with ASD's future, from the perspective of the adult sibling without a disability.

Because of the limited research examining correlates of sibling relationships when one sibling has ASD, we drew upon the broader literature on sibling relationships in the context of intellectual and developmental disability (IDD) to inform our inquiry. This body of literature provides support for a number

of correlates of aspects of the sibling relationship, at both the individual- and family-level; however, research on sibling relationships in the context of disability has generally lacked theoretical guidance (Stoneman, 2005). Among the theories reviewed as relevant to siblings of children and adolescents with ASD by McHale and colleagues (McHale, Updegraff, & Feinberg, 2017), those most applicable to adult sibling relationships and the current analysis include attachment theory (Hazan & Shaffer, 1994), family stress and resilience theories (Patterson, 2002), and equity and exchange theories (Thibaut & Kelley, 1959; Walster, Walster, & Berscheid, 1978). As described below, these theories provide a rationale for examining certain factors as they relate to the sibling relationship in adulthood, especially in the context of ASD.

At the sibling individual level, we examined sibling age. In the general population, sibling relationships decrease in closeness in early adulthood, as work and family demands increase, but then increase in closeness in later adulthood. especially when caregiving for aging parents necessitates communication and coordination (Cicirelli, 1995). This pattern appears altered in the context of disability, perhaps because of the caregiving implications of the sibling with the disability as parents age. Accordingly, the age of the brother or sister with ASD also may condition the sibling relationship. Hodapp and Urbano (2007) found that siblings whose brother or sister with ASD was age 45 or older reported less close and affectionate sibling relationships than siblings whose brother or sister was in young adulthood. Similarly, Orsmond and colleagues (Orsmond et al., 2009) reported that siblings engaged in more shared activities if their brother or sister with ASD was younger in age. Thus, we also included age of the brother or sister with ASD as a family-level covariate.

Although age difference and birth order may impact sibling relationships in the general population, these factors are less important in the context of disability. Research documents that early in childhood both younger and older siblings who have a brother or sister with a disability assume a dominant role as they help to care for, teach and manage the behavior of their brother or sister with a developmental disability (Stoneman, 2005). Siblings who are younger than their brother or sister with disability typically assume this dominant role at the time that their skills are equal to those of their brother or sister with disability. Thus, in essence siblings

often assume the role of an older sibling, regardless of the birth order or age difference. Thus, we did not focus on birth order or age difference in the current analyses.

Prior research examining adult sibling relationships in the context of IDD has shown that the sibling relationship might be conditioned by the gender of each sibling, as well as the gender combination of the sibling dyad. Likely due to socialized gender roles, sisters tend to report more warmth and closer relationships with their brother or sister with IDD than do brothers (Begum & Blacher, 2011; Hodapp, Urbano, & Burke, 2010). Moreover, Orsmond and Seltzer (2000) found that sisters who had a sister with IDD reported the closest sibling relationship and brothers who had a sister with IDD reported the least close sibling relationship. Although the small number of studies examining adult sibling relationships in ASD have reported that gender of the sibling or gender composition of the sibling dyad did not condition the sibling relationship (Hodapp & Urbano, 2007; Orsmond & Seltzer, 2007b; Orsmond et al., 2009), we included adult sibling gender and gender composition of the sibling dyad in the analyses. We also included sibling education in our analyses, as lower levels of sibling education was found to be associated closer sibling relationships in the context of ASD (Orsmond & Seltzer, 2007b), perhaps because the relationship is viewed as more equitable.

In addition to age and gender, adult sibling relationships have been associated with coping skills and mental health of the sibling without the disability. From an attachment perspective, close relationships can contribute significantly to subjective well-being (Hazan & Shaver, 1994). Family stress and resilience theories (Patterson, 2002) also predict that closer relationships will be associated with more positive well-being, and that siblings will utilize coping strategies as protective mechanisms against stress in the sibling relationship. For example, siblings of adults with ASD who used more problem-focused coping strategies reported closer sibling relationships (Orsmond & Seltzer, 2007b; Orsmond et al., 2009). Similarly, Tomeny and colleagues (Tomeny, Ellis, Rankin, & Barry, 2017) found that siblings who expressed more positive attitudes about their relationship with their adult brother or sister with ASD or ID had fewer depressive symptoms. The association between sibling well-being and sibling relationships is likely bidirectional. College age individuals who report supportive sibling relationships were less lonely and

reported fewer depressive symptoms (Milevsky, 2005). Similarly, in later adulthood in the general population, having a closer sibling relationship is associated with fewer reported depressive symptoms (Cicirelli, 1989).

The sibling relationship is likely conditioned not only by the sibling individual characteristics, but also by the characteristics of the brother or sister with a disability. Family stress and resilience theories suggest that challenging behaviors and functional limitations in the brother or sister with ASD might create stress in the sibling relationship. Indeed, challenging behaviors in the brother or sister with ASD are consistently reported to negatively affect the sibling relationship, both in childhood (Hastings & Petalas, 2014; Orsmond & Seltzer, 2009; Orsmond et al., 2009) as well as in adulthood (Hodapp & Urbano, 2007; Orsmond et al., 2009). Similarly, researchers have found that if the brother or sister with ASD had higher levels of functional independence, the siblings engaged in more shared activities together (Orsmond & Seltzer, 2007b; Orsmond et al., 2009; Taylor & Hodapp, 2012).

Attachment theory helps to explain why features of family relationships more broadly and over time may be associated with aspects of the sibling relationship in adulthood (Hazan & Shaver, 1994; Whiteman, McHale, & Soli, 2011). Some contact, even virtual, is viewed as necessary to maintain the sibling bond as illustrated by findings that the frequency of contact between siblings is associated with closer relationships in the general population of adults (Connidis & Campbell, 1995). Similarly, a closer relationship has been observed when siblings have more contact with their brother or sister with ASD in adulthood (Hodapp & Urbano, 2007). The closeness of the sibling relationship in adolescence also appears to be an important correlate of adult sibling relationships in the context of IDD or mental illness (Greenberg et al., 1999). Finally, the relationship that a sibling has with his or her parent(s) may serve as a working model of social relationships in general (Whiteman et al., 2011), and has been shown to be associated with sibling relationship quality in both typical sibling pairs as well as pairs that include a sibling with developmental disability (Brody, 1998; McHale & Crouter, 1996; Orsmond et al., 2009; Portner & Riggs, 2016).

There is some indication that family size may be associated with more positive sibling relationships, although the findings are equivocal. In the context of disability and family stress and resilience theory, the availability of additional siblings to share caregiving responsibilities might contribute to less stress in siblings and a more positive sibling relationship. In the general population, siblings from larger families tend to report closer relationships in middle and later adulthood (Connidis & Campbell, 1995). Two studies reported closer sibling relationships in larger families in the context of IDD or ASD (Meadan, Stoner, & Angell, 2010; Orsmond et al., 2009). However, other researchers have reported that adult siblings from larger families in the general population reported less close relationships with one another (Milevsky, 2005) and Riggio (2006) found no association between family size and sibling relationships.

An important limitation of prior research with adult siblings who have a brother or sister with ASD or IDD is that only one sibling per family participated; thus, the findings reflect differences in these factors across families. In these studies, adult siblings who participated represented the sibling closest in age to the brother or sister with ASD (Begum & Blacher, 2011; Orsmond et al., 2009), the "most involved sibling" from the perspective of the mother (Orsmond & Seltzer, 2007b), a sibling randomly selected from the family (Floyd, Purcell, Richardson, & Kupersmidt, 2009), or a sibling who responded to a national online survey (Hodapp & Urbano, 2007). No prior research has examined multiple siblings within a family, and whether there is variability within families with respect to the conditioning effects of these factors on aspects of the sibling relationship.

In the current analysis, we utilized data from 207 adult siblings from 125 families who reported on positive affect in the sibling relationship with their brother or sister with ASD and how they viewed their brother or sister's future. In some families, only one other sibling was available for participation in the study, but in approximately two-thirds of the families, data were available from two or more siblings in the family. Thus, the aims of the current study were to: (1) Examine variation in aspects of the sibling relationship between and within families that include an individual with ASD; and (2) Examine the individual-level and family-level correlates of aspects of the sibling relationship as reported by adult siblings who have a brother or sister with ASD. We focused on the sibling relationship qualities and perceptions of positive affect in the relationship and pessimism about the future of the brother or sister with ASD. We examined sibling individual-level correlates (age, gender, gender composition of the sibling dyad, education, frequency of contact, sibling

relationship in adolescence, parental support, sibling depressive symptoms, and problem-focused coping skills) and family-level correlates (family size; and age, cognitive limitations, and challenging behaviors in the brother or sister with ASD). In examining the correlates of positive affect in the sibling relationship, we focused on two aspects: the sibling's feelings towards their brother or sister with ASD and their perceptive of the positive affect reciprocated from the brother or sister with ASD. According to attachment theory, we anticipated that the sibling's own feelings about the relationship would be associated with individual-level correlates, while reciprocity would be more highly associated with family-level correlates, such as cognitive limitations and challenging behaviors in the brother or sister with ASD.

#### Method

# **Participants**

Data for this study were collected during a 12-year longitudinal study of families of adolescents and adults with an ASD (Seltzer et al., 2003, 2011). Families participating in this study were recruited via agencies, schools, diagnostic clinics, and the media. The families met three criteria when initially recruited: (a) the family member with an ASD was age 10 or older; (b) he or she had received a diagnosis on the autism spectrum from a medical, psychological, or educational professional, as reported by the parents; and (c) administration of the Autism Diagnostic Interview – Revised (ADI-R; Lord, Rutter, & LeCouteur, 1994) confirmed the parental report of an autism spectrum disorder. Adult siblings (ages 18 years or older) with a brother or sister with an ASD were invited to participate in a mailed survey during the second wave of data collection.

A total of 243 of 351 available siblings participated in the mailed survey at the second round of data collection, for a response rate of 69.5%. For this set of analyses we were interested in examining maternal data in coordination with sibling variables, so we excluded 12 cases where the father was the primary respondent in the interview. These eliminations resulted in a total sample size of 232 siblings with maternal data. We eliminated an additional 25 siblings because of unique circumstances we thought might affect our outcomes: the sibling had more than one brother or sister with ASD (n = 1); half siblings (n = 12); step-siblings (n = 12)

4); and the sibling or the brother or sister with ASD were adopted (n = 8). The sample final sample consisted of 207 siblings from 125 families.

Table 1 presents descriptive information on the background characteristics of siblings and their family members (mothers and brother or sister with ASD). Siblings ranged in age from 18 to 59 years old. Almost all (94.7%) were Caucasian. Just over half of the participating siblings were female. Almost half of the siblings had a college or graduate degree. Most siblings were employed (83.6%) and 28% had a household income of \$70,000 or more a year. Just under one half were married and a similar percentage had children. A few siblings reported they had a child with a disability (7.7%). About two-thirds were older than their brother or sister with an ASD. Just over 10% lived with their parent(s) and 6.3% of siblings lived with their brother or sister with ASD. In 82.1% of the cases, more than one sibling per family participated. However, not all available siblings participated. For example, in 26 families, both of the other two available siblings participated, while in 30 families, only one of the two available siblings participated. Similarly, in 9 families all 3 additional siblings participated, in 1 family all 4 available siblings participated, and in 2 families all available 5 or 6 siblings participated.

The mothers in these families ranged in age from 38 to 83. Most mothers were in good or excellent health. Over two-thirds were married. Family size ranged from 2 children (sibling and brother/sister with ASD; 30% of the sample) to 8 children (inclusive of brother/sister with ASD). The siblings' brother or sister with ASD ranged in age from 12 to 53 and over two-thirds were male. Just under half lived with the parent(s). Over 80% had intellectual disability and over two-thirds (68.8%) had at least phrase speech.

### **Measures**

Aspects of the Sibling Relationship

Siblings completed written measures that assessed two aspects of the sibling relationship: Positive Affect and Pessimism. Siblings completed the Positive Affect Index (PAI; Bengtson & Black, 1973), which includes 10 items measuring positive affect in the relationship. Five questions addressed the adult sibling's feelings toward their brother or sister with ASD (e.g., "How much affection do you have toward your brother/sister?"), and five questions assessed the sibling's perception of the positive affect

from their brother or sister with ASD (e.g., "How much affection do you feel that your brother/sister has for you?"). The questions reflect the dimensions of affection, understanding, trust, fairness, and respect in the relationship. Each item is rated on a scale from 1 (not at all) to 6 (extremely), with higher scores indicating more positive affect. The test-retest reliability, internal consistency and construct validity of PAI were high as reported by the test authors (Bengtson & Black, 1973). Alpha reliability for this sample was .91 for the total scale, .88 for the 5 items of positive affect perceived from the brother or sister with ASD, and .85 for the 5 items of positive affect felt towards the brother or sister with ASD.

Sibling pessimism about the brother or sister with ASD's future was measured with 10 items from the Pessimism scale of the Questionnaire on Resources and Stress (QRS-F; Friedrich, Greenberg, & Crnic, 1983). This scale assesses worries and pessimism about the future of the family member with the disability (e.g., "I worry about what will happen to my brother/sister when my mother can no longer take care of him/her"). Siblings rated each item as 0 (false) or 1 (true) with resulting scores ranging from 0 to 10 (alpha = .68).

Sibling Individual-Level Covariates

Siblings provided background information, such as birthdate, gender, birth order, level of education, income, employment status, marital status, and whether or not they had children (see Table 1).

Siblings completed eight subscales of the Multidimensional Coping Inventory (Carver, Sheier, & Weintraub, 1989). Four subscales (each comprised of four items) measured problem-focused coping: active coping, planning, suppression of competing activities, and positive reinterpretation and growth. Four subscales measured emotion-focused coping: denial, focusing on and venting of emotions, behavioral disengagement, and mental disengagement. Siblings rated each item on a 4-point scale according to how often they used the strategy from 1 'not at all' to 4 'a lot'. Alpha reliability coefficients were .92 and .75 for problem-focused and emotion-focused coping skills, respectively.

Siblings reported depressive symptoms on the Center for Epidemiologic Studies Depression Scale (CES-D; Radloff, 1977). The CES-D is a wellvalidated and reliable measure of depressive affect in

**Table 1** Demographic Characteristics of Siblings and Family Members

	Total				
Adult Siblings	N = 207				
Age in years (M, SD)	35.6 (10.8)				
Female	55.1%				
Education					
High school or less	18.4%				
Some college or Associate's	32.4%				
degree					
College graduate	20.3%				
Some graduate school or	29.0%				
graduate degree					
Household income					
<\$35,000/year	3.9%				
\$35,000-\$69,000	30.4%				
\$70,000+	28.0%				
Employed	83.6%				
Married	49.8%				
Parents	45.4%				
Older than brother/sister with ASD	68.1%				
# Siblings who provided data per fam	nily size				
1 sibling	, 37 (17.9%)				
2 siblings	55 (26.6%)				
3 siblings	45 (21.7%)				
4 siblings	23 (11.1%)				
5 siblings	29 (14.0%)				
6 siblings	17 (8.2%)				
7 siblings	1 (0.5%)				
Mothers	N = 125				
Age in years (M, SD)	59.0 (11.5)				
Married	70.4%				
Health					
Poor	1.6%				
Fair	17.6% 39.2%				
Good					
Excellent	56%				
Household income	3070				
<\$35,000/year	31.2%				
\$35,000-\$69,999/year	21.6%				
\$70,000+	33.6%				
Family size (# of children, including	33.070				
family member with ASD)					
2	37 (29.6%)				
3	43 (34.4%)				
4	43 (34.4%) 22 (17.6%)				
5					
6	11 (8.8%) 8 (6.4%)				
	` '				
7	3 (2.4%)				
8	1 (0.8%)				
Brother/Sister with ASD	N = 125				
Age in years (M, SD)	29.7 (10.8)				
Male	70.4%				
Live with parent(s)	46.4%				
Intellectual disability	84.0%				

the general population (Radloff, 1991). Twenty items assess the frequency of depressive symptoms during the preceding week, ranging from 0 'rarely' to 3

more depressive symptoms. Test-retest reliability, internal consistency and concurrent validity are good (Radloff, 1977). The alpha reliability coefficient for this sample of siblings was .91.

'most of the time'. A higher total score indicates

Siblings reported on the frequency of contact with their brother or sister with ASD using two questions that asked siblings how often they saw their brother or sister in person and spoke with them on the phone (both scored 0 'never' to 7 'daily'). Siblings also completed a one item retrospective report of the emotional closeness of their sibling relationship during adolescence, on a scale from 0 'not at all close' to 3 'very close'.

We used the Perceived Social Support Scales (Procidano & Heller, 1983) to measure siblings' perceived social support from parents. Siblings responded to this 20-item measure for the support that they receive separately from their mother and father (e.g., "My mother/father gives me the moral support I need"). Siblings responded whether each statement was true or false. Scores on each scale range from 0 to 20, with higher scores indicating that siblings perceived greater support. Test-retest reliability, internal consistency and construct validity of the measure are reported to be high (Procidano & Heller, 1983). We averaged the scores reflecting support from mothers and fathers for each sibling.

# Family-Level Covariates

During the first wave of data collection, mothers provided background information about their age, the number of children in the family, and the age and gender of her son or daughter with ASD. Mothers completed measures at the second wave of data collection, on average within 4 months of the adult siblings' participation. They provided updated information about their marital status, income, health, and whether or not the son or daughter with ASD lived at home (see Table 1). At the second wave of data collection, mothers completed the behavior problems subscale of the Scales of Independent Behaviors – Revised (SIB-R; Bruininks, Woodcock, Weatherman, & Hill, 1996). This measure consists of eight challenging behaviors: behavior that is hurtful to self, unusual or repetitive, withdrawn or inattentive, socially offensive, uncooperative, hurtful to others, disruptive, and destructive of property. The mother was asked whether her son or daughter manifested eight challenging behaviors within the last 6 months, and, if so, to rate the frequency and

severity of the behavior, each measured on a 6-point scale. Standardized algorithms (Bruininks et al., 1996) were used to translate frequency and severity ratings into a general summary score, with the possible range from 90 to 141, where higher scores indicated more severe challenging behaviors. Scores below 110 are considered "normal," and scores above 110 are considered to be clinically significant. Challenging behavior scores for this sample ranged from 96 to 146 (M = 108, SD = 10.1). Thus, approximately half of adults with ASD had challenging behaviors in the clinically significant range.

At the second wave of data collection, we also characterized the individuals with ASD as to whether or not they had an intellectual disability, using a variety of sources of information. When possible, we administered the Wide Range Intelligence Test (WRIT; Glutting, Adams & Sheslow, 2000) to the individual with an ASD. In addition, mothers reported on adaptive behavior via the Vineland Screener (Sparrow et al., 1993). Individuals with a standard scores of 70 or below on each instrument were classified as having an intellectual disability, whereas those with scores above 75 on either measure were deemed not to have an intellectual disability. For the remaining cases, independent review of records (including psychological testing records when available, adaptive behavior information, parental report of a prior diagnosis of intellectual disability) by three psychologists, combined with a clinical consensus procedure, was used to determine whether or not an individual had an intellectual disability. Participants were classified as either having intellectual disability (coded as '1') or not having intellectual disability (coded as '0').

# Data Analysis

The first level of analysis examined variation in positive affect and pessimism in the sibling relationship between and within families using bivariate correlations. Covariates were represented on two levels: the family level (e.g., family size, challenging behaviors of brother/sister with ASD) and sibling-specific level (e.g. depressive symptoms, perception of parental support). Siblings within a family experienced the same family-level factors, while data at the sibling-specific level pertained directly to each sibling.

Multilevel models were used to examine associations between the outcome measures and

selected sibling- and family-level covariates. Dependent measures were: (1) sibling positive affect toward their brother or sister with ASD (PA toward), (2) sibling perceived positive affect from their brother or sister with ASD (PA from), and (3) sibling pessimism about the future of their brother or sister with ASD (Pessimism). Intraclass Correlation Coefficients (ICC) were calculated to assess the proportion of variance in the outcome measures explained by within- and between-family covariates.

We selected covariates for inclusion in the multivariate models based on bivariate correlations with positive affect and pessimism, and because of theoretical interest. Sibling-level covariates included own education, perceived parental support, retrospective report of relationship with sibling with ASD during adolescence, sibling age, current frequency of in-person contact with brother or sister with ASD, and own depressive symptoms. Family-level covariates included intellectual disability in the brother or sister with ASD, challenging behaviors in the brother or sister with ASD, and total number of siblings in the family.

#### **Results**

#### Bivariate correlations

Several sibling- and family-level variables were associated with positive affect in sibling relationships (see Table 2). Retrospective report of the sibling relationship in adolescence, frequency of current inperson contact, and parental support were sibling-specific variables that were positively associated with PA total, PA from, and PA toward scores. The sibling's own education had a small but significant negative association with PA total and PA from scores. Intellectual disability in the brother or sister with ASD was a family-level variable that was significantly associated with PA total and PA from scores; the presence of ID was associated with lower levels of PA. No family-level variables were associated with PA toward scores.

Sibling pessimism about the future of their brother or sister with ASD was negatively associated with their own age and positively associated with their own depressive symptoms. All four family-level variables were associated with pessimism: age of brother or sister with ASD and number of siblings in the family were negatively associated with pessimism, while intellectual disability and challenging behaviors in the brother or sister with ASD were positively associated with pessimism.

For total PA, 25% of the variance occurred between families and 75% within families (ICC = 0.246). Sixteen percent of the variance in a sibling's PA toward their brother or sister with ASD was between families, and 84% within families (ICC = 0.157), while 22% of the variance in a sibling's PA from their brother or sister with ASD was between and 78% within families (ICC = 0.221). For pessimism, 36% of the variance occurred between-families and 64% within-families (ICC = 0.364).

Multilevel models focused on PA toward their brother or sister with ASD, PA from their brother or sister with ASD, and pessimism about their brother or sister with ASD's future as dependent variables. We adjusted for family-wise error associated with the sibling positive affect variables such that for the two multilevel analyses, p < .025was considered significant. As shown in Table 3, sibling positive affect toward the brother or sister with ASD was predicted solely by sibling-level variables (though there was a trend for intellectual disability in the brother or sister with ASD being associated with lower PA toward): retrospective report of closeness in adolescence and own depressive symptoms. Siblings who recollected a closer relationship in adolescence reported more positive affect towards their brother or sister with ASD, while those with higher depressive symptoms reported lower positive affect toward their brother or sister with ASD.

The sibling's perception of positive affect from the brother or sister with ASD was predicted by one sibling-level and one family-level variable. Siblings who recollected a closer relationship in adolescence reported more positive affect from their brother or sister with ASD compared to siblings who retrospectively reported a less close relationship during adolescence. Intellectual disability in the brother or sister with ASD was negatively associated with positive affect from that sibling.

Sibling pessimism about the brother or sister with ASD's future was associated with no sibling-level variables and all family-level variables. Siblings who came from smaller families, those whose brother or sister with ASD had more challenging behaviors, and those whose brother or sister had intellectual disability were more pessimistic about their brother or sister's future.

### **Discussion**

In this manuscript, we utilized newer approaches to data analysis that add to our understanding of how the sibling relationship is conditioned by having a brother or sister with ASD. Although research is emerging that informs our understanding of the sibling relationship in this specific context, the research to date has been limited by the selection of only one sibling per family. By using multi-level modeling, we were able to examine the extent to which prior research findings hold when we examine the perspectives of multiple siblings per family. Moreover, we were able to examine within-family variability in the sibling relationship, as reported by different siblings, as well as variability across families. Interestingly, we found that there was greater variability in the sibling relationship with the brother or sister with ASD within families than between families. This finding suggests that the sibling relationship may be conditioned more by the sibling's own experience and characteristics than the characteristics of the brother or sister with ASD. This finding supports more individualist theories about sibling relationships, such as attachment theory, rather than family stress theories that have generally assumed that it is the characteristics of the family member with ASD that "impacts" other family members, including siblings and parents. This finding also reminds us that each person's experience within the family is unique and that, to the extent possible, we should examine family experiences from the perspective of each family member, and not assume that the experience is uniform or similar across family members.

Prior research on adult sibling relationships in the general population has also found considerable within family variation in sibling relationships. In fact, researchers have documented that the relationship each sibling reports within a family is more different than the relationships siblings report in different families (Branje, van Aken, Marcel A. G., & van Lieshout, Cornelis F. M., 2002; Cook & Kenny, 2004; Daniels & Plomin, 1985). For example, Branje et al. (2002) found that adolescent siblings' perceived support from parents was reflective of their own characteristics, rather than the characteristics of their parent. Thus, the findings of sibling relationships in the context of ASD parallel those in the general population. The sibling's self-report of the sibling relationship likely reflects their own subjective experience in the relationship (Cook & Kenny, 2004) and thus it is not surprising that it is influenced by the

**Table 3** Sibling-Level and Family-Level Predictors of Positive Affect in the Sibling Relationship and Pessimism about the Brother/Sister with ASD's Future

	Sibling Positive	e Affect	Sibling Positive Affect from Brother or Sister with ASD					
	toward Brother	or Sister						
	with ASD							
	Coefficient (SE)	р	Coefficient (SE)	р				
Sibling Level								
Own education	-0.444 (0.306)	0.149	-0.428 (0.342)	0.213				
Parental support	0.032 (0.042)	0.450	0.076 (0.045)	0.092				
Retrospective report of adolescent relationship	2.706 (0.465)	< 0.001	3.330 (0.510)	< 0.001				
Own age	-0.001 (0.036)	0.970	-0.055 (0.041)	0.180				
Contact with b/s with ASD	0.455 (0.223)	0.043	0.166 (0.240)	0.489				
Own depressive symptoms	-0.090 (0.039)	0.023	-0.076 (0.042)	0.092				
Family Level								
Intellectual disability in b/s with ASD	-1.682 (0.887)	0.060	-2.884 (1.013)	0.006				
Challenging behaviors in b/s with ASD	-0.001 (0.037)	0.970	-0.008 (0.043)	0.858				
Number of siblings in family	-0.146 (0.231)	0.528	-0.055 (0.268)	0.838				

sibling's own characteristics. A more objective measure, such as an observational measure, may be less reflective of the sibling's own characteristics.

When we examined the factors associated with the sibling's report of the relationship with their brother or sister with ASD, and their feelings of pessimism about the future, we observed that both sibling-level and family-level factors had significant associations. The expectation that the sibling's own feelings of positive affect towards the brother or sister with ASD would be primarily associated with sibling-level correlates, while the sibling's perception of reciprocated positive affect would be primarily associated with family-level correlates was only partially supported. The sibling's retrospective report of their sibling relationship in adolescence was associated with both positive affect towards and from the brother or sister with ASD. Given the retrospective nature of the adolescent sibling relationship measure, the association is likely influenced by the sibling's current feelings. Other individual- and family-level correlates of aspects of positive affect in the sibling relationship were consistent with our predictions. The sibling's feelings of positive affect towards their brother or sister with ASD was associated with their own depressive symptoms. Moreover, if the brother or sister with ASD had intellectual disability, the sibling perceived less reciprocated positive affect.

Overall, the associations with respect to positive affect in the sibling relationship appear supportive of an attachment perspective of sibling relationships. Continuity over time in the sibling

relationship from adolescence to adulthood can be viewed as reflective of the sibling bond; a close bond, in turn, may contribute positively to sibling well-being. As noted previously, however, the association between well-being and sibling relationships is likely bidirectional, and sibling depressive symptoms may contribute negatively to the sibling relationship. This latter finding is consistent with family stress theory, as is the association between intellectual disability in the brother or sister with ASD and lower levels of perceived reciprocated positive affect.

The sibling's pessimistic feelings about the future, however, were predicted primarily by familylevel characteristics, including challenging behaviors in the brother or sister with ASD and having fewer other siblings. The co-occurrence of intellectual disability in the brother or sister with ASD was a significant factor associated with both the sibling relationships and sibling pessimism about their brother or sister's future. If the brother or sister with ASD also had intellectual disability, the sibling reported lower levels of positive affect in the sibling relationship and was more pessimistic about his or her brother or sister's future. This association has previously been reported in the literature (Doody, Hastings, O'Neill, & Grey, 2010; Hodapp & Urbano, 2007). It is not surprising that siblings would be more pessimistic about their brother or sister's future if their brother or sister has more limited cognitive abilities and more significant challenging behaviors, as well as if they have fewer other siblings to share responsibility or to assist when needed. In fact, this frequently reported finding emanates from family

stress theory. Equity and exchange theories (Thibaud & Kelley, 1959; Walster et al., 1978) also predict, however, a less close and rewarding sibling relationship if a sibling is less able to contribute personally to the relationship, as might be the case in the context of more limited skills and more impactful negative behaviors.

Overall, the findings from this analysis generally support, with a few exceptions, prior research on sibling relationships in the context of ASD or IDD that included only one sibling per family. In these prior studies, the selected sibling was either randomly selected, the closest in age, or viewed by the parent as the "most involved." Similar to prior studies, we found that the sibling's retrospective report of their sibling relationship during adolescence and the sibling's own mental health were associated with the quality of adult sibling relationships. Prior research has found that the sibling relationship in adolescence is important. For example, Cuskelly (2016) used longitudinal data to show that having a good relationship in childhood was associated with more warmth expressed by adult siblings towards their brother or sister with Down syndrome. Importantly, Greenberg and colleagues (Greenberg et al., 1999) reported that the sibling's retrospective report of a closer relationship in adolescence with a brother or sister with intellectual disability was predictive of emotional support during adulthood and expectations of future caregiving responsibilities later in adulthood.

Also similar to prior research, we found that siblings who endorsed more depressive symptoms themselves reported a less close sibling relationship (Tomeny et al., 2017). This finding was observed primarily with respect to how much positive affect the sibling reported feeling towards their brother or sister with ASD; not the positive affect they perceived as reciprocated. It is interesting to note that in prior analysis of this data, using only the sibling closest in age to the brother or sister with ASD, we did not observe an association between depressive symptoms and positive affect in the sibling relationship (Orsmond et al., 2009). This dissimilarity in findings suggests that methodological differences in studies may account for differences in findings; selecting the sibling closest in age for analysis may have limited the variability of some measures analyzed. It is important to note that it is likely, as observed with parents of youth with IDD (Orsmond, Seltzer, Krauss, & Hong, 2003), that the association between depressive symptoms and perceptions of the relationship are bidirectional.

Adult siblings' worries about the future of their brother or sister with IDD and/or ASD is a prominent theme in the literature, especially in qualitative studies (Davys et al., 2016; Rawson, 2010). Adult siblings express concern about their brother or sister's access to appropriate services, the type of care they might need in the future, and their health (Davys et al., 2016). The current analysis helps to understand the factors that may contribute to concern or pessimism about the future and what it holds for the sibling and their relationship with their brother or sister with ASD. Not surprisingly, greater pessimism about the brother or sister's future was observed when the brother or sister had more limited cognitive abilities and more impactful challenging behaviors. Siblings were also more pessimistic if they had fewer other siblings, presumably who could help if needed in the future. These findings underscore the need to develop supports for families that include siblings in the future planning process (Arnold et al., 2012; Burke, Fish, & Lawton, 2015; Davys et al., 2016).

Similar to the findings in this study, prior researchers have reported that sibling constellation and demographic characteristics have relatively little influence on the sibling relationship when one sibling had ASD and/or IDD (Floyd, Costigan, & Richardson, 2016; Hodapp & Urbano, 2007). For example, using the same data set, but analyzing only the sibling closest in age to the brother or sister with ASD, we found that family size was not associated with positive affect in the sibling relationship (Orsmond et al., 2009).

The fact that we did not find some associations previously reported in some prior studies may reflect the differences in sampling strategies, and the possibility that the sample used in the current analysis was less biased because we did not only include one sibling per family. We investigated the associations between problem-focused coping and aspects of the sibling relationship because of prior research. However, the bivariate correlations between coping and aspects of the sibling relationship were not significant, so we did not include problemfocused coping in the multi-level models. Given that most prior research included siblings who were either most involved or closest in age, it might be that coping skills are less important to siblings who are less involved or not very close in age. These inconsistent findings warrant further research on the role of coping skills in the sibling relationship.

In the multi-level models we did not find significant associations between the sibling

relationship and sibling contact, parental support, and the gender of each and both siblings. Prior researchers have reported that sibling contact was associated with perceptions of the sibling relationship (Hodapp & Urbano, 2007). It could be the sibling selection factors in prior studies were associated with less variability in some measures; more involved siblings or those closest in age to the brother or sister with IDD/ASD might be more likely to be sisters, have more contact, and report a closer relationship by default. Those nominated by their parents for participation in a study may have a closer relationship with their parent.

Some differences with prior research may also reflect the sibling relationship constructs examined. For example, caregiving expectations and the sibling relationship may have different predictors. Burke and colleagues (Burke, Taylor, Urbano, & Hodapp, 2012) found that siblings who reported a closer relationship with their brother or sister with IDD had higher expectations for future caregiving. But, it is also possible that stress or expectation of future caregiving could negatively impact the sibling relationship. Future caregiving expectations and felt obligations may not correspond to emotional aspects of the sibling relationship.

Although the use of multi-level modeling in the current analysis allowed us to reduce selection bias and examine variability within and between families, this approach is not without its limitations. Not all siblings from all families participated. This aspect of selection bias may affect the variability of the data as well (Marciniak, 2017). In addition, family size is not a random variable, but may be influenced by parental and family factors not measured (Krull, 2007). Finally, the extent to which the findings are influenced by the number of twochild families is not known. Repeated selective sampling of one sibling per family and comparison of the patterns of findings across these samples would need to be conducted to assess this influence (Krull, 2007).

With respect to the sample, the siblings who participated in this study were from families participating in a longitudinal study on family caregiving and autism in adolescence and adulthood; these families were not especially ethnically or racially diverse and had the ability to participate in an ongoing study. With respect to measurement, this secondary analysis of existing data did not allow for a broad examination of sibling relationship variables. We were limited with the measured constructs and the fact that we did not seek the perspective of the

brother or sister with ASD when possible. In particular, our inference about the longitudinal stability of aspects of the sibling relationship is limited by the use of the sibling's retrospective perception of their relationship in adolescence very broadly. Given the important implications of this finding, future research should incorporate longitudinal and prospective measurements of the sibling relationship.

Paralleling the trend with research on sibling relationships in the general population, it is our hope that researchers studying siblings of individuals with disability will begin to use analytic methods that allow for the examination of multiple family members. Multi-level modeling could be used to examine the perspectives of sibling relationships from siblings both with and without a disability in the family. Moreover, this analysis calls for researchers to ask different types of questions about sibling relationships in the context of ASD. Because of a relatively small sample size, we were not able to examine how individual- and family-level covariates might interact to explain within family differences in the sibling relationship. Moreover, as others have recommended (e.g., McHale et al., 2016), we urge sibling researchers to utilize family and social relationship theories to guide their inquiry. Finally, the findings in the present analysis have implications for the development of individualized support programs for siblings that appreciate individualistic and unique experiences within the family.

In summary, this set of analyses provides new insights into the sibling relationship when one sibling has ASD and cautions sibling researchers to carefully consider methodological issues such as sample selection. Perhaps the most important contribution of this manuscript is the finding of greater variability in the sibling relationship within families than across families; what the sibling brings to the relationship may in fact be more important than the limitations or characteristics of the brother or sister with ASD. Thus, as the research literature on sibling relationships in the context of ASD continues to emerge, researchers are encouraged to consider methods such as multilevel modeling that allow for multiple perspectives within the family.

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 Table 2
 Bivariate Correlations for Sibling Individual-Level and Family-Level Variables

						Sibling	g-Level Va	riables								
	1.	2.	3.	4.	5.	6.	7.	8.	9.	10.	11.	12.	13.	14.	15.	16.
1. Positive affect - total																
2. Positive affect – toward	.93**															
3. Positive affect – from	.98**	.77**														
4. Pessimism	16*	19*	12													
5. Adult sibling age	12	09	12	19**												
6. Adult sibling gender	.08	.10	.06	.04	08											
7. Gender composition	.07	.08	.06	.02	06	.92**										
8. Adult sibling education	17*	13	17*	.02	.12	.03	.02									
9. Contact	.32**	. 34**	.28**	.10	22**	. 00	.01	19*								
10. Retrospective report	.56**	.52**	.54**	06	11	. 06	.05	13	.28**							
of adolescent relationship																
11. Parental support	.22**	.18*	.23**	.02	02	.06	.02	26**	.19**	.16*						
12. Adult sibling	13	13	12	.20**	04	01	.00	11	06	06	06					
depressive symptoms																
13. Adult sibling problem-	.09	. 10	.06	10	.17*	.05	.11	.19**	07	.01	11	38**				
focused coping																
						Family	-Level Va	riables								
14. Age of adult with ASD	13	12	11	18*	.79**	11	09	.16*	21**	23**	02	.01	.06			
15. Family size	11	0	10	20**	.45**	09	14*	06	12	.01	11	03	.02	.23**		
16. Challenging behaviors	.02	.00	.03	.22**	45**	.01	01	07	.17*	.05	07	.04	06	36**	28**	
in b/s																
17. Intellectual disability in adult with ASD <sup>a</sup>	18*	11	21**	.14*	05	08	09	16*	.03	.04	.01	04	08	02	.06	.06

<sup>&</sup>lt;sup>a</sup> 0 = no intellectual disability; 1 = presence of intellectual disability

<sup>\*</sup>p < .05 \*\* p < .01