

RISK AND PROTECTIVE FACTORS PREDICTING SIBLING EMOTIONAL
INTELLIGENCE AMONG ADOLESCENT SIBLINGS OF INDIVIDUALS WITH AND
WITHOUT INTELLECTUAL AND DEVELOPMENTAL DISABILITIES

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TABLE OF CONTENTS

	Page
LIST OF TABLES	iv
LIST OF FIGURES	v
Chapter	
I. INTRODUCTION	1
Predictors of Sibling Outcomes	2
Gender	2
Brother/sister characteristics	2
Parent characteristics	3
Potential Sibling Outcomes	4
Adolescent Siblings	4
Challenges in Sibling Research	5
The Current Study	6
Research Questions	6
II. METHOD	8
Participants	8
Procedure	11
Recruitment	11
Survey Completion	11
Measures	12
Dependent Variables	12
Wishes	12
Emotional Intelligence	12
Emotionality	13
Independent Variables	13
Demographics	14
Parental Optimism	14
Parental Perception of Target Child Impact	14
Target Child Behavior Problems	15
Target Child Functional Abilities	15
Total needed services	24
Percentage of unmet service needs	24
Data Analysis	15
Qualitative Analyses	15
Primary analyses	16

Regression analyses	16
Moderated mediation analyses.....	16
Content Analyses	18
III. RESULTS	20
Preliminary Results.....	20
Group Differences.....	20
Correlations.....	23
Regression Analyses.....	26
Moderated Mediation.....	27
Content Analysis.....	28
IV. DISCUSSION.....	30
Research Implications.....	33
Future Directions	34
Limitations	36
Conclusion	37
Appendix	
A. SIBLING EMOTIONALITY SURVEY	38
REFERENCES	58

LIST OF TABLES

Table	Page
1. Demographic characteristics by disability category	10
2. Codes for sibling wishes	19
3. Group differences by disability status	21
4. Group differences by sibling gender	22
5. Control group correlations	24
6. Disability group correlations	25
7. Standardized regression coefficients predicting sibling dysphoric feelings	26
8. Wish types made by siblings in the control and disability groups.....	29

LIST OF FIGURES

Figure	Page
1. Mediated moderation analysis as represented by a path diagram.....	17
2. Moderated mediation models. This conditional indirect effect of ADL on MAACL Anxiety through FIQ Child Cost (a) and ADL on MAACL Hostility through FIQ Feelings (b)	28

CHAPTER I

INTRODUCTION

As individuals with intellectual and developmental disabilities (IDD) are living longer, many typically-developing siblings assume caregiving responsibilities for them from their aging parents. By the year 2030, over 900,000 individuals with disabilities over the age of 60 are expected to be in the care of their aging parents (National Center for Family Support, 2000). However, these caregiving issues are not confined to adulthood. Compared to siblings of typically-developing individuals, siblings also take more responsibility for their brother/sister with an IDD (e.g. Cuskelly & Gunn, 2003; McHale & Gamble, 1989). As adolescent siblings of individuals with IDD have different experiences than siblings of typically-developing individuals, it follows that siblings of individuals with IDD might also experience different outcomes.

Research on siblings of individuals with developmental disabilities is a relatively small field, starting with early qualitative studies (e.g. Farber, 1963; Grossman, 1972; San Martino & Newman, 1974) that primarily collected anecdotes from siblings describing their experience growing up with a brother or sister with IDD. More recent studies have focused on siblings of individuals with different types of disability including autism or Down syndrome (e.g. Orsmond & Seltzer, 2009; Hodapp & Urbano, 2007). Studies have also examined both positive (e.g. Findler & Vardi, 2009; Hannah & Midlarsky, 2005) and negative outcomes for siblings (e.g. Meaden, Stoner, & Angell, 2010; Petalas, Hastings, Nash, Lloyd, & Dowey, 2009), as well as family-specific factors that predict variability among siblings (e.g. Benson & Karlof, 2008;

Hastings, 2007). Within-group analyses of siblings of individuals with IDD have thus yielded some important predictors that differentiate sibling outcomes.

Predictors of Sibling Outcomes

Gender

Numerous studies have implicated the gender of the sibling of the individual with IDD as an important predictor of sibling outcomes. Female siblings play a more supportive role than male siblings (e.g. Orsmond & Seltzer, 2000; Seltzer, Begun, Seltzer, & Krauss, 1991); females also tend to have more plans for future caregiving (Greenberg, Seltzer, Orsmond, & Krauss, 1999). When comparing siblings of individuals with autism vs. Down syndrome, Orsmond and Seltzer (2007) found that the lives of female siblings of individuals with DS were affected the most out of all gender/disability combinations. These, along with numerous other studies (e.g. Begun, 1989; Zetlin, 1986), highlight the importance of including gender as a covariate when studying siblings of individuals with disabilities.

Brother/Sister Characteristics

Original speculation suggested that siblings of individuals with IDD were at risk for negative outcomes because of the comparative lack of parental attention they received, as well as excessive responsibility for their brother/sister (e.g. Lobato, 1983). More recent research has found that specific characteristics of the child with disabilities, specifically their behavior problems, predict negative sibling outcomes. As children with IDD tend to have more behavior problems and mental health issues than their typically developing peers (e.g. Dykens, 2000;

Emerson, 2003), it is possible that the presence of these problems, rather than the presence of a disability in itself, could cause negative sibling and family outcomes. In a longitudinal study, Hastings (2007) found that behavior problems in the child with IDD predicted sibling behavior problems at two years later, above and beyond the sibling's initial level of behavior problems. Neece, Blacher, and Baker (2010) found that parents of children with IDD believed that the impact of the child with disabilities on his/her typically-developing siblings is greater if the child with IDD has more severe behavior problems.

In addition to behavior problems, the brother or sister's level of independent functioning has also been shown to have an impact on sibling outcomes. Orsmond and Seltzer (2007) found that brother/sister functional abilities were positively correlated with positive affect in the sibling relationship (as rated by the sibling) and number of shared sibling activities. Heller and Kramer (2009) also found that brother/sister functioning predicted siblings' plans for future caregiving.

Parent Characteristics

While many sibling studies focus on characteristics of the individual with IDD, parental characteristics can also be important in predicting sibling outcomes. Grissom and Borkowski (2002) found that sibling-reported maternal attitudes toward empathy and prosocial behavior predicted the sibling's self-efficacy in families of children with disabilities, but not in families without a child with disabilities. Other studies have found that parental stress is positively correlated with sibling behavior problems (Cuskelly, Hayes, & Chant, 1998) and negatively correlated with sibling adjustment (Fisman, Wolf, Ellison, & Freeman, 2000). These studies highlight the importance of including parent factors when studying siblings of individuals with disabilities.

Potential Sibling Outcomes

While initial hypotheses suggested that siblings of individuals with IDD were at risk for psychopathology and emotional disturbance (e.g. San Martino & Newman, 1974), a 2001 meta analysis yielded only small negative effects of having a brother or sister with disabilities (Rossiter & Sharpe, 2001). Therefore, researchers have begun to study more subtle effects of having a brother/sister with IDD. One of the more common outcomes measures is that of sibling relationship quality (e.g. Begum & Blacher, 2011; Floyd, Purcell, Richardson, & Kupersmidt, 2009). Because the sibling relationship is typically the longest relationship a person will have (e.g. Seltzer, Greenberg, Orsmond, & Lounds, 2005), the quality of the sibling relationship, as well as how siblings perceive their brother/sister with IDD, can have lasting effects.

In addition to aspects of the sibling relationship, researchers have focused considerably on potential positive outcomes for siblings. First-person reports indicate that some siblings believe that growing up with a brother or sister with IDD has made them more empathetic and understanding of people with disabilities (Flaton, 2006; Grossman, 1972). However, research is still needed to determine whether or not growing up with a brother/sister with IDD leads to more empathy than growing up with a typically developing sibling, as well as which within-group factors promote such outcomes.

Adolescent Siblings

While it is important to study siblings across the lifespan, adolescence can be a particularly trying time for siblings of individuals with IDD. Compared to adult siblings, adolescent siblings reported more embarrassment in regards to their brother/sister with a disability and more concern with social stigma (Wilson et al., 1992). Additionally, adolescent siblings experienced more conflict and less satisfaction with their sibling relationships when compared to adult siblings of individuals with IDD (Begun, 1989). Therefore, adolescence may be a particularly stressful time for siblings of individuals with IDD, and they may be more prone to experiencing more negative stances toward their sibling than siblings of typically-developing individuals.

Challenges in Sibling Research

Hodapp, Glidden, and Kaiser (2005) highlighted several different challenges facing sibling researchers that need to be addressed in order to advance the field. First, sibling studies often contain methodological issues such as lack of or inappropriate control groups (Hodapp, et al., 2005). Another pressing issue concerns mediators and moderators of sibling outcomes. Not all siblings of individuals with disabilities deal with the same set of circumstances; factors such as gender, age, number of siblings, and other environmental differences may drastically affect sibling outcomes. Gender may determine which siblings experience a given outcome (i.e. moderate the effects), while maternal coping style may mediate the effects of having a brother/sister with IDD.

Finally, Hodapp et al. (2005) recommended that sibling researchers balance positive and negative views of sibling outcomes. Original sibling studies and thought pieces (e.g. San

Martino, 1974) deemed siblings as a “population at risk” for negative outcomes, solely because these siblings have a brother or sister with IDD. However, qualitative evidence indicates that many siblings describe benefits of having a brother or sister with disabilities (e.g. Grossman, 1972). Hodapp and colleagues propose that both positive, and negative outcomes are needed to create a fuller picture of the sibling experience.

The Current Study

The current study aimed to examine some of the challenges facing sibling researchers while also addressing issues that are important to families. While target child factors such as behavior problems have been shown to put siblings at risk for negative outcomes, it is possible that certain parent factors such as optimism and positive perception of the target child may serve a protective function for sibling outcomes. This study used a national sample of siblings of individuals with various kinds of disabilities and is among the few to also include a comparison group of siblings of individuals without IDD.

Research Questions

- 1) Do adolescent siblings of individuals with IDD differ from siblings of typically-developing individuals on measures of emotional intelligence and emotionality?
- 2) What target child factors relate to outcomes for siblings of individuals with and without IDD?

- 3) What parent factors relate to outcomes for siblings of individuals with and without IDD?
- 4) Do parent factors predict sibling outcomes above and beyond target child factors?
- 5) Do parent factors mediate the relationship between target child factors and sibling outcomes differently among families of children with and without IDD?

CHAPTER II

METHOD

Participants

The sample included 97 parent-sibling pairs. Of these 97 families, 48 had a child with an intellectual/developmental disability, and 47 had no children with a disability. To be eligible for this study, families needed to have exactly two children, at least one of whom was between the ages of 12 and 18 and has no intellectual or developmental disabilities (henceforth referred to as the sibling). Though the initial instructions stipulated that the non-responding child (henceforth referred to as the target child) must be between the ages of 12 and 18, that criteria was later dropped due to low completion rate.

For the entire sample, the responding parents' age ranged from 31-62 years ($M = 44.48$, $SD=6.06$), target child ages ranged from 3-19 years ($M = 13.95$), and sibling ages ranged from 12-18 ($M = 14.35$). Almost all of the responding parents were female (95.9%). The sample was primarily Caucasian (84.5%), with smaller proportions identified as African American (1.0%), Asian (4.1%), and Hispanic (9.3%). A relatively high percentage of the parents in the sample were currently married (80.4%), and 33.3% of the sample had a household income of over \$100,000. Full demographics by disability category are found in Table 1.

Among families of children with IDD, the following disabilities were present: non-specific mental retardation/developmental disability (32.7%), Down syndrome (20.4%), autism/autism spectrum disorder (53.1%), cerebral palsy (14.3%), and other (18.4%). Other disabilities specified by the parents included ADHD, Angelman syndrome, "deletion of the 13th

chromosome,” neurotransmitter disorder, “severe recruitment,” seizure disorder, neurofibromatosis type 2, and traumatic brain injury.

Table 1

Demographic characteristics by disability category

	Control Group (N=48)		Disability Group (N= 49)		χ^2 /T Value
	Mean (SD)	% of Sample (N)	Mean (SD)	% of Sample (N)	
Responding Parent Gender					
Female		97.9 (47)		95.9 (47)	.34
Male		2.1 (1)		4.1 (2)	
Responding Parent Age	44.04 (5.97)		44.92 (6.17)		-71
Ethnicity					
Caucasian		89.6 (43)		79.6 (39)	3.16
African-American		-		2.0 (1)	
Hispanic		6.3 (3)		12.2 (6)	
Asian		2.1 (1)		6.1 (3)	
Marital Status					
Never Married		4.2 (2)		8.2 (4)	1.16
Married		83.3 (40)		77.6 (38)	
Separated		2.1 (1)		4.1 (2)	
Divorced		10.4 (5)		8.2 (4)	
Household Income					
Below \$15,000		-		2.0 (1)	6.06
\$15,000-\$29,000		4.2 (2)		12.2 (6)	
\$30,000-\$49,000		29.2 (14)		14.3 (7)	
\$50,000-\$69,000		12.5 (6)		16.3 (8)	
\$70,000-\$99,000		20.8 (10)		14.3 (7)	
Over \$100,000		33.3 (16)		32.7 (16)	
Target Child Age	14.00 (3.00)		13.90 (3.42)		.16
Target Child Gender					
Female		56.3 (27)		30.6 (15)	6.10
Male		43.7 (21)		67.3 (33)	
Sibling Age	14.27 (2.01)		14.43 (1.94)		-.39
Sibling Gender					
Female		68.8 (33)		51.0 (25)	3.17
Male		31.2 (15)		49.0 (24)	

Procedure

Recruitment

Participants were recruited by sending e-mails and electronic flyers to local, state, and national groups and agencies that serve individuals with disabilities and their families. These agencies included all centers listed in the Association of University Centers in Disabilities (AUCD) and each listing in the *Wrightslaw Yellow Pages for Kids* (yellowpagesforkids.com), a state-by-state database of services for families of individuals with disabilities. E-mails were sent in batches of five to avoid spam filters, and a total of over 6,500 agencies were contacted. Additionally, an advertisement for the survey was sent out on the Vanderbilt Medical Center listserv, and the study was posted on StudyFinder on the Vanderbilt Kennedy Center website.

Survey Completion

Upon clicking the link to the survey, parents were directed to the welcome page, which listed instructions and participation criteria. The survey was divided into four parts: demographic information, parent information, target child information, and sibling information. Parents were instructed to complete the first three sections on their own, and then have a typically developing adolescent complete the sibling section. Prior to the target child section, parents were asked if either of their children has an intellectual or developmental disability. If the parent responded “yes,” they were shown instructions to treat the child with IDD as the target child, while the child without IDD would be classified as the sibling. If the parent responded “no,” instructions appeared telling the parent to simply choose one of their children to be the target child, and the

other child would answer questions as the sibling. The full survey, including participant instructions, can be found in Appendix A.

The parent section took approximately 20-25 minutes to complete, and the sibling section took approximately 10-15 minutes to complete. A consent page preceded each section; parents could not continue with the survey unless they gave consent for both themselves and the sibling (if the sibling was under 18 years), and the sibling could not proceed unless they gave assent (consent if they were 18 years). Upon completion, families could choose to follow a link to a separate form, where they could provide contact information to be entered into a drawing for a \$50 Target gift cards, with a 1 in 10 chance of winning. Survey responses were stored in a password-protected online database, accessible only by the researcher.

Measures

Dependent Variables

Wishes After giving their consent, siblings were asked to type out three wishes. This question was presented first so as not to influence siblings toward thinking about their brother or sister when choosing their wishes.

Emotional Intelligence Sibling emotional intelligence was measured using the Interpersonal Reactivity Index (IRI; Davis, 1980). The IRI is a self-report measure consisting of 28 items. Participants respond to these items using a 5-point Likert scale (1 = Does not describe me well, 5 = Describes me very well; Cronbach's $\alpha = .81$). These items are divided into four 7-

item subscales: fantasy (e.g. “I really get involved with the feelings of the characters in a novel.”), empathetic concern (e.g. “I am often quite touched by things that I see happen”), perspective taking (e.g. “I believe that there are two sides to every question and try to look at them both”), and personal distress (e.g. “I tend to lose control during emergencies”). The IRI has been used with children as young as 10 (Fabes, Eisenberg, & Eisenbud, 1993) and the validity of the subscales has been confirmed with factor analyses (Pulos, Elison, & Lennon, 2004).

Emotionality Sibling emotionality toward the target child was measured using the Multiple Affect Adjective Checklist - Revised (MAACL - R; Zuckerman & Lubin, 1985). Because the present sample included children as young as 12, the checklist was limited to adjectives at or below a 6th-grade reading level, following the instructions indicated in Lubin, Whitlock, & Rea (1995). For purposes of this study, the adjectives “guilty” and “protective” were added to the list. The final checklist consisted of 114 words, presented in alphabetical order. Siblings were instructed to “Please mark all answers that describe how you generally feel about or toward your brother or sister.”

Responses to the MAACL-R are reliably divided into five domains: anxiety, depression, hostility, positive affect, and sensation seeking. These categories can be further combined into two composite scores: dysphoria (sum of anxiety, depression, and hostility) and PASS (sum of positive affect and sensation seeking). T scores for each of these scales are calculated based on age, gender, and total number of items checked. Adequate reliability and validity have been reported for the scales using the sixth-grade reading level cutoffs (Lubin et al., 1995).

Independent Variables

Demographics Information was collected for each family member (responding parent, non-responding parent, target child, and sibling) regarding age, race, and gender. For the children, information was collected about the child's relationship to his or her parents (biological child of both parents, biological child of parent 1, biological child of parent 2, or adopted). Parents also provided household income, parents' marital status, and zip code. Finally, parents were asked to indicate whether or not each child had any illnesses or disabilities from a given list.

Parental Optimism Parental optimism was measured using the 10-item Revised Life Orientation Test (LOT-R; Scheier, Carver, & Bridges, 1994). The LOT-R measures an individual's expectancies about the future in general and is comprised of 6 scored items (e.g. "In uncertain times, I usually expect the best") and 4 filler items (e.g. "It's easy for me to relax"). Three of the six scored items are reverse-coded (e.g. "If something can go wrong for me, it will."). Item responses fall on a 5-point Likert scale ranging from 0 – strongly disagree to 4 – strongly agree. Cronbach's α for this sample was .82. The 6 scored items are summed into one total score ranging from 0 to 24, with higher scores indicating a more positive outlook on life.

Parental Perception of Target Child Impact The parent's perception of the target child's impact on the family was measured with three subscales from the Family Impact Questionnaire (FIQ; Donenberg & Baker, 1993): parent's feelings and attitudes about the child (e.g. "My child is more stressful"), financial impact of the child (e.g. "The cost of educational and psychological services is more"), and impact of the child on his/her siblings (e.g. "My child is more rejected by

his/her siblings”). Parents were asked to compare the target child to other children of his/her age and rate the child on a 4-point Likert scale (1 = not at all, 4 = very much; Cronbach’s $\alpha = .93$).

Target Child Behavior Problems Child behavior problems were assessed using the 30-item Behavior Problems Index (BPI; Peterson & Zill, 1986). Parents respond to each of the items using a 3-point Likert scale to indicate how well each statement applies to the target child (0 = not true, 1 = somewhat or sometimes true, 2 = very true or often true; Cronbach’s $\alpha = .93$). Responses are then summed into an Internalizing scale (14 items), an Externalizing scale (16 items), and a Total Problems scale (all 30 items). The BPI has been used in the National Longitudinal Study of Youth (NLSY) to assess children ages 4-19 and has shown adequate reliability and validity (Goodnight et al., 2012).

Target Child Functional Abilities Functional abilities were measured using 15 items from the Activities of Daily Living Scale (ADL; Seltzer & Li, 1996). Parents rated the target child on the degree to which the child can perform various skills (e.g. preparing meals, running errands, maintaining friendships) on a 5-point Likert scale (1 = not at all to 5 = very well; Cronbach’s $\alpha = .93$).

Data Analysis

Qualitative Analyses

Primary analyses Primary analyses were conducted on the quantitative data using chi-squares, t-tests, and bivariate correlations. Chi-squares and t-tests were used to compare results by disability status and sibling gender. Correlations were run separately on the disability and control groups.

Regression analyses Hierarchical linear regression analyses were run to determine the predictive ability of target child and parent factors. The first block included target child functioning and behavior problems, and parent optimism was added for the second. Because of the extremely strong correlation between target child behavior problems and parent perception of target child impact ($r = .78, p < .001$), parent perception was not included in model 2 of the regression analyses. Separate regressions were run for the whole sample, the disability group, and the control group. Target child age, sibling age, and sibling gender were controlled for in all analyses.

Moderated mediation analyses The question of whether or not parental factors mediate the relationship between target child factors and sibling outcomes differently for families with children with IDD compared to families without children with IDD, was tested using moderated mediation analyses (Preacher, Rucker & Hayes, 2007). These analyses allow researchers to test both how and when an effect occurs. In this technique, the overall effect of variable X on variable Y is mediated by variable M, but the path from M to Y (b) is moderated by variable W (see Figure 1).

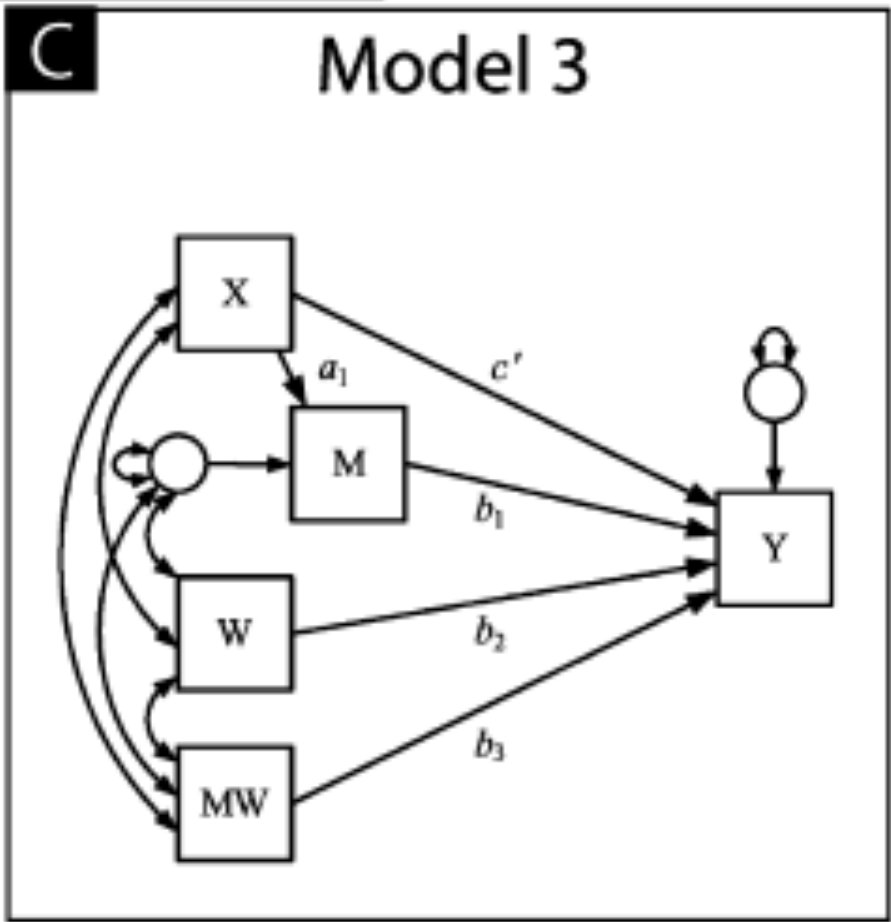


Figure 1: Mediated moderation analysis as represented by a path diagram (Preacher et al., 2007)

- X: Target child factors
- Y: Sibling outcomes
- M: Parent factors
- W: Disability group
- MW: Parent factors by disability group interaction

The conditional indirect effect (CID) of X on Y through M at value W of the moderator variable is expressed as $f(\hat{\theta}|W) = \hat{a}_1(\hat{b}_1 + \hat{b}_3W)$. For purpose of this study, X refers to the target child variables (behavior problems and level of functioning), Y refers to sibling outcome variables (emotionality and emotional intelligence), M refers to parent variables (optimism and perception of the target child’s impact), W is quantified as 0 (family does not have a child with a disability)

or 1 (family does have a child with a disability) and b refers to the pathway from parent variables to sibling variables. The b pathway is proposed to be moderated by the presence or absence of a target child IDD.

Confidence intervals (CI) for the CID were estimated using bootstrapping with 5000 resamples. The conditional indirect effect can be considered statistically significant if the calculated 95% CI does not include 0 (Preacher et al., 2007).

Content Analyses

To develop content codes for the siblings' wishes, one researcher read through each answer, and developed a list of nine content codes. Codes and example responses can be found in Table 2. The nine codes were grouped based on the intended recipient of the wish: Self, Family, and Society. For each category, participants received a code of 1 (at least one of the sibling's wishes contained this theme) or 0 (none of the sibling's wishes contained this theme). Each wish was then assigned one code, so each respondent could have up to three assigned codes. A random selection of 30 responses was then presented to a second researcher for reliability coding, using the code definitions created by the first researcher. Across the 9 categories, median kappas equaled .96, with a range of .68-1.00. According to Cicchetti (1994), kappas above .75 indicate "excellent" inter-rater reliability, while kappas above .60 indicate "good" reliability. Chi-squares were run on each individual code and each coding category (self, family, and society) to compare results by gender and family disability status.

Table 2

Codes for Sibling Wishes

Codes	Examples
<i>Self Codes</i>	
Material	“To have many kittens,” “1 billion US dollars”
Aspirational	“To become a vetanarian (sic)” “Get a full scholarship to MIT”
Fantasy	“All superpowers” “Marry Josh Hutcherson!!!!”
Physical	“To be taller” ”To be thinner”
Family	“I wish I had a dad” “My sister to be nicer to me”
Other	“Happiness” “More time with friends”
<i>Family Codes</i>	
General Family	“My dad has less medical problems” “For our family to be happy”
Target Child	“I wish my brother could speak” “That my brother was normal”
<i>Society</i>	
Society	“Equal rights for all” “An end to world hunger”

CHAPTER III

RESULTS

Because of the large number of analyses, only results with $p < .01$ will be reported as significant.

Preliminary Results

Group Differences As expected, mothers from the disability group reported higher levels of target child internalizing ($t = -3.23, p < .01$), externalizing ($t = -3.59, p < .01$), and total behavior problems ($t = -3.72, p < .001$), and lower levels of functional ability ($t = 9.95, p < .001$) than mothers from the control group. Mothers of children with a disability also reported more perceived child impact on all three FIQ subscales: parental feelings ($t = -4.39, p < .001$), child cost ($t = -7.70, p < .001$), and impact on the sibling ($t = -5.73, p < .001$). Means and standard deviations for each variable by disability group can be found in Table 3.

Among siblings, adolescents in the disability group reported significantly higher levels of anxiety toward their brother/sister ($t = -4.50, p < .001$). There were no differences in emotional intelligence based on disability group; see Table 5. Female siblings scored significantly higher on the total IRI than male siblings ($t = -3.34, p < .01$). Gender comparisons are found in Table 4.

Table 3

Group Differences by Disability Status

	Control Group Mean (SD) N=48	Disability Group Mean (SD) N=49	T-Value
Dependent Variables			
IRI Fantasy	23.23 (5.69)	23.51 (5.73)	-.24
IRI Perspective Taking	20.06 (6.19)	21.84 (6.05)	-1.43
IRI Empathetic Concern	26.10 (4.59)	27.65 (5.43)	-1.52
IRI Personal Distress	17.77 (5.02)	18.14 (5.15)	-.36
IRI Total	87.17 (11.76)	91.14 (15.11)	-1.45
MAACL Anxiety	46.02 (8.57)	56.71 (14.19)	-4.50**
MAACL Depression	50.19 (11.55)	54.86 (12.26)	-1.93
MAACL Hostility	57.98 (12.64)	60.47 (14.18)	-.88
MAACL Positive Affect	46.42 (14.82)	46.31 (13.13)	.04
MAACL Sensation Seeking	66.31 (10.12)	65.73 (10.48)	.28
MAACL Dysphoria	52.92 (12.42)	59.65 (13.96)	-2.51
MAACL PASS	56.38 (18.40)	55.10 (16.26)	.36
Independent Variables			
LOT-R	23.17 (3.29)	21.41 (4.26)	2.27
BPI Internalizing	6.06 (4.27)	9.16 (5.14)	-3.23*
BPI Externalizing	8.52 (5.89)	13.14 (6.75)	-3.29*
BPI Total Behavior Problems	14.58 (9.41)	22.31 (10.94)	-3.72**
ADL Total	58.35 (9.84)	38.53 (9.79)	9.95**
FIQ Child Stress	26.94 (8.46)	34.57 (8.67)	-4.39**
FIQ Child Cost	10.94 (4.41)	19.39 (6.26)	-7.70**
FIQ Sibling Impact	13.48 (4.63)	19.61 (5.86)	-5.73**

*p<.01, **p<.001

Table 4

Group Differences by Sibling Gender

	Males Mean (SD) N=39	Females Mean (SD) N=58	T-Value
Dependent Variables			
IRI Fantasy	21.69 (5.62)	24.50 (5.48)	-2.45
IRI Perspective Taking	20.18 (4.96)	21.48 (6.83)	-1.02
IRI Empathetic Concern	25.31 (5.75)	27.95 (4.27)	-2.45
IRI Personal Distress	16.64 (4.43)	18.84 (5.31)	-2.14
IRI Total	83.82 (11.94)	92.78 (13.60)	-1.45*
MAACL Anxiety	52.21 (10.36)	50.90 (13.26)	.49
MAACL Depression	51.56 (10.36)	53.21 (13.16)	-.66
MAACL Hostility	59.03 (14.39)	59.38 (13.69)	-.12
MAACL Positive Affect	45.41 (11.82)	47.00 (15.23)	-.58
MAACL Sensation Seeking	67.33 (11.77)	65.14 (9.10)	1.03
MAACL Dysphoria	56.31 (12.24)	56.33 (14.52)	-.01
MAACL PASS	54.97 (14.87)	56.24 (18.82)	-.35
Independent Variables			
LOT-R	21.90 (4.03)	22.53 (3.81)	-.79
BPI Internalizing	7.69 (4.86)	7.59 (5.06)	.10
BPI Externalizing	10.97 (6.95)	10.78 (6.62)	.14
BPI Total Behavior Problems	18.67 (10.96)	18.36 (10.91)	.14
ADL Total	46.36 (13.26)	49.67 (14.36)	-1.15
FIQ Child Stress	32.33 (9.72)	29.76 (9.02)	1.34
FIQ Child Cost	16.15 (6.67)	14.57 (6.98)	1.12
FIQ Sibling Impact	16.67 (5.85)	16.52 (6.30)	.12

*p<.01

Correlations Among siblings of individuals with IDD but **not** siblings of individuals without IDD, emotionality related to numerous parent and target child factors. Sibling anxiety toward the target child was significantly related to target child internalizing behavior ($r = .41, p < .01$) and parental perception of child cost ($r = .40, p < .01$) and marginally related to total target child behavior problems ($r = .36, p = .01$). Sibling feelings of depression were significantly correlated with target child internalizing ($r = .40, p < .01$) and total behavior problems ($r = .38, p < .01$). Sibling hostility toward the target child was significantly related to target child internalizing ($r = .54, p < .001$), externalizing ($r = .48, p < .001$), and total behavior problems ($r = .55, p < .001$), as well as parental feelings of stress regarding the target child ($r = .52, p < .001$) and parental perception of target child impact on the sibling ($r = .42, p < .01$). Sibling scores on the dysphoria scale of the MAACL were significantly related to target child internalizing ($r = .57, p < .001$), externalizing ($r = .46, p < .01$), and total behavior problems ($r = .55, p < .001$), as well as parental feelings of stress ($r = .41, p < .01$). Thus, for siblings of individuals with IDD, all negative affect scales of the MAACL were significantly related to target child behavior problems and at least one aspect of parental perception of the target child. Again, none of these correlations were even marginally significant among siblings of individuals without IDD.

Sibling emotional intelligence was not significantly correlated with any parent or target child measures in either group. Correlations for all variables can be found in Tables 5 and 6.

Table 5

Control Group Correlations

	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17	18	19
1. IRI Fantasy																			
2. IRI Perspective Taking	.19																		
3. IRI Empathetic Concern	.20	.54																	
4. IRI Personal Distress	-.05	-.31	-.23																
5. IRI Total	.64	.70	.67	.15															
6. MAACL Anxiety	.15	-.01	-.01	-.11	.01														
7. MAACL Depression	.21	-.16	-.13	.12	.02	.67													
8. MAACL Hostility	.00	-.32	-.14	.04	-.21	.40	.57												
9. MAACL Positive Affect	.07	.48	.28	-.41	.22	.23	.00	-.08											
10. MAACL Sensation Seeking	.11	.06	.00	-.03	.07	-.24	-.27	-.08	.36										
11. MAACL Dysphoria	.11	-.24	-.14	.04	-.11	.71	.86	.89	.00	-.20									
12. MAACL PASS	.10	.41	.24	-.34	.21	.10	-.09	-.09	.95	.63	-.06								
13. LOT-R	.22	.12	-.08	-.02	.13	-.18	.03	.04	.03	.09	.00	.08							
14. BPI Internalizing	.05	-.25	-.12	.12	-.05	.20	.13	.15	-.29	-.22	.18	-.31	-.02						
15. BPI Externalizing	.12	-.21	-.09	.21	.00	.12	-.03	.17	-.33	.07	.11	-.25	.07	.71					
16. BPI Total Behavior Problems	.10	-.20	-.11	.18	-.02	.17	.04	.17	-.34	-.05	.15	-.30	.04	.90	.95				
17. ADL Total	.22	.26	.25	-.11	.29	.10	.03	.23	.18	.31	.17	.26	.03	-.39	-.20	-.30			
18. FIQ Child Stress	-.04	-.11	-.09	.08	-.08	.03	-.11	.09	-.33	-.23	.03	-.35	-.13	.63	.64	.69	-.32		
19. FIQ Child Cost	.01	-.20	-.14	.35	.00	-.09	-.14	-.08	-.23	.08	-.12	-.17	-.08	.36	.43	.44	-.28	.28	
20. FIQ Sibling Impact	-.07	-.08	-.32	.23	-.10	.02	.14	.21	-.34	-.10	.19	-.31	.18	.49	.63	.62	-.40	.53	.42

Bolded correlations p<.01

Table 6

Disability Group Correlations

	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17	18	19	
1. IRI Fantasy																				
2. IRI Perspective Taking	.46																			
3. IRI Empathetic Concern	.44	.60																		
4. IRI Personal Distress	.00	.00	.08																	
5. IRI Total	.72	.79	.79	.37																
6. MAACL Anxiety	.00	-.03	.03	.26	.09															
7. MAACL Depression	.15	.19	.01	.33	.25	.53														
8. MAACL Hostility	-.01	-.05	-.11	.29	.04	.44	.49													
9. MAACL Positive Affect	.21	.38	.41	-.06	.36	.11	-.07	-.24												
10. MAACL Sensation Seeking	.02	.20	.12	-.29	.03	.03	-.27	-.17	.49											
11. MAACL Dysphoria	.04	.02	-.04	.36	.13	.77	.78	.86	-.11	-.17										
12. MAACL PASS	.18	.40	.37	-.13	.31	.11	-.12	-.23	.96	.71	-.13									
13. LOT-R	.17	-.13	.08	-.11	.01	-.16	-.01	-.18	.01	.02	-.16	.00								
14. BPI Internalizing	-.11	-.01	-.11	.05	-.07	.41	.40	.54	-.33	.01	.57	-.24	-.24							
15. BPI Externalizing	-.22	.07	-.23	.07	-.12	.28	.30	.48	-.28	.15	.46	-.17	-.38	.69						
16. BPI Total Behavior Problems	-.19	.04	-.19	.07	-.10	.36	.38	.55	-.33	.10	.55	-.22	-.35	.89	.94					
17. ADL Total	.07	.18	.12	-.33	.03	.00	-.09	.10	.15	.17	.03	.19	-.13	.23	.14	.20				
18. FIQ Child Stress	-.12	-.09	-.18	.05	-.13	.24	.13	.52	-.21	.13	.41	-.11	-.36	.64	.79	.79	.01			
19. FIQ Child Cost	.06	.01	-.11	.10	.02	.40	.22	.19	.02	-.01	.32	-.02	-.27	.02	.30	.20	-.31	.19		
20. FIQ Sibling Impact	.07	.25	-.13	.08	.11	.05	.19	.42	-.27	-.14	.31	-.25	-.47	.51	.63	.63	.17	.55	.17	

Bolded correlations p<.01

Regression Analyses

For the control group, no sibling outcomes were significantly predicted by target child or parent factors, nor did these predictive factors account for a significant amount of variance in control group sibling outcomes. In the disability group, regression model 1 predicted 38% of the variance in sibling dysphoric feelings ($p < .001$), and target child total behavior problems significantly predicted sibling dysphoria in both model 1 ($\beta = .58, p < .001$) and model 2 ($\beta = .61, p < .001$). The addition of parental optimism to model 2 did not add a significant amount of variance. Regression results for analyses predicting sibling dysphoria can be found in Table 7.

Table 7

Standardized Regression Coefficients Predicting Sibling Dysphoric Feelings

Model	Full Sample		Control Group		Disability Group	
	Model	Model	Model	Model	Model	Model
	1	2	1	2	1	2
Target Child Behavior Problems	.54**	.43**	.27	.27	.58**	.61**
Target Child Functioning	-.01	-.01	.27	.27	-.06	-.06
Sibling Gender	.00	.01	-.04	-.04	.10	.11
Sibling Age	-.07	-.07	-.23	-.24	.12	.10
Target Child Age	.11	.11	-.07	-.07	.20	.21
Parental Optimism		-.02		-.03		.07
R²	.20**	.20	.14	.14	.38**	.38
ΔR²		.00		.00		.00

** $p < .01$

Moderated Mediation

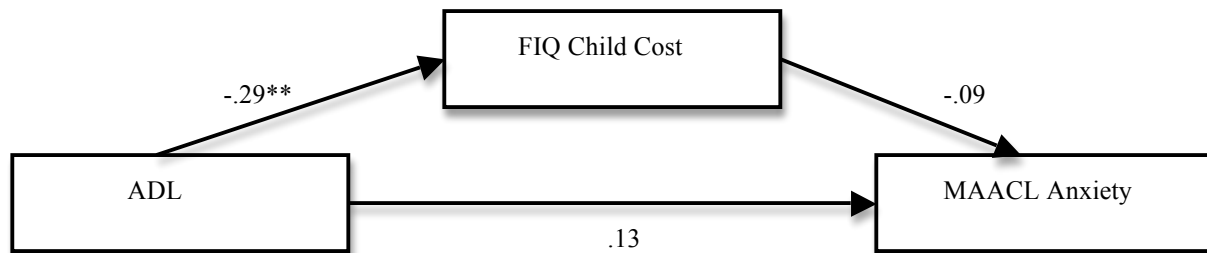
Moderated mediation analyses examined 1) whether parental optimism and perception mediated the relationships between target child variables and sibling outcomes, and 2) whether these mediations were different for families with and without children with IDD. All analyses controlled for sibling age and gender.

Analyses revealed two significant mediated pathways. The relationship between target child functional ability and sibling anxiety toward the target child was mediated by parental perception of child cost, but only for families with a child with IDD. The 95% confidence interval for the conditional indirect effect (CID) of functional ability on anxiety through parental perception excluded zero (CID = $-.28$, $p < .01$, CI: $-.48$ to $-.14$ with 5000 resamples). Additionally, for families of children with IDD, the effect of target child functional ability on sibling hostility toward the target child was significantly mediated by parents' feelings about the target child (CID = $-.22$, $p < .01$, CI: $-.39$ to $-.10$ with 5000 resamples). These mediated relationships are illustrated in Figure 2.

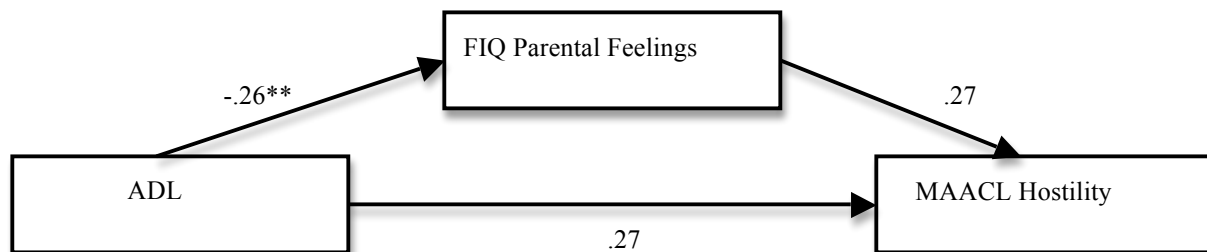
Figure 2

Moderated mediation models. The conditional indirect effect of ADL on MAACL Anxiety through FIQ Child Cost (a) and ADL on MAACL Hostility through FIQ Parental Feelings (b)

a.



b.



$**p < .001$

Content Analysis

Chi-square analyses revealed several group differences in what siblings wished for. Siblings of individuals with IDD were far more likely to wish for something for the target child ($\chi^2 = 21.45, p < .001$), as well as wish for something for any family member ($\chi^2 = 10.63, p < .01$). In contrast, siblings in the control group were more likely to describe fantasy wishes ($\chi^2 = 7.31, p < .01$).

In terms of sibling gender, females were significantly more likely to make fantasy wishes ($\chi^2 = 10.01, p < .01$). None of the wish codes were related to sibling age. Full results of the content analysis can be found in Table 8.

Table 8

Wish Types Made by Siblings in the Control and Disability Groups

	Control Group Percentage (N)	Disability Group Percentage (N)	χ^2
<i>Self</i>			
Material	60.4 (29)	53.1 (26)	.53
Aspirational	41.7 (20)	38.8 (19)	.08
Fantasy	43.8 (21)	18.4 (9)	7.31*
Physical	10.4 (5)	8.2 (4)	.15
Family	4.2 (2)	18.4 (9)	4.86
Other	16.7 (8)	12.2 (6)	.38
Any	97.9 (47)	85.7 (42)	4.77
<i>Family</i>			
General Family	12.5 (6)	20.4 (10)	1.10
Target Child	2.1 (1)	40.8 (20)	21.45**
Any	14.6 (7)	44.9 (22)	10.63*
<i>Society</i>			
Society	33.3 (16)	16.3 (8)	3.77

* $p < .01$, ** $p < .001$

CHAPTER IV

DISCUSSION

The present study was conducted to determine the role of target child and parent factors in predicting outcomes among adolescent siblings of individuals with and without intellectual and developmental disabilities. This research expands the sibling literature by addressing multiple previous methodological concerns, such as the need for control groups and the inclusion of mediators and moderators (Hodapp et al., 2005). Results from this study have implications for both researchers and family service providers.

In this study, findings related to differences between families of children with IDD and those without children with IDD were as expected. Specifically, families of children with IDD differed from families of children without IDD on all expected target child measures of functional ability and behavior problems, with target children in this group having lower levels of functional ability, and higher levels of internalizing, externalizing, and total behavior problems.. Additionally, parents of children with IDD reported more stress caused by the target child, higher cost of raising the target child, and greater perceived impact of the target child on the sibling.

Findings related to the siblings of children with IDD, on the other hand, were more unexpected. First, there were no differences on sibling emotional intelligence between the IDD and non-IDD groups. This finding indicates that, contrary to some anecdotal evidence, siblings of individuals with IDD are not more empathetic than siblings of individuals without IDD. On the other hand, siblings of children with disabilities did feel more anxiety toward the target

sibling than those siblings of children without disabilities. Specifically, siblings of individuals with IDD are more likely than siblings of individuals without IDD to feel tense, afraid, or worried in regards to their brother/sister.

While there were few group differences in sibling outcomes, the samples were divergent in terms of how these outcomes related to target child and parent factors. Among families of children with IDD, target child behavior problems and parental perception of target child impact (stress, cost, or sibling impact) were significantly related to sibling anxiety, depression, and hostility toward the target child. Additionally, while such target child and parent factors were positively correlated with dysphoric feelings, these factors were not negatively correlated with sibling positive affect. This indicates that while the presence of risk factors increases siblings' negative feelings toward the target child, the absence of these factors does not increase positive feelings. Among siblings of individuals without IDD, no parent or target child factors were significantly correlated with sibling outcomes.

These correlational findings were supported by the regression analyses. Once again, sibling empathy and positive affect were not significantly predicted by target child and parent factors. Additionally, target child and parent factors only predicted sibling dysphoria for the disability group, not the control group, accounting for over 2.5 times the variance in the disability group as the same factors did in the control group.

These findings shed light on the importance of family dynamics among families of children with IDD. Fostering a healthy sibling relationship between individuals with IDD and their typically-developing siblings may be even more important in this population, as many typically-developing siblings end up caring for their brother or sister with IDD after the parents are no longer able (Heller & Arnold, 2010). The results of this study indicate that, when fostering

positive relationships between adolescents and their brother/sister with IDD, families and professionals may have to focus on different factors than they would in typically-developing sibling pairs, such as parental feelings toward the target child.

Finally, mediation effects of parent factors on the relationship between target child variables and sibling outcomes among families of children with IDD were found. Siblings of children with lower functional ability were likely to feel more anxiety toward their sibling in part because the parents believed that the target child placed a higher financial burden on the family. Additionally, siblings of children with lower functional ability were more likely to feel hostility toward the target child if the parents reported more negative feelings about the target child.

These findings are of particular interest because many previous studies have found no relationship between target child functional ability and sibling outcomes (e.g. Burke, Taylor, Urbano, & Hodapp, 2011). Indeed, in the present study, bivariate correlations show no significant relationship between target child functioning and sibling outcomes. However, moderated mediation analyses reveal a connection between target child functional ability and sibling feelings toward the target child through parent perception of the target child in families of children with IDD. Specifically, it is the pathway from parent perception to sibling emotionality that is moderated by the presence of a child with a disability. This suggests that while parent perception is affected by child characteristics regardless of the presence of a disability diagnosis, siblings in families of children with IDD are more susceptible to their parents' feelings about the target child than are siblings in families without a child with IDD.

The specific nature of these indirect effects is also important. While parent reports of stressful feelings seem to explain hostile feelings in siblings, parent perception of cost relates to anxious feelings. As measured by the FIQ, parents' stressful feelings about the child can include

endorsing items such as “I feel like I should have better control over his/her behavior” and “My child brings out feelings of frustration and anger.” Likewise, the hostility scale of the MAACL includes items such as “angry,” “annoyed,” and “disgusted.” For the FIQ child cost scale, parents indicate whether or not they think the cost of childcare, medication, and other resources for the target child is more than for other children. Anxiety items on the MAACL include “frightened” and “worrying.” Therefore, like the results reported in Study 1, sibling feelings toward the target child seem to match parent feelings.

Previous research among families of typically-developing children has found that a parent’s relationship with one child can predict qualities of the sibling relationship (Brody, Stoneman, & McCoy, 1994), so it is not entirely surprising that parent factors are related to the sibling relationship. However, the fact that parent factors explain the relationship between target child factors and sibling outcomes only for families of children with IDD is novel and worth further study.

Research Implications

This study highlights the usefulness of recent statistical developments in analyzing family variables. In this case, each statistical method reveals a unique aspect of the sibling story. While t-tests show very few differences in sibling outcomes between groups, bivariate correlations reveal drastically different relationships between variables for the disability group than for the control group. However, if the analyses had not advanced beyond correlations, then results would not have included the interplay between target child and parent variables when predicting sibling outcomes.

Additionally, research should continue to consider different comparison groups when studying siblings of children with IDD. It is possible that time spent with individuals with disabilities is enough to bring the empathy and understanding that previous researchers hypothesized. Therefore, typically-developing children in integrated classrooms might experience similar levels of empathy as siblings of individuals with IDD. Classmates of children with IDD should be considered as participants in future studies of siblings of children with IDD.

Finally, research is needed to develop more divergently valid measures of sibling and family factors. Despite the fact that the FIQ focuses more on parental feelings of control over the target child's behavior rather than the nature of the behavior (e.g. "I feel like I am working alone in trying to deal with my child's behavior"), the measure is highly correlated with the BPI, preventing the inclusion of both measures in a single regression. While it is likely not possible to completely separate parent perception of target child impact from target child behavior problems, more sensitive measures could help determine the relative importance of each factor.

Future Directions

The results of this study indicate numerous directions for future research. The initial finding that, overall, siblings of individuals with IDD report more anxiety towards the target child than do siblings of typically-developing individuals deserves further study. Future projects should utilize more sensitive and varied measures of sibling relationships to determine how said relationships differ between siblings of individuals with and without IDD. Additionally, research is needed to determine the effects of anxiety in the sibling relationship. While some studies have

examined the effects of individual anxiety on the sibling relationship (e.g. Lindhout et al., 2003), no studies have been found that examine the effects of anxiety within the sibling relationship.

Second, the differences in significant correlations between families of children with and without IDD indicate a need for more studies that measure both between group and within group factors. While many sibling outcomes did not differ between groups, the variables that significantly correlate with such outcomes were different. Therefore, future studies of siblings of individuals with IDD should include analysis of not only different outcomes, but different predictors of said outcomes. Such predictors should include various family variables, including measures of how parents interact with each child in the family and a more direct measure of how the target child interacts with the sibling.

Finally, the results of the moderated mediation analyses reveal the advantages of utilizing modern statistical methods to better understand the intricacies of family interactions. Future studies should employ more mediation analyses to determine the differences between direct effects and indirect effects on sibling outcomes. Additionally, statistical methods can be employed to study families with multiple children. While the current study was only open to families with two children, many families of children with IDD have multiple typically-developing siblings. Recent statistical developments, such as multilevel structural equation modeling, can be used to test both family-level variables (e.g. the nature of the target child's disability and the number of children in the family) and individual variables (e.g. sibling age and gender). That way, researchers can determine whether it is more efficient to implement potential interventions at a family level or an individual level.

Beyond research, this study has practical implications. For parents looking to improve the sibling relationship between the target child and typically-developing sibling, it is important to

note that both parent and target child factors play a role. Therefore, the most effective interventions should include changes to both the target child and the parents. Conversely, in the event that interventions aimed at the target child are unsuccessful (i.e. it is difficult to improve level of functioning in areas such as walking or talking), then parent changes can still make a difference in sibling outcomes.

Limitations

Despite numerous useful implications, the present study does have its limitations. First, the response rate was unexpectedly low. Therefore, many analyses could not be performed due to low power, such as a comparison of families of children with different disabilities and a comparison of geographic locations. Consideration is needed in future studies to determine the best methods of gathering data from a large number of families of children with IDD.

In addition, the sample has characteristics that limit generalizability. First, the large number of respondents from the Vanderbilt Medical Center listserv negatively skews the distribution of household income, with a large number of families reporting incomes over \$100,000. Second, the online format of the survey is likely to induce a response bias. Despite the fact that paper surveys were offered, none were distributed. Third, like many family studies, parent respondents were almost entirely female. It is unclear whether the relationships described above apply to all parents or just to mothers. The exclusionary criteria (only families with two children and siblings between the ages of 12 and 18 were eligible), mean that the reported results may not apply to families with more than 2 children or siblings younger than 12 or older than 18.

Lastly, the desire to keep the survey brief led to the elimination of potential factors. For example, parents were only asked to complete perceived impact measures for the target child.

Therefore, it is unclear if these perceptions are specific to the target child, or if the parents have similar outlooks toward all of their children. Additionally, siblings only completed the MAACL once, so we are unable to determine if the reported feelings are specific to the target child or are reflective of the siblings' general mood.

These limitations are offset by a number of strengths. First, despite potential response bias, the control group and disability group were not statistically different on almost all demographic measures, including parent, target child, and sibling age, household income, parents' marital status and parent and sibling gender. These similarities allow us to interpret group differences as the result of the presence or absence of a child with a disability, rather than potentially confounding demographic factors. Second, while the exclusionary criteria may limit generalizability, said criteria give the results a measure of validity. All sibling measures had been previously validated in adolescent populations, and the limitation on the number of children in the family prevents the response bias of having only the self-reported closest-in-age or most involved sibling complete the survey from families of children with IDD, and therefore serve as a representation of all siblings in multiple-children families. Finally, the use of open-ended questions in addition to established measures allows for the analysis of unanticipated differences between siblings of children with and without disabilities.

Conclusion

The present study adds to the extant literature by addressing several concerns regarding sibling research (Hodapp et al., 2005). Results show that, while siblings of individuals with IDD may not differ from siblings of typically-developing individuals on outcome measures, it is important to study these outcomes as variables within the family context, rather than strictly the product of having a brother or sister with a disability.

APPENDIX A

SIBLING EMOTIONALITY SURVEY

Sibling Emotionality

Please read all directions and eligibility criteria before beginning the survey.

Thank you for choosing to participate in the Sibling Emotionality Survey! In order to be eligible for this study, your family must have only 2 children, both of whom must be between the ages of 12 and 18 and still living at home. Your family can participate if a) neither of your children have intellectual or developmental disabilities or b) only one of your children has an intellectual or developmental disability.

This survey consists of four (4) parts. The first three parts will be filled out by only one parent, guardian, or caregiver. The final part will be filled out by one child without intellectual or developmental disabilities.

Part 1: Demographics - Please tell us about the members of your family.

Part 2: Parent - Parents, please answer these questions about yourself.

Part 3: Target child - Please choose one child from your family to think about when you answer these questions. This child will be referred to as the "Target Child" and may NOT complete the "Sibling" questions in the survey.

Part 4: Siblings - Your remaining child will be referred to as the "Sibling" and will answer questions about himself/herself at the end of the survey.

Again, thank you so much for your participation. If you have any questions, please feel free to e-mail carolyn.m.shivers@vanderbilt.edu with the subject line "Sibling Survey Help."

Your responses to this survey will be used for research of adolescent siblings. The survey should take approximately 20 minutes for parents and 15 minutes for siblings. We do not anticipate any risks for your participation. There are no direct benefits to you for your participation. However, your help will further scientific knowledge of how family processes impact teenagers with brothers or sisters. Your answers will be completely anonymous. Your family will be assigned an ID number for data analysis. After completing the survey, you will have the option to be entered into a drawing for one of 40 \$50 Target gift cards. The drawing is completely separate from the study; your contact information will not be connected to your survey responses in any way. You are free to stop the survey at any time. However, because responses are anonymous, there is now way to remove your data from the study once you submit your answers. If your family is deemed ineligible (i.e.your have children outside of the stated age range), your answers will not be included in the study.

I have read this informed consent and the material contained in it. All of my questions have been answered and I freely and voluntarily choose to participate. Yes

Is the child that will fill out the survey (the "Sibling") 18 years of age? No
 Yes

I have read this informed consent and the material contained in it. All of my questions have been answered and I freely and voluntarily choose for my child to participate. Yes

Parent Part 1: Please answer the following questions about your family.

Parent 1 Age _____

Parent 1 Gender Male
 Female

Parent 1 Race White non-Hispanic
 African American
 Asian
 Hispanic
 Native American
 Pacific Islander
 Other

Parent 2 Age _____

Parent 2 Gender Male
 Female

Parent 2 Race White non-Hispanic
 African American
 Asian
 Hispanic
 Native American
 Pacific Islander
 Other

Parents' Marital Status Never Married
 Currently Married
 Separated
 Divorced

Household Income less than \$15,000
 \$15,000 - \$29,000
 \$30,000 - \$49,000
 \$50,000 - \$69,000
 \$70,000 - \$99,000
 over \$100,000

Zip Code _____

Child 1 Age _____

Child 1 Gender Male
 Female

Child's relation to parents Biological child of both parents
 Adopted
 Biological child of Parent 1
 Biological child of Parent 2

Does this child have any of the following:

- ADHD/ADD
- Allergies
- Anxiety
- Asthma
- Autism Spectrum Disorder
- Cerebral Palsy
- Depression
- Diabetes
- Down Syndrome
- Dyslexia
- Genetic Disorder
- Intellectual Disability/Mental Retardation
- Learning Disability
- Mental Illness
- Obesity
- Seizures

Child 2 Age

Child 2 Gender

-
- Male
 - Female

Child's relation to parents

- Biological child of both parents
- Adopted
- Biological child of Parent 1
- Biological child of Parent 2

Does this child have any of the following:

- ADHD/ADD
- Allergies
- Anxiety
- Asthma
- Autism Spectrum Disorder
- Cerebral Palsy
- Depression
- Diabetes
- Down Syndrome
- Dyslexia
- Genetic Disorder
- Intellectual Disability/Mental Retardation
- Learning Disability
- Mental Illness
- Obesity
- Seizures

Parent Part 2

Now, we'd like to learn a little about you, Please answer the following questions about yourself.

- Gender of parent filling out this section
- Male
 Female
- 1 In uncertain times, I usually expect the best
- Strongly Disagree
 Disagree
 Neutral
 Agree
 Strongly Agree
- 2 It's easy for me to relax.
- Strong disagree
 Disagree
 Neutral
 Agree
 Strongly agree
- 3 If something can go wrong for me, it will.
- Strong disagree
 Disagree
 Neutral
 Agree
 Strongly agree
- 4 I'm always optimistic about my future.
- Strong disagree
 Disagree
 Neutral
 Agree
 Strongly agree
- 5 I enjoy my friends a lot.
- Strong disagree
 Disagree
 Neutral
 Agree
 Strongly agree
- 6 It's important for me to keep busy
- Strongly Disagree
 Disagree
 Neutral
 Agree
 Strongly Agree
- 7 I hardly ever expect things to go my way.
- Strong disagree
 Disagree
 Neutral
 Agree
 Strongly agree
- 8 I don't get upset too easily
- Strong disagree
 Disagree
 Neutral
 Agree
 Strongly agree
- 9 I rarely count on good things happening to me.
- Strong disagree
 Disagree
 Neutral
 Agree
 Strongly agree
- 10 Overall, I expect more good things to happen to me than bad.
- Strong disagree
 Disagree
 Neutral
 Agree
 Strongly agree

Parent Part 3

Next, we're going to ask you about your children.

For purposes of this study, intellectual and developmental disabilities will be defined as disabilities that severely limit both intellectual and adaptive functioning. These include, but are not limited to, autism, Down syndrome, and Prader-Willi syndrome. Diagnoses including ADHD, dyslexia, learning disabilities, and psychopathology such as OCD, depression, and anxiety are NOT considered intellectual and developmental disabilities.

With this in mind, do either of your children have an intellectual or developmental disability?

- Yes
 No

Which of the following does your child have?

- Mental retardation/developmental disability
 Down syndrome
 Fragile X syndrome
 Prader-Willi syndrome
 Autism/Autism spectrum disorder
 Cerebral Palsy
 Williams syndrome
 Unspecified developmental disability
 Other condition

Describe other _____

The following questions will be asked about your child with an intellectual or developmental disability. This child will be referred to as the "target child."

Before you answer the following questions, please decide which of your children will answer the questions in the "Sibling" section at the end of the survey. Only one child may complete this section. He/she will be referred to as the "Sibling." Now, please think about your other child (the one who is NOT answering the "Sibling" questions) and keep him/her in mind while you respond to the following questions. He/she will be referred to as the "Target child."

How old is the target child? _____

What gender is the target child?

- Male
 Female

Please rate how often the following statements are true for the target child.

Has sudden changes in mood or feeling

- Never true
 Sometimes or somewhat true
 Often or very true

Feels of complains that no one loves him/her

- Never true
 Sometimes or somewhat true
 Often or very true

Is rather high strung and nervous

- Never true
 Sometimes or somewhat true
 Often or very true

Cheats or tells lies

- Never true
 Sometimes or somewhat true
 Often or very true

Is too fearful or anxious

- Never true
 Sometimes or somewhat true
 Often or very true

- Argues too much
 Never true
 Sometimes or somewhat true
 Often or very true
- Has difficulty concentrating, cannot pay attention for long
 Never true
 Sometimes or somewhat true
 Often or very true
- Is easily confused, seems to be in a fog
 Never true
 Sometimes or somewhat true
 Often or very true
- Bullies or is cruel or mean to others
 Never true
 Sometimes or somewhat true
 Often or very true
- Is disobedient
 Never true
 Sometimes or somewhat true
 Often or very true
- Does not seem to feel sorry after misbehavior
 Never true
 Sometimes or somewhat true
 Often or very true
- Has trouble getting along with other children
 Never true
 Sometimes or somewhat true
 Often or very true
- Is impulsive, or acts without thinking
 Never true
 Sometimes or somewhat true
 Often or very true
- Feels worthless or inferior
 Never true
 Sometimes or somewhat true
 Often or very true
- Is not liked by other children
 Never true
 Sometimes or somewhat true
 Often or very true
- Has difficulty getting his/her mind off certain thoughts
 Never true
 Sometimes or somewhat true
 Often or very true
- Is restless or overly active, cannot sit still
 Never true
 Sometimes or somewhat true
 Often or very true
- Is stubborn, sullen, or irritable
 Never true
 Sometimes or somewhat true
 Often or very true
- Has a very strong temper and loses it easily
 Never true
 Sometimes or somewhat true
 Often or very true
- Is unhappy, sad, or depressed
 Never true
 Sometimes or somewhat true
 Often or very true
- Is withdrawn, does not get involved with others
 Never true
 Sometimes or somewhat true
 Often or very true
- Breaks things on purpose or deliberately destroys his/her own or another's things
 Never true
 Sometimes or somewhat true
 Often or very true

- | | |
|---|---|
| Clings to adults | <input type="checkbox"/> Never true
<input type="checkbox"/> Sometimes or somewhat true
<input type="checkbox"/> Often or very true |
| Cries too much | <input type="checkbox"/> Never true
<input type="checkbox"/> Sometimes or somewhat true
<input type="checkbox"/> Often or very true |
| Demands a lot of attention | <input type="checkbox"/> Never true
<input type="checkbox"/> Sometimes or somewhat true
<input type="checkbox"/> Often or very true |
| Is too dependent on others | <input type="checkbox"/> Never true
<input type="checkbox"/> Sometimes or somewhat true
<input type="checkbox"/> Often or very true |
| Feels others are out to get him/her | <input type="checkbox"/> Never true
<input type="checkbox"/> Sometimes or somewhat true
<input type="checkbox"/> Often or very true |
| Hangs around with kids who get into trouble | <input type="checkbox"/> Never true
<input type="checkbox"/> Sometimes or somewhat true
<input type="checkbox"/> Often or very true |
| Is secretive, keeps things to himself/herself | <input type="checkbox"/> Never true
<input type="checkbox"/> Sometimes or somewhat true
<input type="checkbox"/> Often or very true |
| Worries too much | <input type="checkbox"/> Never true
<input type="checkbox"/> Sometimes or somewhat true
<input type="checkbox"/> Often or very true |

To what extent can the target child perform the following activities?

- | | |
|---|---|
| Walking | <input type="checkbox"/> Not at all
<input type="checkbox"/> A little bit/rarely
<input type="checkbox"/> Somewhat/sometimes
<input type="checkbox"/> Pretty well/most of the time
<input type="checkbox"/> Very well |
| Speaking | <input type="checkbox"/> Not at all
<input type="checkbox"/> A little bit/rarely
<input type="checkbox"/> Somewhat/sometimes
<input type="checkbox"/> Pretty well/most of the time
<input type="checkbox"/> Very well |
| Reading | <input type="checkbox"/> Not at all
<input type="checkbox"/> A little bit/rarely
<input type="checkbox"/> Somewhat/sometimes
<input type="checkbox"/> Pretty well/most of the time
<input type="checkbox"/> Very well |
| Eating | <input type="checkbox"/> Not at all
<input type="checkbox"/> A little bit/rarely
<input type="checkbox"/> Somewhat/sometimes
<input type="checkbox"/> Pretty well/most of the time
<input type="checkbox"/> Very well |
| Preparing meals | <input type="checkbox"/> Not at all
<input type="checkbox"/> A little bit/rarely
<input type="checkbox"/> Somewhat/sometimes
<input type="checkbox"/> Pretty well/most of the time
<input type="checkbox"/> Very well |
| Taking medications (if applicable) | <input type="checkbox"/> Not at all
<input type="checkbox"/> A little bit/rarely
<input type="checkbox"/> Somewhat/sometimes
<input type="checkbox"/> Pretty well/most of the time
<input type="checkbox"/> Very well |
| Grooming/personal hygiene | <input type="checkbox"/> Not at all
<input type="checkbox"/> A little bit/rarely
<input type="checkbox"/> Somewhat/sometimes
<input type="checkbox"/> Pretty well/most of the time
<input type="checkbox"/> Very well |
| Performing household tasks | <input type="checkbox"/> Not at all
<input type="checkbox"/> A little bit/rarely
<input type="checkbox"/> Somewhat/sometimes
<input type="checkbox"/> Pretty well/most of the time
<input type="checkbox"/> Very well |
| Running errands | <input type="checkbox"/> Not at all
<input type="checkbox"/> A little bit/rarely
<input type="checkbox"/> Somewhat/sometimes
<input type="checkbox"/> Pretty well/most of the time
<input type="checkbox"/> Very well |
| Performing basic financial tasks (e.g. balancing checkbook) | <input type="checkbox"/> Not at all
<input type="checkbox"/> A little bit/rarely
<input type="checkbox"/> Somewhat/sometimes
<input type="checkbox"/> Pretty well/most of the time
<input type="checkbox"/> Very well |

Participating in leisure activities

- Not at all
- A little bit/rarely
- Somewhat/sometimes
- Pretty well/most of the time
- Very well

Living independently

- Not at all
- A little bit/rarely
- Somewhat/sometimes
- Pretty well/most of the time
- Very well

Working at a job

- Not at all
- A little bit/rarely
- Somewhat/sometimes
- Pretty well/most of the time
- Very well

Maintaining friendships

- Not at all
- A little bit/rarely
- Somewhat/sometimes
- Pretty well/most of the time
- Very well

Maintaining intimate relationships

- Not at all
- A little bit/rarely
- Somewhat/sometimes
- Pretty well/most of the time
- Very well

Please think about your "target child" when you answer the following questions.

Compared to children and parents with children the same age as my child...

My child is more stressful Not at all
 Somewhat
 Much
 Very much

I enjoy the time I spend with my child more. Not at all
 Somewhat
 Much
 Very much

My child brings out feelings of frustration and anger more. Not at all
 Somewhat
 Much
 Very much

My child brings out feelings of happiness and pride more. Not at all
 Somewhat
 Much
 Very much

When I am with my child, I feel less effective and competent as a parent. Not at all
 Somewhat
 Much
 Very much

It is easier for me to play and have fun with my child. Not at all
 Somewhat
 Much
 Very much

My child's behavior bothers me more. Not at all
 Somewhat
 Much
 Very much

My child makes me feel more loved. Not at all
 Somewhat
 Much
 Very much

I feel like I am working alone in trying to deal with my child's behavior. Not at all
 Somewhat
 Much
 Very much

My child makes me feel more energetic. Not at all
 Somewhat
 Much
 Very much

I feel like I could be a better parent with my child. Not at all
 Somewhat
 Much
 Very much

My child makes me feel more confident as a parent. Not at all
 Somewhat
 Much
 Very much

- 13 I feel like I should have better control over his/her behavior.
- Not at all
 Somewhat
 Much
 Very much
- 14 My child does what I tell him/her to do most of the time.
- Not at all
 Somewhat
 Much
 Very much
- 15 I feel like I know how to deal with my child's behavior most of the time.
- Not at all
 Somewhat
 Much
 Very much
- Compared with other children my child's age...
- 16 The cost of raising my child is more.
- Not at all
 Somewhat
 Much
 Very much
- 17 The cost of child care is more.
- Not at all
 Somewhat
 Much
 Very much
- 18 The cost of food, clothes, and/or toys is more.
- Not at all
 Somewhat
 Much
 Very much
- 19 The cost of home alterations and/or fixing and replacing items in the home is more.
- Not at all
 Somewhat
 Much
 Very much
- 20 The cost of medication, medical care, and/or medical insurance is more.
- Not at all
 Somewhat
 Much
 Very much
- 21 The cost of educational and psychological services is more.
- Not at all
 Somewhat
 Much
 Very much
- 22 The cost of recreational activities (e.g. music, swimming, gymnastics) is more.
- Not at all
 Somewhat
 Much
 Very much
- Compared with other children my child's age...
- 23 The other children in the family help take care of him/her more.
- Not at all
 Somewhat
 Much
 Very much
- 24 My child prevents his/her siblings from participating in activities more.
- Not at all
 Somewhat
 Much
 Very much
- 25 The other children in the family complain about his/her behavior more.
- Not at all
 Somewhat
 Much
 Very much

- 26 The other children in the family feel more embarrassed by his/her behavior. Not at all
 Somewhat
 Much
 Very much
- 27 My child is more rejected by his/her siblings. Not at all
 Somewhat
 Much
 Very much
- 28 The other children in the family invite friends over to the house less often because of his/her behavior. Not at all
 Somewhat
 Much
 Very much
- 29 The other children in the family enjoy spending time with him/her more. Not at all
 Somewhat
 Much
 Very much
- 30 My child uses his/her siblings' toys without asking permission more. Not at all
 Somewhat
 Much
 Very much
- 31 My child breaks or loses his/her siblings' toys more. Not at all
 Somewhat
 Much
 Very much

End of Parent Section

Thank you for completing the parent section. The remaining questions are for the "Sibling" to answer.

Sibling Section

Your answers to these questions will be used in research on teenagers with brothers and sisters. It should take you about 15 minutes to answer these questions. We do not think anything bad will happen to you because you answer these questions. You will not get any direct benefits from answering these questions, but your answers will help scientists understand what it is like being a teenager with a brother or sister. Your name will not be attached to your answers. No one will know which answers are yours. Your answers will be combined with everyone else's answers for research. After completing the survey, you and your family will have the option to be entered into a drawing for one of 40 \$50 Target gift cards. The drawing is completely separate from the study; your contact information will not be connected to your answers in any way. You can stop answering the questions at any time. Once you hit the "submit" button, you can't take back your answers. If you or your family do not fit in the study rules (like if you are not between the ages of 12 and 18), we won't keep your answers.

I have read and understand the information above. I want to be part of the study.

Yes

Gender

Male

Female

How old are you?

Sibling Part 1

If you had three magic wishes, what would you wish for?

Wish 1

Wish 2

Wish 3

Sibling Part 2: Multiple choice

How well do the following statements describe you?

I daydream and fantasize, with some regularity, about things that might happen to me.

- Does not describe me well
- Describes me a little bit
- Kind of describes me
- Mostly describes me
- Describes me very well

I often have tender, concerned feelings for people less fortunate than me.

- Does not describe me well
- Describes me a little bit
- Kind of describes me
- Mostly describes me
- Describes me very well

I sometimes find it difficult to see things from the "other guy's point of view.

- Does not describe me well
- Describes me a little bit
- Kind of describes me
- Mostly describes me
- Describes me very well

Sometimes I don't feel very sorry for other people when they are having problems

- Does not describe me well
- Describes me a little bit
- Kind of describes me
- Mostly describes me
- Describes me very well

I really get involved with the feelings of the characters in a novel.

- Does not describe me well
- Describes me a little bit
- Kind of describes me
- Mostly describes me
- Describes me very well

In emergency situations, I feel apprehensive and ill-at-ease.

- Does not describe me well
- Describes me a little bit
- Kind of describes me
- Mostly describes me
- Describes me very well

I am usually objective when I watch a movie or play, and I don't often get completely caught up in it.

- Does not describe me well
- Describes me a little bit
- Kind of describes me
- Mostly describes me
- Describes me very well

I try to look at everybody's side of a disagreement before I make a decision.

- Does not describe me well
- Describes me a little bit
- Kind of describes me
- Mostly describes me
- Describes me very well

When I see someone being taken advantage of, I feel kind of protective towards them.

- Does not describe me well
- Describes me a little bit
- Kind of describes me
- Mostly describes me
- Describes me very well

I sometimes feel helpless when I am in the middle of a very emotional situation.

- Does not describe me well
- Describes me a little bit
- Kind of describes me
- Mostly describes me
- Describes me very well

I sometimes try to understand my friends better by imagining how things look from their perspective.

- Does not describe me well
- Describes me a little bit
- Kind of describes me
- Mostly describes me
- Describes me very well

Becoming extremely involved in a good book or movie is somewhat rare for me.

- Does not describe me well
- Describes me a little bit
- Kind of describes me
- Mostly describes me
- Describes me very well

When I see someone get hurt, I tend to remain calm.

- Does not describe me well
- Describes me a little bit
- Kind of describes me
- Mostly describes me
- Describes me very well

Other people's misfortunes do not usually disturb me a great deal.

- Does not describe me well
- Describes me a little bit
- Kind of describes me
- Mostly describes me
- Describes me very well

If I'm sure I'm right about something, I don't waste much time listening to other people's arguments.

- Does not describe me well
- Describes me a little bit
- Kind of describes me
- Mostly describes me
- Describes me very well

After seeing a play or movie, I have felt as though I were one of the characters.

- Does not describe me well
- Describes me a little bit
- Kind of describes me
- Mostly describes me
- Describes me very well

Being in a tense emotional situation scares me.

- Does not describe me well
- Describes me a little bit
- Kind of describes me
- Mostly describes me
- Describes me very well

When I see someone being treated unfairly, I sometimes don't feel very much pity for them.

- Does not describe me well
- Describes me a little bit
- Kind of describes me
- Mostly describes me
- Describes me very well

I am usually pretty effective in dealing with emergencies.

- Does not describe me well
- Describes me a little bit
- Kind of describes me
- Mostly describes me
- Describes me very well

I am often quite touched by things that I see happen.

- Does not describe me well
- Describes me a little bit
- Kind of describes me
- Mostly describes me
- Describes me very well

I believe that there are two sides to every question and try to look at them both.

- Does not describe me well
- Describes me a little bit
- Kind of describes me
- Mostly describes me
- Describes me very well

I would describe myself as a pretty soft-hearted person.

- Does not describe me well
- Describes me a little bit
- Kind of describes me
- Mostly describes me
- Describes me very well

When I watch a good movie, I can very easily put myself in the place of a leading character.

- Does not describe me well
- Describes me a little bit
- Kind of describes me
- Mostly describes me
- Describes me very well

I tend to lose control during emergencies.

- Does not describe me well
- Describes me a little bit
- Kind of describes me
- Mostly describes me
- Describes me very well

When I'm upset at someone, I usually try to "put myself in his shoes" for awhile.

- Does not describe me well
- Describes me a little bit
- Kind of describes me
- Mostly describes me
- Describes me very well

When I am reading an interesting story or novel, I imagine how I would feel if the story were happening to me.

- Does not describe me well
- Describes me a little bit
- Kind of describes me
- Mostly describes me
- Describes me very well

When I see someone who badly needs help in an emergency, I go to pieces.

- Does not describe me well
- Describes me a little bit
- Kind of describes me
- Mostly describes me
- Describes me very well

Before criticizing somebody, I try to imagine how I would feel if I were in their place.

- Does not describe me well
- Describes me a little bit
- Kind of describes me
- Mostly describes me
- Describes me very well

Sibling Part 3: Please think about your brother or sister when completing this part of the survey.

Please look at the following list of feelings. Mark all of the boxes that describe how you generally feel about or toward your brother or sister.

Please mark all answers that describe how you generally feel about or toward your brother or sister.

- Active
- Adventurous
- Affectionate
- Afraid
- Agreeable
- Aggressive
- Alive
- Alone
- Amused
- Angry
- Annoyed
- Awful
- Bashful
- Bitter
- Blue
- Bored
- Calm
- Cautious
- Cheerful
- Clean
- Complaining
- Contented
- Cool
- Cooperative
- Cross
- Cruel
- Daring
- Desperate
- Destroyed
- Devoted
- Disagreeable
- Discontented
- Discouraged
- Disgusted
- Displeased
- Energetic
- Enthusiastic
- Fearful
- Fine
- Fit
- Frank
- Free
- Friendly
- Frightened
- Furious
- Gentle
- Glad
- Gloomy
- Good
- Good-natured
- Guilty
- Happy
- Healthy
- Hopeless

- Impatient
- Interested
- Irritated
- Jealous
- Joyful
- Kindly
- Lonely
- Lost
- Loving
- Low
- Lucky
- Mad
- Mean
- Merry
- Mild
- Miserable
- Nervous
- Panicky
- Patient
- Peaceful
- Pleased
- Pleasant
- Polite
- Powerful
- Protective
- Quiet
- Reckless
- Rejected
- Rough
- Sad
- Safe
- Satisfied
- Secure
- Shaky
- Shy
- Soothed
- Steady
- Stubborn
- Stormy
- Strong
- Suffering
- Sunk
- Sympathetic
- Tame
- Tender
- Tense
- Terrible
- Terrified
- Thoughtful
- Tormented
- Understanding
- Unhappy
- Unsociable
- Upset
- Warm
- Whole
- Wild
- Wilted
- Worrying
- Young

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