

RISK FACTORS IN FAMILIES OF CHILDREN WITH DEVELOPMENTAL
DISABILITIES

by

JILLIAN R. TUSO

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DISSERTATION APPROVAL PAGE

Student: Jillian R. Tuso

Title: Risk Factors in Families of Children with Developmental Disabilities

This dissertation has been accepted and approved in partial fulfillment of the requirements for the Doctor of Philosophy degree in the Department of Special Education and Clinical Sciences by:

Laura Lee McIntyre	Chairperson
Wendy Machalicek	Member
John Seeley	Member
Beth Stormshak	Institutional Representative

and

Janet Woodruff-Borden	Vice Provost and Dean of the Graduate School
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Original approval signatures are on file with the University of Oregon Graduate School.

Degree awarded June 2019

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DISSERTATION ABSTRACT

Jillian R. Tuso

Doctor of Philosophy

Department of Special Education and Clinical Sciences

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Title: Risk Factors in Families of Children with Developmental Disabilities

Children with developmental disabilities often present with increased behavioral problems and a decreased social skill repertoire. These characteristics often directly impact caregiver's own stress and pose challenges in the home. Less is known about how the presence of a child in the home with a disability impacts their siblings. Further, the literature is mixed surrounding if brothers and sisters of children with developmental disabilities are more or less adjusted than siblings of children that are typically developing. There is also a gap surrounding how parenting multiple children, when at least one of the children has a developmental disability, impacts parental stress. The current study explored how target child factors, sibling factors, and other parent and family factors can influence parental stress. Forty-one families participated in this study and provided information on themselves, their target preschool-aged child with a developmental disability, and an older identified sibling. Higher behavior problems and lower social skills in the target child predicted parental stress; however, these variables in the siblings did not. Dyadic adjustment was found to serve as a protective factor against parental stress after accounting for the influence of the target child's and the sibling's behavior problems. Target child behavior problems predicted parental stress after accounting for common familial stressors. Future research could explore other parent

outcome variables that might be influenced by multiple children. Future research could be conducted that focuses on sibling adjustment as an outcome, as well as leveraging siblings as informants to get their perspectives on impact of having a brother or sister with a disability. Additionally, sibling perspectives on family life and family adjustment could also be investigated.

CURRICULUM VITAE

NAME OF AUTHOR: Jillian R. Tuso

GRADUATE AND UNDERGRADUATE SCHOOLS ATTENDED:

University of Oregon; Eugene, Oregon
University of Pennsylvania; Philadelphia, Pennsylvania
University of California, Los Angeles; Los Angeles, California

DEGREES AWARDED:

Doctor of Philosophy, School Psychology, 2019, University of Oregon
Master of Philosophy of Education, 2014, University of Pennsylvania
Master of Science of Education, 2013, University of Pennsylvania
Bachelor of Arts, Psychology, 2012, University of California, Los Angeles

AREAS OF SPECIAL INTEREST:

Intellectual and Developmental Disabilities
Prevention and Early Intervention
Family Supports for Families of Children with Developmental Disabilities
Parent Training for Parents of Children with Developmental Disabilities

PROFESSIONAL EXPERIENCE:

Child Therapist, Child and Family Center, Eugene, Oregon, 2017-2018

Practicum Student, Pleasant Hill School District, Pleasant Hill, Oregon, 2016-2017

Family Interventionist, Fisher SNAP Lab, University of Oregon, Eugene, Oregon
2015- 2017

Interventionist, Oregon Parent Project, University of Oregon, Eugene, Oregon,
2012- 2013

GRANTS, AWARDS, AND HONORS:

Graduate Teaching Fellowship, University of Oregon, 2014-2018

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DEDICATION

For my parents, the best support system I could have asked for.

For my siblings, my constant inspiration.

TABLE OF CONTENTS

Chapter	Page
I. LITERATURE REVIEW	1
Children with Developmental Delays and Disabilities	1
Sibling Risk Factors	2
Risk to Parents of Children with DD	4
Marital Adjustment	5
Purpose of the Study	6
Research Questions	7
II. METHODOLOGY	12
Participants	12
Study Procedures	12
Measures	12
Demographics	12
Child Problem Behavior	12
Adaptive Behavior	13
Social Skills	13
Parental Stress	14
Parental Depression	14
Dyadic Adjustment	15
III. RESULTS	16

Chapter	Page
IV. DISCUSSION.....	29
Summary of Results.....	29
Key Findings.....	30
Limitations.....	34
Future Directions.....	36
Conclusion.....	38
REFERENCES CITED.....	39

LIST OF FIGURES

Figure	Page
1. Conceptual Model.....	11

LIST OF TABLES

Table	Page
1. Child, sibling and caregiver demographic variables.....	17
2. Descriptive information of the sample	18
3. Bivariate correlations for parent, child and sibling variables	21
4. Hierarchical regression of target child and sibling problem behaviors predicting parent stress	23
5. Hierarchical regression of target child and sibling social skills predicting parent stress.....	25
6. Hierarchical regression of target child, sibling behavior problems and dyadic adjustment predicting parent stress.....	26
7. Hierarchical regression of familial factors, target child, and sibling problem behaviors predicting parent stress.....	28

CHAPTER I

INTRODUCTION

Children with Developmental Delays and Disabilities

The prevalence of developmental disabilities (DD) in the United States has been on the rise in recent decades, with approximately 1 in 6 children identified as having a DD (Boyle et al., 2011). Developmental disabilities often include diagnoses such as autism spectrum disorder, ADHD, Down syndrome, cerebral palsy, seizures, and language and learning disorders. These DDs often include delays in gross and fine motor skills compared to typically developing infants and children (Provost, Lopez, & Heimerl, 2007).

While we know that children with DD, and more broadly children with developmental delay, are more likely to exhibit behavior problems compared to their typically developing peers (Dosen & Day, 2001), we do not know the extent to which parenting multiple children with delays can impact the family. For example, we know little about the additive effects of caregiving children with disabilities, regardless of whether these children have behavior problems. However, given the increased likelihood of comorbid behavior problems occurring with developmental disabilities, it is plausible that this “double whammy” of developmental disability plus behavior problem may negatively affect caregivers (Crnic, Neece, McIntyre, Blacher, & Baker, 2017). Multiple studies have found that the presence of a child’s behavior problems, more so than intellectual or developmental delay, has the greatest impact on parental stress (Baker et al., 2003; Deater-Deckard et al., 2005).

In addition to being at risk for behavior problems, children with DD are also at an increased risk of receiving a psychiatric diagnosis, including externalizing disorders (Emerson, 2003). Children with DD are also often found to have fewer social skills compared to their typically developing peers (McIntyre, Blacher, & Baker, 2006). This can be seen through fewer social initiations, less well developed adaptive interactive styles, and less overall social play with peers (Guralnick et al., 1998; Gurlanick & Groom, 1987). Supportive parenting interactions have been found to help predict future social skill use in children with developmental delays (Baker et al., 2007).

Sibling Risk Factors

Parents are not the only ones who are at risk for adverse effects of having a child in the home with a DD and behavior problems; siblings in the home also are at risk for maladjustment. Research shows that if there is a child with autism in the home, the family is more likely to include another child with a disability compared to families of children without autism (Bolton et al., 1994). While current evidence suggests an underlying genetic etiology for autism that may be related to increased genetic vulnerability in siblings (Ozonoff et al., 2011), the burden on siblings and caregivers cannot be overlooked. Understanding sibling adjustment and interpersonal dynamics are especially important because research demonstrates that having a positive sibling relationship is linked to more positive psychological adjustment for both children (Voorpostel & Van Der Lippe, 2007). On the other hand, sibling relationships with a lot of conflict are linked to increased anxiety, depressed mood and heightened risk of delinquent behavior (Stocker, Burwell, & Briggs, 2002) for both children. Although the literature is somewhat mixed on the impact of children with DD on their siblings, some

studies find that there are differences in sibling adjustment as a function of child diagnosis. For example, research suggests that children with autism spectrum disorder (ASD) is differentially associated with more negative impact than children with Down syndrome (Fisman et al., 1996; Pollard et al., 2013). Overall, however, the literature suggests that there may be a negative impact on siblings when their brother or sister has a DD (Kaminsky & Dewey, 2002; Orsmond & Seltzer, 2007; Stoneman, 2001).

In order to assess the impact of having a sibling with a DD on another child in the home, Hastings (2007) asked 56 families to report on their children at two different points in time, two years apart. These mothers were asked questions about the problem behaviors of their child with a DD and the problem behaviors of the typically developing. In this study, Hastings et al. (2007) did not find evidence to support that the sibling's behavior predicted the behavior of the child with a DD; however, there was support for problem behavior of the child with DD predicting the sibling's behavior at the second time point. Future research should be conducted to see how the relationship between the sibling's behavior can impact the parent's stress and mental health as an outcome.

Findings from previous studies suggest that parent functioning directly and indirectly impacts adjustment in siblings of children with a disability, and that these children are particularly perceptive and sensitive to parent mood and family conflict (Amato & Fowler, 2002; Nixon & Cummings, 1999). Giallo and Gavildia-Payne (2006) conducted a study to explore the adjustment of siblings of children with disability as impacted by various child, parent and familial factors. Specifically, the authors looked at sibling adjustment and the relationship between stress and coping, as well as what family characteristics may serve as protective factors. However, there is not a current literature

base to understand how sibling characteristics can impact parental stress and mental health. Giallo and Gavildia-Payne found that siblings had significantly higher ratings on emotional symptoms, adjustment difficulties, and peer problem sub scales on the Sibling Daily Hassles and Uplifts Scale (Kearney et al. 1993). When families had regular family routines the siblings had fewer adjustment difficulties. Parent stress was found to be a strong predictor of sibling adjustment difficulties, which is consistent across the literature for siblings of children with disabilities. The authors suggest that this stress is likely bidirectional, and that more stressed out siblings can stress out the parents more as well.

Both mothers and fathers of children with autism have reported that their typically developing children have significantly more emotional problems and lower pro-social behavior than the normative population (Griffith, Hastings, & Petalas, 2014).

Additionally, siblings of children with autism are at a greater risk of both externalizing and internalizing adjustment problems (Fisman, Wolf, Ellison, & Freeman, 2000). While not all developmental disabilities share the same traits as autism, the literature base surrounding children with autism seems to be greater than general developmental delays and disabilities.

Risks to Parents of Children with DD

Parents of children with DD are at an increased risk for many mental health challenges, including heightened stress and depressive symptoms (Estes et al., 2009; Woodman, Mawdsley, & Hauser-Cram, 2015). Overall, these parents report that they are experiencing significantly more distress compared to parents of typically developing children (Baker, Blacher, Crnic, & Edelbrock, 2002; Orsmond, Lin, & Seltzer, 2007). The trend in the literature agrees that raising a child with ASD, or similar developmental

disabilities, negatively impacts parent mental health by increasing their parental reported stress and caregiver burden (Baker et al., 2003; Eisenhower et al., 2005). When parents are more stressed, they are less likely to be using the most effective parenting practices, which impacts the siblings as well as the child with developmental delays (Giallo & Gavidia-Payne, 2006).

As stated before, children with DD are more likely to exhibit challenging and problem behavior compared to their typically developing peers (Estes et al., 2009). When children present challenging behaviors in the home, it can exacerbate parental stress and put parents at risk for increased mental health problems (Lecavalier, Leone, & Wiltz, 2005). Having a child with behavior problems can lead to parents having difficulty finding appropriate childcare, which also increases parental stress (Warfield, 2005). The impacts of increased parental stress interacting with child behavior problems can also bleed into the parent's work life, as Warfield (2005) found that mothers of children with serious behavior problems showed less work interest and greater parenting role stress. Further, the effects of parental stress can be bidirectional in nature, with parental stress serving as both an antecedent and a consequence of a child's behavior problems (Woodman, Mawdsley, & Hauser-Cram, 2015). Using a longitudinal design, Neece et al. (2012) found that a child's behavior problems can both be an antecedent to parental stress, as well as a consequence to parent's stress.

Children with developmental delays also have been found to demonstrate lower social skills compared to their same aged peers (Guralnick et al., 1998; Gurlanick & Groom, 1987). Smith, Oliver, and Innocenti (2001) looked at children's social skill scores and found that it was a stronger predictor of parenting stress than their motor,

communicative, cognitive abilities or adaptive behavior. Estes et al. (2009) suggest that mothers may become distressed when their child does not exhibit pro-social behaviors and it poses challenges for the mothers when they are in public situations.

In addition to child characteristics, families of children with developmental delay are at risk for other familial stressors including access to resources, financial stressors and perceived support. Innoncenti, Huh, and Boyce (1992) conducted a study to compare the impact of child related stressors to family related stressors on parents of children with disabilities. Innoncenti et al. (1992) used the Parenting Stress Index (Abidin, 1990) to assess parent perceptions of stress within the parent-child dyad. They found that child stress domain scores were a stronger predictor of parental stress than parent stress domain scores. This study did not include general demographic factors in their analysis of stress scores, which should be considered in future studies of families of children with disabilities.

Warfield (2005) found that parents that had at least one child with a disability in the home reported less stress when there were fewer other children in the home. This suggests that more children in the home is associated with heightened stress in both mothers and fathers. Further, multiple children in the home was also associated with less income and a greater difficulty finding childcare. Parents' stress seems to be compounded by rearing multiple children, regardless of child DD status. In order to better understand the parenting experience of caregivers, we need to understand characteristics of the child with DD and their siblings as well as parents' relationship with their spouse/partner.

Marital Adjustment

Caregiving for children undoubtedly influences parental stress. This stress can be exacerbated when parents are struggling with their children's behavior problems, which could cause interpersonal challenges in two parent homes. Risdal and Singer (2004) conducted a meta-analysis to see how marital adjustment is affected in parents of children with disabilities. They found that the presence of a disability was positively correlated with an increase in marital strain, as well as an increase in couples that ended their relationships in divorce. Future research should explore which variables can mediate the relationship between disability and different marital outcomes to help best understand how to support this population, and identify which families are at heightened risk for negative outcomes. Hartley et al. (2012) studied parents of children with autism over seven years to see if their child's behavior and health covaried with parent ratings of marital satisfaction. They found that mothers' ratings of marital satisfaction significantly were impacted by the child's behavior problems at that time period.

Purpose of the Study

Raising children with disabilities may put parents at risk for negative psychological well-being (Olsson & Hwang, 2001; Singer, 2006). Much of the current family literature surrounding children with DD looks at a parent-child dyad without including other family members. Studies involving siblings often look at dynamics between just the siblings and do not look at parental outcomes. Very few look at elements within both children that may impact parental stress. We know that parental stress and poor mental health outcomes can be exacerbated by a child's challenging behavior (Lecavalier, Leone, & Wiltz, 2005); however, there is little to no information

about how parental well-being impacts families where there are multiple children in the home.

This is particularly important because of the link between parental stress and parenting skills in managing children's behavior problems (Crnic et al., 2017).

Presumably if a parent is experiencing high stress, that stress will not only impact the target child with DD but other children in the home. Identifying parent sources of stress may help refine parent stress reduction interventions for caregivers of children with DD. Figure 1 is a conceptual model that visually displays variables of interest to the current study.

Research Questions

The current study examined the following research questions:

- 1. How do the social and behavioral profiles of preschoolers with developmental delays relate to the social and behavioral profiles of their older siblings?*

As stated before, we know that siblings of children with DD are at heightened risk for behavior problems (Dosen & Day, 2001). However, little is known about the extent to which the severity and specific shared symptomology is related between siblings (Hastings et al., 2007). With this research question, we hope to find out how the adaptive and maladaptive profiles of preschool children with developmental delay map onto their older sibling's maladaptive profiles as determined by scores on the Vineland-II (Sparrow, Cicchetti, & Balla, 2005), Child Behavior Checklist (CBCL; Achenbach & Rescorla, 2012) and the Social Skills Improvement System (SSIS; Gresham & Elliott, 2008).

- 2. Does the sibling's level of behavioral functioning impact parental stress above and beyond the impact of the target child with developmental delay's behavior problems?*

While research has found that a target child with developmental delay's behavior problems can greatly impact parental stress (Baker et al., 2003; Deater-Deckard et al., 2005; Dosen & Day, 2001;), much less is known about how the sibling's adaptive and maladaptive behavior can impact parental stress. Through this question we hope to find if the presence of a sibling with behavior problems adds to the prediction of parental stress, as well as understanding if the presence of sibling behavior problems moderates the association between target child and parental stress.

- 3. Does the sibling's social skill utilization impact parental stress above and beyond the impact of the target child with developmental delay's social skill levels?*

Similar to the expectations of the sibling behavior problems, we expect to find an impact of the sibling social skill ratings on parental stress. It is possible that parents of children that exhibit higher social skills are buffered from the negative impact from the children with developmental delay.

- 4. Does the primary caregiver's dyadic adjustment rating impact parental stress after accounting for the effects for both the target child and the sibling?*

The literature surrounding dyadic adjustment in parents of children with DD is relatively underdeveloped. While we do not yet know the extent to which dyadic adjustment may serve as a risk or protective factor for parental stress, however we do know that parents of children with disabilities have a higher rate of divorce as well as lower marital satisfaction when there is a child with behavior problems in the home

(Hartley et al., 2012; Risdal & Singer, 2004;). We hope to explore the possible impact and protective factors of having a supportive romantic partner on caregiver stress in families of children with DD and another child in the home.

5. *Do child related stressors (i.e. behavior problems) add to parental stress above and beyond familial stressors (i.e. finances, education level, number of children in the home)?*

Lastly, we want to explore family stressors and how they impact parental stress compared to child characteristics that are often associated with parental stress. The literature shows the impact of target child stressors compared to the impact of financial and similar family stressors (Lecavalier, Leone, & Wiltz, 2005), however these previous studies do not include the possible stressors that may be added with more children in the home.

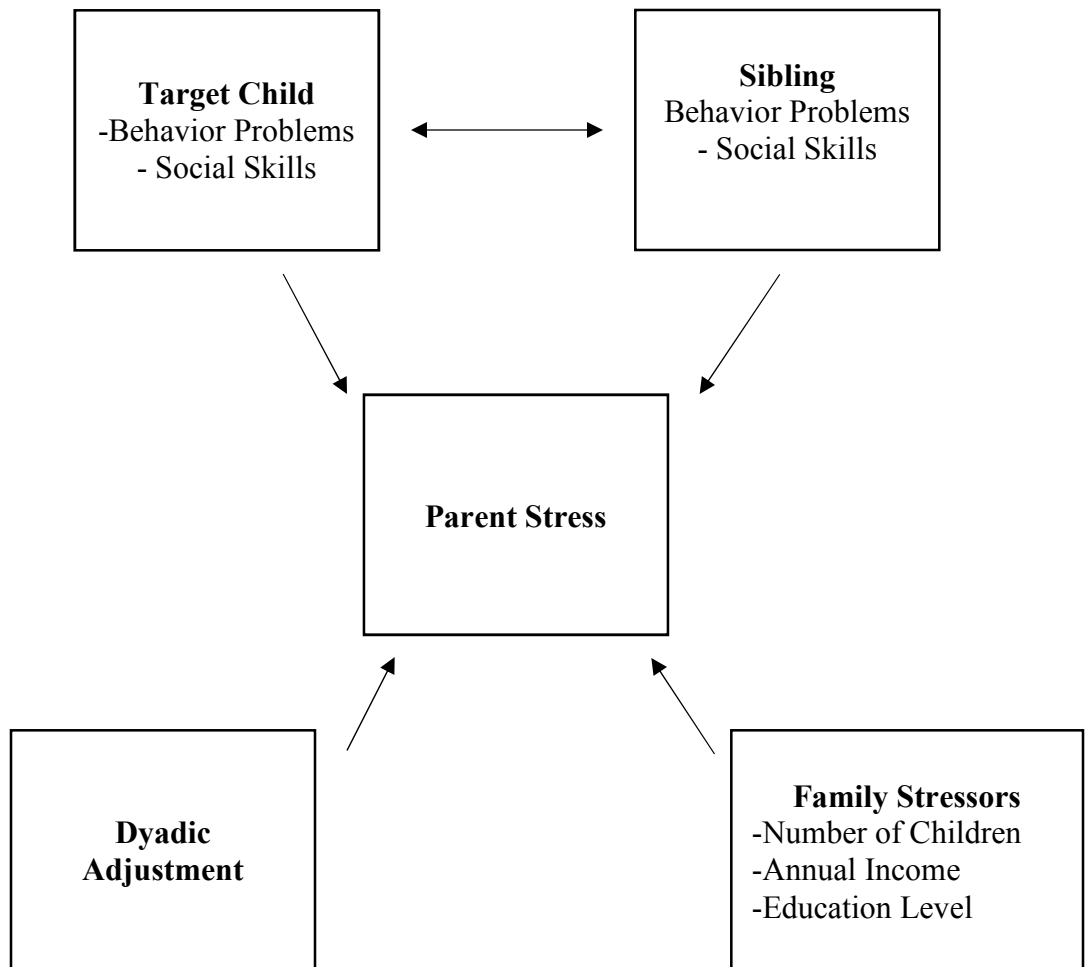


Figure 1. Conceptual Model.

CHAPTER II

METHODOLOGY

Participants

A sample of 41 families with a preschool-aged target child with DD, as well as an older sibling between the ages of 36 and 96 months, participated in this study.

Participants were a subsample of families participating in a larger study titled the Oregon Parent Project (OPP; R01 HD059838, McIntyre, PI). Participants were recruited from preschool and early intervention agencies serving children with developmental delays and disabilities in a midsize city in Oregon.

Procedure

At the intake assessment for the larger OPP study, participants who had a sibling who met inclusionary criteria were asked to participate in an additional study targeting siblings (OPP-SIBS; R01 HD059838-S). Primary caregivers filled out a series of questionnaires about themselves, their target child, and the participating sibling.

Measures

Demographics. A demographic form was filled out by the primary caregiver that included parent, target child and sibling variables. Target child demographic information included age, gender, race, and primary diagnosis. Sibling demographics included age, gender, race and diagnosis (if any). Parent demographic information included parent age, gender, race and diagnosis (if any). Parent demographic information included parent age, gender, race, relationship to child, education level, employment status, marital/partner status, and household income.

Child Problem Behavior. In order to assess child problem behavior, the Child Behavior Checklist (CBCL: Achenbach & Rescorla, 2012) was collected for both the

target child and the sibling to assess internalizing and externalizing symptoms. This scale is a 99-item norm referenced checklist that parents identify if each item is “not true” (0), “somewhat or sometimes true” (1), or “very true or often true” (2), now or within the past two months. The CBCL takes about 15 minutes to complete and provides a total problem score, broad-band externalizing and internalizing scores, and narrow-band scales. Content validity of the CBCL for this population is well documented to have a high reliability and validity (Baker et al., 2003; Ellingsen et al., 2014). This study used the Total Problems scale ($\alpha = .96$ in the current sample).

Adaptive Behavior. Primary caregivers completed the Vineland Adaptive Behavior Scales 2nd Edition (Vineland-II; Sparrow, Cicchetti, & Balla, 2005) to assess the target child’s adaptive functioning. This measure is a written survey that asks 413 questions across five behavioral domains including: (a) communication, (b) daily living skills, (c) socialization, (d) motor skills, and (e) maladaptive/ problem behavior. For this study only the four adaptive domains were used. Each item is scored on the following 4-point likert scale: (2) usually, (1) sometimes / partially, (0) never, (DK) don’t know. The Vineland-II is norm-referenced and has been established as a valid and reliable measure of adaptive behavioral functioning for this age group (Salvia, Ysseldyke, & Bolt, 2010). Scores on this measure cumulate in a composite score with a mean of 100 and a standard deviation of 15. This study used the socialization subscale ($\alpha = .96$ in the current sample).

Social Skills. Primary caregivers filled out the Social Skills Improvement System (SSIS; Gresham & Elliott, 2008) to assess the social skills of the participating siblings. For this study, only the 79-item social skills scale was used that includes the following

subscales: Communication ($n = 7$ items), Cooperation ($n = 6$ items) Assertion ($n = 7$ items), Responsibility ($n = 6$ items), Empathy ($n = 6$ items), Engagement ($n = 7$ items), and Self-Control ($n = 7$ items) (Gresham et al., 2010). Composite standard scores will be used for this study, where the reported mean is 100 and standard deviation is 15 (Gresham & Elliott, 2008). Research has demonstrated adequate reliability and validity for the SSIS (Gresham, Elliott, Vance, & Cook, 2011). The alpha for the Social Skills composite score in the present sample is .90.

Parental Stress. Parental stress was evaluated using the Parenting Stress Index 3rd Edition Short form (PSI-SF; Abidin, 1995). This measure consists of 36 items relative to stress within the parent-child relationship within three scales; Parental Distress, Parent-Child Dysfunctional Interaction, and Difficult Child. Primary caregivers were asked to fill out the form using the target child as the focal child. The PSI-SF is a valid and reliable instrument that is often used to measure parental stress in mothers and fathers (Haskett et al., 2006). The alpha for the Parenting Stress Total Score in the present sample is .91.

Parental Depression. In order to evaluate parent depression, the primary caregivers filled out the Center for Epidemiological Studies Depression Scale (CES-D; Radloff, 1977). This measure consists of 20 items where the parents indicate how often they experience certain events and symptoms on a 4-point Likert scale. Ratings range from 0 (rarely or none of the time) to 3 (most or all of the time). Items are summed to provide a total score (range 0 – 60) where higher scores indicate more depression symptomology. The CES-D is a reliable and valid screening tool for assessing depression

and has been used in a variety of adult and adolescent populations (Hann, Winter, & Jacobsen, 1999; Shinar et al., 1986). The alpha in the current sample is .91.

Dyadic Adjustment. Dyadic adjustment, or the quality of marriage or partner relationship, is determined by scores on the Dyadic Adjustment Scale (DAS; Spanier, 1987). This measure was administered to primary caregivers who reported that they had a spouse or partner living in the home. The DAS is a self-reported scale and has been widely used in marital research since its creation. It is a 32-item questionnaire for married, or un-married co-habiting couples. There are 13 items on dyadic consensus, 10 items on dyadic satisfaction, 5 items on cohesion and 4 on affectional expression. Scores can range from 0 to 151, with higher scores representing stronger dyadic adjustment. The overall dyadic adjustment composite score was used. This measure has been found to be reliable ($r = .96$) and valid (Spanier & Thompson, 1982). The alpha in the current sample is .96.

CHAPTER III

RESULTS

Analysis Overview and Power Analysis

SPSS was used to conduct a variety of data analyses to address the research questions for this study. Descriptive statistics, mean comparisons, bivariate correlations, canonical correlations and regression analyses were run. Due to the relatively small sample size for this study ($n = 41$) we used the strength of the correlation to determine clinically meaning significance of our results. Results of a post hoc power analysis demonstrate that this study is underpowered. A post hoc power analysis with a sample size of 41 was run using a 2 tailed alpha set to $p = .05$. Power was .24 to detect an $sr = .2$. Given that this was an underpowered study, we used $sr = .2$ or greater to indicate clinically meaningful results. Clinically meaningful findings (in addition to statistically significant findings with $p < .05$) were interpreted.

Preliminary Analyses

The first step of the analysis plan was to assess the distribution of the variables to determine if there were any significant outliers, and if the data were normally distributed. Table 1 shows the distribution of the sample ($N = 41$), and there were no identified outliers or apparent skew after the analysis was conducted. Descriptive and demographic data are presented in Table 1 and displays the mean and standard deviation, or number and percentage of the category of interest. There was no extreme violation of assumptions or abnormality in the data, thus no transformations were performed. This includes information on parent variables, target child variables, and some sibling variables. Primary caregivers were on average 32.22 years old ($SD = 7.62$), and

Table 1*Demographic Characteristics of the Sample*

Demographic variable	Descriptive Statistic
Primary Caregiver and Family	
Age (years) <i>M (SD)</i>	32.22 (7.62)
% Female	95.12
% Married/ Living with Partner	65.85
% White	82.92
Annual Household Income in USD <i>M (SD)</i>	\$31,913.12 (\$22,611.29)
% Employed full or part time	34.14
% College degree or higher	21.95
Number of TC's Siblings in Home	1.85 (1.28)
Target Child	
Age (years) <i>M (SD)</i>	3.10 (0.41)
% Male	75.60
% White	73.17
Primary Diagnosis	
% Speech/ Language Delay	63.41
% Developmental Delay	14.63
% ASD	7.37
% Other	14.63
Sibling	
Age (years) <i>M (SD)</i>	5.50 (1.32)
% Biological Sibling	75.10
% Male	63.41
% White	68.29
% with DD/ Learning Problem	41.50

Note. TC= Target Child, ASD = Autism Spectrum Disorder, DD= Developmental Delay.

Table 2*Descriptive Information of the Sample*

Demographic variable	<i>M</i>	<i>SD</i>
Primary Caregiver and Family		
PSI – Total Stress	85.49	17.50
PSI – Parental Distress	29.34	8.22
CESD - Depression	12.32	9.90
Dyadic Adjustment	100.96	32.08
Target Child		
CBCL – Total Behaviors	61.95	12.55
Vineland – Socialization Standard Score	82.83	12.46
Sibling		
CBCL – Total Behaviors	52.95	13.34
SSIS – Social Skills Total	90.37	13.75

Note. PSI = Parenting Stress Index; CESD = Center on Epidemiological Studies Depression; CBCL = Child Behavior Checklist; Vineland = Vineland Adaptive Behavior Scales; SSIS = Social Skills Improvement System.

95.12% of this sample was female. A majority of this sample identified as White (82.9%) and most were married or living with a partner in the home (65.9%). Only 21.95% of primary caregivers in this sample have obtained a college degree or higher, and 34.1% are employed full or part time. The average annual household income for this sample was \$31,913.12 ($SD = 22611.29$). Through these descriptive statistics, no missing data was found.

On average, the target child was 3.10 years old ($SD = 0.41$) and the identified older sibling closest in age was 5.50 years old ($SD = 1.32$). In this sample, 75.1% of the siblings were biological. A majority of both the TC (75.60%) and the siblings (63.41%) were male. In order to participate in this study, the TC had to be previously identified with a developmental disability. The sample included children with speech and language delays (63.41%), developmental delays (14.63%), Autism Spectrum Disorders (7.37%) and other delays (14.63%). Over 40% of siblings who participated in this study have been identified with a developmental disability or learning problem as well.

Table 2 provides descriptive information on the study variables of interest, including the Parenting Stress Index, Child Behavior Checklist, Vineland Adaptive Behavior Scales – 2nd Edition Socialization composite, and the Social Skills standard score of the Social Skills Improvement System. On average, the target child was reported to have higher than average problem behaviors as indicated on the CBCL ($M = 61.95$, $SD = 12.55$). Target children also demonstrated significantly below average social skills as reported on the Vineland Adaptive Behavior Scales – 2nd Edition ($M = 82.83$, $SD = 12.46$). Siblings were found to have slightly higher than average behavior problems ($M = 52.95$, $SD = 13.34$), and slightly decreased social skill levels compared to the average

score on the SSIS ($M = 90.37$, $SD = 13.75$). The average scores on the Parenting Stress Index indicates that most parents in this sample scored in the high range ($M = 85.49$, $SD = 17.50$). On average, parents were below the depression threshold of a score of 16 on the CES-D ($M = 12.32$, $SD = 9.90$). Thirteen caregivers (31.7%) exceeded the threshold, indicating heightened risk for clinical depression. Dyadic Adjustment Scale scores were on average 100.96 ($SD = 32.08$) which is lower than expected of couples that live together (Spanier, 1987).

Question 1: *How do the social and behavioral profiles of preschoolers with developmental delays relate to the social and behavioral profiles of their older siblings?*

This question investigated whether the behavior and social profiles of children with developmental delays related to their siblings. Bivariate correlations were run to determine if the manifestation of behavior and social skill deficits in the target children were also present in the siblings. Results of the bivariate correlations are represented visually in Table 3. Higher levels of target child problem behavior were significantly associated with higher levels of sibling problem behavior, as indicated by parent report on the CBCL for both children ($r = .405$, $p = .009$). However, social skill profiles of the target children and the siblings were not found to be correlated ($r = .045$, $p = .779$).

Additionally, we found that higher levels of target child problem behavior were significantly correlated with lower target child social skills ($r = -.396$, $p = .010$), as well as higher sibling problem behavior was significantly correlated with lower sibling social skills ($r = -.517$, $p = .001$). We also ran a canonical correlation between the target child variables of social skills and behavior problems and the sibling's social skills and

Table 3*Bivariate Correlations for Parent, Child and Sibling Variables*

Variables	1	2	3	4	5	6	7	8	9
1. TC Problem Behavior	–								
2. TC Social Skills	-.396*	–							
3. Sib Problem Behavior	.405**	.045	–						
4. Sib Social Skills	-.075	-.059	-.516**	–					
5. Household Income	.190	-.183	-.118	.048	–				
6. Number of Children	.060	-.318*	-.303	.178	.277	–			
7. Parent Education Level	-.245	.041	-.097	-.015	.243	.136	–		
8. Dyadic Adjustment	.003	-.183	.021	-.014	.240	.370	-.073	–	
9. Parent Stress Index Score	.686**	-.349*	.146	.018	.132	.179	-.221	-.222	–

* $p < .05$. ** $p < .01$. *** $p < .001$.

Note. TC = Target Child, Sib = Target Sibling. Bold font = $r > .2$

behavior problems ($r = .486, p = .037$) which found the sibling variables were significantly correlated. Thus, our hypothesis was supported that child behavior predicts sibling behavior, however this was not true for both variables.

Question 2: *Does the sibling's level of behavioral functioning impact parental stress above and beyond the impact of the target child with developmental delay's behavior problems?*

In order to answer this research question, a hierarchical linear regression analysis was conducted. Target child problem behaviors were entered in Step 1, followed by sibling behavior problems in Step 2, and the interaction between target child and sibling problem behavior variables in Step 3. Results in Table 4 indicate that 47.1% of the variance in parental stress was explained by the presentation of problem behaviors in the target child, which indicates that the target child's problem behaviors significantly predicted parental stress. The addition of the sibling problem behaviors variable in step two did not add to the model ($\Delta r = -.145$), meaning that the addition of the sibling behavior problems was not a significant predictor of parental stress after accounting for the target child's problem behaviors. The interaction of these two variables was not found to be significant in predicting parental stress (see Table 4). Consequently, the hypothesis that sibling behavior problems predict parental stress after accounting for target child behavior was not supported.

Question 3: *Does the sibling's social skill utilization impact parental stress above and beyond the impact of the target child with developmental delay's social skill levels?*

Table 4*Hierarchical Regression of Target Child and Sibling Problem Behaviors Predicting Parent Stress*

Predictor Variable	<i>Unstandardized B</i>	<i>Standard Error</i>	<i>Standardized β</i>	<i>Semi-Partial r</i>	<i>t</i>	<i>F</i>	ΔR^2
Step 1						34.734***	.471
TC Problem Behaviors	.957	.162	.686	.686	5.894***		
Step 2						1.570	.021
TC Problem Behaviors	1.406	.176	.751	.686	5.935***		
Sib Problem Behaviors	-.208	.166	-.158	-.145	-1.253		
Step 3						.415	.006
TC Problem Behaviors	.572	.758	.410	.088	.754		
Sib Problem Behaviors	-.832	.983	-.634	-.099	-.846		
TC x Sib Interaction	.009	.014	.692	.075	.644		

* $p < .05$. ** $p < .01$. *** $p < .001$.

Note. TC = Target Child; Sib = Target Sibling. Bold font = $sr > .2$.

Similar to the analysis that was conducted in Question 2, here we hoped to answer if social skills of the target child and siblings predicted parent stress in this sample. For this hierarchical linear regression, we looked at the target child's social skills (Step 1), the sibling's social skills (Step 2) and the interaction between the two variables (Step 3). Results in Table 5 indicate that the target child social skills were a meaningful predictor of parental stress ($sr = -.349$). However, after controlling for the target child social skills, the sibling social skills were not found to meaningfully predict parental stress. The interaction of these two variables, when added in Step 3, was found to be a meaningful predictor of parental stress ($sr = -.259$). To understand the conditional nature of the interaction term, bivariate correlations between target child social skills and parental stress were computed for low and high sibling social skill groups using a median split ($r = .325$ vs $r = -.341$). This means that lower target child social skills and higher sibling social skills were predictive of more parental stress and that sibling social skills did not buffer against parental stress, as expected. Thus, our hypothesis was not supported.

Question 4: *Does the primary caregiver's dyadic adjustment rating impact parent stress after accounting for the effects for both the target child and the sibling?*

In order to see the impact of dyadic adjustment on parental stress, an additional hierarchical linear regression was conducted and results are presented in Table 6. When entering both the target child and the sibling's behavior problems in the first block, we found that children's behavior problems significantly predicted parental stress; however, it was the target child's behavior that explained 30.47% of the variance. We also found that dyadic adjustment predicted unique variance of parental stress after accounting for effects of the children's behavior problems ($sr = -0.501$). Dyadic adjustment is a strong

Table 5*Hierarchical Regression of Target Child and Sibling Social Skills Predicting Parental Stress*

Predictor Variable	<i>Unstandardized B</i>	<i>Standard Error</i>	<i>Standardized β</i>	<i>Semi-Partial r</i>	<i>t</i>	<i>F</i>	ΔR^2
Step 1						5.393*	.121
TC Social Skills	-.903	.389	-.349	-.349	-2.322*		
Step 2						.000	.000
TC Social Skills	-.903	.395	-.349	-.348	-2.289*		
Sib Social Skills	-.160	8.903	-.003	-.003	-.018		
Step 3						3.061	.067
TC Social Skills	2.752	2.125	1.062	.252	1.295		
Sib Social Skills	68.412	40.142	1.170	.192	1.704		
TC x Sib Interaction	-1.947	1.113	-.1800	-.259	-1.750		

* $p < .05$. ** $p < .01$. *** $p < .001$.*Note.* TC = Target Child; Sib = Target Sibling. Bold font = $sr > .2$.

Table 6*Hierarchical Regression of Target Child, Sibling Behavior Problems and Dyadic Adjustment Predicting Parental Stress*

Predictor Variable	<i>Unstandardized B</i>	<i>Standard Error</i>	<i>Standardized β</i>	<i>Semi Partial r</i>	<i>t</i>	<i>F</i>	<i>ΔR^2</i>
Step 1						4.846*	.316
TC Problem Behavior	1.012	.331	.605	.552	3.057**		
Sib Problem Behavior	-.155	.218	-.141	-.129	-.712		
Step 2						11.586**	.251
TC Problem Behavior	.993	..270	.593	.541	3.678**		
Sib Problem Behavior	-.201	.178	-.183	-.166	-1.128		
Dyadic Adjustment	-.593	.174	-.503	-.501	-3.404**		

* $p < .05$. ** $p < .01$. *** $p < .001$.

Note. TC = Target Child; Sib = Target Sibling. Bold font = $sr > .2$.

predictor of parent stress. Thus, our hypothesis was supported such that dyadic adjustment predicted decreased parental stress after accounting for the child variables.

Question 5: *Do child related stressors (i.e., behavior problems) add to parental stress above and beyond familial stressors (i.e. finances, education level, number of children in the home)?*

One last hierarchical linear regression was conducted to test the effects of child related stressors on parental stress after accounting for familial stressors. Table 7 shows that in the first block we entered the family stressors of household income, primary caregiver education level, and number of children in the home. In the second block we entered the child related stressors for both the target child and the sibling, which were problem behaviors as measured on the CBCL. The first block indicated that the primary caregiver education level was a meaningful predictor of parental stress. After controlling for familial stressors, target child behavior problems explained significant additional variance in this model. Thus, the hypothesis that child behavior predicts parental stress after accounting for familial stressors was supported.

Table 7*Hierarchical Regression of Familial Factors, Target Child, and Sibling Behavior Problems Predicting Parental Stress*

Predictor Variable	<i>Unstandardized B</i>	<i>Standard Error</i>	<i>Standardized β</i>	<i>Semi Partial r</i>	<i>t</i>	<i>F</i>	<i>ΔR^2</i>
Step 1						1.585	.114
Number of Children	2.402	2.215	.175	.168	1.084		
PC Education Level	-2.698	1.531	-.282	-.273	-1.763		
Annual Household Income	.000	.000	.152	.143	.923		
Step 2						13.927***	.393
Number of Children	1.614	1.799	.118	.107	.897		
PC Education Level	-.614	1.241	-.064	-.059	-.495		
Annual Household Income	-.593	.000	-.036	-.032	.269		
TC Problem Behavior	1.003	.200	.719	.594	5.004***		
Sib Problem Behavior	-.158	.185	-.120	-.101	-.853		

* $p < .05$. ** $p < .01$. *** $p < .001$.Note. TC = Target Child; Sib = Target Sibling. Bold font = $sr > .2$.

CHAPTER IV

DISCUSSION

Summary

The purpose of this exploratory study was to investigate the connections between target child related variables, sibling variables and parent/family variables and the impact on parental stress in families of children with developmental delays. We collected a sample of 41 families that had one target child with developmental delays, one older sibling between 3–8 years old closest in age to the target child, and an identified primary caregiver. While previous investigations looked at the relations between target child behavior problems and social skills on parent adjustment, few include the impact of siblings or consider the contributions of other family factors.

In this study we were interested in investigating if sibling behaviors (social skills and behavior problems) predicted parental stress above and beyond the impact of the target child's behavior and social skills. Additionally, we investigated whether the caregiver's dyadic adjustment/marital relationship predicted parental stress, after accounting for the effects of the target child and sibling. Finally, we examined whether child characteristics (social skills and behavior problems of the target child and sibling) predicted parental stress after accounting for the effects of familial stressors.

We found that sibling social skills and behavior did not predict parental stress once the behavior of the target child was accounted for. These findings were counter to our hypotheses. Caregivers' marital relationships/dyadic adjustment did, however, explain unique variance on parental stress, even after accounting for child characteristics. This finding suggests that better dyadic adjustment (i.e., higher relationship satisfaction)

predicts lower levels of parental stress, a finding that was aligned with our hypotheses. One finding that was seemingly counterintuitive was the meaningful interaction of target child and sibling social skills in predicting parental stress. Here we found the opposite of a buffering effect. Higher social skills and lower target child social skills predicted higher parental stress. This finding was unexpected. Finally, we found that target child and sibling behavior problems were a strong predictor of parental stress after accounting for common familial stressors, which supported our last hypothesis.

Discussion of Key Findings

The first research question of this study was to determine the association between target child's behavior and social skills with their sibling's behavior and social skills. The siblings that we recruited for this study were all the older sibling closest in age to the target child. From the descriptive analysis, we also know that 41.50% of the siblings were identified with a developmental delay or learning problem. While this number might seem high, we know that families of one child with a disability are more likely to have another child with a disability than parents of children without delays or disabilities (Bolton et al., 1994). Results from this correlation indicate that the target child and sibling's behavior problems, as reported by the parent on the CBCL for both children, were significantly correlated, and higher levels of problem behaviors in the target child were also found within the sibling. This may be due, in part, to the high percentage of siblings who have disabilities in this sample. This finding is consistent with the literature that demonstrates that siblings of children with autism and other developmental delays and disabilities are at increased risk of externalizing behavior problems (Fisman, Wolf, Ellison, & Freeman, 2000). Surprisingly, siblings who were reported to have delays or

disabilities did not have significantly lower social skills or higher problem behavior than siblings without reported delays or disabilities in the current sample. Although behavior problems of target children and siblings were correlated, the social profiles of the target children and the siblings were not found to be significantly correlated. This could possibly be explained by the older sibling's age (siblings were most likely in school) versus their younger sibling. Although an empirical question, it may be the case that school experiences may have provided siblings with more opportunities to develop and practice social skills interacting with same aged peers on a regular basis. As Çalisandemir, Elibol, and Çakmak (2016) reported, as children grow in early childhood they are more likely to increase their social skill utilization.

Our first hierarchical regression analysis aimed to explore the impact of the sibling's behavioral functioning above and beyond the impact of the target child's behavioral functioning on parental stress. Results indicated that the presence of sibling behavior problems was not significantly predictive of parental stress after accounting for the target child's behavior problems. The literature overwhelmingly supports this finding. Most notably, the behavior problems of the child with DD has a strong and direct impact on parental stress (Baker et al., 2003; Crnic et al., 2017; Deater-Deckard et al., 2005). However, the addition of the sibling variable as a predictor may tell us new information about the family context. This study provided further evidence that the presence of a child with behavior problems in the home was a predictor of parental stress; however, through this model we were unable to support that the sibling's behavior predicted any unique variance to explain parental stress.

A second hierarchical regression analysis was run to determine if target child and sibling social skills had an impact on parental stress. The first step in this analysis indicated that the target child's social skills had a significant impact on the primary caregiver's parental stress. Lower levels of target child social skills predicted higher levels of parental stress, which aligns with the literature (Estes et al., 2009; Smith, Oliver, & Innocenti, 2001). However, sibling's social skill levels did not significantly predict unique variance of parental stress above and beyond the target child's social skill levels. This finding matches the lack of evidence in this sample to support that the sibling of a child with a developmental disability adds to parental stress after accounting for the target child. While the siblings' behavior problems and social skills did not predict parental stress above and beyond the target child's influence, it has been noted within the literature that siblings of children with disabilities often can be well-adjusted (Pilosky et al., 2004). These results suggest that more research should be conducted exploring aspects of multiple children in the home and not only focus on a target child and primary caregiver dyad.

Outside of child variables, families face other stressors that can impact parent stress. The fourth research question in this study aimed to address if dyadic adjustment served as a protective factor for parents raising multiple children, where at least one child has an identified disability. The first step of this analysis reflected previous research questions in this study, and the target child behavior problems significantly predicted parental stress, while the sibling behavior problems did not. However, we also found that dyadic adjustment accounted for a significant amount of parental stress above and beyond the children's behavior. This finding suggests that dyadic adjustment has a strong impact

on parental stress, and that having a supportive partner in the home can help alleviate some of the parental stress that parents of children with disabilities face. The literature base for dyadic adjustment and parenting relationships is underdeveloped for families of children with disabilities. Risdal and Singer (2004) found that higher marital strain was positively correlated to the presence of a child with a disability in the home, which matches the findings in this study. However, our study is able to provide further evidence as to how the marital relationship strain impacts parental stress in comparison to the contributions of the child factors. More research should be conducted on dyadic adjustment and relationship satisfaction with this population of families in order to further explore this relationship.

Other factors are also known to affect parental stress, including household income, number of children in the home and parent's education level. Our results indicate that even after accounting for familial stressors, the target child behavior problems still predicted a unique variance above and beyond these common familial stressors. Lecavalier, Leone, and Wiltz (2005) previously explored how the impact of having a child with a disability impacted parental stress compared to the impact of finances and similar family stressors and found that behavior problems were a stronger predictor than the other factors. The results of this study replicate this finding as well as findings of similar studies (Innoncenti, Huh, & Boyce, 1992). Having more children in the home is often an added stressor to parents as well, especially when one or more of the children has an identified disability (Warfield, 2005). Although this study did not find that factor to be a significant predictor, it is important to keep in mind that only 25% of the sample had four or more children in the home, and everyone had at least two children

in the home. Further research should be conducted using multiple children as predictors of stress, as well as finding other important familial stressors and protective factors that can influence parent stress (i.e., perceived support, marital status, number of service hours for the target child).

Limitations

When reading the results of this study, it is important to acknowledge that this research is not without limitations. First, our sample size of 41 is relatively small, although comparing it to other literature that involves siblings of children with disabilities, it is not unprecedented (Pilowsky et al., 2004). The sample size did limit our ability to use certain statistical analysis given the inadequate power to detect statistical significance; however, some clinically meaningful results were found. In order to address the under-powered nature of this study, recruiting a larger sample in future investigations should be achieved. Additionally, although we found the measure of dyadic adjustment to be a robust predictor of stress, only 24 of our 41 families completed this measure. Not all caregivers reported having a partner in the home and thus were excluded from that research question. However, the significance of the results of dyadic adjustment predicting parental stress sparks the need for more research with larger samples to replicate this important finding.

Other characteristics of our population that limit the generalizability of the results is the lack of diversity within this sample. A majority of the primary caregivers were female and white, as well as a majority of the children were white. While this may reflect the geographical area that these data were collected from, future studies should attempt to gain a more demographically diverse sample. For the purposes of this study,

all of the siblings were an older sibling closest in age. While this helped reduce some of the potential variability for the use of this project, this means that the information may not be generalizable to all siblings of children with disabilities. The experiences of siblings that are younger than the target child with a disability may look differently than the experiences of older siblings. One should take the population used in this study into consideration before attempting to generalize these results across the population.

When describing the siblings, it is also important to consider that we found 41.5% of the siblings were identified as having a developmental disability or a learning problem. For the purposes of this study and our smaller sample size, we did not choose any questions to parse out the differences between siblings where both were identified with a disability to families where only one of the siblings has a disability.

Perhaps the most important limitation to consider for this study is the method bias that occurred and possibly limited our ability to find meaningful results with the sibling population. The Parenting Stress Index was filled out with the target child serving as the index child. Thus, it may have been difficult to parse out the effects of the sibling on parent reports of stress. Future studies could look at broader reports of stress or use multiple measures of parental distress and psychological well-being. Although the Parenting Stress Index is used in multiple studies about children with developmental disabilities, maybe a more updated and global stress measure should be used in the future to better fit studies that look at multiple children and sources of stress. Furthermore, a using a measure that gets at the nuances of parenting multiple children would be a nice addition to the parenting stress literature.

The last limitation of this study is that we used an existing data set in order to answer the questions that we explored above. It is possible that different measures and procedures would have been used to answer similar questions, however we were restricted to the previously collected measures. Data used for this study were collected at one time-point, limiting our ability to imply causation or investigate change over time. The findings in this study do add to the current literature base, and lead to many questions that can be addressed by future studies.

Future Directions

It is increasingly clear that more research should be conducted on families with children with developmental delays and disabilities. Much of the comparative literature is specific to autism spectrum disorders, specifically when looking at factors that impact siblings. Overall, a replication of this study that has a larger sample size might be able to provide us with more answers and result in stronger findings. The findings surrounding dyadic adjustment in this sample were interesting, and definitely can inform future research. Are there other aspects of having a partner in the home that help protect parents from the stress of parenting children with behavior problems? What are those factors and how can family or parenting interventions enhance coparenting and marital adjustment to improve child outcomes?

While this sample was too small to parse out the dyads where both children had an identified disability versus the dyads where one child has DD and the other is typically developing; comparing sibling dyads based on developmental status is an important future direction. It is also possible that siblings where both were identified with a disability contributed a unique stress to parents, which could be an excellent follow up

study to this paper. If a larger and more diagnostically diverse sample is collected, then comparing and contrasting different diagnoses in the target child and sibling could also explain a unique prediction in parent stress. While the current study adds to the current limited literature base, understanding what factors are the strongest predictors of parental stress and also what serves as protective factors are important in supporting families of children with disabilities.

It also has been found in the literature that parents, specifically mothers, of children with disabilities are at risk of depression (Blacher & Lopez, 1997; Veisson, 1999). In this sample we found that over 30% of primary caregivers scored in the clinical range for depressive symptoms on the CES-D. This is almost three times higher than the rest of the U.S. population where 10.4% of women and 5.5% of men are diagnosed with depression (Brody, Pratt, & Hughes, 2018). Future studies could investigate the role of depression as it relates to parental stress in families of children with developmental disabilities. For example, perhaps the presence of multiple children with disabilities or behavior problems can significantly impact a parent's depressive symptoms.

In order to better understand the family structure, future studies could also look into which target child and parent factors influence the sibling's adjustment. In this study, we used parental stress as the outcome, however it is important to understand the bidirectional nature of these factors, and assessing how these impact the sibling can help inform future family interventions. Collecting data at multiple time points and exploring how this relationship exists at different developmental points in the sibling dyads can also contribute to the family literature.

Conclusion

Families of children with developmental delays face a unique set of risk factors and stressors. The limited literature base has led to a need to better understand what factors impact and protect family member's mental and behavioral health. This study identified factors that meaningfully predicted parental stress, most notably the target child's problem behavior and the marital adjustment. We were able to replicate results of previous studies that showed that a target child with a disability's behavior problems and limited social skills can predict parent stress, however we were unable to add some additional explanation of parental stress from the sibling's behavioral and social profile. Dyadic adjustment is relatively unstudied in this population, and the significant results of this study indicate that this is an important predictor of parental stress (outside of child factors) and should be explored further, both in research examining risk and protective factors and in clinical intervention studies. Future research should ask similar questions to a larger, and more demographically diverse sample to get a better glimpse into the lives of families of children with disabilities.

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