

# Intellectual and Developmental Disabilities

## Uplifts, Respite, Stress, and Marital Quality for Parents Raising Children With Down Syndrome or Autism --Manuscript Draft--

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<b>Abstract:</b>	Direct, indirect, and partner effects estimated among uplifts, respite care, stress, and marital quality across mothers and fathers of children with autism spectrum disorder (n=102) and Down syndrome (n=111) were examined in this cross-sectional study. Parents of children with ASD who reported more uplifts and less stress individually reported better marital quality; these wives reported better marital quality as their husbands reported more uplifts and less stress. Wives with children with DS who reported more uplifts, individually along with their husbands reported less stress and better marital quality. Respite was directly associated with marital quality for parents of children with ASD and indirectly associated with marital quality for parents of children with DS with reduced individual stress. Implications are discussed.

## UPLIFTS, RESPITE, STRESS, MARITAL QUALITY

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The double ABCX resiliency model of family stress, adjustment, and adaptation (McCubbin & Patterson, 1983) is often used to understand how families with children with disabilities may respond to stress and achieve positive family adaptation over time. According to this model, families experience stress when significant change disrupts their ability to perform routine roles and tasks at optimal physical or psychological levels. As families respond to events that trigger changes to familial processes (aA, stressors) with appropriate internal and external resources (bB, individual, familial, or community competencies that protect against the impact of initial and additional stressors), positive appraisal (C, the family's perception of the stressor), and effective coping strategies (cC), they may be more likely to positively adapt and reduce negative outcomes such as poor relationship quality (X; McCubbin & Patterson, 1983; Paynter et al., 2013).

The present study used McCubbin and Patterson's model (1983) as the theoretical framework for investigating two model variables: family resources (i.e., uplifts and respite care), and possible association among those resources and the outcomes of stress and marital quality for parents of children with autism spectrum disorder (ASD) or Down syndrome (DS). These resources and outcomes are described below.

### **Family Resources**

#### ***Daily Uplifts for Parents Raising Children with Disabilities***

Uplifts—perceived pleasant experiences—are personal resources that may counterbalance daily stress (DeLongis et al., 1988). Few studies, however, investigate this resource in families raising children with disabilities. One study showed that parents of children

with cerebral palsy who reported more uplifts and less stress reported greater quality of life compared to those who experienced fewer uplifts and more stress. Even when parents experienced larger amounts of stress and more frequent uplifts, they still reported a better quality of life than those who experienced less stress and fewer uplifts (Carona et al., 2013). Parents of children with ASD who experienced more uplifts also reported better marital quality (Author Blinded, 2013).

The amount and intensity of uplifts that caregivers experience may vary across families raising children with different disabilities. Mothers of children with DS have reported more positive parent-child interactions and more rewarding children with DS-sibling experiences compared to mothers of children with unspecified developmental disabilities, cerebral palsy, seizure disorders, fetal alcohol syndrome, and other chromosomal or genetic disabilities (Corrice & Glidden, 2009; Mitchell et al., 2015). Few studies have explored uplift experiences in parents of children with ASD, including whether they report more, or fewer rewarding experiences compared to parents of children with other disabilities. In fact, the majority of research has focused on parents' stressful experiences. Understanding and acknowledging both negative and positive experiences of these parent groups can be critical to inform efforts that may improve individual and family functioning.

### ***Respite Care for Parents Raising Children with Disabilities***

Respite care is a resource providing the family member with the disability or chronic condition with care (e.g., by professional service providers, extended family; Langer et al., 2010) at home or in the community, providing permanent caregivers a short break or temporary relief from daily caregiving responsibilities (Author Blinded, 2016) and providing the family member with a disability a break from their primary caregivers (Breneol et al., 2019). Caregivers who

experience overwhelming responsibilities and demands may benefit from respite care (Doig et al., 2009; Author Blinded, 2013). This care may improve marital quality by reducing rates of burnout, increasing parental well-being (Cowen & Reed, 2002), and allowing caregivers to take time for their own and their spouse's needs (Resch et al., 2010). Although research has linked respite care to improved life satisfaction and family relationships (Cowen & Reed, 2002), few studies have specifically investigated the direct association between respite care and marital quality. Author Blinded (2013) found that respite care was indirectly related to marital quality through a reduction in stress of mothers and fathers of children with DS.

### **Outcomes for Parents Raising Children with Disabilities**

#### ***Parental Stress***

Generally, parents of children with disabilities report higher levels of stress than parents of typically developing children (Miodrag et al., 2015). However, even within this population, caregiving experiences and outcomes may vary depending on each child's disability and individual characteristics. Mothers of preschool-aged children with ASD have reported higher amounts of stress (Dabrowska & Pisula, 2010) and lower positive perceptions of their child compared to mothers of children with DS (Griffith et al., 2010). Over a decade of research has indicated that parents of children with ASD typically report higher levels of stress, anxiety, and depression compared to parents of children with DS (Bonis, 2016). Below are some possible reasons for these differences.

**Known or Unknown Etiology.** While the etiology of DS is known to be a genetic chromosomal condition, science is not likely to identify one specific cause for ASD. For many children, ASD may be difficult to detect at an early age, resulting in a later diagnosis, often around 4 years or older (Zuckerman et al., 2017). Parents of children with ASD may be

concerned about unusual behaviors and development but do not have the knowledge or resources to obtain an accurate diagnosis (Bonis, 2016). In contrast, screening tests for DS may begin prenatally (Pennings et al., 2015) and thus may give parents moderate time to prepare emotionally and temporally to raise a child with a disability.

**Challenging Characteristics.** Deficits in social communication and responsiveness (Bonis & Sawin, 2016) and greater likelihood of aggression and self-injurious behaviors in children with ASD (Bitsika et al., 2017; Bonis & Sawin, 2016) may cause their parents to feel overwhelmed, burned out, and desperate. Conversely, children with DS tend to have increased social awareness and motivation, even when compared to typically developing children (Way & Rojahn, 2012). These characteristics may lead their parents to perceive their situation as advantageous over other families—referred to as the “Down syndrome advantage” (Hodapp et al., 2001; Mitchell et al., 2015; Pastor-Cerezuela et al., 2021).

**Caregiver Burden.** Compared to children with DS, children with ASD may demonstrate higher levels of dependency and a need for constant supervision, which could result in limited couple and family time for their parents (Dabrowska & Pisula, 2010). Additionally, there is a higher likelihood for parents to have multiple children with ASD because of the high risk of sibling recurrence (Grenborg et al., 2013); recurrence is less common in families raising children with DS. Having multiple children with disabilities may further limit the number of breaks for couples, possibly resulting in deeper feelings of isolation, more intense burden for caregivers, and lower levels of couple adjustment.

### ***Marital Quality***

Enhanced marital quality is a personal resource that may contribute more to lower parental stress for parents of children with disabilities than socio-economic status, child

characteristics, and social support (Kersh et al., 2006). Supportive spouses are emotional resources as they understand their partner's feelings regarding caregiving responsibilities and concerns and/or informational resources as the two creatively resolve caregiving issues together (Ekas et al., 2010). Although positive marital quality has been accepted as a possible resource for parents of children with disabilities, few studies have examined specific contributing variables to higher marital quality for caregivers experiencing high stress and low couple satisfaction.

Of the limited research exploring marital quality among these caregivers, qualitative studies have provided ungeneralizable information from small groups of participants (see Whitmore & Snethen, 2018), and most quantitative studies have neglected to investigate perceptions of both mothers and fathers. When fathers' data have been included, many studies fail to link mother and father data. Kersh et al. (2006) investigated marital quality and well-being among parents of children with disabilities but analyzed couple data separately rather than assuming non-independence of dyadic data (Kenny, 1996). According to family systems theory, in interpersonal relationships, one person's emotional state could influence their partner's emotional state. For instance, a husband's stress level might influence his wife's perception of marital quality because his emotional state will influence hers; their scores are linked, not separate. To more completely capture how uplifts and respite care influence marital quality, the current study used an actor-interdependence model to account for partner effects.

### **Stress as a Mediating Variable Among Uplifts, Respite, and Marital Quality**

Respite care offers caregivers more time for nurturing their relationship, which may indirectly improve marital quality by reducing caregiver stress. However, caregivers may not use short breaks for this purpose, but rather to manage other responsibilities (e.g., grocery shopping) and temporal needs (e.g., sleep; Author Blinded, 2016; Nankervis et al., 2011), and to strengthen relationships with others (Nankervis et al., 2011). Few studies have addressed these implications

specifically. Research, however, has indicated that as external stress (e.g., caregiver stress) persists, it may negatively influence other areas of a person's life (e.g., perceptions of the couple relationship; Berge et al., 2006). Coping effectively and providing spousal support may reduce stress spillover and increase marital quality, especially for wives (Brock & Lawrence, 2008). For these reasons, this study includes stress as a mediating variable in relation to uplifts, respite care, and marital quality for both groups of parents.

### **Hypotheses**

This study aimed to bridge gaps in research concerning the caregivers of children with DS or ASD using an actor-interdependence model. Based on trends in the literature, the following hypotheses were tested using data from parental perceptions:

1. Compared to parents of children with DS, parents of children with ASD will report lower levels of uplifts, lower levels of respite, lower levels of marital quality, and higher levels of stress. Compared to their husbands, wives will report lower levels of uplifts, lower levels of respite, lower levels of marital quality, and higher levels of stress.
2. Daily uplifts and respite will be negatively associated with daily stress, and respite will be positively associated with marital quality for both groups of parents. Husband and wife daily stress will be negatively related to their marital quality, and daily uplifts will be positively related to their marital quality (actor and partner effects).
3. The relationships between uplifts and marital quality and also between respite and marital quality will be significantly mediated by stress for both groups of parents.
4. The direct and indirect structural paths from husband and wife uplifts to the outcomes of husband and wife marital quality mediated by husband and wife stress will differ between the two groups. Also, the direct and indirect structural paths from respite

care to the outcomes of husband and wife marital quality mediated by husband and wife stress will differ for parents of children with ASD and parents of children with DS. Although models will be different between parents of children with ASD and parents of children with DS, we did not anticipate how specific paths might differ.

## **Methods**

### **Procedure**

After receiving approval from appropriate institutional review boards, we contacted ASD organizations (e.g., Autism Speaks), DS organizations (e.g., National Association for Down Syndrome, National Down Syndrome Congress), and local and regional schools/programs to recruit couples raising children with ASD and DS, using electronic (e.g., electronic newsletters, websites, email lists, Facebook) and paper formats (e.g., newsletters). Participants were notified that the survey was available online via Qualtrics or on paper copies. The two eligibility requirements for participation in the study were (a) parents had a child with a medical diagnosis or individualized education program indicating ASD or a medical diagnosis of DS, and (b) husband and wife were currently married. Informed consent was obtained before husbands and wives completed the survey independently. Couples received a \$25 gift card as compensation.

### **Participants**

Of the original sample of 112 husband-wife dyads raising children with ASD and 112 husband-wife dyads raising children with DS, 11 couple surveys (ASD = 10 and DS = 1) contained unusable responses (e.g., only one spouse completed a survey, the survey was not fully completed, or a participant completed a survey more than once); therefore, their data were discarded. The final sample consisted of 102 heterosexual married couples with children with

ASD (n = 204 parents) and 111 heterosexual married couples with children with DS (n = 222 parents).

A majority of the parents were White. Of these participants, 24.5% of wives and 19.6% of husbands raising children with ASD considered themselves distressed in their marriage. In contrast, only 9.0% of wives and 1.8% of husbands with children with DS considered their marriages to be distressed. As measured by their scores on the Revised Dyadic Adjustment Scale (RDAS; Busby et al., 1995), a couple is more distressed when there is less consensus on decision making, values, and demonstrations of affection; less stability and greater conflict in the relationship (e.g., increased quarrels, regrets, or considerations of termination of relationship); and less cohesion among couples' communication and shared activities or interests. See Table 1 for husband, wife, and child demographic information.

[Insert Table 1 here]

## **Measures**

### ***Demographic Variables***

Demographic information was collected using an 11-question self-report questionnaire. Parents reported on variables such as relationship status; parental age, sex, race/ethnicity, annual household income, and education level; and child age and sex. Parents also responded to a close-ended question regarding whether or not their children had an educational classification and/or a medical diagnosis of ASD or DS.

### ***Stress and Uplifts***

We assessed parental perceptions of stress and uplifts with the Hassles and Uplifts Scale (HUS; Lazarus & Folkman, 1984). Hassles, a measure of daily stress, are daily events, activities, or tasks that are perceived as routine nuisances, while uplifts are events that make individuals

feel good, happy, or satisfied. Parents rated 53 items on a 4-point Likert scale (1 = *not at all* to 4 = *extreme*) regarding how they considered each item to be a daily hassle or an uplift. Sample items include “Your children,” “Your spouse,” and “Family-related obligations.” We calculated an intensity score for both hassles and uplifts that identified how much each item bothered or satisfied participants by summing all items from the hassles and uplifts measure. Scores ranged from 53 to 212. Cronbach’s alpha for daily hassles was good (parents of children with ASD  $\alpha = .97$ , parents of children with DS  $\alpha = .95$ ). Reliability for daily uplifts was good for parents of children with ASD (husbands  $\alpha = .96$ , wives  $\alpha = .95$ ) and parents of children with DS (husbands and wives  $\alpha = .95$ ).

### ***Respite Care***

We assessed respite care by using the Respite Care Instrument (Author Blinded, 2013), defining respite care as “planned care for the child with ASD and DS to provide relief to the permanent caregiver,” offered through various sources (e.g., extended family, babysitters, community agencies, other means parents identified). Husbands and wives independently reported the amount of respite they received in hours and minutes during a typical week during the school year. Most parents reported only hours; however, when parents did report minutes, we rounded minutes to the nearest 15-minute increment and summed the hours for all children with ASD or DS in the family. If parents had more than one child who received respite services at the same time, the amount of respite was only counted once for that couple. Husbands’ and wives’ reports of respite hours were averaged to create one manifest variable called respite. Since respite care was not assessed using an item-scale measurement, no reliability tests were administered for this instrument.

### ***Marital Quality***

We assessed marital quality by using the Revised Dyadic Adjustment Scale (RDAS; Busby et al., 1995), a 14-item scale that evaluates the consensus (e.g., how often couples agreed on major decisions), stability (e.g., how often couples discussed terminating their relationship), and cohesion (e.g., how often couples exchanged ideas or worked together) of a marital relationship. Participants rated items on a 6-point Likert scale: consensus anchors were 1 (*always disagree*) and 6 (*always agree*); stability anchors were 1 (*all of the time*) and 6 (*never*), and cohesion anchors were 1 (*never*) and 6 (*more often than once a day*). We reverse coded stability items so that higher scores on all subscales indicated higher levels of consensus, stability, and cohesion between married partners. We summed items to create an overall marital quality score for both husbands and wives (14 to 84). Higher scores indicated higher levels of marital quality: scores below 48 suggested that couples were distressed, while scores above 48 suggested that couples were not distressed. The RDAS showed good reliability for parents of children with ASD (husbands  $\alpha = .95$ , wives  $\alpha = .96$ ) and DS (husbands  $\alpha = .85$ , wives:  $\alpha = .83$ ).

### **Analysis Plan**

We calculated descriptive statistics for all study variables (see Table 2). The ASD and DS samples were compared to test for group differences on the personal characteristics. Independent t-tests showed no group differences in means on mother's age  $t(210) = 0.93, p = .35$ , father's age  $t(205) = 1.17, p = .24$ , children's ages  $t(173) = -1.48, p = .20$ , number of children in the family  $t(211) = -1.30, p = .20$ , and number of years married  $t(211) = -0.39, p = .70$ .

Using the IBM SPSS Statistics (Version 23), we conducted analyses of variance to assess differences in mean levels of uplifts, respite care, stress, and marital quality for parents of children with ASD and parents of children with DS. We estimated a two-group actor partner interdependence model (APIM; Kenny et al., 2006) to calculate the effects of husband and wife

uplifts and respite care on husband and wife stress and marital quality for parents of children with ASD and parents of children with DS. To calculate indirect effects, we conducted a bootstrap analysis in Amos 23.0 (Arbuckle, 2014). We used the bootstrapping approach with 10,000 draws to estimate adjusted standard errors for the indirect effects in the model. The alpha level for rejecting the null hypotheses and for group comparisons was set at .05.

[Insert Table 2 Here]

The hypothesized structural equation model (see Figure 1) included husband and wife uplifts and respite care as exogenous variables to measure their direct and indirect effects on husband and wife stress and marital quality. Partner effects were estimated from wife uplifts and stress to husband marital quality and husband uplifts and stress to wife marital quality.

Unstandardized and standardized beta coefficients were calculated to determine the strength of the paths in the structural equation model. Finally, direct and indirect paths were compared across parents of children with ASD and parents of children with DS to determine if paths differed for these two groups of parents. Length of marriage and age of the child with ASD or DS were controlled for in the model because past research indicated they may be associated with marital quality and parental stress (Knoke et al., 2010; Rivard et al., 2014).

[Insert Figure 1 Here]

## **Results**

### **Mean Differences**

To test the first hypothesis, related to differences in levels of uplifts, respite care, stress, and marital quality for parents of children with ASD and DS, four mixed between-within subjects (2 x 2) analyses of variance (ANOVAs) were calculated. In each ANOVA the between-subjects factor was the type of disability (ASD, DS) and the within-subjects factor was the

partner (husband, wife). The dependent variables were uplifts, respite care, stress, and marital quality. In all ANOVAs, the interaction between the type of disability and the partner was not significant.

When daily uplifts was the dependent variable, the main effect for disability was significant,  $F(1, 211) = 8.02, p = .005$ . Parents of children with DS reported more daily uplifts ( $M = 110.81$ ) than parents of children with ASD ( $M = 101.47$ ). No differences in uplifts were found between husbands and wives.

The main effects for disability and couple were not significant when the dependent variable was weekly respite care, but the main effect was significant when the dependent variable was marital quality  $F(1, 211) = 13.00, p < .001$ . Parents of children with DS reported higher marital quality ( $M = 61.72$ ) than parents of children with ASD ( $M = 55.75$ ). The main effect for the couple was also significant: Wilk's Lambda = .98,  $F(1, 211) = 5.32, p = .02$ . Husbands reported higher levels of marital quality ( $M = 59.31$ ) than wives ( $M = 58.16$ ).

When daily stress was the dependent variable, the main effect for disability was significant,  $F(1, 211) = 23.18, p < .001$ . Parents of children with ASD reported higher levels of daily stress ( $M = 115.33$ ) than parents of children with DS ( $M = 96.19$ ). The main effect for the couple was also significant: Wilk's Lambda = .97,  $F(1, 211) = 6.25, p = .01$ . Wives reported higher levels of daily stress ( $M = 107.61$ ) than husbands ( $M = 103.91$ ). These findings mostly supported the first hypothesis—there were no differences in hours of respite care, and there were no differences in levels of uplifts for husbands and wives.

### **Structural Equation Model**

Using multiple group comparisons, an unconstrained bootstrap structural equation model was tested that included husband and wife uplifts along with respite care as exogenous variables,

husband and wife stress as mediating variables, and husband and wife marital quality as dependent variables. Partner effects were also tested in the model. Length of marriage (reported in years) and age of the child with a disability were controlled for in the model. The Bollen-Stine bootstrap index suggested that the model fit is better in most of the bootstrap samples ( $p = .221$ ). The unconstrained model was considered to have acceptable model fit:  $\chi^2(2) = 2.97, p = .23$ ; CFI = .999; TLI = .963; RMSEA = .048; standardized root mean residual (SRMR) = .0292.

The second hypothesis stated that daily uplifts and respite care would be negatively associated with daily stress, and that respite would be positively associated with marital quality for both groups of parents. In addition, husband and wife daily stress would be negatively related to both husband and wife marital quality, whereas uplifts will be positively related to their marital quality (actor and partner effects).

The second hypothesis was partially supported (see Table 3; Figures 2 and 3). In the unconstrained bootstrap model, 10 significant relationships were identified for parents of children with ASD, and 6 significant relationships were found for parents of children with DS. For wives with children with ASD and DS, more uplifts were associated with their own lower stress levels. In contrast, only husbands with children with ASD reported lower levels of stress as they reported more uplifts. For parents of children with DS, more wife uplifts were related to lower stress for their husbands. This relationship was not significant for parents of children with ASD. Husband uplifts were not related to wife stress for either group. Parents of children with ASD who reported more uplifts reported higher levels of perceived marital quality. Similarly, mothers of children with DS who reported more uplifts reported higher levels of perceived marital quality. For fathers of children with DS, the relationship between uplifts and marital quality was not significant. While husbands' reports of uplifts were not related to their spouses'

perception of marital quality for either group of parents, wives' reports of uplifts were related to their spouses' perception of marital quality for both groups of parents.

Respite care was not related to stress for either group of parents; however, wives and husbands with children with ASD who reported more respite care also reported better marital quality. For both groups of parents, increased husband and wife stress were related to a decreased report of their perceived marital quality; only wives with children with ASD reported poorer marital quality as their husbands experienced higher levels of stress.

[Insert Table 3 Here]

[Insert Figure 2 Here]

[Insert Figure 3 Here]

Next, we assessed whether stress would mediate the relation between uplifts and marital quality and the relation between respite and marital quality. This third hypothesis was partially supported. For parents of children with ASD, significant standardized total indirect effects were found for husband uplifts and husband marital quality, husband uplifts and wife marital quality, and wife uplifts and wife marital quality. Based on these total indirect effects, researchers used standardized coefficients to calculate where the mediation occurred (personal or spousal stress). Findings showed that the relationship between husband uplifts and marital quality was mediated by husband stress, husband uplifts and wife marital quality was mediated by wife stress, and wife uplifts and marital quality was mediated by wife stress (see Table 3).

For parents of children with DS, standardized total indirect effects were found for respite care and husband marital quality, mediated by husband stress; respite care and wife marital quality, mediated by wife stress; wife uplifts and husband marital quality, mediated by husband stress; and wife uplifts and wife marital quality, mediated by wife stress (see Table 3).

We explored Hypothesis 4 by estimating a fully constrained model with all the structural paths constrained to be equal for parents of children with ASD and parents of children with DS. By doing so we expected to see that the direct and indirect structural paths from husband and wife uplifts to the outcomes of husband and wife marital quality mediated by husband and wife stress would differ across the two parent groups. We also expected the direct and indirect structural paths from respite care to the outcomes of husband and wife marital quality mediated by husband and wife stress would differ for parents of children with ASD and parents of children with DS.

Results showed that model fit for the fully constrained model was unacceptable:  $\chi^2 (18) = 48.77, p < .001$ ; CFI = .97; TLI = .87; RMSEA = .09. Chi-square difference tests showed that the fully-constrained model was significantly worse for model fit when compared to the unconstrained model ( $\Delta\chi^2 = 45.80, \Delta df = 16, p < .001$ ), suggesting that structural paths differed for parents of children with ASD and parents of children with DS. To determine which specific structural paths were different in these two groups, each structural path was separately constrained.

Chi-square difference tests showed that separately constraining the following structural paths significantly worsened model fit when compared to the unconstrained model: husband uplifts to husband stress ( $\Delta\chi^2 = 5.41, \Delta df = 1, p = .02$ ), respite care to wife marital quality ( $\Delta\chi^2 = 5.21, \Delta df = 1, p = .02$ ), and respite care to husband marital quality ( $\Delta\chi^2 = 4.18, \Delta df = 1, p = .04$ ). In sum, the unconstrained model had the best model fit and indicated differences for parents of children with ASD and parents of children with DS in these three associations.

## Discussion

Given the high levels of stress experienced by parents of children with disabilities (Miodrag et al., 2015) as well as differences in the caregiving experience between parents of children with ASD and parents of children with DS (Bonis, 2016), the goal of this study was to examine relations of uplifts, respite care, stress, and marital quality using an actor-interdependence model. The current study contributes novel findings to the literature investigating some of the variables described in McCubbin and Patterson's (1983) double ABCX model.

Notably, although the parents of children with ASD were similar to parents of children with DS in age, length of the marriage, and the number of children in the family, they had more distressed marriages. Almost 25% of mothers of children with ASD considered their marriages to be distressed, compared to 10% of mothers of children with DS. Similarly, almost 20% of fathers of children with ASD reported distressed marriages compared to only approximately 2% of fathers of children with DS.

### **Hypothesis 1**

#### ***Differences in Uplifts, Respite Care, Stress, and Marital Quality Across Caregiver Groups***

Parents of children with ASD reported significantly more stress, fewer uplifts, and lower levels of marital quality compared to parents of children with DS. The differences in these parental outcomes may be due to the general behavioral and symptomatic differences between these two disabilities, such as the greater social, behavioral, and communication deficits that are associated with ASD compared to DS. As couples experience higher demands (e.g., higher levels of child dependency) and fewer uplifts (e.g., weak social-emotional connections with their child), they may be more likely to view their marital relationship negatively (Gavidia-Payne & Stoneman, 2006), possibly explaining why parents of children with ASD tend to report lower

levels of couple satisfaction compared to parents of children with DS (Santamaria et al., 2012). This may be additional evidence for a “Down syndrome advantage,” suggesting that families raising children with DS may experience more positive outcomes compared to families of children with other disabilities such as ASD (Corrice & Glidden, 2009; Mitchell et al., 2015). In past research this advantage has been associated with higher parental age, higher income, longer marriages, increased maternal education, and more parenting experiences (Mitchell et al., 2015). However, in this study parental ages and length of marriages were similar across child disabilities. Couples also had, on average, the same number of children in their families. These findings suggest that couple outcomes may be better explained by differences in child diagnoses than in parental characteristics. There were no significant differences in the amount of respite care received: On average both groups reported approximately 5 to 6 hours per week.

#### ***Differences in Uplifts, Respite Care, Stress, and Marital Quality Across Gender Groups***

Husbands reported less stress compared to their wives, consistent with previous research indicating fathers of children with ASD tend to report less stress than mothers (Rodriguez et al., 2019). Yet, some research shows that fathers and mothers of children with DS tend to report similar levels of stress (Dabrowska & Pisula, 2010). Reasons for disability group differences in perceptions of stress is unclear in the extant literature. A possible explanation for differences between fathers and mothers in this sample is that studies typically measure stress by using self-report measures, which involve bias. Physiological markers of stress, such as cortisol levels, may be more accurate indicators of stress, as reported by Foody et al. (2015), who found that fathers of children with ASD reported less caregiving responsibility, anxiety, and depression compared to mothers; yet both parents showed similar physiological markers of stress. This suggests that although fathers report lower levels of stress, care of the child may still affect their overall

health. It is not clear in the present study whether fathers experienced different types of stress not measured by the study instrument, or if they masked their stress through denial, control, avoidance of caregiving responsibilities, or other means.

Our finding that fathers of children with disabilities report higher levels of marital satisfaction compared to mothers of children with disabilities moves the field forward in understanding the experiences of both fathers and mothers. This result is consistent with research showing that men generally report higher levels of marital satisfaction compared to women (Jackson et al., 2014). However, we understand that our study is among the first to investigate gender differences in the perceived marital quality of parents of children with disabilities such as ASD and DS. This is salient, given that enhanced marital quality may reduce parental stress (Kersh et al., 2006).

## **Hypothesis 2**

### ***Associations Between Uplifts, Stress, and Marital Quality***

For mothers and fathers of children with ASD and mothers of children with DS, more uplifts were associated with lower individual stress as well as higher perceived marital quality. How these parents perceived their children, spouse, and family-related obligations were associated with the amount of stress and couple satisfaction they experienced. The more positively they perceived relationships and responsibilities (i.e., uplifts), the less stress and more couple satisfaction they reported. Research has shown the importance of uplifts in positive psychological outcomes for parents of children with cerebral palsy (Carona et al., 2013), but few studies have investigated the relationship between uplifts and stress specifically. Given the high levels of stress experienced by these caregiver groups, future research might focus on how to increase uplifting experiences and positive perceptions of responsibilities and marital

relationships, particularly for parents of children with ASD who reported fewer uplifts and more stress than parents of children with DS.

### ***Direct Associations Between Respite Care, Stress, and Marital Quality***

Respite care was not directly related to stress for either caregiver group; however, more respite hours did directly relate to higher marital quality for parents of children with ASD. Respite may provide these caregivers time for their own relationship needs (Resch et al., 2010). When caring for a child with a disability, particularly a child who may exhibit challenging behavior (e.g., aggression, elopement, self-injurious behavior) due to communication or other deficits, parents may have difficulty offering time to other family members, especially spouses, while the child is present. The only time to focus on the needs of a marital relationship might be when other caregivers offer relief to couples so they can spend time together alone. These direct associations must be understood to help provide adequate support for these caregivers. More respite for these couples may be warranted in efforts to enhance their relationship quality.

### ***Actor and Partner Effects Relating to Uplifts, Stress, and Marital Quality***

Based on family systems theory, which suggests that one individual's emotional state may influence their partner's emotional state (Kenny, 1996), and due to the lack of non-independence analysis of dyadic data existing among caregivers of children with disabilities, we assessed relationships of mother and father uplifts, stress, and marital quality interdependently. For parents of children with ASD and for parents of children with DS, as wives reported more positive experiences with their child, spouse, and family-related obligations (i.e., uplifts), their husbands reported better marital quality. Also, wives in this study who reported more uplifts reported higher marital quality. For husbands with children with DS, as their wives reported more uplifts the husbands reported less stress. Husbands' reports of uplifts were not significantly

related to their wives' stress or marital quality in either caregiver group. It may be possible that wives' positive appraisals helped their husbands' perceptions of stress to decrease and their marital satisfaction to increase, but causation cannot be implied. Although husbands with children with ASD did not experience lower amounts of stress, they still experienced improved marital quality related to their wives' uplifts.

While many other factors may have influenced the association between wife uplifts and husband marital quality, wives who had more positive outlooks may have been more open to discussing their parental and spousal attitudes with their husbands. Hearing their wives' positive affirmations not only about their child but also about their marital relationship may have impacted how these husbands felt about their relationship. Future research might include survey questions regarding how often spouses express uplifts to their partners, which may contribute to understanding why wife uplifts played a greater role in their spouses' marital quality compared to husband uplifts strengthening their wives.

For parents of children with ASD, as husbands reported more stress their wives reported lower levels of marital quality, further affirming that the emotional state of one spouse is related to the perceptions of the other spouse (Kenny, 1996), a relationship not reported in the literature regarding parents of children with disabilities. Understanding relationships of spouses' emotional states is paramount for tailoring resources to improve individual and couple outcomes. Professionals might consider recommending services that are likely to emotionally benefit both husbands and wives. For example, respite care providers could counsel parents to designate separate time for husbands and wives to take care of personal needs such as sleep, as well as to schedule time to spend together.

### **Hypothesis 3**

*Association Between Uplifts and Marital Quality Mediated by Stress*

Stress mediated the relation between uplifts and marital quality. Specifically, as husbands raising children with ASD experienced more uplifts, they and their wives reported lower levels of stress, and their lower stress levels were related to their higher marital quality. As wives raising children with ASD experienced more uplifts, they reported lower stress levels, which were also related to higher levels of marital quality. Additionally, as wives with children with DS experienced more uplifts, both wives and their husbands reported lower levels of stress, related to their increased marital quality. Thus, in some cases, when parents are experiencing lower levels of stress, uplifts are associated indirectly with increased marital satisfaction. Although past research has shown direct associations between uplifts and marital quality (Author Blinded, 2013, 2016), this study further contributes by investigating how stress mediates this relationship.

*Association Between Respite and Marital Quality Mediated by Stress*

In addition, mediation was used to understand whether stress helped explain the relationship between respite care and marital quality. For parents of children with DS, receiving more weekly respite care was related to lower levels of partners' stress, which was associated with better marital quality for themselves. However, this mediation was not significant for parents of children with ASD, indicating a Down syndrome advantage. It is unclear why stress would mediate the relationship between respite and marital quality for parents of children with DS, but not for parents of children with ASD. Possibly the parents of children with ASD did not receive enough hours of respite care (only on average 5 to 6 hours per week) individually or as a couple to be appropriately relieved of challenging responsibilities.

**Hypothesis 4: How Associations Vary Across Caregiver Groups**

Our findings also supported the fourth hypothesis, indicating that structural paths were different for the two groups of parents. Uplifts were more directly associated with reduced stress and improved marital quality for husbands raising children with ASD compared to husbands raising children with DS. However, wives' uplifts were more strongly associated with reducing stress for husbands raising children with DS compared to husbands raising children with ASD. Also, while respite care was directly related to husband and wife marital quality for parents of children with ASD, no direct relationship was found between respite and marital quality for parents of children with DS. These findings demonstrated significant differences in parents' experiences including how resources like uplifts and respite care may function differently depending on the child's disability and parent gender. In designing interventions, these factors should be considered.

### **Future Research Directions and Policy Implications**

Examining how and why specific personal resources, like uplifts, are slightly more directly associated with the relationship between stress and marital quality for personal outcomes (husbands whose children have ASD and wives rearing children with ASD or DS), or with relationship partner outcomes (husbands) compared to others (wives) might guide professionals' focus for providing more beneficial resources based on unique caregiver and partner needs. Because respite care did not directly reduce stress for either caregiver group, professionals may want to help caregivers reappraise their specific situation in positive yet realistic ways.

Because the current study did not account for the number of children in the family, particularly older children who might be providers of informal respite care, future research could investigate differences between families with various numbers and ages of siblings. Similarly,

effects for families raising more than one child with a disability may differ from those of families raising only one child with a disability; this warrants further study.

Future researchers could consider investigating the associations including uplifts, respite care, stress, and marital quality among caregivers of children with other types of conditions, including children with multiple disabilities or chronic health conditions, exploring these relationships across parent gender as well.

Future studies might also explore the bivariate relationship between stress and the personal resource of marital quality to understand how marital quality influences stress in caregivers. Examining this relationship might help explain why fathers report less stress and better marital quality compared to their wives, perhaps to distinguish whether marriage is truly a protective resource, as prior research has suggested, or an additional stressor for some caregivers. Researchers might also investigate father involvement in caregiving experiences to ascertain the association among caregiver involvement, levels of stress, and marital quality.

Lawmakers and policymakers are encouraged to draft bills or policies, such as the Recognize, Assist, Include, Support, and Engage (RAISE) Family Caregivers Act (2018), to provide more support to families whose members have disabilities and chronic conditions. Increased financial support could help families access more hours of respite care per week—for couples to both spend more time together and to meet their individual needs. Doing so may indirectly improve the perception of their marital relationships.

### **Limitations**

Several limitations of this study should be mentioned. The first concern was the use of cross-sectional data, which prevents inference of directionality. To better assess directionality of both the direct and indirect relationships, future research should compare uplifts, respite care,

stress, and marital quality for caregiver groups across time. Additionally, since the majority of this sample were in their mid to late 30s and White, the results are not intended to generalize to other groups. Another limitation may be that self-report measures do not always present a clear picture of how much stress caregivers experience. Husbands reported lower stress levels than wives, but they may experience the stress in ways not captured by the study's instrument. Moreover, since some of the questionnaires were completed online, the accuracy of all parental findings (e.g., medical diagnosis of the child) could not be confirmed, and level of functioning of the children were not reported. Finally, our sample was appreciably smaller than the sample sizes recommended by Kline (2011) for using an actor-interdependence model. A larger sample may improve the accuracy and clarity of these findings.

## **Conclusions**

This present study used the double ABCX model as the theoretical framework to investigate how stressors, individual and familial resources, appraisal, and marital quality were related. This study differs from many others in three important ways: (a) the investigation of marital quality in parents raising children with ASD and DS, (b) husbands' and wives' data are linked, using an actor-interdependence model to account for partner effects, and (c) the comparison among the associations of uplifts, respite care, stress, and marital quality across parents of children with two different disabilities such as DS and ASD.

Findings from this study support declarations from previous studies of a "Down syndrome advantage": compared to parents of children with ASD, parents of children with DS reported more uplifts, less stress, and better marital quality. Husbands with children with DS benefited most from their partners' uplift experiences, which lowered their stress level and improved their perception of their marital relationship.

Although an analysis of the mean data suggests a “husband advantage” when compared to outcomes for wives, because of the interdependent nature of the dyadic data, no directionality can be inferred. Nevertheless, husbands on average reported less stress than wives, and their stress was negatively associated with their wives’ uplift experiences, particularly husbands rearing children with DS. Also, husbands reported higher marital quality than wives. Future longitudinal research is warranted to investigate the presence of a potential husband advantage, particularly because the extant literature often excludes fathers of children with disabilities as participants in family research.

Other novel findings are related to respite care across caregiver groups. While respite directly improved marital quality for both mothers and fathers of children with ASD, it indirectly improved marital quality for both mothers and fathers of children with DS by reducing their individual stress.

Results from this study demonstrate significant differences across caregiver groups; therefore, professionals who work with parents of children with ASD or DS should consider implementing individualized interventions that account for differences in family functioning rather than using standardized resources. Based on findings that indicate that parents raising children with ASD have greater distress in their marriages, professionals are encouraged to provide resources such as respite care and marital therapy. Offering therapeutic services for individuals and families might help these parents perceive raising their child as a rewarding experience. Professionals recommending and families obtaining individualized resources may have a strong likelihood that families will experience positive adaptation over time.

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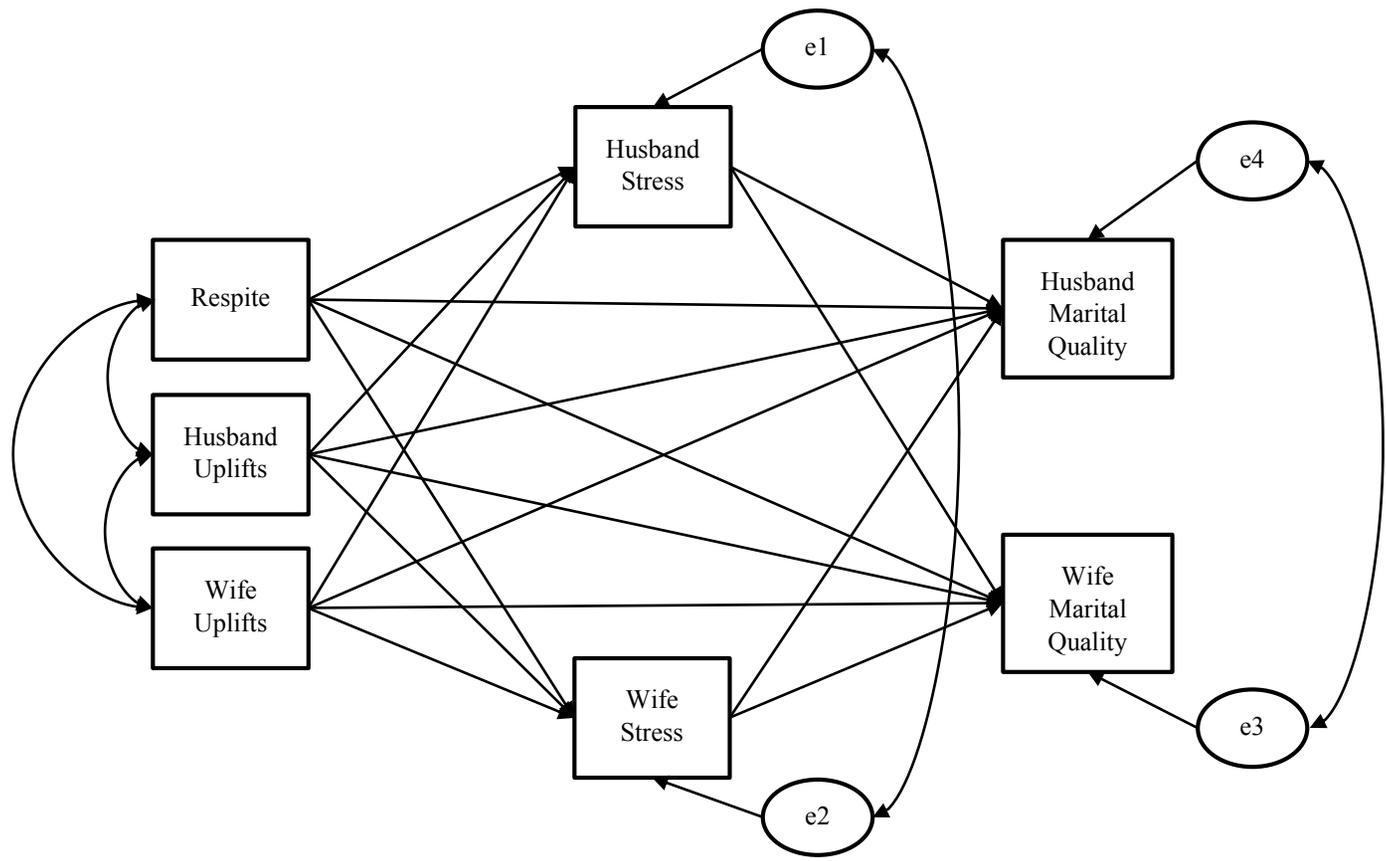
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**Figure 1**

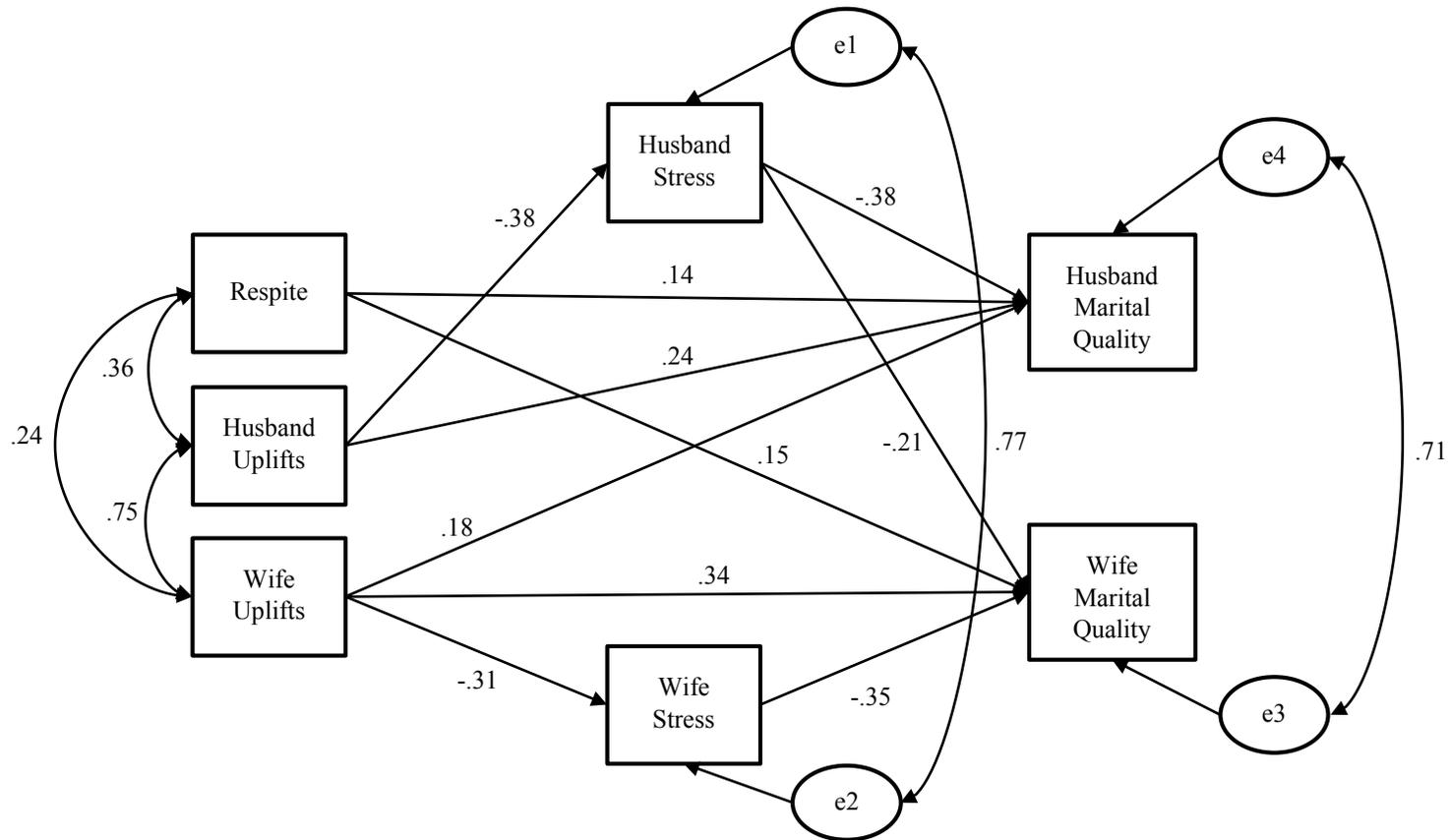
*Hypothesized Structural Equation Model*



*Note.* The hypothesized model represents the bootstrap SEM for both parents of children with ASD and parents of children with DS. Control variables (not shown) are length of marriage and age of child with ASD or DS.

**Figure 2**

*Unconstrained SEM Results for Husbands and Wives With Children With ASD*

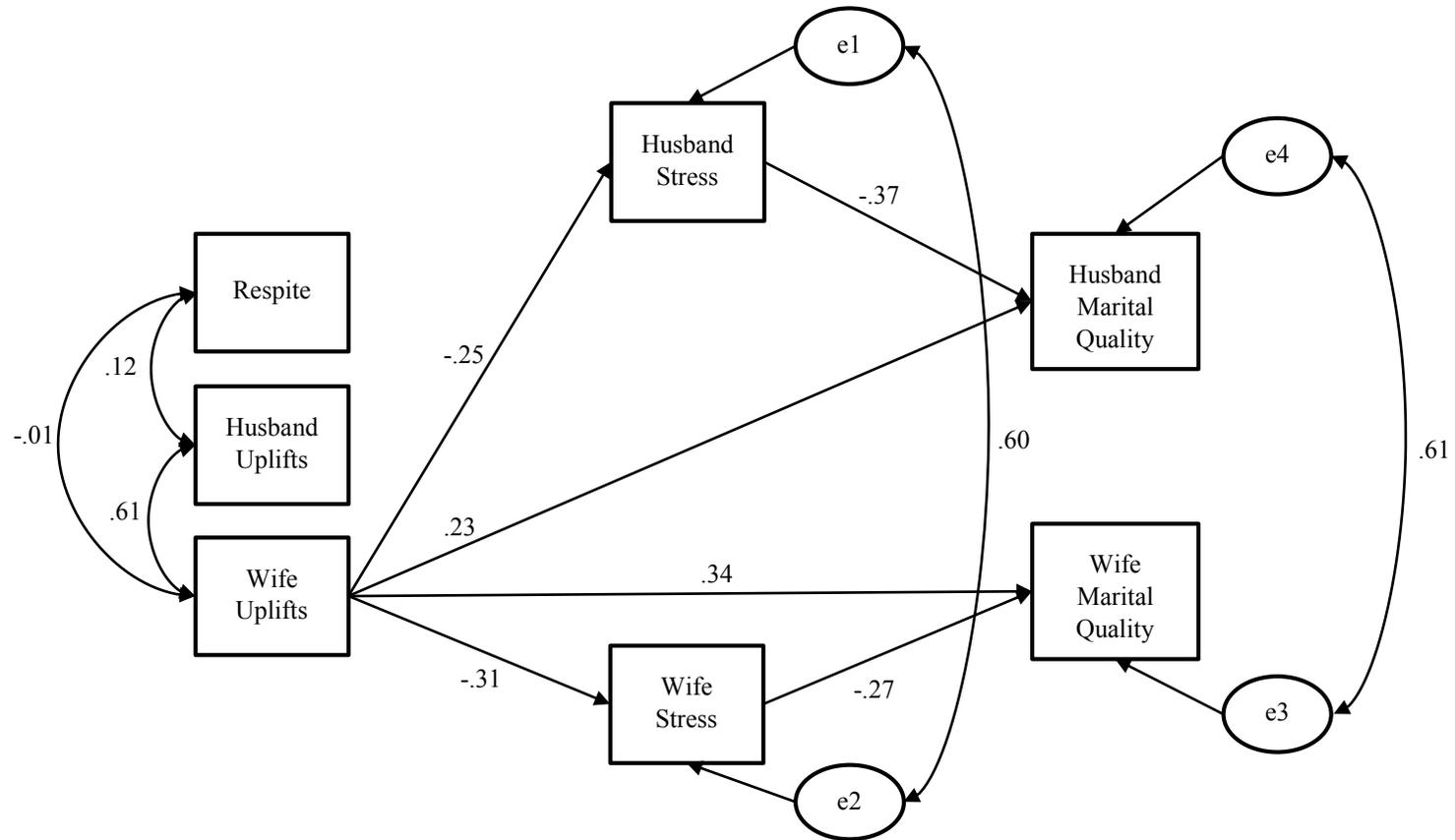


*Note.* Figure shows standardized coefficients for each significant structural path. Only significant paths are shown in the model.

Control variables (not shown) were not related to stress or marital quality for husband and wives with children with ASD.

**Figure 3**

*Unconstrained SEM Results for Husbands and Wives with Children with DS*



*Note.* Figure shows standardized coefficients for each significant structural path. Only significant paths are shown in the model.

Control variables (not shown) were not related to stress or marital quality for husband and wives with children with DS.

## UPLIFTS, RESPITE, STRESS, MARITAL QUALITY

**Table 1***Demographic Information of Participants*

Baseline information	Autism spectrum disorder									Down syndrome								
	Wife			Husband			Child			Wife			Husband			Child		
	M	SD	Range	M	SD	Range	M	SD	Range	M	SD	Range	M	SD	Range	M	SD	Range
Age (in years)	36.93	6.99	22–59	38.25	6.29	23–59	7.49	3.55	1–17	37.88	7.78	23–61	39.39	7.96	25–62	6.44	6.54	0.50–39
Years married	11.22	5.25	1–35	11.22	5.25	1–35				10.87	7.78	0.25–40	10.87	7.78	0.25–40			
Number of children	2.89	1.59	1–8	2.89	1.59	1–8				2.64	1.25	1–8	2.64	1.25	1–8			

*Note.* Descriptive statistics represented by the no-missing data sample size (i.e.,  $n = 102$  husbands and wives with children with ASD and  $n = 111$  husbands and wives with children with DS).

**Table 2**

*Means, Standard Deviations, and Ranges for All Study Variables for Parents of Children with ASD and Parents of Children with DS*

Study variables	Autism Spectrum Disorder						Down Syndrome					
	Wife			Husband			Wife			Husband		
	M	SD	Range	M	SD	Range	M	SD	Range	M	SD	Range
Uplifts	101.13	25.02	53–202	101.81	26.78	55–203	111.91	27.42	60–207	109.70	25.85	52–208
Respite	6.22	8.87	0–38	6.07	8.61	0–35	5.50	9.13	0–40	5.67	10.53	0–49
Stress	115.75	36.80	59–212	114.92	36.91	56–210	99.48	24.53	53–173	92.90	23.98	53–167
Marital quality	56.61	15.80	14–83	55.89	15.02	14–83	60.71	9.93	30–77	62.73	8.66	38–83

*Note.* Descriptive statistics represented by the no-missing data sample size (i.e.,  $n = 102$  husbands and wives with children with ASD and  $n = 111$  husbands and wives with children with DS). Higher means of total scores indicate higher levels of uplifts (possible range 53–212), stress (possible range 53–212), and marital quality (possible range 14–84) reported by husbands and wives. Respite is reported in the total number of hours per week the child with ASD or DS receives.

**Table 3***Unstandardized and (Standardized) Coefficients for the Unconstrained Bootstrap Structural Paths*

Structural direct paths	ASD	<i>p</i>	DS	<i>p</i>
Actor effects				
1. Husband uplifts and husband stress	<b>-.51 (-.38)</b>	<b>.006</b>	-.01 (-.01)	.945
2. Husband uplifts and husband marital quality	<b>.14 (.24)</b>	<b>.006</b>	.05 (.15)	.148
3. Wife uplifts and wife stress	<b>-.45 (-.31)</b>	<b>.017</b>	<b>-.28 (-.31)</b>	<b>.006</b>
4. Wife uplifts and wife marital quality	<b>.21 (.34)</b>	<b>.001</b>	<b>.12 (.34)</b>	<b>.003</b>
5. Respite care and wife stress	.03 (.01)	.938	-.42 (-.16)	.068
6. Respite care and husband stress	-.03 (-.01)	.937	-.41 (-.16)	.082
7. Respite care and wife marital quality	<b>.28 (.15)</b>	<b>.006</b>	-.04 (-.04)	.679
8. Respite care and husband marital quality	<b>.24 (.14)</b>	<b>.017</b>	-.02 (-.02)	.791
9. Husband stress and husband marital quality	<b>-.15 (-.38)</b>	<b>.001</b>	<b>-.13 (-.37)</b>	<b>.001</b>
10. Wife stress and wife marital quality	<b>-.15 (-.35)</b>	<b>.001</b>	<b>-.11 (-.27)</b>	<b>.017</b>
Partner effects				
11. Wife uplifts and husband stress	-.26 (-.18)	.170	<b>-.22 (-.25)</b>	<b>.035</b>
12. Wife uplifts and husband marital quality	<b>.11 (.18)</b>	<b>.035</b>	<b>.07 (.23)</b>	<b>.029</b>
13. Husband uplifts and wife stress	-.34 (-.25)	.067	-.07 (-.08)	.496
14. Husband uplifts and wife marital quality	.04 (.07)	.384	-.04 (-.10)	.374
15. Wife stress and husband marital quality	-.07 (-.17)	.079	-.00 (-.00)	.988
16. Husband stress and wife marital quality	<b>-.09 (-.21)</b>	<b>.022</b>	-.04 (-.10)	.352

Structural total indirect paths	ASD	<i>p</i>	DS	<i>p</i>
<b>Mediating Effects</b>				
17. Husband uplifts and husband marital quality via husband stress	<b>.10 (.18)</b>	<b>.010</b>		
18. Husband uplifts and wife marital quality via husband stress	<b>.10 (.17)</b>	<b>.025</b>		
19. Wife uplifts and wife marital quality via wife stress	<b>.10 (.15)</b>	<b>.031</b>		
20. Wife uplifts and husband marital quality via husband stress			<b>.03 (.10)</b>	<b>.045</b>
21. Wife uplifts and wife marital quality via wife stress			<b>.04 (.11)</b>	<b>.009</b>
22. Respite care and husband marital quality via husband stress			<b>.06 (.06)</b>	<b>.031</b>
23. Respite care and wife marital quality via wife stress			<b>.06 (.06)</b>	<b>.034</b>

*Note.* Standardized coefficients in parentheses. Significant paths in boldface.