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Parent Stress and Perceptions of Language Development: Comparing Down Syndrome and Other Developmental Disabilities

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Abstract

This study extended research on the Down syndrome advantage by examining differences in parent stress and parent perceptions of language development between 29 parents of young children with Down syndrome and 82 parents of children with other developmental disabilities. Parents of children with Down syndrome reported lower levels of total stress, child-related stress, and stress surrounding the parent-child interaction. Parents of children in both groups reported that they felt successful in their ability to impact their children's communication development but did differ on perceptions of difficulty such that parents of children with Down syndrome perceived their children's communication difficulties as less severe despite the children exhibiting similar language skills. Finally, after accounting for potential explanatory confounding variables, child diagnosis remained a significant predictor of parent stress and perceptions of language development. Results highlight the importance of considering etiology when assisting families raising a child with a disability.

Keywords

intellectual and/or developmental disability; Down syndrome; parent stress; parent perceptions of language development

For both young children and adolescents, research has shown that parents of children with Down syndrome exhibit stress levels comparable to parents of typically developing children (Blacher, Baker, & Kaladjian, 2013; Kasari & Sigman, 1997; Povee, Roberts, Bourke, & Leonard, 2012), and tend to fare better than parents of children with autism and other intellectual disabilities (Gerstein, Crnic, Blacher, & Baker, 2009; Herring et al., 2006; Stoneman, 2007). This finding has been demonstrated consistently on a wide variety of family functioning variables including, but not limited to, depression, coping, quality of the parent-child relationship, and the topic of the current study, parent stress. This consistent pattern of findings has led to the use of the term, the “Down syndrome advantage” (Hodapp, Ly, Fidler, & Ricci, 2001). Regardless of etiology, it is common for young children with disabilities to have difficulties with communication and language skills. It is currently unknown whether there may be differences in parent perceptions of language development between parents of children with Down syndrome and parents of children with other developmental disabilities. This study examined if parent stress and parent perceptions of language development differed between parents of children with Down syndrome as compared to parents of children with other intellectual and developmental disabilities.

The Down syndrome advantage is grounded in the idea that children with a specific genetic disorder are likely to demonstrate one or more etiology-related behaviors (Hodapp, 1997). These “direct effects” might include maladaptive behavior, temperament, specific cognitive, linguistic, or adaptive strengths and weaknesses. These etiology-related profiles in turn lead to certain “indirect effects” related to how these specific behaviors influence others in the child’s environment, such as parents. Children with Down syndrome in particular seem to have an etiology-related personality. As a whole, children with Down syndrome are perceived by parents as more sociable, cheerful, exhibit fewer maladaptive behaviors, and have more easygoing temperaments than individuals with disabilities who have other etiologies (Blacher et al., 2013; Capps, Kasari, Yirmiya, & Sigman, 1993; Dykens, 1999; Stoneman, 2007). The theory is that this etiology-related personality type accounts for findings across studies and outcomes that families of children with Down syndrome function better as a whole compared to families of children with other developmental disabilities (Hodapp, 1999; Hodapp et al., 2001).

Early research in the area of parent stress demonstrated this advantage, consistently showing that parents of children with Down syndrome experienced lower levels of stress than parents of children with other intellectual disabilities and autism. This advantage has been shown across younger and older children and when compared to parents of children with autism and parents of children with other disabilities (Hodapp, Ricci, Ly, & Fidler, 2003; Kasari & Sigman, 1997; Ricci & Hodapp, 2003). Parents of children with autism and Down syndrome have shown more overall stress in raising their children as compared to parents of typically developing children, but parents of children with Down syndrome show less overall stress than parents of children with autism (Olsson & Hwang, 2003; Rodrigue, Morgan, & Gefken, 1990; Sanders & Morgan, 1997). More specifically, research would suggest that parents of children with autism have shown greater levels of stress as it relates to characteristics of the child rather than more general dimensions of parent stress when compared to parents of children with Down syndrome (Kasari & Sigman, 1997).

A similar pattern of findings exists for parents of children with other intellectual and developmental disabilities as compared to parents of children with Down syndrome. For parents of children other disabilities, the greater levels of stress have been primarily restricted to child-related stress rather than overall parent stress. Studies have shown that both mothers and fathers of children with Down syndrome did not differ from parents of children with other disabilities on any domain of parent-related stress but showed significantly lower levels of child-related stress, specifically as it related to the child's acceptability to the parent, how reinforcing the child is to the parent, and the demandingness of the child (Hodapp et al., 2003; Kasari & Sigman, 1997; Ricci & Hodapp, 2003).

More recently, research examining this Down syndrome advantage has suggested that it may not be as straightforward as once thought. In fact, some studies have found that this advantage lessened or disappeared once key demographic variables were taken into account. Stoneman (2007) found that when differences in income were controlled for, parents of children with Down syndrome no longer showed lower levels of depression and higher levels of self-reported warm parenting, and observed maternal warmth. Similarly, Corrice and Glidden (2009) found that after controlling for differences in maternal age, mothers no longer demonstrated a greater sense of personal reward about raising their child as compared to mothers of children with other disabilities. Collectively, these authors suggested that since parents of children with Down syndrome are generally older and more financially stable than parents of children with other disabilities, they may be better equipped to handle the stressors and demands of raising a child with a disability. Corrice and Glidden (2009) also found that children with Down syndrome showed a greater level of adaptive behavior as compared to children with other developmental disabilities. When adaptive behavior was controlled, mothers of children with Down syndrome no longer demonstrated greater levels of well-being related to their children than other mothers. Although these studies did not focus specifically on parent stress, they demonstrated that failure to account for these potential demographic differences in etiology research might show an advantage for parents of children with Down syndrome that is misleading.

Another area of interest when examining family functioning is the role of parent perceptions. In the disability literature, the role of parent perceptions has been investigated extensively due to a shift in the early 1990s of the perspective of researchers from a pathological view of families to a view that focuses on positive adaptation and effective coping in families (Turnbull & Turnbull, 1993). This shift has resulted in an increased interest in the experiences and perceptions of having a child with a disability. Not all families have negative or stressful perceptions and experiences. Hastings and Taunt (2002) found that family members reported a range of positive perceptions and experiences that occurred jointly with stressful experiences. In addition, although reporting generally higher levels of stress than families of children without disabilities, they reported similar or higher levels of positive perceptions as compared to families raising children without disabilities. The authors concluded that many families adapt well to the challenges of raising a child with a disability and that these perceptions serve to help families in this process. Hastings, Allen, McDermott, and Still (2002) found that positive perceptions held by mothers may function as a mechanism for coping with the stresses and strains of caring for children with disabilities.

Less is known about parent perceptions of children's communication and language skills and how that may be related to parent stress. When children have significant difficulties with communication, it may add to the stress experienced by parents of children with disabilities. Romski, Sevcik, Adamson, Smith, Cheslock, and Bakeman (2011) examined parent perceptions of early language development and found that parent perceptions of success about how their children were communicating became more positive over time while parents' perceptions of the severity of their child's language difficulties decreased only for children whose intervention included the use of a speech-generating device. The authors suggested that helping parents find more successful ways to interact with their children may permit them to feel more capable in their interactions with their children and decrease their negative perceptions of their children's communication difficulties (Romski et al., 2011). Smith, Romski, Sevcik, Bakeman, and Adamson (2011) examined the effects of a parent-coached language intervention on parent stress and its relation to parent perceptions of communication development in a sample of young children with severe communication impairments. They found that when children had better expressive language at the start of a three month parent-coached language intervention, they perceived their children's language difficulties as less severe and consequently had lower levels of parent stress following the intervention. Brady, Skinner, Roberts, and Hennon (2006) found that mothers' expectations for their child's communication depended on the child's language level. Parents of children who were not speaking focused their expectations on their child attaining any speech or communicative ability, while parents of children who had some speech focused their expectations on improving speech and increasing vocabulary. They also found that challenges related to their child's communication were primarily related to not being able to understand what the child wanted and frustrations surrounding obtaining speech-language services for their child. Although this study focused only on children with Fragile X syndrome, the authors suggested that this information may be common to families who have children with other developmental disabilities, such as autism or Down syndrome. Although research would suggest that the way the parent perceives the personality of their child with Down syndrome leads to lower levels of parent stress in this population, it is possible that this may extend to parent perceptions of language as well. Despite exhibiting significant difficulties with language that are common to the majority of children with disabilities, if parents of children with Down syndrome perceive their children's language skills in a more positive way, parent perceptions of language could be considered as another factor that contributes to the Down syndrome advantage.

The current study had three main goals. The first examined if parents of young children with Down syndrome and parents of children with other developmental disabilities differed on dimensions of parent stress. We hypothesized that consistent with previous research, parents of children with Down syndrome would exhibit lower levels of total stress and child-related stress as compared to parents of children with other developmental disabilities, but would not differ on dimensions of parent-related stress. The second goal was to examine if parents of young children with Down syndrome and parents of children with other developmental disabilities differed on parent perceptions of success and difficulty related their language development. Although previous research has not examined this topic, we hypothesized that the advantage seen in parents of children with Down syndrome would also extend to how

parents perceived their children's language development. Specifically, parents of children with Down syndrome would exhibit greater feelings of success regarding their ability to impact their children's language development and lower perceptions of the severity of their children's language difficulties when compared to parents of children with other developmental disabilities. The third goal was to determine predictors of parent stress and parent perceptions of language development in order to determine if there are variables other than diagnosis that may account for the Down syndrome advantage. We hypothesized that variables such as parent age, parent education, and child adaptive behavior would make a significant contribution to parent stress and parent perceptions of language development above and beyond the effect of diagnosis.

Method

Participants

Participants for this study were 111 toddlers (21 to 48 months of age) and one participating parent or primary caregiver (22 to 57 years of age) who agreed to participate in a longitudinal language intervention study (Ronski et al., 2012; Ronski et al., 2010) for toddlers with developmental delays. Participant selection criteria for all children included the following: an age range between 24 and 36 months; a significant developmental delay, at most 10 intelligible spoken words as observed during assessment; a score of less than 12 months on the Expressive Language Scale of the Mullen Scales of Early Learning (MSEL; Mullen, 1995); at least primitive intentional communication abilities; a primary diagnosis other than delayed speech and language impairment, deafness/hearing impairment, or autism; and English as the primary language spoken at home. Parent-child dyads were recruited from the metro Atlanta area through various early intervention services sites, including physicians, psychologists, and speech-language pathologists. Interested parents contacted the project about their participation.

As part of the initial assessment, each parent-child dyad completed a battery of tests that characterized the way the child understood and used language. The parents also completed measures about parent stress, parents' perception of the child's language development, the child's daily living skills, and intervention history. As part of the larger studies, the parents completed the Parent Stress Index-Short Form (PSI-SF; Abidin, 1995) and Parent Perception of Language Development (PPOLD; Ronski, Sevcik, Adamson, & Bakeman, 2000) prior to beginning intervention. Of the 111 parents, five did not complete the PPOLD at pre-intervention. The measure was still in development when data collection began in late 2000 and was not completed until 2001. Thus 111 participants were included in analyses involving the PSI and 106 participants were included for analyses using the PPOLD. Twenty-nine of the children had Down syndrome and 82 of the children had developmental disabilities of mixed etiology including but not limited to genetic syndromes, seizure disorders, cerebral palsy, pervasive developmental disorder, or unknown medical etiology. All children had hearing and vision within normal limits as described in intake reports.

Table 1 presents the parent and child characteristics at the onset of the study for the children and their participating parent by diagnostic group, including demographic information as well as scores on assessments of receptive and expressive language, adaptive behavior, and

developmental level. Although previous research has primarily focused on mothers and therefore used maternal age as a variable, the current study had a small sample of fathers who participated in this study. Out of the 111 parents, eight were fathers whose ages were comparable to the mothers. For young children, research has shown that fathers tend to report on stress differently than mothers with fathers reporting less stress than mothers (Gerstein et al., 2009; Herring et al., 2006). For parents of children with Down syndrome, research suggests that mothers and fathers are comparable in terms of reported stress (Ricci & Hodapp, 2003). Therefore, rather than exclude fathers from the study, we ran analyses for parent stress both with and without fathers to ensure that any differential responding did not affect results. As a proxy for parent income, we used the highest level of education that the participating parent completed. For the purposes of analyses, this variable was dichotomized as either college degree or higher, and other, which included GED, high-school diploma, or some college. Because parents' perceptions of success and difficulty regarding their children's language were outcome variables of interest, it was important to make sure there were no significant differences on measures of receptive and expressive language age. This was confirmed as independent samples t-tests indicated that there no significant group differences on SICD-R receptive language age, $t(109) = -0.61, p > .05$, or SICD-R expressive language age, $t(109) = -1.32, p > .05$. It should be noted that children with other developmental disabilities exhibited a larger gap between chronological age and receptive language age (3 months, on average) and expressive language age (4 months, on average) as compared to children with Down syndrome. This difference was significant for both receptive language, $t(109) = 2.00, p = .04$, and expressive language, $t(109) = 2.38, p = .02$. However, we do not consider this a clinically significant difference that would impact differences in parent stress or parent perceptions of success and difficulty. As mentioned previously, all children were exhibiting delays of at least 10 months between receptive and expressive language age as well as at most 10 spoken words at the onset of the intervention. Therefore all children were exhibiting language skills significantly below what would be expected for their age.

Measures

Four measures were used to address the questions in this study. Parent stress was measured using the Parent Stress Index-Short Form (PSI-SF; Abidin, 1995). It measured the impact that the parenting role had on an individual's stress level and has a long history of being used to evaluate stress experienced by parents of children with developmental disabilities (Lessenberry & Rehfeldt, 2004). The PSI-SF consisted of 36 items taken from the full-length questionnaire that provided a measure of total stress that a parent was experiencing as well as three subscales. Parent-related stress was evaluated using the Parent Distress (PD) subscale and examined the distress a parent was experiencing in his or her role as a parent. Child-related stress was evaluated using the Difficult Child (DC) scale that examined behavioral characteristics of the child that made them easy or difficult to manage. The Parent-Child Dysfunctional Interaction subscale (P-CDI) examined how reinforcing the child was to the parent and their perception of how the child met the parent's expectations. The Internal consistency alpha for the PSI-SF in the current sample was .93 at pre-intervention. This measure correlates well with the full scale PSI, which has constructive and predictive validity, as well as widespread use with special populations (Abidin, 1995)

The second measure, Parent Perception of Language Development (PPOLD; Ronski et al., 2000), measured parent perception of early communication development and intervention in children who have severe communication delays. Although the PSI-SF addressed parent stress on a general level, it did not provide an indication of parent stress as it related to a child's communication abilities. Consequently, the PPOLD was used to address more specific questions relating to parent perceptions of language development as well as stress parents feel related to their child's communication. This measure addresses topics such as the child's language development, the child's use of language, influences on the child's language development, and stresses related to the child's language development. The PPOLD is a 20-item questionnaire; each item is rated 1 to 5 from strongly disagree to strongly agree. Factor analyses identified two factors: *Success*, which measured parents' perceptions about how well they are affecting their child's communication development; and *Difficulty*, which measured parents' perceptions about the severity of their child's communication deficits. The factor *Success* is comprised of items such as, "My child and I have developed ways to communicate that I find satisfying" and "I am increasingly confident that I can help my child develop ways of communicating". The factor *Difficulty* is comprised of items such as, "My child still has a long way to go before he/she communicates as well as other children his/her age" and "My child's expressive language skills hamper his/her ability to communicate needs and wants". Internal consistency alphas were .86 for *Success*, and .71 for *Difficulty* at pre-intervention. Information about all items that comprise the measure as well as the development and psychometrics of this measure can be found in Ronski et al. (2011).

The third measure, the Sequenced Inventory of Communication Development-Revised (SICD-R; Hedrick, Prather, & Tobin, 2000), assessed receptive and expressive language skills. It was designed to evaluate language skills in young children ages 4 months to 4 years and included a receptive and expressive scale, each of which yielded an age in months. The SICD-R has been shown to be an effective way to measure communication abilities of young children with and without developmental disabilities (Hedrick et al., 2000).

Parents completed the Vineland Adaptive Behavior Scales (Vineland-II; Sparrow, Cicchetti, & Balla, 2005) for the child with a developmental disability. This measure examined adaptive behavior in four domains (Communication, Daily Living Skills, Socialization, and Motor Skills) and was given in an interview format. Scores on these four domains combined to yield an overall measure of adaptive behavior. This measure has a long history of use for individuals with a wide range of developmental and intellectual disabilities. Internal consistency reliabilities of the domain and Adaptive Behavior Composite range from the upper .80s to low .90s.

Results

Diagnostic Group Comparisons on Dimensions of Parent Stress

Means and standard deviations for study outcome variables are presented in Table 2. Independent-samples t-tests were used to examine diagnostic group differences on total parent stress and the three subscales of the PSI: parent distress, parent-child dysfunctional interaction, and difficult child. Results indicated that there were significant diagnostic group

differences on total parent stress $t(109) = 2.59, p < .05, d = 0.57$, difficult child, $t(109) = 4.02, p < .01, d = 0.89$, and parent-child dysfunctional interaction, $t(109) = 1.97, p < .05, d = 0.43$. There were no significant differences between diagnostic groups on parent distress, $t(109) = 1.25, p > .05, d = 0.14$. As mentioned previously, the literature suggests that fathers report on parent stress differently than mothers. We examined the data descriptively and found that fathers did report higher levels of stress than mothers but when we ran the same analyses without fathers we found that the pattern of results remained the same. Consistent with our hypothesis, parents of children with Down syndrome exhibited less total and child-related stress than parents of children with other developmental disabilities but did not differ from parents of children with other developmental disabilities on stress related specifically to parenting. We did find however, that contrary to our hypothesis, parents of children with Down syndrome reported significantly less stress related to the child meeting expectations of the parent.

It is important to note that the average parent stress scores of both groups of parents (see Table 2) were in normal range according to the published norms (Abidin, 1995). This indicates that as a whole, both parents of children with Down syndrome and parents of children with other developmental disabilities were generally functioning well and not exhibiting elevated levels of stress. However, a significantly higher proportion of parents of children with other developmental disabilities exhibited scores on the total stress scale and difficult child subscale that were in the high range. For total stress, Abidin (1995) defines clinically significant levels of parent stress are those at the 90th percentile and above. Using this criteria, 27% of parents in the other developmental disabilities group, compared to 7% of those in the Down syndrome group exhibited scores at or above the 90th percentile, $\chi^2(1, N = 106) = 4.36, p < .05$. For the subscales, Abidin (1995) defines high levels of stress as those at the 85th percentile and above. For the Difficult Child subscale, 38% of parents in the other developmental disabilities group, compared to 7% of those in the Down syndrome group reported high levels of child-related stress, $\chi^2(1, N = 106) = 8.92, p < .01$. Groups did not differ significantly in the proportion of parents exhibiting elevated levels of stress on the Parent Distress or Parent-Child Dysfunctional interaction subscales.

Diagnostic Group Comparisons on Parent Perceptions of Language Development

Independent-samples t-tests were used to examine diagnostic group differences on parent perceptions of success and difficulty regarding their children's language development. Results indicated that there were no significant etiological differences between parents on perceptions of success, $t(104) = -1.58, p > .05, d = 0.35$. This indicates that both groups of parents perceived that they were successful in impacting their own children's communication development. Results indicated that there were significant etiological differences for parent perceptions of difficulty, $t(104) = 2.83, p < .01, d = 0.61$. This indicates that parents of children with Down syndrome perceived their children's communication difficulties as less severe when compared to parents of children with other developmental disabilities. This finding was present even though there were no significant differences between the groups on measures of receptive and expressive language (see Table 1).

Predictors of Parent Stress and Parent Perceptions of Language Development

The above analyses indicated that parents of children with Down syndrome and parents of children with other developmental disabilities differed on total parent stress, child-related stress, the PCD-I dimension of parent-related stress, and parent perceptions of difficulty regarding their children's language development. Therefore it was important to determine if there were predictors other than diagnosis that may account for those differences. To determine appropriate predictors we first examined demographic differences between groups that have differed between diagnostic groups in previous research. As shown in Table 1, there were significant differences between parents of children with Down syndrome and parents of children with other developmental disabilities on both parent and child age. Parents of children with Down syndrome were significantly older, $t(103) = 2.73, p < .01$ than parents of children with other developmental disabilities. This difference was expected given that the risk of having a child with Down syndrome increases with maternal age. However, children with Down syndrome were significantly younger than children with other developmental disabilities, $t(104) = -2.69, p < .01$. The diagnosis of Down syndrome is typically given at birth and parents have the expectation that their child may have language and communication difficulties. Thus, they may seek out intervention services for their children at younger ages than other parents. There were no significant differences between groups on parent education, $\chi^2(1, N = 106) = 0.55, p > .05$. Although children with Down syndrome were significantly younger than children (mean age difference = 2.62 months) with other developmental disabilities, there were no significant differences between the groups on measures of adaptive behavior, $t(104) = -0.992, p > .05$, or developmental level, $t(104) = 1.60, p > .05$. Therefore, the variables chosen for predictors of parent stress and parent perceptions of difficulty were parent age, child age, and adaptive behavior. Although adaptive behavior did not differ between the groups, it was entered into the model as a predictor due to research (Corrice & Glidden, 2009) indicating it predicts parent stress independently and should be examined to determine its unique contribution.

Four hierarchical regression models were used to examine predictors of parent stress and parent perceptions of language development for the four outcomes that previous research suggested differs between parents of children with Down syndrome and parents of children with other developmental disabilities: total parent stress, difficult child, parent-child dysfunctional interaction, and parent perceptions of difficulty. Table 3 presents the findings of each of these four regression models. The findings for each outcome variable are reported in two steps. In Step 1, the demographic variables of parent and child age as well as adaptive behavior were entered as predictors. In Step 2, diagnostic group was entered as a predictor dummy coded as 0 (other intellectual or developmental disability) or 1 (Down syndrome).

Regarding total parent stress, results indicated that diagnosis was a significant predictor of parent stress even after controlling for parent age, maternal age, and adaptive behavior. These results indicate that parents of children with Down syndrome reported lower levels of total parent stress, parents of older children reported lower levels of total stress, and parents reported less stress when children had higher levels of adaptive behavior. Regarding the difficult child subscale, results indicated that diagnosis was a significant predictor of parent stress even after controlling for parent age, child age, and adaptive behavior. These results

indicate that parents of children with Down syndrome reported lower levels of child-related stress than parents of children with other developmental disabilities and reported less child-related stress when children had higher levels of adaptive behavior. Regarding the P-CDI subscale, results indicated that once we controlled for parent age, child age, and adaptive behavior diagnosis was not a significant predictor of parent stress. This indicated that it was adaptive behavior that made the most significant contribution to stress related to the parent-child interaction such that when children had greater levels of adaptive behavior, parents reported that their children were more likely to meet their expectations. As a whole, these results indicated that parents of children with Down syndrome reported lower levels of overall parent stress and reported that their child was less difficult to manage than parents of children with other developmental disabilities.

Finally, regarding parent perceptions of difficulty, results indicated that diagnosis was a significant predictor of difficulty even after controlling for parent age, child age, and adaptive behavior. This indicated that parents of children with Down syndrome still perceived their children's communication difficulties as less severe when compared to parents of children with other developmental disabilities.

Discussion

Past research has revealed conflicting findings regarding the existence of an advantage for parents of children with Down syndrome when compared to parents of children with other intellectual and developmental disabilities. Some studies have confirmed the existence of a Down syndrome advantage (Blacher et al., 2013; Gerstein et al., 2009; Herring et al., 2006; Stoneman, 2007) while others have found that confounding demographic variables such as maternal age, income, and adaptive behavior account for this advantage (Abbeduto et al., 2004; Corrice & Glidden, 2009; Gerstein et al., 2009; Herring et al., 2006; Stoneman, 2007). The purpose of this study was to clarify these findings by examining if this advantage for parent stress in parents of children with Down syndrome held true for parents of young children who participated in a study primarily due to their language skills rather than their diagnosis. Furthermore, we sought to determine if this advantage existed for parent perceptions of language development; variables that have not been examined previously in this literature.

Our first research question examined if there were differences on dimensions of parent stress between parents of children with Down syndrome and parents of children with other developmental disabilities. As a whole, results supported our hypothesis. Parents of young children with Down syndrome reported significantly lower levels of total parent stress and child-related stress than parents of children with other developmental disabilities. Regarding parent-related stress, results partially supported our hypothesis. Consistent with our prediction, parents did not differ on stress related specifically to being a parent but did differ on stress related to the child meeting their expectations which was contrary to what we predicted. Parents of children with Down syndrome reported significantly less stress related to the child meeting their expectations than parents of children with other developmental disabilities. These results are consistent with previous research that has found the Down syndrome advantage for parent stress when comparing groups without the consideration of

potential confounding variables (Blacher et al., 2013; Corrice & Glidden, 2009; Gerstein et al., 2009; Kasari & Sigman, 1997; Stoneman, 2007). These findings are also consistent with research showing that there may be an advantage for parents of children with Down syndrome as it relates to child-related stress rather than parent-related stress (Corrice & Glidden, 2009; Kasari & Sigman, 1997). Our findings regarding parents of children with other developmental disabilities reporting greater stress related to the interaction between parent and child were unexpected. When compared to parents of children with Down syndrome, parents of children with other developmental disabilities were more likely to report that their children were not meeting their expectations and that their interactions with their children were not as reinforcing to the parent. Although previous research has not examined this specifically as it relates to parent stress, this finding is consistent with research showing that parents of children with Down syndrome experience a greater sense of personal reward and more reciprocated closeness (Abbeduto et al., 2004; Corrice & Glidden, 2009). The current sample of children was between the ages of two and three and therefore this finding could be explained by the fact that the expectations surrounding the child may be very different for the two groups of parents. Parents of children with Down syndrome are aware of their child's diagnosis at birth and therefore may have different expectations surrounding their child's development than parents of children with other developmental disabilities whose diagnosis may be more recent or still unclear.

We also found that not only did parents of children with other developmental disabilities exhibit significantly higher child-related stress scores than parents of children with Down syndrome, they were also reporting on average, levels of child-related stress that were approaching what is considered high according to the measure. When we examined these results further, we found that a greater proportion of parents of children with other developmental disabilities as compared to parents of children with Down syndrome scored in the clinically significant and high range on both total parent stress and child-related stress. As noted previously, parents were exhibiting levels of stress that are on average, within the normal range. However, the proportion of parents in the other developmental disabilities group who were reporting levels of stress in the clinical range were significantly greater than that of parents in the Down syndrome group. This is consistent with previous research with similar findings for maternal depression (Abbeduto et al., 2004). These results suggest that even though parents are generally functioning well, there are a significant number of parents who are reporting very high levels of stress related to managing their child and could benefit from additional help and support.

Our second research question examined if parents of children with Down syndrome differed from parents of children with other developmental disabilities on their perceptions regarding their children's language development. Previous research has found that parents of children with Down syndrome tend to fare better than parents of other developmental disabilities on a wide variety of family functioning variables including, but not limited to, depression, coping, quality of the parent-child relationship, and parent stress. However, no study to date has examined differences in parent perceptions of language. The young children in this sample were participating in the larger study due solely to their language difficulties rather than their diagnosis. All children, regardless of diagnosis, exhibited significant communication difficulties as evidenced by having no more than 10 intelligible spoken

words and scores of less than 12 months on measures of expressive language at the onset of the study. Results partially supported our hypothesis. Contrary to expectations, we found that regardless of diagnosis, parents of children in both groups reported greater perceptions of success regarding their own ability to impact their child's language development. Consistent with expectations, we found that parents of children with Down syndrome perceived their children's language difficulties to be less severe at the onset of the study than parents of children with other developmental disabilities. This finding occurred even though children in both groups did not differ on measures of receptive and expressive language. This suggests that even though children in both groups were equally delayed in receptive and expressive language, parents of children with Down syndrome perceived their children as communicating better than parents of children with other developmental disabilities. This may be related to the etiology-related personality initially described by Hodapp and colleagues (Hodapp, 1997, 1999; Hodapp & Dykens, 2001). Research examining this etiology-related personality has found that parents describe their children with Down syndrome as more sociable and cheerful, show fewer behavior problems, and have a more easygoing temperament (Hodapp, 1999; Kasari & Sigman, 1997). Although the current study did not directly measure the aforementioned variables, it seems that if the parents in this study perceived their children as having a more positive personality overall, they might be more likely to overlook their communication difficulties. It will be important for future research to examine if this result is maintained with other samples of children.

Our final research question examined predictors of parent stress and parent perceptions of language development that may in part, account for the advantage that we see for parents of children with Down syndrome. Recent research has found that this advantage may be accounted for by variables such as maternal age, parent income, and child adaptive behavior (Abbeduto et al., 2004; Corrice & Glidden, 2009; Herring et al., 2006; Stoneman, 2007). Therefore we hypothesized that similar variables would account for the Down syndrome advantage in the current study. However, results did not support our hypothesis. We found that even after controlling for parent age, child age, and adaptive behavior, child diagnosis was still a significant predictor of total parent stress, child-related stress, and parent perceptions of difficulty. Specifically when the differences in parent and child age and the effects of adaptive behavior were taken into account, parents of children with Down syndrome still reported lower levels of total stress, child-related stress, and parent perceptions of difficulty. Additionally, parent or child age did not make significant contributions to these outcome variables before examining diagnosis. Only adaptive behavior made a significant contribution prior to examining the effect of diagnosis. The only finding consistent with recent research was stress related to the parent-child interaction. Results indicated that diagnosis did not significantly predict stress related to parent child interaction and that it was adaptive behavior that accounted for the most variance in this dimension of parent stress.

There may be several explanations for these findings. As mentioned previously, the sample for the current study was very young. Aside from the Stoneman (2007) study that used a sample of children from aged two to six, the samples in the other studies that found the advantage for parents of children with Down syndrome disappeared after accounting for confounding variables were adolescents or young adults. It is possible that at younger ages,

the advantage for parents of children with Down syndrome may be stronger and that other variables may account for the Down syndrome advantage as children get older.

Secondly, we previously mentioned that the inclusionary criteria for participation in the current study was different than that of other studies that have examined etiological differences for parents of children with disabilities. Families who participated in previous studies were recruited for the purposes of examining etiological differences in families or to examine general issues surrounding families of children with disabilities. Inclusionary criteria for participation in the current study were based solely on the child exhibiting significant delays in language acquisition. It's possible that children who are exhibiting severe difficulties with language may be different than the typical sample of children or individuals with disabilities and may therefore be more indicative of children who are exhibiting greater overall delays. In that sense, it could be that the etiology-related personality that is characteristic of children with Down syndrome may exert a stronger effect for this population of children. Future research should examine if similar results are obtained when the current sample is examined longitudinally. Although Corrice and Glidden (2009) found that the Down syndrome advantage was stable from the age of 12 to 18, it is unknown if the Down syndrome advantage when found at toddlerhood is maintained into early childhood and adolescence.

One limitation to this study is the sample size of the children with Down syndrome. A recent study by Esbensen and Seltzer (2011) used a within-group analysis to determine if the same variables that account for the Down syndrome advantage between-groups would account for within-group variance. They found the existence of a Down syndrome advantage as it relates to maternal well-being that was not accounted for by other variables such as maternal age. Another within-group analysis that may be important to examine are the effects that other health conditions, such as a congenital heart defect (CHD), may have for children with Down syndrome. A recent study by Visootsak, Hess, Bakeman, and Adamson (2012) found that children with Down syndrome and CHD exhibited lower receptive and expressive language skills as well as lower symbol-infused joint-engagement when compared to children with Down syndrome who did not have a CHD. If children with Down syndrome and a CHD have more difficulty with other areas of development, it is possible that these parents may exhibit a different stress profile than the typical parent of a child with Down syndrome. The relatively small sample of parents of children with Down syndrome in the current study did not allow for a within-group analysis using multiple predictors. A second limitation was the lack of a measure of behavior problems in the current study. Previous research has shown that parents of children with Down syndrome perceive their children to have fewer behavior problems than children with other disabilities (Eisenhower et al., 2005; Blacher & McIntyre, 2006). Although the difficult child subscale of the PSI-SF examines behaviors in the child that makes them easy or difficult to manage, it does not ask about specific behaviors. Without directly measuring this variable in the children in our sample, the role that this may play in the results of the current study is unknown.

Despite these limitations, results of this study have several implications for professional practice and policy aimed at supporting families of children with disabilities. First, part of the Down syndrome advantage could be accounted for by the overall notion that Down

syndrome is a more familiar and generally well-known disability within the population. Research would suggest that having more contact with individuals with disabilities leads to more positive attitudes regarding individuals with disabilities (Yuker, 1994). In that sense, most parents likely knew about Down syndrome before having a child with that diagnosis, may have had contact with an individual with Down syndrome, and became aware of their child's diagnosis either before or at birth. For these reasons and with the knowledge about Down syndrome in the general population, parents likely had access to support groups and more well established networks that are easily accessible to parents of children with Down syndrome. Parents of children with other developmental disabilities may be just coming to terms with their child's diagnosis and find it more difficult to access support groups or networks of other parents to connect with and share experiences. It may be helpful for service providers or clinicians to consider including ways to support parents of children with a non-Down syndrome diagnosis in navigating their way through their child's diagnosis and intervention services. These types of family centered services could include providing parents with effective coping strategies for dealing with the stresses they may encounter, and also the provision of cognitive and/or behavioral strategies that can help parents more effectively deal with behavior problems that may be accounting for the increased stress of these families.

Secondly, the findings regarding parent perceptions of language have implications for policy relating to the involvement of parents as active participants in their child's language interventions. If the etiology-related personality of children with Down syndrome is also driving how parents perceive their child's language difficulties, it will be especially important to consider the active inclusion of parents in their child's language interventions. Part C of the Individuals with Disabilities Act requires the inclusion of parents in early intervention. For communication skills in particular, Part C requires that early intervention professionals assist in teaching parents and other caregivers strategies to enhance their child's communication and language development (Hebbeler et al., 2007). Yet we know that parents in this study were not actively involved in their child's language interventions prior to their involvement with this study. This is especially important for parents of children with a diagnosis other than Down syndrome; giving parents and children strategies to more successfully communicate with each other may have positive effects on how parents perceive their children's communication difficulties which may, in turn, lower the stress that parents of children with a non-Down syndrome diagnosis may be experiencing.

In conclusion, results from the current study further contribute to our understanding of the Down syndrome advantage. Our findings support the existence of a Down syndrome advantage for parent stress by demonstrating its existence in families recruited for a separate purpose and after controlling for variables identified in the literature as potential confounds. Additionally, we examined whether this advantage existed for parent perceptions of success and difficulty related to children's language development; variables that have not been included in previous studies. We found this advantage did exist for parent perceptions of children's language difficulties but not success. Clearly understanding this advantage is complex and a more in depth analysis is needed. As we better understand where and if this advantage for parents of Down syndrome exists, we will be better able to support families of children with other disabilities who may experience more parenting challenges.

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References

- Abbeduto L, Seltzer MM, Shattuck P, Krauss MW, Orsmond G, Murphy MM. Psychological well-being and coping in mothers of youths with autism, Down syndrome, or Fragile X syndrome. *American Journal of Mental Retardation*. 2004; 109:237–254. doi: 10.1352/0895-8017(2004)109<237:PWACIM>2.0.CO;2. [PubMed: 15072518]
- Abidin, RR. *Parent Stress Index Manual*. Third Edition ed.. Psychological Assessment Resources, Inc.; Odessa, FL: 1995.
- Blacher J, Baker BL, Kaladjian A. Syndrome specificity and mother-child interactions: Examining positive and negative parenting across contexts and time. *Journal of Autism and Developmental Disorders*. 2013; 43:761–774. doi: 10.1007/s10803-012-1605-x. [PubMed: 22829243]
- Brady N, Skinner D, Roberts J, Hennon E. Communication in young children with Fragile X syndrome: A qualitative study of mothers' perspectives. *American Journal of Speech-Language Pathology*. 2006; 15:353–364. doi: 10.1044/1058-0360(2006/033). [PubMed: 17102146]
- Capps L, Kasari Connie, Yirmiya N, Sigman M. Parental perception of emotional expressiveness in children with autism. *Journal of Consulting and Clinical Psychology*. 1993; 61:475–484. doi: 10.1037/0022-006X.61.3.475. [PubMed: 8326050]
- Corrice AM, Glidden LM. The Down syndrome advantage: Fact or fiction? *American Journal on Intellectual and Developmental Disabilities*. 2009; 114:254–268. doi: 10.1352/1944-7558-114.4.254-268. [PubMed: 19642708]
- Dykens EM. Direct effects of genetic mental retardation syndromes: Maladaptive behavior and psychopathology. *International Review of Research in Mental Retardation*. 1999; 22:1–26. doi: 10.1016/S0074-7750(08)60129-9.
- Esbensen AJ, Seltzer MM. Accounting for the “Down syndrome advantage”. *American Journal on Intellectual and Developmental Disabilities*. 2011; 116:3–15. doi: 10.1352/1944-7558-116.1.3. [PubMed: 21291307]
- Gerstein ED, Crnic KA, Blacher J, Baker BL. Resilience and the course of daily parent stress in families of young children with intellectual disabilities. *Journal of Intellectual Disability Research*. 2009; 53:981–997. doi: 10.1111/j.1365-2788.2009.01220.x. [PubMed: 19874449]
- Hastings RP, Allen R, McDermott K, Still D. Factors related to positive perceptions in mothers of children with intellectual disabilities. *Journal of Applied Research in Intellectual Disabilities*. 2002; 15:269–275. doi: 10.1046/j.1468-3148.2002.00104.x.
- Hastings RP, Taunt HM. Positive perceptions in families of children with developmental disabilities. *American Journal of Mental Retardation*. 2002; 107:116–127. [PubMed: 11853529]
- Hebbeler, Kathleen; Spiker, Donna; Bailey, Don; Scarborough, Anita; Mallik, Sangeeta; Simeonsson, Rune; Nelson, Lauren. *Early intervention for infants and toddlers with disabilities and their families: Participants, services and outcomes*. SRI International; Menlo Park, CA: 2007.
- Hedrick, DL.; Prather, EM.; Tobin, AR. *Sequenced Inventory of Communication Development Manual - Revised Edition*. Western Psychological Services; Los Angeles, CA: 2000.
- Herring S, Gray K, Taffe J, Tonge B, Sweeney D, Einfeld S. Behaviour and emotional problems in toddlers with pervasive developmental disorders and developmental delay: associations with parental mental health and family functioning. *Journal of Intellectual Disability Research*. 2006; 50:874–882. doi: 10.1111/j.1365-2788.2006.00904.x. [PubMed: 17100948]
- Hodapp RM. Direct and indirect effects of different genetic disorders of mental retardation. *American Journal on Mental Retardation*. 1997; 102:67–79. [PubMed: 9241409]
- Hodapp RM. Indirect effects of genetic mental retardation disorders: Theoretical and methodological issues. *International Review of Research in Mental Retardation*. 1999; 22:27–50. doi: 10.1016/S0074-7750(08)6013-5.

- Hodapp RM, Dykens EM. Strengthening behavioral research on genetic mental retardation syndromes. *American Journal on Mental Retardation*. 2001; 106:4–15. [PubMed: 11246712]
- Hodapp RM, Ly Tran M, Fidler DJ, Ricci LA. Less stress, more rewarding: Parenting children with down syndrome. *Parenting: Science and Practice*. 2001; 1:317–337. doi: 10.1207/S15327922PAR0104_3.
- Hodapp RM, Ricci LA, Ly TM, Fidler DJ. The effects of the child with Down syndrome on maternal stress. *British Journal of Developmental Psychology*. 2003; 21:137–151. doi: 10.1348/026151003321164672.
- Kasari C, Sigman M. Linking parental perceptions to interactions in young children with autism. *Journal of Autism and Developmental Disorders*. 1997; 27:39–57. doi: 10.1023/A:1025869105208. [PubMed: 9018581]
- Lessenberry BM, Rehfeldt RA. Evaluating the stress levels of parents of children with disabilities. *Exceptional Children*. 2004; 70:231–244.
- Mullen, EM. *Mullen Scales of Early Learning*. American Guidance Service; Circle Pines, MN: 1995.
- Olsson MB, Hwang PC. Influence of macro structure of society on the life situation of families with a child with intellectual disability: Sweden, as an example. *Journal of Intellectual Disability Research*. 2003; 47:328–341. doi: 10.1046/j.1365-2788.2003.00494.x. [PubMed: 12787164]
- Povee K, Roberts L, Bourke J, Leonard H. Family functioning in families with a child with Down syndrome: a mixed methods approach. *Journal of Intellectual Disability Research*. 2012; 56:961–973. doi: 10.1111/j.1365.2788.2012.01561.x. [PubMed: 22533693]
- Ricci LA, Hodapp RM. Fathers of children with Down's syndrome versus other types of intellectual disability: perceptions, stress, and involvement. *Journal of Intellectual Disability Research*. 2003; 47:273–284. doi: 10.1046/j.1365-2788.2003.00489.x. [PubMed: 12787159]
- Rodrigue JR, Morgan SB, Gefken GR. Families of autistic children: Psychological functioning of mothers. *Journal of Clinical Child Psychology*. 1990; 19:371–390. doi: 10.1207/s15374424jccp1904_9.
- Romski, MA.; Sevcik, RA.; Adamson, LB.; Bakeman, R. Parent Perception of Language Development. 2000. Unpublished measure
- Romski, MA.; Sevcik, RA.; Adamson, LB.; Barton-Hulsey, A.; Smith, A.; Barker, RM.; Bakeman, R. Comparing augmented language interventions for toddlers with developmental disabilities. 2012. Manuscript in preparation
- Romski MA, Sevcik RA, Adamson LB, Cheslock M, Smith A, Barker RM, Bakeman R. Randomized comparison of augmented and non-augmented language interventions for toddlers with developmental delays and their parents. *Journal of Speech, Language, and Hearing Research*. 2010; 53:350–364. doi: 10.1044/1092-4388(2010/09-0208).
- Romski MA, Sevcik RA, Adamson LB, Smith A, Cheslock M, Bakeman R. Parent perceptions of the language development of toddlers with developmental delays before and after participation in parent-coached language interventions. *American Journal of Speech-Language Pathology*. 2011; 20:111–118. doi: 10.1044/1058-0360(2011/09-0087). [PubMed: 21330651]
- Sanders JL, Morgan SB. Family stress and adjustment as perceived by parents of children with autism or Down syndrome: Implications for intervention. *Child and Family Behavior Therapy*. 1997; 19:15–32. doi: 10.1300/J019v19n04_02.
- Smith A, Romski MA, Sevcik RA, Adamson LB, Bakeman R. Parent stress and its relation to parent perceptions of communication following parent-coached language intervention. *Journal of Early Intervention*. 2011; 33:135–150. doi: 10.1177/1053815111405526.
- Sparrow, SS.; Cicchetti, DV.; Balla, DA. *Vineland adaptive behavior scales*. 2nd ed.. AGS Publishing; Circle Pines, MN: 2005.
- Stoneman Z. Examining the Down syndrome advantage; mothers and fathers of young children with disabilities. *Journal of Intellectual Disability Research*. 2007; 51:1006–1017. doi: 10.1111/j.1365-2788.2007.01012.x. [PubMed: 17991008]
- Turnbull, AP.; Turnbull, HR. *Cognitive coping, families, and disability*. Brookes Publishing, Inc.; Baltimore, MD: 1993.

- Visootsak J, Hess B, Bakeman R, Adamson LB. Effects of congenital heart defects on language development in toddlers with Down syndrome. *Journal of Intellectual Disability Research*. 2012; 56:1–6. doi: 10.1111/j.1365-2788.2012.01619.x. [PubMed: 22151130]
- Yuker HE. Variables that influence attitudes toward people with disabilities: Conclusions from the data. *Journal of Social Behavior and Personality*. 1994; 9:3–22.

Table 1
Parent and Child Characteristics at Pre-intervention by Diagnostic Group

Variables	Down syndrome (n = 29)		Other developmental disabilities (n = 82)	
	Mean	SD	Mean	SD
Parent Age ^a	39.80**	4.28	36.70**	5.97
Parent Gender (% Female)	89.70	—	90.20	—
Parent Education (% College/Post-college)	82.80	—	76.90	—
Parent Race (% Caucasian)	69.00	—	57.30	—
Child Age ^b	28.66*	3.65	31.28*	5.74
Child Gender (% Female)	31.00	—	30.50	—
Child Race (% Caucasian)	62.10	—	54.90	—
Child Adaptive Behavior Composite ^c	69.03	6.79	66.83	8.92
Child Mullen ELC ^d	56.52	9.43	59.71	13.05
SICD-R Receptive Language Age ^{b,e}	18.64	4.68	18	7.32
SICD-R Expressive Language Age ^{b,e}	17.88	5.39	16.61	8.25

^aParent age in years.

^bChild age in months.

^cAs measured by the Vineland Scales of Adaptive Behavior.

^dAs measured by the Mullen Scales of Early Learning.

^eSICD-R = Sequenced Inventory of Communication Development-Revised.

*
 $p < .05$,

**
 $p < .01$

Table 2
Diagnostic Group Comparisons for Study Variables

Variable	Down syndrome (n = 29)	Other disabilities (n = 82)	d
	M (SD)	M (SD)	
Total Parent Stress	67 (19)	78 (20)	0.57*
Parent Distress	24 (8)	25 (8)	0.14
P-CDI	20 (6)	23 (6)	0.43*
Difficult Child	22 (8)	30 (9)	0.89**
PPOLD Success	3.89 (0.57)	3.67 (0.67)	0.35
PPOLD Difficulty	3.08 (0.76)	3.52 (0.66)	0.61*

*
 $p < .05$,

**
 $p < .01$. PPOLD = Parent Perception of Language Development

Table 3
Hierarchical Regression Analysis for the Prediction of Parent Stress and Perceptions of Difficulty

Predictor	Total Parent Stress			Difficult Child			P-CDI			Perceptions of Difficulty		
	R ²	β	R ²	β	R ²	β	R ²	β	R ²	β	R ²	β
Step 1	.14**		.15**		.15**		.12**					
Parent Age		-.10		-.18		-.14		-.09				
Child Age		-.16		-.09		-.17		-.07				
Adaptive Behavior		-.33**		-.32**		.33**		-.33**				
Step 2	.05*		.10**		.03		.06**					
Diagnosis		-.23*		-.33**		-.17		-.26**				
Total R ²	.19*		.25**		.17		.18**					
n	111		111		111		104					

* $p < .05$,

** $p < .01$; P-CDI = Parent-Child Dysfunctional Interaction