

SIGAN L. HARTLEY AND MARSHA MAILICK SELTZER *University of Wisconsin-Madison*

LARA HEAD *Gundersen Lutheran Medical Hospital**

LEONARD ABBEDUTO *University of Wisconsin-Madison***

Psychological Well-being in Fathers of Adolescents and Young Adults With Down Syndrome, Fragile X Syndrome, and Autism

The psychological well-being of fathers of children with developmental disabilities remains poorly understood. The present study examined depressive symptoms, pessimism, and coping in fathers of adolescents and young adults with Down syndrome (DS; n = 59), autism spectrum disorders (ASDs; n = 135), and Fragile X syndrome (n = 46). Fathers of sons or daughters with ASDs reported a higher level of depressive symptoms than the other groups of fathers. Fathers of sons or daughters with DS reported a lower level of pessimism than the other groups of fathers. There were no group differences in paternal coping style. Group differences in paternal depressive symptoms and pessimism were, in part, related to differences in paternal age, the child's behavior problems, risk of having additional children with a disability, and maternal depressive symptoms. Findings from this study can be used to educate providers

and design services for fathers during the later parenting years.

Approximately 1% to 2% of children in the United States have a developmental disability, defined as a severe condition due to a mental or physical impairment that manifests prior to age 22 years that is likely to continue indefinitely and markedly impairs everyday functioning (National Center on Birth Defects and Developmental Disabilities, 2006). Parenting a child with a developmental disability presents extraordinary challenges; parents often must assist their son or daughter with everyday living skills and manage their symptoms and comorbid behavior problems and navigate the complex disability service system (Hodapp & Ly, 2005). These challenges are not limited to the early parenting years, but extend into the son's or daughter's adolescence and adulthood. Adolescents and adults with developmental disabilities often continue to reside with parents (Seltzer, Greenberg, Floyd, Pettee, & Hong, 2001) and, thus, parents continue to have high levels of day-to-day parenting responsibilities and stress (Seltzer et al., 2001; Smith et al., 2009).

These parenting challenges can have a negative effect on parents' well-being; mothers of both young and grown children with developmental disabilities present with more

Department of Human Development and Family Studies, Waisman Center, University of Wisconsin-Madison, Madison, WI 53705 (Hartley@waisman.wisc.edu).

*Gundersen Lutheran Medical Center, 900 South Avenue, La Crosse, WI 54601.

**Present address: UC Davis MIND Institute, 2825 50th St., Sacramento, CA 95817.

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psychopathology than do mothers of similarly aged children without disabilities (e.g., Baker, Blacher, Crnic, & Edelbrock, 2002; Seltzer et al., 2009). The extent of this negative effect, however, varies according to the nature of the child's disability; some child disabilities are related to high rates of parenting stress and poor psychological well-being in mothers, whereas other child disorders have much less impact (Abbeduto et al., 2004; Sellinger & Hodapp, 2005). In contrast to the large body of research on mothers, little is known about the psychological well-being of fathers of children with developmental disabilities. Although mothers tend to bear more responsibility for child care than fathers within families of children with developmental disabilities (Ricci & Hodapp, 2003; Simmerman, Blacher, & Baker, 2001), fathers are not immune to child-related challenges. Indeed, the few studies that have included fathers of younger children with developmental disabilities indicate that fathers often report higher parenting stress and poorer psychological well-being than fathers of children without disabilities (Dyson, 1997; Roach, Orsmond, & Barratt, 1999) and levels of parenting stress similar to those of mothers (Dyson, 1997; Hastings, 2003; Keller & Honig, 2004). These studies also indicate that there is a great deal of variability in paternal psychological well-being. As with mothers, some of this variation may be because of the nature of their child's disability; however, research on fathers is sparse.

Down syndrome (DS), autism spectrum disorders (ASDs) and fragile X syndrome (FXS) constitute three of the most common developmental disabilities. DS, which occurs in 1 in 800 births (Shin et al., 2009), typically results from a noninherited chromosomal error (trisomy 21) and generally leads to mild to moderate levels of intellectual disability (Dykens, Hodapp, & Finucane, 2000). ASDs are a spectrum of conditions marked by impairments in communication, social reciprocity, and restricted or repetitive behaviors (American Psychological Association, 2000). Half to about three fourths of individuals with an ASD also have intellectual disability (Fombonne, 2003), and the majority evidence comorbid behavior problems, such as inattention and disruptive behavior (e.g., Brereton, Tonge, & Einfeld, 2006). ASDs occur in 1 in 110 children (Autism and Developmental Disabilities Monitoring Network, 2009) and are believed to result, in large part, from inherited and noninherited genetic mechanisms (Freitag,

2007). FXS is an inherited genetic condition involving changes to the *FMR1* gene located on the X chromosome, which may occur as often as 1 in 2,500 persons (Hagerman, 2008). FXS results in cognitive impairment ranging from mild learning disabilities to intellectual disability, behavior problems, including inattention and hyperactivity, and an increased risk for ASDs (Bailey, Raspa, Olmsted, & Holiday, 2008).

Differences in the nature (i.e., etiology and behavioral presentation) of DS, ASDs, and FXS may lead to divergent parenting contexts and stressors and thereby differentially affect psychological well-being. The present study was designed to compare the psychological well-being of fathers of adolescent and young adult children with DS, ASDs, and FXS and to identify the factors contributing to potential group differences. Current family services within the field of developmental disabilities are predominately focused on the early parenting years and directed toward mothers, with little consideration of fathers (Parette, Meadan, Hedda, & Doubet, 2010; Turbiville & Marquis, 2001). Information from the present study may be useful in advocating for and designing interventions to involve and address the needs of fathers and the challenges they face in later parenting years. In the general population, paternal psychological well-being has important interconnections with child well-being (e.g., Lovejoy, Graczyk, O'Hare, & Newman, 2000) and maternal well-being (e.g., Walker, Luszcz, Gerstort, & Hoppmann, 2011). Evidence suggests that there are similar interconnections between father, mother, and child well-being in families of children with developmental disabilities (e.g., Hastings, 2003; Stoneman & Payne-Gavida, 2006). Thus, efforts to understand and then develop interventions to promote optimal psychological well-being in fathers of children with developmental disabilities has implications for fostering positive well-being in multiple family members.

FATHER PSYCHOLOGICAL WELL-BEING AND CHILD DIAGNOSIS

Given the paucity of studies comparing the psychological well-being of fathers of young or grown children with different types of developmental disabilities, we turn to research on mothers to inform hypotheses in the present study. The child diagnoses most taxing on mothers may also be the ones that are most taxing

on fathers, as they may alter parenting contexts and stressors in ways that affect both parents. Indeed, our own previous research has found significant positive interspouse correlations in parenting burden within families of adolescents and young adults with ASDs (e.g., Hartley, Barker, Seltzer, Greenberg, & Floyd, 2011).

Mothers of young and grown children with DS, ASDs, and FXS have been shown to experience varying levels of psychological well-being (e.g., Abbeduto et al., 2004; Hodapp, Ricci, Ly, & Fidler, 2003). Research has consistently shown a pattern of "DS advantage," in which mothers of children with DS report lower levels of stress (Hodapp et al., 2003), view caregiving more positively (Sellinger & Hodapp, 2005), and report more support-seeking coping (Poehlmann, Clements, Abbeduto, & Farsad, 2005) than mothers of children with other types of disabilities. In contrast, a pattern of "ASD disadvantage" has emerged in which mothers of children with ASDs report higher levels of stress (Sanders & Morgan, 1997) and increased depressive symptoms (Olsson & Hwang, 2001) as compared to mothers of children with other disabilities, including DS. Our own research suggests that this diagnostic-related pattern of psychological well-being continues in mothers of adolescents and young adults with DS and ASDs (Abbeduto et al., 2004). Our previous research also suggests that mothers of adolescents and young adults with FXS appear to fare somewhat better than mothers of adolescents and young adults with ASDs, but worse than mothers of adolescents and young adults with DS (e.g., Abbeduto et al., 2004; Lewis et al., 2006; Poehlmann et al., 2005).

Although the data on fathers are limited, fathers of young children with DS have also been found to report lower levels of stress than fathers of children with other types of disabilities (Fidler, Hodapp, & Dykens, 2000; Ricci & Hodapp, 2003). Similarly, fathers of young children with ASDs have been shown to report higher levels of stress than fathers of children with other disabilities (Sanders & Morgan, 1997). There have been no studies, however, examining whether these diagnostic-related differences in paternal psychological well-being continue into the son's or daughter's adolescence and adulthood, as is true for mothers. Moreover, the relative psychological well-being of fathers of adolescents and young adults with FXS remains unstudied.

FACTORS CONTRIBUTING TO DIFFERENCES BY CHILD DIAGNOSIS

The pattern of differences in the psychological well-being of mothers of young and grown children with DS, ASDs, and FXS is often attributed to the divergent nature of these disabilities. Specifically, the varying etiology and behavioral presentation of these disabilities leads to different parenting contexts and stressors in terms of parent age, the child's behavior problems, and the likelihood of having additional children with a disability. The chromosomal error that causes DS occurs in a higher proportion of the pregnancies of older women (aged ≥ 35 years), and thus the "DS advantage" is often attributed to increased parent resources due in part to older maternal age and hence greater maturity at the time of the child's birth (Abbeduto et al., 2004; Urbano & Hodapp, 2007), although recent studies have shown that advanced maternal age is not as consistent an explanation of positive maternal well-being outcomes as previously thought (Esbensen & Seltzer, 2011). Moreover, advanced paternal age has recently been linked to an increased risk of having a child with an ASD (Durkin et al., 2008), underscoring the importance of paternal age in studies of parental well-being in families of children with different types of developmental disabilities.

The "DS advantage" has also been attributed to the profile of less negative behaviors (e.g., fewer behavior and sleep problems) and more positive behaviors (e.g., more independent living skills and behavioral flexibility) exhibited by individuals with DS as compared to individuals with ASDs and other disabilities (Cotton & Richdale, 2006; Didden et al., 2008; Esbensen, Bishop, Seltzer, Greenberg, & Taylor, 2010). In contrast, individuals with ASDs and FXS evidence a stressful profile of comorbid behavior problems, including hyperactivity, inattention, and disruptive behaviors (Bailey et al., 2008; Smith et al., 2009), which can intensify during adolescence and young adulthood (Hatton et al., 2006; Taylor & Seltzer, 2010a). Child behavior problems, as opposed to intellectual functioning, have consistently been shown to be a strong predictor of parenting stress (e.g., Baker et al., 2002), and, thus, the more frequent and severe profile of comorbid behavior problems in individuals with ASDs and FXS may be an important contributor to poor parental psychological well-being.

Moreover, unlike parents of individuals with DS, who only have a slightly increased risk of having an additional child with a disability, parents of individuals with ASDs (Piven, 2001) and FXS (Bailey, Raspa, Bishop, & Holiday, 2009) have a substantial heightened risk of having an additional children with a disability because of the inherited genetic etiology of these disorders. Caring for multiple children with disabilities has been shown to take a toll on mothers' well-being (Hartley et al., 2012; Orsmond, Lin, & Seltzer, 2007) and may similarly have a negative effect on fathers' well-being. Paternal age, child behavior problems, and presence of additional children with a disability may similarly account for diagnostic-related differences in the psychological well-being of fathers.

In addition, the psychological well-being of one spouse has been shown to be an important determinant of the psychological well-being of the other spouse in both families of typically developing children (e.g., Dufouil & Alperovitch, 2000; Goodman & Shippy, 2002) and families of younger children with disabilities (Baker, Blacher, & Olsson, 2005). The depressed mood of one spouse has been shown to be transmitted through daily interactions to the other spouse (e.g., Larson & Almeida, 1999; Thompson & Bolger, 1999). Moreover, spousal mental health problems can lead to an additional caretaking burden for the nonaffected spouse and strained marital interactions (e.g., Barling, MacEwen, & Kelloway, 1994; Ruscher & Gotlib, 1988). For some outcome measures, there is evidence that fathers, more than mothers, are negatively impacted by marital distress (Belsky, Youngblade, Rovine, & Volling, 1991; Cummings & O'Reily, 1997) and poor spousal well-being (Walker et al., 2011). Thus, the poor psychological well-being seen in mothers of children with ASDs may contribute to poor psychological well-being of fathers in these same families. Moreover, in many families affected by FXS, mothers have the premutation of the *FMRI* gene and related affect problems (Bailey et al., 2008). Thus, it is important to understand the extent to which differences in maternal psychological well-being can account for variation in the psychological well-being of fathers in these same families.

In the present study, we compared the psychological well-being of fathers of adolescents and young adults with DS, ASDs, or

FXS and examined factors that contribute to potential group differences. Three indicators of fathers' psychological well-being were examined: depressive symptoms, pessimism about the child's future, and coping style. These indicators were selected because they have been shown to vary by child diagnosis in mothers (Abbeduto et al., 2004; Olsson & Hwang, 2001; Poehlmann et al., 2005). To further understand group differences in paternal psychological well-being, we also examined the extent to which paternal age, the child's behavior problems, the presence of additional children with a disability, and maternal depressive symptoms could account for these differences.

We hypothesized that, as seen for mothers, there would be a pattern indicative of a "Down syndrome advantage" and "ASD disadvantage" in paternal psychological well-being. Specifically, we predicted that fathers of adolescents and young adults with ASDs would report a higher level of depression and pessimism than fathers of adolescents and adults with DS. We also predicted that fathers of adolescents and adults with ASDs would report greater use of emotion-focused coping and less use of problem-focused coping than fathers of adolescents and adults with DS. *Emotion-focused coping* is defined as efforts to manage emotions surrounding the problem (e.g., trying to wish away negative feelings or distract oneself) and is generally found to be less effective at buffering the negative impact of stress (e.g., Seltzer, Greenberg, & Krauss, 1995), whereas *problem-focused coping* is defined as efforts to alter the stressor itself (e.g., seeking information and problem solving) and is generally found to be effective at buffering the negative impact of stress (e.g., Hastings & Brown, 2002). We expected fathers of adolescents and young adults with FXS to fall in the middle of these other groups on all measures. We also hypothesized that paternal age, the child's behavior problems, the presence of additional children with a disability, and maternal depressive symptoms would account for a significant portion of the diagnostic-related difference in paternal psychological well-being.

METHOD

The families reported on in the present study overlapped with the sample of families reported in the Abbeduto et al. (2004) study analyzing

maternal psychological well-being. This sample was drawn from two large research projects involving families of individuals with developmental disabilities. The first project involved families of individuals with DS or FXS (Abbeduto et al., 2004) conducted between 1997 and 2004. The second project is an ongoing longitudinal study of adolescents and adults with an ASD (Seltzer et al., 2003, in press). In both projects, families were recruited through local media advertisements, newsletters to national and regional disability organizations, and brochures and postings in clinics, disability listservs, and a university research registry. The present analyses include the subset of 59 fathers who had an adolescent or young adult child (aged 10 to 22 years) with DS, 135 fathers who had an adolescent or young adult child with ASDs, and 46 fathers who had an adolescent or young adult child with FXS.

Sample Members

Adolescents and young adults. Diagnoses of DS and FXS were confirmed through medical reports and genetic testing. One (1.7%) individual with DS and 7 (15.2%) individuals with FXS had received a current diagnosis of an ASD from an independent educational or health professional and scored above a cutoff of 44 (Volkmar et al., 1988) on the Autism Behavior Checklists (Krug, Arick, & Almond, 1980) by at least two of the three informants. This prevalence of co-occurring ASD is consistent with previous reports using larger samples of individuals with DS and FXS (Belmonte, 2006; DiGuseppi et al., 2010). These individuals were included within the DS and FXS groups, respectively,

as co-occurring ASD is an important aspect of these syndromes. Within the ASD project, all individuals had received an ASD diagnosis (Autistic Disorder, Asperger Disorder, or PDD-NOS) from an independent educational or health professional and had a research-administered Autism Diagnostic Interview-Revised (ADI-R; Lord, Rutter, & Le Couteur, 1994) profile consistent with the diagnosis. Nearly all (94.6%) of the individuals in the ASD group met lifetime criteria for a diagnosis of Autistic Disorder, with the remainder meeting criteria for Asperger Disorder or PDD-NOS. None of the adolescents or adults with ASD had a diagnosis of FXS or DS.

Sociodemographic characteristics of the adolescents and young adults are presented in Table 1. The adolescents and young adults ranged in age from 10 to 22 years and were predominately male. There was not a significant difference in the gender of the adolescents and young adults among the diagnostic groups. Adolescents and young adults with an ASD were significantly older than were the adolescents and young adults with DS. Intellectual disability (ID) status was determined using a variety of sources of information. In the ASD sample, IQ was assessed with the Wide Range Intelligence Test (WRIT; Glutting, Adams, & Sheslow, 2000), and adaptive behavior was assessed with the Vineland Screener (Sparrow, Carter, & Cicchetti, 1993). Individuals who had standard scores of 70 or below on both measures (or on educational or psychological records) were classified as having ID. In the FXS and DS samples, IQ was assessed with the nonverbal subtests in the Stanford-Binet Intelligence Scale, fourth edition (Thorndike, Hagen, & Sattler, 1986). Individuals who obtained a

Table 1. Sociodemographic Characteristics of the Sample

	DS (<i>n</i> = 59)	FXS (<i>n</i> = 46)	ASD (<i>n</i> = 135)	Test Statistic
Father				
Married (%)	96.6%	97.4%	96.2%	$\chi^2 = 6.70$
College degree + (%)	54.2%	59.0%	81.0%	$\chi^2 = 25.52^{**}$ a,b,c
Income >\$75K (%)	45.8%	59.0%	44.5%	$F = 0.21$
Total children (<i>M</i> , <i>SD</i>)	3.34 (1.67)	3.02 (1.73)	2.04 (1.02)	$F = 23.23^{**}$ b,c
Adolescent or adult				
Age (<i>M</i> , <i>SD</i>)	15.22 (2.96)	15.63 (2.63)	16.03 (2.83)	$F = 2.98^*$ c
Male (%)	69.6%	79.5%	72.3%	$\chi^2 = 2.10$
ID (%)	100%	92.3%	62.8%	$\chi^2 = 21.95^{**}$ b,c

Note: a = DS versus FXS. b = FXS versus ASD. c = DS versus ASD.

* $p \leq .05$. ** $p \leq .01$.

partial composite IQ of 69 or below on these three subtests were classified as having ID. The adolescents and young adults with DS (100%) and FXS (92.3%) were significantly more likely to have ID than those with an ASD (62.8%). The prevalence of ID across the diagnostic groups is consistent with previous studies using larger samples (Edelson, 2006; Reiss & Dant, 2003).

Fathers. Table 1 also presents the sociodemographic characteristics of the 240 fathers in the present study. All fathers in the sample were identified as the biological father of the target adolescent or adult. The vast majority of fathers were Caucasian, were married, and had at least a college education. A significantly higher percentage of fathers of adolescents and young adults with ASDs had a college education as compared to the fathers of adolescents and young adults with DS, with fathers of adolescents and young adults with FXS in the middle of these groups. There was not a significant difference in household income among the groups, with about half of the families reporting an income of greater than \$75,000. Families of adolescents and young adults with FXS and DS had a significantly higher number of total children than families of adolescents and young adults with an ASD.

Measures

Factors contributing to group differences in paternal well-being. Four factors proposed to contribute to the differences in the well-being of parents of grown children with DS, ASDs, and FXS were assessed: *paternal age*, *child's behavior problems*, *the presence of additional children with a disability*, and *maternal depressive symptoms*. Fathers reported their *age* in years. Mothers were asked to indicate whether there were any *additional children in the family with a disability* (defined as having a physical, mental health, or developmental disability requiring special care). The *behavior problems* of the adolescent or adult son or daughter with the developmental disability were assessed by mothers using eight corresponding items from the Autism Behavior Checklist (ABC; Krug et al., 1980) in the DS and FXS samples and the Scales of Independent Behavior-Revised (SIB-R; Bruininks, Woodcock, Weatherman, & Hill, 1996) in the ASD sample. Both the ABC and SIB-R include questions regarding the presence

(1 = *yes*, 0 = *no*) of eight behavior problems: hurt self, hurt others, destructive, disruptive behavior and tantrums, unusual habits/rituals, offensive behavior, withdrawn, and uncooperative behavior. We used the total number of behavior problems in the present analysis. *Maternal depressive symptoms* were assessed through maternal self-report using the Center for Epidemiological Studies-Depression Scale (CES-D; Radloff, 1977). The CES-D consists of 20 items on which individuals endorse the frequency of depressive symptoms during the previous week using a 4-point Likert scale ranging from 0 (*rarely*) to 3 (*most of the time*). The CES-D has been shown to have excellent internal consistency, test-retest reliability, and validity with other measures of depression (Radloff, 1977). Alpha reliability for this instrument for the mothers in this sample was .90. The mean CES-D score across all mothers was 9.98 ($SD = 10.12$).

Paternal psychological well-being. Three indicators of psychological well-being were assessed. To assess paternal *pessimism*, fathers completed the 10-item Pessimism subscale from the Questionnaire on Resources and Stress (QRS-F; Friedrich, Greenberg, & Crnic, 1983). The Pessimism subscale assesses the parent's perceptions of pessimism regarding the child's immediate and long-term ability to achieve self-sufficiency. Items were endorsed based on whether the father agreed or disagreed with the presented statement. Higher scores reflect greater pessimism. The QRS-F has been shown to have high internal consistency and construct validity (Friedrich et al., 1983). Alpha reliability for fathers on the Pessimism scale in this study was .68, which was slightly lower than in previous studies of mothers (Abbeduto et al., 2004; Essex, Seltzer, & Krauss, 1999). *Paternal depressive symptoms* were assessed with the CES-D (Radloff, 1977). Alpha reliability for the CES-D for fathers in this sample was .91. Scores of 16 or above indicate the potential for the presence of clinical depression. The mean CES-D score across all fathers was 9.76 ($SD = 9.93$).

Fathers reported on their *coping style* on the Multidimensional Coping Inventory (Carver, Scheier, & Weintraub, 1989). This scale consists of 14 subscales comprised of four items each. Items are rated using a Likert scale based on the frequency with which various coping strategies are used during stressful experiences (1 = *not*

at all to 4 = a lot). For this study, we only examined the problem-focused coping (created from the active coping, planning, suppression of competing activities, and positive reinterpretation and growth subscales) and emotion-focused coping (created from the denial, focusing on and venting of emotions, behavioral disengagement, and mental disengagement subscales) summary scores. These summary scores have been shown in previous studies to have strong internal consistency and convergence with other measure of coping (Seltzer et al., 1995). Alpha reliability for fathers in present study was .89 for problem-focused coping and .78 for emotion-focused coping.

Missing Data

At least 75% of all items within a scale or subscale had to be completed by the participant in order for his responses on a measure to be included in the study. The participant's mean score was substituted in place of any item with a missing response. Less than 1% of all items across all participants and measures had missing values.

Data Analysis Plan

There were several significant differences in the sociodemographic characteristics of our three diagnostic groups, including child ID, paternal education, child age, and total number of children. These demographics were not the focus of the present study and were controlled for in remaining analyses. First, one-way analyses of covariance (ANCOVAs), controlling for relevant sociodemographic characteristics (e.g., child age, paternal education, total number of children, and child ID), were conducted to examine differences in our three indicators of paternal psychological well-being by diagnostic group. Second, we conducted group comparisons of the four factors (paternal age, child behavior problems, the presence of additional children with a disability, and maternal depressive symptoms) hypothesized to contribute to the pattern of diagnostic-related difference. Next, we examined the extent to which these four factors accounted for variation in paternal psychological well-being in our sample using hierarchical linear regressions. We hypothesized that once these four factors were controlled for in regression models, the difference in paternal psychological

well-being between our diagnostic groups would be reduced.

RESULTS

Table 2 presents the means, standard deviations, and one-way ANCOVA results for our indicators of paternal psychological well-being by diagnostic group. There was a significant difference by diagnostic group in depressive symptoms and pessimism. There was not a significant difference in the use of emotion-focused or problem-focused coping by diagnostic group. The predicted pattern indicative of a "DS advantage" was found for pessimism. Follow-up Fisher's least significant difference (LSD) post hoc tests indicated that fathers of adolescents and young adults with DS reported a significantly lower level of pessimism than fathers of adolescents and young adults with ASDs or FXS. There was not a significant difference in the level of pessimism between fathers of adolescents and young adults with ASDs versus FXS. In contrast, for depressive symptoms, a pattern of "ASD disadvantage" was found. LSD post hoc tests indicated that fathers of adolescents and young adults with ASDs reported a significantly higher level of depressive symptoms than fathers of adolescents and young adults with DS or FXS. There was not a significant difference in level of depressive symptoms between fathers of adolescents and young adults with DS versus FXS. In terms of clinically significant depressive problems, 30.4% ($n = 41$) of the fathers of adolescents and young adults with ASDs reported scores of 16 or above (cutoff for clinically significant problems) on the CES-D compared to 15.9% ($n = 7$) of fathers of adolescents and young adults with FXS and 6.8% ($n = 4$) of fathers of adolescents and young adults with DS.

Table 3 presents the descriptive statistics for paternal age, number of child behavior problems, number of additional children with a disability, and maternal depressive symptoms by diagnostic group. One-way ANCOVAs indicated a significant difference in paternal age, number of child behavior problems, number of additional children with a disability, and maternal depressive symptoms. Follow-up LSD post hoc tests indicated that the pattern of differences was in the expected direction. Fathers of the adolescents with young adults with an ASD were older than fathers of adolescents and young adults with FXS. There was not a

Table 2. Means, Standard Deviations, and One-Way Analyses of Covariance Statistic, Controlling for Child Age, Paternal Education, Total Number of Children, and Child ID, for Paternal Well-being

	DS (<i>n</i> = 59)	FXS (<i>n</i> = 44/46) ^a	ASD (<i>n</i> = 135)	<i>F</i> statistic
Pessimism	4.37 (2.03)	5.67 (2.21)	6.34 (2.25)	9.99** a,c
Depressive symptoms	6.78 (6.32)	8.56 (8.94)	11.78 (9.96)	8.43** b,c
Problem-focused coping	30.60 (8.23)	32.20 (7.27)	30.48 (8.28)	1.48
Emotion-focused coping	11.17 (5.53)	11.49 (5.19)	12.30 (6.11)	2.12

Note: a = DS versus FXS. b = FXS versus ASD. c = DS versus ASD.

^a*n* = 44 for depressive symptoms.

p* ≤ .05. *p* ≤ .01.

Table 3. Means, Standard Deviations, and One-Way Analyses of Covariance Statistic, Controlling for Child Age, Paternal Education, Total Number of Children, and Child ID, for Factors Hypothesized to Account for Diagnostic Differences

	DS (<i>n</i> = 59)	FXS (<i>n</i> = 46)	ASD (<i>n</i> = 135)	Test Statistic
Paternal age	48.41 (7.25)	45.56 (6.41)	49.77 (9.77)	<i>F</i> = 4.15* b
Behavior problems	0.53 (0.84)	1.73 (1.71)	2.51 (2.01)	<i>F</i> = 29.72*** a,b,c
Additional children with disability	0.19 (0.58)	0.84 (1.03)	0.33 (0.67)	<i>F</i> = 16.62*** a,b,c
Maternal depressive symptoms	6.65 (6.04)	9.18 (6.84)	12.89 (9.01)	χ^2 = 9.42*** b,c

Note: a = DS versus FXS. b = FXS versus ASD. c = DS versus ASD.

p* ≤ .05. *p* ≤ .01.

significant difference in paternal age between the DS and FXS groups or between the FXS and ASD groups. As expected, adolescents and young adults with an ASD exhibited the highest number of behavior problems, followed by those with FXS, with adolescents and young adults with DS exhibiting the fewest behavior problems. Also as expected, the families of adolescents and young adults with FXS had more additional children with a disability than the ASD and DS groups. Fathers of adolescents and young adults with ASDs had more additional children with a disability than fathers of adolescents and young adults with DS. The difference in maternal depressive symptoms by diagnostic group was also in the expected direction; mothers of adolescents and young adults with ASDs reported a higher level of depressive symptoms than mothers of adolescents and young adults with DS or FXS. There was not a significant difference in maternal depressive symptoms between the DS and FXS groups.

Next, hierarchical linear regressions were conducted to examine whether these four factors could, in part, explain the pattern of diagnostic-related differences in paternal psychological well-being. Regressions were conducted separately for depressive symptoms and pessimism. Coping indicators were not examined, as these

indicators did not significantly differ by diagnostic group. In Step 1, the impact of diagnostic group on the indicator of psychological well-being was entered. Dummy-variable coding was used to contrast the diagnostic groups (Cohen, Cohen, West, & Aiken, 2003, pp. 303–310). For depressive symptoms, ASD was selected to be the reference group (i.e., assigned value of 0 in dummy coded variables), to which each of the other diagnostic groups was compared (DS and FXS; assigned value of 1 in each respective dummy coded variable). This decision was based on the pattern of findings indicative of ASD *disadvantage* for depressive symptoms, but no difference between the DS and FXS groups. For pessimism, DS was selected to be the reference group, to which the other diagnostic groups (ASD and FXS) were compared. This decision was based on the pattern of findings indicative of a DS *advantage* for pessimism, but no difference between the ASD and FXS groups. Relevant sociodemographic variables (child age, paternal education, total number of children, and child ID) were also controlled in this step. In Step 2, paternal age, behavior problems, the presence of additional children with a disability, and maternal depressive symptoms were entered. We reasoned that if significant differences between the diagnostic groups at Step 1 were diminished at Step 2, then the factors

(paternal age, behavior problems, the presence of additional children with a disability, and maternal depressive symptoms) entered at Step 2 could be seen as explaining, at least in part, our pattern of diagnostic-related variation in paternal psychological well-being.

Table 4 presents the results of the regression analyses for paternal depressive symptoms. Fathers of adolescents and young adults with ASDs had a significantly higher level of depressive symptoms than fathers of adolescents or young adults with DS and FXS at Step 1. After the other variables were entered into the model at Step 2, however, these group differences became nonsignificant. Additional children with a disability and higher level of maternal depressive symptoms were significant positive predictors of paternal depression at Step 2. The final regression model predicted 15% of the variance in depressive symptoms across fathers. In terms of paternal pessimism (see Table 5), fathers of adolescents and young adults with DS reported a lower level of pessimism than fathers of adolescents and young adults with ASDs or FXS (Step 1). The significant advantage of fathers of adolescents and young adults with DS as compared to fathers of adolescents and young adults with ASDs was sustained even after other variables were entered into the model at Step 2. By contrast, the advantage of fathers of adolescents and young adults with DS compared to fathers of adolescents and young adults with FXS became nonsignificant in Step 2, when other variables were entered into the model. The final regression model predicted 20% of the variance in pessimism across fathers.

DISCUSSION

Despite evidence that fathers are not immune to child-related stress, their psychological well-being has largely been ignored in developmental disability research. The goal of the present study was to examine psychological well-being of fathers of adolescent and young adult children with DS, ASDs, and FXS and the factors contributing to group differences. We found that fathers of adolescents and young adults with ASDs reported more depressive symptoms than fathers of adolescents and young adults with DS or FXS, with the two latter groups experiencing similar levels of depressive symptoms. Fathers of adolescents and young adults with DS experienced less pessimism about their son's or

Table 4. Regression Results for Paternal Depressive Symptoms

	Depressive Symptoms
Step 1	
ASD	—
DS	-.30**
FXS	-.21*
Paternal education	-.01
Total no. of children	.14
Child age	.09
Child ID	.03
Step 2	
DS vs. ASD	-.14
FXS vs. ASD	-.14
Paternal education	.03
Total no. of children	.12
Child age	.13
Child ID	.01
Paternal age	.03
Behavior problems	.14
Additional child with disability	.16*
Maternal depressive symptoms	.23**
Adjusted R^2 ; F value (Step 1)	.07; $F = 3.13^{**}$
Adjusted R^2 ; F value (Step 2)	.15; $F = 3.99^{**}$

Note: Change in R^2 significant at $p < .05$.

* $p \leq .05$, ** $p \leq .01$.

daughter's future than did fathers of adolescents and young adults with ASDs or FXS, with the two latter groups experiencing similar levels of pessimism.

There were no significant differences among the groups in fathers' use of problem-focused or emotion-focused coping, similar to our earlier study of coping in a sample of mothers of adolescents and adults with DS, FXS, and ASDs that overlapped with the current sample of families (Abbeduto et al., 2004). These findings suggest that mothers and fathers of adolescents and young adults with DS, FXS, and ASDs use similar types of coping strategies to deal with child-related stress, yet experience different levels of depressive symptoms and pessimism about their son's or daughter's future. It may be that group differences in depressive symptoms and pessimism are driven by differences in the type and severity of child-related stressors encountered. The challenges related to parenting adolescents or young adults with ASDs, and to a lesser extent adolescents or young adults with FXS, have been found to be more stressful for

Table 5. Regression Results for Paternal Pessimism

	Pessimism
Step 1	
DS	—
ASD	.52**
FXS	.23*
Paternal education	-.01
Total no. of children	-.12
Child age	.07
Child ID	.30**
Step 2	
ASD vs. DS	.44**
FXS vs. DS	.19
Paternal education	-.01
Total no. of children	-.13
Child age	.0
Child ID	.29**
Paternal age	.06
Behavior problems	.04
Additional child with disability	.08
Maternal depressive symptoms	.12
Adjusted R^2 ; F value (Step 1)	0.19; $F = 8.16^{**}$
Adjusted R^2 ; F value (Step 2)	0.20; $F = 5.50^{**}$

Note: Change in R^2 significant at $p < .05$.

* $p \leq .05$, ** $p \leq .01$.

parents than the challenges related to parenting adolescents or young adults with DS (Abbeduto et al., 2004; Lewis et al., 2006; Poehlmann et al., 2005). Thus, despite not differing in their likelihood of using adaptive coping strategies, parents of adolescents and young adults with ASDs, and to lesser extent parents of adolescents and young adults with FXS, may experience poorer psychological well-being as a result of encountering more severe and difficult types of child-related stressors.

A pattern of poorer psychological well-being associated with ASDs as compared to DS was also found in earlier studies of fathers of younger children (Fidler et al., 2000; Sanders & Morgan, 1997). Our study builds on these findings by showing that this difference persists later in the life course. Moreover, this is the first study to present information on the relative psychological well-being of fathers of individuals with FXS. Our overall findings that fathers of adolescents and young adults with FXS fare better than fathers of adolescents and young adults with ASDs but worse than fathers of adolescents and young adults with DS are consistent with

our previous research on mothers (Abbeduto et al., 2004).

We also examined the extent to which factors related to the varying nature (etiology and behavioral presentation) of these disabilities contributed to group differences in paternal psychological well-being. Fathers of the adolescents and young adults with an ASD were older than fathers of adolescents and young adults with FXS. This finding is consistent with recent findings that older fathers are at risk of having children with ASDs (e.g., Durkin et al., 2008). Fathers in the DS group did not significantly differ in age from fathers in the ASDs or FXS groups. In line with expected diagnostic differences, the adolescents and young adults with ASDs in our sample evidenced more behavior problems and their mothers had a higher level of depressive symptoms than was true of the DS or FXS groups. Also as expected, adolescents and young adults with FXS exhibited more behavior problems than the adolescents and young adults with DS. In line with the genetic pathways contributing to these disabilities, fathers of adolescents and young adults with FXS also had more additional children with disabilities than did fathers of adolescents and young adults with DS, with fathers of adolescents and young adults with ASDs in the middle of these groups.

Using hierarchical linear regressions, we found that once these factors (paternal age, child's behavior problems, additional children with a disability, and maternal depressive symptoms) were controlled, most diagnostic differences in paternal depressive symptoms among the groups became nonsignificant. The "ASD disadvantage" in terms of heightened depressive symptoms as compared to both the DS and FXS groups was, at least in part, related to advanced paternal age, child's heightened number of behavior problems, the increased risk of having additional children with a disability, and increased maternal depressive symptoms. The presence of an additional child with a disability and maternal depressive symptoms, however, were the only significant predictors of paternal depression in the overall model.

Similarly, the difference in pessimism between the DS and FXS groups became nonsignificant in the full model when other variables were added. Thus, the "DS advantage" over FXS in terms of pessimism was, at least in part, related to fewer behavior problems by the child, the absence of additional children with

disabilities in the family, and a lower level of maternal depressive symptoms; however, it is important to note that none of these factors was independently significantly related to pessimism in the overall model. In contrast, fathers of adolescents and young adults with DS continued to have a significantly lower level of pessimism than fathers of adolescents and young adults with ASDs in the full model. Thus, the diagnostic difference in pessimism between the ASDs and DS groups may be driven by other factors. Symptoms or impairments of ASDs, apart from behavior problems, may contribute to the increased paternal pessimism of fathers. For instance, as compared to chronological and mental-age matched youth with DS, individuals with ASDs evidence more deficits in social skills (Esbensen et al., 2010; Loveland & Kelly, 1988). These deficits may lead to realistically more pessimistic views of future prospects by fathers. It is interesting to note that ID status was significantly positively related to paternal pessimism; yet, adolescents and young adults with ASDs had lower rates of ID than the other groups.

There are several limitations to this study. Fathers in the present study were recruited through research projects focused on mothers. As a result, fathers were almost exclusively married, in all cases to the biological mother of the son or daughter with the developmental disability, and lived with their spouse. Findings from the present study may not generalize to fathers of grown children with developmental disabilities in alternative family structures (e.g., single, remarried, or stepfathers). In addition, only a subset of the factors proposed to account for differences in parent psychological well-being were examined in this study. Further research is needed to determine the extent to which factors such as the timing and certainty surrounding the child's diagnosis and genetic vulnerabilities related to presence of mild autism-like symptoms in fathers of children with ASDs affect paternal outcomes. In addition, behavior problems were assessed using a summary score based on eight overlapping items from the ABC in the DS and FXS groups and the SIB-R in the ASD group. The extent to which differences in the remaining items on these varying measures influenced reporting of these eight overlapping items is not known. Behavior problems were also reported on by mothers as opposed to fathers, and thus fathers may have endorsed different behavior problems by their son or daughter

than did mothers. Moreover, parents reported on only eight types of behavior problems. A larger portion of diagnostic-related differences in paternal psychological well-being may have been accounted for by behavior problems if we had used a broader and more in-depth measure of behavior problems rated by fathers.

Our indicators of psychological well-being were limited to depressive symptoms, pessimism, and coping styles, as these have been shown to vary in mothers. Future research should examine diagnostic-related variation in other domains of paternal well-being, such as feelings of anger, work and financial stress, and marital satisfaction, as the toll of stress may be more strongly linked to these other domains in men as opposed to women (e.g., Matud, 2004). Finally, future studies should explore indices of positive paternal psychological well-being in fathers of grown children with developmental disabilities, as previous studies on parents of younger children highlight that parenting a son or daughter with a developmental disability can also offer rewards (Stainton & Besser, 1998).

Implications for Practice and Future Research

Despite widespread recognition of the benefits of family-centered services within the field of developmental disabilities, current services and supports are directed toward mothers, with little consideration of fathers (Parette et al., 2010; Turbiville & Marquis, 2001). Moreover, despite the lifelong nature of developmental disabilities, these services and supports are concentrated on families of young children; although there are a variety of early intervention services for parents of young children with developmental disabilities, there are few services for families of adolescents and adults (Howlin, 2005; Taylor & Seltzer, 2010b). In part, this lack of attention to fathers and families of adolescents and young adults with developmental disabilities by intervention programs is because of the relative lack of research on the experiences and needs of fathers and families of grown children. The present study is one of the first studies to begin documenting the factors contributing to the psychological well-being of fathers in families of adolescents and young adults with developmental disabilities and offers important information for designing services to address the needs of this group.

Our findings indicate that fathers of individuals with ASDs, and to a lesser extent FXS, have poorer psychological well-being than fathers of individuals with DS. Whereas 30.4% of fathers of adolescents and young adults with ASDs reported depressive symptoms warranting clinical attention, 15.9% of fathers of adolescents and young adults with FXS and only 6.8% of fathers of adolescents and young adults with DS had a clinically significant level of depressive symptoms. Thus, services should include more intensive supports for fathers of adolescents and young adults with ASDs and FXS as compared to fathers of adolescents and young adults with DS. Research on service effectiveness in mothers suggests that a combination of interventions aimed at improving functioning and reducing behavior problems in the child with the developmental disability (e.g., behavioral support) and helping parents cope with parenting challenges (e.g., respite care and stress management), and coordination of these services (e.g., case management) leads to the best outcomes (e.g., Hastings & Beck, 2004). The mode of service delivery for parent-focused interactions may need to differ for fathers. Turbiville and Marquis (2001) found that fathers of young children with developmental disabilities preferred services that involved multiple family members, and thus family-based services that teach strategies for managing child-related stress that are attended by multiple family members may be most appealing to fathers.

Our findings also indicate that services should focus on fathers who have more than one child with a disability, as these fathers are at greater risk for experiencing depressive symptoms. These interventions that teach fathers how to manage and cope with the multiple child-related stressors related to having more than one child with a disability are needed. These interventions will likely need to include both time management strategies (e.g., how to juggle child-care responsibilities, work, and leisure) as well as stress management strategies (e.g., interventions teaching coping strategies). Our finding of a significant relation between child ID status and paternal pessimism also suggests that intervention programs may need to help fathers redefine their definition of "success" for their adolescent and adult son or daughter with ID. Adolescence and adulthood for individuals with ID often does not include the transitions (e.g., going to college, getting a job, and getting

married) that typically define "success" for adolescents and adults with average IQs. Interventions aimed at helping fathers identify more flexible and obtainable criteria for their child's "success" in adolescence and adulthood may help them be more optimistic about their son's or daughter's future. To be effective, however, fathers should also be assisted in locating and accessing services that help their adolescent or young adult obtain his or her highest level of independence (e.g., support for transition out of high school and job training or job coach).

Perhaps most importantly, findings from the present study suggest that a family systems approach should be used in interventions. Such an approach should recognize that fathers are affected by the nature of their child's disability, in addition to its impact on mothers, and that a father's psychological well-being is connected to the psychological well-being of his wife. Interventions that recognize the importance of family interconnectedness have to potential to foster positive well-being within multiple family members and result in a stronger family system. Finally, it is important to note that only a modest portion of variance in paternal psychological well-being in our sample was attributable to diagnostic differences. Further research on the child and family contextual determinants of psychological well-being is needed to strengthen services for fathers.

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REFERENCES

- Abbeduto, L., Seltzer, M. M., Shattuck, P., Krauss, M. W., Orsmond, G., & Murphy, M. M. (2004). Psychological well-being and coping in mothers of youths with autism, Down syndrome, or fragile X syndrome. *American Journal on Mental Retardation, 109*, 237–254.
- American Psychiatric Association. (2000). *Diagnostic and statistical manual of mental disorders* (4th ed., text revision). Washington, DC: Author.
- Autism and Developmental Disabilities Monitoring Network Surveillance Year 2006 Principal Investigators. (2009). Prevalence of autism spectrum

- disorders – Autism and Developmental Disabilities Monitoring Network, United States, 2006. *MMWR Surveillance Summary*, 58, 1–20.
- Bailey, D. B., Raspa, M., Bishop, E., & Holiday, D. (2009). No change in the age of diagnosis for fragile X syndrome: Findings from a national parent survey. *Pediatrics*, 124, 527–533.
- Bailey, D. B., Raspa, M., Olmsted, M., & Holiday, D. B. (2008). Co-occurring conditions associated with *FMRI* gene variations: Findings from a national parent survey. *American Journal of Medical Genetics. Part A*, 146A, 2060–2069.
- Baker, B. L., Blacher, J., Crnic, K. A., & Edelbrock, C. (2002). Behavioral problems and parenting stress in families of three-year-old children with and without developmental delays. *American Journal on Mental Retardation*, 107, 433–444.
- Baker, B. L., Blacher, J., & Olsson, M. B. (2005). Preschool children with and without developmental delay: Behaviour problems, parents' optimism and well-being. *Journal of Intellectual Disability Research*, 49, 575–590.
- Barling, J., MacEwen, K. E., & Kelloway, E. K. (1994). Predictors and outcomes of elder-care-based interrole conflict. *Psychology and Aging*, 9, 391–397.
- Belmonte, M. K. (2006). Fragile X syndrome and autism at the intersection of genetic and neural networks. *Nature Neuroscience*, 9, 1221–1225.
- Belsky, J., Youngblade, L., Rovine, M., & Volling, B. (1991). Patterns of marital change and parent-child interaction. *Journal of Marriage and the Family*, 53, 487–498.
- Brereton, A. V., Tonge, B. J., & Einfeld, S. L. (2006). Psychopathology in children and adolescents with autism compared to young people with intellectual disability. *Journal of Autism and Developmental Disorders*, 36, 863–870.
- Bruininks, R. H., Woodcock, R., Weatherman, R., & Hill, B. (1996). *Scales of Independent Behavior-Revised*. Chicago, IL: Riverside.
- Carver, C. S., Sheier, M. F., & Weintraub, J. K. (1989). Assessing coping strategies: A theoretically based approach. *Journal of Personality and Social Psychology*, 56, 267–283.
- Cohen, J., Cohen, P., West, S. G., & Aiken, L. S. (2003). *Applied multiple regression/correlation analysis for the behavioral sciences* (3rd ed.) Hillsdale, NJ: Erlbaum.
- Cotton, S., & Richdale, A. (2006). Brief report: Parental descriptions of sleep problems in children with autism, Down syndrome, and Prader-Willi syndrome. *Research in Developmental Disabilities*, 27, 151–161.
- Cummings, E. M., & O'Reilly, A. (1997). Fathers in family context: Effects of marital quality on child adjustment. In M. E. Lamb (Ed.), *The role of the father in child development* (3rd ed., pp. 49–65). Hoboken, NJ: Wiley.
- Diden, R., Sigafos, J., Green, V. A., Korzilius, H., Mouws, C., Lancioni, G. E., O'Reilly, M. F., & Curfs, L. M. G. (2008). Behavioural flexibility in individuals with Angelman syndrome, Down syndrome, non-specific intellectual disability and autism spectrum disorder. *Journal of Intellectual Disability Research*, 52, 503–509.
- DiGuseppi, C., Hepburn, S., Davis, J. M., Fidler, D. J., Hartway, S., Lee, N. R., Miller, L., Ruttenber, M., & Robinson, C. (2010). Screening for autism spectrum disorders in children with Down syndrome: Population prevalence and screening test characteristics. *Journal of Developmental Behavioral Pediatrics*, 31, 181–191.
- Dufouil, C., & Alperovitch, A. (2000). Couple similarities for cognitive functions and psychological health. *Journal of Clinical Epidemiology*, 53, 589–593.
- Durkin, M. S., Maenner, M. J., Newschaffer, C. J., Lee, L.-C., Cunniff, C. M., Daniels, J. L., Kirby, R. S., Leavitt, L., Miller, L., Zahorodny, W., & Schieve, L. A. (2008). Advanced parental age and the risk of autism spectrum disorder. *American Journal of Epidemiology*, 168, 1268–1276.
- Dykens, E. M., Hodapp, R. M., & Finucane, B. M. (2000). *Genetics and mental retardation syndromes: A new look at behavior and interventions*. Baltimore, MD: Paul H. Brookes Publishing.
- Dyson, L. L. (1997). Fathers and mothers of school-age children with developmental disabilities: Parenting stress, family functioning, and social support. *American Journal on Mental Retardation*, 102, 267–279.
- Edelson, M. G. (2006). Are the majority of children with autism mentally retarded? A systematic evaluation of the data. *Focus on Autism and Other Developmental Disabilities*, 21, 66–83.
- Esbensen, A. J., Bishop, S., Seltzer, M. M., Greenberg, J. S., & Taylor, J. L. (2010). Comparisons between individuals with autism spectrum disorders and individuals with Down syndrome in adulthood. *American Journal on Intellectual and Developmental Disabilities*, 115, 277–290.
- Esbensen, A. J., & Seltzer, M. M. (2011). Accounting for the “Down syndrome advantage.” *American Journal on Intellectual and Developmental Disabilities*, 114, 254–268.
- Essex, E. L., Seltzer, M. M., & Krauss, M. W. (1999). Differences in coping effectiveness and well-being among aging mothers and fathers of adults with mental retardation. *American Journal on Mental Retardation*, 104, 545–563.
- Fidler, D. J., Hodapp, R. M., & Dykens, E. M. (2000). Stress in families of young children with Down syndrome, Williams syndrome, and Smith-Magenis syndrome. *Early Education & Development*, 11, 395–406.
- Fombonne, E. (2003). Epidemiological surveys of autism and other pervasive developmental

- disorders: An update. *Journal of Autism and Developmental Disorders*, 33, 365–382.
- Freitag, C. M. (2007). The genetics of autistic disorders and its clinical relevance: A review of the literature. *Molecular Psychiatry*, 12, 2–22.
- Friedrich, W. N., Greenberg, M. T., & Crnic, K. (1983). A short-form of the Questionnaire on Resources and Stress. *American Journal of Mental Deficiency*, 88, 41–48.
- Glutting, J., Adams, W., & Sheslow, D. (2000). *Wide Range Intelligence Test*. Wilmington, DE: Wide Range, Inc.
- Goodman, C. R., & Shippy, R. A. (2002). Is it contagious? Affect similarity among spouses. *Aging and Mental Health*, 6, 266–274.
- Hagerman, P. J. (2008). The fragile X prevalence paradox. *Journal of Medical Genetics*, 45, 498–499.
- Hartley, S. L., Barker, E. T., Seltzer, J. S., & Floyd, F. J. (2011). Marital satisfaction and parenting experiences of mothers and fathers of adolescents and adults with autism. *American Journal on Intellectual and Developmental Disabilities*, 116, 81–95.
- Hartley, S. L., Seltzer, M. M., Hong, J., Greenberg, J. S., Almeida, D., Coe, C., & Abbeduto, L. (2012). Cortisol response to behavior problems in *FMR1* premutation mothers of adolescents and adults with fragile X syndrome: A diathesis-stress model. *International Journal of Behavioral Development*, 36, 53–61.
- Hastings, R. P. (2003). Child behaviour problems and partner mental health as correlates of stress in mothers and fathers of children with autism. *Journal of Intellectual Disability Research*, 47, 231–237.
- Hastings, R. P., & Beck, A. (2004). Practitioner review: Stress intervention for parents of children with intellectual disabilities. *Journal of Child Psychology and Psychiatry*, 45, 1338–1349.
- Hastings, R. P., & Brown, T. (2002). Behavior problems of children with autism, parental self-efficacy, and mental health. *American Journal on Mental Retardation*, 107, 222–232.
- Hatton, D. D., Sideris, J., Skinner, M., Mankowski, J., Bailey, D., Roberts, J., & Mirrett, P. (2006). Autistic behavior in children with fragile X syndrome: Prevalence, stability, and the impact of *FMRP*. *American Journal of Medical Genetics*, 140A, 1804–1813.
- Hodapp, R. M., & Ly, T. M. (2005). Parenting children with developmental disabilities. In T. Luster & L. Okagaki (Eds.), *Parenting: An ecological perspective* (2nd ed., pp. 317–337). Mahwah, NJ: Erlbaum.
- Hodapp, R. M., Ricci, L. A., Ly, T. M., & Fidler, D. J. (2003). The effects of the child with Down syndrome on maternal stress. *British Journal of Developmental Psychology*, 21, 137–151.
- Howlin, P. (2005). Outcomes in autism spectrum disorders. In F. R. Volkmar, R. Paul, A. Klin, & D. Cohen (Eds.), *Handbook of autism and pervasive developmental disorders, vol. 1: Diagnosis, development, neurobiology, and behavior* (3rd ed., pp. 201–220). Hoboken, NJ: Wiley.
- Keller, D., & Honig, A. S. (2004). Maternal and paternal stress in families with school-aged children with disabilities. *American Journal of Orthopsychiatry*, 74, 337–348.
- Krug, D. A., Arick, J. R., & Almond, P. J. (1980). *Autism Screening Instrument for Educational Planning. Examiner's manual*. Portland, OR: ASIEP Education.
- Larson, R. W., & Almeida, D. M. (1999). Emotional transmission in the daily lives of families: A new paradigm for studying family process. *Journal of Marriage and the Family*, 61, 5–20.
- Lewis, P., Abbeduto, L., Murphy, M., Richmond, E., Giles, N., Bruno, L., Schroeder, S., Anderson, J., & Orsmond, G. (2006). Psychological well-being of mothers of youth with fragile X syndrome: Syndrome specificity and within-syndrome variability. *Journal of Intellectual Disability Research*, 50, 894–904.
- Lord, C., Rutter, M., & LeCouteur, A. (1994). Autism Diagnostic Interview-Revised: A revised version of a diagnostic interview for caregivers of individuals with possible pervasive developmental disorders. *Journal of Autism and Developmental Disorders*, 24, 659–685.
- Lovejoy, M. C., Graczyk, P. A., O'Hare, E., & Newman, G. (2000). Maternal depression and parenting behavior: A meta-analytic review. *Clinical Psychology Review*, 20, 561–592.
- Loveland, K. A., & Kelly, M. L. (1988). Development of adaptive behavior in adolescents and young adults with autism and Down syndrome. *American Journal on Mental Retardation*, 93, 84–92.
- Matud, M. P. (2004). Gender differences in stress and coping styles. *Personality and Individual Differences*, 37, 1401–1415.
- National Center on Birth Defects and Developmental Disabilities. (2006). *Monitoring developmental disabilities*. Retrieved from <http://www.cdc.gov/ncbddd/dd/surv.htm>
- Olsson, M. B., & Hwang, C. P. (2001). Depression in mothers and fathers of children with intellectual disability. *Journal of Intellectual Disability Research*, 45, 535–543.
- Orsmond, G. I., Lin, L.-Y., & Seltzer, M. M. (2007). Mothers of adolescents and adults with autism: Parenting multiple children with disabilities. *Intellectual and Developmental Disabilities*, 45, 257–270.
- Parrette, H. P., Meadan, H., & Doubet, S. (2010, August 15). Fathers of young children with

- disabilities in the United States: Current status and implications. *Child Education*, 86.
- Piven, J. (2001). The broad autism phenotype: A complementary strategy for molecular genetic studies of autism. *American Journal of Medical Genetics*, 105, 34–35.
- Poehlmann, J., Clements, M., Abbeduto, L., & Farsad, V. (2005). Family experiences associated with a child's diagnosis of fragile X or Down syndrome: Evidence for disruption and resilience. *Mental Retardation*, 43, 255–267.
- Radloff, L. S. (1977). The CES-D Scale: A self-report depression scale for research in the general population. *Applied Psychological Measurement*, 1, 385–401.
- Reiss, A. L., & Dant, C. C. (2003). The behavioral neurogenetics of fragile X syndrome: Analyzing gene-brain-behavior relationships in child development psychopathologies. *Development and Psychopathology*, 15, 927–968.
- Ricci, L. A., & Hodapp, R. M. (2003). Fathers of children with Down's syndrome versus other types of intellectual disability: Perceptions, stress and involvement. *Journal of Intellectual Disability Research*, 47, 273–284.
- Roach, M. A., Orsmond, G. L., & Barratt, M. S. (1999). Mothers and fathers of children with Down syndrome: Parental stress and involvement in childcare. *American Journal on Mental Retardation*, 104, 422–436.
- Ruscher, S. M., & Gotlib, I. H. (1988). Marital interaction patterns of couples with and without a depressed partner. *Behavioral Therapy*, 189, 455–470.
- Sanders, J. L., & Morgan, S. B. (1997). Family stress and adjustment as perceived by parents of children with autism or Down syndrome: Implications for intervention. *Child and Family Behavior Therapy*, 19, 15–32.
- Sellinger, M. H., & Hodapp, R. M. (2005). Indirect effects of genetic syndromes: Parental reactions to behavioral phenotypes. *Enfance*, 57, 218–226.
- Seltzer, M. M., Almeida, D. M., Greenberg, J. S., Savla, J., Stawski, R. S., Hong, J., & Taylor, J. L. (2009). Psychosocial and biological markers of daily lives of midlife parents of children with disabilities. *Journal of Health and Social Behavior*, 50, 1–15.
- Seltzer, M. M., Greenberg, J. S., Floyd, F. J., Pettee, Y., & Hong, J. (2001). Life course impacts of parenting a child with disability. *American Journal on Mental Retardation*, 106, 265–286.
- Seltzer, M. M., Greenberg, J. S., & Krauss, M. W. (1995). A comparison of coping strategies of aging mothers of adults with mental illness or mental retardation. *Psychology and Aging*, 10, 64–75.
- Seltzer, M. M., Greenberg, J. S., Taylor, J. L., Smith, L., Orsmond, G. I., Esbensen, A., & Hong, J. (in press). Adolescents and adults with autism spectrum disorders. In D. G. Amaral, G. Dawson, & D. Geschwind (Eds.), *Autism spectrum disorders*. New York: Oxford University Press.
- Seltzer, M. M., Krauss, M. W., Shattuck, P. T., Orsmond, G., Swe, A., & Lord, C. (2003). The symptoms of autism spectrum disorders in adolescence and adulthood. *Journal of Autism and Developmental Disorders*, 33, 565–581.
- Shin, M., Besser, L. M., Kucik, J. E., Lu, C., Siffel, C., & Correa, A. (2009). Prevalence of Down syndrome among children and adolescents in 10 regions of the United States. *Pediatrics*, 124, 1565–1571.
- Simmerman, S., Blacher, J., & Baker, B. L. (2001). Fathers' and mothers' perceptions of father involvement in families with young children with a disability. *Journal of Intellectual and Developmental Disability*, 26, 325–338.
- Smith, L. E., Hong, J., Seltzer, M. M., Greenberg, J. S., Almeida, D. M., & Bishop, S. L. (2009). Daily experiences among mothers of adolescents and adults with autism spectrum disorder. *Journal of Autism and Developmental Disorders*, 40, 167–178.
- Sparrow, S. S., Carter, A. S., & Cicchetti, D. V. (1993). *Vineland Screener: Overview, reliability, validity, administration, and scoring*. New Haven, CT: Yale University Child Study Center.
- Stainton, T., & Besser, H. (1998). The positive impact of children with an intellectual disability on the family. *Journal of Intellectual and Developmental Disability*, 23, 57–70.
- Stoneman, Z., & Payne-Gavidia, S. (2006). Marital adjustment in families of young children with disabilities: Associations with daily hassles and problem-focused coping. *American Journal on Mental Retardation*, 111, 1–14.
- Taylor, J. L., & Seltzer, M. M. (2010a). Changes in the autism behavioral phenotype during the transition to adulthood. *Journal of Autism and Developmental Disorders*, 40, 1421–1446. doi:10.1007/s10803-010-1005-z
- Taylor, J. L., & Seltzer, M. M. (2010b). The transition to adulthood for individuals with ASD and their families. In P. Howlin (Chair), *What really matters: Measuring outcome and addressing the needs of adolescents and adults with ASD*. Invited Educational Symposium conducted at the International Meetings for Autism Research, Philadelphia, PA.
- Thompson, A., & Bolger, N. (1999). Emotional transmission in couples under stress. *Journal of Marriage and the Family*, 61, 38–48.
- Thorndike, R. L., Hagen, E. P., & Sattler, J. M. (1986). *Guide for administering and scoring the Stanford-Binet Intelligence Scale* (4th ed.). Chicago: Riverside Publishing.

- Turbiville, V. P., & Marquis, J. G. (2001). Father participation in early education programs. *Topics in Early Childhood Special Education, 21*, 223–231.
- Urbano, R. C., & Hodapp, R. M. (2007). Divorce in families of children with Down syndrome: A population-based study. *American Journal on Mental Retardation, 112*, 261–274.
- Volkmar, F. R., Cicchetti, D. V., Dykens, E., Sparrow, S. S., Leckman, J. F., & Cohen, D. J. (1988). An evaluation of the Autism Behavior Checklist. *Journal of Autism and Developmental Disorders, 18*, 81–97.
- Walker, R., Luszcz, M. A., Gerstorff, D., & Hoppmann, C. (2011). Subjective well-being dynamics in couples from the Australian Longitudinal Study of Ageing. *Gerontology, 57*, 153–160.