

Transition and Change in Adolescents and Young Adults With Autism: Longitudinal Effects on Maternal Well-Being

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Abstract

We investigated how change in the characteristics of 140 adolescents and young adults with an autism spectrum disorder (ASD) would predict subsequent change in maternal well-being and in the quality of the mother–child relationship. Overall patterns of improvement in maternal well-being and mother–child relationship quality were observed during the study. When the son or daughter had declining behavior problems, were prescribed more psychotropic medications, and exited from high school during the study period, mothers' well-being and perception of relationship quality improved to a greater extent. In addition, improvements in maternal well-being and relationship quality were observed in mothers of daughters, in mothers of individuals with mental retardation as well as ASD, and in mothers of those in better health.

Few disorders pose a greater threat to the psychosocial well-being of family members than autism spectrum disorders—ASD (Seltzer, Krauss, Orsmond, & Vestal, 2001). Obtaining an accurate diagnosis often requires a protracted evaluation period. The behaviors of children with ASD, which are often difficult to manage, include temper tantrums, obsessional interests, self-injury, and disrupted sleep. There is no cure for ASD, and the available interventions entail a tremendous investment of time and energy on the part of family members and especially mothers, who tend to be the primary caregivers. Collectively, these challenges can tax even the strongest family system. In fact, past research is strikingly clear that mothers of young children with ASD exhibit higher levels of stress, mental health symptoms, and marital discord than mothers of children with Down syndrome, fragile X syndrome, cystic fibrosis, behavior disorders, mental retardation of unknown etiology, or mothers of typically developing children (Bouma & Schweitzer, 1990; Donovan, 1988; Dumas, Wolf, Fisman, & Culligan, 1991;

Fisman, Wolf, & Noh, 1989; Holroyd & McArthur, 1976; Kasari & Sigman, 1997; Rodrigue, Morgan, & Geffken, 1990; Wolf, Noh, Fisman, & Speechley, 1989).

In contrast to the abundance of studies focused on the impact of caring for a young child with ASD, very little research has focused on mothers of adolescents and adults. In our ongoing research, we have reported that the characteristics of adolescents and adults with ASD are associated with the well-being of their mothers, but these have been cross-sectional analyses. Specifically, we have found that behavior problems, poor health, and social impairments are related to a poorer quality of the mother–child relationship among families with adolescents and adults with ASD (Orsmond, Seltzer, Greenberg, & Krauss, 2006) and that a poorer quality relationship, in turn, is associated with elevations in maternal depressive symptoms (Greenberg, Seltzer, Krauss, Chou, & Hong, 2004). We also found that, compared with their counterparts whose adolescent or adult child had Down syndrome, mothers of individuals with

ASD have elevated rates of pessimism, a poorer quality mother–child relationship, and elevated levels of depressive symptoms (Abbeduto et al., 2004).

Despite the challenges of caring for an adolescent or adult with ASD, the cross-sectional research indicates that there is considerable heterogeneity in the actual toll that caregiving takes on the well-being of mothers (Orsmond et al., 2006). Whereas for some mothers, caregiving has a “wear and tear” effect, other mothers show a pattern of adaptation and either maintain or show gains in well-being. In the present study we explored these patterns of maternal adaptation by examining the conditions under which parenting an adolescent or young adult with autism was experienced positively or experienced as stressful. Data from typically developing adolescents and their families suggest that transition and change among adolescents has a significant effect on the well-being of their parents (Pruchno, Peters, & Burant, 1996; Silverberg, 1996). We explored whether similar relations were found when the adolescent or young adult had an ASD. For this reason, we chose to focus on the impact of characteristics of the person with ASD during his or her transition from adolescence to young adulthood.

The present analysis also brings a longitudinal lens to the question of how characteristics of adolescents and young adults with ASD affect maternal well-being by examining how these processes unfold over time. There is some evidence that the everyday problems associated with the behavior and physical health problems of a child are sources of chronic strain that take a toll on parental well-being over time (Naerde, Tambs, & Mathiesen, 2002). Parents of children with autism face many of these same chronic strains as parents of typically developing children but in much greater intensity and for a longer duration. Thus, we conceptualized characteristics of adolescents and adults with autism (e.g., behavior problems, health problems) as sources of chronic strain that have the potential to erode parental well-being. Because, by their very nature, the effects of chronic strains associated with the care of a child with autism on parental well-being manifest themselves over time, in the present study we examined how change in the core symptoms of autism, behavior problems, use of psychotropic medications, physical health, and educational status (i.e., whether the individual with ASD transitioned out of the school system) during a 3-year period, predicted

subsequent change in maternal depressive symptoms, anxiety, pessimism, and perceptions of closeness in the mother–child relationship. We examined the lagged effects of characteristics of the person with ASD on maternal well-being in order to establish a temporal ordering of effects, thereby addressing one aspect of the complex interrelationship between parent and child effects. We now turn to a review of the literature concerning the effects of individual characteristics associated with ASD on parental well-being.

Regarding autism symptoms, in our prior research (Shattuck et al., in press), we have found that there is a gradual pattern of improvement in the core symptoms of autism during adolescence and adulthood, although residual levels of impairment remain clinically significant and continue to limit quality of life. These findings have been borne out in other studies (Billstedt, Gillberg, & Gillberg, 2005; Fombonne, 2003; Howlin, Goode, Hutton, & Rutter, 2004; Howlin, Mahwood, & Rutter, 2000; Piven, Harper, Palmer, & Arndt, 1996; Rutter, Greenfeld, & Lockyer, 1967; Seltzer, Shattuck, Abbeduto, & Greenberg, 2004).

Less is known about the impact of the core symptoms of autism on maternal well-being, with studies yet to examine their effects when individuals with ASD reach adolescence and adulthood. Studies of mothers of young children have produced mixed results; a recent study suggests that symptom severity was related to maternal depression (Benson, 2006), but other research did not find support for this association (Tobing & Glenwick, 2002).

Regarding behavior problems, one of the strongest and most consistent findings in the literature on correlates of stress among mothers of young children with ASD is the toll taken by the child’s behavior problems on maternal well-being. Behavior problems have been shown to be associated with more maternal stress and higher levels of maternal anxiety and depression (Hastings, 2003; Hastings & Brown, 2002; Tomanik, Harris, & Hawkins, 2004). Considerably less is known about the effects on mothers of behavior problems when the person with ASD reaches adolescence and adulthood, although the available studies, including our own cross-sectional analyses reviewed earlier, indicate that behavior problems continue to be experienced as highly stressful. A qualitative study of parents of adults with ASD reported that 60% cited behavior problems as the most difficult and tiring aspect of caregiving

(Holmes & Carr, 1991). In a recent study, Blacher and McIntyre (2006) found that a higher level of behavior problems in young adults with ASD was associated with poorer maternal well-being.

Counterbalancing the maternal stress caused by behavior problems in children with ASD is the increasing use of psychotropic medications for this population, particularly among adolescents and young adults (Aman, Lam, & Collier-Crespin, 2003). There is growing evidence supporting the efficacy of these medications in reducing behavior problems (Anderson et al., 1989; Gordon, State, Nelson, Hamburger, & Rapoport, 1993; McDougle et al., 1996; Research Units on Pediatric Psychopharmacology Autism Network, 2002), which in turn should reduce the level of maternal stress. Also, because many of the most troubling behaviors associated with autism have a degree of unpredictability, the use of medications may help “even out” the child’s behavior, making the caregiving challenge feel more predictable and under the mother’s control. In addition, mothers may have more frequent contact with her son or daughter’s prescribing physician or psychiatrist when he or she is taking more medications. Having ongoing contact with professionals may be particularly important for mothers of adolescents and young adults who are transitioning out of the school system and who are therefore losing their entitlement to services.

With regard to health, comorbid physical health problems are common among individuals with ASD, affecting 25% to 50% of this population (Billstedt et al., 2005; Bryson & Smith, 1998). Lifetime rates of epilepsy are high (up to 40%), especially among those with mental retardation, and seizures often develop during adolescence (Billstedt et al., 2005; Fombonne, 2003). Researchers have demonstrated that poor health in children and adults with mental retardation is associated with greater maternal caregiving burden (Haveman, van Berkum, Reijnders, & Heller, 1997; Heller, Hsieh, & Rowitz, 1997). However, with the exception of our prior cross-sectional research (Orsmond et al., 2006), the effects of child health problems on maternal stress and well-being have yet to be explored for mothers of adolescents and adults with ASD.

Another factor that is likely to influence the well-being of mothers of individuals with ASD is having their son or daughter transition out of school. There is considerable variability in the age when individuals with ASD make this transition.

Some higher functioning individuals graduate from high school with their similarly aged peers. Others continue in school until age 22 under provisions of the Individuals With Disabilities Education Act. The “transition years” are often perceived to be extremely stressful for families, as adulthood brings an end to the entitlement to services that school-aged children with ASD have received since diagnosis. Once individuals with ASD leave school and lose entitlement to services, there is an increase in parental responsibility for coordinating and arranging for services (Howlin, Alcock, & Burkin, 2005) and, hence, likely an increase in parental stress.

Other characteristics that have been studied as correlates of maternal stress and well-being include the gender of the individual with ASD and whether he or she has received a diagnosis of mental retardation in addition to ASD, although findings have been inconclusive. Earlier researchers found that females with ASD tend to be more severely impaired and have worse long-term outcomes than do males (Wolf & Goldberg, 1986). More recent investigators, however, have reported no differences in long-term outcomes or maternal stress/distress based on the gender of the child with ASD (Billstedt et al., 2005; Bromley, Hare, Davison, & Emerson, 2004; Lecavalier, Leone, & Wiltz, 2006). Counter to expectations, having a comorbid diagnosis of mental retardation or more severe developmental delays in addition to ASD have not been found to be predictive of increases in maternal stress and distress (Bristol, Gallagher, & Schopler, 1988; Bromley et al., 2004; Koegel et al., 1992; Tobing & Glenwick, 2002) and may even have the opposite effect (Lounds & Seltzer, 2007).

The extant research literature on the family impacts of ASD has suffered from four problems that have limited progress. First, most past studies were based on small samples, limiting statistical power to detect change and predictors of change. Second, the majority of studies have been cross-sectional, making it difficult to determine the antecedents and consequences of change, measured prospectively. Third, in most past studies, researchers have used clinical rather than community samples, so there was the risk of overestimating the severity of symptoms due to referral bias. Fourth, few studies have been focused on adolescence and adulthood of individuals with ASD, so investigation of change in individual characteristics and the impact of change on the family sys-

tem has been restricted to short periods during childhood and early adolescence.

The ongoing study on which the present analysis is based was designed to remedy these limitations by utilizing a large community sample ($n = 406$) followed over a period of 4.5 years. For this analysis, we focused on a subgroup of these families ($n = 140$), namely, those in which the son or daughter with ASD was between 13 and 22 years at the start of the study. Our focus on this age group was motivated by two factors. First, this is a stage of life in which individuals with ASD are likely to be experiencing major changes, particularly the transition out of the school system, increasing physical health problems (Billstedt et al., 2005; Fombonne, 2003), and the increased likelihood that he or she will be prescribed psychotropic medications (Aman et al., 2003). Second, although this is a time of great change, it is an understudied period in the lives of individuals with ASD and their families.

Based on the extant literature, we developed the following hypotheses. On an absolute level, we expected that maternal well-being and mother-child relationship quality would improve over time, on average. Glidden and Schoolcraft (2003), in one of the few longitudinal studies of maternal well-being, found that depressive symptoms abated over a 5-year period among mothers of children with intellectual disabilities. We expected this pattern also to be evident among mothers of adolescents and young adults with ASD, reflecting adaptation to the caregiving role. Regarding changes experienced by the individuals with ASD during the study period, we hypothesized that their core autism symptoms and behavior problems would abate over time, consistent with past research that has shown a gradual process of symptom reduction after childhood (for a review, see Seltzer et al., 2004; Shattuck et al., in press). However, we expected that their physical health would worsen due to increased risk of developing co-morbid problems, including seizures (Billstedt et al., 2005; Bryson & Smith, 1998; Fombonne, 2003) and that they would be prescribed an increasing number of psychotropic medications during the study period because the use of these medications with individuals with ASD has been shown to be increasing (Aman, Lam, & Von Bourgondien, 2005), possibly because of growing evidence demonstrating the efficacy of these medications in treating the symptoms associated with autism (Anderson et al., 1989; Gordon et al.,

1993; McDougle et al., 1996; Research Units on Pediatric Psychopharmacology Autism Network, 2002).

We also expected that there would be substantial individual variation in the degree and direction of change in child characteristics over time and that these changes in the adolescent or young adult with ASD would be predictive of changes in maternal well-being. Specifically, we hypothesized that declining autism symptoms, declining behavior problems, increasing use of psychotropic medications, and improving physical health in the son or daughter with ASD would predict subsequent improvements in maternal well-being and mother-child relationship quality. In contrast, we expected that mothers whose adolescent or young adult child transitioned out of the school system during the study period would experience declines in well-being and mother-child relationship quality due to the loss of formal supports and increased responsibility on the family for care and supervision. In particular, we expected that transitioning out of school would lead to increases in pessimism and strains in the mother-child relationship.

In addition to the constructs of interest, we included two background variables as controls in our analyses: gender of the individual with ASD and whether the son or daughter had a diagnosis of mental retardation in addition to ASD, all measured at Time 1. Although a review of the extant literature concerning families of children with ASD suggests that these variables have been inconsistent with respect to their influence on maternal well-being, both have been shown to be related to well-being in our earlier studies of mothers of adults with mental retardation, and thus we include them here (Lounds & Seltzer, 2007).

Method

Sample and Procedure

In the present analysis we used a subsample ($n = 140$) drawn from our larger longitudinal study of families of adolescents and adults with autism ($N = 406$; Seltzer et al., 2003). The criteria for inclusion in the larger study were that the son or daughter with ASD was age 10 or older (age range = 10 to 52 at the beginning of the study), had received an ASD diagnosis (autistic disorder, Asperger disorder, or pervasive developmental disorder [PDD-NOS]) from an educational or health professional, and had a researcher-administered

Autism Diagnostic Interview-Revised– ADI-R (Lord, Rutter, & Le Couteur, 1994) profile consistent with the diagnosis. Nearly all of the sample members (94.6%) met the ADI-R lifetime criteria for a diagnosis of autistic disorder. Case-by-case review of the other sample members (5.4%) determined that their ADI-R profile was consistent with their ASD (i.e., meeting the cutoffs for reciprocal social interaction and repetitive behaviors for Asperger disorder, and for reciprocal social interaction and either impaired communication or repetitive behaviors for PDD-NOS). Half of the participants lived in Wisconsin ($n = 202$) and half in Massachusetts ($n = 204$). We used identical recruitment and data-collection methods at both sites. Families were recruited through service agencies, schools, and clinics. Four waves of data were collected (every 18 months, spanning a 4.5 year period) from the primary caregiver, who was usually the mother, via self-administered questionnaires and in-home interviews that typically lasted 2 to 3 hours.

We examined a subset of families, namely, those in which the son or daughter with ASD was between the ages of 13 and 22 when the study began. As noted, this age range made it possible to focus in on the “transition” years between adolescence and young adulthood, an understudied period in the lives of individuals with ASD and their families. Of a possible 220 sample members between the ages of 13 and 22, there were 80 in which the family was not included in the present analysis for the following reasons: the mother ($n = 3$) or the person with ASD ($n = 1$) died during the study period, the father was the respondent instead of the mother ($n = 7$), we were unable to locate the family at follow-up ($n = 13$), data were missing on the dependent variables ($n = 24$), or the family declined to continue participation throughout the entire 4.5 year study period ($n = 28$). In 4 of the remaining cases, mothers of individuals with ASD completed separate interviews for 2 children with ASD; we randomly chose 1 child from each family as the target child, resulting in the elimination of 4 cases.

We compared the remaining 140 sample members with the 80 excluded cases using Time 1 data and found a predominant pattern of similarity between the two groups as well as a few differences. The two groups did not differ in mother’s age, marital status, physical health, depressive symptoms, anxiety, or psychological well-being nor in the son or daughter’s age, health,

gender, placement status, autism symptoms, or behavior problems. However, mothers who were not included in this analysis had less education, lower incomes, smaller social support networks, and were more likely to be non-White than those who were included.

The adolescents and young adults with ASD included in this analysis averaged 16.9 years of age ($SD = 2.4$) when the study began (Time 1). Three fourths (75.7%) were male and 83.6% were living with their parents. Roughly 61% of the sample members were prescribed psychotropic medications at Time 1, and 16.4% were reported to have a seizure disorder. Approximately 84% of individuals were verbal, as indicated by daily functional use of at least three-word phrases. Nearly two thirds (62.9%) had mental retardation. Thus, the characteristics of the present sample are consistent with what would be expected based on epidemiological studies of autistic disorder (Bryson & Smith, 1998; Fombonne, 2003).

At Time 1, the age of mothers in this subsample ranged from 32.3 years to 65.7 years of age ($M = 45.9$, $SD = 5.6$). Over one half (56.4%) had attained at least a bachelor’s degree. Mothers were primarily married at Time 1 (86.4%) and 96.4% were Caucasian. Almost three fourths (72.1%) were employed, and the average household income was approximately \$59,000 in 1999–2000.

Measures

Our overall approach was to assess whether change in the characteristics of the son or daughter with ASD over the 3-year period between Time 1 and Time 3 would predict subsequent changes in maternal well-being and mother–child relationship quality during the 1.5-year period between Time 3 and Time 4. As such, the dependent variables in this analysis are the measures of maternal well-being, and the independent variables are the measures of the characteristics of the adolescent or young adult with ASD.

Dependent variables. The dependent variables were maternal depressive symptoms, anxiety, pessimism, and ratings of the quality of the mother–child relationship. Maternal depressive symptoms were measured with the Center for Epidemiological Studies–Depression Scale–CES-D (Radloff, 1977). For each of 20 depressive symptoms on this measure, the respondent is asked to indicate how many days in the past week the symptom was experienced (0 = *never* to 3 = *5 to 7 days*). Scores can range from 0 to 60, with a high score

reflective of a greater intensity of depressive symptoms, $\alpha_s = .92$ at Time 3 and $.91$ at Time 4 for this sample.

Maternal anxiety was measured using the Anxiety subscale of the Profile of Mood States (McNair, Lorr, & Droppleman, 1981). This subscale measures the frequency of nine anxiety symptoms in the last week, such as feeling tense, shaky, or on edge (0 = *not at all* to 4 = *extremely*). Total scores range from 0 to 36, with higher scores indicating more anxiety. The Profile of Mood States has been shown to have strong construct validity in past research (Gibson, 1997), $\alpha_s = .92$ and $.90$ at Times 3 and 4, respectively.

Maternal pessimism about the future of the son or daughter with ASD was measured with 10 items from the Pessimism scale of the Questionnaire on Resources and Stress—QRS-F (Friedrich, Greenberg, & Crnic, 1983). Examples of items include “It bothers me that my son/daughter will always be this way” and “I worry about what will be done with my son/daughter when he/she gets older.” Mothers rated each item as 0 (*false*) or 1 (*true*), with resulting scores ranging from 0 to 10. Higher scores indicate more pessimism about the future of the son or daughter, $\alpha_s = .69$ and $.71$ at Times 3 and 4, respectively.

The mother’s perception of her relationship with her son or daughter was measured by the Positive Affect Index (Bengtson & Schrader, 1982), which measures affective closeness. Ten items were used from this scale, 5 questions addressing the mother’s feelings of positive affect *toward* her son or daughter, and 5 questions representing the mother’s perception of positive affect *from* her son or daughter, each rated on a scale from 1 (*not at all*) to 6 (*extremely*). Both sets of five questions address the dimensions of understanding, trust, fairness, respect, and affection in the relationship, with a higher score indicative of more positive relationship quality, α_s for Time 3 and 4 = $.87$ and $.88$, respectively.

Independent variables. We examined 11 independent variables related to the son or daughter with ASD. The initial status independent variables were measured at Time 1 and included the gender of the person with ASD (0 = male, 1 = female), whether the son or daughter had mental retardation in addition to ASD, and his or her autism symptoms, behavior problems, physical health, and psychotropic medications. In addition, change from Time 1 to Time 3 was examined for autism symptoms, behavior problems, physical

health, psychotropic medications, and whether the person with ASD exited the school system.

Mental retardation status (0 = no mental retardation, 1 = mental retardation) was determined using a variety of sources. Standardized IQ was obtained by administering the Wide Range Intelligence Test (Glutting, Adams, & Sheslow, 2000), and adaptive behavior was assessed using the Vineland Screener (Sparrow, Carter, & Cicchetti, 1993). Individuals with standard scores of 70 or below on both measures were classified as having mental retardation, consistent with diagnostic guidelines (Luckasson et al., 2002). For cases where the individual with ASD scored above 70 on either measure, or for whom either of the measures was missing, a review of records by three psychologists, combined with a clinical consensus procedure, was used to determine mental retardation status.

The ADI-R was used to measure autism symptoms. At Times 1 and 3, we administered the 33 items from the diagnostic algorithm that are applicable to adolescents and adults. Ratings of current functioning were made at each point of data collection by interviewers who had participated in an approved ADI-R training program. Interrater agreement between the interviewers and two supervising psychologists experienced in the diagnosis of autism and in the use of the ADI-R averaged 89%, and the average Kappa was $.81$. Kappa statistics from $.81$ to $.92$ can be interpreted as “very good agreement” (Dawson & Trapp, 2004). Past research has demonstrated the test–retest reliability, diagnostic validity, convergent validity, and specificity and sensitivity of the items used in the ADI-R diagnostic algorithm (Hill et al., 2001; Lord et al., 1997).

We recoded each ADI-R item to reflect either no impairment or some degree of impairment (0 = *no impairment*; 1 = *some degree of impairment*). This coding strategy has been used previously (Fecteau, Mottron, Berthiaume, & Burack, 2003; Seltzer et al., 2003; Shattuck et al., in press) and allowed us to capture the qualitative difference between having and not having a given autism symptom. A summary score indicated the number of symptoms for which the individual with ASD had some degree of impairment. Some ADI-R items are administered only to verbal individuals, and, thus, we had only partial data on these items. Therefore, in order to include nonverbal sample members in the present analysis, we excluded verbal items from the summary score, which thus

measured impairments in nonverbal communication, social reciprocity, and repetitive behaviors/stereotyped interests. Higher scores indicated more autism symptoms. We calculated change in autism symptoms by subtracting the Time 1 score from the Time 3 score.

At Times 1 and 3, mothers completed the Behavior Problems subscale of the Scales of Independent Behaviors—SIB-R (Bruininks, Woodcock, Weatherman, & Hill, 1996). This measure consists of eight behavior problems: behavior that is hurtful to self, unusual or repetitive, withdrawn or inattentive, socially offensive, uncooperative, hurtful to others, disruptive, and destructive of property. The mother was asked whether her son or daughter manifested each of these behavior problems within the last 6 months (1 = presence of behavior, 0 = absence of behavior). A total behavior problems score was generated by summing the number of behavior problems, with higher scores indicating more maladaptive behaviors. We calculated change in behavior problems for each individual by subtracting the Time 1 score from the Time 3 score.

Physical health was measured by maternal ratings of their son's or daughter's current health status (1 = *poor* to 4 = *excellent*). Such ratings have been shown to be valid assessments of morbidity and predictive of mortality across a variety of populations (Idler & Benjamini, 1997), even after controlling for known risk factors such as sociodemographic characteristics, chronic health conditions, and health practices. Change in physical health for each individual was calculated by subtracting the Time 1 rating of health from the Time 3 rating.

At Times 1 and 3, the mother provided information about all of her son or daughter's prescription medications. The present analysis included a count of the number of psychotropic medications (antipsychotics, antidepressants, anti-anxiety, sedative/hypnotics, and antimanic agents) prescribed for the son or daughter at Times 1 and 3. Anticonvulsants were classified as psychotropic medications only if the mother indicated that the son or daughter had a behavioral or mental health diagnosis and that he or she did not have a seizure disorder. Change in number of psychotropic medications was calculated by subtracting the number of prescribed medications at Time 1 from Time 3. Although using a count of medications is a somewhat imprecise measure, we

did not collect information about specific dosages until Time 4.

The final variable indicating change in the son or daughter with ASD was whether he or she was in high school at Time 1 but had left high school by Time 3 (1 = son or daughter left high school between Time 1 and Time 3, 0 = son or daughter did not leave high school between Time 1 and Time 3).

Data Analysis

We first sought to describe the degree of change that occurred during the study period in both the adolescent or young adult with ASD and the mother. To do so, we examined change in the son or daughter's autism symptoms, behavior problems, physical health, psychotropic medications, and educational status during the 3-year period between Time 1 and Time 3 and change in maternal depressive symptoms, anxiety, pessimism, and quality of the mother-child relationship during the 1.5 years between Times 3 and 4. Differences between the initial and later measure of each variable were tested using paired *t* tests.

Next, we examined the heterogeneity of change in both mothers and individuals with ASD. Standardized mean differences (*D*) between the initial and later measurements were calculated for each variable using the initial score standard deviation (*SD*) to standardize, which follows procedures for dependent samples outlined by Kline (2004). Specifically, we were interested in the amount of change that occurred in comparison to a well-defined fixed population, so using the *SD* of the initial score provided us with a more interpretable effect size. *D* scores were classified into three categories: *D* scores within one half of an *SD* above or below the initial score mean (i.e., between $-.5$ and $.5$) were classified as no change; *D* scores that were more than one half of an *SD* above or below the initial score were considered to have increased or decreased. The one half *SD* interval was chosen because it is a well-established guideline for what constitutes a medium effect size in behavioral research (J. Cohen, 1988; Kline, 2004).

Finally, conditional change regression models were used to investigate our research questions regarding the effects of change in the son or daughter's characteristics on subsequent changes in maternal well-being and mother-child relationship quality. Separate regression analyses were performed for each continuous dependent variable

(depressive symptoms, anxiety, pessimism, and mother–child relationship quality). First, the Time 3 level of the dependent variable was entered. By controlling for the Time 3 level of the dependent variable, the estimated effects of the independent variables in the model can be interpreted as predicting change in the dependent variable from Time 3 to Time 4 (P. Cohen, Cohen, West, & Aiken, 2002; Werts & Linn, 1970). It is important to note that this model examines *conditional* change, which means that the amount of change is conditioned on the Time 3 level of that variable. Using a conditional model to examine change is generally considered preferable to using change scores as dependent variables, because the latter are susceptible to unreliability and regression toward the mean (P. Cohen et al., 2002; Taris, 2000; van der Kamp & Bijleveld, 1998).

In the second step of the regression models, we entered Time 1 characteristics of the son or daughter (gender, mental retardation, autism symptoms, behavior problems, physical health, and psychotropic medication count). Finally, in the third step, we entered the change measures (whether the adolescent or young adult left high school between Time 1 and Time 3 and the change in autism symptoms, behavior problems, physical health, and number of psychotropic medications from Time 1 to Time 3) to examine the extent to which these variables predicted Time 3 to Time 4 change in maternal well-being and relationship quality. The Time 1 score was entered for each of the change variables in addition to the change score to control for regression toward the mean effects (P. Cohen et al., 2002; van der Kamp & Bijleveld, 1998). In all of our analyses, we used the .05 level of statistical significance and reported trends with p values of .07 or less (labeled as trends).

We did not include age or co-residence status

in the final analyses. Preliminary analysis showed that neither age nor co-residence status at Time 1 uniquely predicted any outcome variable, even though at a bivariate level age was related to changes in maternal anxiety. The narrow age range (13 to 22) and the dominant pattern of co-residence with parents (84%) likely are why neither of these variables was predictive of change in maternal well-being.

Results

Assessing Change in the Son or Daughter's Characteristics, Maternal Well-Being, and Quality of the Mother–Child Relationship

Change in characteristics of the son or daughter. Changes in autism symptoms, behavior problems, physical health, and number of psychotropic medications from Time 1 to Time 3 were examined using paired t tests. Means, SD s, and test statistics are presented in Table 1. On average, autism symptoms declined significantly during the 3-year period between Time 1 and Time 3, and a trend, $p = .055$, was observed for a decline in behavior problems. Physical health remained stable during this time. The average number of psychotropic medications taken by the son or daughter with ASD significantly increased.

This analysis of mean-level change might mask the heterogeneity of patterns of individual-level change. Table 2, which shows the degree of intra-individual change, presents the percentage of individuals who decreased, stayed the same, or increased by at least .5 SD units for each variable over the study period.

Regarding autism symptoms and behavior problems, there was evidence of a great deal of change. As can be seen in Table 2 and consistent with the mean-level change analysis reported

Table 1. Change From Time 1 to Time 3 in Characteristics of Persons With Autism Spectrum Disorder

Son/daughter measure	Time 1		Time 3		$t(1, 139)$	D
	Mean	SD	Mean	SD		
Autism symptoms	15.50	3.54	14.29	4.07	−4.41**	−.34
Behavior problems	4.92	2.01	4.59	2.22	−1.94†	−.17
Physical health	3.24	.67	3.26	.69	.25	.02
Psychotropic medications	.99	1.07	1.24	1.21	3.08**	.23

† $p = .055$. ** $p < .01$.

Table 2. Percentage of Change in Individuals With Autism Who Decreased, Had no Change, or Increased

Son/daughter measure	Decreased		No change		Increased	
	<i>n</i>	%	<i>n</i>	%	<i>n</i>	%
Autism symptoms	67	47.9	47	33.6	26	18.6
Maladaptive behaviors	65	46.4	28	20.0	47	33.6
Physical health	23	16.4	91	65.0	26	18.6
Psychotropic medications	15	10.7	82	58.6	43	30.7

above, when change was observed in autism symptoms, it tended to favor a decline in symptoms. Almost half of the sample declined, whereas only about 20% increased in autism symptoms. Similarly, nearly half of the sample decreased in the number of behavior problems manifested over the 3-year study period, whereas fewer showed an increase. About a third or less of the sample showed no change in autism symptoms and behavior problems over the 3-year period.

Also consistent with the analysis of mean-level change, we observed overall stability for physical health. Well over one half of individuals with ASD had the same physical health rating over the 3-year period, and approximately equal numbers of sample members were characterized by improving as by worsening health over time. As can be seen in Table 2, stability also characterized the number of prescribed psychotropic medications from Time 1 to Time 3; over half were taking the same number of psychotropic medications over the 3-year period. However, when change in medications was observed, it tended to favor individuals taking a greater number of medications at Time 3 than Time 1 by a factor of 3 to 1.

Regarding change in educational status between Times 1 and 3, 30% of this sample ($n = 42$) left high school during the 3-year study period. At Time 4, 11 of these individuals were continuing in postsecondary education, 13 had com-

petitive or supported employment, 12 received sheltered vocational services, and 6 individuals were without formal day activities.

To summarize, based on both analysis of mean-level and individual-level change, the adolescents and young adults in this sample evidenced a pattern of improvement or stability in functioning with respect to autism symptoms and behavior problems during the study period. Nearly one third were prescribed an increasing number of psychotropic medications during this period, and a similar proportion left high school. Physical health changed the least between Times 1 and 3.

Change in maternal well-being and mother-child relationship quality. We used *t* tests to examine changes in maternal depressive symptoms, anxiety, pessimism, and mother-child relationship quality from Time 3 to Time 4, similar to the methods used to examine changes in the son or daughter with ASD. Means, *SDs*, and test statistics are presented in Table 3. On average, maternal depressive symptoms were stable from Time 3 to Time 4, and the average maternal depressive symptoms score was below the cut-off score for clinical depression (score of < 16 ; Radloff, 1977) at both time points. Maternal anxiety declined significantly over this 1.5-year period, whereas pessimism about the son or daughter's future remained stable over the study period. Mothers perceived the quality of their relationship with the

Table 3. Change From Time 3 to Time 4 in Maternal Well-Being and Quality of the Mother-Child Relationship

Maternal measure	Time 3		Time 4		<i>t</i> (1, 139)	<i>D</i>
	Mean	<i>SD</i>	Mean	<i>SD</i>		
Depressive symptoms	12.58	9.91	12.08	9.11	-.71	-.05
Anxiety	10.80	7.17	9.40	6.21	-2.76**	-.19
Pessimism	7.17	2.15	6.97	2.21	-1.67	-.09
Mother-child relationship quality	43.79	7.62	46.39	7.60	7.33**	.34

** $p < .01$.

son or daughter with ASD to have become significantly better over time.

Next, maternal change was classified in terms of decreasing, staying the same, or increasing levels of these measures to reveal the degree of intra-individual change in maternal well-being (see Table 4). Similar to the mean-level analysis, about half of the sample remained the same in depressive symptoms over the 1.5-year period between Time 3 and Time 4, with the remaining mothers split nearly evenly between increasing and decreasing depressive symptoms during this time. As can be seen in Table 4, anxiety showed a different pattern: more mothers became less anxious than more anxious during the 1.5-year period. Over three fourths of the mothers remained stable in their degree of pessimism over time, but those who changed were almost twice as likely to become less pessimistic than more pessimistic from Time 3 to Time 4. Finally, regarding relationship quality, approximately 5% felt less close to their son or daughter at Time 4 than Time 3, while the rest remained as close or became closer during the 1.5-year study period.

To summarize, there was a great deal of stability in these maternal measures during the 1.5 years between Times 3 and 4. However, when change did occur, the dominant pattern was improvement in maternal well-being—less anxiety and a closer relationship with their son or daughter.

For the depression and anxiety measures, normative data are available that make it possible to benchmark whether mothers of adolescents and young adults with ASD differ from the norm in these measures of psychological distress. Fully 30% of mothers had CES-D scores in the clinical range at both Time 3 and Time 4. The probability of having scores in the clinical range was significantly higher in our sample than what has been observed in a normed group of similar-aged wom-

en (23.5%; Gatz & Hurwicz, 1990), binomial test, $p < .05$. In terms of anxiety, mean scores at Times 3 and 4 (10.8 and 9.4, respectively) were significantly higher than a normed sample of similar-aged women (Nyenhuis, Yamamoto, Luchetta, Terrien, & Parmentier, 1999), mean = 8.2, $ts(139) = 4.28$ and 2.29 , respectively, $ps < .05$. Thus, there was an elevated level of psychological distress in these mothers.

Predicting Change in Maternal Well-Being and Mother–Child Relationship Quality

We next examined whether changes in the son or daughter with ASD between Times 1 and 3 predicted change in maternal well-being and quality of the mother–child relationship between Times 3 and 4. Table 5 presents four hierarchical regression models predicting conditional change (hereafter referred to as *change*) in depressive symptoms, anxiety, pessimism, and mother–child relationship quality. The coefficients in this table were derived from the final regression models that included all three steps (the Time 3 dependent variable score; the Time 1 characteristics of the son or daughter with ASD; and the change in autism symptoms, behavior problems, health, psychotropic medications, and school status between Time 1 and Time 3). The total R^2 represents the amount of variance in the dependent variables accounted for by the final models, whereas the R^2 without the Time 3 dependent variable represents the change in variance explained by the second and third step of the hierarchical regression equations. The R^2 accounted for by the change variables represents the change in variance explained by the third step of the regression equations.

As shown in Table 5, mothers of daughters experienced significantly greater reduction in depressive symptoms during the 1.5 years between Times 3 and 4 than did mothers of sons. As can

Table 4. Percentage of Sample Who Decreased, Had No Change, or Increased in Maternal Well-Being and Quality of the Mother–Child Relationship

Maternal measure	Decreased		No change		Increased	
	<i>n</i>	%	<i>n</i>	%	<i>n</i>	%
Depressive symptoms	36	25.7	71	50.7	33	23.6
Anxiety	38	27.1	79	56.4	23	16.4
Pessimism	21	15.0	107	76.4	12	8.6
Mother–child relationship quality	8	5.7	77	55.0	55	39.3

Table 5. Longitudinal Regression Models: Adolescent and Young Adult Characteristics (Times 1–3) Predicting Maternal Well-Being and Relationship Quality (Times 3–4)

Characteristic	Time 4 dependent variable			
	Depressive symptoms	Anxiety	Pessimism	Relationship quality
Time 3 dependent variable score	.59**	.57**	.76**	.82**
Gender (female = 1)	-.14*	-.26**	-.05	.12**
Mental retardation	-.14†	-.15*	.10	.01
Time 1				
Autism symptoms	-.10	.02	-.06	.03
Behavior problems	.13	.18*	-.09	-.05
Physical health	-.07	-.19**	-.06	.16**
Psychotropic medications	-.01	-.04	.13*	-.02
Time 1 to Time 3 change				
Change in autism symptoms	.01	-.03	.02	-.07
Change in behavior problems	.18*	.16*	.05	-.06
Change in physical health	.02	.00	-.07	.01
Change in psychotropic medications	-.14*	-.23**	.03	.03
Left high school	-.16*	-.08	-.03	.09*
Total R ²	.49**	.56**	.67**	.77**
R ² without Time 3 dependent variable	.10*	.19**	.05	.06**
R ² accounted for by change variables	.05*	.06**	.01	.02

Note. Beta weights were standardized coefficients for the final model that includes all steps.

† $p = .053$. * $p < .05$. ** $p < .01$.

be seen in the table, there was a trend for mothers whose adolescent or young adult had mental retardation in addition to ASD to experience more of a reduction in depressive symptoms than mothers of individuals without mental retardation. Consistent with our hypotheses, a decrease in behavior problems and an increase in psychotropic medications predicted a subsequent reduction in maternal depressive symptoms. Counter to our hypothesis, mothers experienced a reduction in depressive symptoms when their son or daughter exited high school between Times 1 and 3. In total, characteristics of the son or daughter with ASD accounted for 10% of the change in maternal depressive symptoms over the 1.5-year period between Time 3 and Time 4.

Regarding predictors of change in maternal anxiety, mothers showed a greater decline in anxiety when the individual with ASD was a daughter and when he or she had mental retardation in addition to ASD. In addition, maternal anxiety decreased when the son or daughter had better physical health and fewer behavior problems at

Time 1. Regarding change in the characteristics of the son or daughter with ASD, a decrease in behavior problems and an increase in the number of psychotropic medications from Time 1 to Time 3 predicted subsequent declines in maternal anxiety. The son or daughter's characteristics explained fully 19% of the variance in change in anxiety.

A different story emerged for maternal pessimism. None of the measures of change in the son or daughter significantly predicted change in maternal pessimism. Counter to our hypothesis, a higher number of psychotropic medications taken by the adolescent or young adult at Time 1 was associated with increasing levels of maternal pessimism, relative to mothers of individuals taking fewer psychotropic medications. Characteristics of the individual with ASD accounted for 5% of the variance in change in pessimism.

In terms of mother-child relationship quality, mothers perceived the relationship to be improving more between Times 3 and 4 when the adolescent or young adult with ASD was a daughter;

when he or she had better physical health at Time 1; and, counter to our expectation, when he or she had transitioned out of high school during the previous 3 years. Characteristics of the individual with ASD accounted for 6% of the variance in change in relationship quality.

Discussion

Although parenting a child with ASD is a significant source of maternal distress, our findings suggest that mothers adapt to these challenges over the adolescent and early adulthood period. The declines in maternal anxiety and improving mother–child relationship quality mirror findings from the study by Glidden and Schoolcraft (2003), who observed improvements in well-being over time for mothers of young children with developmental disabilities. Our findings suggest that maternal well-being continues to improve when sons and daughters reach adolescence and early adulthood.

It is important to note, however, that even at the end of the study period, after a time of improving well-being, a subgroup of mothers still had significant distress as evidenced by elevated levels of depressive symptoms and anxiety. Almost a quarter of the mothers in our study experienced increased depressive symptoms and 16% reported increased anxiety over the study period. Furthermore, comparison with national norms indicated significantly higher levels of depression and anxiety (Gatz & Hurwicz, 1990; Nyenhuis et al., 1999) among the mothers of adolescents and adults with ASD in our sample. Thus, evidence of improved well-being should not obscure the reality that many of these mothers remain at elevated risk for psychological distress.

We also found patterns of change in the characteristics of adolescents and young adults with ASD. The prevalence of core autism symptoms and behavior problems declined, consistent with a number of other researchers who have found that autism symptoms and behavior problems tend to improve over time, on average (for a review, see Seltzer et al., 2004; Shattuck et al., in press). As expected, declines in behavior problems in the person with ASD predicted subsequent declines in maternal anxiety and depressive symptoms. Because the presence of behavior problems has been found to be one of the most stressful aspects of raising a child with ASD (Blacher & McIntyre, 2006), it is not surprising that their

abatement would predict lower levels of maternal depression and anxiety over time. Contrary to expectations, declining autism symptoms were not related to improvements in maternal well-being. This pattern of findings suggests that it may be behavior problems and not the core symptoms of autism that are associated with elevated distress among mothers of individuals with ASD.

The association between the gender of the son or daughter with ASD and change in well-being is unique to this study. In previous research with mothers of children and adolescents with ASD, researchers concluded that child gender was unrelated to maternal distress (Bromley et al., 2004; Lecavalier et al., 2006). However, we found that mothers of daughters were more likely to decline significantly in depressive symptoms and anxiety and to report increasing closeness in the mother–child relationship than did mothers of sons. These findings may be characteristic of the age range in the present sample compared to previous studies. Although abating, maladaptive behaviors are still very prevalent in this group. For mothers of males, the combination of frequent behavior problems and increasing physical size and strength during adolescence and early adulthood (Gillberg, 1984) may be particularly stressful. It is also possible that the association between gender and maternal well-being may reflect normative patterns of parent–child relationships, which tend to be closer between mothers and daughters than mothers and sons at this life stage (Rossi & Rossi, 1990; Ryff & Seltzer, 1996).

Another characteristic of the son or daughter with ASD that was associated with declining maternal anxiety and depressive symptoms was having a co-morbid diagnosis of mental retardation. This finding stands in contrast to some past researchers (Bristol et al., 1988; Bromley et al., 2004; Tobing & Glenwick, 2002), who have found that the severity of intellectual impairments among children with ASD was unrelated to maternal stress, distress, or adjustment. The relationship observed in this study may again be a product of the developmental stage of the sons and daughters with ASD. Nearly one third of the adolescents and young adults exited the school system during the study period, with the remaining approaching the maximum age to receive benefits through the school system (22 years of age). For individuals with mental retardation, continuity between educational and adult services may be easier to arrange, whereas for intellectually average adults

with ASD, formal supports are more sparse and the family may bear more of the responsibility for arranging for continued services.

In contrast to our predictions, leaving high school was related to subsequent reduction in maternal depression and a closer mother–child relationship. This might reflect the fact that mothers may have anticipated this transition with great trepidation, whereas for the most part the young adults have transitioned successfully. Indeed, one quarter of those who left high school continued in postsecondary education, nearly one third had competitive or supported employment, 29% received sheltered vocational services, and only 6 individuals were without formal day activities. Future researchers should delve more deeply into the process of transition in order to replicate our findings and seek strategies for reducing anticipatory concerns.

The findings associating the physical health and psychotropic medication use of the adolescent or young adults with ASD to maternal well-being and mother–child relationship quality are particularly interesting. To the best of our knowledge, this is the first study in which the relations of either of these characteristics with the well-being of mothers of adolescents and young adults with ASD have been examined. Our findings indicated that mothers felt less anxiety and felt closer to their son or daughter with ASD when the son or daughter was in better health, which parallels previous findings among mothers of adults with mental retardation (Haveman et al., 1997; Heller et al., 1997). Regarding psychotropic medications, increasing the number of medications from Time 1 to Time 3 was associated with a decrease in maternal depressive symptoms and anxiety between Time 3 and Time 4. These relations were significant, even after behavior problems and autism symptoms were controlled. Therefore, in interpreting these results, the influence on the mother of medications prescribed to the son or daughter cannot simply be assumed to be the result of changes in the child's behavior and symptomatology. Rather, one interpretation is that an increase in medications might have a short-term ameliorative effect on maternal depressive symptoms and anxiety, possibly due to mothers' increased frequency of contact with the formal service system, particularly psychiatrists and other physicians who prescribe these medications for their son or daughter. Future research is needed to sort out duration of medication use, changes

in dosages, and the effects of psychotropic medication subtypes on maternal well-being.

This study suffered from three methodological limitations. First, the sample in the larger study was a volunteer sample. Complete data over a 4.5-year period was needed in order to be included in this longitudinal analysis, and the families who did not participate throughout the entire study period were lower in socioeconomic status (SES) than those who did participate (although they were comparable in terms of maternal well-being and characteristics of the person with ASD). Furthermore, most of the sample members were Caucasian. These factors place limits on the generalizability of the results to non-White and lower SES populations. Second, we were not able to examine the effects of residential relocation due to the small number of adolescents and young adults who were living outside of the parental home at the start of the study or moved out during this time period. Future research on the transition from adolescence to adulthood should include investigation of the effects of residential relocation and how these effects are distinct from the educational transitions that were modeled here.

Finally, we did not examine bidirectional effects. In this study, we were primarily interested in the effects of children's characteristics on subsequent changes in maternal well-being. Our research questions addressed one aspect of the complex interrelationship between parent and child effects, and future researchers should examine bidirectional relations in order to begin to address issues of causality. Future research should also be conducted to examine the mediating and moderating mechanisms through which children's characteristics affect maternal well-being.

The study also had several strengths. First, it was based on a community sample, reducing the likelihood of referral bias common in clinic samples. Second, we examined changes into adolescence and young adulthood, life stages that are underrepresented in the literature on autism. Third, in this study we extended our understanding of the "linked lives" of family members and revealed how changes in the lives of adolescents and young adults with autism are associated with changes in their mothers' well-being. Although it is perhaps not surprising that increases in the son or daughter's level of behavior problems were associated with declining maternal well-being, the findings regarding improved maternal well-being after the son or daughter exited high school were

not expected and may reflect the fact that the majority of this sample who exited high school moved on to productive adult activities. These findings, if replicated in future research, are grounds for optimism for families whose son or daughter is in the transition years and point to the benefits to the entire family of successful outcomes for individuals with autism spectrum disorders.

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Received 9/12/06, accepted 2/28/07.

Editor-in-charge: William E. MacLean, Jr.

This paper was prepared with support from the National Institute on Aging (R01 AG08768) and the National Institute of Child Health and Human Development (P30 HD03352, T32 HD07489). We acknowledge the extremely helpful statistical consultation provided by Daniel Bolt. Requests for reprints should be sent to Julie Lounds, Waisman Center, University of Wisconsin-Madison, Madison, WI 53705. E-mail: Lounds@Waisman.wisc.edu