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Change in Autism Symptoms and Maladaptive Behaviors in Adolescents and Adults with an Autism Spectrum Disorder

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Abstract

This study examined change prospectively in autism symptoms and maladaptive behaviors during a 4.5 year period in 241 adolescents and adults with an autism spectrum disorder who were 10–52 years old (mean = 22.0) when the study began. Although many individuals' symptoms remained stable, a greater proportion of the sample experienced declines than increases in their level of autism symptoms and maladaptive behaviors, and there were significant improvements in mean levels of symptoms. Individuals with mental retardation had more autism symptoms and maladaptive behaviors than those without mental retardation, and they improved less over time. Compared to adolescents, older sample members (31 and older) had fewer maladaptive behaviors and experienced more improvement in these behaviors over time.

Keywords

Autism symptoms; Maladaptive behaviors; Lifespan development

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Introduction

Autism spectrum disorders (ASDs; Autistic Disorder, Asperger's Disorder, Pervasive Developmental Disorders— Not Otherwise Specified or PDD-NOS) have pervasive impacts across multiple domains of development and are generally lifelong disabilities for the majority of affected individuals (American Psychiatric Association, 2000). Despite the explicit emphasis on development and lifelong impacts, there has been relatively little research examining how the symptoms of autism change across the life course (see Seltzer, Shattuck, Abbeduto, & Greenberg, 2004, for a review). Furthermore, although maladaptive behaviors are often comorbid with ASDs (American Psychiatric Association, 2000), little is known about the manifestation of maladaptive behaviors in this population (Lecavalier, 2005).

The overall purpose of the present study was to extend our understanding of the prevalence of, and predictors of changes in, autism symptoms and maladaptive behaviors among adolescents and adults with ASD using a large community sample. Most available studies of adolescents and adults with ASD have been based on clinic rather than community samples, so there is the possibility of over-estimating the severity of symptom levels and maladaptive behaviors due to referral bias.

Prevalence and Change in Autism Symptoms in Adolescence and Adulthood

The first goal of the present study was to extend our understanding of the prevalence of, and changes in, the core symptoms diagnostic of autism (qualitative impairment in social interaction, qualitative impairments in communication, and restricted repetitive and stereotyped patterns of behavior, interests, and activities). Little research has explicitly examined the relative prevalence of specific symptoms in ASD, though qualitative impairments in social interaction are generally considered the essential defining feature of ASD (Volkmar & Klin, 2005) and they are more heavily weighted in the diagnosis of Autistic Disorder (American Psychiatric Association, 2000). Seltzer et al. (2004) reviewed the prior literature on changes across the life course for people with Autistic Disorder with respect to the core symptoms of autism. The literature review indicates that from childhood to adulthood, there is a general tendency of modest improvement and symptom decline across studies despite wide variation in designs, measures, and diagnostic criteria.

In our ongoing research, we examined changes since early childhood in autism symptoms among a sample of over 400 adolescents and adults with ASD ages 10 to 53 (Seltzer et al., 2003). In one analysis, we used items from the Autism Diagnostic Interview – Revised (ADI-R; Lord, Rutter, & Le Couteur, 1994) to compare parent ratings of autism symptoms in early childhood to "current" ratings of these symptoms (i.e., at the time of the first point of data collection). Overall, 96.5% met the diagnostic threshold for Autistic Disorder in all three domains based on ratings of childhood symptoms, whereas only 54.8% met all three diagnostic cutoffs based on current ratings, when the sample averaged 21.7 years of age. Several other studies have used a similar design comparing prior versus current ADI-R scores and found a similar overall trend of improvement, although there was variability among studies in the specific pattern of change (Fecteau, Mottron, Berthiaume, & Burack, 2003; McGovern & Sigman, 2005; Piven, Harper, Palmer, & Arndt, 1996). Evidence of this general trend towards modest improvement over the lifespan can also be found in clinical follow-up studies (Howlin, Mawhood, & Rutter, 2000; Mawhood, Howlin, & Rutter, 2000). Thus, age is an important predictor of change in autism symptoms.

Past research has examined three individual characteristics in addition to age that may be important correlates of the level of autism symptoms, and the likelihood of symptom change over time: a comorbid diagnosis of mental retardation, language ability, and gender. Having

mental retardation is frequently related to greater severity of autism symptoms, poorer overall outcome, and a decreased likelihood of improvement (Lord & Bailey, 2002; McGovern & Sigman, 2005; Nordin & Gillberg, 1998; Seltzer et al., 2004; Shea & Mesibov, 2005). Conversely, better language ability has been shown to be associated with both better contemporaneous functioning and a greater likelihood of improvement over time (Howlin, Goode, Hutton, & Rutter, 2004; Howlin et al., 2000; Lord & Bailey, 2002; Nordin & Gillberg, 1998; Seltzer et al., 2004; Shea & Mesibov, 2005). In terms of an association between gender and autism symptoms, findings are mixed. A recent cohort study that included 118 children with autism followed into adolescence reported more significant social impairment among females than males (Tonge & Einfeld, 2003). However, other studies have not found gender differences in language level, unusual verbal behaviors, or the level of repetitive behaviors (Howlin et al., 2004).

Prevalence and Change in Maladaptive Behaviors in Adolescence and Adulthood

The second major goal of the present study was to extend our understanding of symptom prevalence and change to the domain of maladaptive behaviors. Maladaptive behaviors are behaviors that interfere with everyday activities, and include self-injurious behavior, withdrawal, uncooperative behavior, aggression, and destruction of property. Although maladaptive behaviors are often exhibited by people with ASD (Aman, Lam, & Collier-Crespin, 2003; Hollander, Phillips, & Yeh, 2003; Shea et al., 2004) and are noted as an associated condition in the DSM-IV definition of autism (APA, 2000), there has been relatively little research documenting their prevalence and course. A longitudinal study of 967 children with different types of intellectual disabilities reported that children with autism had higher levels of maladaptive behaviors than children with fragile × syndrome, Williams syndrome, Prader-Willi syndrome, Down syndrome, or children with an intellectual disability with no specified etiology (Tonge & Einfeld, 2003). The study also noted a significant decline in maladaptive behaviors over the eight-year study period for most groups, including those with autism. A meta-analysis of research on maladaptive behaviors in children and adults with different types of intellectual disabilities found that aggression, disruptive behavior, and selfinjury were significantly more prevalent among those with ASD than other types of intellectual disabilities (McClintock, Hall, & Oliver, 2003). However, a recent study of 487 school children with pervasive developmental disorders (Lecavalier, 2005) found the least prevalent maladaptive behaviors were self-injury and physical aggression. Clearly, more research is needed to confirm the prevalence of different types of maladaptive behaviors among those with an autism spectrum disorder.

Research Aims and Hypotheses

Based on the research reviewed above, we developed several hypotheses first about predictors of the level of autism symptoms and maladaptive behaviors at the beginning of the study period (Time 1), and second about predictors of change in symptoms and maladaptive behaviors from Time 1 to Time 4 (a 4.5 year period). Given the finding of a general pattern of improvement in autism symptoms (Piven et al., 1996; Seltzer et al., 2003), and one study finding a similar pattern of improvement in maladaptive behaviors (Tonge & Einfeld, 2003), we predicted that the prevalence of autism symptoms and maladaptive behaviors would be lower among older individuals. Given the consistent findings of poorer developmental and behavioral outcomes on a variety of measures among those with comorbid mental retardation (Lord & Bailey, 2002; McGovern & Sigman, 2005), we predicted that those with mental retardation (MR) would have more autism symptoms and maladaptive behaviors than those without MR at Time 1. Better language ability has consistently been associated with a lower level of autism symptoms and maladaptive behaviors (e.g., Howlin et al., 2000; Shea & Mesibov, 2005); thus, we predicted that those with better language ability would have fewer autism symptoms and maladaptive behaviors

than those with poorer language ability at Time 1. Inconclusive past findings with respect to gender differences in autism symptoms and maladaptive behavior preclude hypotheses, but we include gender in our analyses, given the disproportionate prevalence of autism in males and females.

Regarding the change in autism symptoms and maladaptive behaviors, we hypothesized that over the 4.5 year study period between Time 1 and Time 4, autism symptoms and maladaptive behaviors would decline among our sample of adolescents and adults with ASD (Mesibov, Schopler, Schaffer, & Michal, 1989; Seltzer et al., 2003). Regarding predictors of change, based on reviews of prior research (Seltzer et al., 2004), we predicted that older age cohorts would show greater decline in autism symptoms and maladaptive behaviors than younger cohorts. Furthermore, based on past research (e.g., Howlin et al., 2004), we hypothesized that individuals without mental retardation would show greater declines in autism symptoms and maladaptive behaviors between Time 1 and Time 4 than those who have MR. Finally, again based on past research (e.g., Lord & Bailey, 2002; Szatmari, 2000), we hypothesized that those with better language abilities would show greater declines in autism symptoms and maladaptive behaviors between Time 1 and Time 4. Prior findings with respect to an association between gender and the likelihood of change are mixed and do not permit specific predictions.

Methods

Sample

The present investigation used data from an ongoing longitudinal study of 406 adolescents and adults with autism (Seltzer et al., 2003). The criteria for inclusion in the larger study were: being age 10 or older, having received an autism spectrum diagnosis (Autistic Disorder, Asperger Disorder, or PDD-NOS) from a health or educational professional (as reported by parents), and having a research-administered ADI-R (Lord et al., 1994) profile consistent with their diagnosis. Nearly all (94.6%) of the sample members met all ADI-R lifetime criteria and the onset of symptoms prior to 36 months of age that qualifies a child for a diagnosis of Autistic Disorder. Case-by-case review of the other sample members included in the study (5.4%) determined their ADI-R profile was consistent with an autism spectrum diagnosis. Furthermore, since 42.6% of the sample had received multiple diagnoses on the autism spectrum, we refer to our sample in this paper as having an ASD.

Half of the participants lived in Wisconsin (n = 202), and half in Massachusetts (n = 204). Identical recruitment and data collection methods were used at both sites. Families were recruited through service agencies, schools, and clinics. Four waves of data were collected (every 18 months) via in-home interviews with mothers that typically lasted about two to three hours, as well as additional data collected from fathers, siblings, and the individual with ASD at various time points in the study. The present analyses use data from the first and fourth points of data collection (Time 1 and Time 4, respectively), thereby representing a 4.5 year period.

The sample for the present analysis included 241 individuals for whom we had complete data on all variables at both Time 1 and Time 4. Reasons for exclusion from the present analyses included missing data on key variables (n = 66), refusals to continue participation throughout the full 4.5 year study period (n = 66), unable to locate (n = 20), death of parent (n = 7), and death of person with autism (n = 6). We compared the 241 sample members in these analyses with the excluded cases, and found a predominant pattern of similarity between the two groups. There were no differences between the two groups with respect to the child's age, health, gender, placement status, autism symptoms, or maladaptive

behaviors as of Time 1. However, those who were not included in this analysis were more likely to be non-white than those who were included.

The 241 sample members for the present study ranged in age from 10 years to 52 years (mean = 22.0, SD = 9.7) when the study began, with 65.6% (*n* = 158) age 10 through 21; 16.6% (*n* = 40) age 22 through 30; and 17.8% (*n* = 43) age 31 and older. Three-fourths were male (75.5%). The proportion living with parents at entry into the study was 66.4%. The other 33.6% lived in a variety of settings including community residences (16.6%), semi-independent living (5.4%), institutions and hospitals (9.5%), and nursing homes (.4%), whereas a few were living independently (1.7%). Approximately one-fourth (22.5%) had a seizure disorder. About three-fourths (74.7%) were able to spontaneously use three-word phrase speech. Two-thirds had mental retardation (68.5%). Thus, the individual characteristics of the present sample are consistent with what we would expect based on epidemiological surveys of Autistic Disorder. With respect to family demographics, about one-half (53.2%) of mothers had at least a bachelor's degree, the mean household income was $55,000 in 1998–1999, and 95% were Caucasian.

Measures

The dependent variables in the present analyses are based on two measures with well-established reliability and validity that were administered to mothers: the Autism Diagnostic Interview – Revised (ADI-R; Lord et al., 1994) and the Problem Behavior scale of the Scales of Independent Behavior—Revised (SIB-R; Bruininks, Woodcock, Weatherman, & Hill, 1996). The ADI-R is a standardized diagnostic interview administered to a parent or primary caregiver and used to diagnose autism based on a specified subset of 37 items that constitute a validated algorithm (Lord et al., 1994). Our study administered these 37 items at Time 1 to confirm diagnostic status. At each subsequent point of data collection, we administered the 33 items from the core diagnostic algorithm that are applicable to adolescents and adults (4 of the 37 items are specific to childhood). Ratings of current functioning were made at each point of data collection by interviewers who had participated in an approved ADI-R training program. All interviews were tape recorded. Inter-rater 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 coefficient (a measure of agreement that adjusts for chance) 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). Individual ADI-R items are scored on an ordinal scale. A code of 0 signifies the absence of a given symptom, while codes of 1 and 2 indicate impairment characteristic of autism. Some items also used codes of 3, but these are routinely recoded as 2s (Lord et al., 1994).

One of our main aims was to characterize the prevalence of each symptom (i.e., the proportion of the sample having any given symptom). Therefore, we recoded each item to reflect either no impairment (coded 0, corresponding to an ADI-R code of 0) or some degree of impairment (coded 1, corresponding to an ADI-R code of 1, 2, or 3). This coding strategy has been used previously (Fecteau et al., 2003; Seltzer et al., 2003) and allowed us to capture the qualitative difference between having and not having a given autism symptom. Also, this coding strategy provides a conservative estimate of change, as an individual is identified as having improved on any given item only if he or she changed from symptomatic to normal functioning between Time 1 and Time 4, or vice versa. Thus, change at the item level is readily interpretable as the change in the proportion of study participants who have a given symptom.

We created four ADI-R sub-scales using 32 of the 33 items based on consultation with one of the instrument's designers (C. Lord). This grouping of items is based on the clustering of items established by the official ADI-R scoring protocol (Lord et al., 1994), our prior work using this instrument (Seltzer et al., 2003), and recent analysis of the factor structure of the instrument (Lecavalier et al., 2006). The 33rd item was used to determine overall level of language status, which is an independent variable in the analysis described below. Therefore, this item was not included in our dependent measure of change in symptoms. The items included in each scale are described in Table 1. Scale scores were created by summing the number of items on which an individual was symptomatic.

Our study also included the Problem Behavior scale from the larger SIB-R instrument. The Problem Behavior scale measures maladaptive behaviors, grouped in three domains (Bruininks et al., 1996): internalized behaviors (hurtful to self, unusual or repetitive habits, withdrawal or inattentive behavior), externalized behaviors (hurtful to others, destructive to property, disruptive behavior), and asocial behaviors (socially offensive behavior, uncooperative behavior). Each behavior was coded as manifested during the past six months ("1") or not manifested ("0"). Four scales were computed by summing the number of maladaptive behaviors manifested within each domain and also a total score across the three domains (see Table 1).

We used the following independent variables in the regression analyses: dummy variables to represent three age cohorts, mental retardation status, overall level of language, and gender. Using dummy variables for age cohorts allowed us to test for nonlinear age-related differences in the level of symptoms both cross-sectionally and longitudinally. Using Time 1 age, the cohorts were defined as age 10 through 21, age 22 through 30, and age 31 and older. Note that the age 10– 21 category does not appear as an independent variable in the regression tables because it is the reference cohort.

Mental retardation (MR) status was determined using a variety of sources of information, with "1" indicating having MR and "0" indicating not having MR. We use "MR status" rather than IQ scores because we did not have an IQ score for all sample members. However, we were able to use multiple sources of information to reliably assess whether each sample member had MR. We were able to obtain consent from and administer the Wide Range Intelligence Test (a brief measure with strong psychometric properties and both verbal and nonverbal sections; WRIT; Glutting, Adams, & Sheslow, 2000) to 50.2% of the present sample, and we administered the Vineland Screener (Sparrow, Carter, & Cicchetti, 1993) measure of adaptive behavior for all sample members. Those with scores above 75 on either measure were classified as not having mental retardation. For those sample members with scores below 75 on either measure, or for whom the WRIT was missing, a review of available records (historical standardized assessments; parent report of prior diagnoses; clinical and school records) combined with a clinical consensus procedure was used to determine MR status.

The overall level of language variable was created from a single ADI-R item, recoded as "0" indicating nonverbal and "1" indicating verbal (defined as using at least 3-word phrases). We included this independent variable in predicting autism symptoms and maladaptive behaviors because of the prominence of language ability in past research as a factor leading to better life course outcomes. (Note that we did not include this independent variable in the regression models predicting impairments in verbal communication, as all sample members included in these models were verbal.) Gender was coded "0" for males and "1" for females.

Data Analysis

We used four approaches to assess change over time. First, differences between the Time 1 and Time 4 subscale scores were tested using paired *t*-tests. Second, differences across time in the prevalence of individual items were tested using the nonparametric McNemar test, the recommended test to use for dichotomous variables that are dependent (Agresti, 1996).

Third, we computed standardized mean differences (*d*) between Time 1 and Time 4 scores for all ADI-R and SIB-R scales using the Time 1 standard deviation as the standardizer following procedures for dependent samples, as specified in Kline (2004). This statistic indicates the difference between the Time 1 and Time 4 means, expressed in standard deviation units. For example, if $d = .50$ then the mean Time 4 score was one-half a standard deviation above the Time 1 score. Conventional guidelines for interpretation suggest that the magnitude of standardized mean differences can be qualified as small (.20), medium (.50), and large (.80) (Cohen, 1988).

Fourth, to characterize the distribution of change for each scale, sample members were classified into three categories based on the magnitude of individual change relative to the Time 1 standard deviation. Sample members whose Time 4 scores were within half the Time 1 standard deviation above or below the Time 1 score were classified as “no change.” Sample members who changed more than half a standard deviation above or below the Time 1 score were classified as having improved or worsened significantly. The half standard deviation increment has long been considered a guideline for what constitutes a “medium” effect size in behavioral research (Cohen, 1988; Kline, 2004), and is also an increment of change that has been found to represent clinically visible change for a variety of behavioral measures (Norman, Sloan, & Wyrwich, 2003).

In addition to describing change, we sought to identify the factors that would predict the initial level of and change in autism symptoms and maladaptive behaviors. Multiple linear regression analysis was used to examine predictors of ADI-R and SIB-R scales both cross-sectionally (at Time 1) and longitudinally (from Time 1 to Time 4). In both the cross-sectional and longitudinal models, the predictors we examined included age cohort, MR status, language ability, and gender. In addition, in the longitudinal analysis, the Time 1 value of the dependent variable is included as a predictor. In this way, independent variable coefficients represent the degree of association with change in the dependent variable above and beyond what one would expect from the Time 1 value of this variable, thereby overcoming concerns typically associated with directly analyzing change scores (Cohen, Cohen, West, & Aiken, 2002; Finkel, 1995; Taris, 2000). The coefficient for the Time 1 score, also known as the stability coefficient, indicates the extent to which the Time 4 score remained consistent with the Time 1 measure of the dependent variable.

Results

Prevalence and Change in Autism Symptoms

We first examined the prevalence, and change in prevalence, of autism symptoms among sample members (Table 2). On the item level, impairment in friendships was the most prevalent symptom, with 91.7% of sample members at Time 1 not having mutually reciprocal relationships with peers (defined as relationships that are not based exclusively on shared stereotyped interests or on being in an intervention setting together). Impairment in reciprocal conversation ability was the second most prevalent symptom (88.3%) at Time 1, though this behavior is measured only for those who are verbal. The three least prevalent symptoms at the start of the study were use of neologisms or idiosyncratic language (31.1%, verbal subjects only), pronominal reversal (36.2%, verbal subjects only), and use of other’s body to communicate (36.9%).

As shown in Table 2, 19 items improved significantly (as indicated by a significant decrease in the percentage of sample members with any given symptom) from Time 1 to Time 4, and the other 13 ADI-R items did not change. No item worsened significantly.

The level of three of the four ADI-R scales decreased significantly from Time 1 to Time 4, indicating improvement (verbal communication impairments, impairments in social reciprocity, and repetitive behaviors and stereotyped interests), whereas nonverbal communication impairments did not change. None of the ADI-R scales worsened during the study period. The standardized mean change statistics (*d*) indicate that repetitive behaviors and stereotyped interests improved more than one-half a standard deviation, suggesting that changes in this domain were clinically visible during the 4.5 year study period (Norman et al., 2003).

Table 3 shows the percentage of sample members who improved, did not change, or worsened on the four ADI-R scales, relative to their Time 1 standard deviations. The percent who improved ranged from a low of 26.1% for nonverbal communication impairments to a high of 58.5% for repetitive behaviors. The percent who worsened ranged from 14.5% for impairments in social reciprocity to 25.7% for verbal communication impairments. The percent who had no change ranged from 22.9% for verbal communication impairments to 54.4% for nonverbal communication impairments. The proportion who improved was larger than the proportion worsened on all four measures.

Predictors of Autism Symptoms

Next we examined predictors of autism symptoms at Time 1 and of changes in autism symptoms between Time 1 and Time 4. Cross-sectional regression models predicting the level of symptoms at Time 1 are presented in Table 4. Regarding the prediction of impairments in nonverbal communication (e.g., conventional and instrumental gestures, pointing to express interest), being in the age 31 and older cohort (relative to those age 10 through 21) and having a diagnosis of MR were associated with more symptoms at Time 1. Regarding the prediction of impairments in verbal communication (e.g., impairments in reciprocal conversation, echolalia), a diagnosis of MR was associated with more symptoms at Time 1. Regarding the prediction of impairments in social reciprocity (e.g., friendships, offering to share, interest in people), having a diagnosis of MR was associated with more symptoms, whereas having better overall language ability (i.e., being verbal) was associated with fewer symptoms. Finally, with respect to the prediction of repetitive behaviors and stereotyped interests (e.g., compulsions and rituals, hand and finger mannerisms), being in the age 31 and older cohort was associated with fewer repetitive behaviors (relative to those age 10 through 21), whereas having a diagnosis of MR was associated with more repetitive behaviors. Variance explained by these predictors ranged from 4% for the repetitive behaviors model to 19% for the impairments in social reciprocity model.

The results of the longitudinal multiple regression analyses are presented in Table 5. The Time 1 measures of the dependent variables (i.e., the stability coefficients) were all significant, with higher Time 1 scores being associated with higher Time 4 scores. Having mental retardation was a significant predictor in all four models. Those with MR improved less over time than those without MR. The only other significant predictor in any of the four models was overall level of language, which predicted change in the level of impairments in social reciprocity. Verbal sample members showed greater improvement in social impairments than those who were nonverbal. In three of the four models, a significant proportion of variance was attributable to the independent variables, net of the Time 1 score, ranging from 6% (for both impairments in verbal communication and repetitive behaviors) to 8% (impairments in social reciprocity), with a trend level of significance for the 3% of variance explained in the impairments in nonverbal communication model.

Prevalence and Change In Maladaptive Behaviors

We next turned to an examination of the prevalence, and changes in the prevalence, of maladaptive behaviors in our sample members. The most prevalent maladaptive behaviors at Time 1 (see Table 6) were unusual or repetitive habits (87.6%) and withdrawal or inattentive behavior (78.8%). The least prevalent were being destructive to property (38.2%) and being hurtful to others (44.4%). The mean total count of maladaptive behaviors at Time 1 was 4.7 (out of a possible maximum of 8).

The proportion of individuals who had maladaptive behaviors decreased significantly over time for seven of the eight behaviors (unusual or repetitive habits, withdrawal or inattentive behavior, hurtful to self, hurtful to others, destructive to property, socially offensive behaviors, and uncooperative behavior), thereby indicating improvement, on average. There was a trend towards improvement for disruptive behaviors.

All four SIB-R scales decreased significantly over time, indicating an overall decline in maladaptive behaviors. The standardized mean change statistics ranged from −.22 (externalized) to −.59 (internalized). The internalized behavior scale and the maladaptive total score changed by approximately half a standard deviation, suggesting the amount of improvement was clinically visible.

Table 7 shows the percentage of sample members who improved, did not change, or got worse (relative to the Time 1 standard deviation) on the SIB-R scales. The proportion of individuals who improved ranged from 30.3% (asocial) to 39.4% (internalized). The proportion with no change ranged from 49.4% (internalized) to 57.7% (both asocial and total). The proportion who worsened ranged from 7.5% (total) to 17.4% (externalized).

Predictors of Maladaptive Behaviors

Lastly, we examined predictors of the level of maladaptive behaviors at Time 1 and changes in maladaptive behaviors between Time 1 and Time 4. Crosssectional predictors of the level of maladaptive behaviors at Time 1 are reported in Table 8. There were no significant predictors of the Time 1 level of internalized behavior, whereas the pattern of significant predictors was the same for the externalized, asocial, and total maladaptive behaviors. Sample members in the oldest cohort had significantly fewer maladaptive behaviors (relative to those age 10 through 21), whereas those who had a diagnosis of MR had more maladaptive behaviors. There was a trend for verbal individuals to have more asocial maladaptive behaviors. Variance explained in the models ranged from 3% (internalized) to 8% (externalized).

Predictors of changes between Time 1 and Time 4 in maladaptive behaviors are reported in Table 9. The Time 1 measures of the dependent variables were all significantly associated with their corresponding Time 4 scores. The pattern of significant predictors was the same for all four models, with two variables predicting change: age cohort and MR status. Being in the oldest age cohort was associated with significantly greater decline during the study in the level of maladaptive behaviors (relative to those age 10 through 21). Those who had MR improved less (i.e., had a significantly smaller decrease in the level of maladaptive behaviors over time) than those without MR. The change in proportion of variance explained attributable to adding the independent variables to the Time 1 score was significant in three of the four models (internalized, asocial, total) and ranged from .05 (asocial) to .07 (total). The change in proportion of variance explained in the externalized maladaptive behaviors model (3%) almost reached significance with a *p*-value of .051.

Discussion

This study yielded several important findings regarding the prevalence of, and changes in, autism symptoms in adolescents and adults with ASD. We found that, at these stages of life, there is a greater prevalence of impairments in nonverbal communication and social reciprocity than in verbal communication or repetitive behaviors and stereotyped interests, as shown on an item-level in Table 2. This pattern of findings lends support to the idea that impaired social reciprocity is both more central and more persistent than the other core symptoms of the autism behavioral phenotype (Mesibov et al., 1989; Volkmar & Klin, 2005).

Our findings also shed light on the nature of change, prospectively measured, in the core symptoms of autism. As in most prior research (reviewed in Seltzer et al., 2004), we found evidence of both improvement and stability. Whereas the overall trend across measures was one of improvement, approximately half of the sample remained stable between Time 1 and Time 4 with respect to nonverbal communication impairments, impairments in social reciprocity, and all measures of maladaptive behaviors. Although worsening of symptoms was observed in only a small minority of sample members, identification of factors differentiating those whose symptoms and maladaptive behaviors worsened is warranted in future research.

Although there was heterogeneity in the distribution of change, every scale with significant mean change was in the direction of improvement. There was significant improvement for 19 of the 32 autism symptoms and seven of the eight maladaptive behaviors. Improvement was especially notable in the domain of repetitive behaviors and interests, with all items in this domain improving significantly during the study period. It is noteworthy that repetitive behaviors, which in early childhood tend to be a very prevalent feature of the behavioral phenotype of autism, were currently among the least prevalent while simultaneously being among the most likely to improve.

At first glance, this last finding might seem contrary to the finding by Piven et al. (1996) that repetitive behaviors were less likely to improve when compared to social and communicative measures. However, Piven et al. were examining the likelihood of change between early childhood and adulthood. In contrast, our analyses examined change during a 4.5-year period *within* adolescence and adulthood. The likelihood of improvement of maladaptive behaviors was greater among those who were age 31 and older at Time 1 as compared to those aged 10 through 21. Thus, it may be that the likelihood that certain sets of symptoms will improve may vary over the life course, with some symptoms being more likely to improve during childhood and others being more likely to improve during later developmental periods. This finding suggests a long-term pattern of phenotypic symptom decline in repetitive behaviors during adolescence and adulthood. It also is possible that this pattern of improvement reflects the cumulative effects of interventions and medications. Overall, our findings underscore the importance of using a life course perspective when considering questions of change and development among people with an autism spectrum disorder.

We predicted that the older cohorts would be more likely to improve between Time 1 and Time 4 than the adolescent cohort. This prediction was supported for all four maladaptive behavior scales, but not for autism symptoms. Thus, reduction in maladaptive behavior continues well into and may even accelerate in midlife for individuals with ASD, whereas autism symptoms appear to improve at a steady rate across different age cohorts. Whether or not a sample member had a diagnosis of mental retardation was the most robust predictor of change in both autism symptoms and maladaptive behaviors from Time 1 to Time 4, similar

to what has been found in earlier stages of life. Those with mental retardation improved less than those without this comorbid diagnosis. Although in childhood, having better verbal skills is predictive of a good prognosis, in adolescence and adulthood it was only predictive of improvement in social reciprocity but none of the other outcomes. Males and females appeared to change to the same degree.

One limitation of this study was the relatively short period of time examined (4.5 years). It is possible that more gradual, but nonetheless clinically important, patterns of change could be captured by a longer study period. Another potential limitation was our reliance on parent-report data, which is generally seen as less desirable than direct observational measures. However, the ADI-R is not a self-administered instrument but rather is scored by trained interviewers based on parent responses to structured probes. It is currently recognized as the "gold standard" measure for evaluating autism symptoms (Filipek et al., 1999), and prior research has established strong agreement between ADI-R ratings based on parent report and expert ratings based on direct clinical assessment (Lord et al., 1994, 1997). Likewise, the SIB-R has been extensively validated in large samples and correspondence between parent and clinician ratings is strong (Bruininks et al., 1996). It is also possible that the repeated interviews alone would lead parents to report improvement. However, we do not think this is the case. Items showed a heterogeneous pattern of change, with some items improving significantly (to varying degrees) and others remaining stable. If change was an artifact of self-report methods, we would expect more uniformity than was observed.

The study also had several strengths. First, it was based on a large community sample, thereby improving power while reducing the likelihood of referral bias common in clinic samples. Second, the study examined changes into adolescence and adulthood, two life stages that are underrepresented in the literature on autism. Third, the study extends our understanding of maladaptive behaviors in this population, which has received comparatively less attention in past research.

The results of this study also have important implications for intervention. Treatment models are much less widely available for adolescents and adults than for young children with autism. Yet, the present analyses as well as prior research indicate that symptoms and behaviors can improve across the life course. Over time, patterns of improvement represent the product of interactions among the ASD genotype, the ASD behavioral phenotype, and the environment, including the family environment, treatments, and interventions. Future research should explore the effects of interventions tailored to adolescents and adults with ASD and their families.

Finally, the tendency towards improvement among individuals with ASD should not be construed as a justification for scaling back the availability of interventions and services under the false assumption that this population's impairments will spontaneously remit to a point where assistance and supervision is not required. To the contrary, despite the overall tendency towards improvement, the majority of individuals in our sample remain significantly impaired and dependent on the assistance of others for daily living. Therefore, our findings should give greater impetus to extending interventions and services for this population across the life course.

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Table 1

Composition of scales

Instrument	Constituent items
Variable name	
ADI-R	
Nonverbal communication impairments (all subjects)	Pointing to express interest, nodding head (to indicate yes), head shaking (to indicate no), conventional and instrumental gestures
Verbal communication impairments (verbal subjects)	Social vocalization, reciprocal conversation, stereotyped utterances and delayed echolalia, inappropriate questions or statements, pronominal reversal, neologisms, verbal rituals
Impairments in social reciprocity	Direct gaze, social smiling, range of facial expression used to communicate, interest in people, response to approaches of others, friendships, showing and directing attention, offering to share, seeking to share enjoyment with others, use of other's body to communicate, offering comfort, quality of social overtures, inappropriate facial expression, appropriateness of social responses
Repetitive behaviors and stereotyped interests	Unusual preoccupations, circumscribed interests, compulsions and rituals, hand and finger mannerisms, other complex mannerisms or stereotyped body movements, repetitive use of objects or interest in parts, unusual sensory interests
SIB-R	
Internalized	Withdrawal or inattentive behavior, unusual or repetitive habits, hurtful to self
Externalized	Disruptive, hurtful to others, destructive to property
Asocial	Socially offensive behavior, uncooperative behavior
Maladaptive total	Combination of all 8 behaviors listed above

Table 2

Prevalence of ADI-R autism symptoms, Time 1 versus Time 4

Scale name	Mean scale scores (SD), percent with the given symptom		Change[a]	*t*, *d* (only for scales)
ADI-R item	**Time 1**	**Time 4**		
Nonverbal communication impairments (all subjects, *N* = 241)	3.08 (1.15)	2.96 (1.27)	−.12	*t* = 1.58 *d* = −.10
Pointing to express interest	83.0%	76.8%	−6.2%*	
Nodding	66.4%	66.0%	−.4%	
Head shaking	72.2%	71.8%	−.4%	
Conventional & instrumental gestures	86.3%	81.7%	−4.6%	
Verbal communication impairments (verbal subjects only, *N* = 179)	4.17 (1.63)	3.68 (1.62)	−.49	*t* = 4.31*** *d* = −.30
Social vocalization	76.7%	68.7%	−8.0%*	
Reciprocal conversation	88.3%	78.0%	−10.3%**	
Stereotyped utterances and delayed echolalia	73.9%	73.5%	−.4%	
Inappropriate questions/statements	69.7%	58.8%	−10.9%*	
Pronominal reversal	36.2%	34.6%	−1.6%	
Neologisms	31.1%	18.7%	−12.4%**	
Verbal rituals	45.3%	36.1%	−9.2%†	
Impairments in social reciprocity (*N* = 241)	10.54 (2.74)	9.81 (3.43)	−.73	*t* = 4.38*** *d* = −.26
Direct gaze	77.6%	67.2%	−10.4%**	
Social smiling	77.2%	64.3%	−12.9%***	
Range of facial expression used to communicate	83.0%	75.1%	−7.9%*	
Interest in people	76.3%	78.4%	2.0%	
Response to approaches of others	80.5%	79.3%	−1.2%	
Friendships	91.7%	84.2%	−7.5%**	
Showing and directing attention	73.0%	71.4%	−1.6%	
Offering to share	86.7%	85.1%	−1.6%	
Seeking to share enjoyment with others	72.2%	63.1%	−9.1%**	
Use of other's body to communicate	36.9%	29.9%	−6.9%*	
Offering comfort	68.5%	68.0%	−.4%	
Quality of social overtures	63.1%	59.8%	−3.3%	
Inappropriate facial expression	82.0%	72.6%	−9.4%**	
Appropriateness of social responses	85.5%	83.0%	−2.5%	
Repetitive Behaviors and Stereotyped Interests (*N* = 241)	3.88 (1.58)	2.98 (1.57)	−.90	*t* = 8.30*** *d* = −.57
Unusual preoccupations	46.5%	30.7%	−15.8%***	
Circumscribed interests	68.5%	50.2%	−18.3%***	
Compulsions and rituals	75.1%	62.2%	−12.9%***	

Scale name	Mean scale scores (SD), percent with the given symptom		Change[a]	*t, d* (only for scales)
ADI-R item	**Time 1**	**Time 4**		
Hand and finger mannerisms	51.0%	42.7%	−8.3%*	
Other complex mannerisms, body movements	39.0%	27.8%	−11.2%**	
Repetitive use of objects or interest in parts	42.7%	34.0%	−8.7%*	
Unusual sensory interests	65.6%	49.8%	−15.8%***	

* $p < .05$,

** $p < .01$,

*** $p < .001$,

† $p = .073$

[a] Differences in proportions tested using the McNemar test for dependent samples

Table 3

Improvement, worsening, and no change in ADI-R measures between Times 1 and 4[a]

Measure	Improved[b]		No change[c]		Worsened[d]	
	n	%	*n*	%	*n*	%
Nonverbal communication impairments (all subjects, *N* = 241)	63	26.1%	131	54.4%	47	19.5%
Verbal communication impairments (verbal subjects, *N* = 179)	92	51.4%	41	22.9%	46	25.7%
Impairments in social reciprocity (*N* = 241)	77	32.0%	129	53.5%	35	14.5%
Repetitive behaviors and stereotyped interests (*N* = 241)	141	58.5%	58	24.1%	42	17.4%

[a] *Note*: ADI-R scales are all scored such that a higher score indicates more symptoms, thus a decrease over time indicates a decline in symptoms

[b] Time 4 score was lower than Time1 by more than 1/2 SD of the Time 1 mean

[c] Time 4 score was within ±1/2 SD of the Time 1 mean

[d] Time 4 score was higher than Time 1 by more than 1/2 SD of the Time 1 mean

Table 4

Regression analyses predicting level of ADI-R autism symptoms at Time 1

Model components	ADI-R measures			
	Nonverbal communication impairments (all subjects)	Verbal communication impairments (verbal subjects)	Impairments in social reciprocity	Repetitive behaviors and stereotyped interests
Age 22–30[a]	.31	−.05	.10	−.22
Age 31 and older[a]	.50**	.01	.65	−.58*
MR status[b]	.55**	1.06***	1.48***	.48*
Overall level of language[c]	−.16	Not in model	−1.48***	.09
Gender[d]	−.14	.04	−.48	−.25
F	5.99***	4.99**	10.86***	1.72
R^2	.11	.10	.19	.04

* $p < .05$,

** $p < .01$,

*** $p < .001$; Unstandardized coefficients

[a] Dummy indicators for Time 1 age, reference category is the age range 10 through 21

[b] 1 = has mental retardation, 0 = does not have mental retardation

[c] 1 = routinely uses at least 3-word phrase speech, 0 = language level less than 3-word phrase speech

[d] 1 = female, 0 = male

Table 5

Regression analyses predicting changes in ADI-R autism symptoms between Time 1 and Time 4

Model components	ADI-R measures			
	Nonverbal communication impairments (all subjects)	Verbal communication impairments (verbal subjects)	Impairments in social reciprocity	Repetitive behaviors and stereotyped interests
Time 1 score	.55***	.48***	.71***	.39***
Age 22–30[a]	.27	−.30	−.01	−.04
Age 31 and older[a]	.22	.00	−.14	.03
MR status[b]	.35*	.84***	1.71***	.71**
Overall level of language[c]	−.01	Not in model	−.83*	−.18
Gender[d]	.15	−.06	.50	.05
F	20.03***	20.62***	44.74***	11.63***
R^2	.34	.37	.53	.23
Change[e] in R^2	.03†	.06**	.08***	.06**

*$p < .05$,

**$p < .01$,

***$p < .001$,

†$p = .057$; Unstandardized coefficients

[a]Dummy indicators for Time 1 age, reference category is the age range 10 through 21

[b]1 = has mental retardation, 0 = does not have mental retardation

[c]1 = routinely uses at least 3-word phrase speech, 0 = language level less than 3-word phrase speech

[d]1 = female, 0 = male

[e]Change attributable to adding the age, MR status, verbal status, and gender predictors to the T1 score

Table 6

Prevalence of SIB-R maladaptive behaviors, Time 1 versus Time 4

Problem	Mean composite scores (SD), percent with any behaviors		Change[a]	*t, d*
	Time 1	Time 4		
Internalized behaviors (*N* = 241)	2.13 (.79)	1.66 (.97)	−.47	$t = 7.44^{***}$ $d = -.59$
Unusual or repetitive habits	87.6%	67.6%	−20.0%***	
Withdrawal or inattentive behavior	78.8%	62.2%	−16.6%***	
Hurtful to self	46.1%	36.5%	−9.6%**	
Externalized behaviors (*N* = 241)	1.33 (1.10)	1.09 (1.09)	−.24	$t = 3.55^{***}$ $d = -.22$
Disruptive behavior	50.2%	43.6%	−6.6%†	
Hurtful to others	44.4%	34.9%	−9.5%**	
Destructive to property	38.2%	30.3%	−7.9%*	
Asocial behaviors (*N* = 241)	1.25 (.75)	.99 (.80)	−.26	$t = 4.98^{***}$ $d = -.34$
Socially offensive behavior	69.7%	53.9%	−15.8%***	
Uncooperative behavior	54.8%	45.2%	−9.6%*	
Maladaptive total (*N* = 241)	4.70 (2.02)	3.74 (2.17)	−.96	$t = 7.38^{***}$ $d = -.47$

*$p < .05$,

**$p < .01$,

***$p < .001$,

†$p = .077$

[a]Differences in proportions tested using the McNemar test for dependent samples

Table 7

Improvement, worsening, and no change in SIB-R maladaptive behaviors measures between Times 1 and 4[a]

Measure	Improved[b]		No change[c]		Worsened[d]	
	n	%	*n*	%	*n*	%
Internalized (*N* = 241)	95	39.4%	119	49.4%	27	11.2%
Externalized (*N* = 241)	74	30.7%	125	51.9%	42	17.4%
Asocial (*N* = 241)	73	30.3%	139	57.7%	29	12.0%
Maladaptive total (*N* = 241)	84	34.9%	139	57.7%	18	7.5%

[a] *Note*: SIB-R scales are all scored such that a higher score indicates more maladaptive behaviors, thus a decrease over time indicates a decline in maladaptive behaviors

[b] Time 4 score was lower than Time1 by more than 1/2 SD of the Time 1 mean

[c] Time 4 score was within ±1/2 SD of the Time 1 mean

[d] Time 4 score was higher than Time 1 by more than ±1/2 SD of the Time 1 mean

Table 8

Regression analyses predicting level of SIB-R maladaptive behaviors at Time 1

Model components	SIB-R measures			
	Internalized	Externalized	Asocial	Maladaptive total
Age 22–30[a]	.18	−.07	−.22	−.10
Age 31 and older[a]	.03	−.69***	−.43**	−1.09**
MR status[b]	.13	.39*	.24*	.77*
Overall level of language[c]	−.13	.20	.23†	.29
Gender[d]	.01	.27	.04	.31
F	1.29	4.09**	3.32**	3.17**
R^2	.03	.08	.07	.06

*$p < .05$,

**$p < .01$,

***$p < .001$,

†$p = .071$; Unstandardized coefficients

[a]Dummy indicators for Time 1 age, reference category is the age range 10 through 21

[b]1 = has mental retardation, 0 = does not have mental retardation

[c]1 = routinely uses at least 3-word phrase speech, 0 = language level less than 3-word phrase speech

[d]1 = female, 0 = male

Table 9

Regression analyses predicting changes in SIB-R maladaptive behaviors between Time 1 and Time 4

Model components	SIB-R measures			
	Internalized	Externalized	Asocial	Maladaptive total
Time 1 score	.49***	.48***	.46***	.52***
Age 22–30[a]	−.16	−.04	.03	−.16
Age 31 and older[a]	−.39*	−.37*	−.40**	−1.12***
MR status[b]	.42**	.38**	.25*	1.01***
Overall level of language[c]	−.09	.12	−.01	.01
Gender[d]	.12	.11	.02	.25
F	12.16***	18.40***	15.48***	22.37***
R^2	.24	.32	.28	.36
Change[e] in R^2	.06**	.03†	.05**	.07***

*$p < .05$,

**$p < .01$,

***$p < .001$,

†$p = .051$; Unstandardized coefficients

[a]Dummy indicators for Time 1 age, reference category is the age range 10 through 21

[b]1 = has mental retardation, 0 = does not have mental retardation

[c]1 = routinely uses at least 3-word phrase speech, 0 = language level less than 3-word phrase speech

[d]1 = female, 0 = male

[e]Change attributable to adding the age, MR status, verbal status, and gender predictors to the T1 score