Social Participation and Its Relation to Internalizing Symptoms Among Youth With Autism Spectrum Disorder as They Transition From High School

Julie Lounds Taylor, Ryan E. Adams, and Somer L. Bishop

In this study, we examined how unstructured (e.g., spending time with friends or co-workers) and structured (e.g., attending social events at a place of workshop, sports teams) social participation changed from before to after high school for youth with autism spectrum disorders (ASD), as well as the longitudinal and concurrent relations between social participation and internalizing symptoms. Participants included 36 families of youth with ASD who were all in their last year of high school at the first time point of data collection, and who were out of high school for an average of 9 months at the second time point. Social participation and internalizing symptoms were determined using parental report. There was no average change in the amount of unstructured social participation after high school exit, although substantial individual variability was observed. Participation in structured social activities significantly declined after high school exit. Youth who had more structured social participation while in high school were significantly more likely to have gains in their unstructured social participation after high school exit. Turning to relationships between internalizing and social activities, more internalizing symptoms while youth with ASD were in high school significantly predicted increasing social isolation after high school exit (both in terms of structured and unstructured activities). Results point to the likely need for additional supports during the transition to adulthood for youth with ASD who have internalizing problems. ***Autism Res*** *2016, 0: 000–000.* © 2016 International Society for Autism Research, Wiley Periodicals, Inc.

Keywords: autism spectrum disorder; transition to adulthood; social participation; internalizing

Introduction

The transition to adulthood is a time of tremendous risk for youth with autism spectrum disorders (ASD). At high school exit, these youth lose entitlement to federally-mandated services, reducing access to many of the formal supports available to them while in high school [Shattuck, Wagner, Narendorf, Sterzing, & Hensley, 2011; Taylor, 2009]. At least partially as a result, disengagement from paid employment and post-secondary education is common [Shattuck et al., 2012; Taylor & Seltzer, 2011]. It is likely that all of these changes in supports and institutional structure also result in increasing social isolation for youth with ASD after high school, yet little is known about how social participation changes during this time. Given the significant implications of social isolation for mental health among typically-developing youth [e.g., Bagwell, Newcomb, & Bukowski, 1998; Bukowski, Laursen, & Hoza, 2010; Danese et al., 2009; Hartup, 1989; Matthews et al., 2016; Sakyi, Surkan, Fombonne, Chollet, & Melchior, 2015], it is imperative to understand how social activities change after youth with ASD leave high school, and how that change is related to their mental health (particularly internalizing symptoms).

It is well-established that individuals with ASD commonly exhibit difficulties in developing friendships and other intimate relationships [Bauminger & Kasari, 2000; Billstedt, Gillberg, & Gillberg, 2007; Chamberlain, Kasari, & Rotheram-Fuller, 2007; Howlin, Goode, Hutton, & Rutter, 2004; Locke, Ishijima, Kasari, & London, 2010; Lyons, Cappadocia, & Weiss, 2011; Petrina, Carter, & Stephenson, 2014]. However, relatively little is known about the extent to which they participate in more structured, group-based social activities in the community – especially during the transition years – and almost nothing is known about how either type of social participation might change as youth with ASD

From the Department of Pediatrics and Vanderbilt Kennedy Center, Vanderbilt University Medical Center, Nashville Tennessee (J.L.T.,); Department of Pediatrics, Cincinnati Children's Hospital Medical Center, Cincinnati, Ohio (R.E.A.,); Department of Psychiatry, University of California San Francisco, San Francisco, California (S.L.B.)

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Address for correspondence and reprints: Julie Lounds Taylor, Vanderbilt Kennedy Center, PMB 40 – 230 Appleton Place, Nashville, TN 37203. E-mail: julie.l.taylor@vanderbilt.edu

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exit high school. Understanding structured social participation as distinct from more unstructured types of social activities (such as friendships or spending time with co-workers) is important; greater levels of structured, group-based social participation likely increase the chances that youth will develop friendships [Laugeson, Frankel, Gantman, Dillon, & Mogil, 2012; Laugeson, Gantman, Kapp, Orenski, & Ellingsen, 2015]. Further, for those youth without close friendships, participating in more structured social activities in the community may serve as an important outlet as well as provide venues to practice social behavior.

The few studies that have focused on social participation during the transition years for youth with ASD consistently find low rates. Using similar questions as in this study, Orsmond and colleagues [Orsmond, Krauss, & Seltzer, 2004] found that about 60% of parents reported that their adolescent and adult offspring with ASD socialized with friends or neighbors a few times a year or less. Only about 25% socialized with school or work friends once a month or more. In this sample of youth and adults ages 10–47, age was not associated with the amount of social participation. In another sample of transition-aged youth with ASD (ages 19–31), Eaves and Ho [2008] reported that just over 30% spent time with other people around a hobby or special interest, and less than 30% attended a social or church group regularly.

Other studies have used the National Longitudinal Transition Study-2 (NLTS-2) – a nationally-representative sample of youth receiving special education services – to examine social participation during the transition years. Shattuck, Orsmond and colleagues, for example, found that over 40% of high school aged youth with ASD never spent time with friends [Shattuck, Orsmond, Wagner, & Cooper, 2011]; this percentage was similar for youth with ASD who were out of high school [Orsmond, Shattuck, Cooper, Sterzing, & Anderson, 2013], and was much higher than for non-ASD youth with other disabilities. Around 45% of high school-aged youth with ASD participated in some sort of non-school structured activity in the previous 12 months (e.g., church youth group, sports team, scouting); youth with ASD were less likely to participate in these activities than youth with speech-language impairments or learning disabilities.

A recent study used the NLTS-2 to examine *changes* in unstructured (i.e., spending time with friends, invited to social activities) social activities and community participation for youth with ASD from before to after high school exit [Myers, Davis, Stobbe, & Bjornson, 2015]. There was no significant change in the percentage of youth who had any contact with friends during the previous 12 months. However, after leaving high school, significantly fewer youth were participating in activities in the community. This decline is particularly concerning because, as noted by Shattuck and colleagues [Shattuck, Orsmond et al., 2011], rates of community participation were already lower than many other disability groups while youth with ASD were in high school. Although examining change over time (instead of comparing cohorts of different ages) is a significant strength of the Myers study, outcome variables only examined whether any social or community participation had occurred in the previous 12 months, and thus differences in amounts of participation (e.g., contact with friends declining from more than once a week to 1–2 times a year) could not be examined. The current study extends this work in three important ways: by looking at changes in the amount of social participation from before to after high school exit; by examining the interplay between types of social activities (e.g., spending unstructured time with friends/coworkers vs. more structured group activities in the community); and by examining how social participation might influence or be influenced by internalizing symptoms.

Social isolation and friendships are consistently linked to internalizing symptoms (particularly mood symptoms) in typically developing children and adults [e.g., Bagwell et al., 1998; Bukowski et al., 2010; Danese et al., 2009; Hartup, 1989; Matthews et al., 2016; Sakyi et al., 2015], but this link is not well-understood in ASD samples. A handful of studies have examined the mental health implications of peer victimization among children and adolescents with ASD [Adams, Fredstrom, Duncan, Holleb, & Bishop, 2014; Cappadocia, Weiss, & Pepler, 2012; Zablotsky, Bradshaw, Anderson, & Law, 2013] and one study found greater internalizing symptoms when adults with ASD had fewer friends [Mazurek, 2014]. Because individuals with ASD are prone to social isolation – both in terms of less time spent with friends and less participation in more structured social activities in the community – it is important to understand the implications of participation (or lack of participation) in social activities for the development of internalizing problems.

However, it is also possible that internalizing problems might be responsible, at least in part, for low levels of social participation during the transition years. Given high rates of internalizing disorders among adolescents with ASD [Leyfer et al., 2006; van Steensel, Bogels, & Perrin, 2011], understanding their implications for other areas of life (such as social participation) are of critical importance. If internalizing problems predict changes in social participation during the transition to adulthood, we may be able to identify those youth who will be at greatest risk for social isolation after leaving high school.

The goal of this study, then, was to examine whether the amount of participation in social activities – both unstructured (e.g., time spent with friends, coworkers) and structured (e.g., participation in church groups,

team sports) – changed from before to after high school exit for youth with ASD, as well as the concurrent and longitudinal associations between social activities and internalizing symptoms. We had three specific aims. In Aim 1, we examined how social participation changed after youth with ASD exited high school. In Aim 2, we explored the interrelations between types of activities (structured vs. unstructured activities). In Aim 3, we investigated the relationships between changes in social participation and internalizing symptoms, with an eye toward understanding whether internalizing problems led to changes in social activities, or whether fewer social activities led to changes in internalizing problems. This research question is particularly novel, as to our knowledge there have been no longitudinal studies that examine the relationships over time between social participation and internalizing symptoms among adolescents or adults with ASD.

Methods

Participants and Design

The present analysis included 36 families of youth with ASD who were part of a larger, longitudinal study. The primary inclusion criteria were that the son or daughter with ASD was scheduled to exit high school within the next 12 months and had received an ASD diagnosis from an educational or health professional. Participants were recruited through other autism-related research studies as well as through local clinics, support groups, service providers, and autism organizations. On entry into the study, ASD diagnoses were confirmed by clinicians with expertize in ASD diagnosis who used a combination of scores from the Autism Diagnostic Observation Schedule [Lord et al., 2000] administered to the youth and the Autism Diagnostic Interview-Revised [Lord, Rutter, & Le Couteur, 1994] administered to the responding parent; all clinicians had achieved external research reliability on these instruments. Data in this analysis were collected at two time points; Time 1 was conducted when youth with ASD were in their last year of high school [$M = 6.36$ ($SD = 3.28$) months prior to high school exit, range of 0.46 to 13.84 months], and Time 2 was collected when youth had been out of high school for about a year or less [$M = 9.90$ ($SD = 2.44$) months after high school exit, range of 5.75–16.54 months]. The average amount of time between data collection points was 16.26 months ($SD = 3.69$) with a range from 10.16 to 26.40 months.

Structured observations and direct testing of the youth were completed at Time 1; parental questionnaires and interviews were administered at both time points. The intent of the larger project was to collect data from families of youth across the spectrum of functioning, resulting in data that are more likely to be generalizable to the population of youth in this age range. Because some of these youth would be minimally-verbal or have very low IQ scores, parent report was our primary method of data collection. All study procedures were approved by the Vanderbilt University Institutional Review Board.

Table 1. Descriptive Information About the Youth With ASD

	n (%)	Mean (SD)
Age at Time 1		
17 years	11 (30.6%)	
18 years	17 (47.2%)	
19 years	2 (5.6%)	
20 years	1 (2.8%)	
21–22 years	5 (13.9%)	
Sex		
Male	30 (83.3%)	
Female	6 (16.7%)	
ADOS Module		
Module 1	4 (11.1%)	
Module 2	1 (2.8%)	
Module 3	0	
Module 4	31 (86.1%)	
Total IQ Standard Score		85.33 (25.65)
Verbal IQ Standard Score		82.54 (24.22)
Non-verbal IQ Standard Score		88.09 (25.32)
Vineland Adaptive Behavior Composite		64.28 (14.47)
Intellectual Disability		
Yes	10 (27.8%)	
No	26 (72.2%)	
Type of school at Time 1		
Regular pubic or magnet school	23 (63.9%)	
Regular private school	3 (8.3%)	
School that only serves students with disabilities	4 (11.1%)	
Home schooled	5 (13.9%)	
Other	1 (2.8%)	

Participant descriptive information is presented in Table 1. The youth averaged 18.71 years of age ($SD = 1.30$) at Time 1. Over 80% were male, and the majority was white non-Hispanic (88.9%). Full-scale IQ scores on the Stanford-Binet [Roid, 2003] ranged from 40 to 137. Over one-third of youth (36.1%) had IQ scores of 100 or above. Using well-accepted IQ and adaptive behavior criteria [American Association on Intellectual and Developmental Disabilities, 2010] just over one-quarter of the sample met criteria for an intellectual disability. All youth were living with the responding parent at Time 1.

The parent sample was composed of 32 mothers and 4 fathers. Parents ranged from 38 years to 59 years of age ($M = 50.27$, $SD = 4.62$) at Time 1. Over two-thirds (69.4%) of parents were married, with 61.1% married to the other biological parent of the son/daughter with ASD. This was a well-educated and well-resourced sample on average; 69.4% of the responding parents had attained a postsecondary degree (Associate's or Bachelor's), and 30.6% had earned a post-bachelor's degree.

The median household income was around $85,000; one-quarter of the sample had annual household incomes below $50,000.

Measures

Social participation. Social, recreational, and leisure activities were measured at both time points using questions from the National Survey of Families and Households [Bumpass & Sweet, 1987] that were modified to be appropriate for adolescents and adults [Orsmond et al., 2004]. These questions were administered to parents, and measured how often youth currently participate in each of ten activities on a 5-point scale (0 = *less than yearly or never* to 4 = *several times a week*). Because the focus on this project was on social activities (not leisure or recreational), we grouped the items into three categories based on their social context. Three items reflected time spent with others outside of a formal group setting, which we termed *unstructured social activities* (spend social time with relatives that he/she does not live with, spend social time with people he/she goes to work with outside of school/working hours, spend social time with friends and neighbors). Four items reflected time spent in the community, often in group settings, with some activities occurring at regularly scheduled times; we termed these *structured social activities* (attending services at a church or synagogue, attending a social event at a church or synagogue, participating in formal or informal recreational activity, playing sports with others). The remaining three items asked about activities with no clear social context (e.g., working on a hobby such as video games or collecting things), and were grouped into a *non-social activities* category that was not analyzed. Sum scores for structured social activities (possible range of 0–16; Cronbach's alpha = 0.48 and 0.64 at Times 1 and 2, respectively) and unstructured social activities (possible range of 0–12; Cronbach's alpha = 0.55 and 0.45 at Times 1 and 2, respectively) at each time point were used in the present analyses.

Internalizing symptoms. The Adult Behavior Checklist [ABCL; Achenbach & Rescorla, 2003], a parent-report scale, was used to measure internalizing symptoms among the youth with ASD at both time points. In the ABCL, parents are asked to rate the frequency of each of 126 problem behaviors on a 3-point Likert scale (0 = not true, 1 = somewhat or sometimes true, 2 = very true or often true). Scores are summed to form eight syndrome scales, which are combined to yield the Internalizing Problems, Externalizing Problems, and Total Problems composite scores. The manual for the ABCL reports adequate reliability and validity for scale and composite scores [Achenbach & Rescorla, 2003]. The Internalizing Problems total score were used in these analyses, with higher scores indicating more symptoms (Cronbach's alpha = 0.87 and 0.86 at Times 1 and 2, respectively).

Data Analysis

Descriptive statistics were used to examine the frequencies of each of the unstructured and structured social activities, both before and after high school exit. We used paired *t*-tests to examine whether participation in unstructured and structured social activities changed from before to after high school exit. To address Aim 2 (interrelations between types of social activities) and Aim 3 (relations between social activities and internalizing problems), we first conducted Spearman Rho correlations to see the concurrent and lagged bivariate relations between social activities (sum of unstructured social activities, sum of structured social activities) and internalizing problems.

To further examine the interrelations between types of activities, we ran two ordinal regression models to test whether: (a) unstructured social activities while youth with ASD were in high school predicted changes in structured activities after high school exit; or (b) structured activities in high school predicted changes in unstructured activities after high school exit. We used ordinal regression models because the distributions of the dependent variables were somewhat non-normal, and could not easily be corrected using standard variable transformations. In each model, we statistically controlled for the Time 1 score of the change variable. Given our relatively small sample size, the models were powered to add an additional 1–2 covariates. We chose to control for the amount of time between waves, as that varied across participants, and for full-scale IQ score, which was moderately correlated with Time 1 internalizing symptoms (spearman rho = 0.32, $P = 0.055$).

The first regression model examined whether Time 1 unstructured social activities predicted change in structured social activities, controlling for the Time 1 score of structured activities, full-scale IQ score, and time between waves. The second regression model tested whether Time 1 structured activities predicted change in unstructured activities, controlling for Time 1 unstructured activities, full-scale IQ score, and time between waves. For Aim 3, we ran four similar ordinal regression models to test whether internalizing problems in high school predicted changes in structured or unstructured social activities (controlling for Time 1 social activities, full-scale IQ, and time between waves), or whether social activities in high school predicted changes in internalizing (controlling for Time 1 internalizing, full-scale IQ, and time between waves).

Table 2. Distribution of Social Participation at Each Time Point

	T1 – in high school				T2 – out of high school			
	Never (0) (%)	1–10 Times a year (1) (%)	Once or twice a month (2) (%)	Once a week (3) or more (4) (%)	Never (0) (%)	1–10 times a year (1) (%)	Once or twice a month (2) (%)	Once a week (3) or more (4) (%)
Unstructured Social Activities								
Social time with relatives	2.8	55.6	19.4	22.2	8.3	52.8	11.1	27.7
Social time with people from school/work	41.7	30.6	13.9	13.9	50.0	25.0	11.1	13.9
Social time with friends/neighbors	36.1	27.8	27.8	8.3	44.4	27.8	11.1	16.6
Structured Social Activities								
Attend religious services	30.6	8.3	8.3	52.8	33.3	11.1	11.1	44.4
Attend social events at places of worship	38.9	25.0	22.2	13.9	44.4	36.1	13.9	5.6
Participate in formal/informal recreational activity	2.8	47.2	33.3	16.7	8.3	47.2	22.2	22.2
Play sports with others	47.2	19.4	13.9	29.5	69.4	13.9	11.1	5.6

Table 3. Spearman's Rho Correlation Matrix Between Social Activities and Internalizing Symptoms

	1.	2.	3.	4.	5.	6.
1. T1 unstructured activities	–					
2. T1 structured activities	0.37*	–				
3. T2 unstructured activities	0.41*	0.42*	–			
4. T2 structured activities	0.17	0.77**	0.34*	–		
5. T1 internalizing problems	−0.20	−0.04	−0.44**	−0.12	–	
6. T2 internalizing problems	−0.26	0.08	−0.26	−0.05	0.79**	–

†$P < 0.01$, *$P < 0.05$, **$P < 0.01$.

Results

Aim 1: Social Participation Before and After High School Exit

Table 2 presents the frequencies of participation in each of the unstructured and structured social activities, both before and after high school exit. While youth with ASD were in high school, 42% *never* spent time with people from school or work outside of school/working hours, and 36% *never* spent time with friends/neighbors; these percentages increased slightly after high school exit. Relatively few people – before and after high school exit – spent time with people from school/work or with friends on a regular basis (i.e., at least once a week or more).

In terms of structured social activities (see Table 2), the most common activity at both time points was attending religious services. Percentages suggested that fewer youth were regularly attending social events at places of worship over time; 14% of youth attended once a week or more while in high school, which declined to about 5% after exit. Further, after high school exit, more youth were reported not to engage in sports with others.

The average amount of participation in unstructured social activities did not significantly change over time ($M = 3.86$, $SD = 2.39$ in high school; $M = 3.72$, $SD = 2.57$ out of high school), $t(35) = 0.29$, $P =$ ns. Structured social activities, conversely, significantly declined after youth with ASD left high school, $t(35) = 3.35$, $P < 0.01$. The average decline was well over one point, from 6.14 ($SD = 3.33$) in high school to 4.46 ($SD = 3.24$) once out of high school, indicating a decline in one of the activities from (for example) once or twice a month to a few times a year.

Aim 2: Interrelations Between Types of Social Activities

Spearman rho correlations between unstructured and structured activities, at both time points, are presented in Table 3. Within a time point, the amount of participation in structured and unstructured social activities was moderately correlated, with correlation coefficients around 0.35. There appeared to be more stability in the rank ordering of structured activities over time, relative to unstructured activities (Spearman rhos = 0.77 and 0.41, respectively). Differences in variability were also observed when examining the percentage of youth who had declining, the same, or increasing structured and unstructured social participation across the two time points. As can be seen in Figure 1, the vast majority of youth had declining or unchanging structured social participation; fewer than 20% had greater structured activity participation after high school. However, nearly

twice as many youth had increases in unstructured social activities after high school exit, and fewer experienced declines. This increased variability was further evident when looking at the standard deviations of the change scores for structured and unstructured social activities, which were 2.29 and 2.83, respectively.

Presented in Table 4 are the results of ordinal regression models testing whether the amount of unstructured social participation in high school predicted changes in structured social participation after high school exit, or whether structured social participation predicted changes in unstructured activities. After controlling for Time 1 structured activities, IQ, and time between waves, Time 1 unstructured activities did not significantly predict change in structured activities. However, youth who participated in more structured activities in high school experienced significantly greater increases in unstructured social participation after high school exit, relative to youth who were involved in fewer structured activities.

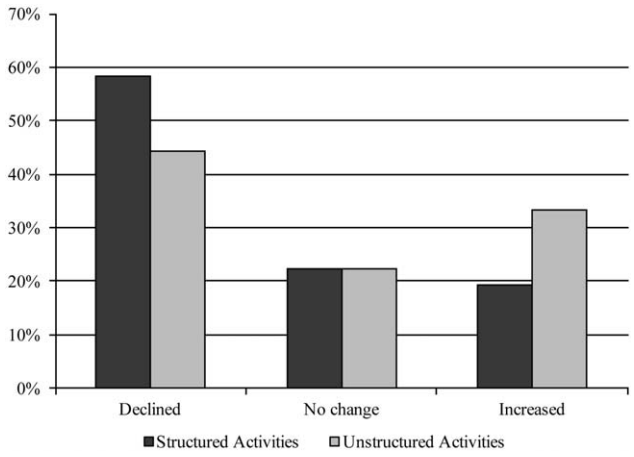

Figure 1. Percent of sample who declined, stayed the same, or increased in structured and unstructured social activities after high school exit.

Aim 3: Relations Between Social Participation and Internalizing Symptoms

Spearman rho correlations – both within and across waves – for relations between social participation and internalizing are presented in Table 3. In terms of *concurrent* relations, social activities were not significantly related to internalizing problems at either time point. In terms of *lagged* relationships, more internalizing problems in high school were related to fewer unstructured activities after high school exit.

Results from ordinal regression analyses examining whether earlier internalizing problems predicted changes in social activities, or whether earlier social activities predicted changes in internalizing, are presented in Table 4. Note that all regression models controlled for the initial score of the change variable as well as the youth's full-scale IQ score and time between waves. Time 1 internalizing problems were significantly related to changes in both structured and unstructured social activities; youth who had fewer internalizing problems while in high school tended to have greater increases (and fewer declines) in both unstructured and structured social activities after leaving high school, relative to youth with more internalizing problems. Social activities did not significantly predict change in internalizing symptoms.

Follow-Up Analyses

One factor that might influence patterns of change in social participation from before to after high school exit is whether the youth with ASD attends a postsecondary educational (PSE) program. To explore this issue, we used analysis of covariance to examine whether PSE participation at Time 2 (within 12 months of high school exit) was associated with changes in structured and unstructured social participation, holding constant the Time 1 scores of social participation and

Table 4. Results From Ordinal Regression Models Examining Inter-Relations Between Types of Social Activities (Aim 2), and Inter-Relations Between Internalizing and Social Activities (Aim 3)

	Beta	SE Beta	Wald χ^2	OR	95% CI of OR
Inter-relations between types of activities					
T1 unstructured activities → change in structured activities	−0.10	0.14	0.52	0.91	0.69–1.19
T1 structured activities → change in unstructured activities	0.21	0.11	4.12*	1.24	1.01–1.52
Social activities predicting change in internalizing problems					
T1 unstructured activities → change in internalizing problems	−0.17	0.13	1.80	0.84	0.65–1.08
T1 structured activities → change in internalizing problems	0.12	0.09	1.74	1.13	0.94–1.36
Internalizing problems predicting change in social activities					
T1 internalizing problems → change in unstructured activities	−0.10	0.04	5.93*	0.91	0.84–0.98
T1 internalizing problems → change in structured activities	−0.07	0.04	3.91*	0.93	0.86–0.999

*$P < 0.05$.

Note. SE = Standard Error; OR = Odds Ratio; CI = Confidence Interval. All regression models control for the Time 1 score of the change variable (e.g., Time 1 internalizing for models with change in internalizing as the dependent variable), youth's full-scale IQ score, and the number of months between data collection waves.

the youth's IQ score. Just over one-half of the sample (52.8%) was in a PSE program at Time 2. Youth who were attending a PSE program had increasing unstructured social participation scores ($M = 0.47$, $SE = 0.56$) while youth who were not attending PSE had decreasing scores ($M = -0.82$, $SE = 0.59$), although the difference between the two groups was not statistically significant, $F(1) = 2.46$, $P = 0.13$. Both groups had declines in structured social participation; that decline appeared somewhat less pronounced for those in a PSE program relative to those not in PSE ($M = -1.09$, $SE = 0.51$ for those in PSE vs. $M = -1.49$, $SE = 0.54$ for those not in PSE), but the difference was not statistically significant, $F(1) = 0.27$, $P = 0.61$.

Discussion

Even with increasing autism awareness and services for transition-aged youth with disabilities over the past $5 - 10$ years, our findings suggest that social isolation remains a common experience for individuals with ASD. Youth with ASD in this sample had low levels of unstructured (e.g., spending time with friends or coworkers) and structured (e.g., going to group activities out in the community) social activities during the transition to adulthood. Results from this small cohort were consistent with what has been found among older individuals with ASD [Orsmond et al., 2004] and in a nationally-representative sample of transition-aged youth [Liptak, Kennedy, & Dosa, 2011; Orsmond et al., 2013; Shattuck, Orsmond et al., 2011]. Specifically, percentages of youth who spent *no* time with friends or neighbors were similar across all studies (at around 40%). The consistency between studies may be cause for concern, as low rates of social participation do not seem to be changing with younger cohorts. All participants with ASD in the NLTS-2 left high school in 2009 or earlier [with about two-thirds leaving prior to 2007; United States Department of Education National Center for Special Education Research, 2014], and in the larger study from which the Orsmond and colleagues [2004] sample was drawn, nearly all participants with ASD left high school prior to 2008 [Taylor & Seltzer, 2010, 2012], with some leaving in the 1980s and 1990s. Meanwhile, in this study, most students left high school in 2013 or 2014.

Our pattern of change in social activities from before to after high school exit was nearly identical to that of Myers and colleagues [Myers et al., 2015]. Like us, they did not observe change in the amount of contact youth had with friends (akin to our measure of unstructured social activities), but they observed a significant decline in the percentage of youth who had community participation (similar to our measure of structured social activities). Our sample and the NLTS-2 (from which the Myers and colleagues sample was drawn) differed in many ways: their sample was large and nationally-representative whereas ours was smaller and regional; their methods relied on special education diagnoses of ASD, whereas we used clinical diagnostic assessment methods; they focused on whether youth had any participation whereas we examined the amount of participation. The two studies also used entirely different questions to assess social participation and isolation. Yet, despite all of these differences, the results were similar. This convergence across studies suggests that, for youth with ASD, declining participation in structured social activities after high school exit is potentially a reliable finding.

Although there was no statistically significant mean level change in unstructured social participation after youth with ASD left high school, we observed substantial variability in this change. Almost 80% of youth had unstructured social participation scores that changed over time, with some youth spending less time with friends/neighbors/classmates/coworkers after high school exit, and other youth spending more time with these individuals. Understanding the factors that lead to someone becoming more socially involved versus less socially involved after leaving high school is an important direction for future research. Although not statistically significant in this sample, follow-up analyses suggested that PSE participation might predict different patterns of unstructured social participation. There are many other ways that the lives of youth with ASD diverge over time (e.g., living arrangements, service access, family involvement, etc.) that could influence patterns of social participation. Longitudinal studies with larger samples are needed to determine the characteristics and circumstances of youth who become increasingly socially isolated versus those who become more socially connected during the transition to adulthood.

Our Aim 2 analyses revealed new information about the interplay between changes in unstructured and structured activities after high school exit. Both patterns of mean change and individual-level change differed between the two types of social participation. Nearly all youth declined in structured social participation, and those who had higher levels of participation while they were in high school tended to also have more participation (relative to this sample) after high school exit. Unstructured social participation, conversely, was more variable. Thus, these two types of social participation should not be treated as one factor, as our analyses suggest (along with Myers and colleagues, 2015) that they are differentially responsive to the transition out of high school, and might have different implications for psychological distress or well-being.

Furthermore, youth who had more structured social participation while in high school were more likely to have gains in their unstructured social participation after high school exit. There are a number of possible explanations for this finding. It may be that encouraging youth to participate in structured, group-based activities facilitates the development of social ties that last through the transition out of high school. Participating in structured activities might also promote the development of new social skills that, over time, carry over into new, less structured settings. Alternatively, there might be characteristics of youth with ASD (such as social motivation) or their families (such as parent initiative to seek out social activities for their son/daughter) that would cause them to be more likely to participate in structured social activities *and* increase in their amount of unstructured social participation over time. Given the important implications for intervention (i.e., offering more opportunities for structured social participation is relatively easy to achieve), future research should further examine whether increasing participation in group-based structured activities while in high school lessens social isolation after high school exit, or whether there are characteristics of the youth with ASD or their families that account for this relationship.

Based on previous research on the negative long-term effects of social isolation in typically-developing adult samples [e.g., Bagwell et al., 1998; Bukowski et al., 2010; Danese et al., 2009; Hartup, 1989; Matthews et al., 2016; Sakyi et al., 2015], we expected that declining social participation might lead to higher levels of internalizing symptoms. Yet, the opposite direction of effects was stronger in this sample. That is, relative to youth with fewer internalizing symptoms, those with greater internalizing in high school were becoming more socially isolated during the transition to adulthood. This is an important finding: Although high levels of comorbid mood and anxiety disorders are regularly found among youth and adults with ASD [e.g., Hofvander et al., 2009; Kerns & Kendall, 2012; Lugnegard, Hallerback, & Gillberg, 2011; Wood & Gadow, 2010], little is known about the implications of these symptoms for other areas of life such as employment, independent living, post-secondary education, and social participation. Not only does understanding what areas of life are most affected by mental health symptoms underscore the importance of effectively treating comorbid mental health conditions, but it also provides insight into what additional supports youth with ASD and comorbid mood or anxiety disorders might need to transition out of high school and into adult roles.

Further, the correlation between earlier unstructured social participation and later internalizing symptoms was substantial, at −0.26. Although this was not statistically significant in our small sample, the magnitude of this effect is similar to what has been found in studies examining the impact of peer victimization on internalizing problems among typically-developing adolescents [Reijntjes, Kamphuis, Prinzie, & Telch, 2010]. Thus, there are likely bidirectional effects that this study was too underpowered to detect. The relatively low internal consistency reliabilities of the social participation subscales also made it difficult to detect some of these more subtle effects. Larger, longitudinal studies that document patterns of internalizing symptoms and social participation as they unfold are needed to better untangle these directional issues and to understand the specific ways that comorbid mental health problems affect the transition to adulthood for youth with ASD. In particular, understanding how social and other activities might impact internalizing symptoms is important, as they are amenable to intervention and could potentially be used as an avenue to improve mental health.

This study has limitations worth noting. First, our measures of internalizing symptoms and social participation were collected via parent-report. Relying on informants runs the risk of missing social activities/contacts that parents do not know about, and parents often have some difficulty reporting on their son/daughter's internalizing symptoms [Gotham, Unruh, & Lord, 2015]. Further, associations between the variables in this study might be inflated by informant bias. Despite these drawbacks, the reliance on informant report was necessary because we included youth with ASD across the spectrum of functioning (some of whom were nonverbal, had very low IQ scores, or otherwise could not self-report). It is also highly characteristic of extant research with adolescents and adults with ASD, meaning that almost nothing is known about how youth with ASD view their own social participation and friendships. Future research should collect self-report measures of social participation and internalizing in addition to informant-report, which would allow for the investigation of social participation and its implications from the perspective of the youth with ASD.

This study relied on a relatively brief measure of social participation. Although this measure has been used previously with adolescents and adults with ASD [Orsmond et al., 2004], our analysis was the first to group items into structured and unstructured activities. Future studies with larger samples should investigate whether this grouping of activities is empirically supported through factor analysis. Given that each subscale had relatively few items, additional items could be developed to more fully capture the range of possible structured and unstructured social activities.

The lack of a comparison group – either typically developing or with a different disability – is another limitation of this study. Without a comparison group,

we were unable to test whether our findings about social participation and its relations to internalizing are unique to ASD, or common among youth who are transitioning to adulthood. Future research should examine whether changes in social participation after high school differ for youth with ASD versus other groups, and whether the implications of participation for internalizing (and internalizing for participation) are similar.

The small sample in this study is another limitation, as it raises concerns about the generalizability of our findings. There are likely relationships between social participation and internalizing that we were underpowered to detect due to sample size. Generalizability is further limited by the lack of socio-economic and racial/ethnic diversity among the participants in this sample. Further, our small sample did not allow us to examine important issues of moderation, such as how IQ might affect the relations between social participation and internalizing (although we statistically controlled for IQ).

Conversely, this sample, although small and relatively well-resourced, had careful diagnostic confirmation using gold-standard ASD diagnostic measures, as well as detailed information about their IQ, language, and adaptive behavior profiles. The wide range of functioning of the youth with ASD included in this sample also aids generalizability. Further, our findings related to change in social activities over time were consistent with those of larger, nationally-representative samples. As this was the first study to look at relations between social participation and internalizing in an adolescent or adult ASD sample, future research should examine whether these findings hold in larger representative samples, as well as examine more complex models of moderation and mediational processes.

In sum, results of this study confirm yet another way that youth with ASD might be at-risk after leaving high school – by becoming more isolated from structured social activities. Many youth maintained their levels of contact with friends, neighbors, and extended family members, although participation in these activities was low to begin with. Youth with more internalizing symptoms appear to be at greatest risk for experiencing declines in both structured and unstructured activities, and might need additional supports during the transition years. Further research is needed to better understand how internalizing problems affect youth's ability to successfully transition to adulthood, as well as the areas of daily life that might be leveraged to improve the mental health of these youth.

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