Employment and Post-Secondary Educational Activities for Young Adults with Autism Spectrum Disorders During the Transition to Adulthood

Julie Lounds Taylor · Marsha Mailick Seltzer

Abstract This report describes the post-high school educational and occupational activities for 66 young adults with autism spectrum disorders who had recently exited the secondary school system. Analyses indicated low rates of employment in the community, with the majority of young adults (56%) spending time in sheltered workshops or day activity centers. Young adults with ASD without an intellectual disability were three times more likely to have no daytime activities compared to adults with ASD who had an intellectual disability. Differences in behavioral functioning were observed by employment/day activity group. Our findings suggest that the current service system may be inadequate to accommodate the needs of youths with ASD who do not have intellectual disabilities during the transition to adulthood.

Keywords Transition to adulthood · Employment · Post-secondary education · Autism spectrum disorders

Introduction

The limited extant research on post-high school activities for adults with autism spectrum disorders (ASD) paints a pessimistic picture of their employment. Howlin et al. (2004) studied a sample of 68 adults with ASD in the United Kingdom, finding that just under one-third had some type of employment. About 13% were in a competitive employment situation, and another 18% were in a sheltered or supported setting. Similar patterns of employment were found in a sample of 45 adults with ASD in the US (Ballaban-Gil et al. 1996); 27% had some sort of work activity. About one-half of those were competitively employed, and the other half were employed in supported positions or sheltered workshops. The remaining individuals had no employment activities at the time of the interview. However, even those who were able to find employment tended to have jobs that were poorly paid. Finally, Eaves and Ho (2008) examined a sample of young adults with ASD in Canada and found that nearly 45% of their sample had never been employed. At the time of their follow-up interview, only 4% were competitively employed, with just one person in their sample able to financially support himself. Thus, under-employment of individuals with ASD is an international phenomenon.

Studies have yet to focus on how characteristics of individuals with ASD predict their post-high school occupational and employment activities. Investigators have, however, examined the behavioral correlates of a related composite measure of social functioning that incorporates independence in employment activities, living arrangements, and friendships (Howlin et al. 2004). The most consistent correlate is IQ; individuals who have ASD and comorbid intellectual disability (ID) have less optimal social functioning (reflecting less independence) compared to those with ASD and higher IQ scores (Eaves and Ho 2008; Farley et al. 2009; Gillberg and Steffenburg 1987; Howlin et al. 2004; Lord and Bailey 2002).
Our research, however, suggests that there may be a subgroup of young adults with ASD without ID who are at risk for poor employment outcomes in adulthood. Taylor and Seltzer (2010) found that improvement in repetitive and maladaptive behaviors slowed more after high school exit for youths with ASD without ID, relative to youths with ASD with ID. Furthermore, the most pronounced change in symptoms and maladaptive behaviors after high school exit was observed for those youths without ID who were from lower income families; these individuals actually showed a worsening of their behavioral profile after high school exit. Improvements in functional abilities are related to more stimulating environments for individuals with Down syndrome (Shepperdson 1995); the slowing in improvement in behaviors for young adults with ASD without ID may be related to less stimulating occupational activities after high school exit, especially for those youths from lower income families who may have greater barriers to service access (Liptak et al. 2008; Thomas et al. 2007).

Indices of behavioral functioning such as autism symptoms, maladaptive behaviors, functional independence, and comorbid psychiatric disorders are also likely related to the employment activities of young adults with ASD in the years following high school exit. Using the aforementioned composite measure of social functioning, investigators have found greater independence for adults with ASD who have fewer autism symptoms (Eaves and Ho 2008; Howlin et al. 2004). Although not a part of the diagnostic criteria of ASD, maladaptive behaviors are often exhibited by people with ASD (Aman et al. 2003; Hollander et al. 2003; Lecavalier 2006; Shea et al. 2004) and are a primary source of stress for caregivers (Hastings 2003; Hastings and Brown 2002; Lecavalier et al. 2006; Tomanik et al. 2004). Maladaptive behaviors interfere with day-to-day functioning and include such behaviors as self-injury, aggression, and uncooperative behaviors. Although they have not yet been studied in relation to employment in early adulthood, it is likely that young adults with ASD and high levels of maladaptive behaviors would require more supports in their adult day activities relative to those with fewer maladaptive behaviors.

Our research has found evidence for relationships between functional independence, comorbid psychiatric disorders and social functioning for individuals with ASD. In a study of adults with ASD aged 22–53 years, reduced independence in activities of daily living and psychological/psychiatric service receipt (indicative of a comorbid psychiatric diagnosis) were related to lower social functioning and less independence in adulthood (Esbensen et al. 2010). These relations are consistent with a study by Farley et al. (2009), who found that adults with ASD and higher adaptive behaviors had more independent social functioning relative to those with lower adaptive behaviors.

Each of the previous studies focused on employment and social outcomes for a wide age range of adults with ASD. The present study extends this research in three ways. First, we evaluated the activities of young adults with ASD who had recently exited the secondary school system. Focusing on a narrow age range allowed us to better understand whether the employment difficulties reported in the literature are evident in the years immediately following high school exit in a cohort that finished high school in recent years. Second, our analysis of adult activities focused on employment/day activities instead of the less specific social functioning composite (e.g., combination of employment/day activities, living arrangements, and friendships) commonly used in extant research. In contrast to most previous studies, we expanded our categorization of employment/day activities to include enrollment in post-secondary degree-seeking educational programs. Finally, we examined the association between post-secondary employment/day activities and ID, as well as concurrent behavioral functioning including autism symptoms, behavior problems, functional independence, and comorbid psychiatric disorders. To the best of our knowledge, this is the first study to relate employment/day activities to concurrent behavioral functioning.

Our study had three research aims. First, we provided a rich description of the occupational and day activities for a group of young adults with ASD who had exited high school within the past 5 years. Second, we examined whether having an intellectual disability was related to the type of employment or day activity. We hypothesized that youths with ASD without ID would be more likely to have post-high school activities that required high levels of independence, such as competitive employment or a post-secondary degree-seeking educational program, relative to those with ID. Based on the Taylor and Seltzer (2010) findings, we also hypothesized that there would be a subgroup of young adults with ASD without ID who would have limited day activities. Our third aim examined the relations between type of employment or day activity and family income as well as the behavioral functioning of the young adults with ASD. We hypothesized that youths with ASD who were participating in day activities that required few supports would exhibit fewer autism symptoms, maladaptive behaviors, and comorbid psychiatric diagnoses and higher levels of functional independence. We further hypothesized that youths with ASD who had limited day activities would have families with lower incomes (reflecting barriers in accessing services).
Method

Sample

The present analysis used a subsample (n = 66) of young adults with ASD drawn from our larger longitudinal study of families of adolescents and adults with ASD (N = 406; Seltzer et al. 2003; Shattuck et al. 2007). The criteria for inclusion in the larger study were that the son or daughter with ASD was age 10 or older (age range = 10–52 at the beginning of the study), had received an ASD diagnosis (autistic disorder, Asperger disorder, or pervasive developmental disorder) from an independent educational or health professional, and had a researcher-administered Autism Diagnostic Interview-Revised (ADI-R; Lord et al. 1994) profile consistent with the diagnosis. Nearly all of the sample members (94.6%) met the ADI-R lifetime criteria for a diagnosis of autistic disorder. Case-by-case review of the other sample members (5.4%) determined that their ADI-R profile was consistent with their ASD diagnosis (i.e., meeting the cutoffs for reciprocal social interaction and repetitive behaviors for Asperger disorder, and for reciprocal social interaction and either impaired communication or repetitive behaviors for PDD-NOS). Half of the participants lived in Wisconsin (n = 202) and half in Massachusetts (n = 204). We used identical recruitment and data-collection methods at both sites. Families received information about the study through service agencies, schools, and clinics; those who were interested contacted a study coordinator and were subsequently enrolled. Five waves of data have thus far been collected: four waves collected every 18 months from 1998 to 2003, spanning a 4.5 year period, and a fifth wave collected in 2008, 10 years after the study began. At each time point, data were collected from the primary caregiver, who was usually the mother, via in-home interviews that typically lasted 2–3 h and via self-administered questionnaires.

In these analyses, we focused on the subsample (n = 66) of youths with ASD who had exited the school system between 2004 and 2008, and had information about post-high school activities in 2008. The individuals with ASD included in this subsample averaged 22.98 years of age (SD = 1.51) at the time of follow-up (2008), with a range from 19.05 to 25.79 years. They had exited high school an average of 2.18 years previously (SD = 1.19) with a range from .22 to 4.34 years since high school exit. Just over 80% were male and 60.6% were still living with their parents. Roughly 19% were reported to have a seizure disorder, and 79.6% of individuals were verbal, as indicated by daily functional use of at least three-word phrases. Nearly three-fourths (74.2%) had an intellectual disability. The median income for families in 2008 was between $70,000 and $80,000, with a range from under $10,000 to over $160,000. Just over 90% of mothers were Caucasian.

Measures

Adult Day Activities

Mothers were asked how many hours a week their son or daughter participated in any of the following activities on a regular basis: post-secondary education, competitive job, supported employment, sheltered workshop, day activity or day habilitation program, individualized programs with support, and volunteer work.

Comorbid Intellectual Disability Status

ID (0 = no intellectual disability, 1 = intellectual disability) was determined using a variety of sources. Standardized IQ was obtained by administering the Wide Range Intelligence Test (WRIT; Glutting et al. 2000) to 50.2% of the larger sample. The WRIT is a brief measure with strong psychometric properties and both verbal and nonverbal sections. Adaptive behavior was assessed by administering the Vineland Screener (Sparrow et al. 1993) to mothers. The 45-item screener measured daily living skills in the youths with ASD and correlates well with the full-scale Vineland score (r = .87–.98). It has high inter-rater reliability (r = .98) and good external validity (Sparrow et al. 1993). Individuals with standard scores of 70 or below on both IQ and adaptive behavior measures were classified as having an intellectual disability (ID), consistent with diagnostic guidelines (Luckasson et al. 2002). For cases where the individual with ASD scored below 70 on either measure, or for whom either of the measures was missing, a review of records by three psychologists, combined with a clinical consensus procedure, was used to determine ID status.

Family Income

Mothers were also asked about their family’s income in the previous year, coded from 1 = less than $10,000 to 14 = $160,000 or more.

Autism Symptoms

The ADI-R (Lord et al. 1994) measured current autism symptoms. Thirty-three items from the diagnostic algorithm appropriate for adolescents and adults were administered in interviews with mothers. Ratings of current functioning were then made by interviewers who had participated in an approved ADI-R training program. Interrater agreement between the interviewers and two
supervising psychologists experienced in the diagnosis of autism and in the use of the ADI-R averaged 89% at the first time point of the study, and the average Kappa was .81. 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). Each ADI-R item was scored on the following scale: 0 = no abnormality, 1 = possible abnormality, 2 = definite autistic-type abnormality, 3 = severe autistic-type abnormality.

We recoded each ADI-R 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; Lounds et al. 2007; Seltzer et al. 2003; Shattuck et al. 2007) and allowed us to capture the qualitative difference between having and not having a given autism symptom. An overall autism symptom score was created by summing the number of items on which an individual was symptomatic. We chose to exclude items related to verbal communication impairments from our sum score due to the presence of non-verbal participants in our sample. Higher scores indicate more autism symptoms.

**Maladaptive Behaviors**

Mothers completed the Behavior Problems subscale of the Scales of Independent Behaviors—Revised (SIB-R; Bruininks et al. 1996). This 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). Mothers who indicated that their son or daughter displayed a given behavior then rated the frequency (1 = less than once a month to 5 = 1 more times/hour) and the severity (1 = not serious to 5 = extremely serious) of the behavior. Standardized algorithms (Bruininks et al. 1996) translate the frequency and severity ratings into an overall maladaptive behaviors score, with higher scores indicative of more severe maladaptive behaviors. Reliability and validity of this measure have been established by Bruininks et al. (1996).

**Functional Independence**

Functional independence in activities of daily living was measured using the Revised ADL Index (Seltzer and Krauss 1989), which includes 20 items in the domains of personal care, housekeeping, meal preparation, mobility and community interaction. For this analysis, the score for functional independence was the number of tasks the individual performed independently. Scores ranged from 1 to 19 for young adults with ASD in this sample.

**Comorbid Psychiatric Diagnoses**

Mothers were asked whether their son or daughter had currently valid diagnoses of: Anxiety disorder (24% of this sample); Attention-deficit/hyperactivity disorder or attention-deficit disorder (ADHD/ADD; 19% of this sample); Bipolar disorder (10% of this sample); Depression (8% of this sample); Obsessive–Compulsive Disorder (23% of this sample); Oppositional defiant disorder (3% of this sample), or Schizophrenia (0% of this sample). A variable indicating whether the son or daughter had any comorbid psychiatric diagnoses was constructed from these questions (0 = no comorbid psychiatric diagnoses; 1 = any comorbid psychiatric diagnosis). We note that although ADHD/ADD remains in the exclusionary criteria for autism, its symptoms frequently occur with ASD (Ehlers and Gillberg 1993; Ghaziuddin et al. 1998; Leyfer et al. 2006; Montes and Halterman 2006), and these diagnoses were indeed given to 19% of our sample members by mental health professionals independent of our research team.

**Results**

**Activities of Young Adults with ASD After High School Exit**

We classified the sample into five categories of post-high school activities: post-secondary degree-seeking program, competitive employment, supported employment, adult day services, and day activities fewer than 10 h a week. Since many individuals had multiple post-high school activities, we developed decision rules to yield five non-overlapping categories. The numbers and percentages of the sample in each category are presented in Table 1.

**Post-Secondary Degree-Seeking Program**

This category was made up of young adults who were taking classes toward a post-secondary degree (n = 9, 14%). Most of these individuals (78%) were co-residing with their families and only one (11%) had a comorbid diagnosis of intellectual disability (ID). Most (78%) were working competitively on a part-time basis in addition to pursuing their studies. These young adults were enrolled in programs such as print technology and digital media major
at a technical college, history or accounting major at a local four-year university, and culinary school.

**Competitive Employment**

The next category reflected young adults who were competitively employed in the community, without receiving supports or adult day services, and who were not enrolled in post-secondary degree-seeking educational programs. Four individuals with ASD (6%) fit this criterion. Most young adults who were competitively employed were living with their parents (75%), and one-half had a comorbid ID diagnosis. Three young adults were working at their jobs for between 20 and 30 h a week with the fourth working between 10 and 20 h; none worked full-time. One individual was working as a bus boy at a restaurant, another was working at a hotel replacing dirty glasses with clean ones, the third was working at the Salvation Army and the final young adult was working on her own bead business.

**Supported Employment**

The supported employment category represented young adults who worked in the community with supports and who did not participate in adult day services at a sheltered workshop or day activity center. In our sample, 8 individuals (12%) fit this category. Three-fourths of them had a comorbid ID diagnosis, and nearly two-thirds (63%) were co-residing with their parents. Two of these young adults were working competitively in addition to their supported job. Examples of supported jobs included working in a restaurant rolling silverware into napkins, folding towels at a hotel, shredding confidential information, washing dishes at a nursing home, and working in a grocery store.

**Adult Day Services**

The receipt of adult day services was the most prevalent category in this sample. Over one-half of the young adults ($n = 37$ or 56%) attended sheltered workshops or day activity centers. All but one (97%) had a comorbid ID diagnosis, and just over 50% ($n = 20$) were co-residing with their parents. In addition to hours spent in sheltered workshops or day activity centers, 38% had some supported employment (mostly less than 10 h a week) and 14% had some competitive employment (with all but one working competitively fewer than 10 h a week). The most common model of adult day services was working out in the community in groups for a limited amount of time to complete a job, and then returning to the day activity center or sheltered workshop for a period of time until there was another opportunity for group employment in the community.

**Activities Less Than 10 h a Week**

Eight young adults with ASD (12%) had either no activities or activities that totaled less than 10 h a week. One-half had a comorbid ID diagnosis and 63% were living with their families. Five of these eight young adults had no day activities, and all of these were co-residing with their families. The remaining three were either competitively employed less than 10 h a week (1 person) or in adult day services less than 10 h a week (2 people), and all of these were living in settings outside of the family home.

**Comparing the Activities of Young Adults with ASD With and Without Comorbid ID**

Table 1 shows the prevalence of the five employment/activity categories for young adults with and without comorbid ID. There was a significant relation between employment/day activity categories and ID status, $\chi^2(4) = 32.72$, $p < .001$. Just over 47% of young adults without ID were in a post-secondary education program compared to 2% of young adults with ID. Adults without ID were three times more likely to be competitively employed than those with ID (12% versus 4%), although the percentages in supported employment were similar (12% in each category). Adults without ID were far less likely to be receiving adult day services (6%) compared to adults with ASD and comorbid ID (74%). Finally, nearly one-quarter (24%) of young adults with ASD without ID had no day activities, which was approximately three times greater than those with ID (8%).

<table>
<thead>
<tr>
<th>Day activity category</th>
<th>Total sample ($N = 66$)</th>
<th>With ID ($N = 49$)</th>
<th>Without ID ($N = 17$)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>$n$</td>
<td>%</td>
<td>$n$</td>
</tr>
<tr>
<td>College/university</td>
<td>9</td>
<td>13.6</td>
<td>1</td>
</tr>
<tr>
<td>Competitive employment</td>
<td>4</td>
<td>6.1</td>
<td>2</td>
</tr>
<tr>
<td>Supported employment</td>
<td>8</td>
<td>12.1</td>
<td>6</td>
</tr>
<tr>
<td>Adult day services</td>
<td>37</td>
<td>56.1</td>
<td>36</td>
</tr>
<tr>
<td>No regular activities</td>
<td>8</td>
<td>12.1</td>
<td>4</td>
</tr>
</tbody>
</table>
Examining Whether Employment/Day Activities were Related to Family Income or Measures of Individual Functioning

We next used one-way ANOVAs and chi-squares to examine whether there were differences in family income, autism symptoms, maladaptive behaviors, functional independence, or percentage with a comorbid psychiatric diagnosis based on the employment/day activity categories. Statistically significant group differences emerged for three of the variables: autism symptoms, maladaptive behaviors, and functional independence. Group means and results of follow-up tests are presented in Table 2. Those who were in a post-secondary degree-seeking program had significantly fewer autism symptoms than young adults who had a supported job or were receiving adult day services, $t(56) = -3.02$ and $-4.58$, respectively, $p < .01$. Young adults who were competitively employed also had fewer autism symptoms than those who had a supported job or were receiving adult day services, $t(56) = -2.68$ and $-3.43$, respectively, $p < .01$. Finally, young adults with ASD who had no day activities had fewer autism symptoms than those who were receiving adult day services, $t(56) = 2.44, p < .05$.

The pattern of high autism symptoms for young adults with ASD who were receiving adult day services was mirrored in the analysis of maladaptive behaviors. Those who were receiving adult day services had significantly more maladaptive behaviors than individuals who were in a post-secondary education program or competitively employed, $t(55) = 2.97$ and $2.03$, respectively, $p < .05$. There were no significant differences in maladaptive behaviors between young adults with no day activities and any of the other categories.

Young adults with ASD who were receiving adult day services had less functional independence relative to all other day activity categories, $t(57) = 7.20, 3.74, 2.85$, and $-3.53$ for post-secondary educational program, competitive employment, supported employment, and no activities, respectively, $p < .01$. Furthermore, those who were in supported employment or who had no regular activities had less functional independence relative to young adults who were in a post-secondary educational program, $t(57) = 3.24$ and $2.44$, respectively, $p < .05$.

Overall, results of between group analyses suggested that those young adults who were receiving adult day services had the highest levels of symptoms and behaviors and the least functional independence. Young adults who were attending a post-secondary educational program or were competitive employed had fewer symptoms/behaviors and greater functional independence. Interestingly, youths with ASD who had no regular daytime activities appeared to fall in the middle, with less functional independence than those who were functioning independently out in the community, but more independence compared to youths receiving adult day services. Furthermore, although the numbers were too small to test for significance, the patterns of differences in group means were similar when only

| Table 2 Differences in family income and behavioral functioning by employment/day activity category |
|---------------------------------|------------------|------------------|------------------|------------------|------------------|
|                                 | College/ university (1) | Competitive employment (2) | Supported employment (3) | Adult day services (4) | No regular activities (5) |
|                                 | M (SD) or %            | M (SD) or %         | M (SD) or %        | M (SD) or %       | M (SD) or %       |
| Family income*                  | 9.67 (3.32)            | 8.00 (5.29)          | 11.00 (2.98)       | 7.53 (3.78)       | 9.71 (3.15)       | 2.00 |
| Autism symptoms                 | 8.78 (3.80)            | 7.33 (5.86)          | 14.88 (3.83)       | 15.91 (3.60)      | 11.71 (6.45)      | 7.89** |
| Maladaptive behaviors           | 104.33 (3.94)          | 103.33 (4.93)        | 108.25 (8.43)      | 114.67 (10.72)    | 110.00 (7.90)     | 3.16* |
| Functional independence         | 15.22 (2.17)           | 13.67 (4.62)         | 9.63 (4.98)        | 5.66 (3.18)       | 10.86 (4.53)      | 4.58, 3.74, 2.85, and 2.44, respectively |
| % with a comorbid psychiatric diagnoses | 33.3% | 66.7% | 62.5% | 51.4% | 85.7% | 4.90 |

Note. F-tests were conducted to examine group differences for all variables except for comorbid psychiatric diagnoses, which used a chi-square. The numbers below the test statistic indicate the groups that were significantly different from each other (i.e., for maladaptive behaviors, those young adults in college/university (1) or competitively employed (2) had significantly fewer behaviors compared to young adults receiving adult day services (4)).

* Family income categories ranged from 1 = less than $10,000/year to 14 = $160,000/year or more. A code of 8 (Mean for Competitive Employment group) corresponded to an annual income of $70,000 to $79,999. A code of 11 (Mean for Supported Employment) corresponded to an annual income of $100,000 to $119,999.

* $p < .05$; ** $p < .01$
examining the sample of young adults with ASD who did not have a comorbid ID.

Discussion

The present study contributes to our knowledge about the transition to adulthood for individuals with ASD by focusing on employment and day activities in the years immediately after high school exit. Anchoring outcomes in 2008 allowed for the exploration of adult activities for children who were diagnosed in the early 1990s, the beginning of the rapid rise in ASD diagnoses (Gurney et al. 2003), but before the current economic downturn which is likely to have further limited the employment opportunities for individuals with ASD.

In general, we found the same low rate of employment during the transition to adulthood as reported in previous studies that used a broader age range (Ballaban-Gil et al. 1996; Eaves and Ho 2008; Howlin et al. 2004). Furthermore, similar to Ballaban-Gil et al. (1996), we found that those who were competitively employed tended to have menial jobs, such as replacing dirty glasses with clean ones at a hotel, and no one in our sample was working full time. Although we measured employment/day activities more than 12 years after the Ballaban-Gil et al. (1996) study, the pattern of underemployment persists for young adults with ASD; if anything, the pattern is more pronounced for the present sample.

One group that was of particular concern was the young adults who had no (or few) formal day activities after high school exit. As hypothesized, a significant subgroup (nearly 25%) of the young adults in our sample who had ASD without ID were in this category, and those without ID were three times more likely to have no day activities than youths with ASD who also had comorbid ID. This divergent pattern likely does not represent a lack of abilities on the part of the youths with ASD, but instead the inadequacy of the current service system to accommodate the needs of youths with ASD who do not have ID as they are transitioning to adulthood. Indeed, only 18% of young adults without ID were getting some sort of employment or vocational services (e.g., supported employment, sheltered workshop) compared to 86% of young adults with ID. Although recommendations should be considered with caution given our relatively small sample of youth with ASD without ID, our findings suggest that more autism-focused adult services are needed that will allow youths with ASD who do not have ID to achieve their maximum level of independence and develop sustainable careers. The current developmental disability service system does not appear to be accommodating the unique needs of individuals with ASD without ID.

The vulnerability of the group who had no daytime activities was demonstrated by the analysis of group differences in behavioral functioning. In terms of functional independence, those who had no day activities had more functional independence than those who were receiving adult day services, but less functional independence than those youths in a post-secondary educational program. Although findings were not significant, likely due to small sample size, the same pattern appeared for autism symptoms and maladaptive behaviors; those who had no activities had symptoms and behaviors that appeared less severe than those who were receiving adult day services. Their symptoms and behaviors appeared more severe than youths who were pursuing post-secondary education or who were competitively employed. Our findings suggest that there might be a group of youths with ASD in the mid-level of functioning—not severe enough to receive adult day services but too severe to function independently—who are “falling through the cracks” during the transition to adulthood. Future research should examine employment and day activities in a larger sample of young adults both with and without ID to determine whether the vulnerability of youths in the mid-level of functioning is apparent in other samples.

In addition, the percentage of young adults who had no daytime activities who had a comorbid psychiatric diagnosis was extremely high (86%). Although the differences in percentage with a comorbid psychiatric diagnosis by employment/day activity group were not statistically significant, this factor was likely a barrier to pursuing post-secondary education and employment for young adults with ASD and should be the focus of future investigations with greater statistical power.

On a more optimistic note, nearly 50% of youths with ASD without ID were pursuing a post-secondary educational degree. Although this percentage is considerably below the rate of college or university attendance for their peers who do not have ASD (62–69%; US Department of Education 2008), it suggests that the pursuit of a post-secondary degree is a viable option for many youths with ASD who do not have ID. Future research should examine whether youths with ASD who begin a degree-seeking, post-secondary program attain that degree, as well as whether having a post-secondary degree translates to a career that is sustainable over time.

The present study is limited by its small sample size, which may have led to difficulties finding group differences in the important variables of family income and comorbid psychiatric diagnoses. Furthermore, the sample in the larger study was a volunteer sample; most of the sample members were Caucasian and the sample was skewed toward those with higher SES. These factors place limits on the generalizability of the results to non-White
and lower SES populations, and studies are needed that examine the implications of race/ethnicity and SES for post-high school activities of youths with ASD. Because our study was not nationally representative but instead drew from two specific geographic locations (Wisconsin and Massachusetts), any application of our findings to other geographic regions should be made with caution.

Despite these limitations, our results nonetheless suggest important avenues for future research. More research with larger samples is needed to describe the transition process for youths with ASD as they exit the secondary school system and enter the adult world. Furthermore, as these results add to the mounting evidence suggesting that individuals with ASD face multiple difficulties in adult life, future research should explore mutable factors that promote a successful transition process and maximize adult outcomes.

Acknowledgments This project was supported by the Marino Autism Research Institute (J.L. Taylor, PI), the National Institute on Aging (R01 AG08768, M.M. Seltzer, PI) and the Eunice Kennedy Shriver National Institute of Child Health and Human Development (P30 HD15052, E.M. Dykens, PI; P30 HD03352, M.M. Seltzer, PI).

References


