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## Postsecondary Work and Educational Disruptions for Youth on the Autism Spectrum

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### Abstract

This study examined vocational/educational disruption in the 2–3 years after high school for 36 youth with autism spectrum disorder (ASD). Data were collected three times from parents: during youth's last year of high school and two times after high school exit. Data were coded into categories indicating any vs. no disruptions in postsecondary vocation/education, and group differences in individual (behavior problems, IQ, adaptive behavior, autism severity, stress reactivity) and family (parent depression, anxiety, quality of life; family income and climate) factors were examined. One-half of youth had experienced a postsecondary vocational/educational disruption; parents of those with a disruption had more depressive and anxiety symptoms and lower quality of life while their son/daughter was still in high school.

### Keywords

autism spectrum disorder; transition to adulthood; employment; post-secondary education; family; parental depression; parental anxiety

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A number of investigators – using both small, well-characterized cohorts and large nationally-representative samples – have found that adults with autism spectrum disorder (ASD) have exceedingly high rates of unemployment and underemployment (e.g., Howlin and Moss 2012; Levy and Perry 2011; Shattuck et al. 2012; Taylor and Seltzer 2011). Difficulties in employment and postsecondary education (PSE) among these adults is perhaps one of the most well-established findings in the realm of life course outcomes of ASD, found in nearly every study that examines this topic.

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Compliance with Ethical Standards

**Disclosure of Potential Conflicts of Interest:** The authors declare no conflicts of interest.

**Ethical Approval:** All procedures performed in studies involving human participants were in accordance with the ethical standards of the institutional research committee and with the 1964 Helsinki declaration and its later amendments or comparable ethical standards

**Informed Consent:** Informed consent was obtained from all individual participants included in the study.

However, this body of work faces a significant limitation that restricts its usefulness: most studies have examined employment or PSE participation at one point in time. Thus, although there is accumulating evidence describing difficulties *obtaining* employment/PSE for individuals with ASD as well as the phenotypic/behavioral factors that are associated with obtaining a job or gaining admittance to a PSE program, almost nothing is known about patterns or predictors of *sustaining* these positions once obtained. In order to best understand how to promote long-term vocational or PSE participation among adults with ASD, it is important to uncover the factors associated with successful entry into the workforce or a PSE program, *as well as* the factors that shield against disruptions in these activities, once they are obtained.

A few researchers have used longitudinal studies to consider employment/PSE participation over time for adults with ASD, focusing on consistency in *type of position* (e.g., working in the community with supports or attending a PSE program) over time, and not consistency in the *position itself*. They suggest that instability is common. For example, Taylor and colleagues (Taylor et al. 2015; Taylor and Mailick 2014) measured vocational/educational activities every 18 months across a decade; they found that adults with ASD tended to move from more to less independent positions over time (e.g., moving from supported employment in the community to sheltered pre-vocational settings). For those adults with ASD without an intellectual disability (ID), few had consistent employment in the community or consistently participated in PSE programs (although many are involved in these activities at a given point in time). Chan et al. (2017) had similar findings for adults with ASD and ID; a very small percentage was consistently participating in community employment over the course of the study. In contrast, Howlin and colleagues (2013) found, in their long-term follow-up study, that most adults with ASD who were employed in their mid-20s were also employed in their 40s.

These studies have shed important light on employment/PSE stability among adults with ASD, yet they almost certainly underestimate the true extent of vocational/PSE disruptions. If an adult with ASD was fired from a competitive job and then had a new competitive job at the next time point of data collection, for example, he or she would be considered consistently employed. The purpose of this study is to take the next step in understanding stability of postsecondary vocational and educational experiences by investigating the incidence of disruption in specific experiences for youth with ASD in the years immediately following high school exit.

Beyond characterizing the frequency of vocational/PSE disruption, the present study examined individual and family factors associated with disruption. A number of researchers (e.g., Howlin and Moss 2012; Shattuck et al. 2012; Taylor and Mailick 2014) have found that youth/adults with ASD who have less severe autism symptoms, greater adaptive behavior skills, fewer problem behaviors, higher IQ scores, and greater family incomes are more likely to obtain an employment or PSE position, and tend to have positions that involve greater independence (e.g., employed in the community with supports versus in a sheltered pre-vocational setting). However, there is some emerging evidence to suggest that different factors might be associated with sustaining employment. For example, in the Taylor et al. studies (Taylor et al. 2015; Taylor and Mailick 2014), autism severity, IQ, and adaptive

behavior were not associated with changes in vocational/PSE position over time (although they were associated with employment/PSE at a single point in time). Further, Chan et al. (2017) found that an indicator of family functioning (maternal social support) was associated with sustained employment among adults with ASD, though family functioning tends not to be independently related to employment/PSE at one point in time. Thus, it is important to understand the characteristics related to vocational/PSE disruptions among youth and adults with ASD, as they may not be the same factors related to initially obtaining these positions.

To our knowledge, this is the first study to examine disruptions in specific vocational and PSE activities for youth with ASD. The present study had two goals: 1) to use a well-characterized, phenotypically-diverse sample with detailed postsecondary activity data to understand the incidence of vocational/PSE disruption in the 2–3 years immediately following high school exit; and 2) to examine which individual and family factors, measured prior to high school exit, differ for those who go on to experience disruption compared to those who do not.

## METHODS

### Participants and Design

The present analysis included 36 families of youth with ASD who represented a wide range of functioning and were part of a larger, longitudinal study (Taylor and Henninger 2015; Taylor, Adams, & Bishop, 2017). The primary inclusion criteria at baseline 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 local clinics, support groups, service providers, autism organizations and other research studies. Upon entry into the study, ASD diagnoses were confirmed by clinicians with expertise in ASD based on scores from the Autism Diagnostic Observation Schedule (Lord et al. 2000) and the Autism Diagnostic Interview-Revised (Lord et al. 1994). Data were collected three times. Time 1 was conducted when youth with ASD were in their last year of high school [ $M=6.40$  ( $SD=3.29$ ) months prior to high school exit, Range=0.46–13.84], and Time 2 was collected when youth had been out of high school for a year or less [ $M=9.93$  ( $SD=2.40$ ) months after high school exit, Range=5.75–16.54]. Time 3 was collected when youth were 18 months to 3 years out of high school [ $M=27.59$  ( $SD=8.27$ ) months after high school exit], with 15 participants out of high school for 18–24 months, 14 participants out for 24–36 months, and 4 out for 36–46 months. Structured observations and direct testing of youth were completed at Time 1; parent questionnaires and interviews were administered at all waves. Study procedures were approved by the Vanderbilt University Institutional Review Board. Participant characteristics are presented in Table 1.

### Measures

**Dependent Variable: Vocational/PSE disruption**—At Times 2 and 3, a detailed vocation and PSE history was collected from parents about their sons/daughters. This included information about each job, vocational activity, or PSE program participated in since high school exit, as well as circumstances surrounding any job/vocational position losses or withdrawals from PSE programs. Using this information, each participant was

coded into one of two mutually exclusive groups: 0 = participated in PSE, employment, or a vocational program after high school exit with no disruptions. This group included youth who continued in the same job, PSE program, or sheltered pre-vocational setting over the post-high school period. It also included youth who were on upwardly mobile pathways (such as moving from a 2-year college to a 4-year college, moving from a supported employment position to competitive employment, or moving from no activities to employment); 1 = experienced at least one vocational/educational disruption after high school exit or never participated in any PSE, employment, or vocational program. This could include (for example), being fired from a job, withdrawing from a PSE program, or losing a position in a sheltered pre-vocational program due to changes in funding. All participants were coded into one of the categories by the authors, resulting in 89.7% agreement. The remaining cases were discussed until consensus was reached.

**Time 1 Factors Prior to Vocational/PSE Disruption**—Youth behavioral and phenotypic characteristics (i.e., individual factors), and family factors were measured at Time 1. Note that all measures were collected from parents except for full-scale *IQ score*, which was collected through direct assessment of youth using the Stanford-Binet (Roid 2003). The adaptive behavior composite from the Vineland Scales of Adaptive Behavior (Sparrow et al. 2005) was used to measure the son/daughter's *adaptive behavior* (higher scores = more adaptive behaviors), the total t-score of the Social Responsiveness Scale (Constantino and Gruber 2005) was used to measure the youth's *autism severity* (higher scores = greater symptom severity), and the total behavior problem t-score of the Adult Behavior Checklist (Achenbach and Rescorla 2003) was used to measure the youth's *behavior problems* (higher scores = more behavior problems). The son/daughter's *stress reactivity* was assessed using the Stress Survey Schedule (Grodin et al. 2001; higher scores = greater stress reactivity).

Family factors included *parental depressive symptoms* measured by the Centers for Epidemiological Studies Depression Scales (Radloff 1977; higher scores = more depressive symptoms), *parental anxiety symptoms* measured by the anxiety subscale of the Profile of Mood States (McNair et al. 1981; higher scores = more anxiety symptoms), *parental subjective quality of life* using the World Health Organization Quality of Life Scale – BREF (WHOQOL Group 1998; higher scores = greater quality of life), *family income* (ranging from 1 = *less than \$10,000* to 14 = *\$160,000 or more*), and *expressed emotion (EE)*. EE, a measure of family climate, was captured through the Five Minute Speech Sample (FMSS) based on the coding manual developed by Magaña et al. (1986). For the FMSS, parents were asked to speak about their son or daughter with ASD for five minutes uninterrupted. These speech samples were recorded, transcribed, and coded as 0 = low EE or 1 = high EE. Respondents are categorized as high in EE if they were rated as high on criticism and/or emotional overinvolvement (see Greenberg et al. 2006; Smith et al. 2008 for further detail of use in ASD samples). All FMSS transcripts were coded by an independent rater with over 20 years of experience in EE coding. All family factor measures have been used in our previous research and are more fully described elsewhere (Baker et al. 2011; Hong et al. 2016; Smith et al. 2008; Taylor, Henninger, & Mailick, 2015).

## Data Analysis

Descriptive statistics were used to examine postsecondary vocational/educational activities and frequency of disruptions. We used independent samples t-tests to investigate disruption group differences in individual and family factors; when the assumption of homogeneity of variance was violated (as indicated by Levene's test), corrections were used. Significance level was set at  $p < .05$ ; p-values between .05 and .10 also were noted.

## RESULTS

### Frequency of Vocational/PSE Disruptions in the Years after High School Exit

At Time 2, the first wave after high school exit, over one-half of the sample was enrolled in a PSE program (2-year, 4-year, or specialized college programs for individuals with intellectual/developmental disabilities) or employed in the community (with or without supports) more than 10 hours a week (52.8%,  $n=19$ ). An additional 16.7% ( $n=6$ ) were spending their days in sheltered pre-vocational settings; the remaining 30.6% ( $n=11$ ) were split between those who had no daytime activities ( $n=6$ ) and those who had vocational/educational activities of less than 10 hours a week (minimal activities;  $n=5$ ). Similar proportions were observed at Time 3: 63.9% of youth ( $n=23$ ) were employed in the community or enrolled in a PSE program; 11.1% ( $n=4$ ) were in sheltered pre-vocational settings; and 25% had no ( $n=7$ ) or minimal ( $n=2$ ) activities.

When considering activities over time, one-half of the sample ( $n=18$ ) were categorized into the "no disruption" group. Within this group, over half of the cases ( $n=10$ ) participated in the same activities (e.g., same sheltered pre-vocational setting, job or PSE program) since high school. Other cases within the "no disruption" group ( $n=8$ ) experienced some form of "upward mobility" including becoming employed while maintaining enrollment in the same PSE ( $n=3$ ), going from taking a few classes to being a full-time student in a PSE program ( $n=2$ ), going from a sheltered pre-vocational setting to a supported job in the community ( $n=1$ ), and going from no activities to a supported job ( $n=1$ ).

The remaining 50% of the sample either experienced a "disruption" ( $n=16$ ) or did not participate in any vocational or PSE activities following high school exit ( $n=2$ ). The most common reason for disruption was either failing out of a PSE program ( $n=5$ ) or choosing to leave a vocational/PSE experience ( $n=5$ ), often due to lack of adequate support. Other cases experienced disruption when fired from their jobs ( $n=4$ ) or due to circumstances outside their control such as family relocation or program changes ( $n=2$ ). The majority of those with a disruption had 1 disruption ( $n=13$  out of 16); one youth had been fired from two jobs, and two youth were fired from four jobs. We also note that for some cases ( $n=3$ ), although there was disruption in one aspect of their vocational/PSE experience, there was stability in another area (e.g., fired from job but remained enrolled in PSE). Notably, of the 8 cases in the "disruption" group who were participating in PSE or community employment at Time 2, all but one were participating in a similar activity at the next time point (e.g., community employment at Time 2, fired from job between time points, different community job at Time 3).

## Disruption Group Differences in Individual and Family Factors

Disruption group means and standard deviations, as well as t-values and effect sizes for group differences are presented in Table 2. We excluded the two participants who had never participated in vocational or PSE activities, resulting in 18 participants in the “no disruption” group and 16 in the “disruption” group. There were no significant relations between group and any of the individual factors (i.e., IQ, adaptive behavior, autism severity, behavior problems, and stress reactivity). In terms of family factors, relative to parents of youth without a disruption, parents of those who experienced a vocational/PSE disruption had higher depression and anxiety symptoms and lower quality of life when their son/daughter was in high school (large effect sizes), and were marginally more likely to be coded as high in EE (medium effect size).

## DISCUSSION

Adding to the growing literature on vocational outcomes for adults with ASD, the present study documented significant vocational and educational instability in the lives of young adults in the years immediately following high school exit. Fully 50% of our sample experienced some form of disruption in vocational/educational activities over a relatively short period of time (< 3 years for most). These disruptions were not minor and included job loss and expulsion from institutions of higher learning. For some cases, there were multiple instances of disruption (e.g., fired from 4 jobs). Further, the number of individuals in our study who were completely disengaged from employment/vocational activities/PSE at each time point (16.7% at Time 2, 19.4% at Time 3) was considerably lower than the number who experienced disruption across the study period (50%). Thus, many youth were losing jobs, pre-vocational positions, or places in PSE programs, and then starting again. These findings suggest that as a field we may need more sophisticated, longitudinal research designs, not only to document dynamic changes in the lives of individuals with ASD, but also to understand the pathways into and out of “successful” life course circumstances.

It is important to note that, though challenges were often observed, the picture of life after high school for young adults in this sample was not universally negative or marked by disruption. The majority (83.3%) was engaged in substantial (i.e., more than 10 hours a week) work, vocational activities, or PSE at some point after high school and half of the sample did *not* experience disruption. This is encouraging, particularly as the key factors which distinguished individuals in the disruption vs. no disruption group were malleable (i.e., parental anxiety, depressive symptoms, and quality of life), suggesting that stable positive outcomes are possible in this period and that contextual factors may play a role.

There are limitations to this study design – such as the relatively small sample size, under-representation of families with lower incomes and less education or who are racial/ethnically diverse, a skewing toward youth who are more cognitively-able, and a reliance on parent-report – that require findings to be interpreted with caution. Nevertheless, this brief report raises several provocative questions.

First, it may be that services and interventions to improve employment outcomes for adults with ASD are not as effective as one would hope because they are focused on the wrong

intervention target. In contrast with much of the literature on what predicts positive vocational outcomes for adults with ASD (e.g., Howlin et al. 2012; Henninger and Taylor 2013), individual characteristics such as IQ, adaptive behavior, autism severity, and behavior problems were not significantly different between those with and without disruptions after high school. In contrast, the two groups differed in parental psychological functioning. Although factors such as social skills and adaptive behavior have been suggested as important intervention targets for improving outcomes (Carter et al. 2014; Hume et al. 2014), the present study provides preliminary evidence for other mechanisms that may promote stability in vocational/educational experiences.

Research and services should focus not only on the factors that promote *obtaining* employment or PSE positions, but also on understanding and developing interventions aimed at addressing the factors that promote *sustaining* these activities. The role of the family has been virtually ignored in studies that examine employment outcomes for adults with ASD; yet, our findings suggest that families may provide supports and scaffolding needed for these adults to sustain employment and PSE. When families are distressed, they may not be able to provide these intensive supports, and disruption occurs. Future studies should more directly examine the link between parent functioning and their ability to provide support to their adult offspring with ASD. It may be that one avenue to promote their vocational/educational stability is to better support their parents. Importantly, these investigations should include both negative and positive indicators of parental/family functioning, as both were related to disruptions in our analyses.

Second, in our study, high levels of job/PSE disruption happened relatively quickly after high school exit. These transition years are a developmental period of instability for many young adults (Arnett 2000), with the average youth having 7 jobs between the ages of 18 and 28 (US Bureau of Labor Statistics, 2016). Job transitions for typically developing youth often reflect self-exploration and upward mobility, but our data suggests that vocational and PSE disruptions for youth with ASD are more likely to reflect poor fit or lack of appropriate supports. The meaning of these disruptions for employment prospects for youth with ASD throughout the lifespan remains to be seen. Although many young adults had a disruption (e.g., job loss or dropping out of a PSE program) and then were able to enter a new position relatively quickly, it may be that repeated disruptions during the critical years after high school exit set the stage for chronic unemployment or underemployment throughout adulthood. Alternatively, stability may be reached after a period of inconsistent vocational and educational experiences.

Longitudinal research is sorely needed to capture detailed information on employment activities throughout adulthood for those with ASD, to better understand the nature and timing of disruptions, as well as the long-term implications of frequent disruptions. Such research will also allow for more stringent tests of directionality of the associations between contextual factors and vocational/PSE disruptions. It may be that parental functioning leads to disruptions, or alternatively that youth instability after high school is a continuation of long-established behavioral patterns that lead to challenges in parental mental health. It is also important for future studies to develop appropriate comparison groups (e.g., typically developing youth or youth with other disabilities who have similar demographic

characteristics) and collect comparable data (e.g., disruptions across multiple types of activities, information on the nature of disruptions to separate upward mobility from other types of instability, similar time frames) to determine to what extent instability among youth with ASD is developmentally normative and when it is excessive. Further research with larger samples is also needed to probe for sex differences in disruption, as women with ASD (versus men) might be particularly vulnerable to instability in vocation/PSE over time (Taylor et al. 2015; Taylor and Mailick 2014).

In sum, our data suggest that, for youth with ASD, vocational/PSE disruptions are common in the years after high school exit. Factors that promote stability in vocation/PSE may be entirely different than those associated with obtaining these positions. Although most employment interventions focus on factors related to obtaining employment, we do a disservice to these youth and families by not understanding how to promote continued success in these positions. Future research is needed to understand employment and PSE participation across the life course, the long-term implications of difficult transitions for individuals with ASD, and the range of mutable factors that facilitate employment/PSE success throughout adulthood.

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**Table 1**

## Descriptive information of the sample

	<b>n (%)</b>	<b>Mean (SD); Range</b>
<b>Youth</b>		
Age (in years) at Time 1		18.67 (1.31); 17.18–22.00
Sex		
Male	30 (83.3%)	
Female	6 (16.7%)	
Total IQ Standard Score		85.03 (25.52); 40–137
Vineland Adaptive Behavior Composite		64.56 (14.56); 23–84
Intellectual Disability		
Yes	10 (27.8%)	
No	26 (72.2%)	
Race/ethnicity		
White non-Hispanic	33 (91.7%)	
African-American	2 (5.6%)	
Other	1 (2.8%)	
<b>Parent</b>		
Age (in years) at Time 1		50.24 (4.66); 38.33–59.19
Sex		
Male	4 (11.1%)	
Female	32 (88.9%)	
Marital status		
Married	25 (69.4%)	
Separated/divorced	9 (25%)	
Never married or widowed	5 (5.6%)	
Highest level of education		
High school diploma or less	4 (11.1%)	
Some college/2-year degree	8 (22.2%)	
4-year degree	10 (27.8%)	
Post 4-year degree	14 (38.9%)	

Table 2

Group differences in individual and family factors by disruption category

	"Disruption" Group (n=16)		"No Disruption" Group (n=18)		t-value	Cohen's d
	Mean	SD	Mean	SD		
<b>Individual Factors</b>						
IQ score	88.50	23.19	82.06	28.57	-0.71	0.25
Adaptive behavior	63.44	16.08	65.17	14.30	0.33	0.11
Autism severity	78.25	11.21	76.83	14.27	-0.32	0.11
Behavior problems	59.00	8.21	58.28	7.14	-0.28	0.09
Stress reactivity	2.21	0.66	1.88	0.50	-1.65	0.56
<b>Family Factors</b>						
Parental depressive symptoms	15.31	12.46	6.39	6.72	-2.55*	0.89
Parental anxiety symptoms	11.00	8.82	5.50	4.44	-2.25*	0.79
Parental quality of life	15.30	1.81	17.09	2.29	2.50*	0.87
Family income	8.13	4.29	8.89	3.31	0.59	0.20
Expressed Emotion	0.50	0.52	0.19	0.40	-1.91 <sup>†</sup>	0.67

<sup>†</sup> p < .10

\* p &lt; .05

\*\* p &lt; .01

Note. SD=standard deviation. We present results from Expressed Emotion as a t-test for ease of presentation; chi-square yields identical results.