

Early work experiences among Supplemental Security Income (SSI) recipients with autism:

Preliminary findings

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Abstract

This study used data from the National Longitudinal Transition Study 2012 (NLTS2012) to examine the prevalence and correlates of early work experiences among Supplemental Security Income (SSI) recipients with autism, compared to recipients with other disabilities. A secondary aim of this study was to characterize the population of SSI recipients with autism spectrum disorder (ASD), ages 13-21 years, enrolled in special education. We first conducted tests of significance to examine between-group differences in early work outcomes by disability status and SSI benefit receipt. Then, we employed logistic regression analysis to identify factors associated with greater odds of participation in early work among transition age youth (TAY) with ASD. Our findings indicate that a substantial proportion (31 percent) of households of TAY with ASD report a history of SSI benefit receipt. This subpopulation of TAY with ASD may be especially vulnerable during the transition into adulthood due to economic disadvantage, health-related challenges and low rates of employment training in high school. Our preliminary findings also suggest that TAY with ASD may be discouraged from participating in early work in fear of losing their benefits, although SSI benefit receipt was not significantly associated with early work among TAY with ASD. Findings from this study can inform rehabilitation policies and services by identifying underserved subpopulations that need a higher allocation of targeted assistance during the transition into adulthood. Implications for policy and practice are discussed.

Keywords: autism, transition, employment, supplemental security income

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Autism spectrum disorder (ASD) is a lifelong neurodevelopmental condition that is characterized by difficulties in social communication and repetitive or restrictive behaviors (American Psychiatric Association, 2013). The most recent estimates indicate that one in 58 American children meet case criteria for ASD (Baio, 2018) and roughly 50,000 adolescents with ASD transition into adulthood each year (Shattuck, Roux, et al., 2012). Findings from nationally representative samples of transition age youth (TAY) with ASD find discouragingly high rates of disconnection from employment after high school (Roux et al., 2013; Roux, Shattuck, Rast, Rava, & Anderson, 2015). When compared with other types of disabilities, TAY with ASD receive needed services less frequently and experience higher rates of disconnection from postsecondary employment and education - even after adjusting for disability severity (Shattuck, Narendorf, et al., 2012; Shattuck, Wagner, Narendorf, Sterzing, & Hensley, 2011). This alarming disconnect can have a profound and long-lasting impact on later economic security and result in increased reliance on public benefits throughout adulthood (Krahn, Howard, & Galambos, 2015). As the number of TAY with ASD continues to grow, so too does the need for rehabilitation services that produce optimal employment outcomes.

Increasing youth's access to work experiences during high school may have a positive impact on later employment (Colley & Jamison, 1998; Fabian, 2007; Luecking & Fabian, 2000; Mamun, Carter, Fraker, & Timmins, 2017; Test et al., 2009). For example, a recent national report found that 90 percent of youth with autism who had a job during high school also had a job during their early twenties, compared to just 40 percent of youth with ASD who did not work during high school (Roux et al., 2015). Early work experiences can also help youth develop

career interests, identify and acquire job-related skills, increase motivation to work and expand social networks (Burgstahler & Bellman, 2009; Zimmer-Gembeck & Mortimer, 2006).

Considering this growing evidence, early work experience has been integrated in several transition frameworks and policies in recent years (Federal Partners in Transition (FPT) Workgroup, 2015; Morris & Goodman, 2013).

The Social Security Administration (SSA) has invested considerable resources in identifying strategies that promote early work experiences among TAY with disabilities (Fraker, 2013). For example, SSA's Youth Transition Demonstration, a multisite project that provided employment services and work incentives to transition age youth on disability rolls, emphasized school-based preparation experiences and work-based learning in their program model (Fraker et al., 2014). SSA also provides several work incentive programs which allow recipients to work without losing their cash benefits and/or Medicaid. The United States Government Accountability Office (2012) also identified the importance of secondary work experiences, recommending that federal agencies work together to ensure that youth with disabilities have an equal opportunity to integrated work-based experiences in high school.

Despite this growing emphasis, outcomes remain poor among child SSI recipients (Davies & Fisher, 2009; Loprest & Wittenburg, 2007). In particular, descriptive studies of child SSI recipients report consistently low participation in work-related experiences among youth (Loprest, 2005; McDonnall & O'Mally, 2012; Rupp et al., 2005; Wittenburg & Loprest, 2007). However, gaps persist in our understanding of early work experiences among SSI recipients with ASD. Much of what we know about child SSI recipients is drawn from heterogeneous samples of youth with disabilities, across a wide range of mental health disorders. These studies highlight disparities in employment by SSI receipt, but do not address how differences in outcomes may

vary as a function of disability category. At present, it is unclear whether these findings persist within the subgroup of SSI recipients with ASD. Identifying correlates of early work that are unique to SSI recipients with ASD can help to ensure that current policies are commensurate with the needs of this growing population.

Literature Review

Overview of the SSI Program.

Administered under SSA, the Supplemental Security Income (SSI) program provides monthly cash payments to financially eligible children and adults with disabilities (Social Security Administration, 2017). In 2011 (the year in which data for this study were collected) the maximum federal SSI payment was \$674.00/month, for an annual rate of \$8,088 (Social Security Administration, 2012). In addition to cash benefits, SSI also often facilitates access to healthcare (Burns & Dague, 2017). For example, although states set their own guidelines about application procedures, thirty-two states and the District of Columbia automatically enroll SSI recipients in Medicaid (Social Security Administration, 2018c).

To qualify for SSI, children under age 18 and their families must meet federally defined assets and income standards as well as categorical criteria for disability. Financial eligibility criteria are drawn from a complex set of rules requiring that the parent's and child's income and assets do not exceed a certain threshold (Social Security Administration, 2017). Monthly SSI benefit amounts vary with changes in recipient income and assets. In general, SSI benefits are reduced \$1 for every \$2 in earnings (above \$65). In addition to meeting financial criteria, children under age 18 must also demonstrate that they have "a medically determinable physical or mental impairment which results in marked and severe functional limitations." Upon their 18th birthday, children are required to undergo a redetermination of eligibility based on adult

disability criteria. For adults, SSA defines disability as the, “inability to engage in any substantial gainful activity (SGA) by reason of any medically determinable physical or mental impairment(s) which can be expected to result in death or which has lasted or can be expected to last for a continuous period of not less than 12 months” (Social Security Administration, 2012). In 2011 (the year in which data for this study were collected) SGA referred to earning from work activity of more than \$1,000 a month (Social Security Administration, 2012).

Transition Age SSI Recipients with ASD.

Children with ASD represent a large and growing share of total SSI recipients with mental disorders – increasing from 8 percent of all recipients with selected major mental disorders in 2004 to 21 percent in 2014 (National Academies of Sciences & Medicine, 2015). Many of these youths will likely continue to rely on SSI well into adulthood. A recent study of age-18 redeterminations found that roughly 91 percent of child SSI recipients with ASD continue to receive benefits as adults (Hemmeter, 2012).

Findings from broad samples of transition age SSI recipients with mental disorders suggest that child SSI recipients face poorer outcomes relative to their peers who do not receive SSI (Davies, Rupp, & Wittenburg, 2009). Transition aged SSI recipients who have difficulty establishing themselves in the labor market risk experiencing disconnection from opportunities to develop human capital and participate in income generating activities. According to a 1995 study, individuals who begin receiving SSI prior to age 18 accumulate over 25 years of benefits on average (Rupp & Scott, 1995).

There has been some research on the factors that influence employment among broad samples of transition age SSI recipients (not specific to autism). Relevant factors are generally grouped into individual/family characteristics and service system factors (Davies et al., 2009;

Wittenburg & Loprest, 2007). Family poverty, single-parent households, minority status, low education achievement, and poor health have all been found to be associated with low rates of labor market participation among young adults and transition age SSI recipients (Bardos & Livermore, 2016; Berry, 2000; Davies & Fisher, 2009). Systems-level factors associated with postsecondary employment include job training experiences and supported employment (Berry & Caplan, 2010; Wittenburg & Loprest, 2007). Several studies have also identified a meaningful relationship between primary impairment and employment among SSI recipients (Mann, Mamun, & Hemmeter, 2015).

Although these studies help to provide a national picture of SSI recipients, early work experience is largely viewed as a covariate, rather than outcome. Most research focuses on heterogeneous samples of youth with disabilities, with many studies focusing on a wide range of mental health disorders. The studies that do include ASD as a subpopulation frequently do not make explicit comparisons. This is problematic because the significant predictors of service use presented in the literature may not transfer to individuals with autism, who often have distinct and complex service needs.

Outcomes of TAY with ASD. Although research related to transition age SSI recipients with ASD is limited, there is a growing body of research on the population of TAY who receive special education services under the ASD disability category. Findings from these studies indicate that TAY with ASD have poorer outcomes relative to their peers with similar disabilities across a wide range of domains including employment, postsecondary education, independent living and social participation. In addition, TAY with ASD experience significantly higher rates of disconnection from services (Shattuck et al., 2011) and are less engaged in transition planning (Shogren & Plotner, 2012).

Most of the research that examines transition and ASD focuses on individual-level factors, such as symptom severity and cognitive ability, to explain variation in postsecondary outcomes (Anderson, Roux, Kuo, & Shattuck, 2018; Henninger & Taylor, 2013). These findings suggest that the core features of ASD – namely challenges with communication and social interaction – inhibit employment. As a result, TAY with ASD often require a higher intensity of instruction (Wehman et al., 2013) and more costly vocational services (Cimera, 2009). In spite of the unique needs associated with having ASD, many TAY with ASD do not receive needed employment services and supports before exiting high school. Recent research shows that secondary students with ASD experience lower rates of paid community work in high school compared to their peers in other disability categories (Roux, Rast, Anderson & Shattuck, 2018). Taken together, these findings suggest that SSI recipients with ASD are an especially vulnerable subpopulation of youth that warrants further investigation.

Despite this, SSI has been vastly overlooked in autism research. Likewise, poverty research rarely disaggregates findings by disability group. Given that disability and poverty are significant predictors of one another, and considering increased number of SSI recipients with ASD, a better understanding of these interactions is essential. To address gaps in extant literature, this study provides a preliminary investigation of the prevalence and correlates of early work among transition age SSI recipients with ASD. A secondary goal of this paper is to characterize the population of SSI recipients on the autism spectrum enrolled in special education. The study's specific aims and hypotheses are as follows:

- 1) To produce and compare national benchmarks of early work experiences between transition age SSI recipients with autism and other disability groups.
- 2) To identify correlates of early work among transition age SSI recipients with autism.

- 3) To determine if there is an association between SSI benefit receipt and early work among TAY with ASD.

The success of SSA's work-related interventions hinges on a holistic understanding of the conditions and characteristics of SSI recipients. Findings from this study will help to build a foundation of population-level evidence that can inform the development and evaluation of SSA's work-related programs and policies.

Methods

This study used data from the National Longitudinal Transition Study 2012 to examine the prevalence and correlates of early work among transition age SSI recipients with ASD, ages 13 through 21 years. A secondary aim of this paper was to characterize the population of SSI recipients on the autism spectrum enrolled in special education. Use of these data is governed by a data-use agreement with the U.S. Department of Education. The analysis of these secondary datasets was deemed exempt by the Drexel University Institutional Review Board.

Data Source.

Funded by the U.S. Department of Education, the National Longitudinal Transition Study 2012 (NLTS2012) examines a large nationally representative sample of youth, ages 13 through 21 years, who received special education services during the 2012/2013 academic school year. The NLTS2012 was designed to identify the challenges transition age youth with disabilities face as they prepare for life after high school. Topics include family and school characteristics, functional abilities, in-school activities, and use of services and supports (Burghardt et al., 2017).

The study's target population consisted of students who had an individualized education plan, which grants access to special education services under Part B of the Individuals with Disabilities Education Act (Individuals with Disabilities Education Act (IDEA), 2004).

Comparison groups included youth who received accommodations under Section 504 of the Rehabilitation Act but had no IEP, and students with neither a 504 plan nor an IEP. Under the IDEA of 2004 a student must meet eligibility criteria under 1 of 12 disability categories to qualify for special education services (34 C.F.R. Part 300 § 300.8 I). To ensure all 12 disability categories were accounted for, the NLTS2012 employed a two-stage sampling design, first stratifying schools by region and district size. Within each district stratum, the study then selected a stratified sample of youth from school rosters and families were invited to participate. The 14 youth sample strata included the 12 IDEA disability groups, youth with a 504 plan but had no IEP, and those with neither a 504 plan nor an IEP. Analysis weights were applied to each disability category and age group yielding nationally representative data that can be generalized to the entire population of youth enrolled in special education.

The NLTS2012 collected data from parent and youth interviews and district surveys. Parent and youth surveys were either administered by telephone, via a computer-assisted telephone interviewing system, or through web-based surveys. The parent survey was administered first and contained questions about the youth's school experiences, hopes for the future and basic information about the household. If the parents consented, youth were asked to complete an additional survey which contained questions about their school experiences and plans for the future. Youth who were their own guardian and over the age of 18 years could consent for themselves. Parents could act as proxies when youth were unwilling or unable to answer the questions (Burghardt et al., 2017). Data for this study were drawn primarily from parent and youth surveys.

Sample.

The study sample included students who had an IEP under the autism disability category. Roughly 955 students in the ASD group had completed youth interviews by the end of the study period, a response rate of roughly 58 percent. Among them, 33 percent of interviews of students with ASD relied on a proxy (Lipscomb et al., 2017). Students who were not enrolled during the reference school year of the parent's survey were excluded. The final ASD sample comprised of 890 transition age youth. However, prior research suggests that the autism category in special education very rarely includes students who would not also meet case criteria for an autism spectrum diagnosis (Yeargin-Allsopp et al., 2003).

We constructed three mutually exclusive comparison groups to contextualize our findings. The intellectual disability (ID) comparison group included 1,020 transition age youth who had an IEP under the ID special education category. Likewise, the emotional disturbances (ED) comparison group included 950 transition age youth who had an IEP under the ED special education category. The final comparison group combined 11,440 transition age youth across the remaining 10 special education categories including: deaf-blindness, hearing impairment, multiple disabilities, orthopedic impairment, other health impairment, specific learning disability, speech or language impairment, traumatic brain injury, and visual impairment. This group also included an additional category of youth who received an IEP but had an unspecified disability.

We chose to compare the ASD group to transition age youth with ID and ED because they are high-incidence impairment categories among child SSI recipients (National Academies of Sciences & Medicine, 2015) that present overlapping attributes of ASD (Matson & Williams, 2013). Findings from nationally representative samples also indicate poorer work-related outcomes among TAY with ASD, ID and ED, relative to other disability groups (Wagner,

Newman, Cameto, & Levine, 2005). A more nuanced comparison across disability groups may help to illuminate mechanisms that underlie differences in work-related outcomes.

Measures.

SSI benefit receipt. SSI benefit receipt was a dichotomous variable measured at the household-level. Participants were asked the following yes-no question, “Did you or anyone in the household get money for {YOUTH} from the Supplemental Security Income or SSI program in the past 2 years?”

Outcomes.

Early work experiences. We examined two dichotomous measures of early work during high school: any work experience and paid work experience. Measures of early work experiences were derived from a series of questions related to student participation in either school-sponsored or non-school-sponsored work. Students were asked if they participated in any school-sponsored work activities (including work-study or co-op job, an internship or school-based business) within the past 12 months. If the student responded “yes,” they were asked if they got paid for that work activity. Students were then prompted to think about paid work other than school-sponsored jobs. Students were asked if at any time in the past 12 months, they did any work for pay, other than work around the house (which included being a babysitter or working for a neighbor). From these questions, we constructed two dichotomous measures of early work experiences: *any work experience* refers to both school-sponsored and non-school sponsored work in the past 12 months, regardless of pay; and *paid work experience* refers to the subgroup of students who participated in *paid* school-sponsored or non-school sponsored work within the past 12 months.

Characteristic of early work experiences. Students who participated in school-sponsored work activities (either paid or unpaid) were asked a series of follow-up questions related to the characteristics of their work experience. We examined whether students reported receiving credit for their school-sponsored work activity (0=no, 1=yes), how many hours a week they usually worked in the school-sponsored job, and whether the school-sponsored work activity was related to a particular job or career interest (0=no-the work is not in a career/job the student is interested in (or) the student does not have a particular job/career interest, 1=yes). Related questions were asked of students who had worked for pay in the past 12 months. We report the time of year the student worked (1=only during the school year, 2=only during the summer, 3=both) and how many hours the student usually worked in the summer and/or the school year.

Covariates. We grouped covariates into the following categories: sociodemographic characteristics, individual impairment, household circumstances and family characteristics, and family and school characteristics and experiences.

Sociodemographic characteristics included child's: sex, race, and ethnicity. Age was reported as both a continuous variable (in years) and as a binary measure (0=less than 18 years old, 1=18 years or older). We included this measure to capture the subgroup of recipients who may receive SSI benefits under the adult program.

Individual impairment. Individual impairment measures included: how well child communicates, child's health, how well child uses an ATM or cash, and how well child gets to places outside of the home. We developed a composite measure of household chores using the following four items indicating how often youth: fixes own breakfast, does laundry, straightens up his/her room or living area, and buys things at the store. All responses were made on a 4-point Likert scale from (1) never to (4) always. We summed the responses into a composite

household chores scale ranging from 4 to 16 (Cronbach's alpha = .86). Findings are presented as a continuous measure and as quartiles.

Household circumstances and family characteristics. Household circumstances and family characteristics included: parent's highest education level; parental employment (0=neither parent has a paid job (or) single parent does not have a paid job, 1=either parent has a paid job (or) single parent has a job); family structure (0=two-parent household; 1=single mother household); number of children or adults in the household; household federal poverty level, or FPL (0=below 185 percent FPL, 1=above 185 percent FPL); English as a primary language in the household; household receipt of TANF in past two years; household receipt of SNAP in past two years; and receipt of government sponsored or public health insurance.

School characteristics and experiences included: high school urbanicity (0=city; 1=suburb; 2=town or rural); youth participation in volunteer work in the past 12 months; and three binary measures indicating whether the youth, parent or staff from a community service agency attended a transition-planning meeting.

Barriers to postsecondary employment. Questions related to employment were only asked if the student was age 15 years or older. Respondents were asked to report whether the following will be an issue: physical or mental health issues could prevent {YOUTH} from working; {YOUTH} might lose SSI or other benefits; and staff at the high school has not provided enough information about career planning or job opportunities.

Analysis.

Rates of missing data per independent variable ranged from 0 percent to 11 percent in the ASD group. Weights and variances were adjusted to account for the sampling of the dataset using the "svy" procedures available in Stata v. 14. To address Aim 1, we first used univariate

proportions and 95 percent confidence intervals to summarize population characteristics and employment outcomes of TAY with ASD relative to other disability groups (Tables 1-2). Then, we employed logistic regression with dummy coding to compare unadjusted rates of early work among TAY with ASD to other disability groups (Table 3). Finally, we compared odds ratios of early work across disability groups while adjusting for covariates (Table 4).

To address Aim 2, we used basic logistic regression to directly model the odds of early work among TAY with autism while adjusting for sociodemographic characteristics, individual impairment, household circumstances and school characteristics (Table 5). To address Aim 3, we conducted bivariate analyses to determine if SSI benefit receipt was associated with greater odds of early work among TAY. We also present descriptive statistics on the proportion of TAY who reported “loss of SSI benefits” as a potential issue to getting a job after high school (note: this question was only asked of TAY ages 15 and older). Reported barriers to postsecondary employment are presented in Table 6.

A secondary purpose of this research study was to characterize the population of SSI recipients with ASD. Therefore, we included a wide range of population characteristics to describe our sample. Many of these characteristics were omitted from our regression models predicting early work due to multicollinearity and concerns related to model fit. We drew from extant research about early work and child-SSI recipients to inform our regression models (Carter, Austin, & Trainor, 2011; Davies et al., 2009; Hughes et al., 2004).

Results

The combined sample of SSI recipients included 2,940 students, or 21 percent of the eligible sample population. About 31 percent (N=290) of households of TAY with ASD received SSI benefits – a proportion similar to the ED group (32 percent, N=310). By comparison, 54

percent (N=560) of households of TAY with ID and 17 percent (N=1,780) of households of TAY with other disabilities received SSI benefits.

Characteristics of SSI Recipients

Table 1 describes the population characteristics of TAY with ASD, relative to their peers in other disability categories. Compared to TAY in other disability groups, those in the ASD group were more likely to be White (72 percent) and live in households above 185 percent of the FPL (30 percent). Roughly 58 percent of TAY with ASD were from families where the highest level of education in the household was high school or less, compared to 75 percent in the ID group ($p<.001$) and 70 percent in the ED group ($p<.001$). The ASD group also reported generally better overall health compared to their peers in other disability categories (with 35 percent reporting excellent health). The ASD group reported the lowest rates of TANF and SNAP receipt across disability groups (11 percent and 43 percent, respectively). Financial expectations were also lowest in the ASD group, with 36 percent of parents reporting that their child definitely/probably will be financially independent by age 30.

In terms of impairment characteristics, the ASD group was most like the ID group with respect to communication ability and functional skills. However, TAY in the ASD group did not complete household chores as frequently as the ID group. Roughly 65 percent of TAY with ASD and ID were 18 years or older, a significantly smaller proportion relative to TAY with ED (88 percent) and all other disabilities (84 percent). Conversely, the ASD group had significantly lower communication and functional skills relative to the ED group. For example, roughly 40 percent of TAY with ASD reported having no trouble communicating compared to 81 percent of TAY with ED. Just nine percent of TAY with ASD could use the ATM machine pretty or very

well (versus 37 percent of TAY with ED) and 40 percent could get to places outside of the home pretty or very well (versus 87 percent of TAY with ED).

There were no group differences related to youth or parent engagement in transition planning. Roughly half of TAY reported that a community service agency attended their transition-planning meeting. All disability groups reported low rates of volunteer experience (between 18-22 percent).

Aim 1. National Benchmarks of Early Work Experiences Across Disability Groups.

Table 2 presents weighted proportions of early work participation and characteristics. In the past 12 months, roughly 36 percent of TAY with ASD had some work experience (either paid or unpaid) and 23 percent of TAY with ASD had worked for pay. There were no significant between-group differences in early work when the outcomes were categorized by payment (i.e., “any work in the past 12 months” and “any paid work in the past 12 months”). However, there were some group differences when outcomes were disaggregated by school-sponsored work and non-school-sponsored paid work. TAY with ASD and ID had higher rates of school-sponsored work and lower rates of paid non-school sponsored work than the other disability groups. Roughly 25 percent of TAY with ASD participated in school-sponsored work. Among them, 41 percent reported that the work activity was related to their career interest and 38 percent were paid for this work. A smaller proportion of TAY with ASD received school credit for this work (59 percent) compared to all other disability groups, although these differences were only statistically significant relative to the ED group.

A significantly smaller proportion of TAY with ASD participated in non-school-sponsored paid work (14 percent) relative to their peers with ID (22 percent), ED (36 percent) and all other disabilities (32 percent). However, the characteristics of these experiences did not

vary across disability groups in terms of type of work and hours worked per week. Among the subgroup of TAY with ASD that participated in non-school-sponsored paid work, roughly 21 percent worked during the school year only, 25 percent worked during the summer only and 54 percent worked during both. On average, TAY with ASD worked 13 hours a week during the summer and 8 hours a week during the school year.

With the exception of school-sponsored work, TAY in the ASD group had lower unadjusted odds of early work compared to all other disability groups (Table 3). Differences in early work between the ASD and ID group were no longer significant after adjustment for sociodemographic and individual impairment (Table 4). However, the adjusted odds of non-school-sponsored paid work were 2.3 ($p < .01$) times higher for the ED group and 2.0 ($p < .001$) times higher for the other disabilities group compared to TAY with ASD.

Aim 2. Correlates of Early Work Among Transition Age SSI Recipients with Autism.

Regarding correlates of early work (Table 5), the adjusted odds of any work experiences were significantly lower among African-American TAY with ASD (OR=0.1, 95 percent C.I. 0.0,0.8, $p < .05$) and 5.5 (95 percent C.I. 1.5,19.7, $p < .05$) times higher among youth who had a community service agency attend their transition planning meeting. The adjusted odds of any paid work experience was higher among those with no trouble communicating (OR=15.7, 95 percent C.I. 1.7,151.0, $p < .05$) and those attending suburban schools (OR=19.3, 95 percent C.I. 1.7,222.9, $p < .05$); however, these estimates may lack precision (as indicated by their wide interval range) due to small sample size.

Aim 3. Association Between SSI Benefit Receipt and Early Work.

We conducted bivariate tests of significance within each disability group to examine whether the odds of early work vary significantly by SSI benefit receipt (data not shown). Early

work, paid or unpaid, did not vary by SSI benefit receipt within the ASD group or the ED group. However, the odds of having any paid work experience were 0.60 times lower among transition age SSI recipients with ID compared to non-recipients ($p < .01$). We also reported descriptive findings related to the perceived impact SSI benefits may have on postsecondary employment. Roughly 52 percent of TAY in the ASD group, ages 15 and older, cited the potential loss of SSI or other benefits as an issue to getting a job after high school (Table 6). This proportion was similar to those presented in the ID group (44 percent), ED group (55 percent) and all other disability categories (40 percent).

Discussion

Prior research suggests that both SSI recipients and TAY with ASD are separately at risk for poor outcomes, yet few studies have described the conditions and characteristics of TAY who meet both conditions. This study used nationally representative data to examine the prevalence and correlates of early work experiences among SSI recipients with ASD and compared them to recipients in other disability groups. A secondary aim of this study was to characterize the population of SSI recipients with autism enrolled in special education. Findings from this study build upon existing research by describing the needs of financially disadvantaged households of TAY with ASD – a profoundly understudied subgroup in autism research. Further, the data examined in this study allow for a more nuanced comparison of outcomes across sociodemographic characteristics and disability severity, which will help to identify determinants of disparate outcomes across diagnostic groups. Organizations can use this information to educate policymakers about the unique needs of TAY with ASD in hopes of leading to more targeted interventions and programs.

Our findings indicate that a substantial proportion (31 percent) of households of TAY with ASD report a history of SSI benefit receipt. This subpopulation of TAY with ASD face several employment barriers related to disability characteristics and poverty. For example, roughly 70 percent lived in households within 185 percent of the FPL and just 61 percent of households had an employed parent. Parent expectations are generally low for TAY with ASD and many parents did not participate in transition planning. Family resources are highly associated with a wide range of postsecondary outcomes including employment, independent living and higher education (Anderson et al., 2018). Studies also suggest that high parental expectations can help to mitigate the adverse effects of low socioeconomic position and disability severity among TAY with ASD (Kirby, 2016). Identifying strategies that promote parent engagement and expectations among TAY with ASD may help to facilitate early work.

Our preliminary findings also suggest that TAY with ASD may be discouraged from participating in early work in fear of losing their benefits, although SSI benefit receipt was not significantly associated with early work among TAY with ASD. SSI recipients in other disability and age groups have reported similar concerns related to employment (Bardos & Livermore, 2016; Livermore & Bardos, 2017; Livermore, Bardos, & Katz, 2017). To promote engagement in work, SSA has implemented several work incentive programs. Notably, the Student Earned Income Exclusion (SEIE) permits students under 22 years to earn up to \$1820 per month without losing SSI benefits in 2018 (Social Security Administration, 2018a). However, few TAY participate in such programs (United States Government Accountability Office, 2017). Wittenburg and Loprest (2007) report that only 22 percent of child SSI recipients age 14 to 17 have ever heard of the SSA work incentives or discussed them with an SSA representative. Likewise, findings from a representative sample of SSDI beneficiaries and SSI recipients

indicate that just 8.7 percent of eligible recipients were aware of the SEIE (Social Security Administration, 2018b). Potential strategies may include leveraging transition planning meetings to communicate to parents and youth the various work incentives offered through SSA.

Some scholars recommend volunteer work to promote the development of human capital among SSI recipients (Campolieti, Gomez, & Gunderson, 2009; Timmons, Zalewska, Hall, & Fesko, 2017). This argument is based on empirical evidence that public benefit receipt increases the propensity to engage in volunteer work, perhaps because unpaid work will not impact benefits (Campolieti et al., 2009). Findings from qualitative studies of TAY with ASD also indicate that volunteer work is associated with the development of career interests and skills (Timmons et al., 2017). That said, non-paid work experiences are not as strongly associated with postsecondary employment as paid work (Carter, Austin, & Trainor, 2012; Mazzotti et al., 2016), suggesting that resources may best be directed towards facilitating the latter. Promoting volunteer work in concordance with, or prior to, paid work experiences may result in better post school outcomes for TAY with ASD. Although TAY with ASD were more likely to engage in unpaid school-sponsored work than their peers in other disability groups, engagement in volunteer work was limited among TAY with ASD (18 percent of TAY with ASD participated in volunteer work in the past 12 months). Further research is needed to identify strategies that promote volunteer work among TAY with ASD.

More than half (roughly 66 percent) of the total number of SSI recipients in the ASD group are between 18-23 years. These findings suggest that a considerable number of TAY with ASD may participate in the adult SSI program; however, it is unclear whether participation rates vary across disability groups. Anderson et al. (in process) used SSA program data to examine the characteristics of working-age SSI awardees (ages 18-64 years) who received their first adult SSI

payment under an ASD primary impairment classification between 2005 and 2017. The authors compared findings to the population of working-age SSI awardees with a primary impairment classification of intellectual disability during the same time period. The study found that roughly nine out of every ten adults in the ASD group were between 18-25 years, compared to 53 percent of adults in the ID group. These findings suggest that the population of adult SSI awardees with ASD is significantly younger than awardees with ID. Indeed, Hemmeter et al. (2012) also found that TAY with ASD apply for SSI at greater rates when they turn 18 years old and have higher allowance rates than other disability groups. While these findings suggest that many TAY with ASD pursue SSI benefits after their 18th birthday, it is unclear if participation rates are proportionate to changes in ASD prevalence among low-income households. To date, we do not have accurate prevalence estimates of adults with ASD, which impedes our ability to compare participation between special education recipients to the general population of transition age young adults with ASD.

Strengths and Limitations.

Because of difficulties identifying disability characteristics in administrative data, little is known about the interrelationships between impairment severity, rehabilitation and employment among SSI recipients with ASD. The NLTS2012 offers the unique opportunity to describe this population's characteristics and compare them to recipients in other disability groups. The NLTS2012 is also the most recently available dataset to provide nationally representative estimates about secondary special education students. Despite these strengths, there are some limitations to the data.

First, survey responses were drawn from self-reports of parents and youth which may have error due to imperfect recall. Moreover, our analyses were confined to a binary, retroactive

measure of early work spanning a 12-month period. We cannot infer causal relationships between variables because the temporal ordering of variables is unclear. For example, we cannot be sure that our independent variables precede our dependent variable. In addition, predictors and covariates overlapped with the time for which households reported receipt of SSI – a period spanning two years. Future analysis of longitudinal data can help to unveil causal relationships across variables and provide measures of SSI enrollment duration. Another consideration is the age range within our study sample, which comprised all TAY (ages 13 to 21 years) who received SSI benefits within the past two years. We chose this wide age range to provide estimates that generalize to all TAY enrolled in special education. That said, we cannot discern whether TAY, ages 18 years or older, received SSI benefits under the child or adult program. Further research is needed to capture possible differences between TAY receiving child SSI and those enrolled in the adult program.

Finally, our findings are not representative of all TAY on the autism spectrum enrolled in SSI. The study's sampling frame consisted of individuals who were already engaged in special education, which may result in an underrepresentation of people who have autism but were not diagnosed by school personnel or medical professionals. That said, findings from nationally representative samples of SSI recipients report high rates of participation in special education, suggesting that our findings are relevant to a substantial portion of the population of SSI recipients with ASD. Rupp et al (2005) reported that approximately 77 percent of SSI recipients, ages 13 to 17 years, have ever received special education services, and 51 percent have received special education within the past 12 months. That said, our data cannot account for the entire population that might be *eligible* for SSI. SSI benefit receipt is commonly underreported in

survey data (Strand, Rupp, & Davies, 2009), which suggests that our sample may underrepresent the true population of SSI recipients with ASD.

Conclusion

This study used data from the National Longitudinal Transition Study 2012 (NLTS2012) to examine the prevalence and correlates of early work experiences among SSI recipients with autism and compared them to those in other disability groups. A secondary aim of this study was to characterize the population of SSI recipients with autism spectrum disorder (ASD), ages 13-21 years, enrolled in special education. Our findings indicate that a substantial proportion (31 percent) of households of TAY with ASD report a history of SSI benefit receipt, which highlights the importance of the SSI program in promoting economic security among many households of TAY with ASD. Despite this, we found that the subpopulation of TAY with ASD who receive SSI may be especially vulnerable during the transition into adulthood due to economic disadvantage, health-related challenges and low rates of employment training in high school. Future research about the conditions, experiences and needs of this subpopulation is needed to build an evidence base for future SSA programs and interventions.

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Tables

Table 1

Sample characteristics, by disability group (weighted proportions and 95 percent confidence intervals)

	<u>ASD</u>	<u>ID</u>	<u>ED</u>	<u>All Other</u>
<i>Sociodemographic Characteristics</i>				
Male	77.3 [71.7,82.0]	58.4*** [53.7,63.0]	75.4 [69.8,80.2]	68.0** [63.8,71.9]
Age (mean)	16.2 [15.9,16.5]	16.5 [16.3,16.7]	15.4*** [15.2,15.6]	15.6*** [15.4,15.8]
18-23	65.7 [59.4,71.4]	65.8 [61.1,70.2]	87.8*** [84.0,90.8]	83.9*** [80.9,86.4]
Race				
White Only	71.7 [65.0,77.6]	56.2*** [49.9,62.3]	52.7*** [45.4,59.8]	59.0** [53.0,64.8]
African American Only	18.4 [13.4,24.8]	36.9*** [31.1,43.2]	34.0*** [27.1,41.8]	30.5*** [25.0,36.8]
Other/Mix	9.9 [6.7,14.3]	6.9 [4.9,9.6]	13.3 [9.3,18.5]	10.4 [7.8,13.9]
Hispanic	16.6 [11.9,22.6]	19.9 [15.9,24.8]	19.9 [14.8,26.1]	22.7 [18.0,28.1]
<i>Individual Impairment</i>				
Communication				
Not at all/Lot of trouble	18.5 [14.0,24.1]	16.6 [13.5,20.3]	1.7*** [0.7,3.6]	7.7*** [5.9,9.8]
Little trouble	41.1 [35.2,47.3]	49.7* [45.5,53.9]	17.3*** [13.0,22.6]	29.5** [25.7,33.6]
No trouble	40.4 [34.4,46.7]	33.7 [29.6,38.0]	81.0*** [75.7,85.4]	62.8*** [58.6,66.9]
Health				
Fair/Poor	7.6 [5.0,11.5]	16.6** [13.5,20.2]	15.9** [12.1,20.8]	13.9* [11.3,16.9]
Good	24.2 [19.2,30.1]	32.4* [28.1,36.9]	28.9 [23.6,34.9]	28.2 [24.1,32.7]
Very Good	33.5 [27.5,40.0]	30.4 [26.4,34.8]	28.0 [22.6,34.1]	25.0* [21.1,29.3]
Excellent	34.7 [29.1,40.7]	20.7* [17.4,24.3]	27.1 [22.1,32.7]	32.9 [28.4,37.8]
How well youth uses ATM machine				
Not at all well/not allowed	83.5 [78.2,87.6]	80.5 [76.2,84.2]	57.9*** [51.4,64.1]	63.3*** [58.6,67.8]

Table 1

Sample characteristics, by disability group (weighted proportions and 95 percent confidence intervals)

	<u>ASD</u>	<u>ID</u>	<u>ED</u>	<u>All Other</u>
Not very well	7.6 [4.9,11.6]	6.9 [4.6,10.3]	5.0 [3.1,8.1]	4.2* [2.8,6.2]
Pretty/very well	8.9 [5.8,13.4]	12.6 [9.7,16.2]	37.1*** [31.3,43.2]	32.5*** [28.0,37.3]
How well youth gets to places outside of the home				
Not at all well/not allowed	54.0 [47.6,60.2]	36.8 [31.8,42.1]	6.4*** [4.2,9.8]	16.7*** [14.1,19.7]
Not very well	5.6 [3.4,9.0]	5.7 [3.9,8.3]	6.9 [4.4,10.7]	2.9* [2.0,4.2]
Pretty/very well	40.4 [34.2,47.1]	57.5 [52.4,62.4]	86.7*** [82.1,62.4]	80.4*** [77.1,83.3]
Household Chores Scale				
Q1	67.5 [60.0,74.1]	56.1* [50.9,61.2]	46.9*** [39.8,54.1]	44.5*** [39.6,49.4]
Q2	19.1 [13.9,25.7]	19.8 [16.3,23.9]	23.0 [17.7,29.4]	16.5 [13.0,20.8]
Q3	7.5 [4.7,12.0]	11.4 [8.1,15.8]	14.4* [10.2,20.0]	20.2** [15.6,25.6]
Q4	5.8 [3.4,9.8]	12.6* [9.8,16.1]	15.6** [11.2,21.4]	18.8*** [15.3,22.9]
<i>Household Circumstances and Family Characteristics</i>				
>185 FPL	30.2 [24.9,36.0]	17.1*** [13.8,21.0]	19.1** [14.3,25.2]	20.8** [17.4,24.7]
Number of children and adults in HH (Mean)	2.8 [2.7,3.0]	3.0 [2.9,3.1]	2.4* [2.5,2.7]	3.0 [2.9,3.1]
English primary language in HH	84.1 [78.3,88.5]	79.5 [74.7,83.6]	84.8 [79.7,88.8]	79.7 [74.8,83.9]
Single Parent HH	47.9 [41.4,54.4]	50.8 [46.0,55.5]	64.2*** [58.2,69.8]	51.1 [46.1,56.0]
Parent Education				
High School or less	57.6 [50.8,64.4]	74.5*** [70.4,78.1]	70.4** [64.7,75.5]	64.6 [59.8,69.0]
Tech or 2 year	22.6 [17.5,28.6]	14.3** [11.6,17.5]	19.7 [15.5,24.7]	21.0 [17.3,25.3]

Table 1

Sample characteristics, by disability group (weighted proportions and 95 percent confidence intervals)

	<u>ASD</u>	<u>ID</u>	<u>ED</u>	<u>All Other</u>
4 year degree or higher	19.8 [14.9,25.7]	11.3** [8.8,14.3]	9.9** [7.0,13.7]	14.4 [11.7,17.7]
Parent Employed	60.8 [54.2,67.0]	62.0 [57.0,66.8]	56.8 [21.0,62.4]	59.9 [55.2,64.5]
Parent reports youth definitely/probably will be financially independent	36.4 [30.5,42.8]	41.8 [36.6,47.3]	75.7*** [70.7,80.1]	71.5*** [67.5,75.3]
TANF	11.0 [7.6,15.6]	17.9* [14.6,21.8]	17.2* [13.1,22.3]	14.6 [11.8,17.9]
SNAP	42.7 [36.8,48.9]	53.8** [49.4,58.1]	59.2*** [52.6,65.5]	52.5** [47.9,57.1]
Government assisted or public health insurance	97.3 [93.0,99.0]	96.2 [93.5,97.9]	95.7 [92.0,97.7]	90.9* [86.9,93.8]
<i>School Characteristics and Experiences</i>				
Urbanicity				
City	31.4 [24.4,39.3]	33.4 [26.7,40.8]	41.8* [33.5,50.5]	35.4 [28.8,42.6]
Suburb	33.5 [26.2,41.6]	26.8 [20.2,34.7]	29.0 [22.0,37.0]	28.9 [23.2,35.4]
Town or Rural	35.2 [28.3,42.8]	40.0 [32.7,47.3]	29.2 [22.0,37.6]	35.7 [29.8,42.0]
Volunteer work	17.8 [13.6,22.8]	22.1 [18.4,26.3]	19.4 [15.2,24.5]	19.2 [15.6,23.3]
Youth Attended Transition meeting	60.7 [51.7,68.9]	68.4 [32.6,73.7]	63.2 [52.7,72.7]	68.4 [60.9,75.1]
Parent attended TM	68.6 [59.3,76.6]	72.1 [66.0,77.5]	60.7 [50.1,70.4]	70.2 [63.8,75.8]
Community agency attended TM	50.1 [39.2,61.0]	48.7 [41.0,56.5]	42.9 [29.3,57.7]	40.6 [32.2,50.0]

Source: National Longitudinal Transition Study 2012

aNo cell counts <3 cases were reported in accordance with the USDE data use agreement. All n's have been rounded to the nearest 10.

*p < .05, **p < .01, ***p < .001.

Table 2

Work outcome in past 12 months, by disability group, (weighted proportions and 95 percent confidence intervals)

	<u>ASD</u>	<u>ID</u>	<u>ED</u>	<u>All Other</u>
Any work	35.9 [30.1,42.3]	39.6 [35.1,44.3]	41.9 [36.2,47.8]	38.1 [33.6,43.5]
Any paid	23.0 [17.6,29.3]	26.7 [22.9,31.0]	40.0*** [34.2,46.0]	32.7 [28.1,37.7]
School-sponsored work	25.4 [20.2,31.2]	23.6 [20.1,27.5]	9.4*** [6.1,14.1]	12.7*** [9.7,16.4]
Received credit	58.8 [44.7,71.6]	71.2 [62.7,78.4]	91.8** [76.2,97.5]	75.8 [63.3,85.0]
Paid	38.4 [25.6,53.0]	26.5 [19.3,35.1]	56.8 [35.5,75.8]	21.8 [12.8,34.5]
Hours/week (Mean)	5.6 [4.4,6.8]	5.8 [4.9,6.8]	9.2* [6.1,12.3]	7.2 [5.4,9.1]
Related to career interest	41.3 [28.6,55.3]	53.2 [44.0,62.2]	38.1 [20.7,59.2]	45.0 [32.5,58.2]
Paid non-school sponsored work	13.9 [9.9,19.2]	22.0* [18.3,26.2]	35.9*** [30.5,41.8]	31.6*** [27.0,36.5]
Type of work				
School-only	21.4 [10.3,40.0]	17.7 [11.6,26.0]	9.2 [4.9,16.8]	9.5 [5.0,17.2]
Summer-only	24.7 [13.5,41.0]	23.5 [15.6,33.7]	28.8 [20.3,39.1]	19.3 [14.1,25.8]
Both	53.9 [35.7,71.1]	58.9 [49.3, 67.9]	62.0 [51.2,71.6]	71.3 [63.3,78.2]
Summer Hours/week (Mean)	13.2 [5.9,20.6]	8.5 [6.4,10.6]	13.7 [11.0,16.3]	13.9 [11.0,16.7]
School Hours/week (Mean)	7.7 [4.9,10.5]	6.0 [4.6,7.4]	6.9 [5.3,8.5]	8.3 [6.5,10.1]

Source: National Longitudinal Transition Study 2012

^aNo cell counts <3 cases were reported in accordance with the USDE data use agreement. All n's have been rounded to the nearest 10.

*p < .05, **p < .01, ***p < .001.

Table 3

Unadjusted odds ratios of outcomes in past 12 months, compared to ASD group (odds ratios, 95 percent confidence intervals)

	<u>ID</u>	<u>ED</u>	<u>All Other</u>
Any work	1.2 [0.9,1.6]	1.3 [0.9,1.8]	1.1 [0.8,1.6]
Any paid work	1.2 [0.8,1.8]	2.2*** [1.5,3.4]	1.6* [1.1,2.4]
School-sponsored work	0.9 [0.6,1.3]	0.3 [0.2,0.5]	0.4*** [0.3,0.7]
Paid non-school sponsored work	1.8* [1.1, 2.7]	3.5*** [2.2,5.5]	2.9*** [1.8,4.5]

Source: National Longitudinal Transition Study 2012

^aNo cell counts <3 cases were reported in accordance with the USDE data use agreement. All n's have been rounded to the nearest 10.

*p < .05, **p < .01, ***p < .001

Table 4

Adjusted odds ratios of outcomes in past 12 months, compared to ASD group (odds ratios, 95 percent confidence intervals)

	<u>ID</u>	<u>ED</u>	<u>All Other</u>
Any work	1.0 [0.7,1.4]	1.2 [0.7,1.8]	1.0 [0.7,1.5]
Any paid work	1.0 [0.7,1.5]	1.6 [1.0,2.5]	1.2 [0.8, 1.9]
School-sponsored work	0.8 [0.5,1.3]	0.4** [0.2,0.8]	0.5 [0.4,0.9]
Paid non-school sponsored work	1.5 [0.9,2.4]	2.3** [1.4,3.9]	2.0*** [1.2,3.2]

Covariates: sex, age, ethnicity, race, overall health, communication skills, how well youth uses atm, how well youth gets to places outside of the home, frequency of household chores

Source: National Longitudinal Transition Study 2012

^aNo cell counts <3 cases were reported in accordance with the USDE data use agreement. All n's have been rounded to the nearest 10.

*p < .05, **p < .01, ***p < .001

Table 5

Logistic regression models of early work experience among transition age SSI recipients with ASD (odds ratios, 95 percent confidence intervals)

	<u>Any work in past 12 months</u>	<u>Any paid work in past 12 months</u>
Sex (female)	0.5 [0.1,1.8]	3.1 [0.5,18.7]
Age	1.0 [0.6,1.5]	1.3 [0.7,2.5]
Race (White Only)		
African American Only	0.1* [0.0,0.8]	0.2 [0.0,2.9]
Mixed/Other Race	0.8 [0.0,17.4]	12.8[0.4,443.6]
Ethnicity (non-Hispanic)	0.6 [0.1,5.6]	1.0 [0.1,15.5]
Communication Skills (does not communicate)		
Little trouble	1.6 [0.3,7.8]	3.3 [0.3,40.9]
No trouble	4.3 [0.8,24.5]	15.7* [1.7,151.0]
Overall Health (fair/poor)	1.0 [0.6,1.8]	1.5 [0.7,3.2]
Get to places outside of the home without help (not at all)		
Not very well	12.5 [0.6,247.3]	6.9 [0.6,73.4]
Pretty or very well	1.0 [0.2,4.3]	1.3 [0.2,8.4]
Household >185 percent FPL	2.6 [0.5,12.6]	0.9 [0.2,4.5]
Parent employed	2.5 [0.3,24.7]	5.3 [0.7,41.5]
Parent reports youth definitely/probably will be financially independent	1.1 [0.2,4.8]	1.5 [0.3,7.5]
High school urbanity (city)		
Suburban	1.6 [0.3,7.8]	19.3*[1.7,222.9]
Town or rural	0.3 [0.1,1.2]	5.7 [0.5,62.4]
Community agency attended transition meeting	5.5* [1.5,19.7]	9.1* [1.5,56.0]

Source: National Longitudinal Transition Study 2012

^aNo cell counts <3 cases were reported in accordance with the USDE data use agreement. All n's have been rounded to the nearest 10.

*p < .05, **p < .01, ***p < .001

Table 6

Reported challenges facing youth in getting a job after high school among youth ages 15 years or older, by disability group (weighted proportions and 95 percent confidence intervals)

	<u>ASD</u>	<u>ID</u>	<u>ED</u>	<u>All Other</u>
Physical or mental health issues could prevent youth from working	19.6 [1.5,79.9]	34.1 [8.9,73.2]	a	81.3 [54.7,94.0]
Youth might lose SSI or other benefits	51.8 [44.2,59.5]	43.9 [38.2,49.7]	54.8 [46.2,63.2]	40.0* [34.5,45.7]
Staff at the high school has not provided enough information about career planning or job opportunities	37.8 [30.8,45.4]	45.4 [40.1,50.8]	45.7 [38.0,53.6]	32.6 [27.4,38.3]

Source: National Longitudinal Transition Study 2012

^aNo cell counts <3 cases were reported in accordance with the USDE data use agreement. All n's have been rounded to the nearest 10a

*p < .05, **p < .01, ***p < .001