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Loss in Services Precedes High School Exit for Teens with ASD: A Longitudinal Study

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Abstract

The present longitudinal study investigated changes in service receipt and unmet service needs spanning 14 years before and after high school exit in a large community-based sample of individuals with ASD ($n = 204$), of whom 59% had co-occurring intellectual disability (ID). Using multi-level models, potential discontinuity of service patterns at the point of high school exit were examined, as well as the rate of change in services received and needed during the high school years and into the post-high school period. Differences between those with and without ID were probed. Study findings indicated that overall, sample members experienced a reduction in receipt of services *during* high school, particularly for those without co-occurring ID. After high school exit, sample members experienced a decline in services received; for those without ID, there was a continuous rate of loss of services after leaving high school but for those with ID, there was a sharp decline in services received. Unmet service needs increased right after high school exit for both those with and without ID. These patterns reflect loss of entitlement for services that accompanies high school exit, and the limited availability of adult services for individuals with ASD. This study documented not only the post-high school service cliff that has been the subject of much concern, but also that the loss of services begins long before high school exit and that sub-groups of the population with ASD are particularly vulnerable.

Lay Summary

In this research we studied changes in the number of services received before and after high school exit in a large sample of individuals with ASD. With each passing year during high school, individuals with ASD received fewer services. At the time of high school exit, there was a sharp drop in the number of services received, particularly for those with co-occurring intellectual disability. This study found not only that there is a post-high school service cliff, but also that the loss of services begins long before high school exit.

Keywords

services; adolescence; adulthood; transition; autism; intellectual disability

The Individual with Disabilities Education Act (IDEA) provides a federal mandate that states offer school-based services for students with a disability, including an autism spectrum disorder (ASD). The number of children diagnosed with an ASD rose rapidly in the 1990s (Gurney et al., 2003), introducing a growing wave of individuals receiving services for ASD through the school system. As of 2016, over half a million students with ASD were receiving services under IDEA (U.S. Department of Education, 2018); however, they are only covered under IDEA until they leave secondary school (either with their peers or through age 21). After leaving high school, what becomes of these individuals in terms of the services they receive and need? The present study addresses this question.

When individuals with ASD exit high school (and become ineligible for receiving services under IDEA), they often report a dramatic loss in services. For example, using data from the National Longitudinal Transition Study-2 (NLTS2; a nationally representative sample of youth receiving special education services), Shattuck and colleagues (2011) reported low percentages of service receipt among individuals with ASD during the first two years after exiting high school; 9.1% were receiving speech therapy, 23.5% were receiving medical evaluation and assessment, 35% were receiving mental health services, and 41.9% were receiving case management. Nearly 40% did not receive any of these services. This level of service receipt was far lower than what was observed when youth with ASD in the NLTS-2 were in high school (Levine, Marder, & Wagner, 2004).

Although there has been much discussion about the “service cliff” (i.e., the loss of services individuals with ASD face upon exiting school-based services and entering the adult service system), little is known about the patterns of change in service utilization by youth with ASD leading up to high school exit. There is some evidence suggesting that the decline in services begins *earlier* than at high school exit. Taylor and Henninger (2015) compared use of services by a small sample of 39 individuals with ASD in their last year of high school to youth with ASD in the NLTS2 ages 13 – 16. Compared to the younger individuals in the NLTS2, individuals in their last year of high school reported substantially lower receipt of several services, including speech language therapy, in-home/in-classroom aide, occupational/life skills, and transportation services. Furthermore, two-thirds of individuals in their last year of high school reported one or more unmet service needs; in contrast, less than half of their younger counterparts reported at least one unmet service need. Relatedly, using cross-sectional methods, Turcotte and colleagues (2016) compared service use across four age groups: preschool age, elementary age, middle/high school age, and adults. Across a number of services, the likelihood of service use was lower not only after high school exit, but also for individuals with ASD who were nearing high school exit. Together these findings suggest that individuals with ASD experience a decline in service use during the transition to adulthood, and that this decline actually begins prior to the time when eligibility (through IDEA) ends. However, all of these existing studies are cross-sectional and do not examine change over time.

The present study is the first to our knowledge to examine changes in service receipt in the same group of individuals, allowing us to determine whether loss of services around high school exit in the extant research is confounded by cohort effects or reflects true change in service receipt. The present study will also add to our knowledge about service use by examining change in unmet service needs in addition to change in services received during the transition period.

Considering whether the Youth with ASD has an Intellectual Disability when Examining Service Change

Perhaps the most consistent predictor of service receipt during the transition to adulthood is whether the youth with ASD has an intellectual disability (ID). Large studies such as the NLTS2, as well as smaller cohort studies find that youth with ASD and greater cognitive or adaptive behavior impairments receive more services on average than youth with ASD with less cognitive or adaptive behavior impairments (e.g., Shattuck et al., 2011, Taylor & Henninger, 2015). However, it is currently unknown how having ID in addition to ASD might impact change in service receipt over time. Further, it is unclear whether receipt of fewer services for those with ASD without ID (vs. those with ASD and ID) reflects service needs that are unmet, or less need for services. Taylor and Henninger (2015), for example, found that youth with ASD who had higher adaptive behavior scores were receiving significantly fewer services than those with lower adaptive behavior scores, but did not necessarily have higher levels of unmet service needs.

However, studies examining constructs related to service use during the transition years suggest that youth with ASD without ID might be more negatively impacted by high school exit and, as such, likely are not getting all their service needs met during this time. In a series of studies drawing from the same sample as the current study, Taylor & Seltzer (2010, 2011a) showed that while youth with ASD improved in problem behaviors, autism symptoms, and the quality of the mother-adolescent relationship during high school, the rate of improvement slowed or even stopped after high school exit. Further, compared to youth with ASD and ID, those without ID demonstrated greater slowing of improvement in symptoms, behaviors, and the mother-adolescent relationship (Taylor & Seltzer, 2010, 2011a). Additionally, in the years immediately after high school exit, youth with ASD without ID are more likely than those with ID to be disengaged from any vocational activities, again suggesting service needs that are not met (Taylor & Seltzer, 2011b). These studies suggest that changes in service receipt and unmet service needs might differ during the transition to adulthood for youth with ASD who do versus do not have ID; the current study will be the first to directly address this question.

The Present Study

The objective of the present study was to examine changes in service use during the transition out of high school and into the adult service system for youth with ASD. This study addressed the limitations of extant research by: a) using longitudinal data collected over a 14-year period to track changes in services; and b) examining both service receipt and unmet service needs. We addressed the following research questions:

1. For individuals with ASD, is there a change in the number of services received (i.e., discontinuity in level of service use) and in the rate of change of service use (i.e., discontinuity in slope) after high school exit? Does the impact of exiting high school on service use differ for individuals with ASD who have ID vs. those who do not?
2. For individuals with ASD, is there a change in the number of unmet service needs and in the rate of change of unmet service needs after high school exit? Does the impact of exiting high school on unmet service needs differ for individuals with ASD who have ID vs. those who do not?

We hypothesized that, on average, individuals with ASD would experience declining services while in high school and then a further drop in services at high school exit. We also hypothesized a corresponding increase in unmet service needs in the years preceding high school exit, with an additional increase in unmet needs at the time of exit. We hypothesized greater changes in service receipt and unmet needs for those with ASD without ID, compared to those with ID.

In this analysis, we controlled for key demographic variables that have been shown to relate to service use for individuals with ASD in previous research. For example, youth with ASD whose families have higher incomes tend to receive more autism-related services than those from families with lower incomes (Liptak et al., 2008; Thomas, Ellis, McLaurin, Daniels, & Morrissey, 2007). Further, the adult service system differs dramatically by state (Braddock, Hemp, Tanis, Wu, & Haffer, 2017), and residential status (i.e., living with family versus in agency-supported settings) has recently been shown to be an important predictor of service receipt among adults with ASD (Dudley, Klinger, Meyer, Powell, & Klinger, 2018). Finally, the sex of the adult with ASD impacts employment outcomes in adulthood (Taylor & Mailick, 2014; Taylor, Henninger, & Mailick, 2015). As such, in the present study we controlled for annual family income as well as residential status, state of residence, and sex of the individual with ASD in all analyses.

Method

The data for this study came from a larger, longitudinal study of families of adolescents and adults with an autism spectrum disorder (ASD; $N = 406$; Woodman, Smith, Greenberg, & Mailick, 2016; Seltzer et al., 2011). To participate in the study, the son or daughter with ASD had to be age 10 or older (age range = 10 – 52 at the beginning of the study) and have received an ASD diagnosis (autistic disorder, Asperger disorder, or pervasive developmental disorder) from a health or educational professional. Furthermore, the Autism Diagnostic Interview-Revised (ADI-R; Lord et al. 1994) was administered to each participant to verify that their ADI-R profile was consistent with their diagnosis. The ADI-R lifetime criteria for a diagnosis of autistic disorder was met by 94.6% of the sample. The ADI-R profiles of the remaining 5.4% of sample members were reviewed on a case-by-case basis and found to be consistent with their parent-reported diagnosis of Asperger's disorder or Pervasive Developmental Disorder-Not Otherwise Specified (PDD-NOS).

Half of the participants lived in Massachusetts ($n = 204$) and half lived in Wisconsin ($n = 202$). Data collection and recruitment procedures were identical at both sites. Recruitment information about the study was distributed to schools, service agencies, and clinics and through media announcements, along with instructions for interested individuals with ASD and their families about how to enroll in the study. Data collection in the larger study spanned 10 waves across 15 years. Analyses in the current study used data from four of the waves spanning 14 years during which data on service utilization were collected: Wave 1 (1998 – 2000), Wave 2 (2000 – 2001), Wave 3 (2002 – 2003), and Wave 9 (2011 – 2012).

Participants and Procedures

Data were collected at each wave from the primary caregiver (usually the mother) through the combination of a self-administered questionnaire and an in-home, 2 – 3 hour interview. Because the focus of this study was on service change from before to after high school exit, the sample for the present study was restricted to individuals with ASD who were still in high school at Wave 1 or had exited high school within the previous 18 months ($n = 269$). Date of high school exit was calculated for the sample, and defined as the month and year that the individual with ASD stopped receiving services through the school system (regardless of age). Because the analyses for this project focus on time since high school exit, individuals for whom the specific date of high school exit was not available were excluded, yielding an analytic sample of 204 (see Table 1).

The majority of individuals in the analytic sample were male (74.5%) and had a co-occurring intellectual disability diagnosis (58.8%). Age of individuals with ASD at Wave 1 ranged from 10.78 – 23.46 years ($M = 16.61$, $SD = 3.20$). Most participants lived with a family member (usually their parent or parents) at wave 1 (78.9%). Median household income at Wave 1 (in 1998–2000) was \$40,000 – \$49,999.

Individuals excluded from the study due to a missing high school exit date were younger ($p = .049$), had lower household incomes ($p = .028$) and maternal education levels ($p = .004$), and their mothers were more often of a racial/ethnic minority group ($p = .021$). There were no differences between participants and non-participants in terms of ID status, sex, residential status (living with family vs. other living arrangement), or resident state (Massachusetts vs. Wisconsin).

The data collection protocol was approved by the Institutional Review Board at the University of Wisconsin-Madison. Written consent was obtained from all participants.

Measures

Outcome variables

Count of services received.: At each wave used in this analysis (Waves 1, 2, 3, and 9), mothers reported whether their son or daughter was currently receiving each of the following 9 services: physical therapy, occupational therapy, speech therapy, psychological and psychiatric services, crisis intervention program, personal care services, recreational or social activities from an agency, transportation services, or respite care. Services received at each time point were totaled to generate a count of the number of services received, with

higher scores indicating more services. If more than 3 items were missing for an individual in a given wave, no count of services received was calculated for that individual in that wave.

Count of unmet service need.: For each service *not* received, mothers reported whether the service was needed. At each wave, a count of services needed was calculated following the same procedures for calculating the count of services received.

It is important to acknowledge that the receipt of services and experiencing unmet service needs are not simply the inverse of each other (e.g., one could be receiving psychological services but still have unmet service needs such as a need for a greater number of therapy hours). However, we note that for the present study, the two outcomes were methodologically linked in our approach to data collection as unmet need was only assessed if a given service was not received.

Time-varying, within person independent variables

Time centered at high school exit.: The date of high school exit and whether the individual with ASD was still in high school at each time point was determined through detailed record review (Taylor & Seltzer, 2010; Taylor & Seltzer, 2011). The date of each wave's interview was also determined. Using this information, a time variable (in years) was created for each individual at each wave by subtracting the high school exit date from the interview date. This time variable was negative for an individual before high school exit and positive afterward. For the purposes of this study, we focus on date of high school exit (i.e., the month and year that the individuals with ASD stopped receiving services through the school system) instead of age, as some youth with ASD graduate with their peers and cease receiving school-based services at age 18, whereas others remain in school and continue receiving school-based services until they are 22.

High school exit status.: A dichotomous variable was created at each wave indicating whether (=1) or not (= 0) the individual with ASD was currently in high school. Within the 18 months before the study began (before wave 1), 12% of the analytic sample had exited high school. By wave 2, 25% had exited and by wave 3, 40% had exited. By wave 9, all sample members had exited high school.

Household income.: Annual household income was reported by mothers at each wave on a scale of 1 – 7 with ranges of \$0 - \$10,000 to \$70,000 or more. A dichotomous indicator of income was created with incomes less than \$70,000 scored as 0 and incomes greater than \$70,000 scored as 1.

Residential status.: A dichotomous variable was created at each wave indicating whether (=1) or not (=0) the individual with ASD was living with a family member (usually 1 or 2 parents) or in some other arrangement (group home, independently, etc.).

Between-persons, independent variables

ID status.: A dichotomous variable was created indicating whether (1) or not (0) the individual with ASD had been diagnosed with an ID. ID status was determined through a combination of sources, including the Wide Range Intelligence Test (WRIT; Glutting et al., 2000) and the Vineland Screener (Sparrow et al., 1993). Consistent with diagnostic guidelines (Luckasson et al., 2002), individuals with standard scores of 70 or below on both IQ and adaptive behavior measures were classified as having an ID. Some individuals with ASD scored below 70 on one measure, but above 70 the other or were missing one of the measures. For these cases, records were reviewed by three psychologists, who used a clinical consensus procedure to determine ID status.

Resident state.: A dichotomous variable was created to indicate whether the individual with ASD lived in Massachusetts (=1) or Wisconsin (=0) at Wave 1.

Sex.: A dichotomous variable was created indicating whether the individual with ASD was female (=1) or male (= 0).

Analytic Plan—This study examined whether there was a discontinuity in the level of service use and unmet service need upon high school exit. In addition, this study examined whether the *rate* of change in service use and unmet service need over time differed before and after high school exit. We also examined whether the pattern of service use and unmet service need differed for individuals with and without ID. To address these questions, we tested a series of nested multilevel models following the procedures outlined by Singer and Willet (2003) and Hox, Moerbeek, and van de Schoot (2018).

Specifically, a series of random intercept multilevel regression models were fit, first for service use and then for unmet service need. Poisson regression was used because the outcomes, number of services received and number of unmet service need, were counts. Service use and unmet service needs over time were modeled by the effect of the time variable centered at high school exit. A discontinuity in the level of service use or unmet service need was modeled by the dichotomous predictor high school exit status (0 = still in high school; 1 = exited high school). A discontinuity in the rate of change was modeled through an interaction between the centered time variable and high school exit status.

Deviance/likelihood ratio tests (Hox et al., 2018; Singer & Willet, 2003) were used to compare models. In comparing models, the simplest model is preferred unless a more complex model with discontinuities fits the data significantly better. Analyses were conducted using the lme4 package (Bates, Machler, Boker, & Walker, 2015) in R version 3.5.0 (R Core Team, 2018) and RStudio version 1.1.453 (RStudio Team, 2018). Model building followed a bottom-up approach starting with time as the only predictor. Next, high school exit status and time X high school exit status were added as predictors followed by demographic covariates (i.e., family income, residential status, state of residence, and sex). Then the 2-way interactions between (a) ID and time and (b) ID and high school exit were added. Significant interaction terms were retained.

Results

Services Received

Estimates from the final regression models are found in Table 2. Regarding Research Question 1, adding high school exit status to the baseline model that included only the time variable significantly improved model fit ($\chi^2 = 7.37, df = 1, p = .007$), indicating that individuals with ASD experienced a discontinuity in level of service use upon high school exit. The interaction between time and high school exit status was statistically significant and improved model fit ($\chi^2 = 3.89, df = 1, p = .048$), indicating that the rate of change in service use after high school exit was different than the rate of change prior to exit. The addition of demographic covariates also improved model fit ($\chi^2 = 50.90, df = 5, p < .001$). Both interactions between ID and time, and ID and high school exit were statistically significant and improved model fit ($\chi^2 = 6.30, df = 2, p = .043$). The amount of change in service use upon high school exit and the overall rate of change of service use differed for those with versus without ID. The only significant covariate was state of residence, with individuals in Massachusetts receiving more services than individuals from Wisconsin.

The average trajectories of service use for individuals with and without ID are shown in Figure 1. For ease of interpretation, trajectories of service use were calculated separately for individuals with ASD with and without ID. Individuals with ASD and ID experienced a gradual, marginally statistically significant ($p = .080$) decline in use of services prior to high school exit, and a statistically significant drop in the number of services received ($p = .004$) upon high school exit. Afterward the rate of change in service use remained flat ($p = .540$). In contrast, individuals with ASD without ID experienced a far steeper decline in service use prior to high school exit ($p < .001$). Service use did not shift substantially upon high school exit ($p = .650$). The rate of change in service use continued to decline after high school exit, but at a slower rate than prior to high school exit ($p = .023$).

Unmet Service Need

Addressing Research Question 2 (see Table 2), adding high school exit status to the baseline model that included only the time variable significantly improved model fit ($\chi^2 = 8.79, df = 1, p = .003$), indicating that individuals with ASD experienced a discontinuity in level of unmet service needs upon high school exit. The interaction between time and high school exit status was significant ($\chi^2 = 4.61, df = 1, p = .032$), indicating that the rate of change in unmet service needs after high school exit was different than the rate of change prior to exit. The addition of demographic covariates also improved model fit ($\chi^2 = 16.88, df = 5, p = .005$). Interactions with ID (ID x time; ID x high school exit) were not statistically significant ($\chi^2 = 0.07, df = 2, p = .964$); thus, patterns of unmet service need did not differ by whether the adult had ID and these interactions were not retained in the final model. Significant covariates included residential status, sex, and household income. Unmet service needs were greater for individuals with ASD who were male, had lower household incomes, and lived with a family member (see Table 2).

The average trajectory of unmet service needs is plotted in Figure 2. Sample members experienced essentially no change in unmet service needs prior to high school exit ($p = .272$), a significant jump in need upon exit ($p = .009$), and a gradual decline in unmet service needs thereafter ($p = .012$).

Posthoc Analyses

To identify which services experienced a decline in use during the transition to adulthood, we fit mixed effects logistic regression models to predict the probability of receiving each service over time (i.e., physical therapy, occupational therapy, speech therapy, psychological and psychiatric services, crisis intervention program, personal care services, recreational or social activities from an agency, transportation services, or respite care). Time, high school exit status, their interaction, and state of residence were retained as predictors. Models were fit separately for individuals with and without ID. Figure 3 plots the average probabilities for each service over time. When examining the graphs, three overall patterns emerged: (1) For both those with and without ID, speech therapy, occupational therapy, and respite services *declined before and at high school exit*; (2) For both those with and without ID, there was *little change* in physical therapy, psychiatric services, and crisis services.; and (3) For those with ID (but not those without), personal care services, transportation services, and recreational services *increased over time*. Note that psychiatric services uniquely maintained a high probability of utilization across the transition to adulthood for both groups, with much lower utilization for the other services in this group. (Data available from authors).

Discussion

Adding to the growing literature on the transition to adulthood for individuals with ASD, the present study examined patterns of service use and unmet service needs before and after high school exit. The number of formal services received was substantially lower after sample members left high school than prior to high school exit. Yet this study revealed that the patterns differed markedly for those who had ASD and ID versus those who had ASD without ID.

Surprisingly, both sub-groups of sample members experienced a reduction in receipt of services *during* high school (though the decline in services received for those with ASD and ID was at a trend level). The difference between those with ID and those without ID became more pronounced as the sample members approached the end of their high school years. Those who had ASD but no ID experienced a much sharper decline in the number of services they received *during* high school than those with ID, and this decline continued for them after high school exit. In contrast, for sample members who had ASD and ID, high school exit was followed by a sharp drop in services (the proverbial “service cliff”) and this lower number of services received persisted after high school exit. To summarize the pattern we observed (see Figure 1), individuals with ASD had a very divergent pattern of receiving services – both before and after high school exit -- depending on their ID status.

It may be that declining service provision prior to high school exit (especially for those without ID) reflects an intentional attempt to transition youth with ASD from school-based to adult services. One of the increasingly recognized ways of handling this transition is

through interagency collaboration, or collaboration between school-based and adult service providers. In practice, this can include adult service providers attending transition planning meetings while students are still in school, and youth beginning receipt of adult services prior to high school exit (thus, smoothing the “services cliff”). There is evidence that interagency collaboration produces improved post-school outcomes for students with disabilities (Haber et al., 2016; Morningstar, Kleinhammer-Tramill, & Lattin, 1999; Oertle & Trach, 2007; Test et al., 2009); however, it rarely happens. In the NLTS2, for example, only 19% of students with ASD had a vocational rehabilitation representative as an active member of the transition team (Shogren & Plotner, 2012). Findings from the present study further highlight the need for coordinated transition services to avoid gaps in critical supports for individuals with ASD as they enter adulthood.

Given what is known about the behavioral phenotype of ASD in adulthood, as well as the low rates of employment and independence for adults with ASD (Henninger & Taylor, 2013; Howlin & Moss, 2012; Roux, Shattuck, Rast, Rava, & Anderson, 2015; Taylor & Seltzer, 2012), it cannot be argued that these adults no longer have a need for services. Indeed, unmet service needs increased right after high school exit for both those with and without ID (see Figure 2). Rather, these data can best be interpreted in the context of loss of eligibility for services, with adult services offering considerably fewer needed services to individuals with ASD than IDEA-mandated services. Although the number of unmet service needs declined gradually after high school exit, this parent-reported pattern may reflect changing parental assessments of service needs. Specifically, it may be that when contending with the limited accessibility of adult services, over time parents lower their perceptions of the services that their son or daughter needs.

Analysis of individual services received before or after high school exit (Figure 3) revealed that almost no sample members received therapeutic services (speech therapy, physical therapy, occupational therapy) after leaving high school, although continued impairments in these areas during adulthood have been well documented (Henninger & Taylor, 2013; Howlin & Moss, 2012; Roux et al., 2015) and thus the need for such services continues. Psychiatric services continue to be provided at a high level, possibly due to the need for medication management that only increases during adulthood (Esbensen et al. 2009), and transportation, personal care, and recreational services increased following high school exit for individuals with ID.

In prior work, we examined the transition to adulthood to learn how the behavioral phenotype and the mother-teen relationship change during this turning point (Taylor & Seltzer, 2010, 2011). These analyses showed that during high school, there was improvement in behavior problems, autism symptoms, and the mother-teen relationship, but this improvement slowed or stopped after high school exit. Findings from this series of studies can shed light on results from the present analyses. For example, in our prior work we found a greater negative impact of high school exit on behavioral development and the mother-teen relationship for those with ASD without ID, compared to those with ID (Taylor & Seltzer, 2010, 2011). The present study extends these findings by suggesting that different service-related experiences for those with ASD with vs. without ID begin long before transition, but intensify as high school exit draws closer. Only measuring service changes

from before to after high school exit is inadequate to capture the majority of transition-related service loss for those without ID, as much of the service loss occurs while they are still in high school.

In our earlier work we also found that, after leaving high school, mothers rated their relationship with their sons as declining in warmth, whereas their relationship with their daughters became warmer (at least from the mothers' perspective) after high school exit (Taylor & Seltzer, 2011). Most pertinent to this present study of service receipt and unmet service needs, mothers reported less positivity in their relationship with both their sons and daughters over time if the teen had higher levels of unmet service needs. As daughters in this analysis had fewer unmet service needs, this might help explain why their relationships with their mothers were less negatively affected than were sons. The difference in unmet needs that we observed is another example of sex-related patterns within ASD. Sex differences in adulthood is an emerging area of research that will be important to understanding the unique needs of women with ASD.

Findings from the present study, in combination with the larger body of work on change before and after high school exit, reveal the complexity of high school exit for teens with ASD. It is a time of significant risk, with slowing of phenotypic gains, declining access to services, and for sons, declining closeness in their relationship with their mother. Although these analyses were based on a large longitudinal study, the research design does not make it possible to parse which of these changes may have been the cause (or the result) of the others, and investigating their inter-relationship remains an important priority for future research.

Finally, findings regarding family income and residential placement replicate and extend previous research. Our finding that youth and adults had more of their service needs met when their families had higher incomes is consistent with our studies as well as a large body of literature suggesting that family income is a key determinant of service access from diagnosis through adult services (Liptak et al., 2008; Shattuck et al., 2011; Thomas et al., 2007). Our finding regarding more unmet service needs for those living with family is consistent with other research suggesting that adults with ASD who live outside of the family home tend to receive more services (Dudley et al., 2018). Those who live away from family often live in agency-supported residences that provide other services in addition to residential supports. Hence, their residence could have provided a pathway to services in adulthood that living with family does not offer. Overall, these patterns underscore the heterogeneity of the population with ASD and how this heterogeneity plays out over the life course with respect to unmet service needs.

Our research did not include indicators of the quality of services or family satisfaction with services, or the relationship between the number of services received and the quality of these services. It may not be the number of services that matters but rather the type, intensity, and focus of each available service that determines whether needs are met. It is conceivable that receiving a few very high quality services is more important during the transition to adulthood than receiving multiple services of marginal quality. Our measures of services received and unmet service need were based on parent report, which might not reflect

professionals' perceptions of what services are needed nor the perceptions of adults with ASD about their own service needs. An additional limitation concerned the specific services that were measured in the present study and the lack of a focus on transition services. Further, our sample was drawn from just two states, and we observed state-level differences in the services that were received by individuals with ASD. This difference underscores the need for nationally-representative data in future research.

Yet another important limitation of this study was its lack of racial and ethnic diversity. As noted, family income is associated with disparities in services throughout the lifespan. This is a significant gap in the present research and warrants attention in future studies. Intervention research is also needed to identify strategies to help adults with ASD and their families advocate for and obtain needed services during the transition years and into adulthood. Promising models are currently being developed and these warrant replication and dissemination (DaWalt et al., 2018; Taylor et al., 2017).

Juxtaposed against these limitations was the prospective research design and the large and well-characterized sample. By studying patterns before and after high school exit, it was possible to examine within-person change in service utilization, extending past cross-sectional approaches. Importantly, the present study documented not only the post-high school service cliff that has been the subject of much anecdotal commentary, but also that the loss of services begins long before high school exit and that sub-groups of the population with ASD are particularly vulnerable.

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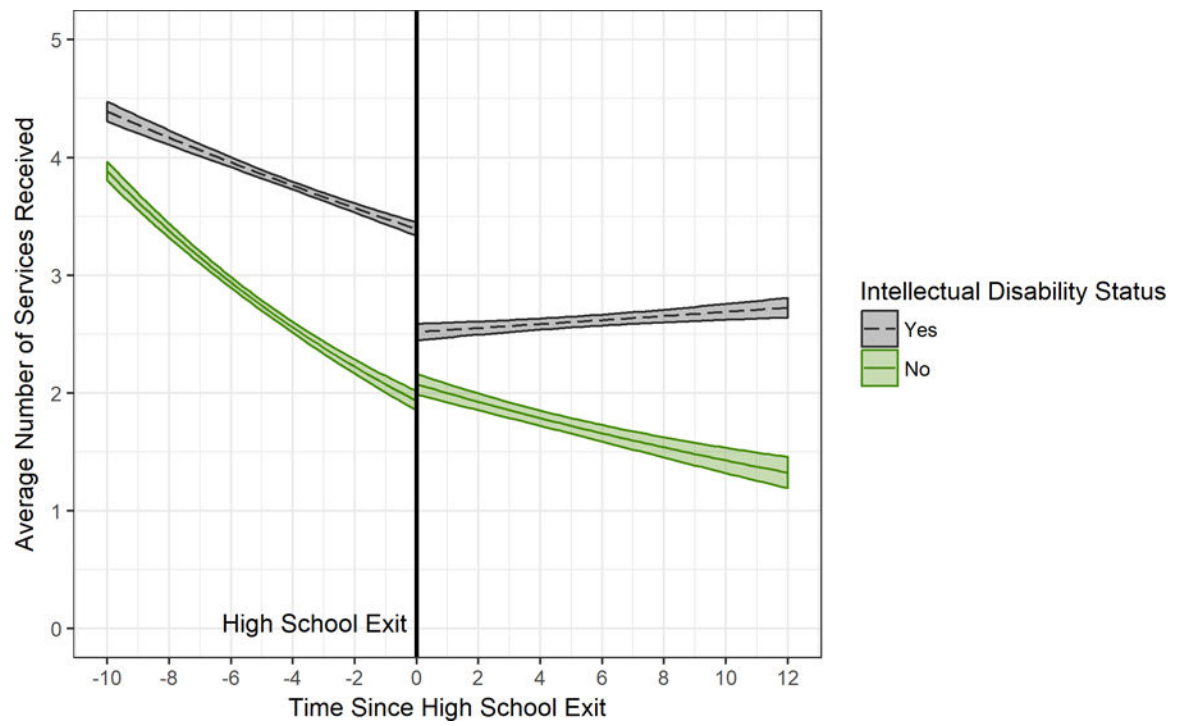


Figure 1.
Average number of services received during the transition to adulthood.

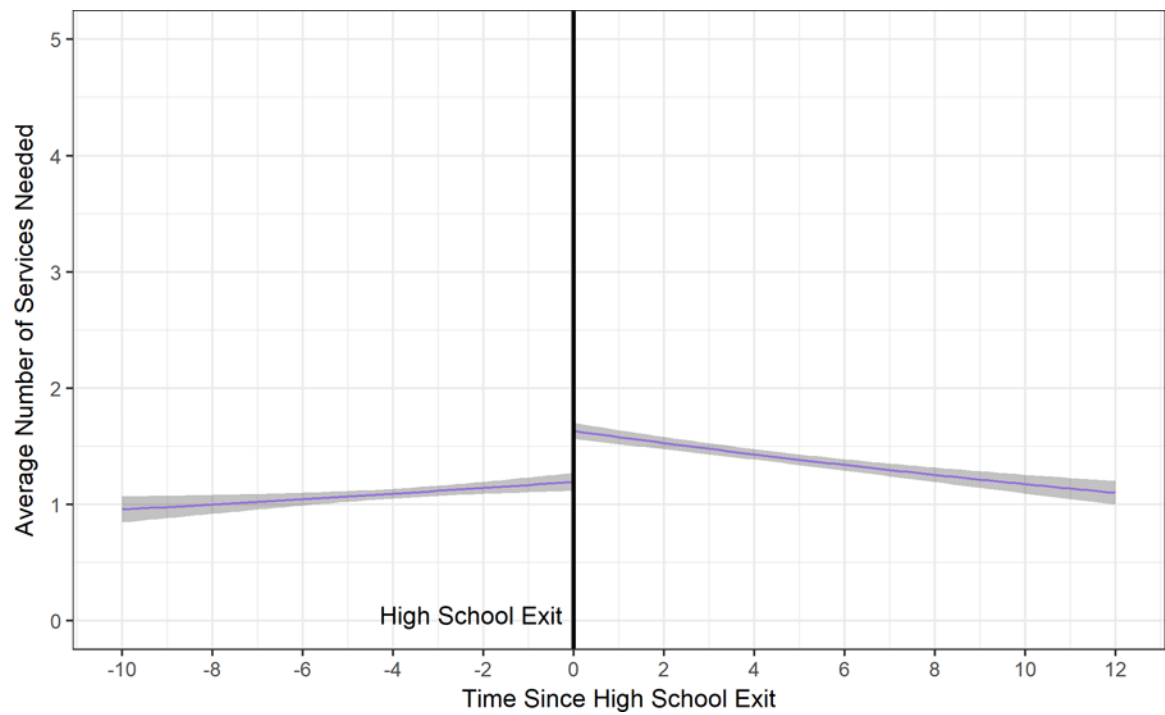


Figure 2.
Average number of services needed during the transition to adulthood.

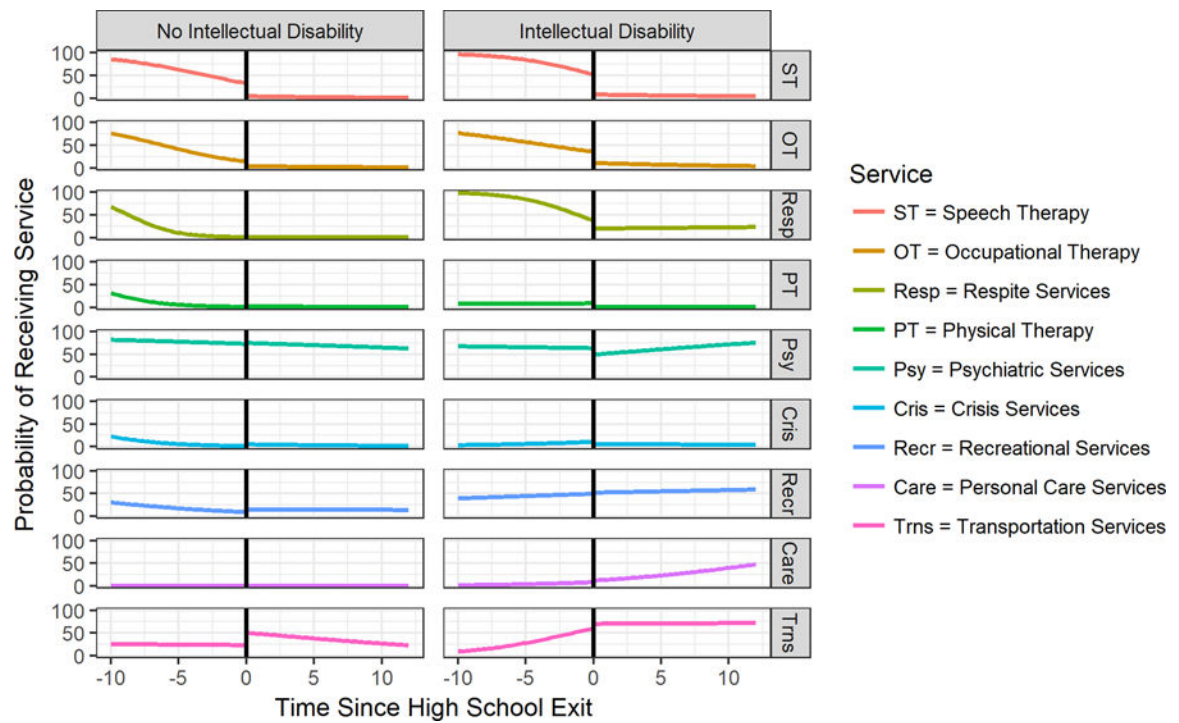


Figure 3.
Probability of receiving services during the transition to adulthood.

Table 1

Descriptive statistics at Time 1 (Analytic Sample n = 204)

Variable	<i>M (SD)/Count (Percentage)</i>
Age (in years)	16.61 (3.20)
Sex	
Male	152 (74.5%)
Female	52 (25.5%)
Intellectual Disability	
No	84 (41.2%)
Yes	120 (58.8%)
Residential Status	
Living with Family Member	161 (78.9%)
Other	43 (21.1%)
Family Income	
Less than \$70k	114 (57.6%)
Over \$70K	84 (42.4%)
Mother's Education	
Some high school/Graduated	35 (17.2%)
Some college/Associate's	61 (29.9%)
Bachelor's	38 (18.6%)
Post-graduate	70 (34.3%)
Mother's Race/Ethnicity	
White, non-Hispanic	191 (93.6%)
Other Race/Ethnicity	13 (6.4%)
State	
Wisconsin	101 (49.5%)
Massachusetts	103 (50.5%)

Table 2

Mixed effects regression (Poisson) predicting number of services received and needed

	Services Received: Final Model				Services Needed: Final Model			
	<i>b</i>	<i>S.E.</i>	<i>p</i>	<i>e^b</i>	<i>b</i>	<i>S.E.</i>	<i>p</i>	<i>e^b</i>
Intercept	0.58	0.12	< .001	1.78	-0.09	0.17	.581	0.91
Time	-0.07	0.02	< .001	0.93	0.02	0.02	.272	1.02
Exited High School (HS)	0.07	0.15	0.649	1.07	0.31	0.12	.009	1.37
Has ID	0.56	0.11	< .001	1.75	0.10	0.11	.348	1.11
Mass.(vs. Wisc.)	0.27	0.07	< .001	1.31	-0.01	0.11	.890	0.99
Lives with Family	-0.11	0.07	.120	0.90	0.24	0.10	.022	1.27
Sex: Female	0.09	0.08	.231	1.09	-0.26	0.12	.037	0.77
Income: <\$70,000	0.02	0.06	.771	1.02	0.21	0.09	.016	1.24
Time X Exited HS	0.03	0.02	.046	1.03	-0.05	0.02	.020	0.95
Exited HS X ID	-0.37	0.19	.047	0.69	---	---	---	---
Time X ID	0.04	0.02	.012	1.04	---	---	---	---
AIC	2763.12				2280.17			
BIC	2818.15				2326.03			
Log Likelihood	-1369.56				-1130.08			
Number of Observations	725				725			
Number of Groups (Participants)	204				204			
Variance: Intercept	0.12 (0.34)				0.33 (0.57)			

e^b The exponentiated regression coefficients are rate ratios, which are a type of effect size measure for Poisson regression. For example, prior to high school exit, the rate of service use by individuals without ID was $e^{(-0.07)} = 0.93$ times less each year; that is, there was a $1.00 - 0.93 = 7\%$ decrease each year. Similarly, the rate of unmet service need was $e^{(0.31)} = 1.37$ times greater immediately after high school exit than just prior.