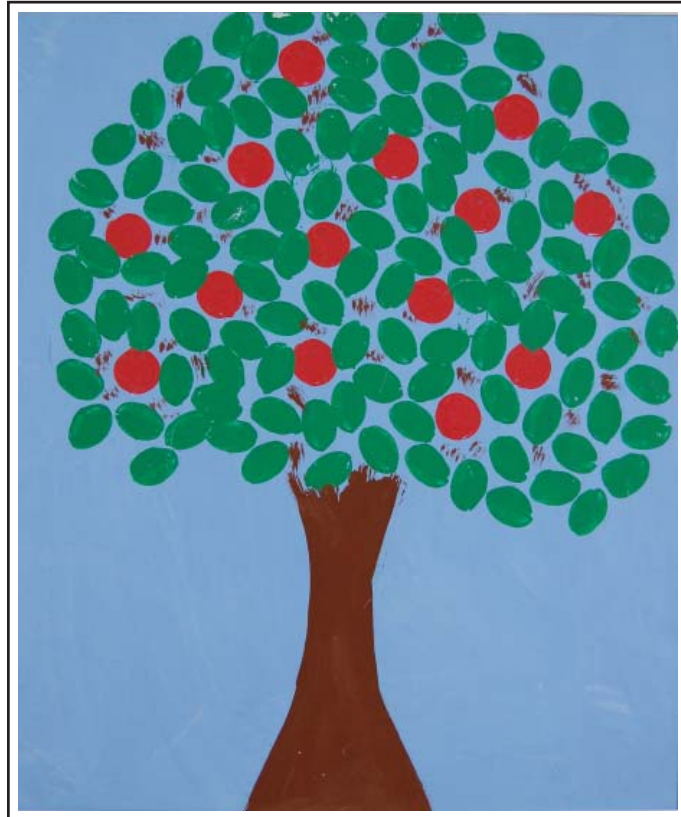


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## Adolescents & Adults with Autism A Study of Family Caregiving



### **Report #13**

**The Transition Out of High School and Into Adult Life for  
Young Adults with Autism Spectrum Disorders**

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## **Table of Contents**

	<b><u>Page</u></b>
<b><u>Section I:</u></b>	
Introduction	1
<b><u>Section II:</u></b>	
Impact of Exiting High School on Autism Symptoms and Behaviors	2
Autism Symptoms	3
Behavior Problems	6
<b><u>Section III:</u></b>	
Examining the Vocational Activities of Youth with ASD in the Years after Leaving High School	9
<b><u>Section IV:</u></b>	
Summary and Conclusions	12

## **Section 1: Introduction**

Over the years, participants in our study have provided us with great depth and breadth of information about the development of their sons and daughters with ASD. By collecting the same information at multiple times of data collection, this study has helped us to better understand the course of development for adolescents and adults with ASD and their families, as well as how critical life transitions impact development.

This report describes the impact of one such transition - leaving high school. Mothers of youth with ASD often describe the transition out of high school and into the adult service system as “falling off a cliff” because of the loss of services during this time. However, there is very little research evidence about how youth with ASD and their families are impacted by this major life change.

Data in this report came from families of youth with ASD who exited high school during our 10-year study period. We used data collected at five points: 1998-1999 (referred to as Time 1); 2000-2001 (Time 2); 2002-2003 (Time 3); 2004-2005 (Time 4) and 2007-2008 (Time 5). Although we know that it can be arduous for families to continue to participate in the study over these many years, having data collected at multiple times has allowed us to make new discoveries about how youth with ASD change before and after leaving high school.

We report our findings in two sections. First, we present our research examining how leaving high school impacts autism symptoms and behavior problems. Second, we shed light on why this transition might be difficult by examining post-high school vocational activities.

Leaving high school and entering the adult service system is a time of great change for individuals with ASD, which can be difficult for many families. Our hope is that by bringing attention to the challenges faced by young adults with ASD, our research can be used to inform services, interventions, and programs geared toward helping young adults transition successfully and reach their maximum potential.

We are grateful to the families who have participated in all phases of the study and shared their lives with us. This report presents another example of new and unique insights about ASD that are gained from the ongoing participation of families in our study. We look forward to the opportunity to use this information to enhance intervention efforts and to advocate for policies to address the service needs of individuals with ASD who are transitioning to adulthood and their families.

## **Section II: Impact of Exiting High School on Autism Symptoms and Behavior Problems**

We first examined how leaving high school impacted changes in autism symptoms and behavior problems. Our earlier work showed that symptoms and behaviors were improving (becoming less severe) over time, but we hypothesized that the disruptions in schedule and loss of services after leaving high school would result in a slowing of that improvement.

To examine this question, we included data from 242 youth with ASD who graduated or left high school during the study period (or who were still in high school at Time 5). These youth with ASD averaged 16 years of age at the start of the study (in 1998) with a range from 10 to 23 years. About 80% of youth were living with their parents at the start of our study.

Although there are a number of possible ways that we could define leaving high school, such as by graduation date or the date that youth stopped taking classes in the school building, we chose to define “exiting high school” as the time that services were no longer being received through the secondary school system. For some individuals, this meant that their exit from high school happened when they graduated with their same-aged peers. For other individuals, their exit from high school happened when they reached the age of 22 and timed out of services. Yet others left school at age 17, but did not graduate.

At every point of data collection, mothers provided information about their son or daughter’s current educational and work activities. From this information, we were able to determine whether each individual with ASD was receiving services through the school system at each time point of our study. Mothers also answered questions about their son or daughter’s autism symptoms and behavior problems at every time point. This information was used in combination with the information on high school exit to determine how symptoms and behavior problems were changing while youth with ASD were in high school, and whether leaving high school impacted that pattern of change.

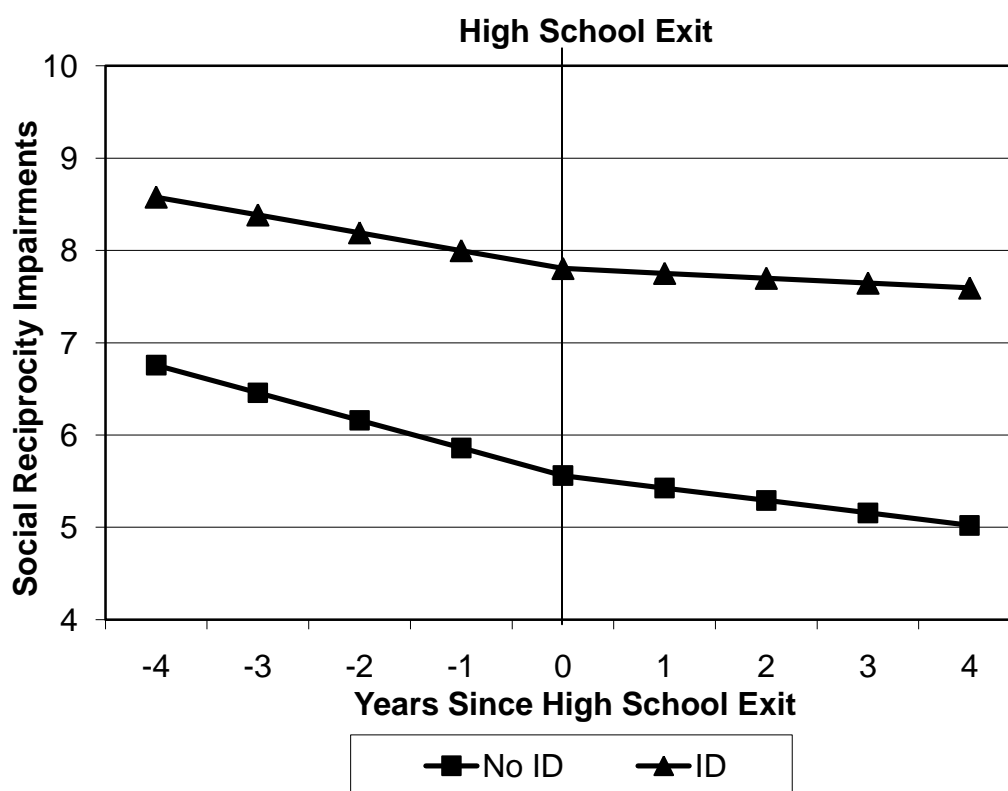
One of our key variables of interest was whether youth with ASD had a co-occurring intellectual disability. We suspected that there would be fewer adult services geared toward the unique needs of those with ASD *without* an intellectual disability, and therefore leaving high school would be a significant disruption for these individuals. We hypothesized that youth with ASD who had an intellectual

disability would more easily fit into the current adult disability service system, and would thus be relatively less affected by leaving high school.

### Autism Symptoms

We measured categories of autism symptoms corresponding to the three domains of impairments in ASD: impairments in social reciprocity; impairments in communication; and repetitive behaviors and stereotyped interests. We found that for all categories, autism symptoms were significantly improving while youth with ASD were in high school. However, in all three categories, that improvement significantly slowed down after leaving high school. An example of this pattern is shown in Figure 1, which plots the change in impairments in social reciprocity before and after leaving high school.

Figure 1. Change in Impairments in Social Reciprocity Before and After Leaving High School

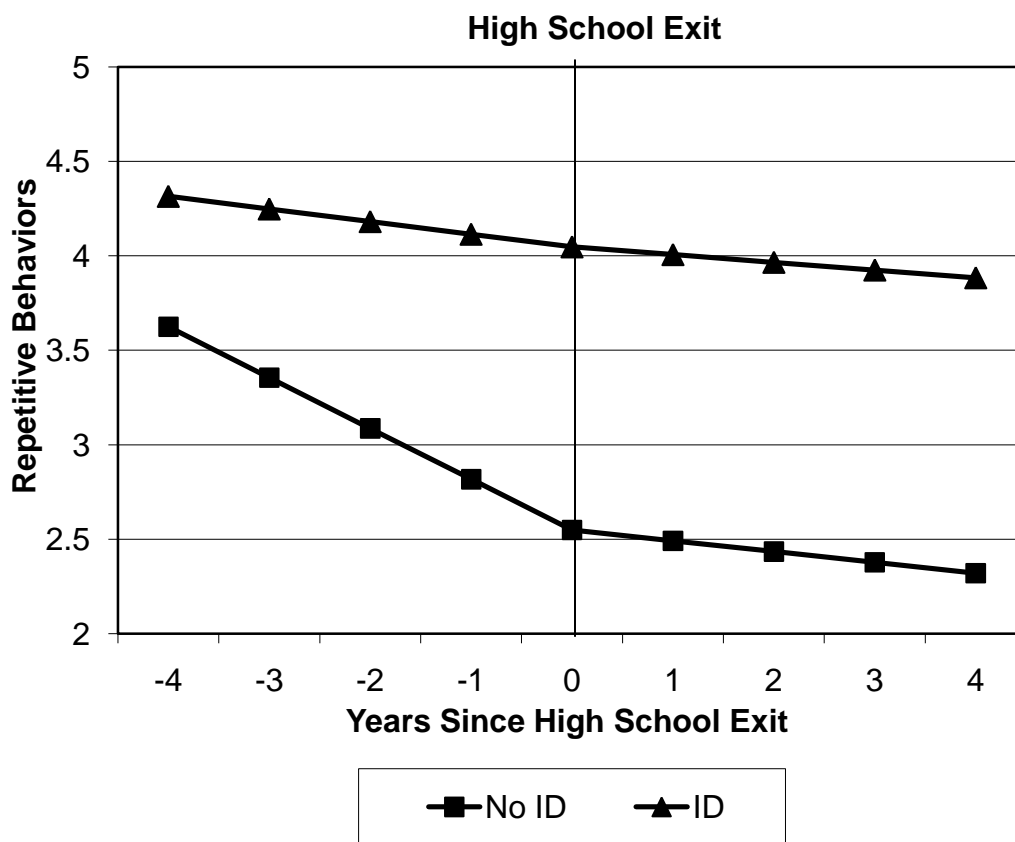


In this Figure, triangles represent youth with ASD who have a co-occurring intellectual disability (ID). Squares represent those without an intellectual disability. It is important to note that higher scores signify more impairments; therefore, improvement in social reciprocity is observed when the lines are going down over time.

We found that while youth with ASD were in high school (the lines to the left of the “0” point), impairments in social reciprocity were improving for both those with and without an intellectual disability. However, after leaving high school, that improvement significantly slowed down (the lines to the right of the “0” point) for both youth with ASD who had an intellectual disability and those who did not.

We found a slightly different story when we examined how leaving high school impacted changes in repetitive behaviors and stereotyped interests (called repetitive behaviors from here on out). Figure 2 plots changes in repetitive behaviors before and after leaving high school.

Figure 2. Change in Repetitive Behaviors Before and After Leaving High School

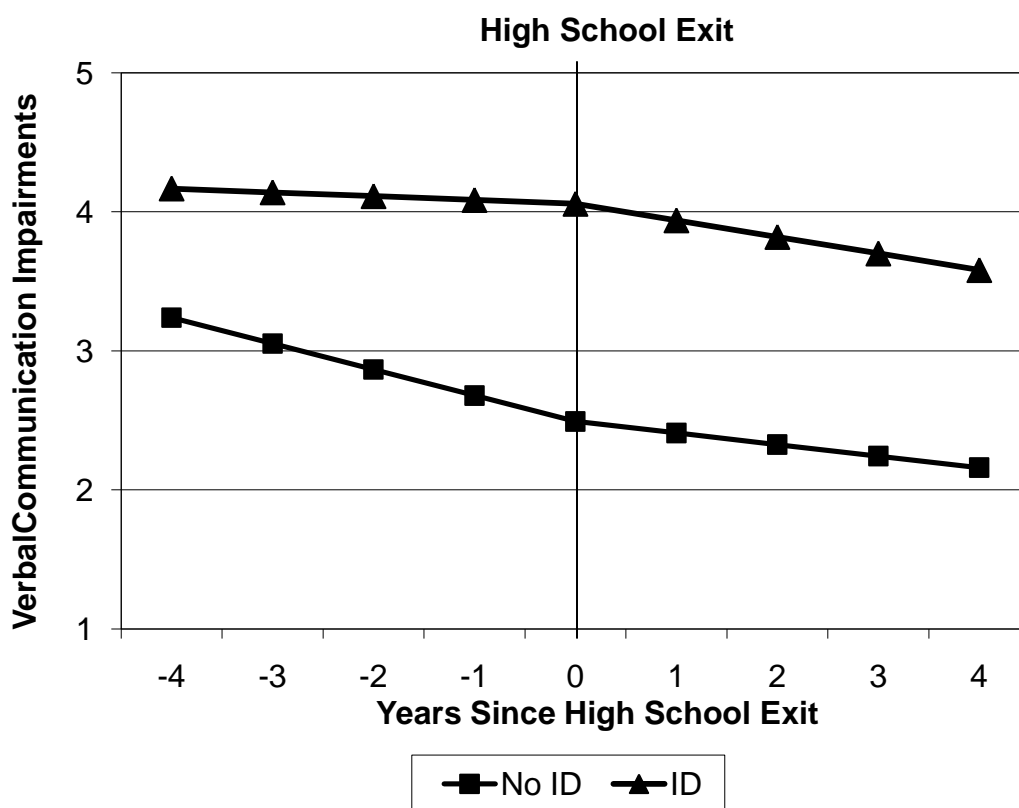


Similar to what we saw before, repetitive behaviors were improving while youth with ASD were in high school, regardless of whether they had an intellectual disability. However, improvement slowed down dramatically after high school

exit, but just for youth with ASD who did *not* have an intellectual disability. On the other hand, leaving high school had very little impact on changes in repetitive behaviors for youth who had a co-occurring intellectual disability.

Changes in verbal communication impairments before and after youth with ASD left high school are presented in Figure 3. Again, we observed a greater slowing of improvement for youth who did *not* have an intellectual disability. This led us to conclude that for repetitive behaviors and verbal communication, leaving high school had a greater negative impact for youth with ASD who did not have an intellectual disability.

Figure 3. Change in Verbal Communication Impairments Before and After Leaving High School

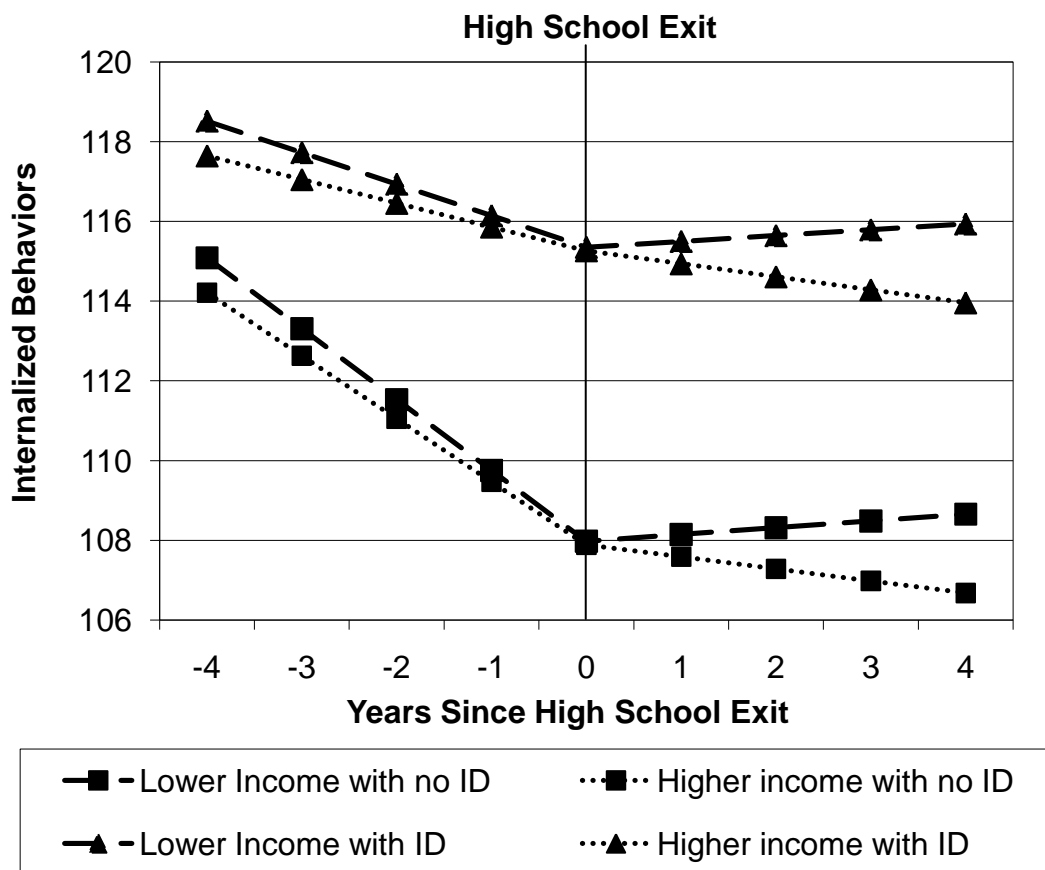


## Behavior Problems

Next we examined how leaving high school impacted changes in behavior problems. We analyzed behavior problems in three separate domains. The first was *internalized behaviors*, which encompasses behaviors such as being hurtful to oneself, unusual or repetitive habits, and withdrawn or inattentive behavior. The second domain was *externalized behaviors*, made up of such behaviors as being hurtful to others, destructive of property, or being disruptive. Finally, we analyzed *asocial behaviors*, comprised of social offensive and uncooperative behavior.

Similar to what we observed for autism symptoms, behavior problems in all domains significantly were improving while youth with ASD were in high school, both for those with and without an intellectual disability. For internalized behaviors, that improvement significantly slowed down for the entire sample (on average) after high school exit. For externalized and asocial behaviors, improvement significantly slowed down for subgroups of youth with ASD. Figure 4 depicts change in internalized behaviors before and after leaving high school. The role of family income in predicting this change is described on the following page.

Figure 4. Change in Internalized Behaviors Before and After Leaving High School



Squares represent youth with ASD without an intellectual disability and triangles represent those with an intellectual disability. Just like we observed for autism symptoms, improvement in externalized behaviors slowed more after leaving high school for youth who did *not* have an intellectual disability relative to those with a co-occurring intellectual disability. For internalized behavior problems, however, family income also played an important role. Figure 4 shows changes for those families whose incomes were at the bottom 25% of our sample (lower income) and those whose incomes were at the top 25% of our sample (higher income). There was a greater slowing of improvement after leaving high school for youth with ASD who were from lower income families (dashed lines) relative to those from higher income families (dotted lines).

Change in externalized behaviors before and after youth with ASD left high school is presented in Figure 5. Once again, we see a greater slowing of improvement for youth with ASD without an intellectual disability and those whose families have lower incomes.

Figure 5. Change in Externalized Behaviors Before and After Leaving High School

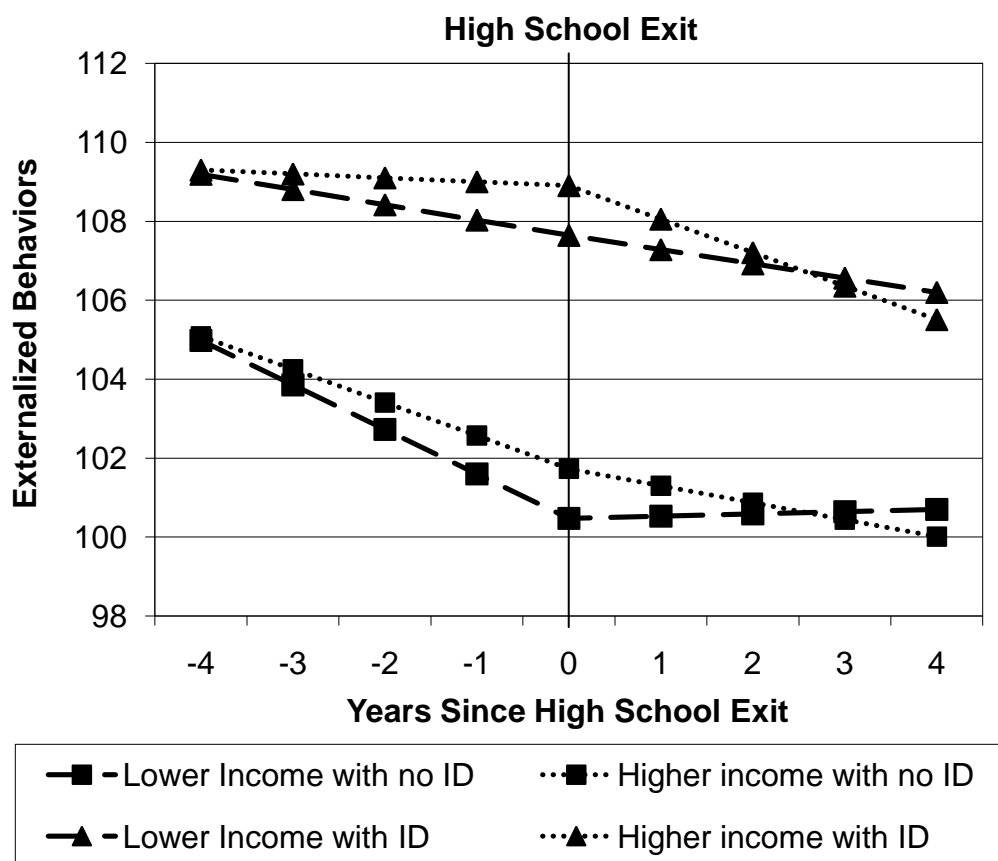
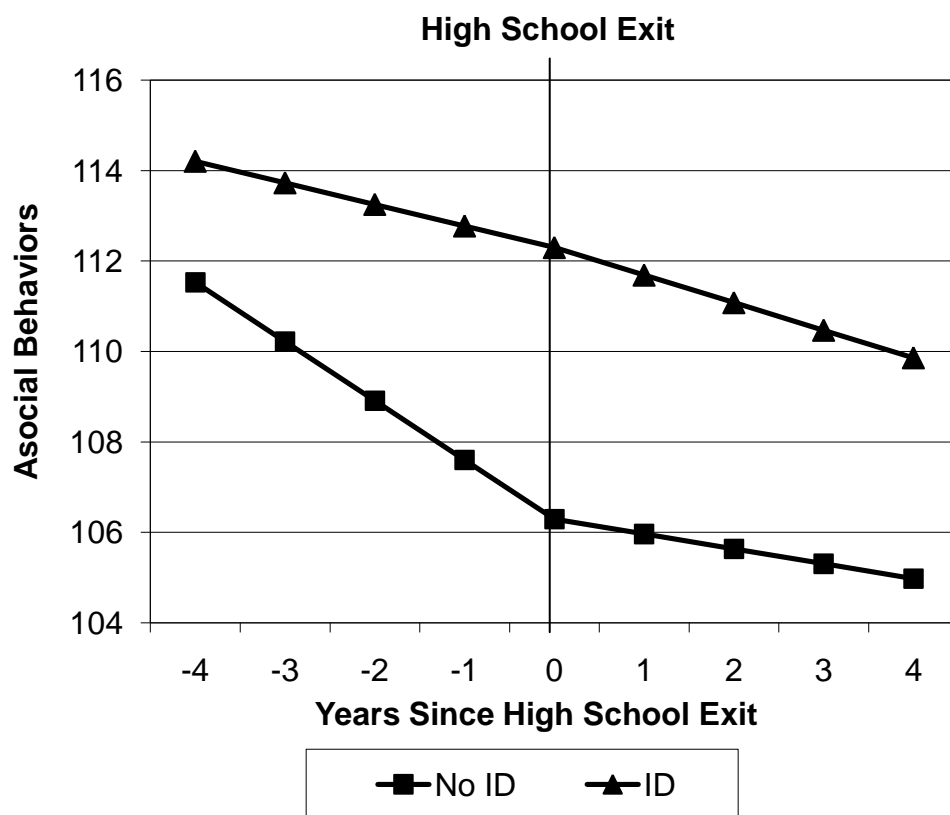


Figure 6 shows change in asocial behaviors before and after leaving high school. We see the same effect of intellectual disability status. Specifically, there is a slowing of improvement in asocial behaviors after leaving high school for youth with ASD who do *not* have an intellectual disability. For those with a co-occurring intellectual disability, asocial behaviors continued to improve at the same rate after leaving high school.

Figure 6. Change in Asocial Behaviors Before and After Leaving High School



In sum, these findings suggest to us that leaving high school disrupts the improvement in autism symptoms and behavior problems that is observed while youth with ASD are in high school. Disruption seems to be most evident for youth with ASD who do not have an intellectual disability and for those whose families have fewer financial resources.

### **Section III: Examining the Vocational Activities of Youth with ASD in the Years after Leaving High School**

The next step in our research on the transition to adulthood was examine at the educational, work, and vocational activities of youth with ASD in the years after they left the school system. The research that we presented in Section 2 suggested that individuals with ASD who did *not* have an intellectual disability might be *more* negatively affected by leaving high school. We hypothesized that this could be because there are fewer services geared toward the unique needs of these adults, and thus they may have a more difficult time finding meaningful and appropriate vocational activities after they leave high school. Young adults with ASD and a co-morbid intellectual disability might benefit more from the current adult service system and therefore would integrate more easily into existing vocational programs after they leave high school.

We used a smaller sample for this research question. We included 66 young adults with ASD who left high school between Times 4 and 5, and examined their vocational activities at Time 5. Youth averaged 23 years of age at Time 5, with a range from 19 to 26. They had left high school an average of 2 years previous to Time 5. Approximately three-fourths had an intellectual disability and 60% were living with their parents.

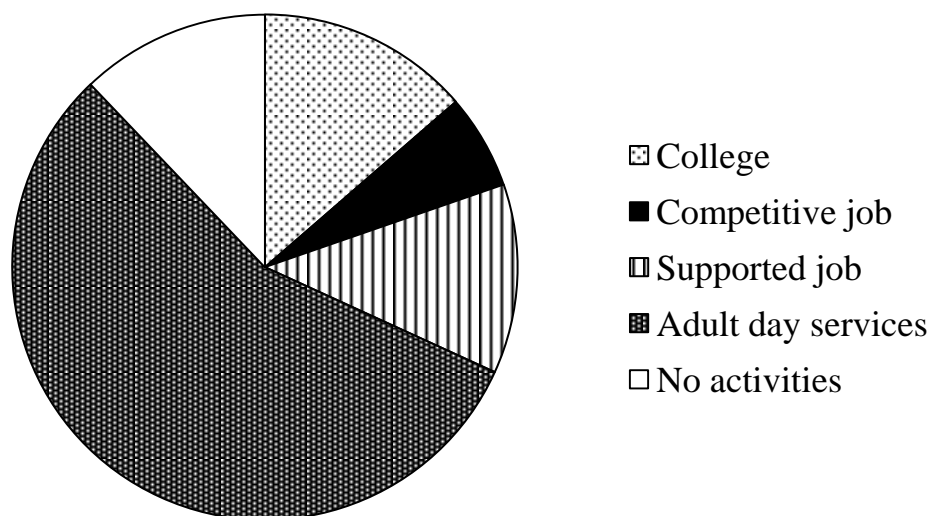
We used a detailed record review to develop five categories of post-secondary educational and vocational activities. This was quite complicated, as many youth with ASD were involved in more than one type of day activity simultaneously, such as spending part of their week in a sheltered workshop, working with supports in the community, and also taking a college class.

The five categories we developed are as follows:

- ❖ Post-secondary, degree-seeking program. This category was made up of all young adults who were taking classes toward a post-secondary degree (regardless of their other occupational activities).
- ❖ Competitive employment in the community. This category included all young adults who were competitively employed in the community, without receiving supports or adult day services, and who were not enrolled in post-secondary degree-seeking educational programs.

- ❖ Supported employment. This category represented young adults who worked in the community with supports and who did not receive adult day services from a sheltered workshop or day activity center.
- ❖ Adult day services. Any young adult who was attending sheltered workshops or day activity centers fit into this category.
- ❖ No/few day activities. This category was made up of young adults who had vocational or educational activities that totaled less than 10 hours a week.

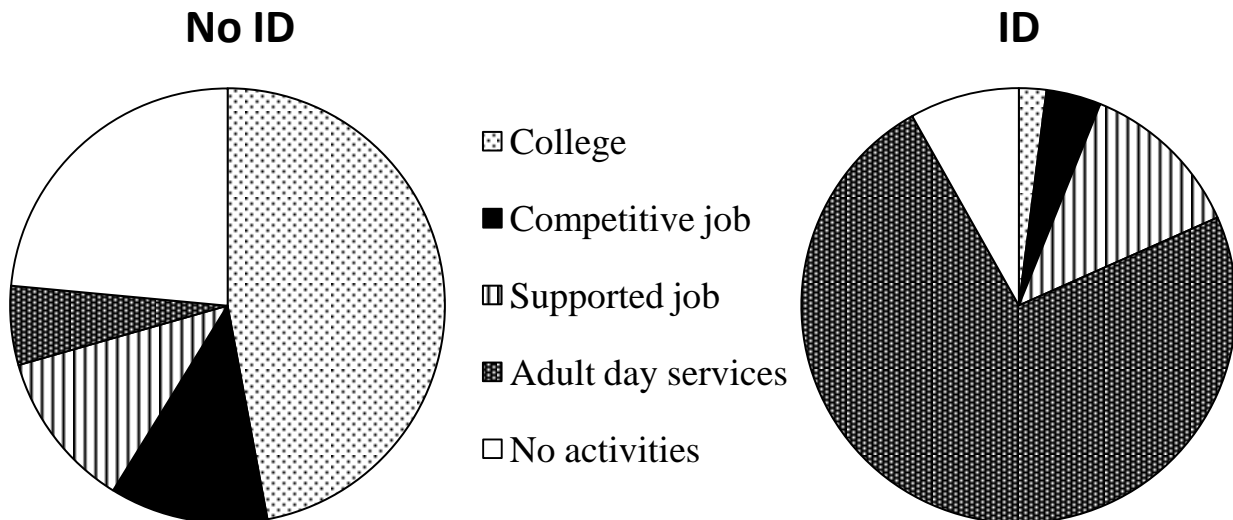
Figure 7. Prevalence of Vocational Activity Categories



As can be seen from Figure 7, the majority (56%) of young adults with ASD were receiving adult day services. Roughly similar percentages were enrolled in a post-secondary degree seeking program (14%) or had a supported job (12%). Only 6% were in the competitive employment category. It should be noted that none of the competitive jobs were full-time, and all were entry-level (such as working as a bus boy or replacing dirty glasses with clean ones at a hotel). Approximately 12% of the young adults with ASD had no regular vocational or educational activities.

We were interested in comparing the activities of young adults who did and not have a co-occurring intellectual disability. The break-down of vocational activities categories for these groups are presented in Figure 8.

Figure 8. Prevalence of Vocational Activity Categories for Those With and Without an Intellectual Disability



Nearly 50% of the young adults with ASD *without* an intellectual disability were in a post-secondary, degree seeking program, compared to 2% of those with an intellectual disability. Adults *without* an intellectual disability were also three times more likely to be competitive employed (12% compared to 4%). Adults with a co-occurring intellectual disability were far more likely to be receiving adult day services. Nearly three-fourths of these adults fit into this category, compared to only 6% of those without an intellectual disability. Perhaps most concerning, one-quarter of adults without intellectual disabilities had no regular vocational activities. This percentage was three times greater than what was observed for those with an intellectual disability.

We followed up this analysis by examining how those who had no vocational activities differed from the other groups. In general, we found that these young adults without vocational activities had autism symptoms and maladaptive behaviors that were less severe than those who were receiving adult day services, but more severe than those who were in college or working competitively in the community. It appears that young adults with no vocational activities may be “falling through cracks.” That is, their impairments are not so serious as to require sheltered vocational activities, but they are unable to function independently in the community without some type of service and supports.

## **Section IV: Summary and Conclusions**

This report has presented information about the impact of leaving high school and entering adult life for individuals with ASD and for their families. Our study is one of the first to examine how individuals with ASD themselves are affected by this transition, and from it we can draw several important conclusions.

- ❖ The transition out of high school and into the adult service system is indeed a significant turning point in the lives of youth with ASD. Family members have often told us of the anxiety that they feel about their son or daughter leaving high school, and the difficulties they face transitioning from the school to adult service system. Our study validates these observations by finding that this turning point is associated with disruptions in improvements in the son or daughter's behavioral functioning.
- ❖ Youth with ASD *without* an intellectual disability seem to be most affected by leaving high school. We see greater slowing of improvements in symptoms and behaviors for these youth. This is likely tied to our findings that these same youth are more likely to have no daytime activities in the years after they leave high school. It is our observation that there are few to no adult services geared toward the unique needs of adults with ASD who do not have an intellectual disability. These young adults may be “falling through the cracks” after they leave high school, and researchers and policy makers should continue to explore the best ways to help them reach their maximum potential.
- ❖ Familial economic resources are likely an important contributor to how smoothly a young adult with ASD transitions out of high school and into the adult service system. Other studies have found that families of young children with ASD who have fewer economic resources have a more difficult time getting an ASD diagnosis for their child and face more barriers to receiving ASD services. Our study suggests that these income-related barriers may remain in place after youth with ASD leave high school. Just as quality school and health care services should be available to everyone, regardless of income, so should quality and varied services for adults with ASD.

We hope that the information that we have shared is interesting to you and shows how much we have learned from your participation in our study. We wish to once again express our gratitude for your continued support of our research. These

results have provided families, researchers, and practitioners with an important new understanding of how the transition out of high school is experienced by youth with ASD and their families. We will take this research to policy makers to show that appropriate services and interventions are important for youth with ASD who are transitioning out of high school and into the adult service system, and not just for young children with ASD. Ultimately it is our goal that this research will inform policies and interventions aimed at helping adults with ASD reach their maximum potential during the transition years and beyond.