Transition to Adulthood for Youth with Autism: A Research Report

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Acknowledgements

This project is supported by a grant from the National Institute of Mental Health (K01 MH092598), with core support from the Vanderbilt Kennedy Center Intellectual and Developmental Disabilities Research Center (supported by U54 HD083211 from the National Institute of Mental Health) and the Vanderbilt Institute for Clinical and Translational Research (supported by CTSA UL1 TR000445 from the National Center for Advancing Translational Sciences). I gratefully acknowledge support from the Vanderbilt Kennedy Center and the Department of Pediatrics at Vanderbilt University Medical Center.

We are extremely grateful to the mothers, fathers, adolescents, and adults with an autism spectrum disorder who have given so generously of their time and shared their lives with us. We also wish to thank the collaborators, students, and staff who have worked on this project over the years, particularly Amie Duncan, Ph.D., and her staff at Cincinnati Children’s Hospital Medical Center, and Vanderbilt project managers Natalie Henninger and Rebecca Johnston. Finally, thank you to Sydney Waitz-Kudla, Sophie Meskis, and the Vanderbilt Kennedy Center Communication and Graphics staff for their hard work on this report.

The mission of the Vanderbilt Kennedy Center for Research on Human Development (VKC) is to facilitate discoveries and best practices that make positive differences in the lives of persons with developmental disabilities and their families. As a national Intellectual and Developmental Disabilities Research Center, the VKC brings together scientists and practitioners in behavior, education, genetics, neuroscience, and other disciplines to work together to improve knowledge of development and learning. As a University Center for Excellence in Developmental Disabilities, the VKC provides innovative leadership in training, research, services, and dissemination in Tennessee and beyond. VKC TRIAD (Treatment and Research Institute for Autism Spectrum Disorders) focuses on improving assessment and treatment services for children with autism while advancing knowledge and training. Graphic services supported in part by EKS NICHD Grant U54 HD083211 to the Vanderbilt Kennedy Center, vkc.vumc.org, April 2018
Section I: Introduction

This project stems from work suggesting that the exit out of high school and into the adult world is a time of great change for youth with autism spectrum disorder (ASD) and their families. Previous research has found that after youth with ASD leave high school, they experience a slowing of improvement in their autism symptoms, behavior problems, and daily living skills. However, there are limited numbers of studies that have closely examined the transition process for these youth, and that give us a clear understanding of the characteristics, supports, and experiences that can lead to a smoother versus a more difficult transition.

This project was designed to do just that—to understand the changes that occur for youth with ASD and their families during the transition years, and to examine the factors that were associated with a successful transition experience. To investigate these questions, we recruited a sample of 41 families of young adults with ASD, all who were in their last year of high school. We then followed these families over time, collecting data in the youth’s last year of high school, when the youth had been out of school for less than a year (about 9 months on average) and again when they had been out of high school for 2-3 years. Although we know it can be difficult and time consuming for families to continue to participate in studies over a number of years, collecting data at multiple times has allowed us to make new discoveries about how life changes during the transition years.

In this report, we present some selected findings from this project. As you will see, we have been able to deeply examine the hopes, dreams, and expectations of youth with ASD (Section 2), patterns of service access and factors associated with unmet service needs (Section 3), rates and predictors of mental health problems among youth with ASD (Section 4), and patterns of change over time in vocational, educational, and social participation (Section 5).

Leaving high school and entering adult service systems is a time of great change for individuals with ASD. 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.
Section II: Postsecondary Hopes and Expectations

In the first publication from this study, we aimed to understand the expectations that youth with ASD had for life after high school in terms of school, work, friendships, and living arrangements. We additionally looked at how these youth defined adulthood.

We asked five open-ended questions of the young adults with ASD at their first study visit during their last year of high school. The questions were:

- What do you think your life is going to be like after you leave high school in the area of:
  - a. Work?
  - b. Where you will live?
  - c. School?
  - d. Friends?
- What do you think a person must do to be considered an adult?

We collected responses from 31 youth. Perhaps not surprisingly, the students with ASD in this study expected to attain many of the same goals as their peers following high school. Nearly all youth who answered our questions (90%) expected to attend more school after leaving high school, 62% planned to work, and 77% had some plan surrounding friendships upon graduation.

![Plans Upon Leaving School](chart)

School
Among the 90% of students with ASD who discussed postsecondary education plans, 36% of students expected to pursue either a 4-year degree or higher, 25% expected to attend a 2-year degree or vocational program, and over a third (36%) did not specify the type of college they planned to attend.

![Education Plans](chart)

Work
All of the youth who answered these questions either expected to work following high school or stated that they were uncertain about what their future employment situation would be. Many hoped to find meaningful jobs that were “stress-free” and “enjoyable.”
**Friendships**

Most youth were optimistic about friendships following high school with only two individuals expecting not to have friends. Several participants were also hopeful that making friends in adulthood would be easier than it had been while they were in high school.

![Living Arrangement Expectations](image)

- **Reside in parental home**
- **Leave parental home**
- **Move out eventually**
- **Does not know what to expect**

*Not mutually exclusive categories*

**Living Arrangements**

Almost half of the individuals we interviewed expected to reside in their parents’ home following high school, with some of that group intending to move out eventually. The remainder of these individuals planned to either live alone, with roommates, or with friends or significant others. In addition, almost half of the sample planned to eventually relocate out of state.

**Defining Adulthood**

When asked how they would define adulthood, youth with ASD most often cited characteristics of independence, maturity, and personal responsibility as being important markers. Additionally, many individuals viewed the transition to adulthood as linear, meaning that they believed the achievement of one adult role was needed in order to pursue another (e.g., college leads to friends, a career).

Overall, we found that the adolescents in our sample mirrored the general population in the sense that they, too, had varied outlooks for their postsecondary futures. This diversity in expectations reemphasizes the need for individualized education plans for individuals with ASD, specifically in terms of transition planning. For adolescents with ASD to be successful, we believe it is important to begin preparing them for adulthood starting in high school. One helpful way to accomplish this goal is by offering community-based services that help with attaining employment, living, and social transition outcomes. Ideally, these services would start in high school and continue through the transition out of the school system.

These findings are available in the following publication:

Section III: Access to Services Among Transition-Age Youth with ASD

One of the major goals of the grant was to understand patterns of service use and access among youth with ASD as they transition to adulthood. Thus, the next step in our research was to look at service needs and barriers among youth with ASD during their last year of high school. To achieve that goal, we collected data from parents about which services their son/daughter was receiving from a list of 27 services such as speech/language, vocational, and mental health services. For each service that the youth was not receiving, we asked whether he/she needed that service. Asking these questions allowed us to examine which services were currently being received, and which service needs were currently unmet. The services that we examined are included in the graph below:

On average, when they were in their last year of high school, youth were receiving about 3 services, with a range from 0 to 9. The majority of youth (89.7%) were receiving at least 1 service at this time. As depicted by the green bars, the most frequently accessed services included mental health services, speech/language or communication services, vocation-related services (career counseling/job skills training), in-home/in-classroom aide, and medical services. Each of the remaining services were received by 25% of less or the sample.
We found that two-thirds of the sample reported having at least one service need that was not being met. The most common unmet service needs (blue bars in the graph) included vocation-related services and occupational/life skills training, both of which are very transition-focused services. We believe this could indicate the types of services valued and pursued as parents are preparing for their child’s transition out of high school.

We next looked at what characteristics of youth and their families were associated with: (a) youth getting more services, and (b) youth having a greater number of service needs that were currently unmet; note that these are not the same, as some youth who are getting few services may not need additional services, whereas others getting few services might need many services. The areas we examined as predictors of services were as follows:

Youth characteristics:
- presence or absence of a co-occurring intellectual disability
- race/ethnicity
- autism symptom severity
- co-occurring psychiatric disorders (such as mood or anxiety disorder)
- behavior problems
- adaptive behavior (everyday life skills such as grooming, following rules, utilizing social skills)

Family characteristics:
- family income
- parental health
- parental depressive symptoms
- parental anxiety

Youth and family characteristics associated with the number of services youth were receiving, as well as with unmet service needs, are shown in the table below.

<table>
<thead>
<tr>
<th>Youth who received more services tended to:</th>
<th>Youth with more unmet service needs tended to:</th>
</tr>
</thead>
<tbody>
<tr>
<td>❑ Have a co-occurring psychiatric diagnosis</td>
<td>❑ Be from a racial/ethnic minority group</td>
</tr>
<tr>
<td>❑ Have lower levels of adaptive behavior</td>
<td>❑ Have more behavior problems</td>
</tr>
<tr>
<td></td>
<td>❑ Have parents with greater anxiety</td>
</tr>
</tbody>
</table>

Our findings suggest that youth who are receiving the most services tended to have more functional limitations and psychiatric symptoms such as anxiety or depression. Further, youth who were from racial/ethnic minority groups, who had high levels of behavior problems, and whose parents had high levels of anxiety were more likely to need services that they currently were not getting. These findings point to a group of youth who are less likely to receive the services that they need, and thus might be at greater risk for a poor transition to adulthood.

Although not a primary focus of this paper, we also noted that youth with ASD who did not have an intellectual disability were far less likely than those with an intellectual disability to be receiving vocational and life skills training. Yet, even for those youth with ASD who did not have an intellectual disability, parents often reported that these types of training were needed. Our findings suggest that even among those young adults with ASD who are exclusively receiving academic instruction in school (e.g., main-streamed), life skills and vocational skills training might be helpful and could smooth the transition out of high school and into postsecondary educational and vocational activities.
These findings are available in the following publication:

## Section IV: Traumatic Experiences and Mental Health in Youth with ASD

We examined the relationship between cumulative stressful life events, trauma, and how those experiences affected mood and anxiety symptoms among youth with ASD. The idea for this project came from our experiences when families came to Vanderbilt for their first study visit. We noticed that many youth seemed to be showing symptoms of depression and anxiety. When talking to the parents, we also noticed that many youth had experienced major, negative life events at some point in the past. Although stress and trauma have been shown to be related to mental health issues in many other groups, there were no studies that examined how they might be related to the mental health of youth with ASD. We wondered if higher rates of negative life events could be one reason why studies tend to observe high rates of anxiety and depression among youth with ASD. If we found a relationship, it could point to the need for additional monitoring and intervention for youth who experience a potentially traumatic event, with the goal of preventing the emergence of co-occurring mood or anxiety symptoms.

The list of 27 potentially traumatic events are presented in the table below. Parents were asked to report if each of those events had occurred to their son or daughter at any point in their lives. They were then asked to rate how affected the youth was by that event on a scale of 1 (not at all) to 5 (extremely). If parents said that their son or daughter was extremely affected by an event (rated it a “5”), we considered that to be a trauma.

<table>
<thead>
<tr>
<th>Event</th>
<th>Percent of youth who experienced this event</th>
</tr>
</thead>
<tbody>
<tr>
<td>Has anyone else close to youth ever died as a result of a serious accident, injury, or illness?</td>
<td>55.6%</td>
</tr>
<tr>
<td>Has anyone in the home ever had a serious accident, injury, or illness that was life threatening or caused long-term disability?</td>
<td>50%</td>
</tr>
<tr>
<td>Did you go through a divorce or separation at any point in youth's life?</td>
<td>30.6%</td>
</tr>
<tr>
<td>Has anyone in the home ever not had a job for a long time when he/she wanted to be working?</td>
<td>30.6%</td>
</tr>
<tr>
<td>Has youth ever been bullied by his/her peers to such an extent that he/she had to go to the doctor or you considered changing schools?</td>
<td>27.8%</td>
</tr>
<tr>
<td>Has anyone else close to youth ever had a serious accident, injury, or life-threatening illness (but lived)?</td>
<td>27.8%</td>
</tr>
<tr>
<td>Has anyone in the home ever been sent away or kicked out of the house because he/she did something wrong?</td>
<td>16.7%</td>
</tr>
<tr>
<td>Has anyone in the home ever been sexually, physically, or emotionally abused?</td>
<td>13.9%</td>
</tr>
<tr>
<td>Has your family ever been in a major fire, flood, earthquake, or other natural disaster?</td>
<td>13.9%</td>
</tr>
</tbody>
</table>
Every individual in our sample had experienced at least one major life event, with an average of four events per person. The number of those events that were experienced as traumatic for the youth in our sample (defined by parents saying that youth were “extremely” affected by the event) ranged from 0 to 5, with a little over one-half experiencing at least one trauma. The most common events included the death of someone close to youth as a result of accident, injury, or illness (55.6 %); life-threatening injury or illness of someone in the home (50 %); parental divorce/separation (30.6 %); and unemployment within the home (30.6 %).

Events that we might think of as typically being “traumatic” were not always experienced as such for youth with ASD (at least as rated by parents). For example, being in a major fire, flood, earthquake, or natural disaster was only experienced as “traumatic” for 40% of youth. Being bullied to a significant extent was rated as being traumatic for

<table>
<thead>
<tr>
<th>Event</th>
<th>Percent of youth who experienced this event</th>
</tr>
</thead>
<tbody>
<tr>
<td>Was youth ever forced to live apart from one or both parents?</td>
<td>11.1%</td>
</tr>
<tr>
<td>Has anyone in the home struggled with substance abuse or addiction?</td>
<td>11.1%</td>
</tr>
<tr>
<td>Has anyone in the home ever been physically assaulted or mugged?</td>
<td>11.1%</td>
</tr>
<tr>
<td>Was youth ever abandoned by one or both parents?</td>
<td>11.1%</td>
</tr>
<tr>
<td>Have you ever lost your home because of a natural disaster?</td>
<td>8.3%</td>
</tr>
<tr>
<td>As a child, did youth ever live in an orphanage, foster home, or group home, or was he/she ever a ward of the state?</td>
<td>8.3%</td>
</tr>
<tr>
<td>Has anyone in the home ever been shot at with a gun or threatened with another weapon?</td>
<td>8.3%</td>
</tr>
<tr>
<td>Has youth ever been told that someone else he/she was close to had taken his/her own life?</td>
<td>8.3%</td>
</tr>
<tr>
<td>Has youth ever failed a grade in school?</td>
<td>8.3%</td>
</tr>
<tr>
<td>Has anyone in the home, or someone youth is close to ever been incarcerated?</td>
<td>8.3%</td>
</tr>
<tr>
<td>Has youth ever gone through a difficult breakup?</td>
<td>8.3%</td>
</tr>
<tr>
<td>Has anyone in the home ever taken his/her own life?</td>
<td>5.6%</td>
</tr>
<tr>
<td>Has youth witnessed anyone in the home being sexually, physically, or emotionally abused?</td>
<td>5.6%</td>
</tr>
<tr>
<td>Did youth ever discover that a girlfriend or boyfriend was unfaithful?</td>
<td>2.8%</td>
</tr>
<tr>
<td>Has youth ever been told that someone he/she was close to had been killed?</td>
<td>2.8%</td>
</tr>
<tr>
<td>Has anyone in the home ever been killed?</td>
<td>0</td>
</tr>
<tr>
<td>Has anyone in the home ever died as a result of a serious accident, injury, or illness?</td>
<td>0</td>
</tr>
<tr>
<td>Has youth ever witnessed something violent happen to someone or seen someone killed?</td>
<td>0</td>
</tr>
</tbody>
</table>
50% of youth. Parents also had the option to note other types of traumatic events—in these circumstances, parents noted things that their son/daughter experienced as traumatic, that we might not necessarily ask about in our structured questionnaires (such as passing out while waiting in line or death of a family pet). These findings suggest that how youth with ASD experience an event is likely more important than simply whether the event occurred.

We next examined the relationships between trauma, life events, and co-occurring mood and anxiety symptoms. Using a range of data (self-reports of symptoms, parent-reports of symptoms, history of diagnoses, current medication use), we classified each youth into one of three categories for both mood and anxiety symptoms: (1) definite, clinical levels of symptoms; (2) sub-threshold levels of symptoms (in other words, some evidence that symptoms were there, but without clear evidence), and (3) no/little evidence of symptoms. Using these categories, we observed a relationship between mood symptoms and the percentage of youth who had a traumatic event (presented in the figure below).

Experiencing at least one traumatic event was related to a greater chance of demonstrating mood problems in youth with ASD. This suggests that trauma might be significant in the development of co-occurring psychiatric problems in individuals with ASD. However, we also found that there were many youth who experienced a traumatic event who did not develop a mood disorder. An important future direction of research will be to understand what is different about those youth with ASD who experience trauma and go on to develop clinical-level mood symptoms versus those who do not.

It is important also to note that mood and anxiety disorders were very common among the youth with ASD in this sample. Only one-third of the youth had no/little evidence of mood or anxiety symptoms, and nearly 50% had symptoms that were severe enough to meet criteria for clinical-level mood or anxiety symptoms. Thus, co-occurring psychiatric symptoms are an important consideration during the transition to adulthood, and should be addressed.

These findings are available in the following publication:
Section V: What Happens Next for Youth with ASD?

All these initial publications focused on data collected while youth were in high school. Of course, we were also interested in understanding how life changed for youth and families after the young adults with ASD left high school. To begin to investigate these types of questions, we examined how participation in structured social activities (typically done in group settings, such as going to a religious group or attending an organized group event) and in unstructured social activities (such as spending time with friends or coworkers outside of school/work settings) changed for youth with ASD from before to after leaving high school. To examine these changes, we asked parents about the social, recreational, and leisure activities that their sons and daughters with ASD were involved in at two time points—during their last year of high school and when they had been out of high school for about 9 months (on average).

Using this information, we found that social isolation for individuals with ASD was a common experience while youth were in high school and after leaving high school. For example, as can be seen in the figure below, the vast majority of youth rarely spent social time with friends or neighbors both before and after leaving high school.

Across the sample, we saw an average decline from before to after high school in the amount of time youth spent in structured social activities. However, we saw a different pattern for unstructured social participation. Time spent in unstructured social activities remained the same, on average, from before to after high school. That average masked a large amount of individual-level change. While some youth become more isolated from unstructured social participation, others increased in the amount of time they spent with friends/co-workers/classmates/etc. This was interesting to us, since there is some common lore that most youth with ASD become more isolated as they enter into adulthood. We found patterns of change in unstructured social participation that were much more variable.

Finally, we found that youth who had more structured social participation while in high school were more likely to increase their amount of unstructured social participation after they left high school. These findings must be interpreted cautiously since there are many factors that might explain the relationship between structured activities and change in unstructured activities over time. For example, structured activities might generate social ties that persist beyond high school. Another explanation is that structured social activities might help improve social skills, which would be relevant for unstructured participation as well. If the benefits of structured social participation truly persist beyond high school, this points to promising areas of intervention to promote social engagement for young adults with ASD across the transition out of high school.
Finally, a recent paper examined both waves of data that we collected after youth left high school to determine the percentage of youth with ASD who experienced instability in their vocational and educational positions in the 2-3 years after leaving high school. Most studies of vocational and educational activities are focused on youth with ASD obtaining a vocational or educational position, but we had some preliminary evidence to suggest that keeping those jobs or educational positions, once obtained, might be an even bigger challenge.

As can be seen in the figure to the right, nearly all youth participated in a vocational or educational position at some point in the 2-3 years after leaving high school. This was promising, since the percentage of youth engaged in vocational or educational activities was higher than other estimates, and might represent improvements in policy and services around the transition out of high school. However, we saw high rates of instability, with 50% of the sample experiencing job/vocation loss or dropping out of a college program during this short timeframe. This study suggests that much more work is needed to understand the factors that are associated with obtaining and maintaining postsecondary vocational and educational positions.

These findings are available in the following publications:


Section VI: Summary and Conclusions

This report has presented information about the experiences of youth with ASD and their families as they leave the school system and enter the adult world. Our study is one of the first to carefully examine how things change for youth and families during this time of transition. From it, we can draw several conclusions.

- Youth with ASD have many of the same hopes, dreams, and plans for life in adulthood as youth in the general population. Unfortunately, they are often not getting the services and supports necessary to make those dreams a reality. Service systems need to do better at providing services related to transition (such as training in vocational skills or daily living skills), and in smoothing the pathway for continuous services from before to after high school.
- Mental health problems are a reality for many youth with ASD, and they might be influenced by difficult life experiences. We need much more research to understand the many factors that are associated with the emergence of anxiety and depression, so that we can identify those youth who are most at-risk and learn how to effectively alleviate these symptoms.
- The pathways that youth with ASD take after leaving high school greatly vary. Some youth enter college programs, jobs, or vocational programs and successfully continue those positions over time. Other youth take a slower start, beginning at a 2-year college or a less independent vocational position, and develop greater independence over time. Other youth struggle, leaving college programs or jobs. Similarly, some youth become more socially connected after leaving high school, whereas others become more isolated. We are only beginning to understand what distinguishes youth who have smoother pathways versus those who struggle.