

"I NEVER PLANNED **NOT** TO GO TO COLLEGE":
VOICES OF YOUNG ADULTS WITH ASPERGER
SYNDROME TRANSITIONING TO COLLEGE: WHAT
TRANSITION SERVICES THEY GOT AND NEEDED

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General Transition to College

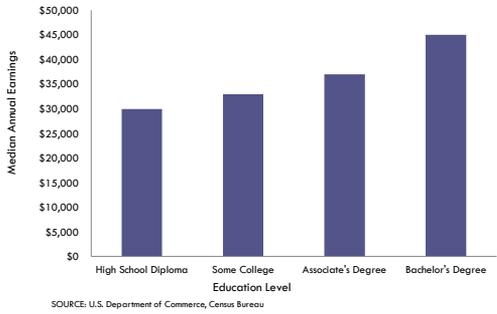
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- Of the 3.1 million youth (ages 16-24) who graduated from high school in 2011, 68.3% enrolled in colleges or universities.
- Between 2000 and 2010, undergraduate enrollment in degree-granting postsecondary institutions increased by 37%, from 13.2 to 18.1 million students.
- Between 1973 and 2008, the share of jobs in the U.S. economy which required postsecondary education increased from 28 percent to 59 percent. According to projections, the share of postsecondary jobs will increase from 59 to 63 percent over the next decade.



The median annual earnings of a full-time worker (age 25-34) in 2010

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Disability in College



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- A postsecondary education goal is required for all students with disabilities who have transition plans.
- 60% of youth with disabilities engage in postsecondary education within 8 years of leaving high school while 19% attended a 4-year college or university.
- Despite the majority of students who reported they intended to finish their programs, only 34% had earned a degree when they left.

College Barriers

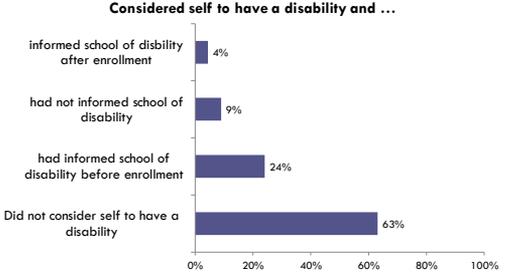
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- From IDEA entitlement to services in high school to Section 504 of the Rehabilitation Act and ADA eligibility in college
- Social Skills
- Communication
- Self-Advocacy
- Executive Functioning
- Narrow area of interest



Extent to which young adults with disabilities ever enrolled in a postsecondary school considered themselves as having a disability and informed postsecondary schools of disability

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SOURCE: U.S. Department of Education, Institute of Education Sciences, National Center for Special Education Research, National Longitudinal Transition Study-2 (NLTS2), Wave 5 parent interview and youth interview/survey, 2009.

Asperger syndrome in College

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58% of students with autism in the NLTS-2 study had attended some postsecondary education.



Transition services is a coordinated set of activities for a child with a disability that ...

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- (a) is designed to be within a **results oriented process**, that is focused on **improving the academic and functional achievement** of the child with a disability to facilitate the child's **movement from school to post-school activities ...**
- (b) is based on the **individual child's needs**, taking into account the child's **strengths, preferences, and interests...**

Definitions

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- **COORDINATED:** These activities have a purpose and a goal. They are selected with a plan in mind to accomplish a specific goal.
- **RESULTS ORIENTED PROCESS:** We are focused on the "outcomes" of the students instead of the "process". The central question is: *What has the student learned?*
 - *Did he learn the skills needed to pursue employment?*
 - *Did she learn the skills needed to pursue further education?*

Purpose of our study

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How do we help students with Asperger Syndrome prepare for and succeed in college?

Study

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Research Questions:

- 1. *What unique personal and contextual barriers do young adults with Asperger syndrome (AS) face when enrolling and remaining in college?*
- 2. *What high school transition services do these individuals need to be successful in their first year of college?*



Study

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Method

- 1-hour, semi-structured interviews
 - Young adults diagnosed with AS and their parent
 - Teacher who knew them during high school
 - Vocational Rehabilitation counselor
- 2 interviews each with young adults and their family
- 27 interviews in total

Analysis

- Coded interviews to identify themes
 - Transition experiences
 - Supports and services received and needed

Study



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- **Participants**
 - ▣ Recruitment: VR, school districts, and developmental pediatrician
 - ▣ Five males, ages 19 – 22 at first interview
 - ▣ Medical diagnosis of Asperger or high functioning autism
 - ▣ Age of diagnosis: 3 were 4-years old; 2 were 17 & 18
 - ▣ High School Experiences
 - Two graduated HS in 4-years with regular diploma
 - Two were home schooled and obtained GED
 - One obtained modified diploma and remained in HS transition program
 - ▣ Years enrolled in college at first interview, 0 to 3 years
 - Three enrolled in community college
 - One enrolled in 4-year university
 - One enrolled in adult continuing education course

College Status at 2nd Interview



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- **Brent** –completed 1 adult continuing education course; services from Brokerage and private AS service provider
- **Hunter** –final term of automotive mechanics course on track to graduate with AA; received no services
- **Irwin** – completed three years of work for BS in general social science; received no agency services, utilized educational supports on campus
- **Jeff** – completed 6 courses; 15 hours; VR services
- **Jorge** – completed 1 year of general education courses at community college; received no agency services, utilized educational supports on campus for help with navigation around campus

What unique personal and contextual barriers do young adults with Asperger syndrome face when enrolling and remaining in college?

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- Commonly Known Barriers
 - ▣ Communication - asking for assistance
 - ▣ Executive Functioning – lack of follow-through
 - ▣ Social Skills – desire for friends
- Hidden Barriers
 - ▣ Anxiety
 - ▣ Not eating on campus
 - ▣ Reliance on HS personnel



What made a difference?

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- Self awareness/disability awareness
- Level/type of motivation
- Family support/involvement
- Coordinated transition services
- Clear post-school goals

Self-Awareness

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Little Awareness	Some Awareness	Most Awareness
<ul style="list-style-type: none"> • Describes some characteristics relevant to him • Parrots what he's heard about AS • Knows he needs help, doesn't seek it 	<ul style="list-style-type: none"> • Hasn't learned about AS • Doesn't inform others • Doesn't use accommodations 	<ul style="list-style-type: none"> • Explains his needs • Understands limitations & where help is needed • Seeks assistance

Quotes: Self-Awareness

Little Awareness	Some Awareness	Most Awareness
<ul style="list-style-type: none"> • "What is the saying, if you've met one person with Asperger syndrome, you've met one person with Asperger syndrome". 	<ul style="list-style-type: none"> • "You wouldn't know I had autism if she didn't tell you. Maybe I do have it but I just pretend I don't ..." • "I don't really know how I can answer that question. I guess it just means that certain things are gonna be harder in life. I still don't really know what autism is exactly. Again, I never really cared to find out. It never really seemed important". 	<ul style="list-style-type: none"> • "I struggle socially definitely. I don't read a lot of social cues and that's kind of problems in school and socially. I don't have really a click of friends". • "Social interaction and a problem with adapting, I suppose, are the two main problems". if I am off schedule I sort of get a little crazy. Like I lose a sense of stability. So if I don't have a schedule, I'll sort of forget to sleep, and bathe, and eat, and drink. Go a while without doing all that".

Motivation to Attend College

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- Internal**
 - Desire for stable income
 - Long-term goal
 - Self expected, family norm
- External**
 - Family's desire for him
 - Transition planning questions lead to "gotta go to college"
- External to Internal**
 - Told to attend college, then he saw the benefit

Quotes: Motivation to Attend College

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- Internal**
 - *"I never decided not to.... I never really thought about not going to college. I always knew I was going to".*
- External**
 - *Mom: "I asked him half a dozen times to look in the book and mark some things he thought he'd be interested in. After six or so times of asking him to do it, it was time to draw back, wait for something to change".*
- External to Internal**
 - *"It gives me something to do. It occupies a lot of my time. And it gives me valuable skills, which I will use quite often, probably.*

Family Support/Involvement

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-  **Facilitator**
 - Provided information; visited colleges; supported his decisions
-  **Relinquisher**
 - Stopped attending IEP meetings when he turned 18; decisions and actions were his to make
-  **The Doer**
 - Enrolled him in college; registered him until his last term; applied for his financial aid
-  **The Director**
 - Sought agency involvement from many sources; wanted agency personnel to do what was needed for him to attend college

Coordinated Transition Services

None	Low	High
<ul style="list-style-type: none"> • Home schooled • No connections to other agencies or support 	<ul style="list-style-type: none"> • Family, school, young adult, & agencies have different goals & visions • Refused services in college 	<ul style="list-style-type: none"> • Intentional planning • Family, school, and young adult have the same goals & vision

Quotes: Coordinated Transition Services

Low	High
<ul style="list-style-type: none"> • School: "It also became clear that he wasn't going to take off and go to school and he was not going to take off and have a job and be able to work..." • "periodic random encouragement is about the best I can think of" 	<ul style="list-style-type: none"> • "I always thought of it as just another stage in school. College wasn't really the highlight of my goal. My goal was the biologist". • Parent: "We were all looking at options for him".

Post-School Goals linked to College linked to Career Aspirations

Unintentional	Intentional
<ul style="list-style-type: none"> • Variety of HS electives • HS diploma doesn't permit federal financial aid • HS experiences not linked with current job • College degree aligned with a career; just not in the field he's interested in pursuing 	<ul style="list-style-type: none"> • HS classes clearly aligned with stated postsecondary goal • Standard HS diploma • College classes aligned with stated career goal • Strong, personal goal setters

What high school transition services do these individuals need to be successful in college?

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- Coordinated Services: Individualized, purposeful, and results oriented – looking beyond high school
 - ▣ Families and agencies
 - Working together to support the youth
 - ▣ Self-Advocacy – Self-Awareness
 - Knowledge of and ability to describe their disability and needed accommodations
 - ▣ Communication
 - Ability to and strategies for ask for assistance; email v. talking
 - ▣ Executive Functioning
 - On-going supports with accountability; structure
 - ▣ Social Skills
 - Strategies for making friends Not to feel isolated and different

What high school transition services do these individuals need to be successful in college?

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- Coordinated Services: Individualized, purposeful, and results oriented – looking beyond high school
 - ▣ Anticipating hidden barriers and potential problems
 - Over-reliance on high school staff
 - Anxiety and mental health concerns
 - Individual idiosyncrasies
 - Not eating on campus
 - Talking to himself
 - Vomiting when nervous



What high school transition services do these individuals need to be successful in college?

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- Recognition and anticipation of potential hidden barriers – Mental Health
 - ▣ Anxiety – test anxiety, social anxiety
 - ▣ Depression
 - ▣ Lack of sleep
 - ▣ Panic attacks
 - ▣ Socialization
 - ▣ Not eating



Discussion, Questions, & Comments



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Contacts



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