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COMING OF AGE: AUTISM AND THE TRANSITION TO ADULTHOOD

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*This is the first in a series examining the research and reality of the transition to adulthood, with advice from experts who have studied the process and young adults who have lived it. Other articles include parts 2) **Daily Living Skills: A Key to Independence**, 3) **Autism and the College Experience**, and 4) **Finding a College Program**.*

The road to adulthood officially begins for many teens when they graduate from high school and move on to a first job or college, to paying bills and living on their own. But for people with autism, and their families, leaving high school is a more monumental step, one that will transform their relationship to services and supports.

In the coming years, an unprecedented number of students with autism spectrum disorder (ASD) will leave high school and flood the U.S. adult disability system, where services are based on the availability of funding and waiting lists abound. An estimated 50,000 Americans with ASD will turn 18 each year[1], part of "a surge of children" diagnosed in the 1990s.[2]

"We know there's a crisis coming," said Dr. Peter Gerhardt, chair of the Organization for Autism Research's Scientific Council. "It's not just a money crisis. It's a service crisis." Who will provide the services these young adults needs? These soon-to-be adults are coming of age in a time of shortage. The goal of independent living, shared by all teens, may seem farther from view for those on the spectrum.

WHAT DO WE MEAN BY THE TRANSITION?

> *When you get to be 18 or 21, it's like falling off a cliff. We don't do a great job of educating parents about what's going to happen after school ends.*

Technically, the transition is a formal process that begins by age 16 for a student who receives U.S. special education services. That is when school systems must begin helping those students plan for life after high school, such as college, work, vocational training, independent living and adult disability services.

Teachers will ask students about their interests and develop goals to be inserted in the student's Individualized Education Program (IEP). Adult service agencies may be invited to participate, since they may be handling the student's needs after he leaves high school or reaches age 21.

But don't assume a young adult is merely transferring between two equal disability systems, one for children and one for adults. The adult system is different at its core.

A student with a disability who is eligible for U.S. special education services is *guaranteed* to receive them until he graduates high school or turns 21. Not so with adult services. That same student may be *eligible* for adult services, such as housing assistance, day programs, supported employment and job training. But whether and when he receives those services depends on funding. States

often administer such programs through developmental disability and vocational rehabilitation agencies. The states set their own guidelines for eligibility and funding.

Many states have waiting lists for adult services, particularly housing. For example, Connecticut had 15,000 people with intellectual disability who were eligible for services in 2013, but only limited funding. To receive funding, someone on a waiting list had to be in a crisis, such as facing homelessness, abuse or a progressive illness. Many states parcel out funds for adult services to those who are in crisis or have the most severe needs.

"When you get to be 18 or 21, it's like falling off a cliff," said Zosia Zaks, a Certified Rehabilitation Counselor who works with adults with ASD. "We don't do a great job of educating parents about what's going to happen after school ends."

The responsibility for obtaining services also shifts. Public schools are tasked with finding children with disabilities and providing them services. But in the adult system, you must apply for services and ask for what you need. "It requires self-advocacy," explained Mr. Zaks, program supervisor at the Hussman Center for Adults with Autism in Towson, Md.

YOUTH WITH AUTISM AT RISK AFTER HIGH SCHOOL

The same shift occurs at the college level. That IEP that parents and teachers worked so hard to develop year after year? It does not apply to U.S. colleges and universities. A new set of rules, based on different laws, awaits students at the college level.

Once in college, students with disabilities will have to request the accommodations they need to be successful, and their schools need only provide the "reasonable" ones. Parents who consider themselves experts on their child's special needs may find themselves largely shut out of the process after high school because of privacy laws. Students who have experience making their needs known will fare better in this self-advocacy system.

Not surprisingly, the road to adulthood can be rocky. More than half of the youth with ASD had no job and no involvement with postsecondary education in the two years after leaving high school, according to a study in the journal *Pediatrics*. In fact, they fared worse than their peers with other types of disabilities in several measures of post-high school outcomes.[3] Students with ASD from lower-income families and those with greater impairments are at especially high risk.

"It appears that youth with an ASD are uniquely at high risk for a period of struggling to find ways to participate in work and school after leaving high school," according to the research team, led by Paul T. Shattuck Ph.D. They also warned of "potential gaps in transition planning" for youth with ASD,[3] a caution mentioned by other researchers studying the post-high school employment of people with autism.[4]

But don't panic. There are things parents, teachers and schools can do to help with the transition.

START TRANSITION PLANNING EARLY

> *Parents ask me, 'When should I start with transition planning?' I say, 'Age six,' and people look at me like I'm out of my mind.*

Ernst VanBergeijk Ph.D.

For one, you can begin planning sooner. Experts say that transition planning ideally begins when children are very young, as parents and schools lay the foundation for skills needed to negotiate adult life.

"Parents ask me, 'When should I start with transition planning?,'" said Ernst O. VanBergeijk, Ph.D., M.S.W., associate dean and executive director of the Vocational Independence Program at New York Institute of Technology. "I say, 'Age six,' and people look at me like I'm out of my mind. 'That's way too early,' they say. But I say, you need to visualize your child at age 21. What is it like to be an independent adult? What are the building blocks for independent living skills?"

Daily living skills – which include personal hygiene, housekeeping and handling money – can be taught beginning in early childhood, he said. Complex skills can be broken into small steps and gradually increased in complexity as a child gets older and learns to do each step, he said.

Take work and money management skills, for example. A parent can begin by teaching her child to perform simple chores and giving him an allowance for the work, he said. The child can learn about money by placing his coins into separate tins for spending and saving.

The payoff for learning these skills is high. A 2014 study of adults with ASD found that those with better daily living skills were more independent in their job and educational activities.[5]

FOCUSING ON DAILY LIVING SKILLS IN THE TRANSITION YEARS

Schools may not always consider daily living skills when drafting transition goals for a diploma-bound student. Parents can request that those skills be included in the IEP, said Dr. Amie W. Duncan, a psychologist who has studied this issue. Her research team found that half of the students with ASD and average or above average intelligence had deficits in daily living skills.[6]

Another item to consider: adding "travel training" as a transition goal. Travel training is hands-on teaching about how to travel safely to jobs and other destinations using public transportation.

Some programs, such as Project SEARCH, help move students with disabilities into workplaces during the transition years.

Elizabeth Cuff, 20, participated in Project SEARCH at Kootenai Medical Center in Coeur D'Alene, Idaho. Ms. Cuff, who has Asperger's Syndrome, worked in different jobs, including the Information Technology (IT) department. There, her computer skills made her a

natural fit. "Things really clicked for me because I felt at home there," she said. She imaged computers and iPads, installing standard sets of software at one time. "They told me I was really good at it," and I said, 'I'm not that good,' and they said, 'No, you're *really* good.'"


Liz Cuff with Tigger

She enjoyed her time in IT. "I made a lot of friends. Technically they were my coworkers, but I thought of them as friends," she said. "There was a lot of video game talk, and I'm kind of a gamer at heart."

Unfortunately, she did not land a computer job after leaving Project SEARCH, but she is working part-time washing dishes and other tasks. Ms. Cuff, a participant in the Simons Simplex Collection autism research project, has other career dreams. An artist with an interest in design, she hopes to open an old English style tea shop one day.

As part of the transition process, children should be encouraged to think about their interests and preferences, with an eye toward future employment, several experts said. One symptom of autism is an intense absorption in an object or topic. "Obsessions, when properly directed, can lead some children into a successful career," Dr. Temple Grandin told an interviewer.[7] She should know. A woman with autism, she turned her obsession with cattle chutes into a successful career designing livestock facilities around the world.

Students also can develop their interests, abilities and self-advocacy skills by participating in volunteer work and school clubs such as Best Buddies.[8] Best Buddies is a program in the United States and other countries that fosters friendships between students with and without developmental disabilities.

Ms. Cuff offers this advice to others facing the transition to adulthood: "Just move forward day by day, and cross the bridge when it comes."

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Additional Resources:

IAN's Transition to Adulthood Series:

- Part 2: Daily Living Skills: A Key to Independence for People with Autism
- Part 3: Autism and the College Experience
- Part 4: Finding a College Program for Students with Autism
- Take our nonscientific poll on high school transition plans

Also:

- A Place of Their Own: Residential Services for Soon-to-Be Adults with Autism
- Autism Beyond High School
- Transition Toolkit by Autism Speaks
- Project SEARCH and Best Buddies International

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