Transition Planning for Autistic Youth

Paul Shattuck, Ph.D.

Dr. Paul Shattuck is a nationally recognized expert in autism spectrum disorders. He was a pioneer in the understanding of autism in adulthood and the measurement of autism outcomes. Dr. Shattuck is currently focused on ways to measure and improve the performance and equity of systems of care for vulnerable populations using collaborative community engagement. He is also collaborating with foundations on a range of health and disability topics. He has a deep passion for translating scientific findings into useful guidance for policy and practice in the areas of health and social services. Dr. Shattuck has a Ph.D. in social welfare from the University of Wisconsin-Madison. He is a member of Mathematica's Equity Community of Practice. He was the founding leader of the A.J. Drexel Autism Institute's Life Course Outcomes Program, the National Autism Data Center, and the Transition Pathways Community Partnership Initiative.

Dr. Shattuck spoke with Cindy Lentz, Creative Director of Autism Advocate Parenting Magazine, about transition planning for autistic youth.

AUTISM ADVOCATE PARENTING MAGAZINE: Transitioning from a teen to an adult can be very difficult. What are some of the biggest challenges during this time for an autistic youth?

Dr. Shattuck: One of the biggest challenges during this time is cultivating self-advocacy skills in teens and young adults, and helping them learn the process of advocating for themselves. In the media, we have television shows with autistic characters, and we have autistic self-advocacy groups that are very visible and vocal. The popular mainstream media presents an image of an autistic college student who is very articulate and capable of expressing his or her own needs. In my experience, however, there are a lot of young people in their teens and 20s who are not as comfortable displaying their autism. A lot of autistic youth don't want their roommate, professor or employer to know they have autism. One of the biggest challenges is to help those who struggle with their sense of identity to become effective self-advocates and to be able to ask for help when they need it.

AAPM: How do parents prepare their child for adulthood?

Dr. Shattuck: We need to be preparing our children in all sorts of ways from an early age. More than anything, we need to give them the basic skills of being able to ask for help, being able to advocate for themselves, and being able to know themselves. One of the challenges of becoming a young adult is moving from a place in which other people are telling you what to do with your life, to a place where you decide what you are going to do with your life. This is especially true for a child with a disability whose schedule, therapies, and doctor's appointments have been managed for them their whole life. Now, they are in a place where they need to decide how they want to structure their own life.

As your child transitions from a teen to an adult, the amount of independence you give will depend on your child's unique set of strengths and challenges. If your child has self-injurious or eloping behavior, you would not leave him or her alone for a weekend. Others might be ready to spend a day by themselves to practice some independence. You have to gauge what is appropriate for your own child's circumstances.

With that in mind, consider the concept known as the "dignity of failure." It states that you should allow your children to make mistakes and experience consequences because that is part of growing up. We all learn through trial and error, and by experimenting and experiencing consequences. There is often a desire to prevent our children from experiencing adversity. By the time adolescence has rolled around, parents have seen their kids suffer socially, physically, and developmentally. Parents have often seen their child be rejected, teased and bullied, and it has created an ambient level of anxiety and fear that is completely understandable. It's hard, but we need to push ourselves as parents to face our fears and do as much "letting go" as we can – at a level that is appropriate for each individual teen's capabilities. This creates the elbowroom that teens need to flex and develop, and to experience failure at a level that is safe and appropriate for the child's unique profile of challenges. It's not our job to prevent our children from experiencing all possible discomfort. It's our job to help our children learn how to manage and navigate discomfort and adversity. Of course, these suggestions have extremely different implications for youth who are at different levels of ability or severity of impairment.

AAPM: What skills does an autistic adolescent need to be successful in adulthood?

Dr. Shattuck: This answer is unique for each person. There are teens on the spectrum who still struggle with basic self-care skills, and others who are heading off to college. However, one of the challenges that begins to emerge in adolescence and young adulthood, and that often catches both parents and the young people off guard, is mental health. Indeed, there is a higher prevalence of co-occurring mental health conditions among teens and young adults on the autism spectrum versus other teens. This includes depression, anxiety, OCD and ADHD. While it often catches parents and teens off guard, its emergence is logical if you consider the factors. Up until high school, most teens have had a very structured and predictable routine. When you leave high school, several things happen. First, you step off the services "cliff." In other words, you go from being entitled to some degree of services to having limited entitlement as an adult. Next, the daily structure that high school provides falls away, which can be very destabilizing. Also, for those young people who have a social appetite and who yearn for connection with peers, the natural daily opportunity for peer interaction is no longer provided. So, it is not a surprise that there is an increase in depression and anxiety at this transitional time. These challenges require a whole new level of self-regulation, emotional self-awareness and emotional intelligence, but this is a population for whom those are core aspects of the disability.

I caution parents to be aware of these possible challenges. For young people to be successful in adulthood, they need to work closely with their parents to manage this time of transition. Leaving high school is more than just a graduation ceremony — it's a profound transition in the structure of daily routines. Parents should try to help their child prepare for behavioral, mental health and mood challenges as much as possible.



- Teach your children to ask for help and to advocate for themselves.
- As your child transitions from a teen to an adult, the amount of independence you give will depend on the child's unique set of strengths and challenges.
- It's not our job to prevent our children from experiencing all discomfort. It's our job to help our children learn how to manage and navigate discomfort and adversity.
- There is a higher prevalence of co-occurring mental health conditions among teens and young adults on the autism spectrum compared to other teens. Be prepared to help your child through these difficulties.
- Parents should help their teen find access and exposure to authentic work experiences.
- Understand the adult autistic experience by talking to autistic adults and interacting with them.
- Get to know other parents raising an autistic child.
- Learn and understand your child's unique profile of strengths and challenges.



AAPM: What advice do you have for teens who are going to post-secondary education or looking for employment after they graduate from high school?

Dr. Shattuck: Employment is a challenge across the board for young adults, whether they have autism or not. However, the strongest predictor of being able to get and keep a job after high school is having had a job or meaningful work-related experience *during* high school. Parents and schools should help their teen with access and exposure to authentic work experiences. This can include volunteering in the community, or any work-like experience that is out of the school and out of the classroom. It should be a work experience in which your child has to show up on time, be accountable to other people, be able to uphold a routine, and learn and execute new tasks. This will increase the child's chances of being successful in a job after high school.

Some young adults will not go right into the workforce and may consider university, college or vocational training. There seems to be a presumption in the United States that everyone should get a college education. In my experience, however, there are many young people on the spectrum who are very talented with their hands and who thrive with manual tasks and routines. This could be professional baking, food preparation, carpentry, plumbing, or other skilled trades. If this is the route you and your child decide to take, you will have to advocate for these paths while your child is in high school.

Whatever your child's path, prepare him or her with the skills needed to succeed, either in the workplace or in post-secondary education.

AAPM: What last words of advice do you have for families entering this phase of life?

Dr. Shattuck: You're an expert on your own child, and autistic individuals are experts on the autistic experience. One of the best things that parents can do during elementary, middle and high school is to get to know autistic adults. Start reading accounts of autistic adults, and take the opportunity to mingle with autistic adults. Understand the adult autistic experience by talking to autistic adults and interacting with them. This will give invaluable insight into how to help your own child, and will build your empathy and understanding of the challenges that your child experiences.

Do the same with parents. Start networking and going to conferences and parent meetings to get to know other parents raising an autistic child. If you have a kid in middle or high school, make an effort to get to know parents who have kids in college or in their 30s. Other parents are the experts on the parenting experience.

The autism spectrum is incredibly diverse. Everyone has a really unique profile of strengths and challenges. As my last piece of advice, I would like parents to know that one of the best ways they can be of service to their child is to be the curator of that child's developmental and health profile. Understand your child's unique strengths and challenges. Pay careful attention to how these strengths and challenges shift over time. Become a student of your child's ever-shifting patterns of strengths and challenges so you can be an effective voice and advocate for your child. You are the one point of continuity in your child's life. You are embarking on a journey. One aspect of that journey is that you're going to have a revolving door of professionals, educators, and people coming in and out of your child's life who try to help in various ways. They don't know your child like you do. Part of how you can best help your child is to become the steward and curator of the evolving description of your child's unique capabilities and challenges.

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