

# Joint Statement on Rethinking Transition into Adulthood Among Autistic Youth

---

## Position Statement

Autism research, as a field, has done an inadequate job in considering how profoundly the concepts of “becoming an adult” and “transitioning into adulthood” differ across autistic youth. In this position statement, the Autism Transitions Research Project (ATRP) formally challenges the conceptualization of transition and calls upon the research community to rethink the transition into adulthood among autistic youth.

There are two ways to think about how youth transition, or move, from adolescence into adulthood. One way is how the government defines transition in laws and other policies. The other way is how young people themselves, and their parents, experience becoming an adult at a particular time in history, in the place where they live, within different cultural contexts, and supported by particular people.

### What is the transition to adulthood?

Transition to adulthood is the process of moving from adolescence to adulthood. Transition is a complicated journey with many steps that happen at different times - such as leaving high school, finding a doctor that sees adults, and new activities (driving or using public transportation, social activities, work).

The transition to adulthood is more accurately phrased as transitions into adulthood to reflect all the changes that occur as a youth becomes an adult. These changes might be personal (employment, education, relationships, living arrangements, health care, and others). Or they could mean new services (Vocational Rehabilitation, Developmental Disability Services, SSI, Medicaid).

Transition is also complicated because changes in one area can influence changes in other areas. Where one lives, for example, influences where one works and goes to school. How a person views “becoming an adult” differs based on their background – their culture, their access to education and resources, the expectations of their family, the time period in which they are growing up, and other factors.

For years, autism researchers in the U.S. have written and talked about the transition to adulthood in the same way as the government. The government says that youth become legal adults at the age of 18 years. This is the age when youth can vote, and when they can qualify on their own for adult services like Medicaid and SSI. This is also the age when youth gain the right to oversee their own special education services, medical information, and decisions.

But becoming an adult involves more than simply turning 18. In the U.S., the goals of special education, by law, are to help youth grow up to be adults who work, continue their education, and live independently after high school. In the 1970’s when the special education law was written, becoming an adult often meant that you got a job, got married, and lived on your own after high school. Many disability services and supports in the U.S. are still set up with these same goals in mind.

For youths themselves and their families, times have changed. Now, young adults often continue to live with family after high school, and even after college. They are less likely to be able to afford to live on their own. They are less likely to go to college or a university. They are more likely to view

adulthood as being in charge of their money and making decisions on their own. They also value friendships and other relationships as they become adults.

When researchers talk about transition, they are often thinking about policies and services, and whether youth are receiving the services and supports they need to help them successfully transition to becoming an adult. But what it means to become an adult differs based on your world view and your position in life.

Unlike those they research, autism researchers, as a group, are not diverse. They often come from white, middle-to-upper class backgrounds. They may think about adulthood using the same lens that they grew up with, which means that they may value goals like having a full-time job, a college degree, and living apart from family. But this perspective does not reflect the worldviews or realities of many families in this country.

Parents from other cultures may expect their autistic young adult to continue living with them, and they may expect to continue providing for that young adult. They may place more value on how the young adult contributes to the family, than whether the young adult can provide for themselves. The word “transition” itself may mean different things to different people. And different families may have an entirely different perspective on using public services and benefits - due to lack of trust in service providers and health care systems.

The ATRP team believes that understanding how different autistic youth experience their transitions into adulthood requires us to consider how people’s background interacts with their autism. An autistic youth who is a Latino male will probably have different transition experiences than an autistic youth who is an Asian female from a non-English speaking family or a Black autistic trans youth. We must have respect for the roles that cultures and identities play in determining how one views adulthood, how they interact with professionals, and how they use services.

Demonstrating respect through research requires researchers to use a community-informed approach to understand the experiences and perspectives of transition-age youth by:

- Involving autistic youth and their family members in transitions research, and providing opportunities for them to take leadership and help shape projects planning and implementation
- Asking questions versus making assumptions
- Supporting community partners to be the people who ask questions
- Recognizing that researcher’s views of transition are based in their own experiences and world views
- Communicating together about what is needed, our perspectives, and our responsibilities to the communities we intend to support
- Advocating for flexible sources of funding to allow for conducting community-engaged research

Approximately 1,173,000 autistic youth will reach their 18th birthday over the next decade.\*\* These young people come from a wide range of backgrounds and cultural identities related to race, ethnicity, economic status, religion and geographic origins. Cultural identities intersect with other characteristics such as gender, sexuality, and disability identities to create unique perspectives and experiences around life events such as becoming an adult. The challenge to researchers is to

consider that each of these 1,173,000 youth will have a unique experience during their transitions into adulthood; to acknowledge the vastness of these complexities; and to recognize the need for alternative approaches to research to capture contemporary transitions.

---

\*This position statement does not reflect the view of the Health Resources and Services Administration which funds the Autism Transitions Research Project.

\*\* The most recent Centers for Disease Control and Prevention estimate of the prevalence of autism among 8-year-old children in the USA is 27.6 per 1000. Multiplying prevalence by population estimates of the number of 18-year-olds in the USA, we estimate that approximately 117,300 youth on the autism spectrum will turn 18 years old in 2024—equating to roughly 1,173,000 over the next decade.

\*\*\* Services and support are resources and assistance specifically designed to help individuals with disabilities (such as autism) to navigate daily life, develop essential skills, and address unique challenges. These services can include therapies, educational accommodations, and community programs tailored to support the well-being and growth of these individuals."