

Topical Briefs: Transition to Adulthood

The transition to adulthood can be a particularly vulnerable time for youth with intellectual and/or developmental disabilities and their families. I/DD Research has shown poor outcomes for this population across multiple domains, which suggests the current models of school-based transition planning are not meeting the needs of youth who have disabilities.

This is currently what we know:

- Recent studies have shown youth with I/DD are less likely than youth with other disabilities to attend postsecondary education, work, live independently, or see friends at least weekly in the early years after leaving a high school (Newman et al., 2011).
- The U.S. Department of Labor (2012) estimates that in 2011, just 27% of adults between the ages of 16 and 64 years with disabilities were employed compared with 70% of adults without disabilities.
- Youth and their parents, participants from vocational rehabilitation, and agency personnel and advocates continue to be disengaged in the transition planning process despite the requirements of IDEA stipulating students, representatives from agencies, and parents are to be invited (Friedman et al., 2013).

Basic Transition Tips for Caregivers:

1. **Be knowledgeable about the rights and responsibilities of your son or daughter.** Be especially aware of their rights and responsibilities under the Americans with Disabilities Act (ADA) and Individuals with Disabilities Education Act (IDEA). (<http://www.ada.gov/cguide.htm>) Your son/daughter is responsible for using the information. Seek information if it is not readily available.
2. **Make sure your child's Individual Education Plan (IEP) and/or general education includes critical skill areas.** Skill areas that will develop and enhance your child's self-sufficiency, self-determination, and self-esteem are extremely important during this time. These life skills and attitudes will be vital to successful independent participation as a contributing member of society:
 - Self-help and safety
 - Social
 - Fine and gross motor
 - Communication
 - Financial literacy
3. **Teach your child basic self-advocacy skills.** It is important that your child learn how to self-advocate. Knowing how to speak up for yourself, make decisions about your own life, and how to find supports are critical skills that support lifelong success. (<http://www.wrightslaw.com/info/self.advocacy.htm>)
4. **Encourage your child to participate in and lead their IEP meetings.** The National Longitudinal Transition Study-2 (NLTS) found 67.4% of youth with Autism Spectrum Disorder did not attend their own transition planning meetings or attended with

minimal participation; only 2.6% led the planning. Encourage your child's teachers to find innovative ways to accommodate your child's participation in their IEP meetings.

5. **Encourage early discussion of transition planning early on.** Transition planning should start in middle school. The last reauthorization of IDEA **requires** schools to address transition planning by a student's 16th birthday through the identification of post-secondary goals and related transition services.
6. **Work with your son or daughter to create a vision for the life they want to live.** Bring together key individuals (family, friends, and community members) to map out a Circle of Support (<http://www.iidc.indiana.edu/?pageId=441>) - a network of people to provide informal supports in daily life. Begin the process of planning for other life transitions (see charting the Life Course Perspective Framework at <http://supportstofamilies.org/cop/life-course-framework/>).
7. **Encourage your child's school to work collaboratively with vocational and employment service organizations.** Invite representatives from vocational rehabilitation and other programs that your family and child are interested in to your child's IEP meetings. By learning what is expected of your child to be successful in these programs the skill building can be incorporated into their education.
8. **Determine the agencies from which your child may receive support or services as an adult.** Attend planning sessions and request attendance at planning sessions or IEP meetings from such organizations as:
 - Community College or University Representative
 - County Mental Health Services
 - Department of Vocational Rehabilitation
 - Employment Development Department
 - Medicaid
 - Regional Disability Support Centers
 - Regional Occupational Programs
 - Social Security Administration
 - Community or State Department of Intellectual/Developmental Disabilities
 - Disability Support Organizations (e.g., CHADD, The Arc, UCP)
 - Community Home Based Service Agencies (group home agencies, transportation services)
9. **Insist on measurable postsecondary outcomes with supports and services.** Measurable outcomes will lead towards the accomplishment of goals once your child graduates or ages out of special education services and will hold the team accountable.
10. **Prior to enrollment in college, make sure that your son/daughter has all the paperwork and current documentation needed to obtain services.** The number of post-secondary education programs for individuals with disabilities is growing at a rapid rate. In North Carolina alone, there are over nine school programs with plans of continued expansion at universities and community colleges. <http://www.cidd.unc.edu/psea/>

11. **Once you have gathered the necessary paperwork, make copies and turn it over to your son/daughter as the first step toward assuming responsibility.** By including your son or daughter in the process they will have an opportunity to take ownership over parts of their future.

12. **Create care binders to help organize medical records and other important documents.** Transitioning from pediatric to adult care will also occur for your child. Creating a medical summary to pass on to the adult provider, and keeping a “care binder” with relevant information will make the transition smoother for your family and child.

For more information please see:

Bureau of Labor Statistics. Persons with a disability: labor force characteristics- 2010.

www.bls.gov/news.release/pdf/disabl.pdf

Friedman, N. D., Friedman, N., Warfield, M., & Parish, S. (04). Transition to adulthood for individuals with autism spectrum disorder: Current issues and future perspectives. *Neuropsychiatry* 3, 181-192; 192.