



Health Care Transition: Moving From Adolescence to Adulthood

Moving into adulthood can be challenging for any young person with or without autism spectrum disorders (ASDs). While much attention is given to transitioning from high school to postsecondary education or to the workforce, parents should also be mindful of the transition to new doctors and medical service systems. Many doctors who care for children with ASDs do not also care for adults. Families must plan ahead for this transition.

When do we start planning for transition?

National professional organizations, including the American Academy of Pediatrics, recommend that families of children with disabilities begin planning and setting long-term goals for the future health care needs of their children at age 12 years. A health care transition plan should be developed with health care professionals by the time the child is 14 years old. Starting early allows for time to teach self-management skills and to prepare children and families for the choices they will need to make.

What are some health care (medical) issues?

Some of the medical concerns of puberty, including increased risk of seizures, decrease in adulthood. However, certain safety and general health concerns that were present during adolescence persist. In particular, parents of individuals transitioning into adulthood should make sure to educate their children about common pitfalls.

- *Safety.*
 - *Traveling.* Parents of adults with ASDs need to make sure that their adult children are safe travelers, whether the adult child drives, rides a bike, walks, takes public transportation, or has another way of getting around the community. Even as a passenger, individuals must be able to self-monitor and refrain from distracting the driver and must be comfortable wearing a seat belt.
 - *Sexual well-being.* Adults with ASDs must learn about sexual relationships and appropriate and inappropriate behavior. Individuals with ASDs may not fully understand the consequences of sexual activity (including pregnancy and sexually transmitted infections) or the potential for sexual abuse and other victimization.

- *General health.* Many individuals with ASDs may not have the ability to communicate health symptoms or may not know that it is important to do so. Families of adults with ASDs must help to ensure that their adult children make and keep regularly scheduled visits to doctors, including routine gynecologic and dental care. Families should also routinely inquire about the health of their loved ones with ASDs, as the individuals themselves may not think to consider monitoring their health on a regular basis.

What are some behavior and psychiatric issues?

Some psychiatric disorders are more common in young adults. Anxiety, depression, and obsessions may increase with the change of routine that occurs after high school ends and with the demands of postsecondary education or employment. Additionally, preexisting psychiatric disorders or symptoms may be more obvious as an individual gets older and may affect individuals with ASDs differently than when they were younger. Some behavior issues to look for are

- *Sleep problems.* (Ask your child's pediatrician about the "Sleep Problems" handout.) Sleeping too much may be a sign of depression. Not sleeping enough may lead to health concerns. Older teens and young adults with and without ASDs often get into a pattern of staying up late and sleeping late.
- *Obsessive and compulsive behavior.* It may be hard to distinguish the repetitive behaviors common in people with ASDs from obsessive-compulsive disorder (OCD). Generally, OCD is very distressing, while repetitive behaviors associated with ASDs are stress-relieving.
- *Self-injury.*
- *Hyperactivity, short attention span, or easy distractibility.*
- *Ritualistic or stereotyped behaviors.*
- *Anger or tantrums.*
- *Irritability or withdrawal.* These symptoms may occur because of increased awareness of differences, changes in routine, or rejection by or lack of peers. They may also be caused by depression.

For more information, ask your child's doctor about the "Behavioral Challenges" handout. If you observe any disturbing symptoms in your adult child with ASDs, encourage him to make an appointment to see a doctor and offer to accompany him to the appointment. If your child is uncomfortable having you involved now that he is an adult, enlist the help of a trusted friend or sibling when possible.

How do we prepare for health care transition?

- *Make a plan.* Work with your teen's pediatrician to make a plan for the health-related skills that she will need (for example, communicating personal and family medical history), how she will gain those skills, and timing of transition to adult health care services.
- *Take care of insurance issues.* Check with your current health insurance plan to find out about extended coverage until 27 years of age for uninsured dependents.
- *Consider guardianship after age 18 when necessary.* Unless there is a guardianship or other custodial arrangement in place, your child's personal health information, including all health care encounters, will be private (in other words, will exclude parents) on your child's 18th birthday. Planning for this eventuality will need to begin well before age 18.

How do we find doctors for our adult child with an ASD?

It is important to find a doctor who is knowledgeable, communicates well with your child, is available for questions, and accepts your child's insurance. You should also consider where the doctor is located and how your child will travel to and from appointments. Additionally, issues such as the waiting room environment may affect your decision, particularly if your adult child has sensory sensitivities.

Your adult child with an ASD should take part in choosing a new adult doctor for himself and should feel comfortable communicating even sensitive subjects to this new person. While it is ideal to find doctors comfortable with ASDs, this is not always possible. If you start the transition process early enough, however, you will have time to meet with a new doctor for your child prior to his 18th birthday. This will allow you to share information about your child's needs. A goal for a smooth transition to adult services would include transfer of care to a primary care practice that provides a medical home.

Adapted from the Autism Society of America. Living with autism. www.autism-society.org. 800/3AUTISM (800/328-8476)

The recommendations in this publication do not indicate an exclusive course of treatment or serve as a standard of medical care. Variations, taking into account individual circumstances, may be appropriate. Original document included as part of *Autism: Caring for Children With Autism Spectrum Disorders: A Resource Toolkit for Clinicians*, 2nd Edition. Copyright © 2013 American Academy of Pediatrics. All Rights Reserved. The American Academy of Pediatrics does not review or endorse any modifications made to this document and in no event shall the AAP be liable for any such changes.

Reference

American Academy of Pediatrics, American Academy of Family Physicians, American College of Physicians Transitions Clinical Report Authoring Group. Supporting the health care transition from adolescence to adulthood in the medical home. *Pediatrics*. 2011;128(1):182–200

Resources

American Academy of Pediatrics HealthyChildren.org:
www.HealthyChildren.org

Autism Speaks Transition Tool Kit: www.autismspeaks.org/family-services/tool-kits/transition-tool-kit

Council for Exceptional Children: www.cec.sped.org

Disability.gov: www.disability.gov

ERIC: Educational Resources Information Center:
www.eric.ed.gov

National Center on Secondary Education and Transition:
www.ncset.org

National Dissemination Center for Children with Disabilities:
www.nichcy.org

National Health Care Transition Center: www.gottransition.org

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of Pediatrics



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