

# Health

Ensuring and maintaining your child's health as he or she becomes an adult will be critical. It is important to understand and be on top of the changes that are happening for your child – physically, mentally and emotionally – as well as the shifts in many health-related policies, benefits and entitlements as he or she ages into adulthood.

## Finding the Right Doctor

As children mature into young adults, pediatricians are no longer appropriate as their primary care physicians. It can be challenging to find a primary care physician who accepts insurance or Medicaid of adults with autism and more importantly, who understands young adults on the spectrum.

It is important that the primary care physician treats your child as an individual like every other patient, not just an individual with autism. Remember to advise the primary care physician to make sure that he or she doesn't see every health or behavior problem as a result of autism and understands your child as a whole person.

You should begin the search for a primary care physician early, though the transition doesn't usually occur until age 21. Start by asking your pediatrician for some names of doctors in the area who may be appropriate for your son or daughter. Ideally, there should be communication at the beginning between the pediatrician and the new doctor to ensure that everyone involved is fully informed of your child's state of health.

One of the most essential things to consider when selecting a doctor is that your child feels comfortable with him or her, as it is critical that your child is able to express any health-related feelings or concerns. This process is another important time for him or her to self-advocate.

While little is known about the interaction of ASD and aging, it is generally accepted that adults with ASD

- 1) tend to be fairly poor self-reporters when it comes to health issues; and
- 2) as a group tend to be fairly sedentary.

As such, concerns related to the long term health and wellness of adults with ASD should be at the forefront of any discussion of appropriate services.

- *The Current State of Services for Adults with Autism*, prepared by Peter F. Gerhardt, Ed.D.

## Mental Health

Unfortunately, mental health issues can complicate the transition process. The teenage years are already a time of turmoil and change and an adolescent with a mental health diagnosis can have a more difficult time managing the emotions that come along with these years.

Many individuals with autism are also diagnosed with mental health disorders like depression, anxiety and Obsessive Compulsive Disorder. Psychiatric diagnoses are not developmental disorders and often times they may not be visible during childhood.

This is often further complicated by the assumption that certain behaviors and emotions are connected to the individual's autism diagnosis, when the behavior may not be related to the diagnosis at all. It is important that your child's primary care physician is able to distinguish between the two so that he or she can treat these conditions and behaviors effectively.

If you suspect that your young adult may be suffering from a psychiatric disorder, you may want to speak with his or her doctor about a screening, which will consist of questionnaires that will indicate if your child needs further evaluation and/or interven-

tions. Keep in mind that screening results are not a formal medical diagnosis. The results may indicate if a visit with a trained medical professional such as a psychiatrist is needed to make a diagnosis and develop a treatment plan.

Common psychiatric disorders among individuals with autism include anxiety, attention deficit hyperactivity disorder (ADHD), Obsessive Compulsive Disorder and depression. The Autism Speaks website contains detailed information about the signs and symptoms of each of these conditions, as well as effective ways to treat them.

A number of research studies have found that a significant percent of children with autism lack access to mental health services when they need them. Parents often have a stigma around mental health issues which unfortunately prevents their children from getting treatment and making progress. In addition, the mental health care system can be difficult to navigate. If you have trouble finding a psychiatrist for your child, look into mental health clinics that are staffed by social workers. Treatment for mental health issues is of vital importance, especially for individuals with autism, so it is critical to take the necessary steps to access these services so that your child has a better chance of living a life of purpose and dignity.

In addition, individuals with autism are more likely to have new onset seizures during puberty or after they have completed puberty than at any other time since before they entered school. While the likelihood is still not very high, if your child does experience a seizure, a neurologist can administer tests to determine the cause. Most seizure disorders can be managed with the right medication.



## Personal Hygiene

Personal hygiene is an important life skill that all young adults with autism must understand no matter what level of support is needed. Skills such as bathing, using deodorant, brushing teeth, washing hands and shampooing hair are all important skills that need to be taught for young adults to become as independent as possible. While other young adults may wake up in the morning and have a set routine, your child may need more explicit instruction and reminders of the steps to take each morning and night. Visuals in the bedroom and bathroom can be helpful. *Taking Care of Myself* by Mary Wrobel is a great curriculum about healthy hygiene, puberty and personal care for young people with autism. It includes easy-to-understand directions, as well as visuals for many of the topics that need to be addressed. Teaching hygiene associated with private parts early can serve as a good bridge to sex education and help with the prevention of sexual abuse.

See the Developing Independent Living Skills section of this kit for information on the importance of teaching self-care skills and effective ways to make sure your child learns personal hygiene skills to the best of his or her ability, regardless of other challenges.

## Puberty and Sexuality

The onset of puberty is a difficult time for all older children and adolescents, and the changes can be especially difficult for those with autism. Preparation is key so it is essential to teach your child in advance about these changes. Your child should understand what is happening to his or her body, as well as what will happen in the future.

The more information you share with your child in advance, the more ready he or she will be for events such as menstruation or erections and ejaculation. Other changes like the growth of pubic hair or under arm hair should be covered as well. While it may be uncomfortable, you can never be too thorough or explicit in getting this information across to your child. It

is important to stress that these changes are a natural part of life for everyone and should not be viewed as odd or scary.

Many parents feel nervous and anxious when it comes to teaching their children about sexuality, especially children with autism. Many incorrectly feel that it is less important to teach young adults with autism about this subject because they think they are less likely to be exposed to issues related to this topic. But sexuality education is arguably more important for individuals with autism because they are less likely to learn about it from other sources such as peers, movies, etc. It is also crucial for them to understand the difference between appropriate and inappropriate behavior, and to distinguish between the various types of healthy relationships.

A developmental approach is most effective when teaching sexual education to young adults with autism. Each skill and behavior should be taught as a series of developmental sequences or hierarchy of events. For example, you can break the road to sexual intercourse into steps such two people meet, they become friends, go on a date and hold hands, etc.

It is important to teach these subjects as you would any other and to remember that you are the person responsible for teaching your child about sex and sexuality. Be sure to promote and emphasize appropriate behavior and stop and redirect any kind of inappropriate behavior. Encourage your young adult to ask you any questions and answer the questions in a simple and direct manner.

Dr. Shana Nichols, Ph.D., a specialist in autism and sexuality, suggests that a sexuality education curriculum include: the body, privacy, boundaries/touch, expressing affection, social skills and exploitation prevention. It is also important to stress the difference between public and private with regards to places, body parts, behaviors, etc.

Sexuality education is about more than just puberty and sex. Dr. Nichols also reports that relationship skills are often overlooked for young adults. The focus on teaching social and relationship skills often



happens in the preschool years, but these skills are just as important later on, most especially during adolescence. At this time, there are new concepts to learn and understand like the different types of relationships and how they are similar and different. All relationships, including those with strangers, teachers, doctors, family members, etc. need to be addressed very directly to understand what makes each of them healthy and appropriate.

Though the idea may seem overwhelming, it is critical to start as EARLY as possible and to be as DIRECT as possible!

## Conclusion

As many physical, mental and emotional changes happen as children enter adolescence and approach adulthood, it is important to monitor your child's health in each of these areas. Talk to your child's doctor about the changes you can expect and make sure you and your child are as prepared as possible for the changes in advance. Preparation and knowledge will make a world of difference when it comes to the health of a young adult with autism.