

HEALTH

“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., Organization for Autism Research

When thinking about the health of an adolescent or young adult with autism, physical health, mental health, and sexuality are three of the most critical issues to be addressed. All three areas are vital to the overall wellbeing of your young adult with autism.

Physical Health

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 the insurance or Medicaid of adults with autism, and who understands autism - more specifically, young adults with autism. It is important that the primary care physician treats the patient as an individual like every other patient, not just as an individual with autism. You should advise the primary care physician to make sure not to see every health or behavior problem as a result of autism.

It is important to start early to find a PCP (primary care professional) for all young adults who are transitioning from pediatrics to other forms of health care. Ideally, there should be communication at the beginning between the pediatrician and the new doctor to ensure that everyone involved is fully informed of the individual's state of health. It may be a good idea to ask your pediatrician for the names of some primary care physicians in the area that may be appropriate for your son or daughter. The transition should occur around age 21.



Minnesota Medicine and Children's Clinics in Minnesota have provided a road map for transitioning between healthcare providers, which can be found at www.childrensmn.org/ForHealthProfessionals/ForHealthProf.asp.

Since your young adult will likely have a long-term relationship with his or her new doctor, it is extremely important that he or she feels comfortable with the physician. It



may be helpful if the new doctor can start off with similar services that the individual was using with his or her pediatrician, in order to cushion the changes that come with this transition. Young adults with autism should be able to make choices and have a rapport or comfortable relationship with their doctors before starting routine check-ups or any other forms of treatment. The process of changing doctors is another important time to self advocate.

Dr. M. Paige Powell, and Dr. Sherry Sellers Vinson of Texas Children's Hospital and Baylor College of Medicine stress the importance of ensuring that the primary care physicians and dentists are adhering to all age-related preventative health guidelines, not just issues involving autism.

Other Considerations

■ According to Dr. M. Paige Powell and Dr. Sherry Sellers Vinson, individuals with autism are more likely to have new onset seizures during puberty than at any other time since before they entered school, or after they have completed puberty. While the likelihood of new onset seizures for young adults with autism is not very high, if an individual with autism has one, he or she will require immediate medical attention and investigation. A neurologist can provide further medical interventions.

For some additional information about seizures, see the Daniel Jordan Fiddle Foundation Epilepsy Brochure: <http://fiddle.readvantage.com/news/attach/DJF-EpilepsyBrochure.pdf>.

In addition, like with any adolescent entering puberty, adolescents with autism who have tics are likely to have more as they enter adulthood. Catatonia is also most likely to occur when an individual with autism is entering puberty. Visiting a neurologist or psychiatrist will be helpful in dealing with these conditions.

Female Health Needs

■ Most doctors suggest that all women should start seeing a gynecologist at 18, unless the teenager is experiencing pain and irregular periods before then. To prepare a young woman for her first gynecological check-up, you may want to discuss the reason for the visit and explain that this is something that all women do. As with many of the other skills that you have taught your daughter over the years, you may need to break the process down into small steps. A social story or visual schedule may also be helpful. Some professionals suggest that it may be helpful to bring young women with autism to their mother's check-ups at the gynecologist, so that they can ask questions and see what will happen during their own check-ups.

Mental Health

■ Psychiatric diagnoses are not developmental disorders. Oftentimes symptoms of these diagnoses may not be visible during childhood. Unfortunately, mental health diagnoses can complicate the transition process. The teenage years are already a time of turmoil and change, and an adolescent with psychiatric diagnosis can



have a more difficult time managing the emotions that come along with these years. This is often further complicated by the assumption that certain behaviors and emotions are connected to the individual's autism diagnosis, when the diagnosis in fact may not be related to the behavior at all. The most common mental health issues that affect individuals with autism include anxiety, depression, and obsessive compulsive disorder.

If you suspect that your young adult may be suffering from a psychiatric disorder, you may want to speak with his or her primary care physician about a screening. The screening will consist of questionnaires that will indicate if the individual needs further evaluation and/or interventions. You may want to keep in mind that screening results are not a formal medical diagnosis. The results of screening 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.

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 with autism to become as independent as possible. Teaching these important skills to children and young adults also decreases the risk of possible molestation or abuse.

If you haven't begun to teach your child about these issues, it is never too late to start. *Taking Care of Myself* by Mary Wrobel provides a 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 can serve as a good bridge to sex education.

Physical Changes

■ Parents often times need specific information on how to best prepare their young adults with autism for some of the changes that will happen to his or her body and for events such as menstruation or erections and ejaculation. Young adults with autism should understand what is happening to their bodies, as well as what will happen in the future. 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. There are several books listed in the resource section at the end of this section that address the changing bodies of adolescents and ways in which these subjects can be addressed.

Sexuality

■ Many parents feel nervous and anxious about teaching their children about sexuality, especially children with autism. Many feel that it is less important to teach young adults with autism about this subject because they feel that 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 health relationships.

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

Autism and Sexuality *by Dr Peter F. Gerhardt*

Although generally difficult to talk about in an open and honest manner, sex and sexuality are central to our understanding of ourselves as individuals and are integral to our individual determination of quality of life. Contrary to some preconceived notions about sexuality instruction it is not designed to titillate, arouse or excite and it does not focus primarily on the physical act of having sex. Sexuality instruction, instead, focuses first and foremost on personal safety and self knowledge. So while sexuality education may be both frightening and complex, it should be considered an integral element of a comprehensive transition plan assuming that the goal of such a plan education is to be a safe, competent, and confident adult.

Perhaps surprisingly, sexuality education starts very early in life (differences between boys and girls; using the boys room or girls room, etc.) and continues well into adulthood (dating, marriage, and parenting). Comprehensive sexuality education consists of instruction in three distinct (yet interrelated) content areas: 1) Basic facts and personal safety; 2) Individual values and; 3) Social competence. As such, an instructional focus on some basic safety skills should be considered both necessary and appropriate for individuals on the autism spectrum. These skills would include, but not be limited to, closing and locking bathroom or stall doors, understanding personal privacy and who can and who cannot help you in the bathroom or with personal care skills, body part identification using adult terminology (e.g., penis instead of peepee), using public restrooms independently, the restriction of nudity to personal bathroom or bedroom, and the issue of personal space for both self and others.

Sexuality education with learners with ASD is often regarded as a “problem because it is not an issue, or is an issue because it is seen as a problem.” (Koller, 2000, p. 126). In practice this means we generally ignore sexuality as it pertains to learners with ASD until it becomes a problem at which point we generally regard it as big problem. A more appropriate and, ideally, more effective approach is to address sexuality as just another, albeit complex, instructional focus, the teaching of which promotes the ability of the individual to be safer, more independent and more integrated into their own communities resulting in a more positive quality of life.

References: Koller, R., (2000). *Sexuality and adolescents with autism*. *Sexuality and Disability*, **18**, (125-135).



“For a long time our son was a little boy with autism, which was a certain kind of challenge. Now that he’s a teenager with autism – and a teenager who notices girls – we’re faced with something else altogether.”

*- “Adolescence, Without a Roadmap”
by Claire Scovell LaZebnik, New York Times*

Start Early!

Major preparation is key to sexuality education. TEACCH (Treatment and Education of Autistic and Communication related handicapped CHildren) suggests that parents and professionals begin discussions about sexuality around age 10, two to three years before the average child enters puberty. Individuals with autism are very resistant to change. It is important to give them plenty of notice regarding what will happen as they enter adolescence and adulthood. You should teach them about these changes long before they occur. Starting early eases the process significantly.

Be Clear and Direct!

Clear and direct education is essential and 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 which can be analyzed and broken down into several levels.

For example, Shana Nichols, PhD, a specialist in autism and sexuality, suggests it may help to teach girls a road map to certain relationships:

Girl and boy meet → girl and boy start say hi to one another → girl and boy keep talking as friends → girl and boy start to spend more time together, may go to the movies, etc → girl and boy hold hands → girl and boy go on dates. This roadmap can continue all the way until marriage and family if applicable.

Teach these subjects as if you would teach any other subject. 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.

The skills and knowledge regarding sexuality that come so naturally to young adults are generally gained indirectly from social cues, peers, movies, etc. People with autism often don’t pick up the same information from these sources, which leads to a huge gap in sexual knowledge and understanding. Direct education will help close this gap.

Dr. Nichols suggests that a sexuality education curriculum include: the body, privacy, boundaries/touch, expressing affection, social skills, and exploitation prevention.



Advice for Parents

In *Puberty and Children on the Autism Spectrum* from Living with Autism, the Autism Society has provided advice for parents when teaching their children about puberty and sexuality:

- Before you can effectively communicate your values about sexuality to your children, you need to know what you believe and why.
- You are the main educators of sex for your son and/or daughter. Whether you are comfortable or not, wouldn't you rather they get factual information from you than follow a classmate's or friend's advice?
- You must be "askable" (Gordon & Gordon, 2000). This means you should be prepared for any question or incident that involves your son or daughter's sexuality. Always say "That is a good question." You can decide to answer the question immediately or say "We'll discuss it when we get home." If you answer with a positive tone, then your child will continue to ask questions. Also, remember to answer the questions simply and directly. Don't give too much information to your adolescent.
- Children are not perfect. They make mistakes and it's up to us to turn their mistakes into lessons.
- Remember to use the same teaching strategies that you have used to teach your children other skills. Apply these strategies to teaching them about menstruation and nocturnal emissions as they go through puberty. Some of these strategies may include visual schedules or check off lists, videos, facts in books, pictures of what is happening to their bodies, stories to predict what might occur, or specific terminology. Think of puberty as just another stage of development. Embrace this time and move forward.

www.autism-society.org/site/DocServer/LWA_Puberty.pdf?docID=4182

Basic Skills to Remember

The concept of *public versus private* is extremely important. Lots of inappropriate behavior can be avoided if young adults with autism are able to understand these two concepts. For example, it is critical to understand the concepts of public versus private parts, public versus private places, public versus private activities, public versus private subject matters, and so on.

It is also important to teach children and young adults with autism that there is an appropriate time and place for everything. For example, it is okay to disrobe, only in private places, before showering or changing.



Relationship Skills

Dr. Shana Nichols, PhD, reports that relationship skills are often overlooked for young adults. The focus on teaching social and relationship skills often happens in the pre-school 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. It is time to move past basics onto subtleties, nuances, etc. Dr. Nichols suggests that parents and professionals explicitly teach young adults with autism about different types of relationships, and how they are similar and different. These types of relationships include: relationships with strangers, acquaintances, service providers, classmates, teachers, bus drivers, doctors, family members, etc. All of these relationships need to be addressed very directly to understand what makes each of them both healthy and appropriate.

Prevention of Abuse

The concept of appropriateness when it comes to relationships is critical in sexuality education, in order to prevent abuse. Unfortunately, with lack of knowledge about inappropriateness and abuse, individuals with developmental disabilities are more likely to be victims of sexual abuse. According to Dr. Nichols, “individuals with autism are extra vulnerable due to difficulties recognizing ‘red flags’ and interpreting thoughts, feelings, and behaviors of others.” It is essential for young adults with autism to understand what types of behavior are inappropriate. You should teach them to be aware and assertive, as well as to come back and tell you when anything happens that they feel may have been inappropriate.

“The true issue is prevention of abuse, not pregnancy. So it comes down to education directed to personal and sexual safety – starting with closing and locking the bathroom door, knowing who can and can't help with menstrual care, and understanding the difference between good touching and bad touching.”
– Dr. Peter Gerhardt

There are several resources in the back of this section that may be helpful as you work with your young adult with autism to understand sexuality.



Health Resources

Mental Health

Autism and Mental Health Issues

Center for Autism and Related Disabilities at the University of South Florida

<http://card-usf.fmhi.usf.edu>

Mental Health Aspects of Autism and Asperger Syndrome

by Mohammad Ghaziuddin

Taking the Mystery Out of Medications in Autism/Asperger's Syndrome

by Luke Tsai

Autism, Epilepsy & Seizures: How to Recognize the Signs and Basic First Aid When You Do

The Daniel Jordan Fiddle Foundation

<http://fiddle.readvantage.com/news/attach/DJF-EpilepsyBrochure.pdf>

National Institute of Mental Health (NIMH)

www.nimh.nih.gov

Sexuality

Girls Growing Up on the Autism Spectrum: What Parents and Professionals Should Know About the Pre-Teen and Teenage Years

by Shana Nichols, Gina Marie Moravcik and Samara Pulver Tetenbaum

What Autistic Girls Are Made Of

by Emily Bazelon (*New York Times Magazine*, August 5, 2007)

Taking Care of Myself: A Healthy Hygiene, Puberty and Personal Curriculum for Young People with Autism

by Mary J. Worbel

Autism-Asperger's and Sexuality: Puberty and Beyond

by Jerry and Mary Newport

Sex, Sexuality and the Autism Spectrum

by Wendy Lawson

Asperger's Syndrome and Sexuality: From Adolescence Through Adulthood

by Isabelle Henault



Sexuality and Autism

TEACCH Report (Treatment and Education of Autism and Communication related handicapped Children)

www.autismuk.com/index9sub1.htm

Growing Up with Autism: Developing a Healthy Sexuality Curriculum for Young Adults

presentation by Shana Nichols, Ph.D.

Adolescence, Without a Roadmap

by Claire Scovell LaZebnik

New York Times

www.nytimes.com/2005/10/16/fashion/sundaystyles/16LOVE.html

Living with Autism: Puberty and Children on the Autism Spectrum

Autism Society

www.autism-society.org/site/DocServer/LWA_Puberty.pdf?docID=4182

Sexuality Information and Education Council of the United States

www.siecus.org

General Transition Resources

The Current State of Services for Adults with Autism

prepared by Peter F. Gerhardt, Ed.D., Organization for Autism Research

http://nyc4a.org/pdf/oar_survey_11309.pdf

Guiding Your Teenager with Special Needs Through the Transition from School to Adult Life: Tools for Parents

by Mary Korpi



