

INFORMATION SHEET*

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Physical Health Care Considerations in Teens with Autism Spectrum Disorder

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Overview

The teenage years begin with puberty and end at young adulthood. The teen years can bring about big changes, with the onset of puberty, physical development of the body, and changes in how one thinks, feels, and acts. Teens with autism spectrum disorder (ASD) experience these changes too, but the changes may not be well understood by the teen or those who care for him/her. Unfortunately, many teens with ASD don't receive sufficient preparation for managing their health care needs or their transition to the adult health care system. This Information Sheet is one of a 2-part series on health care. It presents considerations on two topics in physical health care: Health Care Transition and Puberty & Sexual Development. Part 2, due out in the spring of 2015, will address psychological health. It will present information on the importance of teaching skills needed for emotional well-being and adult living.

Health Care Transition: Research shows that teens with ASD and their parents often have limited access to effective health care transition preparation, including dental care. Preparation for adult health care includes:

- Identifying and switching to an adult primary health care provider who is knowledgeable and experienced in health issues in ASD (e.g., seizure disorder, gastrointestinal disorders) and a dentist who is knowledgeable and experienced in oral health care in ASD.
- Ensuring continued health insurance coverage.
- Teaching the teen about various health care behaviors (e.g., scheduling appointments when ill or for routine checkups; getting prescriptions refilled, medication management, brushing teeth and flossing).

The American Academy of Pediatrics (AAP) recommends the following for physicians to do:

- Work collaboratively with the parent and teen to plan for transition early, as young as 12 years of age, and to set long-term goals for future health care needs.
- Develop a Health Care Transition Plan for the teen by 14 years of age. This allows for time to teach the teen the needed health care self-management skills that will prepare him/her for the health care choices they will make as a young adult. Many of the instructional methods listed in the next section can be useful in teaching these health care behaviors.

Understanding Puberty & Sexual Development: Puberty and sexual development in ASD is reported to be similar to development in teens without ASD. However, teens with ASD may not have a good understanding of this aspect of their development. This can lead to embarrassing and inappropriate behaviors and subsequent peer rejection and poor social outcomes. Therefore, education is needed. Despite the lack of research on specific effective curriculums for teens with ASD, there are certain topics that should be included. This includes education on:

- Body parts and reproduction facts.
- Feminine hygiene self-care.
- Contraception and sexually transmitted disease.
- Social rules of privacy.
- Intimate relationships such as dating and marriage.
- Safety and abuse prevention (including internet and on-line safety).

Several sexuality education curriculums have been developed for teens with other developmental disabilities that can be modified for use with teens with ASD (see resources listed below). While education typically occurs informally between parent and child, with peers, and with some structured teaching through school-based health class using a general sex education curriculum, for teens with ASD parents will often be the primary teachers to support the development of skills in this area. Methods that can be useful in teaching include:

- Direct Instruction (tell, show, do, practice).
- Discrimination Training (example: when certain sexual behaviors can and cannot be engaged in; recognizing unsafe situations or behavior).
- Social Scripts (example: for dating)
- Social Stories for various topics (example: intimate relationships and rules of privacy)
- Activity Schedules (example: for feminine hygiene self-care)
- Rule Boards (examples: for social rules about privacy, internet safety, contraception)
- Reinforcement system for improving the learning of the skills.

Find Out More

Below are some resources that may be helpful in planning out health care transition plans.

Books:

Growing Up with Autism by Robin L. Gabriels & Dina Hill is available at www.guilford.com

Making Sense of Sex by Sarah Attwood is available at Amazon: <http://www.amazon.com/Making-Sense-Sex-Forthright-Relationships/dp/1843103745>

*** Amazon has other books on Puberty, Sexuality etc. for individuals with ASD that you might find useful.

Curriculums:

Taking Care of Myself: A Hygiene, Puberty and Personal Curriculum for Young People with Autism by Mary Wrobel is available at Amazon:

http://www.amazon.com/gp/product/1885477945/ref=pd_lpo_sbs_dp_ss_3?pf_rd_p=1944687722&pf_rd_s=lpo-top-stripe-1&pf_rd_t=201&pf_rd_i=1843103745&pf_rd_m=ATVPDKIKX0DER&pf_rd_r=03AADEV RTE0F59CEMD4D

The Institute on Disability and Human Development at the University of Illinois has a list of various resources related to sexuality education. <http://ahs.uic.edu/dhd/sdc/resources/curricula/>

Websites:

The American Academy of Pediatrics has a Health Care Transition Center web site: www.gottransition.org

Autism Speaks provides information on health care in the teen years, including information on sex education, and this information can be downloaded: <http://www.autismspeaks.org/family-services/tool-kits/transition-tool-kit/health>

Research Opportunity:

The University of Rochester is seeking children ages 14 to 25 years and their parents to participate in a health literacy project. The child must have a diagnosis of ASD and read and speak English. For more information about this opportunity contact Jill Aldrich, Project Coordinator at 585-275-7734.

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