



## Body Changes and Hygiene: Pimples, Puberty and Privacy Part 2

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February 28, 2017  
Rochester Regional Center for Autism Spectrum Disorder  
Strong Center for Developmental Disabilities



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## RRCASD

- Provides Community Education and Technical Assistance to increase knowledge of ASD and available regional resources.
- Strives to enhance community resources through new activities and product development:

- Information & Referral
- Webinar Series
- Newsletters
- Information Sheets on ASD-related topics
- Community Presentations & Events
- Parent/Guardian & Professional Development Programs



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## House Keeping

- To reduce background noise during the webinar, please put yourself on 'mute' through your phone or computer.
- Please feel free to type any questions into the 'chat' box on your screen. We will review/answer questions during the Q & A at the end of the webinar.

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## Learning Objectives

- Increase understanding of...
  - Puberty issues in adolescents
  - Strategies to address social and sexual issues in teens with autism
  - Medical management options to utilize to help support interventions
- Be able to identify:
  - Key areas for the teen that may require instruction as it relates to puberty, social awareness and sexuality.
  - Some key points to instructional strategies to “teach” concepts, skills and behaviors.

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## Definition

- Puberty is: the condition of being or the period of becoming first capable of reproducing sexually marked by maturing of the genital organs, development of secondary sex characteristics, and in the human and in higher primates by the first occurrence of menstruation in the female.

– Per Merriam-Webster

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## Funny Video

- <https://www.youtube.com/watch?v=CQZglO-d9Q4>

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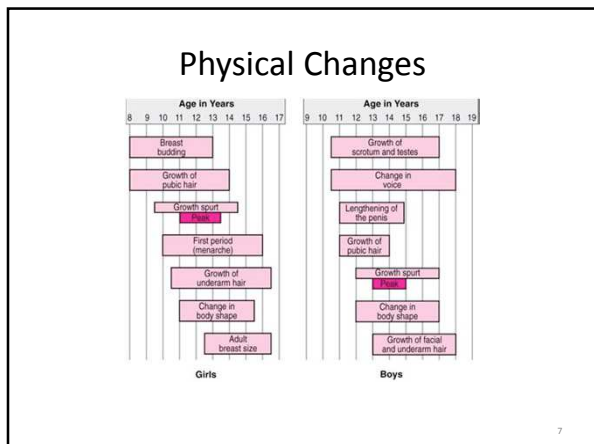
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### Factors That Affect Puberty

- Ethnicity
- Medications
- Nutrition
- Medical factors

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### Seizures

- Most frequently occur in children under age 3
- Pre-teens 11-14 second common age for onset
- Usually these are motor seizures
- Can be hard to distinguish between seizures, stereotypies and tics
- Can be affected by cyclical hormonal cycle in females

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## 2 Hit Model Theory

- Children with ASD are born with a neurologic vulnerability that manifest the symptoms of ASD and can cause poor outcomes in childhood.
- The 2<sup>nd</sup> hit is the hormonal changes in puberty and the developmental tasks can overwhelm the neural vulnerabilities leading to poor outcomes.
- Multiple studies have shown a 30% decline in skills during puberty, but many others show a gradual improvement by adult in most areas.

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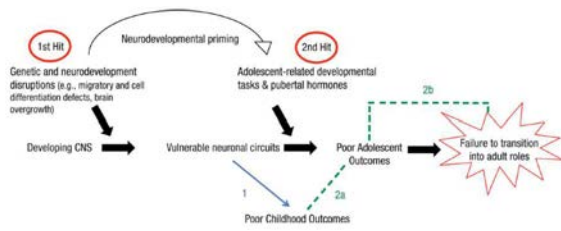
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## 2 Hit Model, cont'd



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## Common Behavior Situations

- Social
- Hygiene
- Mental health
- Safety
- Sexual issues



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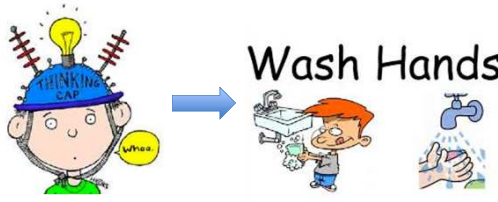
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### From Thinking to Doing



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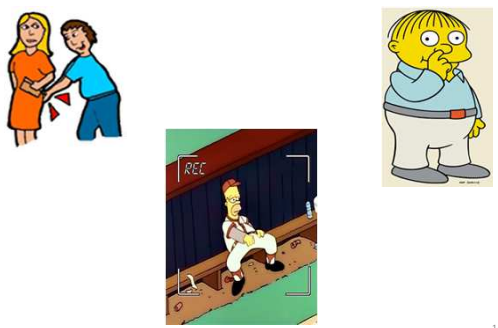
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### Social Difficulties



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### Diagnostic Criteria per DSM V

- Persistent deficits in social communication and social interaction across multiple contexts, as manifested by the following, currently or by history (examples are illustrative, not exhaustive; see text):
  - Deficits in social-emotional reciprocity, i.e. abnormal social approach, failure of normal back-and-forth conversation, reduced sharing of interests, emotions, or affect, failure to initiate or respond to social interactions.
  - Deficits in nonverbal communicative behaviors used for social interaction, ranging, i.e. poorly integrated verbal and nonverbal communication, abnormalities in eye contact and body language or deficits in understanding and use of gestures, a total lack of facial expressions and nonverbal communication.
  - Deficits in developing, maintaining, and understand relationships, ranging, i.e. difficulties adjusting behavior to suit various social contexts, difficulties in sharing imaginative play or in making friends, absence of interest in peers

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### A Developmental Thought?

- One of the developmental tasks of adolescence is to explore their independence and develop as sense of self.
- **Who Am I?**
- One way that a person develops a sense of self is as a result of various social interactions in a changing environment.
- It is important to have a sense of self in order to form strong adult based relationships.

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### Possible Contributing Factors

- Individuals with ASD typically have deficits in the stages of development in social communication and social interaction.
- Individuals with ASD have difficulty in reading social cues and the ability to understand one's own and others' thoughts, beliefs and desires (*Undeveloped Theory of Mind*).
- May not have sufficient contexts, limited opportunities and experiences to develop relationships.

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### Contributing Factors, cont'd

- Teens may have unique sensory preferences.
- Teens may have repetitive stereotyped behaviors or thoughts/preoccupations.
- May have restricted interests not shared by other peers.
- Often people with ASD are sheltered from typical situations both in schools and the community: limits opportunities for growth.

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## Social Relatedness

- 40% of youth with ASD never socialize outside of school with friends: reduced further once out of school.
- Typically-developing teens with social isolation often have symptoms of anxiety and depression.
- Greater participation in structured group-based social programs increase friendship development.
- Teens that participated in more structured activities in high school had better unstructured participation after high school.
- Teens with greater mood issues had more social isolation after leaving high school.

Taylor, J.L., Adams, R. E., and Bishop, S. L. (2016) Social participation and its relation to internalizing symptoms among youth with ASD as they transition from high school. *International Society for Autism Research, Wiley Periodicals Inc*, 0: 000-000, 1-10.

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## Long-term

- Children that had better peer engagement and recognition of other's emotions when younger were more responsive as adults to other's emotions.
- In general, adults with ASD were more socially isolated and had fewer friendships or romantic relationships (studies reviewed prior to 2013).
- Long-term review did find that some adults improved their daily living skills and possibly communication, however social skills were still lagging.
- The core features of ASD remain constant over time, however some of the behaviors improve with time.
- It was felt that studies reviewed after 2000 showed slightly better outcomes, which may reflect more effective interventions (early diagnosis, better educational support).
- Community support and integration was found to benefit social participation and outcomes.

Magiati, I., Tay, X. W., Howlin, P. (2014) Cognitive, language, social and behavioral outcomes in adults with autism spectrum disorders: A Systematic Review of longitudinal follow-up studies in adulthood. *Clinical Psychology Review* 34, 73-86.

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## Case Example #1

- An 11-year-old boy with ASD was noticing that the bodies of the girls in his class were changing. Like many boys his age he became interested in those changes and the *female body*. However, his response to the interest was to stare at the chest area whenever he was interacting with a female student or teacher at his school.

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### Case Example #2

- A 12-year-old boy with ASD was becoming preoccupied with the body changes he was noticing with his female classmates. Not unlike many boys his age, he was noticing that girls were developing “bumps on their chests.” He was extremely interested; however, his response to this interest was to intimately touch the breasts of a female classmate without any prior indication or consideration of his intent.

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### Touching Others & Being Touched

- It will be necessary to instruct where the young person can touch others and where it is okay to be touched as well as touching of self.
- This will include teaching the different contexts and behaviors for each type of relationship.
- Also, we should monitor what is modeled and accepted when the individual is younger and then felt to be “awkward” or unacceptable when the individual is a young adult or adult.

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### Case Example #3

- When a 14-year-old girl in a middle school special education classroom is told she cannot do something that she wants or is interrupted from doing something that isn’t appropriate in the classroom, she will immediately and rapidly disrobe in the presence of all of her classmates & school personnel.

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### Teaching Approaches

- Assessment of skills
- Individualization of target skill(s)
- Selection of curriculum, materials etc. and method of instruction (*social stories, comic strip conversations, social scripts, role play, video modeling, social autopsies, social thinking and problem solving etc.*)
- Task analysis of the steps leading to the skill
- Explicit instruction of the steps leading to the skill development and feedback
- Practice, practice, practice (repetition) and *Peer Mediated* strategies
- Create opportunities and *in vivo* training
- Reinforcement, Application and Generalization

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### Visual Strategy for Friendship

- <https://youtu.be/k0xgjUhEG3U>
- Friendship algorithm

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### Other Interventions

- When instructional strategies are not sufficient, you may need to consider other options.
- What is triggering the behaviors? Internal irritability and intolerance *vs* impulsivity *vs* anxiety *vs* excessive demands exceed ability etc.
- Is the teen too anxious which limits ability to implement strategies?
- Is the teen too inattentive to social cues or too impulsive to inhibit responses?

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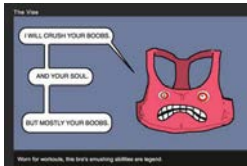
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## Hygiene Concerns



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## Hygiene Concerns

- Onset of body odor, pimples, menstruation, hair growth and breast growth
- Need to learn new hygiene skills
- Need to learn to tolerate shaving
- Need to learn to tolerate wearing a bra

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## Steps in Achieving Good Hygiene Practices

- Teaching body parts and awareness of hormones and related issues such as hair growth, body odor, bad breath and need for increased hygiene practices.
- Teaching Hygiene Supplies
- Using Hygiene Schedules and Sequencing Associated Behaviors

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## Use of Stories, Visuals and Video Modeling

- Stories to explain how the body is changing and about concepts such as "body odor" and why it is important to smell clean/fresh versus dirty/stinky are often helpful.
- Sequencing a written list of steps/ icons/pictures of the steps in the correct order for the individual to perform to teach the order eventually fading out the need for visuals as prompts.
- Use of video modeling to teach the skill.

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## Menstrual Management

- Parents often express concerns about menstruation: menstrual suppression, hygiene, discomfort, management, behavioral changes.
- Similar concerns for all teenage girls
- Conservative treatment first and increase as needed based upon response
- Monitor for school absences due to menses
- Contraception based upon interview with teen
- Surgery is not indicated

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## Teaching About Menses (The Period)

- Girls may experience fear at the onset of their periods. Tracking their menstrual cycle.
- Preparation for possible side effects such as stomach swelling, bloating, cramping and general discomfort or pain.
- Instruction of hygiene product use and when to change the pad/tampon or clothing and increased need to perform other hygiene-related activities such as additional showering.
- Instruction and use of a mood scale
- Keeping track of sleep and appetite

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## Menstrual Suppression

- Discuss with qualified provider, University of Rochester OB/GYN, Pediatric and Adolescent Gyn office, 585-273-3608
- Need to consider potential interactions with other medications, especially anticonvulsants.
- Underlying medical conditions
- Need to monitor for bone health
- Breakthrough bleeding common depending on method chosen
- Medication adherence issues

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### Premenstrual Syndrome

- Occurs in 80% of women of reproductive age and can cause difficulty for 20-40% of women and 5% significant impact of lifestyle, occurs in women with disabilities-18% in the study.
- Characterized by behavioral and physical changes corresponding with clear hormonal cycle (luteal phase, days 14-28), improves with menses typically.
- Track behaviors over a period of time to assess correlation with menses between home and school.

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### Treatment for Premenstrual Symptoms

- Similar to other females with over the counter ibuprofen or acetaminophen.
- Hormonal contraception
- SSRI medications for premenstrual dysphoria disorder (PMDD) may be indicated.

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### Teaching About Nocturnal Emissions

- Boys during puberty may experience “wet dreams” when they wake up in the morning.
- Generally the first nocturnal emissions (wet dreams) occur after the growth spurt is done.
- It will be important to reassure that nocturnal emissions are a normal part of growing up and provide instruction on what to do when this occurs.

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### Teaching About Erections

- Boys during puberty may experience several erections throughout the day that are not in their control and require little, if any, stimulation.
- It will be important to provide instruction on what to do when an erection occurs, especially in public places and some preventative measures to decrease the occurrence.

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### Masturbation

- Masturbation is part of typical male/female development and sexuality.
- Instruct precisely the places, time and conditions under which masturbation is appropriate.
- Individuals with ASD who enjoy self-stimulatory behaviors can exhibit obsessive-compulsive tendencies.
- Watch for potentially unsuccessful masturbation and related frustration.
- Instruct safety and hygiene.
- Watch for unusual triggers, inappropriate expression and use of dangerous strategies.

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### Mental Health Issues



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## Mental Health Issues

- People with ASD have an increased frequency of co-morbid mental health diagnoses.
- Usually this is anxiety, depression, mood issues, and/or attention difficulties.
- Girls with ASD can also have higher rates of eating disorders and poor self image.
- Higher rates of mood issues can negatively impact social participation rates.

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## Case Example #4

- A 15-year-old girl is described as “shy” and not “exercising her potential.” She has limited interaction with peers and she prefers to engage in “alone” activities when she has study hall. She generally has poor eye contact and when feeling stressed, she engages in some behaviors such as flipping her hair repeatedly and chewing her finger nails until they bleed. Classmates sometimes mimic her behaviors. She has an upcoming assignment to do an oral class presentation as part of her ELA class. She has been absent recently on the days she has ELA class, and is refusing assistance from her teacher.

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## Therapy First



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## Medical Management

- Current recommendation from The American Academy of Child and Adolescent Psychiatry is for appropriate therapy to address concerns.
- If therapy is not fully effective, consider medication options.
- If teen is unable to participate in therapy and behaviors continue, consider medication options.
- Commonly used medications include: stimulant medications, SSRIs, atypical antipsychotics, mood stabilizers, and others.



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## Sexual Side Effects

- Stimulant medications can suppress linear growth, but often will catch up when stopped and adult height is generally not affected.
- Atypical antipsychotics can cause weight gain and gynecomastia, sexual dysfunction in libido, arousal, and orgasm.
- SSRIs can cause libido suppression and erectile dysfunction.
- Propranolol rarely can cause libido suppression.

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## Sex and Sexuality

- All teens are capable of being a sexually active person.
- Studies have shown that people with ASD do have typical sexual interest, engage in a wide range of sexual interests, are interested in having romantic and/or sexual relationships with others and actively seek them out. They can identify as asexual, homosexual and heterosexual.
- Current available literature **does not** support that *inappropriate* sexual behaviors are related to age, sex, verbal ability, cognitive ability or adaptive functioning.

Fernandes, L.C., Gillberg, C. I., Cerdlerlund, M., Hagberg, B., Gillberg, C, Billstedt, E. (2016). Aspects of Sexuality in Adolescents and Adults Diagnosed with Autism Spectrum Disorder in Childhood, Journal of Autism Developmental Disorders 46: 3155-3165.

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### “Who can I talk to?”

- It will be important as a family to discuss with the young person who they can talk to if they have questions.
- This too may require some instruction and helping the young person to understand who they can talk to & what they can talk about.

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### Importance of Boundaries

- <https://youtu.be/w2bV-573ITQ>
- Relationship boundaries

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### Sexual Abuse Risk

- At risk situations
- A 2007 study reported that 1 in 3 girls and 1 in 10 boys will be sexually assaulted by age 18, and this may be an under-representation.
- The rate for children with a disability may be as high as twice that.
- Risk factors:
  - Limited communication skills to resist and report events
  - Lack of understanding other’s deceptive emotions and intents
  - Need to please others (taught to be nice)
  - Trusting of adults (often in adult-based worlds)
  - Lack of understanding about sex

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### Sexual Abuse Risk, cont'd

- Lack of credibility
- Difficulty in detecting and recognizing a potential danger
- Difficulty determining appropriate from inappropriate or criminal behavior
- Isolation
- Need for affection and attention
- Economical, physical, and psychological dependency
- Deficits in interpersonal skills
- General tendency of submission and obedience to rules
- Lack of decision making power and control
- Lack of self-esteem
- Ignorance of the right to refuse to perform actions

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### Evaluating for Abuse

- Evaluating for abuse
- Dependent upon physical evidence, often rare in sexual abuse
- Previous history reported by child or family
- Statements made by the victim
- No consistent behavioral responses in children/teens

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### Strategies

- Provide appropriate sex education
- Provide education to **say NO**
- Need to allow our teens to engage in relationships
- Set appropriate modeling for greeting and physical contact at young age

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## Factors that Lead to Inappropriate Sexual Expression

- Punitive or discouraging attitudes of caregivers and others
- Lack of social and sex education
- Intense interests and behaviors
- Lack of interpreting social cues and not understanding the concept of consent
- Difficulty understanding social rules and the various contexts

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## Resources

- Rochester Regional Center for Autism Spectrum Disorder (RRCASD).
  - On-line educational resources, webinars, Information & Referral services.
  - Contact information:
    - Website: [www.golisano.urmc.edu/rrcasd-nyautism](http://www.golisano.urmc.edu/rrcasd-nyautism)
    - E-mail: [rrcasd@urmc.rochester.edu](mailto:rrcasd@urmc.rochester.edu)
    - Tele: 1-855-508-8485
- Autism Speaks: website: [www.autismspeaks.org](http://www.autismspeaks.org)
  - This site contains various toolkits and guides for home, school, work, safety, health/medical, etc.

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## Resources

- Books/ Curriculums
  - Healthy Bodies: A Parent's Guide on Puberty for Girls/Boys with Disabilities. Materials and toolkits available at: <http://kc.vanderbilt.edu/HealthyBodies/>
  - Hygiene and Related Behaviors for Children and Adolescents with Autism Spectrum and Related Disorders: A Fun Curriculum with a Focus on Social Understanding <http://www.amazon.com/Behaviors-Children-Adolescents-Spectrum-Disorders/dp/1934575429>
  - Taking Care of Myself: A Healthy Hygiene, Puberty and Personal Curriculum for Young People with Autism. Wrobel, M.
  - Girls Growing Up on the Autism Spectrum : What Parents and Professionals Should Know About the Pre-teen and Teenage Years. Nichols, S., Maravick, G.M., Pulver-Telentbaum, S.
  - The Growing Up Book for Boys: What Boys on the Autism Spectrum Need to Know! (2015) Hartman, D.
  - The Growing Up Guide for Girls: What Girls on the Autism Spectrum Need to Know! Hartman, D.

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## Resources

- The Boy's Guide to Growing Up: Choices and Changes During Puberty (2012) Couwenhoven, T.C. (Designed for individuals with Intellectual Disabilities--written at the third grade reading level)
- The Girl's Guide to Growing Up: Choices and Changes During Puberty (2012) Couwenhoven, T.C. (Designed for individuals with Intellectual Disabilities--written at the third grade reading level)
- Sexuality and Relationship Education for Children and Adolescents with Autism Spectrum Disorders: A Professional's Guide to Understanding, Preventing Issues, Supporting Sexuality and Responding to Inappropriate Behaviours. Hartman, D.
- Making Sense of Sex: A Farthright Guide to Puberty, Sex and Relationships for People with Asperger's Syndrome. (2008) Attwood, S.
- Autism-Asperger's & Sexuality: Puberty and Beyond. (2002) Newport, J., Newport, M.
- What's Happening to Tom?: A Book About Puberty for Boys and Young Men with Autism and Related Conditions (Sexuality and Safety ----\*\*Farthright Material for Instruction). Reynolds, K.E.
- Things Tom Likes: A Book About Sexuality and Masturbation for Boys and Young Men with Autism and Related Conditions. Reynolds, K.E.
- What's Happening to Ellie?: A Book About Puberty for Girls and Young Women with Autism and Related Conditions (Sexuality and Safety---\*\*Farthright Material for Instruction). Reynolds, K.E.
- Things Ellie Likes: A Book About Sexuality and Masturbation for Girls and Young Women with Autism and Related Conditions. Reynolds, K.E.

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## Resources

- The American Girl Series, The Care and Keeping of You, The Body Book for Girls
- The Asperkid's (Secret) Book of Social Rules: The Handbook of Not-So-Obvious Social Guidelines for Tweens and Teens with Asperger's Syndrome. (2013) O'Toole, J.C.
- How to Teach Life Skills To Kids with Autism and Asperger's McIlwee Myers, J.
- Social Skills Stories: Functional Picture Stories for Readers and Nonreaders K-12 A.M. Johnson & J.L. Susnik , Mayer-Johnson (e.g., teaching appropriate proximity when interacting with others "Tad too Close") [www.mayer-johnson.com/social-skills](http://www.mayer-johnson.com/social-skills)
- More Social Skills Stories: Very Personal Picture Stories for Readers and Nonreaders K-12 A.M. Johnson , Mayer-Johnson. (e.g., social issues such as nose picking) [www.mayer-johnson.com/social-skills](http://www.mayer-johnson.com/social-skills)

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## Resources

- Websites
  - Teaching Nose-Blowing to a Child or Adult with Autism, Dr. Mary Barbera, You-tube video with step instruction <http://marybarbera.com/>
  - Social Skills Stories-Books, Games & Multimedia/Mayer-Johnson [www.mayer-johnson.com/social-skills](http://www.mayer-johnson.com/social-skills)
  - Free Visual Sequences: [www.visualaidsforlearning.com](http://www.visualaidsforlearning.com)
  - Autism Speaks provides information on considerations for supporting your child in learning important life skills: <https://www.autismspeaks.org/family-services/community-connections/teaching-important-life-skills>

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## Question & Answer

Please Note: A Webinar Evaluation Survey and information regarding a Certificate of Attendance for today's webinar will be sent to your email. If you have any questions, please contact the RRCASD at [rrcasd@urmc.rochester.edu](mailto:rrcasd@urmc.rochester.edu).

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## 2016-2017 Webinar Series

Intervention Strategies for the Reduction of Repetitive Behavior in Persons with ASD

**Wednesday, April 5, 3:00 p.m. – 4:30 p.m.**

*David B. McAdam, Ph.D., BCBA-D, LBA*

*Debbi Napolitano, Ph.D., BCBA-D, LBA*

*University of Rochester School of Medicine*

**Registration Period: March 15-March 29**

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