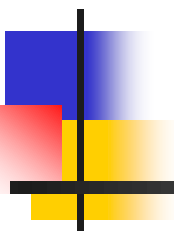
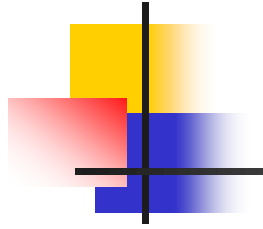


Teens and adults: puberty, sexuality and dating with SLOS

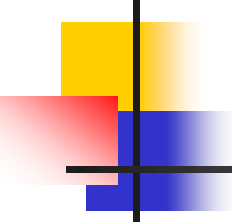


Elaine Tierney M.D.
Kennedy Krieger Institute
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of Medicine



Puberty refers to the physical changes in the body that makes a person able to sexually reproduce.

Adolescence is the period of emotional and social transition between childhood and adulthood.



Puberty and adolescence resource guide for parents of adolescents with autism

https://www.autismspeaks.org/sites/default/files/documents/atn/puberty_tool_kit.pdf



Body Changes

- Start early with teaching privacy. Help your child learn when that is and how to safely obtain it.
- Model appropriate hygiene behavior.
- Use the correct language for body parts and body functions.
- Start practicing early.



Boundaries

- Boundary: Something that indicates a limit or end.
- Boundary Violating Behaviors: Any behavior which results in infringement of another person's well being.

From: Mangiere, Fagan and Freeman, YAI presentation, 2004

- Physical – touch and distance
- Social – talk and roles in relationships
- Emotional – trust and feelings/affection
- Cognitive – concrete coaching and redirection



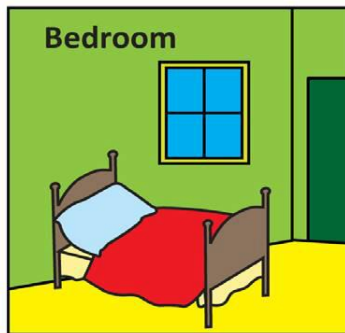
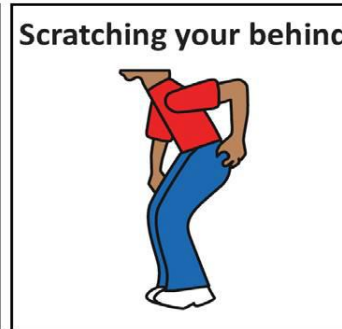
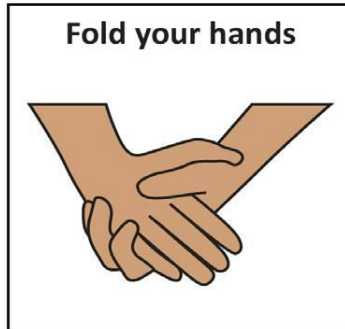
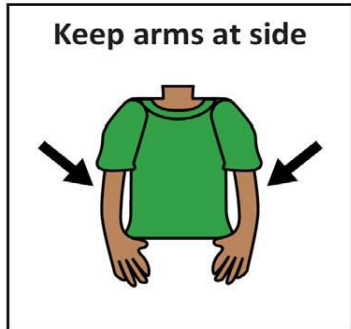
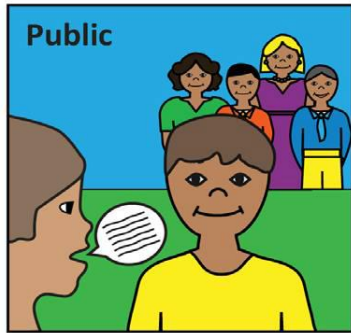
Circles Concept

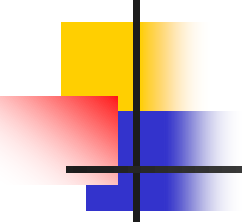
- **Purple** – Private circle, self
- **Blue** – Hug circle, those closest to self
- **Green** – Far away hug circle, friendship, specific event
- **Yellow** – Handshake circle, acquaintances, little emotional attachment
- **Orange** – Wave circle, casual acquaintances, children, neighbors
- **Red** – 1) Community helpers, 2) Strangers

Public/Private Behaviors – Story

Private Parts

Public places are where other people can see me. **Private** means away from other people, like in my bedroom or bathroom with the door closed. Everyone has **private** parts of their body. I can tell what parts of my body are **private** because I cover them with my underwear. I don't touch my private parts in public where other people can see me. I don't ever put my hands inside my pants in public. I can help myself remember not to touch by putting my hands by my side, crossing my arms, or folding my hands. Sometimes I need to touch my private parts, like when I itch or my underwear is uncomfortable. I can ask to go to the bathroom. When I am alone in my bedroom or bathroom, I can touch my private parts.



- 
-
- Private means saying or doing something by yourself, with your parents or with the trusted doctor. You can discuss behaviors that must be done in private (undressing, urinating, touching private parts).

- For more info:

<http://parents.teachingsexualhealth.ca/our-children/sexual-development>



Exploitation & Abuse, slide 1

Risk of Exploitation

- Lack assertiveness
- Overly dependent
- Expectations of compliance
- Uncertainty of roles
- Trapped by limits



Exploitation & Abuse, slide 2

Prevention Education

- Recognize behaviors leading up to sexual assault
- Know rights and protections
- Plan for saying “no” and who to access for help, and other safety procedures



Communication Tips, slide 1

- Parents are the primary sexuality educators
- Be an “askable parent” – Reward questions
- Find “teachable moments”
- Don’t wait – offer information
- Feeling uncomfortable is normal – Relax
- Talk about the joys of sexuality
- Listen (and observe)



Communication Tips, slide 2

- Facts are not enough – share feelings & values
- Be aware of what they are taught in the community
- Affirm that you care as much about development of healthy physical self-concept as about them finishing their spinach!
- Address the question behind the question – Am I normal? Am I ok? Am I acceptable????????????



Premenstrual symptoms, slide 1

- Premenstrual symptoms (PMS) can occur four months before the 1st menstrual period begins.
- Antidepressants in the Prozac family (selective serotonin reuptake inhibitors-SSRI) are the main treatment for the mood and irritability.



Premenstrual symptoms, slide 2

- Hormonal treatment (birth control pills) can dramatically improve symptoms for most individuals, although for some it can worsen the symptoms.
- Regular exercise and balanced diet
- There is some evidence that vitamin B6 can help.



Menstrual periods:

- Hormonal treatments (also frequently known as birth control) can greatly lessen or stop menstrual flow.
- Depo-Provera is an injection that is made every 3 months. It is also highly effective as a birth control with the failure rate (pregnancy rate) of one third of 1%.



Sexuality

- Sexuality can be defined as the integration of physical, emotional, intellectual, and social aspects of an individual's personality which expresses their maleness or femaleness.
- From: Who Cares? A Handbook on Sex Education and Counseling Services for Disabled People by Cornelius, Chiporus, Makas, and Daniels, 1979.



Physical aspects of sexuality

- Practice appropriate touch
- Demonstrate safe physical boundaries
- Teach the concept of public v. private
- Discuss body changes through maturation
- Accept normal experimentation



Safety planning for wanderers

- Security: consider securing doors and windows
- Identification: carry ID at all times. Shoe tags can be used. Temporary tattoos.
- Practice telling people who he or she is and that he or she has SLOS or autism
- Technological devices exist
- Can visit local police and fire departments to introduce your child and alert them to his needs.



Safety planning for aggression 1

- The stress of increased social aspects at school, puberty changes, and the normal need to separate from the parents can lead to increased aggression.
- Have activities in your child can do when upset to avoid meltdowns-favorite toys, listening to music.



Safety planning for aggression 2

- Adjust schedules to lessen stress.
- Use headphones if your child can tolerate them. If there is a favorite DVD or music, they might leave the headphones on. Soft earplugs can be tried as well.



Internet safety

- Teach your child the science of cyber bullying and the threat of people asking information.
- There are also several social networking sites designed specifically for individuals with ASD. Two notable resources are **WeAreAutism.org** and **WrongPlanet.net**.



Internet Safety Parent Tips:slide 1

- Never give out personal or private information, like your real name, account numbers, passwords, and address or phone number to others you do not know.
- Do not continue interactions with people that make you feel bad by saying mean things or calling you names.



Internet Safety Parent Tips:slide 2

- Do not send money or private banking information to others that may be nice to you but are untrustworthy, especially if they do not match their photo(s) and refuse to see you in person (or on video chat) for a long time.
- Tell a family member or trusted adult if people are making you feel bad or asking you to do, say or show things you don't want to do.



Day programming needs:slide 1

- 1) Public schools are required to serve individuals with disabilities from age 3-22.
- 2) I recommend that you work with your state developmental disability agency to place a child on the wait list for a day program for when he or she is an adult (the wait lists are years long so it is helpful to get on the wait list ahead of time.



Day programming needs:slide 2

- 3) The National Dissemination Center for Children with Disabilities has information on transitioning to adulthood
<http://nichcy.org/schoolage/transitionadult>. The website also has a feature that you can listen to.



Transition services, slide 1

- Transition services prepare students to move to the world of adulthood.
- Transition planning begins during high school at the latest.
- IDEA requires that transition planning start by the time the student reaches age 16.



Transition services, slide 2

- Transition planning takes place as part of developing the student's Individualized Education Plan (IEP).
- The IEP team considers areas such as postsecondary education or vocational training, employment, independent living, and community participation.

Psychiatric conditions in adolescence



- Mood disorders such as depression and bipolar disorder can present in adolescents
- In SLOS, obsessive-compulsive disorder has been seen to worsen in adolescence.