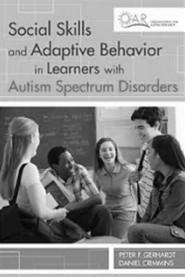


Puberty, Sexuality, & Adaptive Behavior with Learners with Autism Spectrum Disorders

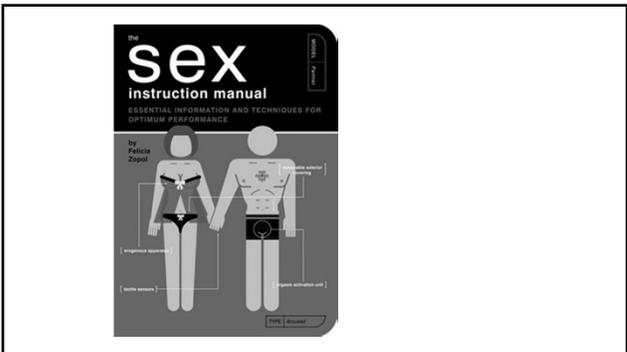
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This would seem a bit of shameless self promotion **BUT** all the proceeds go the Organization for Autism Research so it is really a shameless bit of fund raising.

Sex and sexuality are just components of adaptive behavior

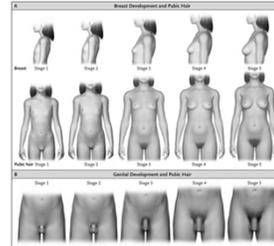
The following presentation contains language and imagery of a sexual nature and may be considered inappropriate for younger listeners and viewers.

Let's then start at the start



## Puberty



## Puberty

According to Medilexicon's on-line medical dictionary puberty is a sequence of events by which a child becomes an adult, characterized by the beginning of gonadotropin secretion, gametogenesis, secretion of gonadal hormones, development of secondary sexual characteristics, and reproductive functions.

In girls the first signs of puberty may be evident after age 8 with the biological process largely completed by age 16. In boys, puberty normally begins at age 9 and is largely completed by age 18. Ethnic and geographic factors may influence the time at which typical milestones may occur.

## Puberty

Boys in US are starting puberty earlier than ever, according to a study published in the Nov issue of the journal Pediatrics. In the study, lead author Marcia Herman-Giddens from UNC School of Public Health found boys starting to develop sexually 6 mos to 2 yrs earlier than usual.

There has even been some discussion of ASD being associated with early onset or precocious puberty. In general, puberty can be thought of as a river being held in check by a dam. Negative or inhibitory impulses hold back puberty from starting early. Any "crack" in the dam can bring on puberty earlier by canceling these inhibitory impulses. Little data exists to support or refute this theory however.

## Puberty and Girls

- Sexual organs - the girl's clitoris & uterus (womb) will grow.
- Menstruation begins - one of the first things that happens during a girl's puberty is the start of her monthly menstrual cycle.
- Breast changes - the girl's breast will start to grow.
- Vaginal discharge - vaginal discharge may start or change.
- Body hair - hair will begin to grow in her pubic area - firstly along the labia and then under her arms and on her legs.

## Puberty and Girls (cont)

- Skin - as girl's oil & sweat glands grow her skin will become more oily & she will sweat more. Acne is common among girls during puberty.
- Emotions - a girl's emotions may change, especially around the time her period comes each month. These emotional roller-coaster type changes, which may include irritability, are mainly due to fluctuating hormone levels that occur during the menstrual cycle.

## Puberty and Boys

- Scrotum, testicles and penis - the boy's scrotum will begin to thin and redden and his testicles will grow. Usually around the age of 13 his penis will grow & lengthen while testicles continue to grow.
- Voice change - the boy's voice will "break" or "crack" due to maturation of larynx.
- Wet dreams - boys may ejaculate during their sleep and wake up in the morning with damp sheets and pajamas. This does not mean the boy was having a sexual dream.
- Involuntary erections - These will occur without the penis being touched and without sexual thoughts triggering them.
- Breast enlargement - swelling of the breasts occurs with many boys during puberty.

## Puberty and Boys (cont)

- Skin - the boy's skin will become more oily during puberty. He will also sweat more. It is not uncommon for boys to develop acne during puberty.
- Body size - growth spurts occur during a boy's puberty. This growth peaks at about two years after the onset of puberty.
- Body hair - hair will start to grow around the pubic area, under his arms, on his legs and arms, and on his face. Facial hair usually starts around the upper lip and chin.
- Emotions - boys may experience mood swings; one moment they are laughing and then they suddenly feel like crying. Boys may also experience intense feelings of anger. This is partly due to the increased levels of hormones in their body, as well as the psychological aspects of coming to terms with all the physical changes that are taking place. It helps if the boy can talk to a family member, or a good friend. A recent study\* indicates that mood swings may be explained by biological changes in the adolescent brain.

\*\*Reversal of neurosteroid effects at alpha4beta2delta GABAA receptors triggers anxiety at puberty."Hui Shen, Qi Hua Gong, Chiye Aoki, Maoli Yuan, Yevgeniy Ruderman, Michael Dattilo, Keith Williams and Sheryl S Smith. Nature Neuroscience Published online: 11 March 2007; doi:10.1038/nrn1868.

## Puberty and ASD

- There is very little research on impact/intersection of puberty & ASD.

In fact, a quick search of the PsyScan database using "autism" and "puberty" as keyword search terms results in only 18 articles between 1979-2012. A similar search of the PubMed database results in 71 articles between 1963-2012. These results, while not unexpected, are still disheartening.

## Puberty and ASD (cont)

- There is a tendency for parents & professionals to ignore or misinterpret:
  - Emotional impact of adolescence on growing individuals with ASD.
  - Reflex, or spontaneous, erections as being sexual in nature
  - Genital stimulation as something to punish
  - Sexuality in general & sexual interest of an individual in particular
  - Importance of anticipating this development & planning for such.
  - Personal (i.e., sexual) safety and the 5-year rule

## Puberty and ASD

- During puberty we can expect a certain % of individuals with ASD to develop a seizure disorder. Seizures are indeed more common in both children and adults on the autism spectrum.

Epilepsy rates among those with autism spectrum disorders (ASD), range from 20 to 40 percent, with the highest rates among those most severely impaired by autism. Conversely, about 5 percent of children who develop epilepsy in childhood go on to develop autism.

## ASD, Puberty, and Behavior

- Ongoing debate regarding the impact of puberty on the display of challenging behavior. None of these discussions, have resulted in any general agreement or actual data. What seems to be true, is:
  - For some individuals the onset of puberty may be associated with an increase in challenging behavior.
  - This increase, however, may then be reinforced as a result of their newly realized increase in size and strength (i.e., the behavior is now more effective).
  - We, not surprisingly, do tend to see behavior challenges associated with menstrual cycles.
  - A new class of behavior maintained by R+ in the form of sexual stimulation may develop.
  - But other factors such as curriculum, boredom, staffing, restrictiveness of the environment etc. may also be related.

Sadly...

- Sex and sexuality, as serious topics for discussion, are ones that many of us would rather avoid than address.

This may be even more true when the issue is sexuality and learners with ASD.

Now add the personal and societal constraints that move sexuality out of the realm of simple behavior and we have a cohort of skills in which there is high interest but limited intervention.



But really, how much research is there on sexuality education & intervention in ASD?



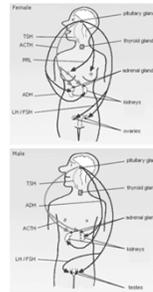
Research Findings

- Controversy over curriculum domains
- Agreement that physiological & sexual development occurs universally
- Limited research in area of efficacy
- Lack of consensus over: sessions, language used, teaching methods, content, goals, & parent ed
- Different needs: Males & Females

Research Findings

- People with disabilities have less information
- Few studies conducted
- Documented studies seldom review individuals in typical community settings
- Lack of consensus over: sessions, language used, teaching methods, content, goals, & parent ed
- Different needs: Males & Females

### A Couple of Good Reasons Why We Should Teach Human Sexuality Education To Individuals With ASD



### Number 4

They Have The Same Hormones & Urges & Need To Make The Same Choices As Their Peers



### Number 3

The Internet and other readily accessible media

### Internet Rule #34

If you can imagine it, then it exists as internet porn.

### Another **facebook** friend

How are you doing today?? you are a really cool and enchanting dude that's why i did opt for a message to you ok winks....Just want to know more about you with due respect that's if you don't mind. do take care and have a wonderful day feel free to reply ok.....with regards Fiona

### Number 2

### Sexual Abuse

### Self-Protection...Teach

- Refusing to be touched is a right
- Secrets about being touched are not OK
- Self-protection skills
  - Who can/can't touch individual & where on his/her body
  - How and when to say "No"
  - How to ask for assistance
  - How to recall remote events & convey where individual touched him/her

(American Academy of Pediatrics, 1996; Nehring, 2005; Roth & Morse, 1994; Volkmar & Wiesner, 2004)

### Number 1

Because they are people & like all people Individuals with Autism have the right to learn all they can to enable them to become sexually healthy persons

Healthy Sexuality



As a general rule of thumb about 60% of sexuality education should be at home, about 30% can be done in the context of the school and, when necessary, about 10% by specialists.  
But I sort of just made that up

### First

Sex is just behavior. - J. Bering, (2012)

### Second

Despite much discussion about decision making skills in the self-determination literature (e.g., Clark, et al., 2004), there continues to be "lack of evidence [supporting the] effectiveness of sex education and training for persons with developmental disabilities" (Duval, 2002, p. 453) which Behavior Analysis is able to provide.

### Third

- Many of basic instructional goals in sexuality ed boil down to complex discrimination skills. Eg.
  - Boy or Girl
  - Men's or Lady's room (or Blokes v. Shielas; Senors v. Senioritas; et al)
  - Where or with who you can/cannot:
    - Be naked
    - Masturbate
    - Curse
    - Help with toileting or menstrual care
    - Leave school with
    - Touch certain parts of your body

### Working Definitions

- Sexuality is an integral part of personality of everyone: man, woman, and child. It is a basic need and an aspect of being human that cannot be separated from other aspects of human life. Sexuality is not synonymous with sexual intercourse [and it] influences thoughts feelings, actions, and interactions and thereby our mental and physical health” (WHO, 1975)

### Working Definitions (cont)

- Sex can simply mean gender, whether you’re male or female. Sex can also mean the physical act of sexual intercourse.
- Sexuality education is a life-long process that encompasses many things: the biological, socio-cultural, psychological and spiritual dimensions of sexuality.

### Further complicating things

- There are different types of sexual language including:
  - Formal/polite – Vagina
  - Technical – Labia, Cervix, Clitoris, Vulva
  - Cute – Va-jay-jay, Muffin, Little man in the boat, Punani, Lady parts, etc.
  - Slang

### Myths about Sexuality



Myth 1: Folks on the spectrum have little or no interest in sexuality

Myth 2: Persons with ASD are hypersexual

Myth 3: Folks with ASD are solely heterosexual

### The Truth Is...

Persons with ASD are sexual beings. However, individual interest in sex or in developing an intimate sexual relationship with another person varies widely across individuals at all ability levels. As such, there is a significant need for individualized, effective instruction for persons with ASD across the ability spectrum.

### What we dont know

In two (somewhat) recent studies, (McCabe & Cummins, 1996; Szollo & McCabe, 1995) researchers concluded that individuals who have an intellectual disability have lower levels of sexual knowledge and experience in all areas except menstruation and body part identification when compared to a typical student population.

Watson, Griffiths, Richards, & Dysktra, (2002). Sex Education, In Griffiths, Richards, Federoff, & Watson (Eds.). Ethical Dilemmas: Sexuality and Developmental Disability. (pp 175-225). Kingston, NY: NADD Press

### Can sometimes hurt us.

Stokes, Newton, & Kaur (2007) examined the nature of social and romantic functioning in adolescents and adults with ASD. What they found was that individuals with ASD were more likely than their NT peers to engage in inappropriate courting behaviors; to focus their attention on celebrities, strangers, colleagues, and exes; and to pursue their target for longer lengths of time (i.e. stalking).

Stokes, M., Newton, N., & Kaur, A. (2007). Stalking, and social and romantic functioning among adolescents and adults with autism spectrum disorder. Journal of Autism and Developmental Disorders, 37, 1969-1986.

### Sexuality ed should be proactive

Griffiths, (1999) notes that most learners with a developmental disability receive sexuality education only after having engaged in sexual behavior that is considered inappropriate, offensive or potentially dangerous. This may be considered somewhat akin to closing the barn door after the horse has run.

### Basic guidelines for teaching

- Think ahead and be proactive
- Be concrete
- Serious, calm, supportive
- Break larger areas of info into smaller, more manageable blocks
- Be consistent, be repetitive
- What are the practical implications
- Teach all steps and in the correct order
- Consider using multiple instructional mediums
- Incorporate social dimension of sexuality when & where approp.

### Teaching materials

- Commercial products include:
  - Anatomically-correct dolls
  - Anatomical models of body parts
  - Written materials and pictures
  - Slide shows and videos
- Shop carefully-- most products not created for people with ASD, and they are expensive



### Teaching materials (cont)

- Creating your own is easy & less costly
- Resources include:
  - Medical and nursing textbooks
  - Patient education materials
  - Sexuality education books at the library
  - Google Image search
  - Planned Parenthood
  - Homemade digital photos & videos (NOT of nudity or private activities)

### Remember

- Individuals with ASD tend to be concrete thinkers who interpret things literally, so:
  - Be frank during instruction
  - Provide clear visual and verbal examples
  - Avoid euphemisms
- For example... (Rated R)

### Goals of a comprehensive sexuality education

- Provide accurate information
- Develop personal values
- Develop the necessary social competence

### Information

- Provide information that is accurate, timely, and presented in such a way as to be understood. Potential areas of information include:
  - Human growth, development and puberty
  - Masturbation
  - Sexual abuse, personal safety and STDs
  - Pregnancy, childbirth and parenthood
  - Sexual orientation

### Central Instructional Concepts

- Public versus private behavior
- Good touch vs. bad touch TM
- Proper names of body parts
- “Improper” names of body parts
- Personal boundaries & spaces
- Masturbation
- Avoidance of danger/Abuse prevention
- Social skills and relationship building
- Dating skills
- Personal responsibility and values

### What to teach and when: Some general guidelines.\*

- Preschool through Elementary
  - Boys v. girls
  - Public v. private
  - Basic facts inc. body parts
  - Introduction to puberty (your changing body)
  - Introduction to menstrual care
  - Appropriate v. inappropriate touching

Source: Schwier, K.M., & Hingsburger, D. (2000)

### MS to HS and Beyond..

- Puberty & Menstruation (if not yet addressed)
- Ejaculation and wet dreams (if not yet addressed)
- How to say “no” (if not yet addressed)
- Masturbation (if not yet addressed)
- Public restroom use
- Attraction and sexual feelings
- Relationships and dating
- Personal responsibility and family values
- Love v. sex
- Sexual preference
- Laws regarding sexuality
- Pregnancy, safe sex, birth control
- Etc.

### Same techniques we use to teach other skills can be used for sex ed.

- Can be used for sexuality ed.
- Some examples:
  - Picture schedules
  - Shaping
  - Cognitive rehearsal
  - Personalized stories
  - Video-modeling
  - Discrete Trial Instruction

### Masturbation

- Is normal & should not be condemned
- Exploration of genitals for self-pleasure begins in infancy
- Most people with autism learn to do it on their own, although some may have difficulty reaching orgasm
- Ineffective masturbation may contribute to ritualistic behaviors in some people with autism
- Masturbation may be the only realistic outlet for sexual release for some people with autism  
(Ailey et al., 2003; Koller, 2000; Nehring, 2005; Volkmar & Wiesner, 2004)

### Preventing problems

- Designate where it is OK to masturbate
  - Individual’s bedroom
  - Avoid teaching use of bathroom
- Teach rules for appropriate time/place
- Teach that sometimes it is not an option
- Provide private time
- Schedule private time & help individual understand

(Baxley & Zendell, 2005; Koller, 2000; NICHCY, 1992; Volkmar & Wiesner, 2004)

### Handling problems

- Interrupt behavior, don’t punish or overreact
- Remind student of rules for appropriate masturbation by referring to the visual cues he/she uses
- Redirect the student to:
  - An activity that requires use of hands
  - A physical activity
  - An activity that requires intense focus
  - To his/her bedroom, if available
- Reinforce student when he/she is engaging in appropriate behavior

(Baxley & Zendell, 2005; Koller, 2000; NICHCY, 1992; Volkmar & Wiesner, 2004)

### Goals : Values

- To develop personal values reflective of family, religious & cultural values in such areas as:
  - Personal responsibility
  - Self esteem
  - Right v. Wrong
  - Reality v. Fantasy
  - Interpersonal respect
  - Personal limits

### Key Concepts: What Are Values?



### The Social World



### A quick opinion here:

I currently think that no other set of adaptive competencies relies so heavily on extremely subtle environmental cues for their correct display than do social competencies. So in this special case, the "Applied" is as critical as are the "Behavior" and the "Analysis".

Absent context, the vast majority of social competencies are meaningless. I would, therefore, point out that independent of how evidence-based your interventions may be, teaching social skills well but out of context is really no better than teaching these skills poorly, either in or out of context.

### Goals: Social

- Promote the development of adequate and effective social repertoires inclusive of:
  - All sexual behavior being social behavior
  - Decision making skills (who, what, where, when)
  - Personal space
  - Personal advocacy
  - Refusal skills (i.e., a functional "no")
  - Avoidance of dangerous situations
  - Dating
  - Pretty much everything else

Source: NICHCY News Digest, Vol. 1(3), 1992. Available on-line at [nichcy.org](http://nichcy.org)

### What do we mean by SOCIAL SKILLS?

Social skills might best be understood as access and navigation skills... they are how we acquire desirables and avoid negatives by successfully navigating (and manipulating) the world around us. They are complex, multilayered skills that are bound by both content and context.

### The Increasing Demands of the Social World

- Your social demands are often lowest within your home. Why? Because you set the rules of acceptable behavior.
- Your social demands at work are higher. However, work is a somewhat scripted social environment and one with a secondary measure of competence (i.e., production).



### The Increasing Demands of the Social World

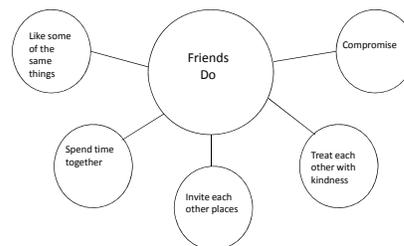
- Next comes the community at large. Why? Because in the community you have less control over events and actions that impact you.
- Lastly comes the world beyond your community. Whether a different social circle or different country, chances are your social skill repertoire may be less than adequate.



### The social context of urinals...

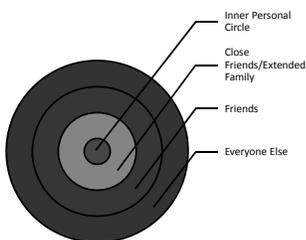


The Urinal Game:  
Choose wisely  
neophyte



Graphic Organizers:  
Social Issues

### Circles of Comfort and Safety



- Can help with my personal needs
- Can help me but not in the bathroom or in private
- Can help me but can only touch my hands/arms/shoulders and with permission
- Need to get others to help me and cannot touch me.

### Challenges to Sexuality Education for Learners with ASD

- Social dimension of sexual behavior
- Differentiation between public & private behavior & reality v. fantasy
- Ensuring maintenance of learned skills, particularly sexual safety
- Balancing individual safety with personal respect and rights
- Issues related to law enforcement



Be the change you wish to see in the world” - Mahatma Gandhi

Don't dream it. Be it!



Save the World with Behavior Analysis



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