




Sexuality on the Spectrum: What We Know and What We Don't Know

Peter F. Gerhardt, Ed.D.
Amy Gravino, M.A., C.A.S
*OAR Webinar
October 15, 2018*



“No group in this country faces the sort of sexual and reproductive restrictions disabled people do: we are frequently preventing them from marrying, bearing or rearing children, learning about sexuality, having sexual relationships and having access to sexual literature [] sexual confusion arises as a consequence of society forcing us to internalize the notion that we are sexually inferior.” (Waxman, 1994, p. 86-86).

Waxman, B.F. (1994). It's time to politicize our sexual oppression. In B. Shaw (Ed.), The Ragged Edge: The Disability Experience from the First 15-Years of the Disability Rag. (p. 82-87) Louisville, KY, The Avocado Press.



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

As a general rule of thumb about 60% of sexuality education should be at home, about 37% can be done in the context of the school and, when necessary, about 3% by specialists. But that is just my personal opinion

Let’s just quickly talk about risk.

To Control for Risk

The most important consideration you need to understand is you need to know the limits of your knowledge and expertise. When in doubt, get assistance from someone more expert in this area.

The second thing you need is a good understanding of typical sexual development to determine what is/is not an important target for intervention.

Last but
Not Least

You and/or your organization need to develop policies on *Sexuality Education, Instruction and Intervention* and, if appropriate, Instructional Risk.





Working Definitions...

- ❑ *Sexuality* is an integral part of the 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)
- ❑ *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.

But 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 – *Snatch, Beaver, Twat, Pussy, etc.*

In addition...

Individuals with autism can be concrete thinkers who interpret things literally. For example:

Some responses of adults with autism during an assessment* of sexual knowledge



Q: Tell me about this picture.

A: “[T]he people were sitting on the couch ‘being friends.’”

http://www.cambodyssey.com/UnderstandingSex/healthsex/img/sex_sofa.jpg

(Konstantareas & Lunskey, 1997, p. 411)

Sex Education in the US

While sex and sexuality are central to our mere existence as species, they are topics for discussion that many of us would rather avoid than address.

This is even truer when it comes to Sex Ed in schools. According to the CDC, fewer than half of all high schools and only 20% of middle schools offer a comprehensive Sex Ed curriculum. Further, only 23 states mandate Sex Ed at all and, of those, only 13 require it to be medically accurate. (Orenstein, 2016)

Orenstein, P. (March 20, 2016). *When did porn become sex ed?* *New York Times Sunday Review*. pp1, 6.

And it is worse for individuals with an Intellectual or Developmental Disability

Richards, et al (2006) noted that, historically, individuals with and IDD have been viewed *as sexually deviant, prone to criminality, asexual, and problematic to society*. Despite significant progress over the last 5 decades, the sexuality of individuals with DD is still grossly misunderstood by society. *And although today the sexuality of individuals with an IDD is not ignored, denied or punished, the perception of people with an IDD as perpetual children, irrespective of their age, lingers with significant, negative consequences.*

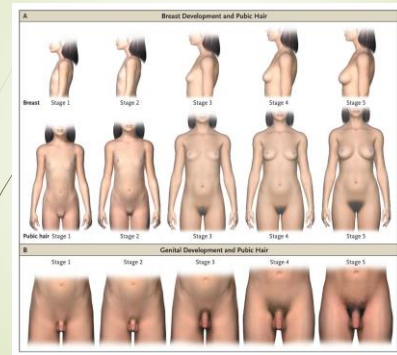
Richards, D., Miodrag, N., & Watson, S. L. (2006). Sexuality and developmental disability: Obstacles to healthy sexuality throughout the lifespan. *Developmental Disabilities Bulletin*, 34(1-2), 137-155.

But We Are All Sexual Beings

Typical children are taught many things about their own sexuality from the day they were born. For example, they learn:

- ❑ How they are touched by others;
 - ❑ The way their bodies feel to them;
 - ❑ What their family believes is okay and not okay to do;
 - ❑ The words that family members use (and don't use) to refer to parts of the body; and
 - ❑ From watching the relationships around them.
- ❑ In addition, as they grow they acquire a great deal from outside sources including television, music, friends and their interactions with the world around them.

Then There's Puberty



Puberty

- ❑ The sequence of events by which a child becomes an adult
- ❑ Characterized by the beginning secretion of gonadal hormones, development of secondary sexual characteristics, and reproductive functions.
- ❑ In girls puberty normally begins 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.

Puberty and ASD

- ❑ There is a tendency for parents and professionals to ignore or misinterpret:
 - ❑ The emotional impact of puberty/adolescence on individuals with ASD.
 - ❑ That genital stimulation is a universal phenomena that often begins in the womb.
 - ❑ The importance of anticipating puberty, adolescence, and sexual behavior and planning for such. Hence, my adherence to the 5-year rule

How much research is there on sexuality education and related interventions in ASD?





A few things we probably do know
(Kellaher, D., 2015)

- ❑ At least some of our gap in understand sexuality and sexual behavior in ASD stems from an general lack of understanding about sexuality and sexual behavior.
- ❑ High verbal individuals appear similar to typical peers in terms of sexual interest.
- ❑ While high verbal adults may know the language of sexuality, this does not seem to equate to qualitative or quantitative knowledge or behavior.
- ❑ There appears to be a greater diversity of sexual expression with high verbal individuals with higher reported rates of asexuality, bisexuality, and homosexuality, particularly among women.

A few things we probably do know
(Kellaher, D., 2015)

- ❑ Although data are limited there are published reports of paraphilic behavior among HV males but none involving HV females. The gender difference is due, most likely, to multiple confounding variables but it does appear that every permutation of sexual behavior we see in the typical community exists in the HV/ASD community.
- ❑ In ASD, however, some paraphilic behavior represent “counterfeit deviance” (Hingsburger, Griffiths, & Quinsey, 1991) in that it originates from an absence of knowledge, experience, or specific social competencies.

Kellaher, D.C. (2015). Sexual behavior and ASD: An update and discussion. Current Psychiatry Reports, 17, Published online March 2015

Hingsburger, D., Griffiths, D., & Quinsey, V. (1991). Detecting counterfeit deviance: differentiating sexual deviance from sexual inappropriateness. Rehabilitative Mental Healthcare Newsletter, 51-54.

Most Recently

McDaniels & Fleming (2016), in their review of 92 articles published on sexual education with individuals with ID concluded that:

- ❑ As a result inadequate sexual education Individuals with ID are placed at a greater risk for sexual abuse, STDs, and misinformation than warranted.
- ❑ Formal, individualized, and specific sexual education for learners with ID is lacking.
- ❑ There is a paucity of published data resulting in little information as to appropriate and empirically validated sexual education content and processes for learners with ID

McDaniels, B, & Fleming, A., (2016). Sexuality Education and Intellectual Disability: Time to Address the Challenge. Sexuality and Disability, 34, 215-225.

A Couple of Good Reasons Why We Should Teach Human Sexuality Education To Everyone, Including Individuals With Autism Spectrum Disorders

Number 5

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



Number 4

All sexual behavior is social behavior and, as such, is particularly challenging for individuals with ASD



Number 3

The Internet and other readily accessible media



Just how accessible is pornography?

In a national survey of youth ages 10-17 years, Mitchell, et al (2003) reported that 25% of youth had unwanted exposure to sexual pictures on the Internet in the past year. The use of filtering and blocking software was associated with a modest reduction in unwanted exposure, suggesting that it may help but is far from fool proof. The authors urge that social scientific research be undertaken to inform this highly contentious public policy controversy.

Mitchell, K. J.; Finkelhor, D.; and Wolak, J. (2003). The exposure of youth to unwanted sexual material on the internet: A national survey of risk, impact, and prevention. *Youth Society*, 34, 330-358.

For example, a search for “woman in kitchen” in Bing images with the safe filter off finds:




Number 2

The Criminal Justice System



For high verbal individuals, errors and mistakes in the area of sexuality are far more likely to result in involvement with criminal justice system than for low verbal individuals. In those cases, disclosure may be all that stands between an individual and incarceration.




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



So what better way to understand the unique sexual experiences of individuals on the spectrum...



...Than with a real life Naughty Autie to tell you all about it!

Who Do You Talk to About Sex and Dating?

- ❖ Family
- ❖ Therapist or Counselor
- ❖ Religious leader
- ❖ Friends
- ❖ Don't have anyone to talk to/Don't feel comfortable talking about it



But in 1996, like most any 13-year-old girl...



HOWEVER...

Age of First Interest ≠ Age of First Experience

- ❖ There was a disconnect between what I was curious about and learning opportunities that I had to explore it.

Puberty Predicaments

- ❖ Feeling disconnected from my body
- ❖ No time to “talk”
- ❖ Learned about sex from peers and online
 - ❖ Reading erotica



Social Difficulties Lead To...

- ❖ Finding friendships online
- ❖ Relationships
- ❖ Vulnerability to predators



The disappointment of real life opposite sex experiences...

- ❖ Falling for the boy next door (or across the street)
- ❖ First French kiss
- ❖ Senior prom




Age 19: First Boyfriend, Finally!

- ❖ Learning how to be a “girlfriend”
- ❖ What was expected vs. what I was able to do
- ❖ Perils and pitfalls of a first relationship
 - ❖ The night on the stoop



Beginnings of Body Awareness and Self-Discovery

- ❖ Pubic hair
- ❖ Becoming “connected” to my body
- ❖ Seeing myself as a sexual being for the first time
- ❖ Relationships as learning experiences



Stalking

- ❖ Man (who had autism) saw me at a conference and became obsessed
- ❖ Met in person
- ❖ Drove to friend's workplace (MA to PA)
- ❖ Aftermath
 - ❖ Understanding that this actually was stalking




Love, Autism Style



- ❖ Age 22: Fell in love for the first time
- ❖ The process of saying "I'm in love with you"
- ❖ Preparing to lose my virginity

So here we have a young woman with autism in love, getting ready to have sex, with no idea of what to expect or do...



Sexual Intercourse Comment Card

Thank You For Having Sexual Intercourse with Me! If you could, please take a moment to fill out this

Sexual Intercourse Comment Card!

so that I may better serve your needs in the future. Thanks Very Much, and Please Come Again Soon!



...And the questions on the back:

1. What did you enjoy most about this sex session?

2. What do you think could have been better?

3. What happened that you would like to have happen again?

4. What didn't happen that you would like to have happen in the future?

5. Please rate the following from 1 (horrible, awful, pathetic) to 5 (excellent, kickass, hot as all hell):

The outfit I initially had on, pre-intercourse ____

My facial expression(s) during intercourse ____

My vocal volume/the overall quality of my noises ____

My physical actions during intercourse (i.e., thrusting, clenching, etc.) ____


My ability to get you off ____

6. Is there anything I can do in the future to get you aroused more quickly and maximize your pleasure during our session?

7. Any other comments, thoughts, suggestions?


8. Finally, please rate this sex session on a scale of 1 to 10 (1 being the absolute worst, you'd rather have sex with a leper; 10 being holy crap I've reached nirvana amazing): ____

Thank You For Filling Out This Card! :-)



Heartbreak Hotel

- ❖ My first heartbreak, a.k.a. "The worst pain ever"
- ❖ Being a "target" and keeping my head held high
- ❖ Learning how to move on



The Era of Empowerment



- ❖ Finding inner strength
- ❖ Learning how to move on, part 2



Seattle Saga: Epilogue

- ❖ New beginnings in New Orleans
- ❖ A different kind of closure



Using ABA to Teach Dating Skills

- ❖ Participants
 - ❖ Diagnosis
- ❖ Treatment Package
 - ❖ Didactic instruction
 - ❖ In vivo roleplaying
 - ❖ Video modeling
 - ❖ Generalization
- ❖ Dependent Variables
 - ❖ Eye contact
 - ❖ Vocal tone (monotone)
 - ❖ Physical proximity
 - ❖ Number of utterances

Limitations of Study/Problems with Using ABA to Teach Dating skills

- ❖ Difficulty obtaining participants/limited participant pool
- ❖ Participants differ from expected criteria
- ❖ Lack of change in data from baseline to generalization
- ❖ Cannot control outcome in the real world

The 4 Main Goals of Sexuality Education

- I. Provide accurate, factual information
 - i. **Straight forward and relatively easy**
- II. Develop the necessary social competencies and cultural awareness
 - i. **Less straight forward and more complex**
- III. Promote individual safety
 - i. **Amazingly complex**
- IV. Develop appropriate values and beliefs.
 - i. **Outside my area of expertise**

Information

Public/Private Discriminations at Home

- ☐ From an early age families need to be clear and consistent with family rules about privacy
- ☐ Restrict nudity in public parts of the house
- ☐ Dress and undress in bedroom or bathroom
- ☐ Close doors and window shades for private activities
- ☐ Teach use of robe
- ☐ Caregivers should model knocking on closed doors before going in

(American Academy of Pediatrics, 1996; NICHCY, 1992; SIECUS, 2001)


Guidelines for teaching

- ❑ Think ahead and be proactive
- ❑ Be concrete
- ❑ Serious, calm, supportive
- ❑ Break larger areas of information 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 the social dimension of sexuality when and wherever appropriate

*Source: L. Mitchell, RCSW, The Cody Center


The 6 Rules of Presentation:

- ❑ Simple
- ❑ Visual
- ❑ Individualized
- ❑ Repetitive
- ❑ Fun
- ❑ Concrete



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 were not created for people with ASD, and they are expensive
- ❑ Some times (most times) it is best to make your own materials




SOCIAL COMPETENCE

Two Important Skills We Often Ignore, Punish, or Extinguish

A Functional “No”
&
Situational Noncompliance

Strategies for Professionals

- ❖ Recognize that dating is not one skill, but multiple series of skill sets
- ❖ Address the issue of consent
- ❖ Create/enforce boundaries with clients that they can apply to the real world



Strategies for Professionals



- ❖ Teach skills at age/developmental appropriate level
- ❖ Find ways to open a dialogue
- ❖ Acknowledge sexual needs and desires of individuals with ASD

Strategies for Parents



- ❖ Be a safe space for your child.
- ❖ Discuss issues at an age/maturity-appropriate level
- ❖ Talk about abuse

Sexual Abuse and Autism

- ❑ Brown-Lavoie, Viecili, & Weiss (2014) noted that individuals with ASD reported higher levels of sexual victimization that did typical controls.
- ❑ Mandell et al (2005) reported that 18.5% of their sample (156 children) had been physically abused while 16.6% had been sexually abused.
- ❑ Sevlever, Roth, & Gillis (2013) noted that more systematic research on the prevalence and risk factors of sexual abuse and/offending is in great need if we are to adequately address this issue. The bottom line, this is an area where Behavior Analysis may have it's greatest impact.


Brown-Lavoie, S.M., Viecili, M.A., & Weiss, J.A., (2014). Sexual knowledge and victimization in adults with ASD. Journal of Autism and Developmental Disorders, 44, 2185-2196
Sevlever, M., Roth, M.E. & Gillis, J.M. (2013). Sexual abuse and offending in ASD. Sexuality and Disability: 31, 199-200.
Mandell, D.S., et al (2005). The prevalence and correlates of abuse among children with autism served in comprehensive community-based mental health settings. Child Abuse and Neglect. 29, 1359-1372.

Target skills to reduce abuse

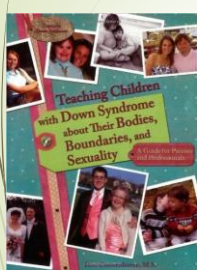
- ❑ Target discrimination between who can/cannot touch the individual and where on his or her body. This includes hugs, kisses, tickles, etc.
- ❑ Target independent toileting, showering, menstrual care, and dressing.
- ❑ Target closing and locking bathroom doors.
- ❑ Target independent public restroom use.
- ❑ Target functional noncompliance via the word "No".
- ❑ Target the recall of temporally distant events and report where instances of physical contact.

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

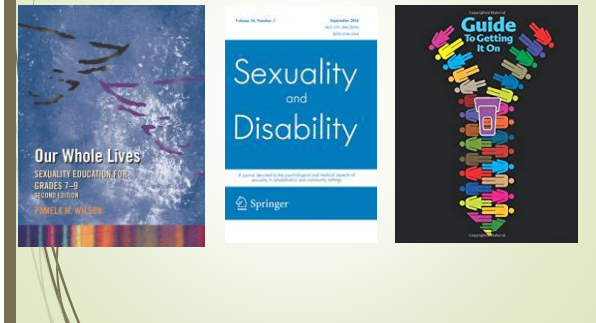
Sexual Abuse and Autism

- ❖ Sexual abuse occurs at higher rates among autistic people than neurotypical, but is reported much less frequently. Why?
- ❖ Double stigma
- ❖ Teaching what abuse looks like, how to report it
- ❖ Stranger Danger

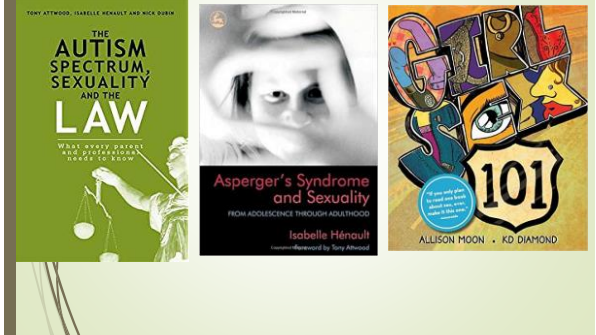
Some Resources



Some Resources



Some Resources



Contact Information for Amy

Amy Gravino, M.A., C.A.S.
A.S.C.O.T Consulting
271 Route 46 West, Suite G104
Fairfield, NJ
amy@amygravino.com



- ❖  www.AmyGravino.com
- ❖  AmyGravino.blogspot.com
- ❖  [Twitter.com/AmyGravino](https://twitter.com/AmyGravino)
- ❖  Facebook.com/AmyGravinoFanPage

Questions

