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

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"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).


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.

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.

Let's just quickly talk about risk.
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’.”

*(Konstantareas & Lumsley, 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)


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.


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 understanding sexuality and sexual behavior in ASD stems from a 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 represents “counterfeit deviance” (Hingsburger, Griffiths, & Quinsey, 1991) in that it originates from an absence of knowledge, experience, or specific social competencies.

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.


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

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.


Number 2

The Criminal Justice System

For example, a search for “woman in kitchen” in Bing images with the safe filter off finds:
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
Age 22: Fell in love for the first time

The process of saying "I'm in love with you"

Preparing to lose my virginity

Love, Autism Style

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 so 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 sex with me?
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, disgusting) to 5 (excellent, perfect, best, as desired):
   - My oral skills (kissing, sucking, licking, etc.) ...
   - My sexual expression/being intimate ...
   - My overall sexual satisfaction during intercourse ...
   - My overall ability to get you off ...

   Is there anything I can do to get you aroused more quickly and maintain your pleasure during our sessions?

6. Any other comments, thoughts, suggestions?
7. Finally, please rate the sex session on a scale of 1 to 10 (1 being the absolute worst, 10 being the absolute best) and how it related to our activities today (if relevant):

Thank You for Filling Out This Card!~2

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

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

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
- Sometimes (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

布朗-拉沃伊，维切利，& 韦斯 (2014) 指出，具有 ASD 的个体报告的性侵犯率高于典型对照组。
曼德尔等 (2005) 报告，他们的样本中 18.5% 的儿童被身体虐待，而 16.6% 被性虐待。
塞弗勒，罗思，& 吉利斯 (2013) 指出，尽管有更系统的研究来确定性侵犯和犯罪的风险和因素，但在性侵犯和犯罪方面仍有很大的需求，如果我们希望更有效地解决这个问题。


目标技能以减少性侵犯

- 目标区分谁可以触摸该个体以及触摸该个体的部位。这包括拥抱、亲吻、挠痒痒等。
- 目标独立如厕、淋浴、青春期卫生管理、着装。
- 目标关闭和锁定浴室门。
- 目标独立使用公共卫生间。
- 目标通过“不”来解决功能不合作。
- 目标回忆和报告遥远事件的性侵犯。

（美国儿科学会, 1996; 芙利安, 2005; 罗思 & 马尔泽, 1994; 沃尔克 & 维斯纳, 2004）

性侵犯与自闭症

- 性侵犯在自闭症患者中的发生率高于典型的，但在自闭症患者中报告的频率要低得多。为什么？
- 双重歧视
- 教育性侵犯的定义以及如何报告

危险
Some Resources

Contact Information for Amy

Questions