Taking the Sci Fi out of Sex: Uncomplicating Sexual Issues in ASD

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Disclaimer
This presentation openly discusses sexual material in a direct way. Although we have no intention of offending anyone, there are topics and images that may make some uncomfortable.

Materials shared in this presentation are for education purposes and are supported by current peer-reviewed research.

Outline presentation
1. Why is this topic important?
2. Unique challenges for ASD individuals
3. Sex Ed in Action: Interventions
A 2016 (Hannah & Stagg) study interviewed individuals with ASD. Every participant with ASD reported feeling dissatisfied with sex education in school.

“I feel like I’ve been given the tools, but I just didn’t use them because they weren’t clear enough.”

“I think they’ve got to teach people who are the right people to go with... more skills on how to find the right sort of partner.”

When asked what he felt most unprepared for, one participant replied, “A relationship.”

Parent-Child Sexuality Communication

<table>
<thead>
<tr>
<th>MOST LIKELY COVERED TOPICS</th>
<th>LEAST LIKELY COVERED TOPICS</th>
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<tbody>
<tr>
<td>Privacy and body parts 98% (89%)</td>
<td>Activities other than intercourse 29%</td>
</tr>
<tr>
<td>What kinds of touch are ok 95% (91%)</td>
<td>Symptoms of STIDs 27%</td>
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<tr>
<td>Public/private discussion topics 91% (67%)</td>
<td>How to use a condom 19% (10%)</td>
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<td>Hygiene 91% (89%)</td>
<td>How to choose birth control 14%</td>
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<td>How to ask someone on a date (21%)</td>
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<td>How to decide whether or not to have sex (19%)</td>
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*Scores in () indicate low functioning ASD group, per the study. Holmes & Herle, 2014

Professionals teaching sex ed have described the need for sex ed to persons with ASD given:

- People having a right to the information
- Preventing inappropriate behaviors; and
- Increasing pro-social skills.

The top three topics in sexuality education by perceived importance by these professionals were:

- Communication
- Sexual Abuse, assault, violence, and harassment
- Help seeking

Results revealed deficit-oriented perception about ASD.
National Sexuality Education Standards, 8th Grade

- Explain the health benefits, risks and effectiveness rates of various methods of contraception, including abstinence and condoms;
- Identify medically accurate sources of pregnancy-related information and support including pregnancy options, self-surrender policies and prenatal care;
- Describe the steps to using a condom correctly;
- Apply a decision-making model to various sexual health decisions;
- Demonstrate the use of effective communication skills to reduce or eliminate risk for STDs, including HIV;
- Identify local STD and HIV testing and treatment resources; and
- Analyze the ways in which friends, family, media, society and culture can influence relationships.

Also need to dispel myths:

- Hypersexuality in ASD
- Persons with ASD are socially/sexually deviant
- People with ASD don’t like sex
- Vodka tampons can’t make you drunk. And, they’re painful.
- Sex isn’t as good with a condom
- Sex should last for hours
- Sex is only between heterosexual couples
- Sex is as cute, cuddly, and clean as seen on TV

Why include sexual education?

- Avoiding the clear and specific teaching about sexuality and dating skills further sets individuals with ASD apart from peers and sets them up for failure in more complicated social situations.
  - Tullis & Zangrillo, 2013

- Sex education in schools is lacking in general but for most youth, information is readily shared and discussed through peer interactions. Being isolated from peer groups denies you this opportunity, and for those with ASD, they don’t know what knowledge they are missing out on (i.e., What is dirty talk and how literal do you take it?).
  - Hannah & Stagg, 2016
Levels of sexual interest in adolescents and adults with ASD are comparable to their typically developing peers. However, research shows education about sexuality and development are not proactive for those with ASD. It’s often brought up as a reaction to negative sexual behaviors. ASD adults are more likely to have poor body image, poor self-esteem, and inaccurate knowledge of sexual activity.

Majority of adults on the spectrum have been involved in romantic relationships and want to be in relationships, but have difficulty in initiating and maintaining these relationships.

Boys with ASD report more sexual experiences than their parents are aware of, particularly in regard to solo experiences (2016).

Unique Challenges for People with ASD

Legality, Sexuality & ASD

The legal system often experiences challenges as they encounter individuals with an ASD who are either the victim of, or the perpetrator of sexual offenses. Lower levels of sexual knowledge and increased inappropriate sexual behavior are cited as leading to the conclusion that many individuals with an ASD are likely to have a poor understanding of legalities around sexual rights and inappropriate behaviors. Everyone has difficulty with initiating and maintaining relationships, however, people with autism have greater difficulty with interpreting signals, especially those that indicate intentions and feelings.

There is an over representation of ASD-groups currently found in forensics samples. It appears that individuals on the spectrum may be at increased risk for coming into contact with the criminal justice system due to their difficulties with discerning and following appropriate behavior.

Pechere (2016)
The article from The Marshal Project asserts that lumping the compulsive behavior of someone who is autistic with sociopaths and pedophiles who view child porn can be inaccurate and harmful.

One man highlighted in a report who was caught and sentenced to prison for downloading child pornography said, "There's always a part of me that feels I should have known better, but the fact is, I didn't... After the fact, once it's explained to you, it becomes obvious. How could I have not known that? But that's where a lot of shame comes from."

2016 study, two participants admitted to stalking, but neither showed understanding or awareness of the seriousness of it. "I literally just saw him on the street. And then pretty much just stalked him."

Sexual Abuse Victims/Survivors
Individuals with autism spectrum disorders (ASD) may be disproportionately at risk of experiencing sexual abuse and victimization.
Sexual abuse and trauma can be expressed differently by people with an ASD. Do not expect the typical. Interviewing will be difficult due to the language and information processing problems. Learning how to talk with people on the spectrum will strengthen your ability to connect and build trust. Preparation is key.
Remember the "illusion of competency".
Do not use open-ended questions. Speak using concrete simple sentences.
Do not put together multiple ideas.
Do not use words with double meanings or idioms.
Do not expect or force them to make eye contact.
Do not be sarcastic or threatening. Do not make promises you cannot keep.
Do not attempt to confuse or trick them.
Give them enough time to process the question. Their first response may be "I don't know" or "I don't care". This will be a way to get time. They may answer just to get you to go away.
Empathize and show respect to them in order to get respect back.
Include a parent or trusted adult in questioning. Especially someone who speaks "aspie". If you ask, "Do you understand?" they will likely say "yes" even when they don't. They may not know that they don't understand. Check it out by using different language. (Watch for echolalia or scripting.)
Use visual aids.
Let them do a calming activity while interviewing.
Do not interfere with stimming behavior.
They may answer in a way they think you expect them to. They may want to please. They will not tell you they don't understand.
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Consent

Women on the Spectrum
Women with High Functioning Autism (HFA) are reported to have a poor levels of overall sexual functioning and well-being than males with HFA; but are also or at greater risk of adverse sexual experiences including naïve promiscuity, sexual assault, and abuse.
Sexual Orientation

Research is beginning to show that more individuals with ASD are gay or bisexual than would be expected compared to the general population (2016, 2017 studies; greater difference for females).

- A notable number of participants indicated sexual attraction to neither men nor women
- Needs more research
- Needs more education
- Difficult for some with ASD to reconcile due to black and white thinking; however some are more accepting given a life of uniqueness
- Should be included in sexual health education
Gender Variance, Gender Dysphoria & ASD

There is increasing clinical evidence that there is an over-representation of gender variance among those with an ASD. Studies indicate that gender variance is present 5-7% of youth with an ASD as compared to 1% of their neurotypical peers.

Studies show that those who identify as gender dysphoric have higher autism scores even if they are not diagnosed with an ASD. The more gender non-conforming the higher their ASD traits were.

Studies of gender diversity in the ASD population date back to 1981.

Hypotheses:
- Extreme male brain
- Difficulty with social interactions
- Communication differences
- Confusion of gender vs. OCD
- ASD are more open to talking about it; don’t need to conform to society expectations

Initial Clinical Guidelines for Co-Occurring Autism Spectrum Disorder and Gender Dysphoria or Incongruence in Adolescents

Strang, Meagher, Kenworthy, de Vries, Menzelle, & Lebowitz (2006)

Assessment:
- Should be done by those with an expertise in ASD and GD; use a team if needed
- ASD should not exclude anyone from receiving the GD diagnosis or treatment
- Determine if an attraction to their birth gender is GD or same-sex attraction
- Every GD person should be screened for an ASD
- Are current gender tools appropriate/adequate for someone with an ASD

Treatment:
Social issues:
- It may be difficult/shameful producing to express gender publicly, while some may be unaware of their gender expression
- Co-occurrence can lead to more social isolation
- Much of their social contact is through the Internet
Medical Safety:
- Medical compliance is critical, so executive function deficits for those with an ASD may create difficult circumstances including taking medications to communicating with medical professionals.

- Clarify expectations: What is realistic?
- Those with an ASD often believe that they need medical interventions first before other aspects of transitioning gender.

Risk of Victimization/Safety:
- Those with an ASD are already at a higher risk of bullying and report negative peer interactions.

Young Adulthood:
- This is a very challenging time for young adults with an ASD so targeted psychoeducation regarding all aspects of transition, both gender and to adulthood, are important.

Romantic Relationships, GD and ASD

It can be difficult for a young person with an ASD and GD to understand why potential partners may respond differently to a transgender person regarding issues of dating and sexual attraction. GD can make it more difficult to find a romantic partner as that person needs to understand and accept both the ASD and the GD.

What can we do?

- We need more research, but more importantly, we need more understanding and acceptance.
- If there is no one with ASD and Gender Dysphoria expertise then use a team approach.
- There is currently no consensus on treatment.
- Educate parents/caregivers. Need for age appropriate, comprehensive information.
- Educate other professionals.
Technology
Potential for negative outcomes with sexting. Research shows increased levels of anxiety, depression, harassment from peers and even suicide.

Legal impacts: What is developmentally appropriate vs what is legal?

How do you know the person on the other end is who they say they are?

An informed use of technology should be included in sexual education.

Pornography
Developmentally appropriate curiosity vs. what is legal

Taboo topics: Pokeporn, animae porn, paraphilias

Challenge in finding sex positive pornography. Sites like FrolicMe, CrashPad, BabeLand, Abby Winters, Pink Label TV, many more available

Romantic Relationships
• New set of social skills
• Hygiene
• Where/how to meet people?
• Flirting
• Interpreting behavior of others
• Expression of emotions
• Sensory experiences
• Ending relationships in a respectful way
Paraphilias and ASD

Paraphilias are recurring sexual behaviors or impulses that may involve unusual objects, activities or situations that are not generally considered sexually arousing by others.

Paraphilias were present in almost 1/4 of the study group, which surpassed those known in the general population (Fernandez).

Recognize that people may have unique interests that turn them on, and not all special interests are sexual.
What is Sexual Health?
“A state of well-being and a positive, respectful, safe and pleasurable approach of sexuality and sexual relationships”.

Get Comfortable with the “Weird”

- Be aware of yourself. It’s not awkward if we don’t make it awkward.
- It may not be weird to someone else.
- If you don’t know, be willing to learn.
- Be willing to share where you are at.
- “This is new for me so I need some time to learn about it.”
- Always follow through if you say you will.
What should be included in sexuality education for ASD?

- Basic reproductive education
- Skills for personal health examinations
- Menstrual care skills
- Choosing and using contraception
- Making informed decisions about sexual intercourse
- Rules about privacy
- Consent
- Masturbation
- Technology
- Developmentally appropriate, lifespan
- Sexual identity and orientation, LGBTQ affirming
- Prevention of abuse
- Complex social skills regarding dating and marriage
- Hidden curriculum
- Safety and protection from abuse
- Be mindful of developmental differences
- Relationship education needs to come first!

This is not an exhaustive list! Sexuality education must lead to independent decision making about dating, sexual relationships, and marriage to improve independence and quality of life.

Consider Content

Naked Homunculus mascot with erection takes a nap on a sanitary pad.

“[144x433]That they would be commended to their wedlock actions, and be happy in the fruit of the labour, must observe to copulate at distance of time not too often, nor too seldom.”

On what not to say on a date: “Never Tell Your Boyfriend You’re on the Pill.”

Be Comprehensive

Don’t limit topics.
Adults may have to be the ones to bring it up.
If you don’t know, offer to find research and information.
Always follow through.
### Who should teach sexuality topics?

Parents are primary, however many parents delay or avoid this. A 2011 study showed most youth with ASD reported learning about sexuality by themselves or from peers rather than parents. Research shows moms are predominant source of sexual information, even for sons.

Tailor to developmental level, lifespan approach.

- Medical Staff: Primary care provider, school nurse
- OTs: sensory
- SLPs: communication in relationships
- Mental Health Therapists: sexual & gender identity, relationships
- Case managers, Paraprofessionals, teachers, school counselors
- PCA’s, any self-care providers

Team approaches can normalize and take the stigma away from talking about sexuality.

EVERYONE!

### Focus on Health and Safety

Gives a framework for decision making.

### Staying Safe

- [Image of people exercising and medication]
- [Text: Staying Safe]
Take out the guess work

Be direct & literal.
Avoid innuendos and slang.
However, know when to use slang (i.e. dirty talk, age appropriate conversations with peers)
Use visual aids- graphics, drawings, photos

IF WE ARE NOT CLEAR, WE ARE NOT BEING FAIR

Would you go out to dinner with me tomorrow? I want to take you on a date.

I would love to take you out sometime.

Embed social skills into Sex Ed

How to tell if someone likes you
How to ask someone out
How to know how and when to end a relationship
Discussing sexual relationships with a significant other
Consent
When not to talk about sex

*Not a comprehensive list

"I already knew a lot about sex, mostly from television. Are there insults the most common form of language?"
Masturbation

**TEACH TIME AND PLACE**

**DON'T NEGLECT THE HOW!**

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### Therapies

- Know what you are providing/recommending; traditional therapies may need to be modified.
- Make sure you understand the risks and benefits of various interventions.
- Know the unique aspects of working with someone with an ASD.
- Include aspects of the Hidden Curriculum to inform treatment.
- Assess for Executive Functioning deficits and include interventions.
- Hormone treatments and other medical interventions.

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### Social Stories and Special Interests

**Minecraft and Sexual Education**

“Steve knows talking about his penis with his friends makes them uncomfortable.”
Give access to resources

- Research & Education
- Online forums & support groups
- Help arrange annual exams and sexual health appointments
- Opportunities to engage with neurotypical peers

*This list is not limitless

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References


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A Social Story about Sex

BY KEVIN

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Everyone is curious about sex.
It’s OK to think about it.

It’s OK to ask trusted adults about it.

Who is a trusted adult?

1. Mom
2. Barb
3. 
4. 

It’s not OK to talk about sex in public.

That includes school.

That includes stores, activities

Where else can’t I talk about sex?

1.
2.
3.

Why can’t I talk about sex in public?

I hear people talk about sex on TV, in songs, in movies, and other kids talk about it at school. That can be really confusing.

It is against the school rules.

It is against the law. It can be considered sexual harassment.

What is sexual harassment?

How people might respond to me talking about sex.

They might be embarrassed.

They might be angry.

They might be upset.
My friends do it too and they laugh when I do. But I need to remember that...

Talking about sex might get them in trouble too.

They might not want to be my friend if I do.

People might keep me away from my friends if we talk about sex.

I want friends.

Sex talk is private. If I have questions...

I can ask my parent.

I can ask my doctor.

I can ask a trusted adult.

What if my friends are talking to me about it?

What can I do?

1. Ask them to stop
2. Take a deep breath and think of something different to talk about
3.
4.
It’s OK to be curious about sex and think about it.

But I can’t talk about it in public.

And I can NEVER touch someone else’s private parts or have them touch mine.

I can find better ways to make friends.

What I can talk about to make friends.

1. Minecraft
2. Legos
3. 
4. 
5.

Just try your best!!

Kevin wants a picture of him in a Steve head for the last page.