



Sexuality Education And Individuals with ASD: What you Should Know but Probably Don't.

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Dr. Gerhardt has an association with the following programs or organizations but receives no compensation for that association. None of the information contained in this presentation is relevant to those associations



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Presentation Notes

- ❑ As a general rule I avoid using the terms “high functioning” or “low functioning” to describe where someone falls on the autism spectrum. The reason is these terms often just describe degree of vocal verbal behavior and not actual level of functioning. So instead I generally use “high verbal” or “low verbal” which I think is more accurate.
- ❑ A primary challenge in preparing a presentation on the subject of sexuality is the complexity of the topic and the diversity of the autism spectrum. Biological development, and the resulting behavioral manifestations, are generally the only commonalities across a very diverse spectrum. As such, when working in this particular area of human behavior, the assessment of individual competencies, interests, deficits, excesses, etc. is essential.

“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 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 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 there are no data on that as I just made that up.



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
- Technical
- Cute
- Slang

In addition...

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

Important

While high verbal adults often know the language of sexuality, this does not seem to translate into a more comprehensive knowledge of, or behavior related to, sexuality. (Kellaher, 2015)

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



And for individuals with IDD

Richards, et al (2006) noted that, historically, individuals with DD been viewed ***as sexually deviant, prone to criminality, asexual, and problematic to society.*** Despite significant progress over the last 5 decades in many areas, the sexuality of individuals with DD is still grossly misunderstood by society. ***And although today the sexuality of individuals with DD is not entirely ignored, nor is sexual behavior universally punished, the perception that people with developmental disabilities as perpetual children, irrespective of their age, still 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.

This despite the fact that...

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.

Onset of Puberty

Over the past 2-3 decades the age of puberty onset has decreased. For girls, breast development, typical of 11-year-olds a generation ago, is now occurring in more seven-year-olds. Research indicates that childhood obesity may be the primary causative factor. However, family stress and chemical exposures in the environment may also play a role, but the data are unclear as to degree of contribution. For boys, the data are murkier, but one study did suggest that they, too, may be starting puberty earlier than before—perhaps by as much as six months to two years. (Maron, 2015)

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.
 - ❑ The function of reflex, or spontaneous, erections at the onset of puberty in males.
 - ❑ That genital stimulation is a universal phenomena that often begins in the womb.
 - ❑ Safety intervention is a long-term project hence, my adherence to the 5-year rule

Mental Health Concerns in Adolescence

Children & adults who have a DD and a co-existing psychiatric disorder are one of the most underserved cohorts in the US. Beginning in adolescence, individuals with a developmental disability are **two to four times more likely to have a psychiatric disorder than their typical peers.** (Fletcher, et al., 2007)

Anxiety Disorders

Vasa, et al (2013) examined age-related differences in the prevalence and anxiety in a large sample of children & adolescents with ASD in the US and Canada. **Findings showed that the prevalence of anxiety in each age group exceeded the prevalence of anxiety in the general population. Adolescents and school age children had the highest prevalence of clinical (40%) and subclinical anxiety (26%), respectively.**

Vasa, R. A., et al, (2013). Age-related differences in the prevalence and correlates of anxiety in youth with autism spectrum disorders. *Research in Autism Spectrum Disorders*, 7(11), 1358-1369.

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Okay, Back to Sexuality and ASD



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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 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 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. *Habilitative Mental Healthcare Newsletter*, 51-54.

And 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 Individuals With Autism
Spectrum Disorders

Number 6

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



Number 5

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

Number 4

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. More recently, Madigan, et al, (2018) reported a similar percentage of unwanted exposure (20.7%) but also reported that 11.5% of youth had experienced solicitation on-line. 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.

Madigan, S, et al, (2018). The prevalence of unwanted online sexual exposure and solicitation among youth: A meta-analysis. *Journal of Adolescent Health*, **63**, 133-141.

For Typical Kids

According to Crabbe and Corlette (2010), porn has become a central mediator of young people's sexual understanding and experience and a "go to" source for information of sex and sexuality in the absence of any formal sex education.

Crabbe, M. & Corlette, D. (2010) Eroticizing inequality: Technology, pornography, and young people. *DVRCV Quarterly*. 3, 1-6. Accessed on line on 3/36/16 at: <http://www.awe.asn.au/drupal/sites/default/files/Crabbe%20Corlett%20Eroticizing%20Inequality.pdf>

Rule 34

**“IF IT EXISTS, IT
EXISTS AS INTERNET
PORN. NO
EXCEPTIONS.”**

But there are other
risks online

From a friend

➤ *"Hey, I added you since you look familiar, but once I looked at your page, I knew I was mistaken.. but hey, you seem like a good guy so I'll just introduce myself :) I'm quirky, funny, and never afraid to have a good time.. I recently moved here about six months ago from a small town in Idaho for work and like it so far! Check out my profile.. if you want to' I would love to meet sometime for lunch. Any way.. I wanted to attach more photos of me but it's giving me some stupid error! If you give me your email addy I can send the pics to you that way. Hope to hear from you soon!"*



Autism Specific Internet Dating

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The screenshot shows the AutisticDating.net website in a browser window. The browser's address bar displays "autisticdating.net". The website header includes "AutisticDating.net" and the tagline "Unique Screening Process for Safety Purposes". A search filter panel on the right allows users to specify their gender, the gender they are seeking, age ranges, country, and zip code. Below the search panel are fields for "Member Login" (username and password) and a "Register Now" button. A sidebar on the left contains a "Site Blog" with several entries, including "Imagination and Real Caring - by Phil" and "TO MY FRIEND (by Phil)". The main content area features a "Welcome to AutisticDating.net" message and a "Register Now" button. Below this, there is a "Browse Singles Now!" button and a list of members near Schenectady, New York, United States, with columns for usernames, gender, and location. The bottom of the browser window shows a standard Windows taskbar.

The screenshot shows the Autistic Personals website. The header features the "Autistic Personals" logo and a "Sign in" button. The main content area is titled "Welcome to the Best Autistic Personals Club!" and "Start Dating with Autistic Singles!". It includes a brief description of the site's purpose and a "Step 1: What are you looking for" form with dropdown menus for "I am a:", "Male", "Looking for:", and "Female". A prominent orange "Next >" button is visible. The background of the page shows a couple embracing in a field of yellow flowers. At the bottom, the text reads "Autistic Personals – Bringing Together Singles with ASD!" and "Our Autistic Personals are for those who have autism, Asperger's syndrome or any of the so-called autism spectrum disorders (ASD). People with ADS can have".

The screenshot shows the AUTISM Dating Service website. The header features the "AUTISM Dating Service" logo. The main content area is titled "MEET LOCAL AUTISTIC SINGLES AND START DATING". It includes a "Step 1: What are you looking for" form with dropdown menus for "I am a:", "Male", "Looking for:", and "Female". A prominent blue "NEXT >" button is visible. The background of the page shows hands holding puzzle pieces. At the bottom, the text reads "Have an account? Sign in >" and "Registration is Fast and Easy! Find Autistic Men and Women! Chat, Send Flirts, IM, and More!".

Number 3 – Sexual Abuse

- ❑ 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 its 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, 189-200.

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.

Behavior Analysts Need to Target Skills with the Potential 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)

Number 2

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The Criminal Justice System



Griffiths, (1999) noted 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.

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.



- ❑ Individuals with intellectual and other developmental disabilities present unique characteristics that may contribute to the development of behavior considered offensive or criminal (Griffiths & Fedoroff, 2008).
- ❑ Low levels of sexual knowledge coupled with high levels of interest/motivation and limited understanding of sexual rights and legalities (Pecora, Mesibov, & Stokes, 2016) are associated with higher rates of involvement in the criminal justice system than might otherwise expected (e.g., Loftin & Hartlage, 2015).

Griffiths, D. & Federoff, J.P., (2008). Persons with Intellectual Disabilities Who Sexually Offend. In F.M. Saleh, A.J. Grudzinskas, J.M. Bradford, & D.J. Brodsky (Eds) *Sex Offenders: Identification, Risk Assessment, Treatment, and Legal Issues*, p 352-374. New York: Oxford University Press.

Pecora, L.A., Mesibov, G.B., & Stokes, M.A., (2016). Sexuality in High-Functioning Autism: A Systematic Review and Meta-Analysis. *Journal of Autism and Developmental Disorders*

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





Instructional Considerations

Four Basic Goals

1. Provide accurate Information
2. Develop the necessary social competencies
3. Develop personal values
4. Promote individual safety

Information

(the easy part)

Central Instructional Concepts

- Public versus private behavior
- Who can/cannot touch you and where
- Proper names of body parts
- “Improper” names of body parts
- Personal boundaries/personal 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
- Bathing, dressing, and privacy

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

Middle School & 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 v private behavior
- Public restroom use
- Attraction and sexual feelings
- Relationships and dating
- Personal responsibility and family values
- Sexual preference
- Laws regarding sexuality
- Pregnancy, safe sex, birth control
- Etc.

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)

Some Guidelines for Instruction

- 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

- Creating your own is easy and 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)

A Few Facts about Masturbation

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- A majority of men and women masturbate. However, men are more likely to have masturbated tend to do it more often than women.
- People of all ages masturbate. Younger people are more likely to report doing it, but they're not the only ones masturbating.
- Persons of all sexual orientations masturbate including those who identify as asexual.
- Vibrators are frequently used by women during masturbation (the vibrator has been around for a very long time). However, a national survey found that almost 17% of men reported having used a vibrator during masturbation.
- During masturbation an individual's heightened sexual arousal can make almost anything/anyone seem sexually appealing. There are some interesting implications for this in the development of unusual sexual interests.
- Frequent masturbation could be good for your health and overall immune system functioning.

A quick summary

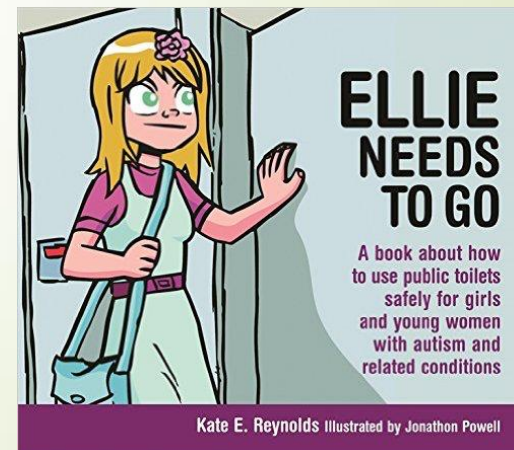
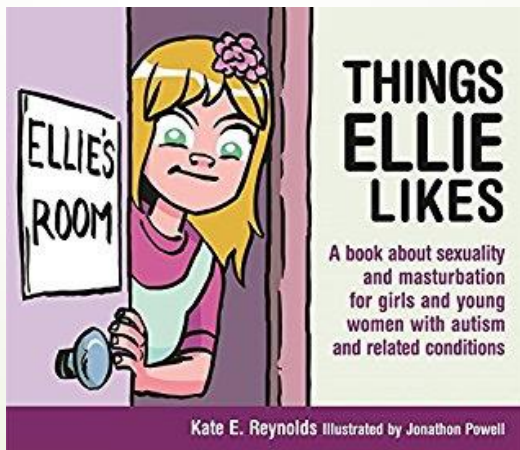
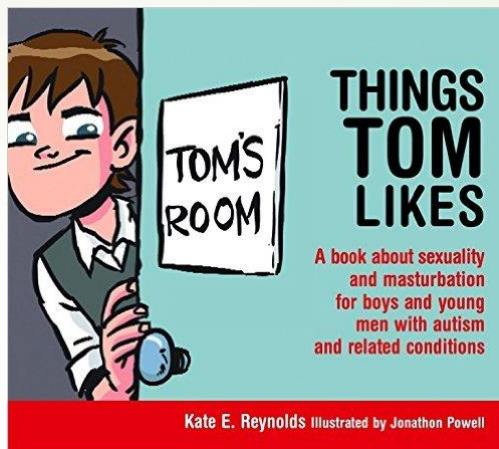
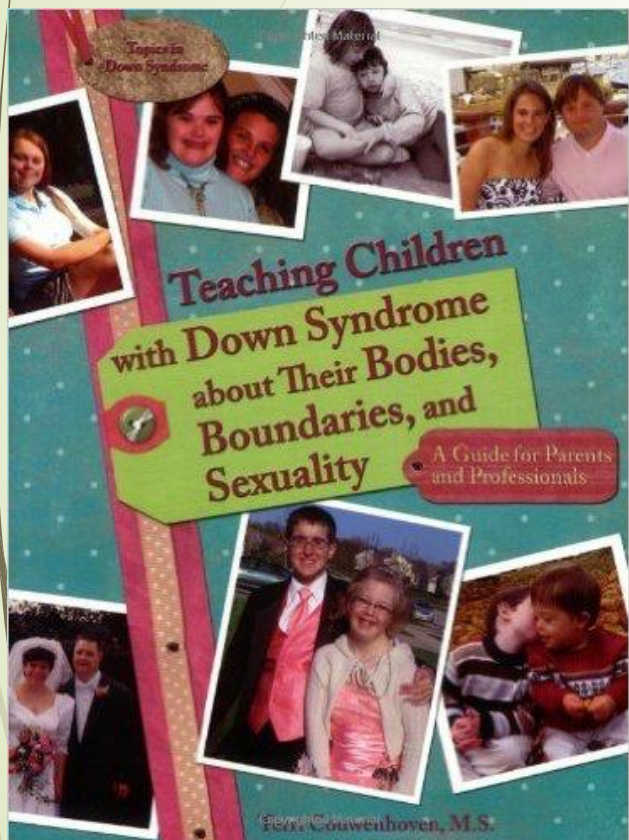
Challenges to Sexuality Education for Learners with ASD

- Lack of a comprehensive evidence-based for intervention
- Highly specialized area of intervention
- Professional discomfort with the topic in general
- Public perception of individuals with ASD as “little children in big bodies”
- The social dimension of sexual behavior
- Family values may be contrary to individual needs

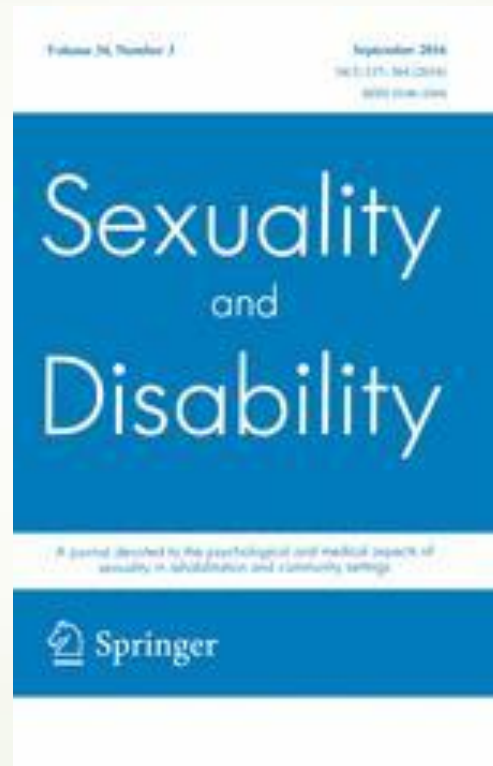
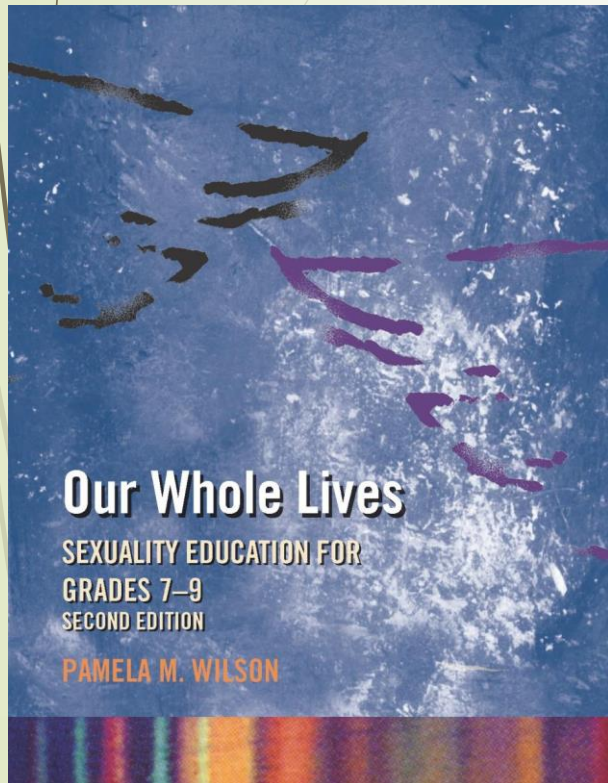
Challenges to Sexuality Education for Learners with ASD

- Differentiation between public and private behavior and reality v. fantasy
- Ensuring the maintenance of learned skills, particularly those associated with sexual safety
- Balancing individual safety with personal respect and individual rights
- Professional "over-emphasis" on compliance.
- Issues related to law enforcement

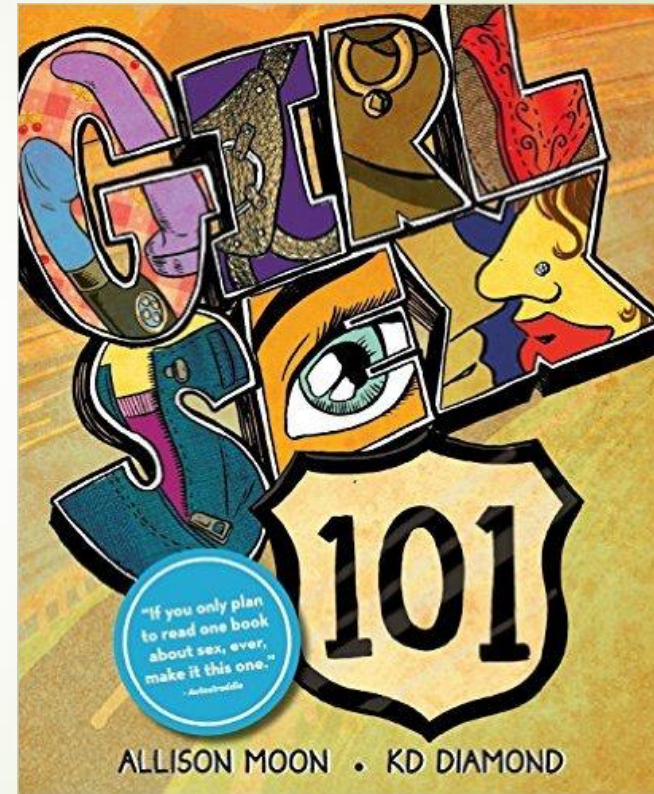
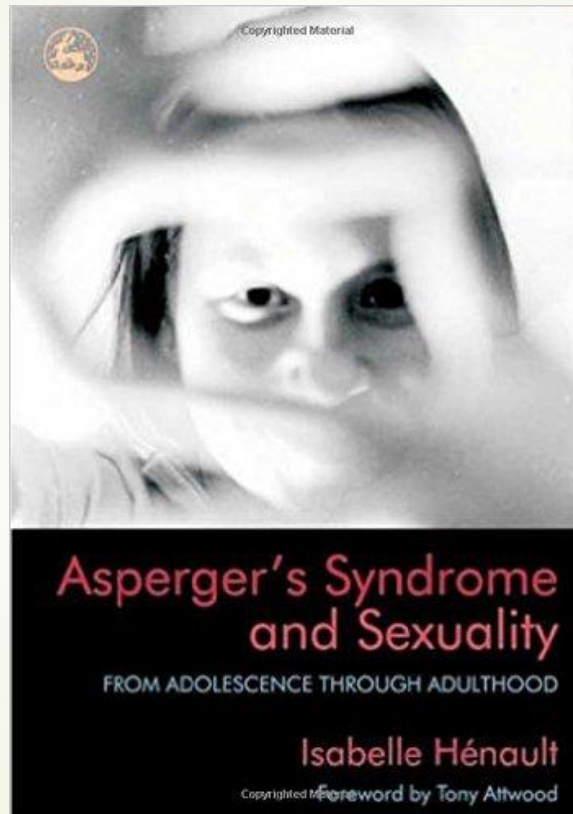
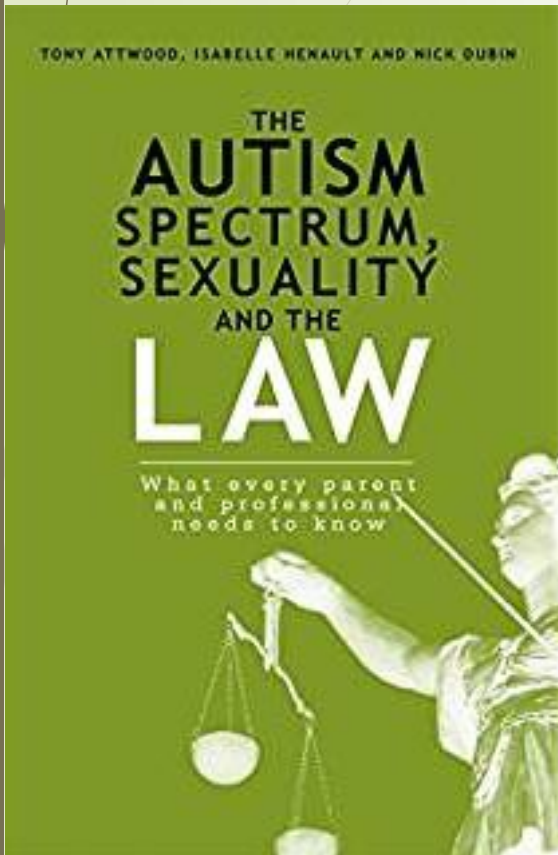
Some Resources



Some Resources



Some Resources





**A failure is not always a mistake,
it may simply be the best one can
do under the circumstances.
The real mistake is to stop trying.**

© 2009 www.thinkquotes.com

B.F. Skinner
1 9 0 4 - 1 9 9 0

Therapeutic
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