

## Sexuality & Sexuality Instruction with Learners with Autism Spectrum Disorders and Other Developmental Disabilities

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The mission of the Organization for Autism Research (OAR) is to apply research to the challenges of autism.

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## Why Research is Important

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- Seeing is not believing
  - Correlation does not mean causation
  - With a population of 297,000,000 people, one in a million occurrences happen to 297 Americans each day just as a matter of chance and coincidence.
  - As professionals, we have an ethical obligation to our clients to provide treatment and intervention that is evidence-based and, thereby, most likely to be effective.
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This presentation contains language of a sexual nature and may be considered inappropriate for younger listeners.

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## Why is ABA the ideal field to address the need for sexuality education?

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## Because ABA is...

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- Data-based
- Analytical
- Able to be replicated
- Socially important
- Contextual
- Accountable (Sulzer-Azaroff & Mayer, 1991)

All of which are directly relevant to the provision of sexuality education and support for learners with ASD.

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## In addition...

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- ❑ ABA-based instruction requires documentation of skill development compared to baseline levels
  - ❑ Through task analysis, ABA-based instruction breaks larger areas of information into smaller, more discrete, tasks
  - ❑ ABA-based instruction is able to promote both generalization and maintenance of newly learned skills to the benefit of the learner
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## And...

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- ❑ 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.
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## And lastly...

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“...happiness among people with profound multiple disabilities can be defined, reliably observed, and systematically increased” supporting the fact that “the contributions of behavior analysis for enhancing the quality of life among people with profound and multiple disabilities may be increased significantly.”

C. Green & D. Reid, 1996

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## Why sexuality education?

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### Defining Characteristics in Adulthood

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- ❑ Career choices
  - ❑ Where and how we live... Lifestyle issues
  - ❑ Leisure, recreation, and hobbies
  - ❑ Our public social circle
  - ❑ Our private social circle inclusive of sexual relationships
  - ❑ Quality of life concerns
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### However...

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- ❑ 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.
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## Sexuality Defined

- "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)

## Historical Considerations (Sobsey, 1994)

- Eugenics Movement
  - Starting in the late 1800's laws were passed banning marriage or sexual intercourse involving women with a developmental disability or epilepsy (Sobsey, 1994).
  - From 1907 to the mid 1980's over 60,000 individuals with a developmental disability were sterilized without their consent or, at times, knowledge.

## Historical Considerations (Sobsey, 1994)

- Both programs were designed to 1) protect learners with a developmental disability from sexual abuse and 2) eliminate developmental disabilities by restricting reproduction.
- Until the mid-1960s such actions remained relatively commonplace with displays of sexuality by learners with developmental disabilities punished as inappropriate or deviant.

## Myths about Sexuality

- In the community at large, there continue to exist a number of myths regarding sexuality and learners with ASD including:
  - Persons with ASD and other developmental disabilities have little or no interest in sex.
  - Persons with ASDs and other developmental disabilities are hypersexual.
  - Persons with ASD are solely heterosexual

## But 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.

## In fact...

- In two 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

### And for the Learner with ASD...

- sexuality education is complicated by language and communication problems and social deficits. Unfortunately, while sexual feelings and interest may be high, a primary information source available to neurotypical teens, (i.e., other teens), is generally not available. (Volkmar & Wiesner, 2003)

### Sexuality education 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.

### Some 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

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

### Some guidelines for teaching

- What are the practical implications\*
- Consider using multiple instructional mediums\*
- Incorporate the social dimension of sexuality when and wherever appropriate
- Teach all steps and in the correct order\*

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

### Goals of a comprehensive sexuality education

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

### Goals of Comprehensive Sexuality Education: 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 Concepts/Basic Information

- Public versus private behavior
  - Good touch versus bad touch
  - Proper names of body parts
  - "Improper" names of body parts
  - Personal boundaries
  - Masturbation
  - Social skills and relationship building
  - Avoidance of danger/Abuse prevention
  - Dating skills
  - Personal responsibility and values
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### What is Private? What is public?

- Brushing ones hair?
  - Holding hands?
  - Touching your genitalia
  - Using mouthwash
  - Flatulence
  - Kissing your mother? Your girl/boyfriend?
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### What to teach and when... some general guidelines.\*

- Preschool through Elementary
  - Boys v. girls
  - Public v. private
  - Basic facts inc. body parts
  - Introduction to menstrual care

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

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### What to teach and when... some general guidelines.\*

- Middle School to High School
    - Puberty
    - Menstruation
    - Ejaculation and wet dreams
    - Appropriate v. inappropriate touching
    - How to say "no"
    - Attraction and sexual feelings
    - Masturbation
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### What to teach and when... some general guidelines.

- High School on up
    - Relationships and dating
    - Personal responsibility and family values
    - Love v. sex
    - Sexual preference
    - Laws regarding sexuality
    - Pregnancy, safe sex, birth control
    - Etc.
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### Goals of Comprehensive Sexuality Education: VALUES

- To develop personal values reflective of family, religious and cultural values in such areas as:
    - Personal responsibility
    - Self esteem
    - Interpersonal respect
    - Personal limits
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## Goals of Comprehensive Sexuality Education: SOCIAL

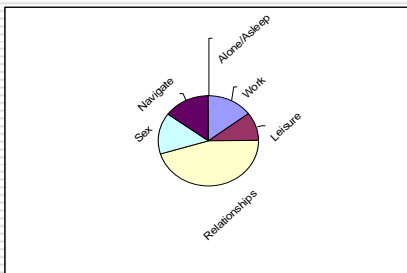
- Promote the development of adequate and effective social repertoires inclusive of:
  - Decision making skills
  - Personal advocacy
  - Peer refusal skills (i.e., a functional “no”)
  - Avoidance of dangerous situations
  - Dating

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

## The Social Dimension of Sexuality

Intimate and consensual sexual relationships involving more than one person generally require some degree of social competence which will, in most cases, present a challenge to the learner with ASD.

## Areas of life in which we use social skills



## What do we mean by the term “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. At its heart, an intimate sexual relationship is a social relationship.

## further...

- Social skills, by definition, are bi-directional (i.e., it is impossible to be social by yourself)
- As such, social competence relies as much on the interpretation of the receiver as on the intent of the sender. As such, both participants need to demonstrate a certain level of social and decision-making competence
- When two or more people are together, some form of a social repertoire is generally expected

## A brief tour of the social world



## The Increasing Demands of the Social World

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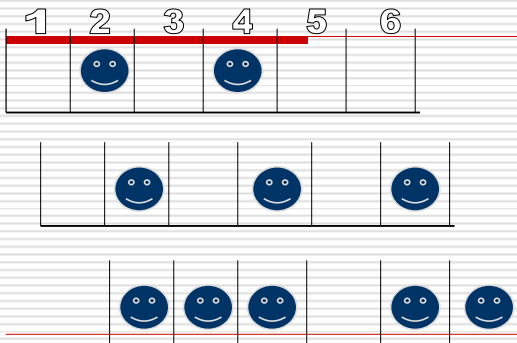
- Your social demands are often lowest within your home. Why? Because you set the rules of acceptable behavior.
  - Your social demands at work are higher. However, work is a somewhat scripted social environment and one with a secondary measure of competence (i.e., production).
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##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

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- 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.
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## The Urinal Game: Which to Choose?



## Promoting Positive Decision Making

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- The parameters of choice making go far beyond simple forced choice responses and include:
    - Where to...
    - With whom...
    - When to...
    - What to do before or after...
    - When to end...
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## Personal factors impacting competent decision making

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- Individual's history of decision making
  - Individual communicative competence
  - Individual social competence
  - Long and short term consequences of previous decisions
  - Current risk/benefit analysis competencies
  - Relationship between current skill sets, desires and rights
  - Level of individual support, direction and oversight
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## Consent...

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## The Question of Personal Consent

- One's ability to give free and informed consent defines a consensual sexual relationship. Unfortunately, and particularly with reference to more able individuals, this area is one where there is little consensus regarding the, 1) definition of consent, 2) assessment of competence to give consent, and 3) the implications of current guidelines (or lack thereof) regarding how families and other caregivers might best address an individual's desire to give consent while providing a degree of protection from abuse or exploitation.

## Definitions of consent

- The ability to provide consent exists if the person demonstrates an understanding that his or her body is private, of the sexual nature of the act, and has the ability to say "no". (ARC, 1998)
- Other definitions (e.g., Ames & Samowitz, 1995) include the requirements that consent be informed, voluntary, and that the individual demonstrates the ability to act upon knowledge through responsible, interpersonal behavior.

## Definitions of consent

- In New York State regulations are in place to ensure that individual rights to sexual expression are not restricted within the limits of one's consensual ability. Determination of ability to offer consent may include (but not necessarily be limited to), the use of some measure of sexual knowledge, an individual assessment and evaluation with particular attention to individual decision making competencies, family input, and input from involved professionals (e.g. psychologists, physicians, etc.).

## Definitions of consent

- However, laws as to who may offer consent vary on a state by state basis with some states using guardianship status as a determinant and others requiring specific, documented determinations of competency to offer consent.

## Staff Training....

## Staff Training

- In supporting individuals with ASD in sexuality instruction and activities, support staff require training in:
  - The sexuality policy of the organization
  - Definition of abuse, potential abuse situations and statistics on abuse
  - Nature of instruction provided to clients
  - Appropriate client/staff interactions

## Staff Training

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- Training in respectful provision of personal care training and needs
  - Ways to protect individual safety, privacy, and personal freedoms
  - Ethical decision making
  - Training in reporting suspected or actual instances of abuse
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## Sexual Abuse

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## Sexuality Education – Abuse and Exploitation

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- Despite our best efforts, people with developmental disabilities are victims of sexual abuse and exploitation at a rate much higher than that of the NT population. While appropriate education in sexuality issues cannot assure that no person will be the victim of sexual abuse, failure to provide such training would certainly appear to increase the risk.
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## Sexuality Education – Abuse and Exploitation

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- Mythologies related to sexual abuse:
    - There is no real risk
    - Well, he/she would never be in that situation anyway
    - I can ensure 24 hour/day protection and guarantee that he/she doesn't even have the opportunity for appropriate, let alone inappropriate, sexual relations
- Adapted from: Schwier, K.M., & Hingsburger, D. (2000)
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## Sexuality Education – Abuse and Exploitation

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- As of now, the best defense we can offer individuals with developmental disabilities to be as free from sexual abuse as possible is...

**A comprehensive sexuality education!**

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## Challenges to Sexuality Education for Learners with ASD.

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- The social dimension of sexual behavior
  - 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
  - Issues related to law enforcement
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## Case Study Discussion I

(adapted from Watson, Griffiths, Richards & Dykstra, 2002)

- An 8 year old girl named Caroline has an autism spectrum disorder and a seizure disorder currently controlled through medication. Her receptive comprehension is greater than her expressive vocabulary although both are limited. She is generally independent in toileting, showering, and dressing but often requires supervision to ensure "quality control". Although she is only 8, staff have discussed with the family the possibility of starting menstrual care training with Caroline.
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## Case Study Discussion I

(adapted from Watson, Griffiths, Richards & Dykstra, 2002)

- Is it necessary to start menstrual care training now?
  - What restrictions might be put on any such training?
  - What might be taught regarding her need for some supervision in the bathroom, showering or dressing?
  - Is Caroline potentially vulnerable to sexual abuse?
  - Who has the final say?
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## Case Study Discussion II

(adapted from Watson, Griffiths, Richards & Dykstra, 2002)

- Peter is a 16 year old student with an ASD diagnosis. Peter attends high school where half his classes are in special education and half, including gym, in general education. Recently, there have been three reports of Peter masturbating after gym class. Peter has a girlfriend, Susan, who is 15 and attends the same school where she is enrolled, part time, in special education classes. Initially, Peter and Susan would see each other only at school as neither set of parents approved of their dating because of their ages and disabilities.
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## Case Study Discussion II

(adapted from Watson, Griffiths, Richards & Dykstra, 2002)

- Teachers have recently observed the couple becoming more intimate (e.g., holding each other closely for extended periods of time, kissing in the hallway). When approached about their behavior in school, they generally reply that "They are in love and everyone else is doing it."
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## Case Study Discussion II

(adapted from Watson, Griffiths, Richards & Dykstra, 2002)

- Should sexuality education be provided to Peter and Susan?
  - Should it be done in the context of the special education or regular education curriculum?
  - Should they be taught separately or together?
  - What should be taught?
  - To what extent should sexual intimacy be part of this instruction?
  - Should staff receive training?
  - To what extent should both families be involved?
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# Some final thoughts

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But what is happiness except the simple harmony between a [wo]man and the life [s]he leads.

**Albert Camus (1913 - 1960)**

That's the difference between me and the rest of the world!  
Happiness isn't good enough for me! I demand euphoria!

**Calvin, speaking to Hobbs**

If I had to live my life again, I'd make the same mistakes, only sooner.

**Tallulah Bankhead (1903 - 1968)**

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