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

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Let’s start by talking about the importance and implications of adaptive behavior

Adaptive Behavior

- Adaptive Behavior is defined as those skills or abilities that enable the individual to meet standards of personal independence and responsibility would be expected of his or her age and social group. Adaptive behavior also refers to the typical performance of individuals without disabilities in meeting environmental expectations. Adaptive behavior changes according to a person's age, cultural expectations, and environmental demands. (Heward, 2005)."

And a new item from a child in Ontario

- Many bowling alleys and restaurants have ice in the urinals to keep them fresh so it is important to let kids know never to eat ice they find in the bathroom.

Sex and sexuality is an extensively under-researched area of adaptive functioning in adolescents & adults with ASD

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

Lisa Mitchell's Top 10 Reasons Why We Should Teach Human Sexuality Education To Individuals With Autism Spectrum Disorders

Number 10…

Low Reading Ability Hinders Learning From Written Materials

Number 9…

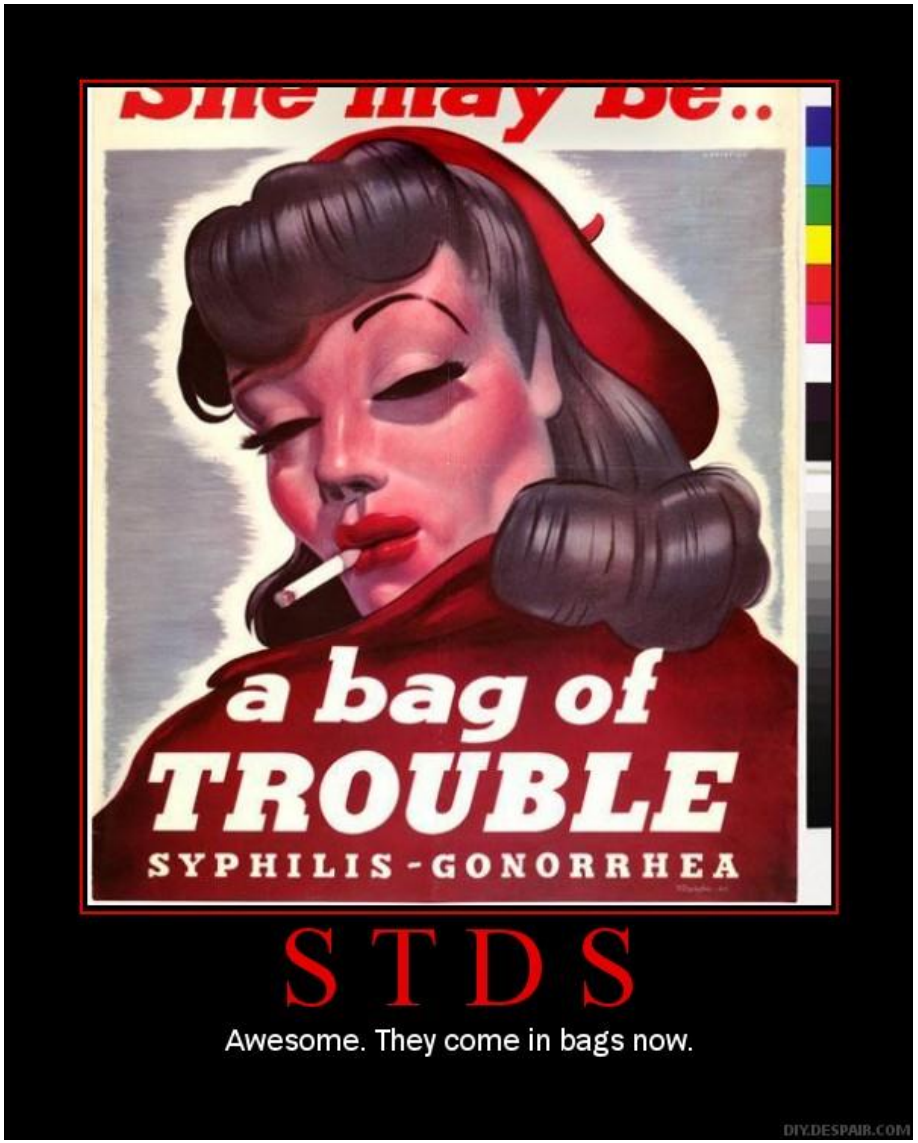
Many Individuals With ASD Do Not Have Even Basic Knowledge About Sexuality

Number 8…

Many Individuals With ASD Do Not Know When & Whom To Ask Questions

Number 7…

To Prevent The Spread Of HIV/AIDS & STD's Within The DD Population

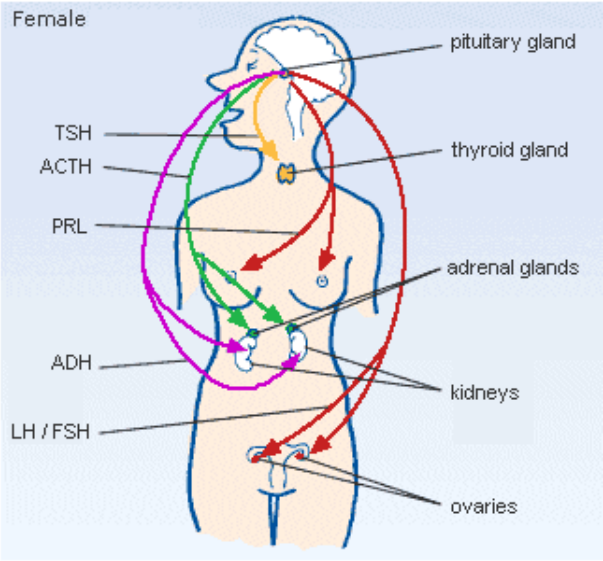


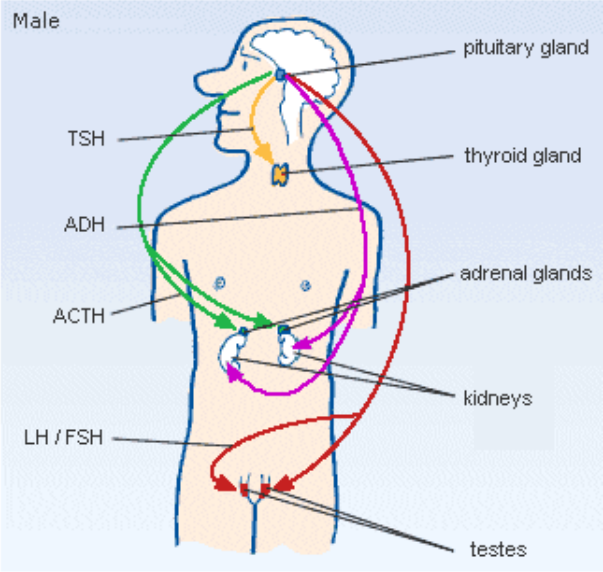
Number 6…

The Internet and other readily accessible media

Number 5…

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





Number 4…

Many Have Low Self-Esteem & May Do Anything To Be Accepted By Peers

Copyright Rex Sikes

Number 3…

Sexual Abuse

Self-Protection

- Teach that refusing to be touched is a right
- Teach that secrets about being touched are not OK
- Teach self-protection skills
  - Who can/can't touch the individual and where on his/her body
  - How and when to say "No"
  - How to ask for assistance
  - How to recall remote events and convey where an individual touched him/her

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

Number 2…

Limited Opportunities For Socialization & Normalizing Socio-Sexual Experiences, Compounded By Social Skill Deficits

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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

Why ABA to teach this stuff?

- 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.

- 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.

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.

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).
  - Between 1907 & 1957 (and later in some cases), some 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 have little or no interest in sexuality.
  - Persons with ASD 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.

But…

- Individuals with ASD may have sexual feelings that are out-of-sync with their level of social development and awareness
- As kids grow older, their social and sexual skill sets are likely to become more disparate with their chronological age and appearance
- Other people, however, will base expectations on their chronological age, NOT their developmental age

(American Academy of Pediatrics, 1996; Koller, 2000; Volkmar & Wiesner, 2004)

What we don't know…

- In two (somewhat) 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

can sometimes hurt us.

- Stokes, Newton, & Kaur (2007) examined the nature of social and romantic functioning in adolescents and adults with ASD. What they found was that individuals with ASD were more likely than their NT peers to engage in inappropriate courting behaviors; to focus their attention on celebrities, strangers, colleagues, and exes; and to pursue their target for longer lengths of time (i.e. stalking).
  - » Stokes, M., Newton, N., & Kaur, A. (2007). Stalking, and social and romantic functioning among adolescents and adults with autism spectrum disorder. *Journal of Autism and Developmental Disorders,* **37,** 1969-1986.

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)

For example…

- 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, etc.*

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.

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

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)

Guidelines for making materials

- Individuals with autism may attend to irrelevant details, so avoid visual clutter and make the relevant stimuli obvious
- Skills that are not generalized are not useful skills, so provide multiple examples of the same concept to aid generalization
- For example…

This is Claire

Which one is Claire?

This is Allison

Which one is Allison?

This is Nancy

Which one is Nancy?

Which is Nancy?

A final guideline

- Individuals with autism can be concrete thinkers who interpret things literally, so…
  - Be frank during instruction
  - Provide clear visual and verbal examples
  - Avoid euphemisms
- For example… (Rated R)

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

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

Q: Tell me about this picture.

A: "[T]he people were sitting on the couch 'being friends'."

(Konstantareas & Lunsky, 1997, p. 411)

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

http://www.ural.ru/gallery/news/people/sex/bed.jpg

Q: What does this picture show?

A: "[t]wo people lying on a towel."

(Konstantareas & Lunsky, 1997, p. 410)

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

Q: What is this man doing?

A: "[T]he hand is somewhere; he chopped it off."

http://www.reuniting.info/images/0bedSM.jpg

(Konstantareas & Lunsky, 1997, p. 411)

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 Instructional Concepts

- Public versus private behavior
- Good touch versus bad touch ™
- Proper names of body parts
- "Improper" names of body parts
- Personal boundaries/personal spaces
- Masturbation ("Private Touching")
- 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

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

- *Middle School to High School and 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 restroom use
  - Attraction and sexual feelings
  - Relationships and dating
  - Personal responsibility and family values
  - Love v. sex
  - Sexual preference
  - Laws regarding sexuality
  - Pregnancy, safe sex, birth control
  - Etc.

The same techniques we use to teach other behaviors…

- Can be used for sexuality education, too.
- Some examples:
  - Picture schedules
  - Shaping
  - Cognitive rehearsal
  - Personalized stories
  - Video-modeling
  - Discrete Trial Instruction

I am getting older and I am growing up.

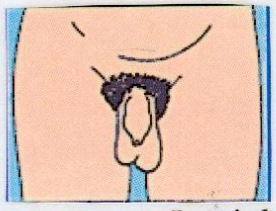
Part of growing older is having my body change. I get taller and I weigh more.

Another change is that hair is growing on my body in new places.

There is hair growing on my face,

under my arms,

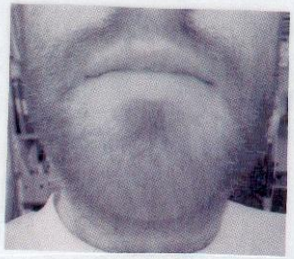
and on my private parts.



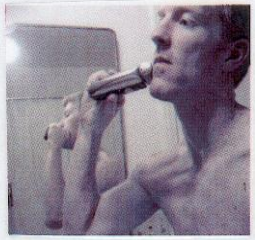
Every adult has hair in these places. It might feel weird to have hair growing, but I should let the hair grow under my arms.

Men sometimes shave the hair that grows on their face like Dad and Uncle [redacted]

Some men don't shave their face and they grow a beard, like [redacted]



My teachers and my family will help teach me how to shave my face so that I can do it safely.



It is exciting to grow up and become an adult.

Public/Private Discriminations

- Be clear about social and family rules about privacy and modesty
  - Restrict nudity in public parts of the house
  - Dress and undress in bedroom or bathroom
  - Close doors and shade windows 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)

Public/Private Discriminations

- Some concepts to teach:
  - Naked vs. wearing clothes
  - Places where it is OK to be naked (and where it is not)
  - Which parts of the body are private
  - What kinds of activities are private
  - Where it is OK to do private activities

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

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
  - Right v. Wrong
  - Reality v. Fantasy
  - Interpersonal respect
  - Personal limits

Key Concepts: Values

- Homes, schools & day programs are laboratories where our people learn values by observation, limitation, reward and punishment.
- Be consistent in approving or disapproving of certain behavior.
- Approval or positive reinforcement is more effective than punishment in teaching values.
- Encourage curiosity, independent thinking, problem solving and self-expression.

Slide Courtesy of Lisa Mitchell

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

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.

Social Threads of Discussion From the Douglass Group

- "I just want someone to show me the rules."
- Independence, and respect for one's independence are important.
- "If you NTs have all the skills, why don't you adapt for awhile?"
- It's not so much knowing the skill but using the skill.
- Reports of social isolation are prevalent

The Increasing Demands of the Social World

- Your social demands are often lowest within your home. Why? Because you set the rules of acceptable behavior.

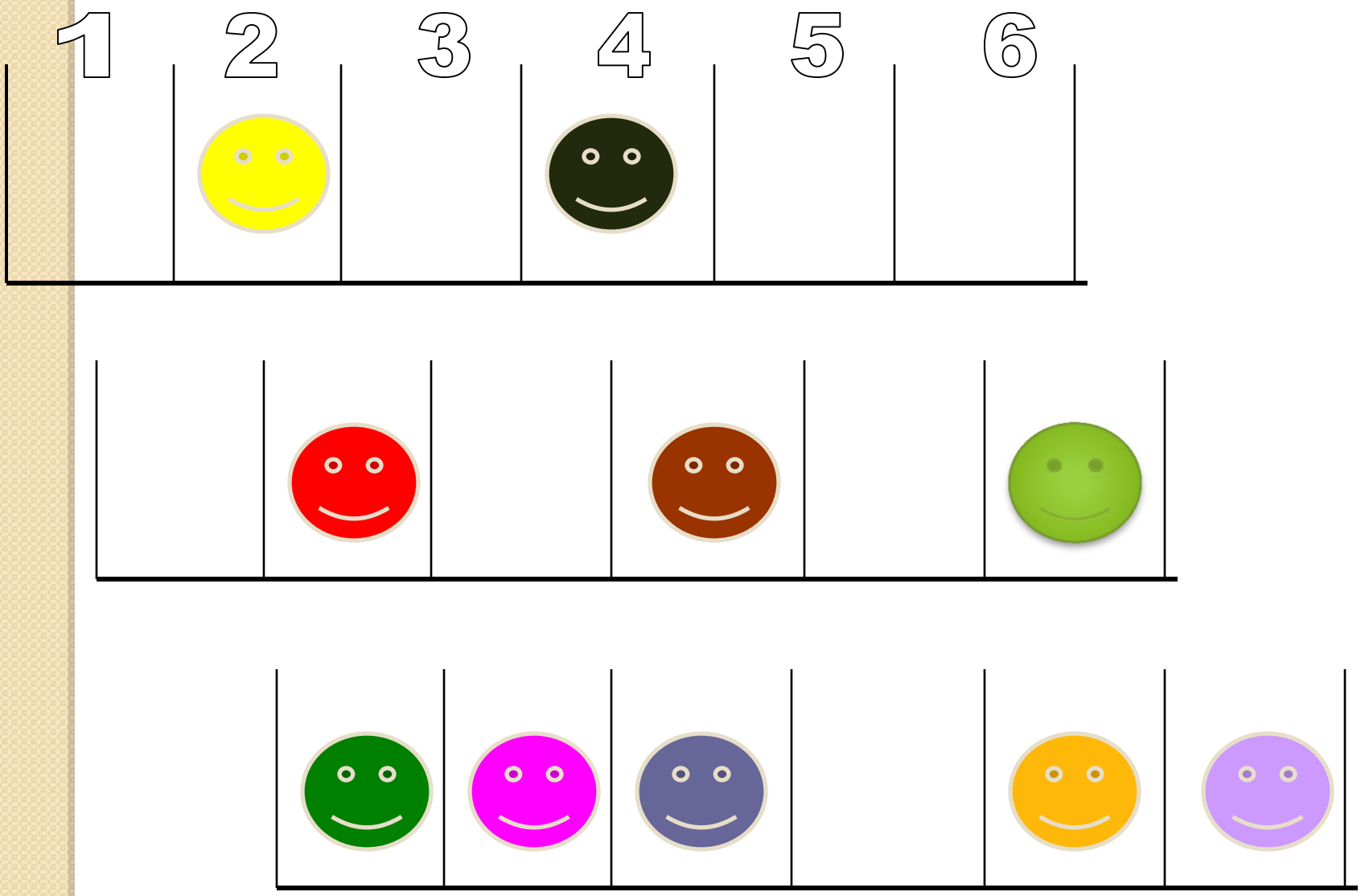
- Your social demands at work are higher. However, work is a somewhat scripted social environment and one with a secondary measure of competence (i.e., production).

The Increasing Demands of the Social World

- 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 you social skill repertoire may be less than adequate.

The Urinal Game: Which to Choose?



Masturbation

- Is normal and should not be condemned
- Exploration of genitals for self-pleasure begins in infancy
- Most people with autism learn to do it on their own, although some may have difficulty reaching orgasm
- Ineffective masturbation may contribute to ritualistic behaviors in some people with autism
- Masturbation may be the only realistic outlet for sexual release for some people with autism

(Ailey et al., 2003; Koller, 2000; Nehring, 2005; Volkmar & Wiesner, 2004)

Preventing problems

- Designate where it is OK to masturbate
  - Individual's bedroom
  - Avoid teaching use of bathroom
- Teach rules for appropriate time/place
- Teach that sometimes it is not an option
- Provide private time
- Schedule private time and help individual understand the schedule

(Baxley & Zendell, 2005; Koller, 2000; NICHCY, 1992; Volkmar & Wiesner, 2004)

Handling problems

- Interrupt the behavior but don't punish or overreact
- Remind the student of the rules for appropriate masturbation by referring to the visual cues he/she uses
- Redirect the student to:
  - An activity that requires use of hands
  - A physical activity
  - An activity that requires intense focus
  - To his/her bedroom, if available
- Reinforce student when he/she is engaging in appropriate behavior

(Baxley & Zendell, 2005; Koller, 2000; NICHCY, 1992; Volkmar & Wiesner, 2004)

Challenges to Sexuality Education for Learners with ASD.

- 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

Recommendations for Future Research and Practice

- Assessment methods to identify functionally relevant skills (i.e., true adaptive behavior) for development in the community
- Effective behavior analytic instruction in community-referenced safety skills. Issues related to long term maintenance
- Retrospective studies of "successful v. unsuccessful" adults on the spectrum to help indentify effective strategies and interventions
- Effective methods of community training to promote great levels of social inclusion for learners with ASD across multiple environments

Recommendations for Future Research and Practice

- Effective models of transition intervention resulting in more positive outcomes.
- Cost-benefit analyses of current models v. less "facility-based" models of adult services and support
- Issues related to staff recruitment and retention
- Family support issues and intervention for parents of adults

Recommendations for Future Research

- Implications of fluency-based interventions on the development of adaptive responding with older learners
- Competency-based models of staff training in the provision of community-based instruction
- Implications of instruction in social survival skills v. more typical social competence skills.
- Effective instruction in the areas of sexuality and sexual safety
- Models of therapeutic intervention in the criminal justice system

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