Autism and Sexuality

Maria R Urbano, M.D.
Associate Professor
Co-Director, ASD Program
Dept. of Psychiatry and Behavioral Sciences
Eastern Virginia Medical School

DSM-IV-TR Autism

- Impairment in Social Interactions
- Impairment in Communication
- Restricted interests/repetitive behaviors
- Present prior to the age of 3

DSM 5 Diagnosis

- Social Communication—social reciprocity, nonverbal communication, develop and maintain relationships
- Repetitive Patterns of Behavior/Restricted Interests—repetitive movements or speech, intense interests, resistance to change, unusual sensory sensitivity
- Present in early childhood but may not become evident until social demands exceed ability; limit and impair function
**CDC Study 2008**

- Autism and Developmental Disorders Monitoring Network
- 14 sites across country-not representative of whole U.S.
- Same statistical methods used as in 2006 and 2002-looking at children 8 years of age
- 1 in 88 children in 2008; 23% increase from 2006 and 78% increase from 2002
- 1 in 54 boys and 1 in 252 girls

**Sexuality**

- Puberty is a physical stage when boys and girls are capable of sexual reproduction
- Sexuality is the “possession of structural and functional traits of a particular sex”.
- Sexuality is “preoccupation or involvement in sexual matters”.
- Sexuality is a value-laden physical, mental, and emotional process

**UN Statement of Rights (1971)**

- Individuals with ASD “…have the same rights as other people of the same age who are living in that country”
TEACCH Report

- “People with autism of all levels of severity experience sexual drives, behaviors, and feelings with which at some point in their lives they will need assistance”

- Sexuality must be addressed in terms of the values of the family

Case

Challenges of Typical Puberty and Development

- Physical Changes
- Sexual Feelings/Thoughts
- Sexual identity
- Relating to others
- Increased expectations
Pubertal Changes

- Females
  - Breast Development
  - Menarche

- Males
  - Genital development
  - Nocturnal Emissions
  - Spontaneous Erections

Pubertal Changes

- Body mass/composition
- Hair — distribution, texture
- Voice — growth of larynx
- Skin — increase in sebaceous secretions

Sexual Thoughts and Feelings

- Understanding a new body
- Interpreting bodily sensations
- Incorporating new social scenarios
- Restructuring concepts of male vs female
- Processing a tremendous increase in information
- Coordinating and regulating thoughts and feelings about one’s identity
Sexual orientation/Gender identity

- Gender identity develops at 18 months of age and is complete by age 3-4 years
- Society plays a part in how gender is expressed-sexual role
- Gender is separate from the choice of a sexual partner-sexual aim

Case

Psychosexual Relatedness

- Awareness of self in relation to other changes-awareness of differences
- View of other as a potential sexual partner
- Exploration of another’s thoughts and feelings and body
- Age appropriate behaviors
- Physical boundaries revisited
Children with Autism

- Oftentimes, children with ASD are thought of as sexually immature when, in fact, their physical maturity is right on schedule with their peers. (Konstantareas & Lunksky, 1997; Ludlow, 1991; Stokes & Kaur, 2005).
- The assumption of sexual immaturity has, on occasion, led to insufficient or no services concerning sexuality for children with developmental disorders (Konstantareas & Lunksky, 1997).

Challenges for Children with Autism

- Children, adolescents and adults with Autism struggle with sexuality and sexual development due to limitations in their social understanding.
- Single most important factor - their lack of interaction with same age peers contributes to their lack of knowledge of sexual appropriateness for their own age group.

Challenges for ASD Adults

- Social judgment
- Poor decision making skills/everyday memory problems/planning
- Emotional dysregulation
- Sensory sensitivities
Social Judgment

Difficulty with social cues and interactions which is the root of most inappropriate behaviors

- Cognitively, the world is perceived differently
- Sensations can be overstimulating or self-soothing
- Not able to read social cues
- Problems with self-awareness
- Lack of everyday experience
- Concrete patterns of thought

Decision Making Skills

- Poor Planning/initiation of behavior
- Forgetting to make plans or contact another
- Lose focus on another/can’t keep attention
- Inflexibility
- Losing information

Emotion Dysregulation

- Certain emotions are ok in certain places
- Anxiety
- Anger
- Empathy/attunement/indifference
- Self awareness
Sensory Sensitivities

- Eye contact aversion
- Dislike of touch
- Oversensitivity of sound
- Physical sensations

Privacy/Boundaries

- Personal Space/Interpersonal Distance
  - Seating arrangements
  - Standing in line
  - Touching other people/permission to touch
- Concept of Privacy
  - Close doors
  - Knock on doors
  - Common shared space vs. private spaces

The Hidden Curriculum

- “The unwritten social rules that govern our behaviors in a variety of different contexts.”
  (Myles, B.S. and Simpson, R.L., 2001)
Context Blindness

Context is what is going on in the environment, outside and inside our brain, that influences our way of giving meaning to things. The ability to select elements in the context that are useful and meaningful and to use them is context sensitivity. The neurotypical brain is inherently context sensitive.

- Autism as Context Blindness, Peter Vermeulen 2009

Case

Keys to Developing Social Skills

- Reading the Social Situation
  - Recognizing different perspectives of others
  - Recognizing non-verbal communication
  - Attending to the relevant social cues
  - Associating those cues with past experience
  - Questioning misunderstood information
    - Staci Carr, EdM, MS, VCU ACE
Keys to Developing Social Skills

- Appropriate hygiene and dress
- Maintaining personal distance
- Social reciprocity in conversation
- Requesting clarification of ambiguous verbal and non-verbal signals
- Self-advocacy
- Development of an autobiography

Intimacy/Sexuality Nuances

- All the rules change
- Flexibility is necessary
- Focus is on the other in relation to the self
- Eye contact is essential
- Non-verbal communication may supersede verbal communication

Sexual Well-being in ASD Adults

- Adults with high functioning ASD
  - 56 men and women living in the community
- Sexual satisfaction varied with the level of ASD Symptoms
  - Those in dyads had greater sexual assertiveness and satisfaction
  - Men in dyads reported greater sexual satisfaction, lower sexual anxiety, and fewer sexual problems
  - Men also had better solitary sexual well-being but less sexual knowledge

Byers et al 2012
Choice of Partner
- Sexual Role
- Gender Identity
  - Male
  - Female
- Choice of Partner
  - Heterosexual
  - Homosexual
  - Bisexual

Case

Sexual orientation in ASD
- Higher degree of asexuality
- Greater rigidity in understanding of sexual roles
- Maybe more conservative in their views based on negative caregiver attitudes
- Sameness may be less confusing than another level of difference in choosing a partner
**Gender Dysphoria in ASD**
- Clinics are reporting an overrepresentation of individuals with ASD in their gender identity referrals
- In GID clinic in Netherlands, among 204 children and adolescents seen, 7.8% had ASD (Zashti 2011)

**Masturbation**
- Soothing/stimulating
- Need for privacy
- Possible self injury
- Social taboo
- Family values
- May be only sexual experience/pleasure someone with ASD may have

**Sexual Victimization/Safety**
- Trusting/vulnerable nature
- Internet contacts
- Desire to be accepted socially
- Not understand meaning of behavior
- Not understand consequences of behavior
  - Unwanted pregnancy
  - Sexually transmitted disease
  - Emotional Trauma
Sexual Abuse Statistics
- Murphy and Elias, 2006, 2.2 times greater risk of sexual abuse than those without a disability
- Mansell, Sobsey, Wilgosh, & Zawallich noted that those with ASD were very susceptible to sexual predation, coercion and abuse (1996).
- 16-25% of those with ASD are likely to be sexually abused

Case

Inappropriate Sexual Behaviors
- Permitted behaviors are governed by social appropriateness that is gathered through social cues

Understanding the “rights”
- Right person
- Right age
- Right Place
- Right Time

Staci Carr, Ed.M, MS, VCU ACE
Inappropriate Sexual Behaviors

- Public masturbation
- Public disrobing
- Touching members of the opposite sex
- Hugging in a sexualized manner
- Inappropriate comments
- Persistent, intrusive behavior
- Angry displays if rejected
- Misinterpreting “kindness”
- Misinterpreting of coercion by others to act inappropriately resulting in ridicule

Legal Concerns

- Assault charges
- Stalking
- Molestation
- Internet pornography

Case
Sex Education

- Children with ASD are not all the same because of the severity of their disorder and comorbid disorder(s).
- Sexual education must be adapted to their level of function and learning style—pictures are better than words; role playing
- The educational environment should minimize the potential for sensory or emotional overload to reduce anxiety.

Families and Sex Education

- Encourage families to discuss sexual issues with their child with ASD
- Families have a difficult time seeing their child as a sexual being and prefer to think of them in platonic relationships
- Families are worried about poor judgment concerning sexual activity yet frequently fail to discuss it

Sex Education

- Can begin with identifying body parts and their function; begin prior to age 10
- Can be discussed in relationship to self care and personal hygiene
- Acknowledge the presence of physical sexual sensations as normal
- Reinforce that sexuality is a private matter in our society
Sex Education
- Appropriateness of sexual behavior in a social setting
- Learning where and when behaviors are ok such as disrobing, touching others
- Need for privacy for self pleasuring activities
- Counseling availability to discuss relationship/sexual issues as they occur

Sex Education
- Medication side effects affecting sexual response
- Consider birth control methods, e.g. oral or injection contraceptives
- Education concerning pregnancy and sexually transmitted illnesses

Case
Closing Summary

- All individuals with ASD have sexual feelings
- All individuals with ASD need education to assist them with understanding feelings and behaviors and how to express them in a manner appropriate to society’s rules and their family values
- The goal of education is to provide safety for those with ASD while improving quality of life

Resources

- American Psychological Association
- Center for Disease Control and Prevention
- AutismSpeaks.org
- Journal of Autism and Developmental Disorders
- Autism journal

Resources

- Adults on the Autism Spectrum Leave the Nest: Achieving Supported Independence
- Sexuality and Autism TEACCH Report
  - http://www.autismuk.com/index9sub1.htm
- Sex, Sexuality, and the Autism Spectrum