



Approaching Conversations about the "Birds and Bees" with People with IDD

Jenee' Lewis-Walker, Psy.D. Licensed Clinical Psychologist NCSS Director of Child Mental Health/Program Facilitator

Clarification/Rules of Engagement

In this presentation, out of respect for differences in preferences around language, person-first language will be used interchangeably.

Information provided is intended to initiate thoughtful dialogue surrounding the various perspectives surrounding the topic of dating and relationships within the IDD communality.





Learning Objectives

Participants will:

- Examine historic and current systemic barriers that have contributed to access, education, and support
- Identify and explore psychosocial factors influencing sexuality and dating in people with IDD
- Explore puberty, health, and maturation through an IDD lens
- Identify inclusive strategies for supporting healthy, age-appropriate, and de-stigmatized sexual development
- Identify potential tools and resources to assist with empowering people with IDD to navigate sexuality and strategies for dating.





Riddle?

What is something most people crave, something that money can't buy, and something no one can define????





LOVE "The birds and the Bees"













Maslow's Hierarchy of Needs





























A core concept of positive psychology **is PERMA+**, a theory of wellbeing that enables people to flourish and be in flow. PERMA+ incorporates core elements of happiness and health, leading to personal fulfillment, meaning and well-being.

This promotes resilience!





(Seligman, 2011)

What do you believe?

Consciously... Subconsciously*

- People with IDD are asexual or childlike
- People with IDD can be sexually inappropriate
- People with IDD shouldn't have sex because it is unsafe
- Talking about sex makes you uncomfortable, especially when talking about sex and people with IDD
- They can't understand consent.
- You think people with IDD have a right to express themselves sexually, but with careful guidance and supervision
- Sexuality and sexual expression are important and basic human rights universal to all people and should not be taken away
- Sexual freedom is a civil right (granted by the government)





Timeline of Relevant History

- 1883, Sir Francis Galton (cousin of Charles Darwin), coined the term "eugenics" "the cultivation of race" or "the science of improving stock"
- 1905, Binet test published, strengthened the eugenics movement by giving it additional momentum
- 1907, Indiana passed the first law allowing "undesirables and defectives" such as those with IDD to be involuntarily sterilized
- 1909, California passed laws allowing sterilization of "undesirables"
- 1912, "The Kallikak family" published, best seller, promoted eugenics movement, written by Dr. Henry Herbert Goddard (Director of Research at the Training School for the feeble-minded in New Jersey, third institution of its kind in US) "When we conclude that had the nameless girl been segregated in an institution, this defective family would not have existed." Connection between institutions, eugenics, and sterilization
- 1920, study stated the "mentally defective" are those who are not able to have a home and for whom "the only permanent parent is the State"





Timeline of Relevant History cont.

Buck v. Bell (Grenon & Merrick, 2014)

- 1924, superintendent of a Virginia state school requested 18- year-old Carrie Buck sterilized
- In his opinion she was "feeble-minded" and "promiscuous"
- Had given birth to an "illegitimate" child
- Her mother and grandmother had been suspected of having IDD
- Supreme Court Justice Oliver Wendell Holmes ruled in favor of the compulsory sterilization stating:

"It is better for all the world, if instead of waiting to execute degenerate offspring for crime or to let them starve for their imbecility, society can prevent those who are manifestly unfit from continuing their kind. . .three generations of imbeciles are enough."





Historical Research = Some Progress

- Research during the 1970's and 80's tended to focus on managing, controlling, and limiting sexuality (Berner, 2021), often classifying men with IDD as potential aggressors and women as potential victims (McCarthy, 2014)
- Most recent research reflecting sexual experiences and sexual identities of people with IDD with an emphasis on personal agency, autonomy, and choice.





How do cultural influences impact our expectations and approaches to sexuality?

Adolescence / Puberty Media Music Religion Family History Age













IDD People are High Risk for Abuse & Exploitation

People with IDD are more susceptible to sexual abuse (one in three adults has experienced sexual abuse; Svae, Blixt, & Sondenaa, 2022). Maybe impacted by:

- Culture of compliance
- Many different caretakers
- Need for assistance with personal hygiene
- Expressive communication deficits
- · Lack of sex education and knowledge





Common Vulnerabilities

External Factors:

- Social isolation
- Overprotection (by parents and staff)
- · Limited circles of friends and social contacts
- Avoidance of topic by others (including and especially health professionals)
- Attitudes and perceptions of parents, teachers, staff, etc.
- Infantilization beliefs ("childlike" and asexual)

(Ailey, Marks, Crisp, & Hahn, 2003)





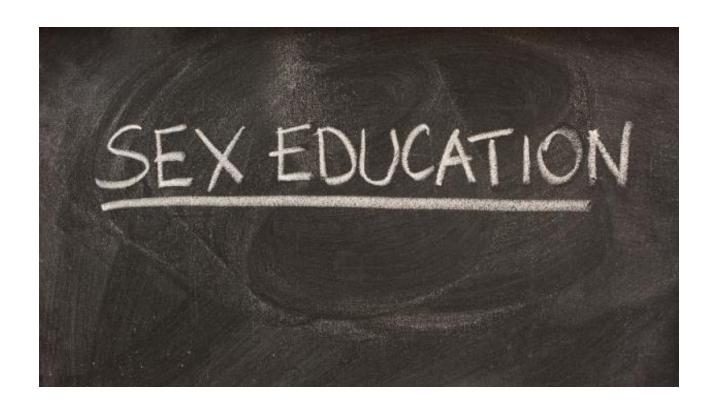
Common Vulnerabilities:

Internal Factors:

- Difficulty with Social Cues and Boundaries
- Impulse Control and Regulation (Executive Functioning)
- Communication Barriers
- · Limited Understanding of consent of healthy relationships
- Social Anxiety or Low Self esteem
- Dependency on caregivers
- Mental Health Issues
- Rigid Thinking or Difficult with change







Why is Sexual Education Important

Reportedly, levels of sexual interest in adolescents with IDD were comparable to their neurotypical counterparts.

Physical maturation ≠ Social and Cognitive maturation without knowledge and understanding:

- The ability to develop meaningful social and romantic relationships is reduced.
- The risk for negative sexual experiences, including sexual victimization, is heightened

Common Problematic or "inappropriate" sexual behaviors:

- Inadequate self-care
- · Deficits in understanding privacy and boundaries
- Repetitive patterns and sensory related experiences or fascinations related to sexuality





(Corona et al., 2016; Tullis & Zangrillo, 2013)

Key Aspects of Sexual Health

Sexual health is important across the lifespan - regardless of age, gender, sexual orientation, or relationship status. It supports not only individual well-being but also healthy relationships and communities.

- 1. Physical Health
- 2. Emotional & Mental Well Being
- 3. Consent & Safety
- 4. Education & Communication
- 5. Sexual Rights





(Dekker et al., 2015; Corona et al., 2016)

Psychosexual Emotional Functioning

How a person experiences, expresses, and integrates emotions related to their sexuality and intimate relationships.

How a person's emotions influence and are influence by their sexual behaviors and relationships with oneself

- Emotional Regulation in sexual contexts
- Emotional Intimacy
- · Attachment and Trust
- Self-Esteem and Sexual Confidence
- Consent and Emotional Safety
- Sexual/ Emotional Trauma
- Emotional Communication
- Culture and/or Religion





Navigating the Complicated World of Dating & Relationships





















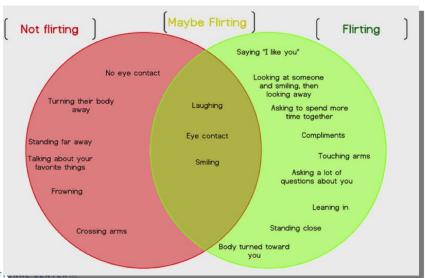
Stages of Dating

- Attraction
- Getting to know each other
- Casual Dating
- Exclusivity
- Deeper Connection
- Commitment
- Navigating Challenges
- Long-Term Partnership















Communication and Exclusivity







Communication and Exclusivity





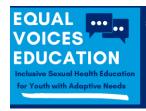


Available Resources/Curriculums

- Supporting Teens with Autism on Relationships (STAR) Program
- Intimate Relationships & Sexual Health
- Sex Education/Puberty Resources for Individuals with Special Needs/Disabilities and for Their Families, Partners, Caregivers, Educators, https://disabilityhealth.medicine.umich.edu/sites/default/files/downloads/SexEducationResources.pdf







Six 1-hour modules that can be presented as a series or scheduled individually.

Available as live, virtual or pre-recorded sessions.



Develop an understanding of the importance of consent, boundaries, and how to identify unhealthy relationships. Youth will be able to recognize abuse and know who to contact for help.



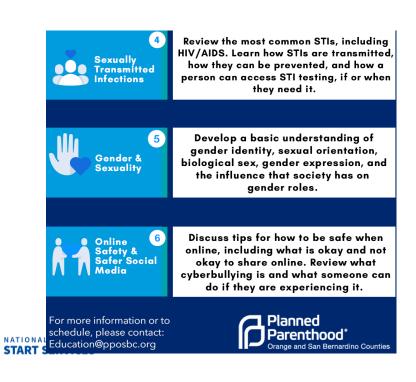
Increase knowledge of the changes that happen to the body during puberty, the importance of maintaining proper hygiene, and appropriate behavior in public and private places.



Learn about how pregnancy happens and how birth control can help protect against pregnancy. Increase knowledge on birth control methods, their effectiveness, and the importance of using them accurately and consistently.









Supporting Teens with Autism on Relationships (STAR) Program STAR Program

What is it?

A parent-mediated sexuality education program for autistic youth without ID

Parent Curriculum:

Charting the Course

Boardwalk Adventure (An interactive computer game)

Objectives:

An online interactive program

Leveraging their learning strengths in visual instruction

The practical application of concepts and skills

Groups:

Grouped by age

Age appropriate questions on the Youth sexual knowledge questionnaire Video Vignette tests





Intimate Relationships & Sexual Health

What is it?

 A curriculum for teaching adolescents/adults with ASD with "high-functioning autism spectrum disorders" and other social challenges.

Focus:

• Sex education & relationship education

Outline of curriculum:

- · Assessing students' knowledge & learning priorities
- · Introduces students to concepts they will be studying
- · Raises awareness of some issues related to portrayal of sexuality in the media
- Earlier sessions=technical aspects of sex education (anatomy, reproductive health, sexual responses, partnered sex, contraception, and STI's
- Latter sessions=social aspects of romantic relationships (preparing for dating, regular dating, stages of relationships, moving into longer term relationships)
- Addresses attitudes, values, differences (e.g., sexual orientation), and sexual coercion
- Final lesson= feedback evaluation





Final Reflections

- How can we normalize conversations with support systems to address sexual development in the IDD-MH community?
- How do you view your role with assisting the support systems you work facilitate these conversations.
- Are you comfortable with approaching this topic?





Questions/Final Discussion







References

START SERVICES

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