Comprehensive and Systemic Sexuality and Relationship Education for Young Adults with Autism

Rebecca Kammes, PhD, LMFT
About me
Learning Objectives

- Comprehensive
- Systemic
- Developmentally Appropriate

Sexual Education

- Increase Health and Well-Being
- Decrease Abuse/Exploitation
- Better Interpersonal Relationships
I/DD and the Education Gap

56% of students with mild ID received no sex ed
84% of students with moderate/profound ID received no sex ed
Estimates of around 40-60% of individuals with ASD leave High School with no sex education
60% of teachers believed students with ID could benefit from sex ed

• Opt-out policy for those in special education
• Lack of “real-world” opportunities to learn
• Difficulties integrating information from movies, porn, etc.

(Barnard-Brak et al., 2014; Brown & McCann, 2018; Chrastina & Vecerova, 2020; Sun et al., 2018; Treacy et al., 2018)
Interventions and Outcomes

• When younger, focus is on anatomy/physiology
• For adults, focus is abuse prevention and relationship development
• Further alienation when combined with social skills concerns
• Sensory issues often not considered
• Adults lack initial sexual knowledge

• Sex education is a nuanced topic
• Often becomes a focus when it becomes an “issue”
• Myth of asexuality
• Myth of perpetual offender

(Black & Kammes, 2021; Cheak-Zamora et al., 2015; Esbensen et al., 2010; Holmes et al., 2016; Marsack et al., 2018)
Healthcare Consequences

Issues with basic hygiene, health maintenance, and health/reproductive advocacy

- 1 in 3 women with a disability do not have a usual healthcare provider
- 1 in 4 women with a disability did not have a routine check-up in the past year
- Overinvolvement of guardians/caregivers
- Unintended pregnancies

(CDC Disability and Health Promotion, 2020; Shapiro, 2018)
Amy

YA with ASD

Sensory issues related to giving birth and menstrual pain

Lack of access to healthcare

ASD and ID

Hysterectomy when 23 without her consent

Linda
# IPV/SV Statistics

<table>
<thead>
<tr>
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<th>General Population</th>
<th>Disability</th>
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<tr>
<td><strong>Sexual Violence</strong></td>
<td>20% of women</td>
<td>41.6%</td>
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<tr>
<td></td>
<td>2.6% of men</td>
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<tr>
<td><strong>Intimate Partner Violence</strong></td>
<td>25% of women</td>
<td>37.4%</td>
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<tr>
<td></td>
<td>10% of men</td>
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People with IDD 7x more likely to experience abuse, women 12x more likely

(CDC, 2020; Chirwa et al., 2020; RAINN, 2020; Shapiro, 2018)
Disability Specific Abuse and Consequences

- Use of diagnoses to create connection and manipulate
- Taking advantage of misreading social cues and sensory concerns
- One abuser manipulated a victim into staying in the relationship, stating “no one else would want her” because of her disability
- Using derogatory labels related to disability during arguments (e.g. “crazy” or “moron”)
- Amplified mental health symptoms following SV/IPV experience (e.g. depression, self-harm, suicidal thoughts)
- Feelings of physical and emotional isolation and mistrust of others—further abuse experiences
- Substance abuse/”negative behaviors” increased
- Overall health decline and physical injuries as component of SV/IPV experience

(Bonomi et al 2018a, b; Nichols et al 2018)
Language and Misunderstanding

Inability to discuss abuse experiences if you don’t have the terms

AAC users

Taylor

Maria

Abe

Clara
What Next

Policy changes in order to make it more accessible—in the meantime, community programs and parent training programs are key.

Change societal views of sex ed as the big bad monster.

Don’t have to know a lot about the topic, you just have to be open, honest, and willing to deal with a little discomfort.
Comprehensive Sex Ed
Romantic Relationships

Punished for intimate experiences
Loneliness
Sex as secretive
Abusive experiences
Focus on abuse prevention and not desire/positive experiences

A desire for intimacy
BUT
Restrictive programs/policies/family rules

A desire for friendships/peers
BUT
Others in control of their social lives

A desire for a sexual identity and experiences
BUT
Family/staff/society expectations place barriers

(Black & Kammes, 2019)
Comprehensive Sex Ed Topics

1. Biological & Reproductive
   - Anatomy/Physiology
   - Sex differences
   - Pregnancy
   - Birth Control

2. Health and Hygiene
   - Hygiene
   - Health and Wellness
   - Alcohol and Drug Use
   - STD/HIV Prevention
   - STD Epidemiology
   - Body and Disease

3. Relationships
   - Relationship/Social Skills
   - Responsibility to Partner
   - Family Types and Roles
   - Feelings and Expressions
   - Dating and Marriage
     - Parenting
     - Sexual Orientation

4. Self-Protection/Self-Advocacy
   - Protection against Abuse
     - Sexual Feelings
   - Sexuality as Positive Aspect of Self
   - Sexual Behavior other than Intercourse
   - Appropriate and Inappropriate Touching
     - Decision Making
     - Safe Sex Practices
   - Reduction of Fear and Myths
     - Personal Rights
     - Sexual Discrimination
   - Saying “no”—sex/drugs/alcohol
SHARE Curriculum Review

- Employment skills, social coaching, and sex education
- 18+, mostly ASD
- Small groups, small program
Curriculum Review

What are mutual friends? What category under relationships would they fall under?

Can you force a friendship to become a romantic relationship?

does sex need to be sexual in a relationship?

Are they gay/straight/other?

Does minster birth control (Pills) during oulation if how much does the woman temp go up?

Are there natural Condoms

Burning question: Why do girls like boys but not necessarily fall?

Is it right to date someone at least 10 years older/younger than you?

(Kammes et al., 2020)
3-Part SHARE

01
Sexual Health Education
- Anatomy & Physiology
- Health & Hygiene
- STI & Other Diseases
- Safe Sexual Practices

02
Intimate Relationships and Sexuality Expression
- Finding Potential Partners
- Long-Term & Short-Term Relationships
- Sexuality Expression
- Safety in Relationships

03
Dating & Relationships in the Real World
- Online Dating
- Community Outings
- Putting Knowledge into Practice
- Practical Knowledge
Tiered Models of Intervention

- Assessment is key
- Many different things fall under the umbrella of “sex ed”
- Need to think about knowledge and behaviors
- Healthy relationships are just as important

(Black & Kammes, 2021)
Systemic Sex Ed
Thinking Systemically
Let’s Talk About Parents

- Parent-initiated
- Supplemented sex ed in school
- Increased comfortability
- You don’t have to say and teach everything—you just have to do something

ROI Parent Groups

- 46% of articles
- 48% of articles
- 6% of articles
**STUDY 1**

- **Data Collection**
  - Parent Online Survey
    - n=50
    - Parent perceptions
    - Comparison of adult child experiences
  - Parent Phone Interview
    - n=20
    - Parent experiences
    - Follow up questions from survey

- **Analyses**
  - Descriptive Statistical Analysis
  - Group Comparisons
  - Qualitative thematic analysis

- **Findings**
  - Merge results for comparison
  - Interpret findings: convergence/divergence in findings

**STUDY 2**

- **Goals:**
  - Examine experiences with sex ed
  - Examine experiences of romantic relationships
  - Examine how systemic involvement is different for those with I/DD compared to their siblings and others

- **15 interviews**
- **Adults with I/DD and Autism**
- **Currently in romantic relationships**

**Mixing Data for Development**

**Mixing Data for Complementarity**
Parents: I/DD vs. TD

(Kammes et al., 2020)
What do Parents and Adults Say?

- Impact of Lack of Knowledge
  - Abuse Experiences
  - Inappropriate Behaviors
  - Parents as Main Educators

- Importance of Support Personnel
  - Independence
  - Caretaking
  - Coaching

- Discrimination
  - Marriage Inequality
  - Services in the Community
  - Out in the Community

- Everyday Issues
  - Transportation
  - Meeting People
  - Future of the Relationship
Notes about Including Systems

Always be thinking about WHO can get involved and at WHAT LEVELS

Recognize that adults with Autism desire romantic relationships, may need help to see that vision through

Always be aware of policy restrictions—may take multiple people to help
Remember...

Sexual Education

- Comprehensive
- Systemic
- All-inclusive topics
- Tiered Interventions

Who to Involve
In what ways
Policies

Developmentally Appropriate

Increase Health and Well-Being

Decrease Abuse/Exploitation

Better Interpersonal Relationships
Thinking Ahead

• Need to stop viewing sex ed as "scary"—it as an important and necessary component of health and well-being

• A lot of programs/organizations already work really hard on this issue—content is out there, need to increase access and to engage multiple parts of the system to enhance services

• Look in your area and find programs that exist—if there isn’t one think about making one—reach out to experts, local providers, and educate yourself
Thank You

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REFERENCES


