How to Talk About Sex: Questions of Adults with IDD About Sexuality

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Goal of this Presentation

To provide insight into the questions adults with IDD have regarding sexuality and intimate relationships after taking a 12-week sex education program.

To understand how these questions fit into the larger context of sex education and how they impact what we should be doing for adults with IDD.
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Couple and Family Therapist

Professional Experience with Adults with IDD and their Families:
Couples Therapy
Sex Therapy
Sex Education
What We Already Know About Intimate Relationships and IDD

- Intimate relationships and sexuality expression is a healthy component of adult life (Beckes & Coan, 2011; Moos, 2003; Robles, 2014)

- Adults with IDD are often restricted from having these experiences (Black & Kammes, in press; English, Tickle & dasNair, 2018; Fulford & Cobigo, 2018)

- Sex education often “skips” relationships, leaving this issue up to parents, caregivers, staff, and siblings to teach (Foley, 2012)

- High rates of abuse/exploitation within the population, and inappropriate relationships in adult programs (Hollomotz & The Speakup Committee, 2008; Stavis, 1991; Ward, Bosek & Trimble, 2010; Yacoub & Hall, 2008)

- Concern that adults with IDD are being denied the right to experience romantic relationships and sexuality expression (Richards, Miodrag, & Watson, 2006)
Research Questions

• After attending a sex education course, in what topics do adults with IDD still have gaps in knowledge?

• What are the specific questions that adults with IDD have regarding sexuality?
ASPPIRE: SHARE Program

• ASPPIRE is a program in Mid-Michigan for adults with disabilities aimed at issues related to social coaching (including employment skills and sex ed)

• All participants are aged 18-35 and have a mild/moderate ID

• Majority of participants have ASD

• Sexual Health and Relationship Education (SHARE)

• 12-week program

• Curriculum & materials developed by ASPPIRE founder based on previous experience teaching sex ed in special education classes
SHARE Curriculum

1. Introduction to Group
2. Anatomy & Reproductive Systems
3. Puberty, Sexual Health & Hygiene
4. Sex
5. Contraception, Birth Control & Pregnancy
6. Sexual Abuse, Exploitation & Law Enforcement
7. Types of Relationships
8. Stress & Anxiety in Relationships
9. Making Friends and Dating
10. Long-Term Relationships
11. Relationship Problems
12. End of Group Party
The Use of Notecard Questions

Throughout each session participants are offered the opportunity to write out questions they have regarding the topic on notecards and turn those in anonymously. Can also have group facilitator write out the question while they relay it verbally.

- Provides a check-in with participants
- Allows facilitators to ensure they are teaching what is most helpful
What are mutual friends? What category under relationships would they fall under?

Can you force a friendship to become a romantic relationship?

Does the mother get scratchy when giving birth by he baby?

Burning question

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

Does sex need to be central to a relationship?

Questions:

Is there any Guy Birth Control (pill)

During ovulation how much does the woman's temp go up?

Are there natural Condoms

Why do guys like boobs but not necessarily fat?
# Coding Categories

**Blanchett & Wolfe, 2002**

## 1. Biological & Reproductive
- Anatomy and physiology
- Gender differences
- Pregnancy
- Birth control

## 2. Health & Hygiene
- Hygiene
- Health and wellness
- Alcohol and drug use
- STD/HIV prevention
- STD epidemiology
- Body and disease

## 3. Relationships
- Relationships/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
- Use of condoms
- Reduction of fear and myths
- Personal rights
- Sexual discrimination
- Saying “no” to sex/drugs/alcohol/tobacco
Data Analysis & Interpretation

Using Coding Scheme

Independent Coder 1 Results

Independent Coder 2 Results

Independent Coder 3 Results

Merging and Interpreting Independent Results

Based on Quantitative and Qualitative Coding Results

2 Main Themes & 6 Subthemes

Presented to Stakeholders, then Merged with Initial Results

Stakeholder Feedback

Final Results & Implications
Initial Coding Results

Themes

- Relationship Experiences
  - Relationships Overall
  - Social Norms
  - Sexual Behaviors
  - Communication

- Sexual Health Knowledge
  - Health & Hygiene
  - Anatomy & Physiology
Stakeholders Involved in Feedback

- ASPPIRE EXECUTIVE DIRECTOR
- CREATOR OF THE SHARE PROGRAM
- 2 PROGRAM FACILITATORS
- 2 PREVIOUS SHARE PARTICIPANTS
### Stakeholder Feedback

<table>
<thead>
<tr>
<th>Most codes fall into the relationship category</th>
<th>Least codes in health and hygiene</th>
<th>New themes “social norms” &amp; “sexual bx”</th>
<th>New theme “communication”</th>
<th>Anatomy &amp; Physiology as areas of concern</th>
</tr>
</thead>
<tbody>
<tr>
<td>Most questions fall into relationship category because other categories covered better in sex ed courses or more focused on</td>
<td>Hygiene seems to be more addressed in session and it might be easier for participants to ask about in person so not as many cards about it</td>
<td>Issues with needing “black &amp; white” thinking but these aren’t really that way, so that’s why adults have so many questions about them One person’s idea—all of these ideas need to be broken up into “myths”, “norms”, and “laws” as a way of discussing them</td>
<td>Communication is super hard to discuss, as a facilitator doesn’t now how to bring it up other than talking about it as they ask questions Consent is easy as a topic but not so easy in practice</td>
<td>More tangible and concrete so easier to ask about SHARE teaches these first so there is probably more energy around this because of that</td>
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Results Category: Relationship Experiences
• The majority of codes fell into the “relationships” category

• Despite topic being discussed in group
  • Facilitators mentioned they often find themselves “rushing through” these sections of the SHARE curriculum
  • Not covered as much in sex ed courses because “hard topic to teach“ and most focus more on the anatomy/physiology

• Participants want to know about actual relationship experiences

“Does sex need to be central to a relationship?”

“Can you force a friendship to become a romantic relationship?”
Social Norms

• Themes that emerged across multiple codes

• Many participants asked questions regarding social norms and expectations within relationships and sexuality

“The joke is a man will last a minute. So actual sex is not like a porn video. Will my partner understand that?”

“What are the rules of texting?”
Sexual Behaviors

- Theme that emerged across codes
- Questions related to sexual behaviors outside of just intercourse
- Related to the theme of social norms

“Is sex addiction real?”

“Is it ok to masturbate while in a relationship?”
Communication

• Theme that emerged across codes

• Questions related to how to talk with others about sexuality

• Specific questions related to how to talk about sexual topics with a partner

“When do you know when it is a right time in a relationship to start have sex?”

“Consent v. non-consent with drinking”
Results Category: Sexual Health Knowledge
Health & Hygiene

Had the least amount of codes

Facilitator feedback indicates that these topics are well covered in the curriculum & are often easier to talk about

Participant feedback indicates that these topics are covered often throughout their lives and so they have less questions
Anatomy & Physiology

Still lots of codes for this, despite the SHARE curriculum covering this more extensively.

Feedback indicated these are easier topics to ask about because they are more concrete. Also, these topics have been covered before, so it may be easier for participants to know what questions they want to ask.

SHARE teaches this first, so facilitators indicated there may be more energy around this topic and asking questions.
Implications of The Study
Implications for Practice

• Sex education that is more applicable, focuses on developing healthy relationships or done within relationship context
• The social nature of relationships makes them a hard topic to teach
• Working more systematically with family/staff/others
• Sex ed needs to be more embedded within other adult programs (ex: vocational programs)
• Change our thinking and start thinking in terms of creating good relationship experiences
• Think about utilizing peers and staff in a different way
Implications for Research

• Importance of including the voices of adults with ID and hearing what they have to say

• Providing a way for individuals to discuss these topics that isn’t as direct so that it is easier for them

• Need to evaluate sex ed programs to ensure they are actually meeting the needs of the individuals they serve

• Need to further examine how sex ed for adults needs to be different from adolescents to be more meaningful and based on other adult issues (i.e. living situation)
Next Steps & Moving Forward
Future of the SHARE Program

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 Within Relationships

03  Dating & Relationships in the Real World
   • Online Dating
   • Community Outings
   • Putting Knowledge into Practice
   • Discussions of Practical Knowledge & Experience
**Research Next Steps**

- **Determine**
  - Determine best ways to train clinicians/facilitators on this topic

- **Understand**
  - Understand the role of parents and other caregivers to figure out how to best utilize that resource

- **Interview**
  - Interview adults with IDD to about methods of delivery of sex ed information
Thank You!


• Foley, S. (2012). The UN convention on the rights of persons with disabilities: A paradigm shift in the sexual empowerment of adults with down syndrome or more sound and fury signifying nothing? Sexuality and Disability, 30, 381-393.


