Sexual Education Curriculum for Youth with Autism Spectrum Disorders

November 2, 2018
Yael Granader, Ph.D.
Pediatric Neuropsychologist
The Stixrud Group

Outline

- What do we know about ASD and sexuality?
- How do we improve outcome?
  - Charting the Course
  - Model session
  - Does Charting the Course Work?
  - Questions?

WHAT DO WE KNOW ABOUT ASD AND SEXUALITY?

Background

- The majority of intervention research for ASD focuses on promoting independence and quality of life\(^1,2\)
  - NOT sexual education research
- Youth with ASD mature sexually on a typical trajectory\(^3\), but social cognition lags, impacting understanding of sexually appropriate behavior\(^4\)
- Social-communication challenges in ASD extend to sexuality, dating, and relationships\(^5\)

Challenges in ASD promote risk

- The risk of exploitation is higher than the general population\(^6\):
  - Difficulty recognizing dangerous situations
  - Struggles interpreting thoughts, feelings, intentions, and behavior of others
  - 78% of adults with ASD reported sexual victimization as compared to 47% of typically developing individuals\(^7\)
    - Females with ASD reported higher rates of adverse sexual experiences compared to males with ASD or their TD counterparts\(^8\)
  - Cognitive inflexibility prevents carrying over learned skills into new situations

Disclosure

- Nothing to disclose
What do we know about sexuality in ASD?

- Historically, individuals with ASD were thought of as asexual or disinterested in relationships, now we know:\[6,9,10:\]
  - Sexuality and relationships are an important part of autistic life
  - Many individuals with ASD have same levels of sexual interest as typically developing (TD) peers
- Only 7% of adults with ASD reported that they had no desire to be in a romantic relationship\[11\]

What do we know about sexuality in ASD?

- However, youth with ASD:
  - Have less sexual knowledge about STIs, contraception, and reproduction than TD peers\[7,12\]
  - Acquire sexual knowledge from non-social sources compared to TD peers\[7\]
  - Display more inappropriate sexual behaviors, such as undressing, masturbating in public, or touching strangers inappropriately\[13\]

Higher Incidence of Gender Variance and Varied Sexual Attraction

- Parents of youth with ASD 7 times as likely to report that their child expressed gender variance compared to TD peers\[14\]
- Females with ASD reported more variance in their sexual attraction compared to non-ASD females\[15\]
  - One study found similar findings in males\[14\]
  - Another study did not find these differences in males

Specialized Sexual Education

- Sexuality education needs of those with ASD are not being addressed by current educational frameworks\[10\] and there is explicit need for a specialized curriculum
  - Excel with concrete, difficulty with abstract\[19,20\]
  - Learning strengths in visual instruction

Specialized Sexual Education

- Tackling Teenage Training\[18\]
  - Clinic-based program
  - Preliminary study in The Netherlands found improvement in psychosexual knowledge in youth with ASD
  - Focus groups wanted a parent-delivered curriculum

How do youth with ASD learn about sex?

- Individuals with ASD demonstrate an overreliance on caregivers more than their typically developing peers for information related to sexuality\[16\]
- In reality, parents of youth with ASD have been found to struggle with how to teach these topics and tend to focus more on sexual abuse instead of sexual health in general\[17\]
HOW DO WE IMPROVE OUTCOMES?

Solving the Problem: The STAR Project

- DANYA International, with help from autism experts, created a parent-mediated, sexuality education program for youth with ASD without intellectual disability, entitled the Supporting Teens with Autism on Relationships (STAR)

- The STAR project includes:
  - Charting the Course: Curriculum for parents of youth with ASD
  - Boardwalk Adventure: Interactive computer game for youth with ASD

Charting the Course

- Teaches parents how to help their youth (9-18) with ASD develop appropriate social behaviors:
  - Private versus public sexual behavior dating
  - How to discuss sexual topics with peers
  - How to avoid exploitation
- Utilizes simple diagrams, worksheets, sample conversations between parent and their child, and common questions (with sample concrete answers) from teens

Boardwalk Adventure

- Not currently available for general public
- Players create a character and visit a boardwalk, where they play games to earn tickets to a concert
- Games revolve around puberty, personal hygiene, friendships and relationships, dating, and sexuality-related topics
Charting the Course: Chapters

- **Values:** beliefs, decision making
- **Puberty:** reproductive maturity, hygiene, emotional changes
- **Relationships:** friendships, attraction and interest in others, progressing relationships
- **Sexual Feelings and Behaviors:** masturbation, shared sexual behavior
- **Maintaining Sexual Health:** sex specific health, STIs, contraception, gender identity, sexual harassment

Charting the Course

- The purpose of this workshop is to give you information and resources to educate your child with ASD about sexuality and relationships.

- Charting the Course is a one-of-a-kind program which will give hands-on, detailed ways to approach topics about sexuality in a way that best fits your child.

- Some questions you may have:
  - Will talking about sexuality make my child more likely to have/want to have intercourse?
  - Will my child be able to have a serious relationship? Will he or she want to?
  - Do I need to teach my child about sexual intercourse?
EXAMPLE TOPICS FROM CHAPTER ONE

Private vs. Public Behaviors and Conversations

- Define public and private body parts
  - Wearing t-shirt and shorts is fine
  - Showing others your underwear or genitals is not acceptable

- Define private and public spaces
  - Be very specific (e.g., bedroom with door closed, bathroom at your home—not public restrooms)

Hygiene

- Hygiene is a responsibility and routine that keeps your body clean and healthy. It involves:
  - Smelling clean
  - Wearing clean clothes and socks
  - Washing your body and hair regularly
  - Brushing and flossing your teeth
  - Eating healthy
  - Sleeping well
  - Hygiene impacts relationships with others
  - You can help your child establish and personalize a hygiene routine

Private vs. Public Behaviors and Conversations

- Practice understanding of public and private in different situations
  - If you had an erection at school, is that something you would talk about during class? Who could you talk to about having an erection?
  - If you are having your period is that something you should bring up during class? Who could you bring it up to, how, and when?

ACTIVITY
EXAMPLE TOPICS FROM CHAPTER TWO

Relationships

- There are different types of friendships and everyone has qualities they prefer. Generally:
  - Share interests
  - Supporting and caring
  - Listens
  - Easy to talk to
  - Trustworthy
  - Respectful
  - Kind
  - Honest
Relationships

- Being a friend vs. acting friendly
  - In general, when someone is your friend they may:
    - Be happy to see you
    - Smile
    - Listen to you
    - Want to connect with you again (email, phone, meet in person)
  - When someone is acting friendly you may not know them very well (acquaintance, stranger)
    - Be polite, casual, avoid conversations about personal information
  - Not a friend, when someone:
    - Expects a bribe or gift to be friends
    - Teases relentlessly
    - Makes you feel uncomfortable

Shades of Friendship

One step that can be helpful in understanding friendships is to give categories to individuals your adolescent may encounter in life. Some resources use “relationship circles,” here, we’ll refer to them as “shades.” Understanding the Shades of Friendship that make up different friendship categories can give a more concrete understanding of friendships. As is most often the case, there are many shades of friendship in life, so your adolescent with ASD will need support and practice in deciphering where people might fit in his or her life.

Once able to recognize a person and practice associated behaviors and conversations that might match their shade, then your child is better equipped and more comfortable to interact with these friends.

<table>
<thead>
<tr>
<th>Friendship Shade: Stranger</th>
<th>Definition</th>
<th>Behavior(s)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Do not know this person</td>
<td>Do not know this person</td>
<td></td>
</tr>
<tr>
<td>Have never seen him before</td>
<td>Have never seen him before</td>
<td></td>
</tr>
<tr>
<td>May recognize him from the bus (for example)</td>
<td>May recognize him from the bus (for example)</td>
<td></td>
</tr>
<tr>
<td>Be polite, casual</td>
<td>Be polite, casual</td>
<td></td>
</tr>
<tr>
<td>Avoid conversations about personal information</td>
<td>Avoid conversations about personal information</td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Friendship Shade: Acquaintance</th>
<th>Definition</th>
<th>Behavior(s)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Have seen you before</td>
<td>Have seen you before</td>
<td></td>
</tr>
<tr>
<td>Not as well known</td>
<td>Not as well known</td>
<td></td>
</tr>
<tr>
<td>Be polite, casual</td>
<td>Be polite, casual</td>
<td></td>
</tr>
<tr>
<td>Avoid conversations about personal information</td>
<td>Avoid conversations about personal information</td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Friendship Shade: Casual Friend</th>
<th>Definition</th>
<th>Behavior(s)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Have seen you several times</td>
<td>Have seen you several times</td>
<td></td>
</tr>
<tr>
<td>Connection with you is more than casual</td>
<td>Connection with you is more than casual</td>
<td></td>
</tr>
<tr>
<td>Be polite, casual</td>
<td>Be polite, casual</td>
<td></td>
</tr>
<tr>
<td>Avoid conversations about personal information</td>
<td>Avoid conversations about personal information</td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Friendship Shade: Everyday Friend</th>
<th>Definition</th>
<th>Behavior(s)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Have seen you several times</td>
<td>Have seen you several times</td>
<td></td>
</tr>
<tr>
<td>Connection with you is strong</td>
<td>Connection with you is strong</td>
<td></td>
</tr>
<tr>
<td>Be polite, casual</td>
<td>Be polite, casual</td>
<td></td>
</tr>
<tr>
<td>Avoid conversations about personal information</td>
<td>Avoid conversations about personal information</td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Friendship Shade: Close Friend</th>
<th>Definition</th>
<th>Behavior(s)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Have seen you several times</td>
<td>Have seen you several times</td>
<td></td>
</tr>
<tr>
<td>Connection with you is strong</td>
<td>Connection with you is strong</td>
<td></td>
</tr>
<tr>
<td>Be polite, casual</td>
<td>Be polite, casual</td>
<td></td>
</tr>
<tr>
<td>Avoid conversations about personal information</td>
<td>Avoid conversations about personal information</td>
<td></td>
</tr>
</tbody>
</table>

Defining Shades of Relationships

As with friendship, or interest in others, your adolescent may or may not be ready or interested yet in dating or a romantic relationship. On the other hand, maybe he or she is already ready to get to know boys and girls in a way that they can fully understand the progression of more serious relationships. Whatever the case, understanding the progression of relationships, appropriate behaviors, conversations, and skills for each level is important.

Of course, your teenager does not have to date, or your family may have certain values as they relate to dating and relationships. Understanding relationship progression is one factor as deciding in another decision. You can support and prepare your teen, and he or she can use the information as long as they are ready.

A visual representation of progressing relationships (such as above) makes relationships seem linear or that they have a natural fluidity and progression. There are certainly elements that do reflect this, certain steps to follow, and ways to build relationships. At the same time, we know that relationships are not always linear, that you have an additional interest and start to casually date, you will not automatically be in a serious dating relationship. There will be changes and learning along the way. Helping your adolescent see that while understanding the basics of how relationships grow is important, yet, at the same time, there is no definite path to developing relationships, and it is not easy as following certain steps to have a happy, healthy relationship.
DOES THIS PROGRAM WORK?


Objectives

1. Will parents use Charting the Course and do parents and teens like it?

2. Do parents and teens who participated in Charting the Course improve their knowledge related to sexual health and development compared to a comparison intervention?

3. Does it make a difference whether the groups are self-guided or led by a facilitator?
Participants & Procedures

- 84 youth (68 males) with ASD and their parents
- Aged 9-18 (M=13.1, SD=2.1)
- Full scale IQ ≥ 80

- Three Study Groups:
  - Facilitator Led Charting the Course and Boardwalk Adventure programs
  - Self-Guided Charting the Course and Boardwalk Adventure programs
  - Comparison group, which received a self-guided drug abuse prevention intervention

Parent Measures of Interest

- Parent Knowledge:
  - Specific to Charting the Course curriculum, regarding sexual knowledge

- Parenting Self-Efficacy Scale:
  - “I can always explain: what is happening when a girl gets her period, why a person should use a condom, ways to have fun without sexual intercourse, wet dreams, birth control”

- Parenting Outcome Expectancy Scale:
  - “If I talk with my child about sex topics, I will feel: proud, responsible, did the right thing, embarrassed, ashamed”

Feasibility and Satisfaction

- Feasible to deliver
  - Clinicians could deliver the intervention in 6 sessions following a course outline and 2 phone training sessions

  - Parents reported liking the FL groups and appreciated the leader’s guidance in using the curriculum

  - Parents in both groups indicated overall strong acceptability of the Charting the Course curriculum
  - Youth with ASD commented that they were hesitant to complete the worksheets with their parents
  
  - Mixed feedback about Boardwalk Adventure game

Youth Measures of Interest

- Teen Knowledge:
  - Specific to Charting the Course curriculum, regarding sexual knowledge

- Social Self-Efficacy Scale:
  - self-efficacy with regard to friendships and romantic relationships: start a conversation with someone you don’t know well, find someone to spend recess with, stand up for yourself, express your feelings to another teen

- Video Vignette Skills Application Test:
  - Video clips from popular shows assessing social cognition

DID PARENT SKILLS IMPROVE?

- Sexual health knowledge
- Perceived self-efficacy
- Parent outcome expectancy
Did Parent Skills Improve?: Between-Group Changes

- Comparison of STAR groups (combined facilitator-led and self-guided groups) vs. Comparison group
  - STAR groups made greater gains in sexuality knowledge
  - No difference in parent self-efficacy
  - No difference in parent outcome expectancy

Did Parent Skills Improve?: Within-Group Changes

- STAR groups combined:
  - Significant improvements in:
    - Parent sexuality knowledge
    - Parent self-efficacy
    - Parent outcome expectancy
- Comparison group:
  - Significant improvements in:
    - Parent self-efficacy

DID TEEN SKILLS IMPROVE?
- Sexual health knowledge
- Self-efficacy
- Social understanding

Did Teen Skills Improve?: Between-Group Changes

- Comparison of STAR groups (combined facilitator-led and self-guided groups) vs. Comparison group
  - STAR groups made greater gains in sexuality knowledge
  - STAR groups made greater gains in youth social knowledge
  - No difference in youth self-efficacy

Did Teen Skills Improve: Within-Group Changes

- STAR groups combined:
  - Significant improvements in:
    - Teen sexuality knowledge
    - Teen social knowledge
- Comparison group:
  - No significant improvements on youth measures administered

Limitations

- Small sample size
- Overrepresentation of males
- Differences in age of youth across groups at baseline
- Lack of standardized measures regarding sexuality knowledge
- Variation in randomization
  - Facilitator-led groups were a sample of convenience (if had conflict with schedule could not join)
Conclusions

➤ Curriculum was feasible and acceptable
➤ Curriculum was equally effective with or without clinicians supporting parents
➤ No differences between facilitator-led and self-guided groups
➤ Less drop outs in facilitator-led groups, but not significant
➤ Parents and youth participants gave positive feedback about the program

References


References

14: Griffiths DM, Quinsey VL and Hingsburger D (1989) Sexuality in autism spectrum disorders and within-group analyses
17: Griffiths DM, Quinsey VL and Hingsburger D (1989) Sexuality in autism spectrum disorders

References
