Gaps, Barriers, and Recommendations for Improving Sexual and Reproductive Health of Individuals with Intellectual and Developmental Disabilities from the Perspectives of Healthcare Providers

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Background

- Adolescents with I/DD may be at increased risk of STIs and unwanted pregnancies due to…
  - Increased rates of sexual abuse
  - Difficulty identifying unsafe situations
  - Difficulty accessing adequate sexual health education

(Jones et al., 2012; Spencer et al., 2005; Sullivan & Knutson, 2000; Borawska-Charko et al., 2017; Barnard-Brak, Schmidt, Chesnut, Wei, & Richman, 2014)
Background

• Health providers play a **vital role** in providing a comprehensive sexual education to their adolescent clients.

(Marcell, Burstein, & Committee on Adolescence, 2017).
Purpose

- The purpose of the present study is to describe the factors that influenced health care providers’ decisions about type, amount, and format and provide recommendations to improve sexual health education for individuals with I/DD.
Methods

- Sub-analysis of a larger grounded theory study
- Instrumental case study design
Twelve healthcare providers participated in the study, representing the following professions:

- Physicians
- Nurses
- Social workers
- Behavioral health providers
- Rehabilitative therapists, such as occupational and physical therapists

9/12 were female.
Methods

• Semi-structured interviews
  • Face to face or over the phone
• Audio recordings transcribed
Data Analysis

- **Constant Comparative Method**

  - **Open Coding:**
    - 2 Study Personnel
    - 3 Transcripts

  - **Meeting to Determine Consensus**
    - First Draft of Coding Structure

  - **Open Coding:**
    - Updated Previous 3 Transcripts with Coding Structure
    - Same 2 Study Personnel
    - 3 New Transcripts

  - **Meeting to Determine Consensus**
    - Third Draft of Coding Structure

  - **Open Coding:**
    - Updated Previous 3 Transcripts with Coding Structure
    - Same 2 Study Personnel
    - 3 New Transcripts

  - **Meeting to Determine Consensus**
    - Final Draft of Coding Structure

  - **Open Coding:**
    - Updated Previous 3 Transcripts with Coding Structure
    - Same 2 Study Personnel
    - 3 New Transcripts

  - **Axial Coding**
    - Same 2 Study Personnel

  - **Selective Coding**
    - Third Study Personnel Advised
    - Hypotheses Determined
Trustworthiness

- Triangulation
- Audit Trail
- Checked for Representativeness
- Negative case analysis
Data analysis revealed two major themes, **Context and Characteristics**, that influence providers’ administration of sexual and reproductive health information to individuals with I/DD.

### Results: Gaps and Barriers

- **Context**
  - Client Initiated
  - Parent Education
  - Reactive Response

- **Characteristics**
  - Parent
  - General
  - Level of Understanding
  - Resources and Referrals

**Sexual health Education**
Focused on safety, varied significantly, and narrow in scope
“Because of the general questions I may ask them during therapy sessions, like ‘how is school going?’ And some of the older kids, they bring up boyfriends and girlfriends spontaneously. So, I kind of ask questions about that.”
"So, I try to make the inference that we need to teach them things that other (kids) would be learning at the same time, more so, so that they can do it safely. We don’t know what their hearing, we can’t control that, but if we can feed them the correct information that would be ideal."
“I think the most interaction I have with them is after there’s been an issue. So, I’m more a response team than proactive team.”
Characteristics: Parents

“I would say the number one barrier I’ve noted is the parents having the attitude that their child is not sexually active, kind of like it couldn’t be a possibility.”
“Occasionally religious concerns or concerns as to whether it’s okay to look at pornography or masturbate may come up. Those are really hard things to address regardless of who your population is because that’s really a personal decision, but they often look to the doctor to see if this is okay or if it isn’t (okay).”
Characteristics: Level of Understanding

“…Her parents were very open to discussing that they don’t feel like there’s been any sexual activity, but I have no way to explore (that) with the patient (or) what her knowledge is on what we’re talking about”
“Even in my training it wasn’t something that was really discussed, like how to go about having those conversations. So it’s kind of hard to start those conversations, but usually when you do it leads to other good discussions, but it’s opening it up for discussion that can be the hardest.”
Results: Topics

• Providers commonly discussed topics including:
  • Protection
  • Appropriate sexual behaviors
  • Safety
  • Relationships
Results: Recommendations

• For Providers:
  • Guided Conversations

• For Clients with I/DD:
  • Videos
  • Visuals

• Setting:
  • Individualized
Conclusions

• The providers’ approach had three related features:
  • Focused on safety
  • Varied significantly depending on the situation
  • Narrow in scope

• These results demonstrate the need for resources to improve comprehensive sexual health education for adolescents with I/DD.
Limitations

• Small sample size
• Convenience sampling
• Variations in professional roles
• Volunteer interest
Future Directions

• Additional research with larger samples is needed to determine the roles of each multidisciplinary provider during the provision of sexual health education for individuals with I/DD, as well as the most effective resources.
References Cont.


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