

# A Collaborative Approach to Improving Accessibility of Sexual Health Education for Individuals with Intellectual and Developmental Disabilities

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# Background

- Adolescents with intellectual and developmental disabilities, including those with Down Syndrome are at risk for:
  - Increased rates of sexual abuse
  - Difficulty identifying unsafe situations
  - Increased rates of sexually transmitted infections
  - Negative outcomes associated with pregnancy

(Jones et al., 2012; Spencer et al., 2005; Sullivan & Knutson, 2000; Borawska-Charko et al., 2017; Mandell et al., 2008; Parish et al., 2015)

# Background

- Most schools aren't covering sex ed!
- Little research has been done analyzing the effects of accessible sexual health education programs.
- Parents report discomfort discussing these topics with their children.
- Direct support providers report discomfort and lack of preparedness discussing these topics.

(Barnard-Brak, Schmidt, Chesnut, Wei, & Richman, 2014; Pownall et al., 2012; Wilson & Frawley, 2016; Saxe & Flannagan, 2016; Thompson, Stancliffe, Broom & Wilson, 2014)

# Purpose of this Study

- The purpose of this study was to improve the accessibility of sexual health education for individuals with intellectual and developmental disabilities (I/DD) ages 15-30 years.

# Methods

## Aim 1:

- Mixed-methods, grounded theory study design
  - Four key stakeholder groups
  - Focus groups and interviews
    - Constant comparative analysis
  - General Sexual Knowledge Questionnaire



# Methods

## Aim 2:

- Developed interactive learning activities based on the recommendations and gaps identified in Aim 1
- Tested the usability, usefulness, and desirability of each activity
- Assessed sexual health knowledge for each topic before and after using SocioSexual Knowledge and Attitudes Assessment Tool Revised (SSKAAT-R)

# Methods

- Aim 3
  - Tested the feasibility of a five-week, biweekly, community-based sexual health education program
    - Recruitment rates
    - Retention rates
    - Attendance rates
    - Assessment completion rates
    - Adherence to treatment protocol
    - Satisfaction

# Results

- Aim 1:
  - Participants recommended using a proactive and formal education provided by multiple stakeholders and that learning should be continued.





# Results

- Barriers:
  - Parental characteristics
  - General characteristics
  - Embarrassment
  - Limited organizational policies and/or standards
  - Limited professional education for providers and educators.
- Gaps:
  - Pregnancy, reproduction and family planning (42% average)
  - Contraception (37.5% average)
  - Safety (45.3% average)
- Recommended:
  - Videos
  - Visuals
  - Universal design for learning
  - Direct, explicit instruction



# Results

- Aim 2:

- Usability of activities:

- Gender unicorn (76%)
    - Virtual reality script (75%)
    - Identity video (66%)
    - Anatomy video (89%)
    - STI infographic (85%)
    - Family planning video (63%)
    - Dating video (75%)

- Revisions:

- Contraceptives infographic (56%) was refined (97%)
    - Puberty visuals (46%) was refined (94%)



# Results

- Aim 3:
  - Recruitment rates (90%)
  - Retention rates (77.8%)
  - Attendance rates (98.2%)
  - Data collection procedures:
    - Pretest (86%)
    - Posttest (100%)



# Results

- Aim 3:
  - Adherence to treatment protocol:
    - Review/reminders (5-10 minutes) = 53%
    - Content (30-50 minutes) = 67%
    - Interactive learning activities (15-25 minutes) = 47%
    - Question & Answers (5-10 minutes) = 27%
  - Data suggests that changes are needed to the current treatment protocol to improve feasibility.
    - More time for sharing!

# Updated Schedule

<b>Consent</b>	<b>Day 0</b>	<b>30 mins</b>	<b>Review capacity to consent questions and consent, assent, or parent permission documents.</b>
<b>Week 1</b>	Day 1	2 hours	Intro/Assessments
	Day 2	90 mins	Effective Communication & Relationships (friendships, familial and introduction to intimate relationships)
<b>Week 2</b>	Day 3	90 mins	Healthy Relationships, Boundaries, and Decision-Making (introduce sexual decision-making and consent)
	Day 4	90 mins	Anatomy and Physiology and Puberty and Adolescent Development
<b>Week 3</b>	Day 5	90 mins	Gender Identity and Sexual Orientation
	Day 6	90 mins	Gender Identity and Sexual Orientation continued and Sexual Activities (re-incorporating sexual decision-making and consent)
<b>Week 4</b>	Day 7	90 mins	Pregnancy, Reproduction, and Parenting
	Day 8	90 mins	Protection – Contraception, STDs, and HIV/AIDS
<b>Week 5</b>	Day 9	90 mins	Safety (identifying abuse and reporting abuse), local resources.
	Day 10	2 hours	Review, final assessment and party

# Satisfaction

- Overall, participants were satisfied!
  - There weren't consistent favorite or least favorite activities or topics identified among participants.
  - They felt their questions were **answered (85.7%) & heard (85.7%)**.
  - They were **comfortable** with the instructors (85.7%).
  - Most participants felt they would **recommend** this group to a friend (85.7%), would take the group **again** (71.4%) or would like to **continue learning** about sexual health (71.4%).

# Implications

- How will this impact families of children with Down syndrome?
  - **Community-based sexual health education programs are feasible!**
  - Gains in knowledge were noted in recognized gap areas, including:
    - Pregnancy, reproduction and family planning (3 point improvement)
    - Contraception (7.6 point improvement)
    - Safety (8.9 point improvement)
  - Identified a need to **separate groups based on sexual health knowledge**
  - Identified a need to **include parents or caregivers** throughout (i.e. parent handouts or parent education component)

# Implications

## Research:

- Develop and test the effects of **resources for parents, educators, and health providers** to support individuals with I/DD, including Down Syndrome.
- **Learning activities** should be tested further among a larger, more diverse sample.
- **Larger, pilot RCTs** needed to confirm effects of accessible sexual health education programs.



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**Thank you!**

