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

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Acknowledgements: Sarah Anderson, Eugene Scanlan, Anna Murray, Richard Neff, ShopWorks Theater Company

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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

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

Thank you!