Symposium Title: A Mixed Methods Study to Develop Accessible Sexual Health Education Learning Activities for Adolescents and Young Adults with Intellectual and Developmental Disabilities

Authors: Elizabeth K. Schmidt, MOT, OTR/L, Natalie Robek, BS, Megan Dougherty, BS, Bree Host, Carolyn Sommerich, M.S., BMSE. Ph.D., Brittany Hand, MOT, OTR/L, Ph.D., Susan Havercamp, Ph.D., Lindy Weaver, MOT, OTR/L, Ph.D., Amy Darragh, Ph.D., OTR/L, FAOTA

Introduction: Adolescents and young adults (AYA) with intellectual and developmental disabilities (I/DD) are at increased risk for experiencing sexual abuse (Jones et al., 2012) and are at increased risk for sexually transmitted infections (Mandell et al., 2008), indicating a significant need for an accessible sexual health education (SHE) for AYA with I/DD. The purpose of this study was to address gaps and barriers present in SHE for AYA with I/DD using a user-centered approach. To this end, this study: 1) identified the gaps, barriers, and recommendations for SHE as described by AYA with I/DD, parents, health providers, and educators; 2) developed activities to address the identified gaps and barriers; and 3) tested the usability of these activities for a modified SHE program.

Methods: A mixed-methods, grounded theory study design with four stakeholder groups (AYA with I/DD, parents, health providers, and educators) was utilized in conjunction with the General Sexual Knowledge Questionnaire for AYA with I/DD to identify gaps, barriers, and recommendations for SHE. Focus groups and interviews were analyzed using a constant comparative method to identify gaps and barriers in SHE and a thematic analysis was used to identify recommendations for SHE. Educational activities that were recommended to improve understanding of sexual health information for AYA with I/DD were developed and/or sourced from available materials. Iterative usability testing with AYA with I/DD and educators confirmed the usability, usefulness, and desirability of each activity using a pre-established set of criteria. Further, the SocioSexual Knowledge and Attitudes Assessment Tool-Revised was used to assess learning after engaging with each activity.

Results: Participants in the mixed methods study (n=37) reported barriers to SHE such as (1) parental characteristics, (2) general characteristics, (3) embarrassment, (4) limited organizational policies and/or standards and (5) limited professional education for providers and educators. Gaps in knowledge included pregnancy, reproduction, and family planning (average score = 42%), contraception (average score = 37.5%), and sexually transmitted infections (average score = 45.3%). Participants recommended using a proactive and formal education provided by multiple stakeholders and that learning should be continued. They reported videos, visuals, universal design for learning, and direct, explicit instruction as the best learning modalities. Educational activities were developed or sourced from available resources based on these results. The following activities were found usable by individuals with I/DD (n=7) and educators (n=2): gender unicorn (76%), virtual reality script (75%), identity video (66%), anatomy video (89%), STI infographic (85%), family planning video (63%), and dating video (75%) acceptable. The contraceptives infographic (56%) and puberty visuals (46%) were refined and reevaluated in a fourth iteration, where they were deemed acceptable (97% and 94% respectively).

Discussion: The findings suggest that parental and general characteristics, embarrassment, a lack of organizational policies and/or standards and limited professional education opportunities were preventing access to SHE for AYA with I/DD. The identified barriers have significant implications for future programs and policies. Future research should focus on developing and testing the effects of resources for parents, educators, and health providers to support AYA with I/DD. Furthermore, this study found that AYA with I/DD were lacking information on pregnancy, reproduction, and family planning, contraception and sexually transmitted infections. Activities were sourced or created to aide AYA with I/DD in understanding these topics and were found to be accessible to this population. These resources should be tested further among a larger, more diverse sample to confirm its generalizability and use within a SHE program.
References/Citations:
