

AUCD Sexual Health Special Interest Group (SIG)
Tuesday April 23, 2019
Meeting Notes

Attendees:

Tara Lutz
Jennie Todd
Courtney Lanham
Elizabeth Walling
Rosemary Hughes
Nick
Liza Stack

MaryBeth Szydowski
Katherine McLaughlin
Tanisha Clarke
Lindsay Sauve
Lindsey Mullis
Julie Atkinson

Event and Activities for 2019

- A. Webinar series: "Sex Talk for Self-Advocates" continues. #5 Birth Control recording at: https://www.aucd.org/template/event.cfm?event_id=8555&id=740&parent=740
- B. Webinar on the importance of sexual health for people with IDD
Joe Shaprio from NPR and Barbara Thomas from the TALL Institute. Recording at: https://www.aucd.org/template/event.cfm?event_id=8549&id=975&parent=975

Discussion

- A. Standardized measurements for sexual health and disability:
 - Rosemary Hughes shared that measures for assessing abuse awareness and knowledge are non-existent and for Safety Project had to create measures with low reliability. This is a huge challenge.
 - MaryBeth asked clarification question about what is meant by a standardized measurement - are we talking about standards like certain skills by particular age or tools for measurement that are valid and tested on large enough sample size. Both are lacking. There are no parallel for students with disabilities for sex ed standards in schools.
 - Lindsay Sauve - has looked at the sex education protocol tool (Wolfe and Blanchett) for standards for sex education curricula for people with IDD. Not currently on this area but Lindsay willing to do a work group in this area.
 - Katherine McLaughlin – National standards for sex education in schools are not a good fit for students/individuals with IDD. Evidence-Based Interventions (EBI) are wanted by folks and becoming a funding challenge
 - MaryBeth – EBI vs evidence-informed, there is confusion on the definitions what meets the requirements for state laws, which tend to be vague.
 - Liza Stack (from chat) - Right now there is just so little out there to meet the needs of some of our students with the most significant needs. We are doing our best to align with the California Healthy Youth Act requirement that also addresses the developmental level of our students. We do use instructional evidence-based practices for instruction, such as visual supports and task analyses, and other methods that have been identified to support student

learning. We are in the process of developing pre- and post- tests that we can use with our students based on the content we are providing

- Lindsay and Katherine - Idea to bring developers for FLASH to the conversation as they are working to identify accessibility and content improvements. Katherine met one of the authors and said they were looking ahead in the future to review the special ed curriculum.
- Rosemary talked about measurement adaptations to surveys using images, likert scales with images, and hotlinks for more difficult concept definitions. Changed some of the wording as long as the content of the questions weren't altered. Offered to share the article about this process (attached to email). There is lots we can do to existing instruments without altering the underlying meaning.

B. AUCD presentation proposals

- Sexual health SIG and Abuse and Neglect SIG working on a proposal about positive solutions for abuse prevention and sexual health education.
- Elizabeth – West Virginia is working on proposal about sexual health training for parents and caregivers
- Lindsay Sauve – working on a poster with intern doing support group work for youth with IDD. Transition age 16-21.
- Rosemary Hughes – measurement proposal – how to adapt measure for IDD populations
- Tara Lutz – Proposal about a needs assessment for teachers
- Katherine McLaughlin – thinking about ideas, possibly the role of social media on relationships
- You do not have to be within the AUCD network to present. All proposals are welcome.

C. Family trainings on sexual health

- Elizabeth and Courtney Lanham – WV looking into creating training resource for parents and families. Want to recognize milestones. What questions are being asked by individuals with IDD? Resources on how to respond, how to talk with children and adults with IDD when they have questions.
- MaryBeth – Parent resources can be found at CDC website – protective factors, OWL series, amaze.org – youtube videos for 10-14yo and younger, subject starters. amaze.org, https://www.youtube.com/watch?v=Z0l2KrS_v2k
- Lindsay S. - <http://sproutflix.org/>
- In North Carolina parents are becoming educators, they are the experts on their children, how they learn, what they need.

D. Sharepoint for resources

- The SIG wants to have a centralized place for resources

- Google vs. Dropbox or Box – some institutions have accounts to Box or Dropbox, but these may be hard to access outside of the institution or have limited storage. Google may be a better option.
- Lindsey and Julie to follow up with Tanisha about other options.

Open Discussion

A. Comments and concerns

- Lindsey M. doing a workshop for special education teachers on sexual health. Looking for resources – please share with her if you have any.
- Liza - Next group is deaf and hard of hearing with lack of communication resources that include this topic area. If you know of resources please share. Julie is following up on communication boards related to sexual health and will share resources.

Next Meeting - Doodle Poll: <https://doodle.com/poll/ws3py6x79zsrevh2>