

AUCD Sexual Health Special Interest Group (SIG)

Wednesday January 9, 2019

Attendees with Contact Info

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16. Jill Harris
17. Marth Beth Szydlowski
18. Marianne
19. Chelsea

Overview

- A. New listserv directions
 - a. Active member can send emails to listserv by addressing emails to:
aucd_sh@lists.aucd.org
 - b. Responses go to everyone regardless of where you select “reply” or “reply all”
 - c. If you want to only respond to the sender, forward the message to the sender

2019 Events and Activities

- A. Webinar series: “Sex Talk for Self-Advocates” continuation
 - a. Next webinar on February 13th @ 2pm EST on Relationship Experiences – our educators will be joined by five self-advocates talking about their relationships
 - b. Register here: https://www.aucd.org/template/event.cfm?event_id=8445
 - c. Share this opportunity within your state
- B. Webinar on the importance of sexual health for people with IDD - Joe Shaprio from NPR and Barbara Thomas from the TALL Institute
 - a. Save the Date! **Tuesday April 30th @ 2:00 EST**
- C. Webinar with Rosemary Hughes as a follow up from the Nov. meeting on the Safety Project
 - a. Working on a date, TBD

Sexual Health SIG Future Directions – open discussion

- A. Many are challenged by the lack of funding for sexual health efforts. Some have used the following sources to fund work:

- a. Core
 - b. Charging participants of trainings small fees (\$5) - MariAnne mentioned no formal funding although recently asked to do parent training and partnering with local agency willing to partner with Project Search to cover staff time for training. Resulted in a small fee for participants to cover travel time not work time. So goal moving forward is to charge agency fee.
 - c. Internal institutional funding opportunities – Annie Woodruff received funding through a grant process internal to our institute – Lindsey also commented on internal funding available at Kentucky UCEDD
 - d. Volunteer time - Staci Carr shared trainings done for parents and Project SEARCH interns are done as a volunteer. I look forward to more funding to target research and usefulness of trainings and curricula that are implemented
 - e. Governors council grants – Jennie Todd shared they have just started a 2 year grant with the Indiana Governor's Council to research and then develop a sexual education training for women with disabilities and their partners.
 - f. Interdisciplinary partnerships (OT)
 - g. Federal institutions like National Institute on Disability, Independent Living, and Rehabilitation Research (NIDILRR) or Office on Violence Against Women (OVW) or CDC cooperative agreement with AUCD
- B. Discussion of sexual health education legislation in some states.
- a. There are few resources for sex ed teachers on sexual health for students with IDD.
 - b. Staci Carr (VCU) mentioned legislation in her state was looking to add sex ed to the IEP for students. Students are currently not included in sexual health opportunities.
 - c. Theresa parks from Illinois mentioned legislation they are pursuing to require sex ed for adults receiving funding from dept of adults and human services and agreed that parents have been biggest push back but also from providers questioning about training development and holding stakeholder meetings statewide. Self-advocates in state have really supported and given a voice to the issue to indicate the need for this education in these kinds of settings.
- C. Linda Sandman (IL) has been partnering with OT on a project specific to sexual health and Down Syndrome – potential webinar on project and to how utilize interdisciplinary partnerships.
- D. Assessments and tools on sexual health, abuse, victimization are lacking and needed. Concern with lack of standardized measurement for evaluation which also affects securing grant funding. Need to focus on the development of sexual health tools that are validated.
- E. Stigma still exists around this topic, how to help get information out to our states when there is hesitation to share sexual health information. Peggy Helm-Quest noted the importance of this and how we can really put this out there that the stigma of

even posting or relating that this is available can be better remedied. For example, sharing the self-advocate webinar, several partners were hesitant to share as a resource. Even public health professionals felt uncomfortable with the topic so need to focus on addressing the assumptions and stigma.

- a. Upcoming webinar on sexual health should help to address this concern
 - b. Developing partnerships is a way to help educate and reduce stigma
 - c. Training providers who are uncomfortable
- F. How do we share resources across the SIG? Discussion narrowed on the use of a sharepoint where research, contact information for SIG members, literature, funding opportunities could accessed by members. This could also include a platform for open conversations among members.
- a. Mentoring group – are members of the SIG willing to offer TA to others?
Potential through the sharepoint.

Next Meeting: April date and time to be determined

Please complete this Doodle Poll: <https://doodle.com/poll/3cnqp4685qrybtv2>

Please note the time zone when completing your poll. This is set for our usual 2:00 EST

Action Steps

- A. Look into share point options
- B. Send doodle poll for April quarterly meeting
- C. Schedule informal discussion meetings for members to share what they are doing
- D. Have Joe and Barbara address concerns and strategies around stigma