**Symposium Title:** Healthy Sexuality, Abuse and Exploitation, and Sex Education Among Individuals with Intellectual Disabilities

**Chair:** Rebecca Kammes

**Discussant:** Marisa Fisher

**Overview:** Individuals with intellectual disabilities (ID) are considered a vulnerable and at-risk population when it comes to sexual abuse and exploitation. It was recently found through U.S. Department of Justice data that adults with ID are seven times more likely to be victims of abuse than their typically developing (TD) peers (Shapiro, 2018). Sexual health and healthy relationship education are considered major components of preventing abuse and exploitation (Coyle, 2016). However, despite increased vocational and adaptive behavior programs aimed at expanding previously unmastered skills, there is still a distinct lack of sexual health education for adults with ID (Chrastina & Vecerova, 2018). One of the reasons behind this is that stakeholders (e.g. parents, educators, therapists) often believe that other stakeholders should be responsible for teaching sex education (Nichols & Blakeley-Smith, 2009). This often leads to stakeholders waiting for others to educate the individual with ID, leaving that individual with large gaps in knowledge. Often times, sex education is not covered until there is an issue with sexual behavior or the individual is in a situation in which their lack of knowledge becomes apparent (Holmes, et al., 2016). Because of these issues with gaps in knowledge and lack of programming, it is important to continue working with individuals with ID and their families to determine areas of need (Frawley & Bigby, 2014) and to continue implementing programs in high-need areas. The four presentations in this symposium will address concerns related to sexuality education and abuse prevention for adults with ID. The first presentation will provide information from a systematic literature review regarding abuse/exploitation among adults with disabilities who also have communication challenges and discuss how this adds another layer of vulnerability to this population. The second presentation will provide insight into special education teachers’ views on topics and methods that should be included in sex education for students. The third presentation will provide insight into the role that parents play in the sex education of their child with an ID and how this contrasts with their role with their TD children. The final presentation will present the outcomes of a community-engaged research project in which adults with ID and other community members engaged in the choosing and implementation of a sex education program specifically aimed at healthy sexuality and relationships. Collectively, these presentations will highlight the importance of understanding the impact of multiple systems and factors on sexual abuse and exploitation among individuals with ID, and to continuing adapting sex education for these individuals in order to meet these needs.

**References**


**Paper Title:** Abuse Amongst Individuals with Significant Disabilities and Complex Communication Needs

**Authors:** Sarah Monaco
**Introduction:** Limited research exists on abuse (physical, sexual, verbal/emotional, mental/psychological, financial/economic, and cultural/identity) amongst individuals with developmental disabilities who use Augmentative and Alternative Communication (AAC), despite the urgent need. Some studies have found that over 70% of people with disabilities reported they had been victims of abuse (Baladerian, Coleman, & Stream, 2013). Restricted access to vocabulary (Baladerian, 1991) and lack of communicative competency (Isaacs, Ericson, & Perlman, 1994) are barriers to detection and disclosure of abuse by individuals who use AAC (Collier, McGhie-Richmond, Odette, & Pyne, 2006). This study aimed to extend the literature on abuse amongst this population by providing a systematic review.

**Methods:** A systematic electronic search of several databases was conducted, including the Educational Research Information Center (ERIC), PsychINFO, PsychARTICLES, and ProQuest. Combinations of the following keywords used included: Augmentative and Alternative Communication/AAC, intellectual disabilities, developmental disabilities, significant disabilities, physical abuse, sexual abuse, verbal abuse, emotional abuse, mental abuse, psychological abuse, financial abuse, economic abuse, cultural abuse, and identity abuse. An ancestral search was also conducted.

**Results:** The bulk of the research conducted on abuse amongst individuals with developmental disabilities focuses on physical abuse and sexual abuse. Children with disabilities were 3.79 times more likely to be physically abused than children without disabilities, and significantly more girls than boys were victims of sexual abuse (Sullivan & Knutson, 2000). Mental/psychological, financial/economic, and cultural/identity abuse were often overlooked. Only three studies specifically included individuals who use AAC.

**Discussion:** The results of this review showed the urgent need for more research in this area. While the statistics on abuse amongst individuals with developmental disabilities are staggering, this population is largely excluded from sexual education programs in schools across the country. Many of the participants in one study (Collier et al., 2006) reported that they did not receive sex education from their parents, schools, or healthcare providers. Traditional sex education programs frequently include information on identifying and reporting different types of abuse. The exclusion of this population in these classes contributes to their marginalization.

**References/Citations:**
where cultural and attitudinal variables may affect what is taught to vulnerable populations (Yucesan & Alkaya, 2017). This study surveyed teachers’ perceptions about sexuality education content for individuals with mild and severe disabilities in the United States and Turkey. The study sought to identify what content teachers thought should be included in curricula, whether that content varied by severity of disabilities, and if there were differences in content between teachers in the US and Turkey.

Methods: A survey was developed to assess the relative importance of sexuality education content based on national standards developed in the US. The Sex Education Content Questionnaire contained 8 topic areas as well as 55 subtopics subsumed under each topic. Respondents were asked to indicate whether a content area should be included in a sex education curriculum for students with DD for individuals with either mild or severe disabilities. One hundred and sixty-three special education teachers participated in this study. The Turkish sample included 84 participants (65 female, 19 male); the US sample included 79 participants (67 female, 12 male). An analysis of variance (ANOVA) was completed for between-group comparisons of each subtopic as well as overall mean score to explore differences between Turkish and American participants on each item. In addition, the influence of participants’ characteristics was tested via ANOVA analyses using an alpha coefficient of .05 for comparison between two participant groups.

Results: Special education teachers’ responses revealed that the teachers from US (M = .828, SD = .295) had more positive perceptions than teachers from Turkey (M = .544, SD = .415) overall. Responses also revealed significant differences and more positive perceptions for teachers from US in every topic of the questionnaire and under both categories of high functioning and low functioning individuals with disabilities. Subtopics related to internal facts and functions were identified as not needed for students with more significant disabilities (e.g., “Understanding the internal female reproductive organs functions and ovulation”; understanding the internal male reproductive organs functions” and “fertilization/ reproduction/ how pregnancy occurs”). The majority of all participants from both countries thought that safety skills be taught to both groups of students with DD (e.g., Distinguishing private from public; Avoiding coercion). Some subtopics were rated as not necessary for students with mild or severe disabilities in the US. (e.g., consequences of abortion). This subtopic was not included in the Turkish sample because abortion is illegal in the country.

Discussion: The results of the survey serve to explore the following: a) what content should be included in a comprehensive sex education curriculum; b) whether some subtopics should vary based on level of disability (ethical, quality of life issues, predisposed assumptions); c) whether subtopic content can be adequately adapted for individuals with more severe disabilities; and d) whether curriculum in other countries should/can be modified to meet the needs of students of different cultures. The results lead to pointed discussion related to what, if any, sexual education should be afforded to individuals with DD and who has the ability and right to decide this.

References:
- Sexuality Information and Education Council of the United States (SIECUS). Washington, DC. Author.
information from parents can lead to secretive explorations which are often inappropriate (Hollomotz & The Speakup Committee, 2008). Adults with ID experience higher rates of sexual abuse and exploitation, exacerbated by the lack of knowledge they have regarding healthy sexuality (Bernert & Ogletree, 2013). Because of the significant role of parents, there is a distinct need to further understand how parents view their role in the continued sexuality education of their adult with ID.

Methods: This study used a convergent mixed methods design that included an online survey of 50 parents (46 mothers, 4 fathers) who had both an adult children with ID and a typically developing (TD) adult child. A subset of 20 parents (19 mothers, 1 father) taken from parents who completed the survey were then interviewed using phone or video conferencing methods. Both the online survey and interviews were created to ask parents to compare their opinions, experiences, and perceived roles in the sexuality education of their adult child with an ID to that of their TD adult child.

Results: The results from this study fell into two main themes with 8 subthemes. The first theme is the parental role in sex education. This included the subthemes of overall poor education in school for both children, parents as the best sex educators for their adult with ID, distinct differences in teaching sex education to adults with ID compared to TD adults. The second theme is the parental role in sexuality expression. This included the subthemes of differences in sexuality practices between the two adult children, barriers to sexual experiences for the adult with ID, the role of parental monitoring, the intersection of caretaking and sexual behaviors, and parents distinctly blocking sexuality experiences for adults with ID.

Discussion: The findings of this study demonstrate that due to poor in-school sexuality education and the important role of the parent in the lives of adults with ID, parents feel they are their child’s best sexuality educator. Findings also highlight that parents play a more significant role in monitoring and management of sexuality expression for adults with ID compared to TD adults. The findings of this study emphasize the role of negative stigma and safety concerns and how that influences parent perceptions of the sexual development of their adult with ID. Parents struggle with feeling unprepared for their role as the primary sex educator for their child with ID, despite the knowledge that it will fall to them. They also must step out of their comfort zone to fulfill this role. Parents need and desire coaching and guidance on how to best educate their child on sexuality and intimate relationship experiences.

References

Paper 4 of 4

Paper Title: Community-Engaged Research on Healthy Relationships for Adults with Intellectual and Developmental Disabilities in Hawaii

Authors: Rhonda Black⁴, Rebecca Kammes¹
**Introduction:** Socio-sexual knowledge and attitudes affect socialization of people with intellectual and developmental disabilities (PWIDD) and their ability to form meaningful relationships (Galea, Butler, Iacono, & Leighton, 2004). Much of the professional literature is focused on the problematic aspects of sexuality, such as sexual abuse, sexually transmitted diseases, and inappropriate sexual behaviors (Siebelink, deJong, Taal, & Roelvink, 2006). There is a body of literature that reports sexuality interventions that aim to reduce this kind of risk (Egemo-Helm et al., 2007). However, it should also be a high priority to move beyond abuse prevention in these interventions and assist PWIDD in developing skills that contribute to effective communication, problem-solving and making and maintaining healthy relationships (Frawley & Bigby, 2014). PWIDD and those who work closely with them should also be directly involved in the choosing and implementing of these interventions in their communities, as they are the ones most directly impacted (Frawley & Bigby, 2014).

**Methods:** This project used a community-engaged research model to determine and implement a relationship education program that was specifically applicable and impactful to the community of Hawaii PWIDD. The Hawaii Department of Health (DOH) contacted the researcher about providing education regarding sexuality and healthy relationships for PWIDD and staff who work with these adults. Using the iPERCED model for engaged teaching and learning (Commuter Affairs and Community Service, 1999), an investigative stakeholder meeting was conducted designed to identify the specific concerns of the population. From these meetings it was determined that several adults service agencies would participate in the program, and which program to implement based on community need. The Friendships and Dating Program (FDP) was the curriculum used for implementation. The FDP is an intervention aimed at helping PWIDD develop skills related to maintaining healthy relationships, as opposed to only abuse prevention (Ward, Atkinson, Smith & Windsor, 2013). The researcher provided healthy relationship instruction in a train-the-trainer model where agency staff observed and assisted. Twenty-four participants with IDD from three separate community agencies were involved in the program. Following implementation the researcher conducted engaged feedback and evaluation with all those involved in the project (Commuter Affairs and Community Service, 1999).

**Results:** Quantitative results for 19 participants indicated an average decrease of 1.21 incidents of interpersonal violence which was a statistically significant difference ($p = .036$). Baseline $M = 2.32$, $SD = 3.20$; Post-test $M = 1.11$, $SD = 1.94$. Social Network Assessment data for 22 participants indicated an increase of 0.5 people *other than staff and family*, a statistically significant difference ($p = .038$). Baseline $M = 1.68$, $SD = 1.84$; Post-test $M = 2.18$, $SD = 2.36$. Qualitative data indicated that as a result of the lessons, participants demonstrated more assertiveness, especially in saying no, and telling their peers when their personal space boundaries were violated. Participants also engaged in more appropriate hugs following FDP implementation. Difficulties with the program included: (a) not being sure that the participants with less developed verbal skills fully understood the content, (b) getting agency staff to collect data, (c) getting programs to take ownership and continue implementation, and (d) the measures that accompanied the curricula were not very sensitive to knowledge or behavioral performance gains.

**Discussion:** Getting buy-in from state-level and agency administrators, parents, case managers and direct support staff was essential to addressing the community need. Although all parties agreed that the topic was important, devoting time and resources to addressing the need proved more difficult. It is important to not only train direct support staff to implement such a program, but to also plan for it becoming part of what they do on a regular basis. The train-the-trainer model was important to the Hawaiian community, due to the current lack of services on this topic and the distance between potential services providers in Hawaii. It is also important for all stakeholders to commit to ongoing professional development and support to address community needs. Those working with and for PWIDD must continue direct instruction and provide ongoing opportunities for practice and engagement to enact long-term change. PWIDD directly benefit from members in the community coming together and working to support their needs.

**References:**


1Michigan State University
2The College of New Jersey
3Penn State University
4The University of Hawaii—Manoa