

Supporting the Sexual Health of College Students with IDD: A Call for Trainings for Inclusive Postsecondary Education Program Staff

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The purpose of this study was to examine the sexual health needs, beliefs, and access to resources for support staff of students with intellectual and/or developmental disabilities (IDD) in an inclusive postsecondary education (IPSE) program. Sixteen support staff from an IPSE program in the Southeast United States were recruited. Online surveys containing open-ended and Likert scale items were administered. Staff reported that students had limited sexual health knowledge. Students and staff commonly felt uncomfortable discussing sexual health topics. A majority of the staff had not attended any sexual health trainings. IPSE programs lack the necessary sexual health policies for staff to effectively address students' sexual health questions.

Keywords: sexual health, intellectual disabilities, developmental disabilities, college students, support staff

The World Health Organization (WHO, 2016) stresses that sexuality is a central aspect to being human, and sexual health services and education should be afforded to all people, including individuals with intellectual and/or developmental disabilities (IDD) (Friedman & Owen, 2017). Unfortunately, the sexuality of individuals with IDD has typically been categorized as dangerous or problematic, and individuals with IDD have been labeled as asexual beings who have limited sexual needs and desires (Friedman & Owen, 2017; Advocates for Youth, n.d.; Treacy, Taylor, & Abernathy, 2018). Consequently, disparities in access to sexual health resources continue to exist for individuals with IDD (Parish & Saville, 2006). Individuals with IDD are sexually assaulted more than seven times the rate of people without disabilities (National Public Radio (NPR), 2018). Individuals with IDD have the right to be educated about their anatomy, bodily functions, and their sexuality, in order to fully understand themselves and engage in healthy decision making (Grieve, McLaren, Lindsay, & Culling, 2009; Kirby, Coyle, Forrest, Roller, & Robin, 2011; Klein & Breck, 2010; Murphy & Elias, 2007; Travers & Tincani, 2010).

Engaging in responsible sexual behaviors is considered an important developmental milestone during the transition from adolescence to adulthood (Betz, Hunsberger, & Wright, 1994; Tolman & McClelland, 2011). This developmental transition combined with the transition to inclusive postsecondary education (IPSE) programs presents an opportunity for students with IDD to engage in sexual exploration, build upon their desire of meeting new people, and form new romantic relationships. During this transition students with IDD may turn to their IPSE support staff to answer questions and concerns regarding sexuality, sexual health, and relationships. The purpose of this research was to explore staff's access to sexual health resources and trainings as well as their personal beliefs and values about the sexual health needs of individuals with IDD.

There are over 260 IPSE programs nationwide that are attempting to create, expand, and/or enhance high-quality, inclusive higher-education experiences to support positive and holistic outcomes for individuals with IDD. The total number of IPSE programs in the United States has increased by approximately 67.5% in the past 6 years, and this new population of college students will continue to grow (Think College, 2017). Professional staff, including those in IPSE programs, have a major influence on the identity development of students with IDD (Tamas, Brkic Jovanovic, Rajic, Bugarski Ignjatovic, & Peric Prkosovacki, 2019). Therefore, it is important that IPSE program staff have access to sexual health trainings and resources to address students' concerns that may arise due to their limited sexual health knowledge, access to inclusive resources, and sexuality education (Friedman, Arnold, Owen, & Sandman, 2014; Treacy et al., 2018).

Limited participation in sexual health trainings is one of the biggest contributors to communication difficulty and awkwardness between staff and individuals with IDD (Evans, McGuire, Healy, & Carley, 2009). A study conducted with staff of a day and residential program found that around two-thirds of the staff have experienced a time where they had to deal with a client's sexuality. However, only 22% had taken a course on sexuality (McConkey & Ryan, 2001). Similarly, Evans et al (2009) found that 53% of staff of a community-based program for individuals with IDD had discussed sexuality with their clients, but only 12% received training on how to discuss sexuality with their clients. Among all studies, the highest percentage of staff that had been trained in handling sexuality-related issues was 41% (Meaney-Tavares & Gavidia-Payne, 2012). The lack of education for support staff leads to inadequate knowledge among staff, as well as a gap in awareness of the sexual needs, conduct, and desire of individuals with IDD. This gap in training also lowers the possibility that students with IDD will receive adequate information. A statewide study found that teachers of individuals with IDD believed that it was important to provide sex education to their students, but most taught it only rarely; and if they did, they were more likely to teach abstinence-only concepts due to their lack of training and preparation for discussing the topic (Howard-Barr, Rienzo, Pigg Jr., & James, 2005; Treacy et al., 2018). Limited trainings may make IPSE staff feel ill-equipped to address sexuality-related issues.

Studies have shown that many professionals often exhibit anxiety and unwillingness to have conversations about sexuality with individuals with IDD (Abbott & Howarth, 2007; Meaney-Tavares & Gavidia-Payne, 2012). Travers et al. (2016) notes that "explicit and frank discussion regarding human development, relationships, sexual behavior, and

sexual health may be difficult and elusive for professionals and caregivers of people with disabilities” (p. 234). A barrier to sexual communication between staff and individuals with IDD includes the personal beliefs and attitudes of staff related to the sexuality of individuals with IDD.

Staff members’ attitudes are often based on concerns for the welfare of the person with IDD, because they know the various health and social difficulties that students can face (Gilmore & Chambers, 2010). Students’ comfort with discussing sexual health topics with staff is often based on the underlying idea that staff will be receptive to their questions, which is strongly based on their sexual attitudes. This means that students with IDD might find themselves constantly trying to navigate and adjust to support staffs’ attitudes, which adds to the complexity of communication. Over the last twenty years, staffs’ attitudes have shifted from being extremely restricted to somewhat mixed attitudes towards the sexuality of individuals with IDD (Meaney-Tavares & Gavidia-Payne, 2012; Young, Gore, & McCarthy, 2012). These attitudes have been shown to vary based on several characteristics of the individual with IDD and the individual staff member. Women with IDD are perceived as more sexually innocent, while men with IDD are considered sexually motivated and more likely to be characterized as engaging in inappropriate touch (Young et al., 2012). Staff members who are younger and/or receive more sexual health training and have higher levels of education are more likely to report more liberal attitudes regarding sexuality (Grieve, McLaren, Lindsay, & Culling, 2009; Tamas et al., 2019). To date, the sexual attitudes of IPSE program staff have not been investigated. Because sexual attitudes tend to vary based on the environment in which people work, it is important to understand the sexual attitudes of support staff at academic institutions, and how their attitudes vary by gender, length of employment, and number of direct contact hours with students per week.

Method

Data were collected as a part of a larger convergent mixed method study conducted at one IPSE program in North Carolina. In the larger study, interviews were conducted with students with IDD and staff members completed an online questionnaire to learn about students’ sexual health needs and knowledge. Incentives were not offered to participants. For the purposes of this study, we utilized data from the staff questionnaire to answer the following questions: 1) What are staffs’ personal values and level of comfort in discussing sexuality related topics with students? 2) How does this vary by demographic characteristics? 3) How does guardianship of students impact staffs’ communication with students about sexuality related topics? 4) What are the sexual health training needs and opportunities for professional development of staff?

Participants

The IPSE program that was involved in this study provides “inclusive individualized services”. The current definition of inclusive individualized services describes these services as including individualized services in college courses, as well as certificate and/or degree programs (audit or credit). Within inclusive individualized services, each student’s vision and career goals drive the student’s services, there is typically no IPSE

program base on campus, and there is a focus on establishing person-centered career goals that direct the course of study and employment experiences for each student. Additionally, the IPSE program is built on a collaborative approach with an interagency team, and the IPSE program and collaborating agency work together to identify a flexible range of services and to share costs (Grigal, Hart, Papay, Smith, & Domin, 2017). Support staff were recruited through purposive convenience sampling, through which the online survey was administered via Qualtrics to the entire population of staff. Out of a sample of 30 staff members, 16 completed the survey. Demographic characteristics of the staff are provided in Table 1. Staff provided informed consent before seeing any questions on the survey. All research was conducted in compliance with the university's internal review board.

Table 1. Demographic Characteristics of Support Staff (N=16)

Variable	N (%)
Sex	
Male	6 (37.5)
Female	10 (62.5)
Staff Position	
Program Staff	8 (50)
Organizational Staff	5 (31.3)
Student Support Staff	3 (18.8)
Direct Student Contact Per Week	
None	3 (18.8)
1-8 hours	4 (25.0)
9-16 hours	2 (12.5)
17-24 hours	3 (18.8)
25-32 hours	4 (25.0)
Length of Employment	
<1 year	5 (31.3)
1-3 years	4 (25)
4-6 years	1 (6.3)
7-10 years	4 (25)
10 years or more	2 (12.5)
Received Sex Ed Growing Up	
Yes, abstinence only	9 (31.3)
Yes, comprehensive	11 (68.8)
Received a Sexual Health Question from a Student in the Last Year	
Yes	9 (56.3)
No	7 (43.8)

Procedures

A total of 40 questions were administered online to IPSE program support staff via Qualtrics. The full survey included questions about their personal beliefs, personal values, sexual health trainings, and access to resources. We also asked six open-ended questions about sexual health resources, ability to answer sexual health questions, sexual rights of students, on- and off-campus resources, and the legal guardian's role in students' sex education. Basic demographic information was collected including sex, length of employment, position, and amount of direct support time with students. For the purposes of this study, we focused on questions that addressed personal values and comfort with discussing sexuality-related topics, as well as previous sexual health training needs, and access to on- and off-campus resources.

Measures

Personal Values and Comfort with Sexuality-Related Topics

Seven questions addressed support staffs' personal values and comfort with sexuality-related topics. Sample questions were, "I am aware of my own values, beliefs, and assumptions when discussing sexuality-related topics with students with IDD" and "I am uncomfortable discussing certain sexuality topics with students with IDD." Response options were on a Likert scale (1=strongly disagree, 2=disagree, 3=agree, 4=strongly agree). Items were not combined to produce a sum score or cohesive scale. They were treated as individual questions.

Sexual Health Training Needs & On- and Off-Campus Resources

Support staff were also asked if they had previously attended a sexual health training and/or workshop in the last two years, the content of the workshop, and their desires to attend sexual health training and workshops in the future. They were also asked if they had received sexual health questions from students with IDD and how they found resources for these students. The open-ended questions focused on their description of students' with IDD level of sexual health education, level of awareness and use of sexual health resources, ways of finding sexual health on-campus resources for students with IDD, level of comfort in providing sexual health information and resources, and how situations are handled when parents and/or guardians of students are opposed to sexual health information being shared or discussed.

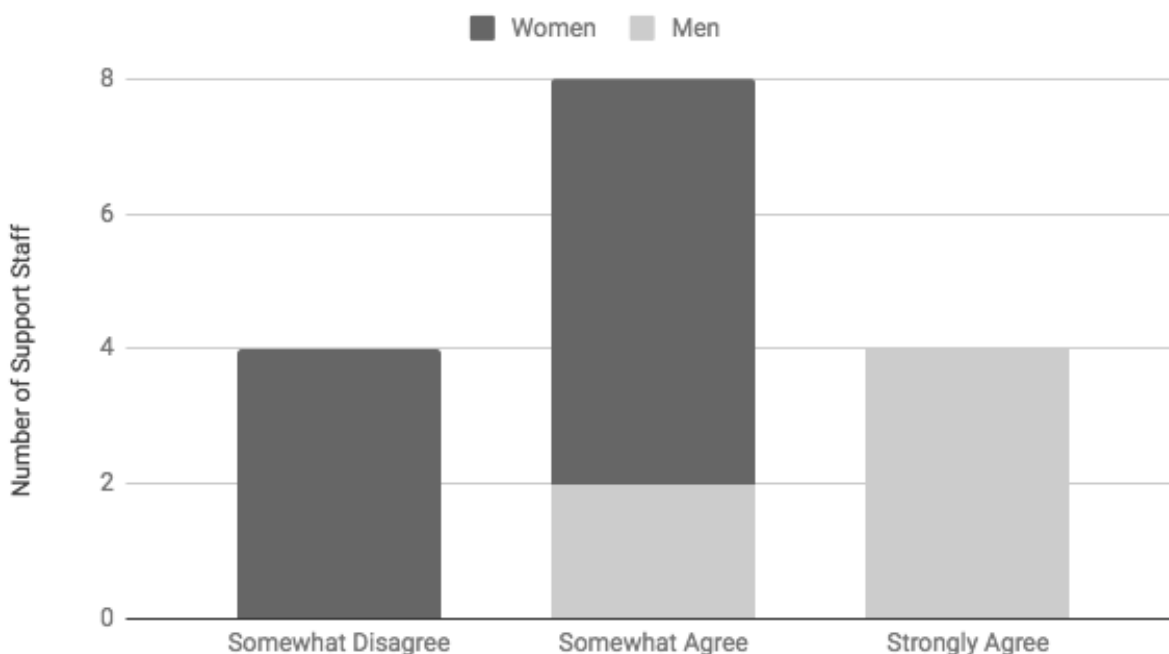
Analysis

Data analysis included a separate analysis for quantitative and qualitative data (Creswell & Clark, 2017). Quantitative data was analyzed using IBM SPSS version 25. Descriptive statistics and chi-square analyses were utilized to explore differences in personal beliefs and personal values by gender, length of employment, and their amount of direct support time with students. The qualitative answers were downloaded verbatim from Qualtrics, and a process of inductive thematic analysis was utilized.

Results

The results of the chi-square analyses showed that associations between staffs' personal beliefs and length of employment, previous sex education, and their amount of direct support time with students were non-significant. There was a significant association between gender and the belief that health professionals are better positioned to talk about sexuality than they [staff members] are. Of the staff, 67% of males strongly agreed and 33% somewhat agreed with that statement, compared to 40% of females who somewhat disagreed [$\chi^2(2) = 9.6, p = 0.008$] (see Figure 1). In the open-ended questions, staff mentioned that they "would refer students to a professional if they did not know the answer or the situation required more expertise, but if a student felt comfortable sharing with them that rapport is important" (Female, staff member for 1-3 years). The staff even reported disclaimers about their sexual health knowledge. One staff member stated, "If I received more training I may feel more comfortable... [and I] try to share information without a bias" (Female, staff member for 1-3 years). Another staff member believed that staff and students needed more opportunities to learn about sexual health resources on campus.

Figure 1. Staff's Belief That Healthcare Professionals are More Qualified



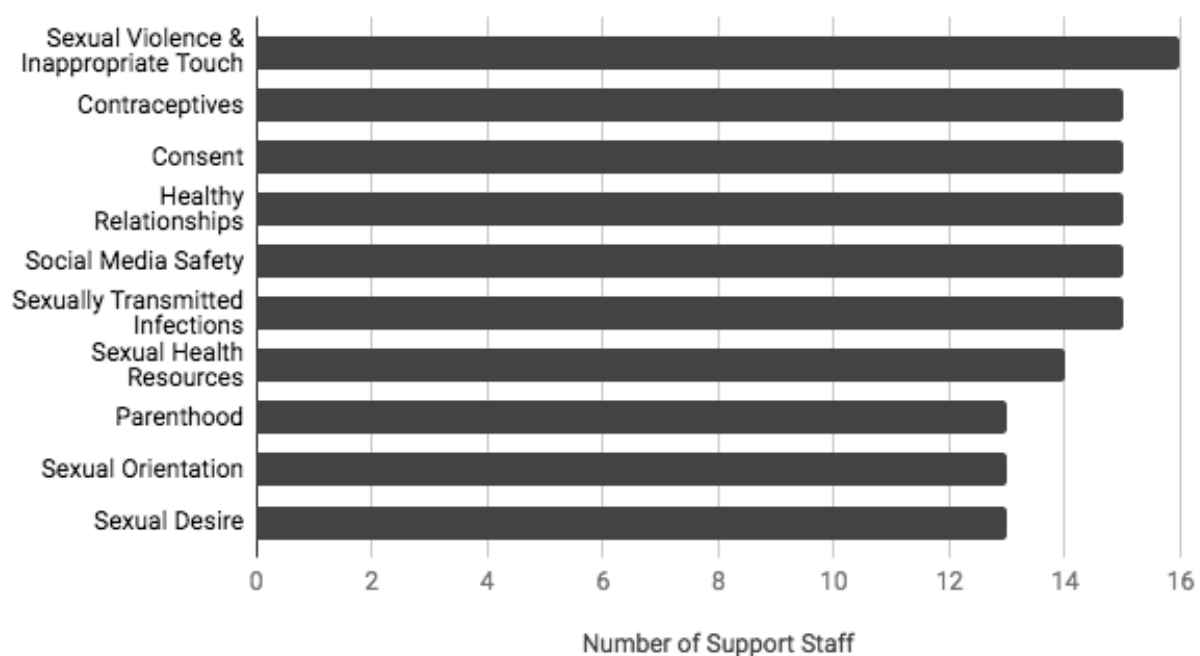
$$\chi^2(2) = 9.6, p = .008$$

Overall, 100% of staff strongly agreed or somewhat agreed that sex was a normal part of life for individuals with IDD, that developmentally-appropriate sex education should be mandatory for students with IDD, that access to sex education is a human right, and that staff are aware of their own values, beliefs, and assumptions when discussing sexuality-related topics. Staff confirmed these answers in their open-ended questions by stating, "I believe that every person has sexual rights and learning about sexual health is important to understand for everyone" (Female, staff member for <1 year), "I feel it is

counterproductive to shame them [students] or to be unwilling to support them” (Female, staff member for 1-3 years), and “I believe that sex is a natural part of college life and adulthood. Students should have access to sexual health information so they can make informed decisions” (Male, staff member for 1-3 years).

Twelve staff members (75%) reported feeling comfortable discussing sexuality-related topics with students. They stated, “Yes, I believe I do feel comfortable providing this information and resources, because I understand the importance of all students having this information” (Male, staff member for <1 year), and “I feel comfortable. We work with adults and they are capable of understanding sex” (Male, staff member for 7-10 years). However, from the open-ended questions, one staff member reported, “I would feel more comfortable with a student of the same sex and would refer students to another staff person of the same sex” (Male, staff member for 4-6 years). Staff also reported on topics they thought students should learn about (see Figure 2).

Figure 2. Topics That Staff Believe Students Need To Learn About



Within the online survey, the sixth open-ended question asked staff about how they handle situations with students when the student’s parent(s), caregiver(s), and/or guardian(s) are opposed to sexual health or sexuality information being shared and discussed with the student. There were several responses to this question that supported the importance of and need for the involvement of parents of students in conversations regarding sexual health. One staff member explained, “I have had students seek support and information that they did not feel comfortable talking to their parents about and/or did not want their parents to know” (Male, staff member for 4-6 years). Another staff member explained, “It is a very difficult situation to wade through. Conversations with both parties, together and separate, are needed. Eventually a middle ground can be experienced” (Male, staff member for 7-10 years).

There were two basic frequency results that were alarming. First, 37.5% of staff somewhat agreed that they make assumptions regarding the sexual orientation or gender identity of the students in the program. Secondly, only two staff members reported ever having a sexual health training, but 56.3% of staff reported receiving a sexual health question from a student in the last year. These two staff members attended Safe Zone, an LGBTQ+ awareness and ally training ("The Safe Zone Project," 2018). The other staff who reported they had not received a health training had varying levels of interest in receiving future training on the topic: nine staff members wanted to attend more workshops, four did not, and three said maybe. Finally, only seven support staff believed that they needed to attend a sexual health training to be able to support the students.

Discussion & Future Directions

With the rise of IPSE programs across the United States, it is important that college students with IDD have access to staff who are trained in sexuality education and who can serve as a confidential resource for them. The purpose of this exploratory study was to identify the personal values, beliefs, and sexual health needs, including trainings and resources of staff members, within one IPSE program. The results of the current study confirm that support workers lack adequate sexual health training. Staff members believed that access to sexual health information was the sexual right of their students. However, there were several barriers to staff discussing sexual health topics, including feeling qualified and comfortable.

The results from this study show that staff believed that students should be taught a wide range of sexual health topics, including healthy relationships, consent, birth control, and anatomy. However, most male staff felt that they were not as qualified to provide sexuality education as a health professional. These results could be explained two ways. First, female staff members may believe that they are better qualified than health professionals, because they have potentially built higher levels of rapport with the students. However, rapport does not equate to professional qualifications. Only one female in the entire sample attended a sexual health training, so these female staff technically had the same amount of knowledge as the males in our sample. Thus, males may be more accurate reporters for this measure. Secondly, this finding could also be related to the concerns of discussing sexual health information with students of the opposite sex and the lack of policies to support staff. Previous research has found that support staff were unaware of sexuality-related policies (e.g., policies around being able to discuss sexuality-related issues with clients, reporting and discussing inappropriate public sexual behaviors) at their place of employment, that their employers lacked these policies, or that they were too ambiguous or restrictive (Abbott & Howarth, 2007; Saxe & Flanagan, 2016; Wilson, Parmenter, Stancliffe, & Shuttleworth, 2011; Yool, Langdon, & Garner, 2003). Our study confirms the findings that many staff report little to no formal training on the topic of sexual health (Eisenberg, Madsen, Oliphant, Sieving, & Resnick, 2010; Klein & Breck, 2010; Preston, 2013; Travers, Tincani, Whitby, & Boutot, 2014). In order to increase the support staffs' comfort, IPSE programs should have policies and guidelines related to the staffs' ability to educate students about sexual health issues. Sexual health policies could be incorporated into the staffs' sexual health training. Sax and Flanagan (2016) state that

“trainings would not only prevent them [staff] from having to use their own moral judgements to deal with sexuality-related situations, but it would help to alleviate their feelings of unpreparedness and consequently increase their confidence to deal with such situations” (p. 452). Additionally, the presence of sexual health policies and guidelines for IPSE staff will further reinforce the importance of staff feeling and being adequately prepared to support students when sexuality-related situations arise. The results of this research revealed that only seven of the surveyed staff believed that they needed to attend a sexual health training to support the students. We believe that the presence of sexual health policies and guidelines for IPSE staff could increase the staffs’ beliefs in the importance of sexual health training and create a culture of shared responsibility of keeping students safe during this period of exploration.

Along with the need for staff to be better prepared, it is also important to include parents of students with IDD in conversations regarding sexual health. Previous research has shown that many supports do not provide sexual health information to individuals with IDD, because they are afraid of the family’s reactions and possible legal actions, and only provide information when an individual displays inappropriate behaviors (Lafferty, McConkey, & Simpson, 2012; Schaafsma, Kok, Stoffelen, & Curfs, 2017). The findings of this study support the importance of and need for the involvement of parents of students in conversations regarding proactive education and awareness around healthy relationships and sexual health to address the disconnect between some parents and their student. This type of disconnect can lead to negative outcomes for the student, especially when sexuality and knowledge of sexual health is not supported by the parent. The importance of individualized supports that focus on the whole student with IDD, including his or her support network, is well cited in the literature (Think College, 2018). The topic of sexual health for college students with IDD should be embraced holistically, with a focus on not only the student’s engagement and knowledge building, but also the student’s parent(s), caregiver(s), and/or guardian(s). These individuals most often play vital roles in the support networks of students with IDD. Their meaningful involvement in conversations regarding sexual health of students with IDD will support the overall sexual health of the students. Opportunities for parent education, programs, and collaborations with IPSE program staff should be explored to increase parents’ knowledge and confidence with the roles parents play in supporting their students’ sexual health development (Kok & Akyuz, 2015; Suter, McCracken, & Calam, 2009).

Along with parents of students with IDD, the IPSE program staff should also be provided with necessary information and tools to support students in the area of sexual education (Stein, Kohut, & Dillenburger, 2018). The literature reveals that effective sex education programs for individuals with IDD should address aspects such as social skills, reproduction, body changes, anatomy, prevention of sexual abuse, consent, personal safety, boundaries, and sexual orientation (Walker-Hirsch, 2007; Woodward, 2004). However, sexual health programs for individuals with IDD lack reliability and validity and are often not implemented to fidelity (Grieve, McLaren, & Lindsay, 2007; Preston, 2013). Research has found that when trained sexuality educators deliver sex education curricula to students with IDD, they are more likely to use vague terms or lack the ability to not use overly technically terms, which diminishes meaningful comprehension of information and opportunities for application beyond the classroom for students (McDaniels & Fleming,

2016; Treacy et al., 2018). Collaborations between IPSE staff and certified sexuality educators could enhance the learning experience for individuals with IDD and provide opportunities for both groups of professionals to learn from one another and to help students with IDD achieve optimal sexual health. If IPSE program staff completed comprehensive, targeted trainings regarding sexuality and sexual health of individuals with IDD, they would feel more confident, skilled, and at ease when conversations and/or situations arise concerning the sexual health of a student with IDD. In these important moments, staff could turn to knowledge and information from trainings instead of having to use their own judgements.

Limitations

Despite the benefits, this study did have limitations. This study was limited by the small sample size. We only sampled one IPSE program at one university, and only 16 staff participated in the survey. Our staff sample was diverse in gender, but we did not collect demographic information that could inform us about the staff's diversity regarding race. Future studies should incorporate the collection of more detailed demographic information of staff. Our study cannot be generalized beyond this one IPSE program at this one university, because it is not representative of students and staff in other IPSE programs at other universities. We believe there was potential response bias among staff, with most staff agreeing with most of the belief questions that sexual health education is a necessity and should be made mandatory. Staff may have felt the need to say "yes" in order to express equal rights and opportunities for the students, when they really didn't believe these things were true. Finally, the IPSE program that we focused on is located in an abstinence-only state in the Southeastern United States. Therefore, the college students in this IPSE program who are natives of this state may have had less exposure to comprehensive sex education. We may not see the same results if we replicated this study in more liberal parts of the United States that provide comprehensive sex education.

Conclusion

To our knowledge, this was the first study to explore the sexual health related topics with IPSE program staff who serve and support college students with IDD. Our study adds to the literature by illuminating the need for sexual health trainings for IPSE program staff. Creating a sex-positive and inclusive environment through professional development opportunities will aid in the sexual health promotion of students with IDD. Connections and collaborations between IPSE programs and on-campus organizations and other personnel, such as peer health educators, wellness centers, and sexual violence coordinators, should be made to increase access to sexual health information through inclusive sex education programs. Policies to support IPSE staff in facilitating these difficult conversations should be created, as well as mandatory trainings for all incoming and returning staff. Further investigation is needed on the sexual health knowledge and training of IPSE program staff and students with IDD across the nation.

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