The sexual health needs and perspectives of college students with intellectual and/or developmental disabilities and their support staff: A brief report

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Abstract:

The purpose of this mixed methods pilot study was to examine the sexual health needs, knowledge, and access to resources for students with intellectual and/or developmental disabilities (IDD) and their support staff in an inclusive postsecondary education (IPSE) program. Four college students with IDD and sixteen support staff from an IPSE program in the Southeast United States were recruited in 2018. Semi-structured interviews were conducted with students. Online surveys, which contained open-ended and Likert scale items, were administered to all support staff. Students and staff both reported that students had limited sexual health knowledge, were uncomfortable discussing sexual health, and reported little interest in the topic. Both students and staff provided recommendations for creating inclusive sexual health programs and marketing strategies. Students have limited information about sexual health and are not included in sexual health programming in meaningful ways. Staff lack the training needed to address students' sexual health questions. This study also makes a significant contribution to the dearth of literature on the sexual health of college students with IDD.

Keywords: College students | Intellectual disability | Developmental disability | Sexual health | United States | Mixed methods

Article:

Introduction

The total number of inclusive postsecondary education (IPSE) programs in the United States have increased by 67.5% in the past 6 years, and this new population of college students will continue to grow [1]. There are approximately more than 260 IPSE programs for students with intellectual and/or developmental disabilities (IDD) across the United States. These IPSE programs aim to provide opportunities for individuals with IDD to be able to attend college.

These IPSE programs attempt to create, expand, and/or enhance high-quality, inclusive higher education experiences to support positive and holistic outcomes for individuals with IDD [2].

Despite the growing number of college students with IDD, their sexual health experiences and needs have not been empirically explored. Within the research on adolescents and adults with IDD, studies reveal lower levels of sexual knowledge among individuals with IDD when compared to individuals without IDD [3, 4, 5]. When compared to individuals without IDD, individuals with IDD are more likely to experience sexual victimization [3], have less knowledge of ways to minimize the risk of HIV/AIDS infection, and lower confidence levels in their ability to practice safer sex [4]. As a result of limited opportunities for sex education, adults and adolescents with IDD may also lack the experience and skills necessary to form healthy relationships, and understand and establish appropriate sexual boundaries, which in turn may result in negative health outcomes (e.g., anxiety, depression, impaired self-esteem, sexually transmitted infections, sexual abuse) and sexual exploitation [6, 7, 8].

The acknowledgement of personal attitudes and beliefs regarding the sexuality of individuals with IDD is critical for IPSE program support staff. Attitudes of support staff can reflect the idea that intimacy and sex are inappropriate and should be discouraged among individuals with IDD [5]. However, these beliefs may vary based on the staff's characteristics. Staff that are younger, higher professional status [9], and/or received specific trainings related to sexual health are more likely to have more positive attitudes [10]. These beliefs may also influence the staff's perspective on who should receive sex education and who should not. There are also several barriers that staff and other supports may perceive, such as lack of confidence, fear of accountability, and being unwilling or embarrassed to engage in communication about sexual topics [11]. The lack of adequate training on these issues has been illuminated in several studies and is the biggest contributor of communication difficulty and awkwardness [12, 13, 14, 15, 16, 17].

With sexual health being a key component of health and wellness for students on college campuses across our nation, this new and growing population of college students (i.e., students with IDD) cannot be forgotten. While higher education institutions provide increasing support for students with IDD, the sexual health needs and resources for these students are not well documented. This mixed method pilot study presents perspectives from both college students with IDD and their support staff from one IPSE program at one university in the Southeast United States. A convergent mixed methods design was used. This is a type of design in which qualitative and quantitative data are collected, analyzed separately, and then merged [18]. In this study, responses from a survey for support staff were used to examine if sexual health knowledge positively influenced the perceived importance of and the desire to have sexual health training for support staff at the IPSE program. The qualitative data, which was collected through interviews, explored sexual health experiences and needs of college students with IDD within the same IPSE program. The reason for collecting both quantitative and qualitative data was to converge and corroborate results among the two forms of data to bring greater insight into the problem than would be obtained by either type of data separately [18]. This study addressed the following three research questions:

1. What are students' with IDD perceptions of sexual health experiences, needs, and access to resources on a college campus?
2. Is there an association between support staffs' sexual health values and demographic characteristics?
3. What is the relationship between support staffs' and students' with IDD perceptions of sexual health?

Methods

Setting

The setting from which participants were recruited was a four-year IPSE program in the Southeast United States. This IPSE program falls higher on the continuum of inclusion by providing inclusive, individualized services to students with IDD. The support structure of this IPSE program consisted of two different types of support staff. Academic support staff were employed by the university, while student life support staff were employed by a partnering nonprofit organization, whose mission was to provide person-centered, habilitative supports to individuals with IDD. This IPSE program did not have any type of sexual health programming or supports in place for students with IDD.

Participants and Procedures

Participants for the individual interviews were four college students with IDD (1-male, 3-female) from an IPSE program. Students were recruited through purposive convenience sampling, through which students' designated support leaders recommended specific students for recruitment. A total of 10 students were initially recommended. Six of these students were not interested or comfortable discussing the topic, two did not respond, and two agreed to participate. Five additional students were recommended for recruitment. Three of these students were not interested or comfortable discussing the topic and two agreed to participate. A total of four students were recruited for the final sample. Individual interviews were set up in-person ($n = 1$) and via WebEx ($n = 3$), because recruitment occurred over summer break. Interviews were audio-recorded with participants' permission.

The online survey was administered via Qualtrics to the entire population of staff ($N = 30$) and a total of 16 completed the survey (see Table 1). Recruitment of both samples included informed consent, with an option for an in-person verbal review of the consent form for students. All research was conducted in compliance with the university's internal review board. Informed consent was obtained from all individual participants included in the study. Since there is such limited empirical research on this topic, a mixed methods approach was chosen to comprehensively explore the topic. As described within measures, collecting qualitative data through individual interviews with individuals with IDD is most effective in research [19], and was chosen as the data collection strategy among students in this study.

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 h	4 (25.0)
9–16 h	2 (12.5)
17–24 h	3 (18.8)
25–32 h	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)

Data Collection

Student Interview Guide. A semi-structured interview with a total of one grand tour question and eight probing questions was utilized. Each interview was approximately 20–30 min in length.

Grand Tour Question. Can you tell me about your experiences with using health resources (such as the Health Center, Wellness programming, etc.) on campus?

Grand Tour Probing Questions. How do you use (or want to use) health resources (such as the Health Center, Wellness programming, etc.) on campus? What has interfered with or gotten in the way of your participation in and access to any health and wellness programs on campus?

Sexual Health Questions. Is there any information about sexual health that you would like to know more about? Is there any information about sexual health that your parent(s) or family member(s) have shared with you? Have you participated in any sexual health programs on campus, or received any information about sexual health while on campus? What has interfered with or gotten in the way of your access to any sexual health and wellness resources on campus?

Ending Questions. What would you change about sexual health and wellness resources on campus, to make them even better? How do you think your Campus and Community Support (CCS) staff or any other support staff could help you with getting connected to and involved in sexual health and wellness resources on campus?

Staff Survey. A total of 40 questions were administered online to IPSE program support staff through the use of Qualtrics. Six of these questions were open-ended and produced qualitative data to match the types of questions asked in the interviews with students. Data that emerged from these open-ended questions contributed to answering the third research question. Basic demographic information was collected, including sex, length of employment, position, and amount of direct support time with students.

Measures

Personal Beliefs About Sex Education for Students with IDD. Eight questions focused on personal beliefs about sex education for students. The scale was modified to focus on students with IDD instead of the general population. Response options were on a Likert scale (1 = strongly disagree, 2 = disagree, 3 = agree, 4 = strongly agree). Sample questions included "Students with IDD should be discouraged from asking sexual-related questions", "Sex is a natural and normal part of life for students with IDD", and "It is a risk to provide sex education to students with IDD".

Personal Values and Comfort with Sexuality-Related Topics. Seven questions addressed 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).

Sexual Health Training & On- and Off-Campus Resources. 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 asked if they had received sexual health questions from students and how they found resources for these students. The open-ended questions focused on their description of students' level of sexual health education, level of awareness and use of sexual health resources, ways of finding on-campus sexual health resources for students, 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 [18]. Quantitative data were analyzed using IBM SPSS version 25. Descriptive statistics and Fisher Exact test were utilized to explore differences in personal beliefs and personal values by gender, length of employment, and amount of direct support time with students. Qualitative data were analyzed using a process of inductive content analysis [20]. Typed transcripts were prepared and analyzed

through the creation of memos, coding, identification of significant quotes, visual mapping strategies, and the identification and interpretation of emergent themes [20]. Interrater reliability was established as both researchers completed a separate initial analysis of all qualitative data before coming together to compare and combine findings. At the conclusion of these separate analyses, integrated data analysis was used to develop integrated results and interpretations that expand understanding, provide comprehensive results, and compare the results of students and staff [18].

Results

The inductive content analysis of transcripts from interviews with students revealed a total of eight themes. The results of this inductive content analysis contributed to answering the first research question: What are students' with IDD perceptions of sexual health experiences, needs, and access to resources on a college campus? The eight themes included the following, which are ordered with the most frequently identified theme listed first and followed by the number of times the theme was identified in parenthesis: limited knowledge of sexual health and sexual health resources (13); lack of interest in sexual health for now (13); awkwardness and lack of comfort talking about sexual health (12); wanting support with sexual health from friends and/or support staff (9); ideas for improving sexual health programs (8); barriers to participation in sexual health programs (7); and autonomy (6). The theme, limited knowledge of sexual health and sexual health resources (13), was linked to the following theme: limited conversations with parents about sexual health (8) (Fig. 1).

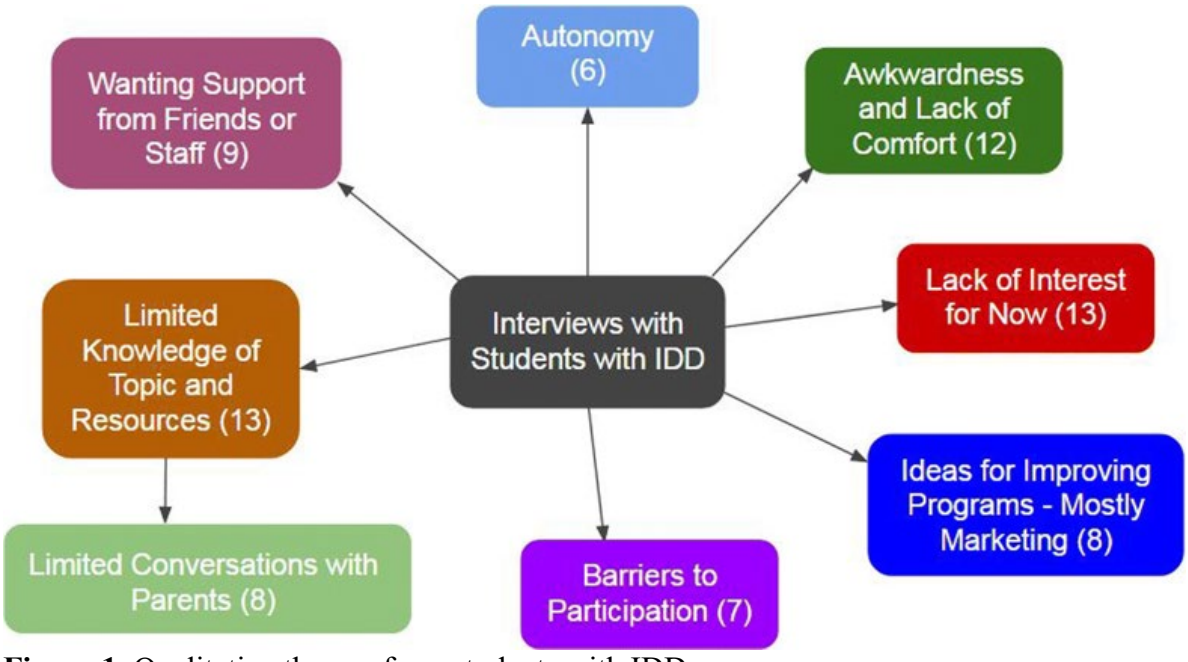

Figure 1. Qualitative themes from students with IDD

During their interviews, students continued to offer a variety of ideas for improving sexual health programs and resources on campus. Students discussed the idea of coordinators/facilitators of sexual health programs and events to allow for and encourage email communication prior to programs and events. This way, students could communicate with coordinators/facilitators to get

a better idea of what to expect and to ask any questions they may have about the upcoming program or event. Students discussed the idea of having videos of programs and events available for students to access online. This way, students can watch a video to see what they missed if the day and time of the event or program interfered with their schedule, or students could watch a video to increase their comfort before deciding to attend a program or event in person. Students also discussed how the availability of written information to take home and read after sexual health programs and events would increase their ability to gain a better understanding of sexual health topics. A student who had previously attended and really enjoyed a sexual health program on campus discussed the need for programs and events to occur more frequently. Lastly, students offered ideas to improve the marketing and advertisement of sexual health programs and events on campus, including more posters in prime locations on campus and more online advertising.

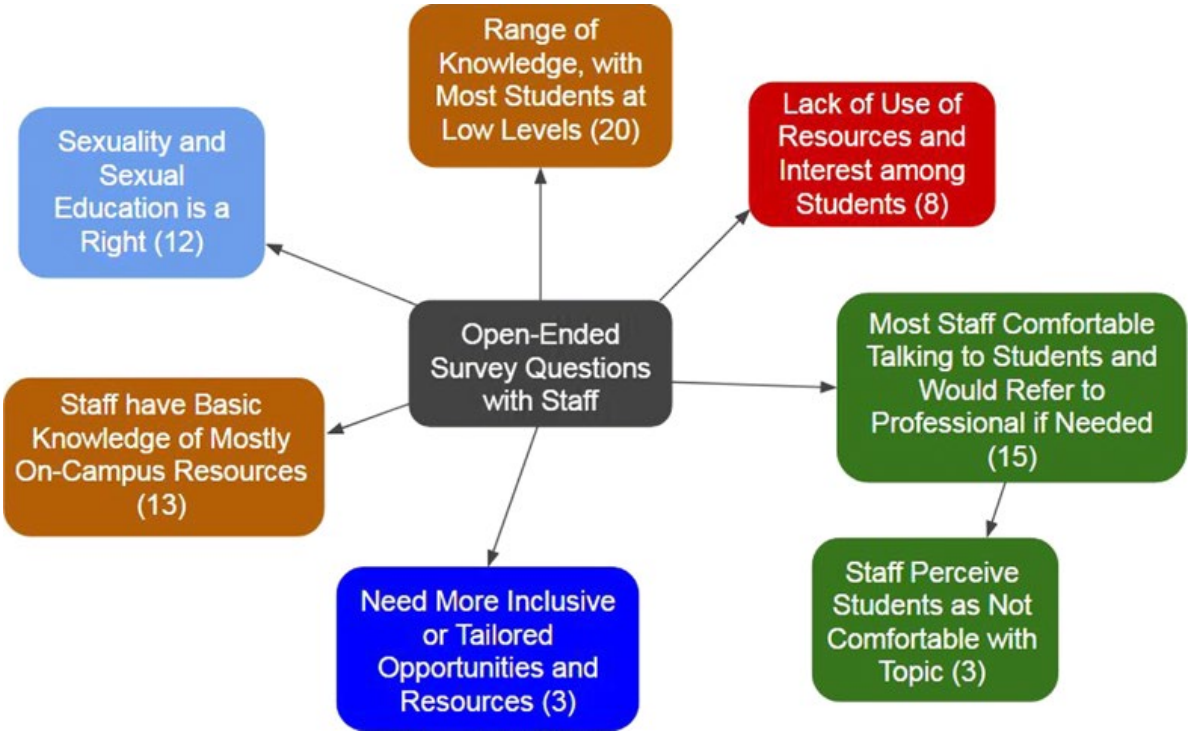

Figure 2. Qualitative themes from IPSE program support staff

The inductive content analysis of answers to open-ended questions from the survey with staff revealed a total of seven themes. The results of this inductive content analysis contributed to answering the third research question: What is the relationship between support staff's and students with IDD's perceptions of sexual health? The seven themes included the following, which are ordered with the most frequently identified theme listed first and followed by the number of times the theme was identified in parenthesis: range of sexual health knowledge among students, with most students having low levels of knowledge (20); most staff feel comfortable talking to students about sexual health and would refer students to a professional if needed (15); staff have a basic knowledge of mostly on-campus sexual health resources (13); sexual health is a right (12); staff feel there is a lack of use of sexual health resources and interest in sexual health resources among students (8); and campus needs more inclusive and tailored sexual health opportunities and resources for students (3). The theme of most staff feeling comfortable talking to students about sexual health and having intentions to refer students to a

professional if needed (15) was linked to the following theme: staff perceive students as not being comfortable with the topic of sexual health (3) (Fig. 2).

A lack of comfort with the topic of sexual health among students was confirmed by students and staff. During interviews, students said, “I am totally uncomfortable with being a part of that”, “To talk about sex with someone, I find it very awkward”, and “I don’t care who you are, I just feel awkward”. Staff said, “Many students don’t feel comfortable in the conversation”, and, “I think most students may not be comfortable expressing their feelings”. Students’ lack of interest in sexual health programming was confirmed by students and staff. During interviews, students said, “A few years from now after college…that is something I will learn more about”, “I will probably learn more right after college”, and “I don’t want to learn more right now, not yet”. Staff said, “Students have not shown high interest in attending sexual health events on campus”. A lack of sexual health education among students was confirmed by students and staff. During their interviews, students said, “I don’t think I was ever told that [information about sexual health]”, and “I learned a little in high school, but you don’t learn that stuff [about sexual health] in school”. Staff quotes echoed this theme by explaining, “Multiple students have explicitly shared with me that they do not feel that they have received appropriate sexual health education in a way that has prepared them for college life”. While staff described a range of sexual health knowledge existing among students, students revealed low levels of sexual health knowledge. Staff said “There is a large range [of sexual health knowledge]”, and “Students range from no education and no desire for education to well-educated and high interest in being educated”. During interviews, students made comments that revealed low levels of sexual health knowledge, including “I know where babies come from”, “It is just about my privates. It did something cool and it makes me think about the person that I like”, and “I have never heard of that [sexually transmitted infections] before”.

One major confirmation among staff was that all staff agreed that access to sex education was a human right. In the open-ended questions, staff reported, “The student is not a child and has a right to their own sexuality”, “Everyone has the right to be safe and sexually active if they chose to be”, and “I believe that every person has sexual rights and learning about sexual health is important to understand for everyone”. All staff reported in the open-ended questions that they would be comfortable talking to students, even going as far to say, “If a student trusts me enough to open up about their sexuality, I feel it is counterproductive to shame them or to be unwilling to support them in all aspects of their life”.

Results of the quantitative analysis of staffs’ survey responses contributed to answering the second research question: Is there a statistically significant association between support staff’s sexual health values and demographic characteristics? 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, and that access to sex education is a human right, and that they are aware of their own values, beliefs, and assumptions when discussing sexuality-related topics. Around 18% of staff believed that students did not have the opportunity to exercise their sexual self-advocacy. Finally, 37.5% of staff somewhat agreed that they make assumptions regarding the sexual orientation or gender identity of the students. The results of the Fisher exact test showed that there were not significant associations between staffs’ personal beliefs and length of employment, previous sex education,

and their amount of direct support time with students. There was a significant association between gender and the belief that health professionals are better positioned to talk about sexuality: 67% of males strongly agree and 33% somewhat agree with that statement, compared to 40% of females who somewhat disagreed ($p = .008$).

Discussion

Comparisons of Thematic Findings from Students and Staff

When comparing the thematic findings from interviews with students with thematic findings from answers to open-ended questions in the survey with staff, there were several confirmations and discrepancies. A lack of comfort with the topic of sexual health among students was confirmed by students and staff. Findings from the literature reveal that prejudices concerning the sexuality of individuals with IDD are still very prominent in families and the community at large [16]. These prejudices could be contributing to the "taboo" nature of the topics of sexuality and sexual health among individuals with IDD, which could potentially explain the overall lack of comfort that was revealed through our findings.

Students' lack of interest in sexual health programming was confirmed by students and staff. When referring to the literature, it is important to point out that a lack of interest in sexual health among individuals with IDD is most often due to an overall lack of exposure and feeling that sex is a taboo topic [21]. These findings are consistent with research showing that people with IDD demonstrate lower levels of sexual health knowledge [21].

A lack of sexual health education among students was confirmed by students and staff. Students and staff both provided quality recommendations for improving sexual health programming on campus. These recommendations are discussed in the future directions section. These findings are consistent with research showing that individuals with IDD, especially those with low IQs, tend to receive very little or no sexual education [22].

Along with confirmations, there was also an important discrepancy identified during triangulation. This discrepancy contributed to answering the third research question: What is the relationship between support staff's and students' perceptions of sexual health? While staff described a range of sexual health knowledge existing among students, students revealed low levels of sexual health knowledge. During interviews, students made comments that revealed low levels of sexual health knowledge. With this discrepancy, it is important to point out that staff's description of a range of sexual health knowledge among students may be the more accurate assumption, because they are describing the entire population of students enrolled in their program. Conversely, interviews represent descriptions of sexual health knowledge from only four students. While the existing literature on individuals with IDD demonstrates low levels of sexual health knowledge [21], this finding may serve as a demonstration of the potential of the college environment in broadening students' with IDD knowledge base in several areas of adult life, including sexual health.

Comparisons of Qualitative and Quantitative Data Results

When comparing the qualitative results to the quantitative data, we found several confirmations and discrepancies. The results of this comparison contributed to answering the third research question: What is the relationship between support staff's and students' perceptions of sexual health? One major confirmation among staff was that all staff agreed that access to sex education was a human right. These findings show that despite the fact that students have limited opportunities to enact their sexual rights and sexual self-advocacy [23], supports believe students with IDD have the same basic rights to sexual and reproductive health as other college students. This presents the opportunity for supports to discuss with students how they can advocate for themselves and advance the current research and work that is being done to advance the rights, opportunities, and practices for students with IDD [23].

We highlighted that students feel awkward and uncomfortable speaking to staff. This could be a result of students feeling as if staff are making assumptions about not only their sexual behaviors, but their sexuality, as well. Among staff, 37.5% agreed that they make assumptions regarding the sexual orientation and gender identity of their students. Historically, supports have not acknowledged the development of sexual identity for people with IDD, nor have they had the skills, knowledge, or experience to support LGBTQ students with IDD [12, 24]. This is still evident with only two supports attending a SafeZone Training [25], which provides all training workshops to faculty, staff, and students across campus. We recommend that more staff should attend these free trainings to learn how to support students who may identify as LGBTQ, and review the list of 50 key recommendations and best practices for supporting people with IDD who identify as LGBTQ [26].

During our triangulation, we found a discrepancy between staffs' beliefs in their ability to talk about sexual health with students. All staff reported in the open-ended questions that they would be comfortable talking to students. However, 43.7% of staff reported that they felt uncomfortable discussing sexuality topics with students, and 37.5% believed that students would rather receive information from a health professional than staff. Our results also revealed that male staff were more likely to report that health professionals are in a better position to talk about sexuality. This finding could be a result of male staff working with female students. One student and one staff member both stated that they were uncomfortable with talking about sex with the opposite sex. This is a clear example of the need for detailed policies for discussing sexual health with students to ease staffs' concerns when these situations arise, and to create safe space where staff do not have to use their own judgements [27, 28, 29, 30].

Limitations

Despite the benefits, this study did have limitations. This study was limited by the small sample size. We only sampled one IPSE program and only four students within the program participated in the interviews. Our student sample was diverse in race, but not in gender. Future studies should incorporate more men and more students who identify as LGBTQ. 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 the small sample reflects overall discomfort with the topic of sexual health among college students with IDD. We also 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.

Conclusions and Implications

Our thematic findings revealed several quality recommendations for the improvement of sexual health programs and resources on campus. During interviews, students discussed the importance of and desire for support from friends and/or staff with sexual health. IPSE programs typically have support services set up for students with IDD that are designed to provide individualized supports and services for the academic and social inclusion of students in academic courses, extracurricular activities, and other aspects of college life and the institution of higher education [1]. The ideas offered by students with IDD related to improving sexual health programs and resources on campus (i.e., coordinators/facilitators allowing and encouraging email communication prior to programs and events; having videos of programs and events available for students to access online; availability of written information to take home and read after programs and events; more frequent occurrence of programs and events; and specific suggestions for improving marketing and advertising of programs and events) should be considered for future implementation.

In order to effectively instigate the recommendation from the literature [22] for more inclusive and tailored sexual health opportunities and resources for students with IDD, there are important considerations from the literature. Evidence-based sexual health programming is most effective, and evaluative input from participants is essential for ongoing improvements [31]. Sex education should be situated as a proactive strategy, rather than a crisis response. Parents of students with IDD and IPSE program staff should be provided with necessary information and tools to support students in the area of sexual education [22].

Future research on the sexual health of college students with IDD is needed. With the rise of IPSE programs for students with IDD, and students being exposed to more sexual freedom and hookup culture on college campuses, it is likely that students with IDD will be more likely to explore their sexuality during this time. More mixed methods research is needed to explore this topic to the fullest. Qualitative methods are useful for telling rich stories about sexual exploration and health, while quantitative data allows researchers to collect large data across IPSE programs and universities. To date, there is limited research on the sexual health of college students with IDD. Our hope is that future research will expand our knowledge on the sexual health of college students with IDD, their sexual development during college, as well as the opportunities they have to exercise their sexual self-advocacy. Focusing on barriers to gaining information on sexual health and sexual self-advocacy, such as lack of sexual health services, systematic barriers, and access to counseling and education, will help in achieving sexual health equity among this population [23].

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