

Intellectual and Developmental Disabilities

The Continuum of Support for Building Intimacy Knowledge in College for Students with Intellectual Disability

--Manuscript Draft--

Manuscript Number:	IDD-D-20-00026R1
Article Type:	Research
Keywords:	Post-secondary education, intellectual disability, sexuality education, intimacy, college
Corresponding Author:	Chelsea VanHorn Stinnett, Ph.D. University of South Carolina Columbia, SC UNITED STATES
First Author:	Chelsea VanHorn Stinnett, Ph.D.
Order of Authors:	Chelsea VanHorn Stinnett, Ph.D. Anthony J. Plotner, Ph.D. Kathleen Marshall, PhD
Manuscript Region of Origin:	UNITED STATES
Abstract:	Post-secondary education (PSE) programs allow for college students with intellectual disability to experience a higher level of autonomy in choice-making, which they may not have experienced in their family home or high school. This includes choice-making related to romantic and sexual relationships. The Continuum of Support for Intimacy Knowledge in College Survey (CoSIK-C) was used to examine how PSE programs support college students in building their intimacy knowledge. Types of resources and services used to build intimacy knowledge and the frequency and context in which support was provided were identified and varied across programs. Implications for practice and future research are provided.

The Continuum of Support for Building Intimacy Knowledge in College for Students with
Intellectual Disability

ABSTRACT

Post-secondary education (PSE) programs allow for college students with intellectual disability to experience a higher level of autonomy in choice-making, which they may not have experienced in their family home or high school. This includes choice-making related to romantic and sexual relationships. The *Continuum of Support for Intimacy Knowledge in College Survey* (CoSIK-C) was used to examine how PSE programs support college students in building their intimacy knowledge. Types of resources and services used to build intimacy knowledge and the frequency and context in which support was provided were identified and varied across programs. Implications for practice and future research are provided.

Key words: Post-secondary education, intellectual disability, intimacy, sexuality education

The Continuum of Support for Building Intimacy Knowledge in College for Students with Intellectual Disability

Positive intimacy experiences, including engaging in romantic relationships and sexual activity, contribute to overall emotional well-being and a higher quality of life for all people, including people with intellectual disability (Arias et al., 2009). In recent years, students with intellectual disability have had more opportunities to experience college life (Grigal et al., 2019). College provides an ideal atmosphere for personal growth, but it also forces students to make frequent choices that could impact their overall happiness and safety when it comes to engaging in intimate relationships.

Emerging adults in college explore choice and freedom to a degree that they may not have experienced in their family home (Arnett, 2000; Evans et al., 2009). High school provides a protected environment where students are likely to be exposed to an abstinence-based sexuality education curriculum (National Conference of State Legislatures, 2020), whereas college campuses naturally expose students to experiences they may not have had in high school, such as opportunities to have privacy to engage in intimacy. Young adults attending college are more likely to encounter opportunities for intimate risk-taking and decision-making, as the transition from high school to college involves an evolution in thought regarding sexual freedom and values (Evans et al., 2009). Within this setting, students with intellectual disability can explore love and sex more independently, however supports are often necessary to ensure their level of knowledge related to intimacy allows for capacity for independent choice-making (Dukes & McGuire, 2006).

Post-secondary programs for students with intellectual disability allow students to be exposed to many different opportunities and ideas that they may not have experienced in high

school. While high school programs can serve students through age 21, college programs typically serve students between the ages of 18 and 26. These students live on campus, attend classes with their peers, go to sporting events and participate in clubs and organizations. Meeting new people and learning how to develop and maintain relationships, both platonic and romantic, are significant to the development that occurs in an individual as a result of living and learning on a college campus (Evans et al., 2009). Like many college students, those with intellectual disability are also exploring their own values related to intimate relationships. Exploring sexual desire is an innate need (Harlow, 1958) and supporting students with intellectual disability to navigate emotional and sexual needs associated with intimate relationships is critical to increasing happiness and overall quality of life (Arias et al., 2009; McDaniels & Fleming, 2018).

Context and Need for the Study

Over the last decade, college programs for individuals with intellectual disability have been established at Institutes of Higher Education (IHEs) across the country, to provide more rigorous and age-appropriate preparation for post-school life. To date, there are approximately 300 postsecondary education (PSE) programs for students with intellectual disability (Think College, 2020). Key legislative and funding initiatives have helped to catalyze the number of these programs on college campuses. The Higher Education Opportunity Act (HEOA, 2008) authorized the use of federal financial aid to support greater access to PSE programs, leading to the expansion of many programs across the country. In an effort to support the development of model, comprehensive PSE programs, the U.S. Department of Education has awarded millions of dollars in Transition and Postsecondary Programs for Students with Intellectual Disabilities (TPSID) grants (U.S. Department of Education, 2015).

There is great variability in the types of PSE programs (e.g., length of program, residential options, level and types of supports) and the IHEs that sponsor them (Grigal et al., 2019). Programs provide services and supports across several domains including academics, independent living, employment, self-determination, and social engagement (Plotner et al., 2018). While most PSE programs focus primarily on skill development in career, academics, and independent living access (Grigal et al., 2012), yet the acquisition of social skills and building interpersonal relationships are also desired outcomes associated with attending a PSE program (Miller et al., 2018). Post-secondary education programs for students with intellectual disability are uniquely situated to meet the needs of students in the process of identity development which occurs during college, through the acquisition of self-determination skills, risk-taking, and the application of learned experiences to achieving desired agency.

Although the number of PSE programs for students with intellectual disability have grown within the past decade, more information is needed in order to understand to how they support students in their social skill development. Articles within the PSE literature base primarily focus on program development, with few focusing specifically on social support (Whirley et al., 2020). More information regarding social engagement outcomes are important, given that they are traditionally poor for young adults with intellectual disability, despite postsecondary education enrollment status. Only 58% of young adults with intellectual disability indicate that they interact with friends outside of work weekly, compared to 78% of people across disability categories (Newman et al., 2009). Articles within the PSE literature base about social skill development focus largely on the development of platonic friendships (Butler et al., 2016; Nasr et al., 2015). Few articles refer to how PSE programs support building students' intimacy knowledge (Graff et al., 2017).

Intimacy is an important aspect of life for people with intellectual disability, in that they express the same need for intimacy as those without disability (Castelao et al., 2010; Siebelink et al., 2006; Yau et al., 2009). Many adults with intellectual disability report that they are sexually active or desire to be (Gil-Llario et al., 2018), however almost half never receive education in this area (Barnard-Brak et al., 2014; Isler et al., 2009). Without appropriate education, adults with intellectual disability may lack intimacy knowledge across a variety of topics, including knowledge of physical characteristics, an understanding of how to engage in sexual intercourse, pregnancy, appropriate masturbation, legal aspects and social norms, and the use of contraception to prevent STD contraction (Borawska-Charko et al., 2016). Lack of intimacy knowledge may leave people with intellectual disability more susceptible than their peers without disabilities to experience negative outcomes associated with engaging in intimacy, which could include unplanned pregnancy, sexually transmitted disease (Dekker et al., 2014), or sexual abuse (Akrami & Davudi, 2014).

There is a modest literature base regarding current approaches to intimacy education for adults with intellectual disabilities. Wolfe et al. (2019) reviewed commercially available, comprehensive curricula developed for individuals with developmental disabilities, in order to identify the scope of sociosexual content covered. Few curricula align with health education standards and few address more controversial topics such as gender and sexual identity and abortion. Another concern throughout the literature is the lack of evidence of the ability of people with intellectual disability in generalizing knowledge of intimate concepts and applying this knowledge to real-life scenarios (McDaniels & Fleming, 2016). This is a particularly relevant concern in a college setting, where students learn concepts in a classroom, then leave those classrooms to immediately apply that knowledge to social situations they encounter daily.

Finally, intimacy education is often provided reactively after a student engages in sex, which increases the likelihood of misinformation, abuse, STDs, and behavioral issues (Gougeon, 2009).

Students with intellectual disability attending PSE programs may experience risk-taking and autonomy to a degree that they did not experience in high school (Plotner & Marshall, 2015), as the role of choice-maker shifts from parent to student during the transition to college life (Evans et al., 2009). The need for all students to have access to intimacy knowledge is critical for the health, safety, and well-being of all people living and learning on campus (Lechner et al., 2013). To date, there is no literature that examines the full continuum of supports related to building intimacy knowledge of students with intellectual disability in college. Hence the purpose of this study was to contribute to the literature base by identifying which supports are being provided to PSE students with intellectual disability in building their sexual health and intimacy knowledge, how often and what context they are being provided, as well as the frequency and level of satisfaction of intimacy education professional development offered to PSE staff members. Two overarching research questions guided the study:

1. How are PSE programs supporting college students with intellectual disability in building their intimacy knowledge? and
2. How often is professional development related to building students' intimacy knowledge provided to PSE program staff members?

METHOD

This exploratory study utilized survey research to examine how PSE programs are supporting students in building their intimacy knowledge, which will allow program administrators to consider the type and frequency of support to provide students in building sexual agency on a college campus. The research questions are designed to provide insight into

the ways PSE staff support students with intellectual disability in their programs in areas of intimacy knowledge, as well as the extent to which they are prepared to deliver these supports.

Participants

One program staff member who coordinates supports for students from each of the 265 (as of winter, 2018) PSE programs for students with intellectual disability served as the targeted population for this study. Think College, the national coordinating center for PSE programs for students with intellectual disability, provides a database for information specific to each program across the country. This database was used to identify an email point of contact for each of the 265 programs. If an email was not listed for the program on the Think College database, the researcher visited the individual program website to identify the contact information associated with the program. An email with details of the study and instructions for completing the survey were sent to a staff member from each program. Instructions included in the email request for participation and the welcome page of the survey stipulate that only one full-time staff member from each program who coordinates day-to-day supports for participants should complete the survey. To ensure the receipt of only one response per program, respondents were asked to provide the name of their PSE program in an effort to prevent duplicative responses.

Staff members from 96 of the 265 programs responded, however 88 completed the survey for an overall response rate of 33%. Respondents represented 36 states within the United States. Participants included directors, assistant directors, coordinators, leadership staff, and others (e.g. instructors). Approximately one-third (32.3%) of respondents had 3-4 years of experience with their current PSE program. An additional 40.6% have 5 years or more experience with their current PSE program.

Program Demographics and Characteristics

Table 1 provides summary statistics of program demographics and other characteristics of the PSE programs including state, dual-enrollment status, type of institution, and total institutional student population. Dual-enrollment refers to the partnership between at least one local school district and at least one college or university (IHE) where a student who has not yet exited high school is receiving both high school and college credit for coursework completed at the IHE. The education provided by the IHE meets the qualifications for designation as transition services on a student's IEP, paid for with IDEA part B funds. Sixty-seven percent of PSE programs represented in this study have existed for five or more years. Approximately 75% of programs are non-dual enrollment. Fifty-one percent of the responding PSE programs are housed in four-year colleges and universities, and 23.3% of programs are housed in large IHEs with a total student population over 25,000.

Intellectual disability (94.5%) and Autism Spectrum Disorder (95.6%) were the most frequently represented disability categories amongst PSE student populations. Approximately two-thirds of PSE programs report supporting students with Multiple Disabilities (68.1%), Specific Learning Disability (61.5%), Other Health Impairment (61.5%), and Speech or Language Impairment (60.4%). Other disability categories that were represented at PSE programs include Traumatic Brain injury (41.8%), Visual Impairment (37.4%), Hearing Impairment (35.2%), Orthopedic Impairment (27.5%), Emotional Disturbance (26.4%), Deafness (15.4%), and Deaf-Blindness (6.6%).

Instrument

Instrument development. The instrument was developed based on existing literature surrounding intimacy experiences and education for people with intellectual disability as well as

literature from the college student development field and PSE programs. In order to ensure that the survey questions were reliable and valid, the instrument was reviewed by a group of experts consisting of a program director, assistant director, and coordinator from one PSE program, and a director from Think College. Feedback regarding the items' adequacy in covering the full continuum of support that a PSE program may offer, clarity of each item, and recommendations for additional concepts to add was gathered via a survey feedback form created specifically for this instrument. Feedback from the expert review was used to add items that could contribute to identifying the understanding the supports being offered by programs, ensure each item was relevant and easy to interpret, and to eliminate redundancies.

The Continuum of Support for Intimacy Knowledge in College Survey (CoSIK-C).

The *Continuum of Support for Intimacy Knowledge in College Survey* (CoSIK-C), a 36-item survey, was developed for the purpose of this study. The first section of the CoSIK-C consists of five items aimed at collecting demographic information specific to individual staff members. The second section consists of 15 items related to PSE program demographics. The third section of the CoSIK-C consists of 10 items aimed at identifying the continuum of support (e.g., assessment, services, and resources) that PSE programs may use to build participants' intimacy knowledge. In this section, respondents are also asked to describe the context in which the PSE program provides support related to building participants' intimacy knowledge, the practices used to build this knowledge, the topics covered within these supports, and the frequency of professional development offered to staff in this area. Multiple response options across categories were used in section three to capture the breadth of the continuum of support PSE programs provide students in learning about intimacy.

Throughout the survey, participants were asked to reflect upon two different types of

intimacy instruction: emotional and sexual intimacy. Emotional intimacy involves a feeling of closeness or being emotionally or physically involved with another person with reduced formalities, freedom of communication, and an appropriate level of interdependence (Birtchnell, 1997). Emotional intimacy refers to experiencing closeness while being listened to, understood, and valued within a relationship (Schaefer & Olson, 1981). In this study, knowledge related to emotional intimacy is referred to as romantic relationship knowledge (RRK). Sexual intimacy refers to engaging in sexual activity to gratify physical needs (Schaefer & Olson, 1981). Throughout this study, this type of intimacy knowledge is referred to as sexual activity knowledge (SAK).

Procedures

Approval to conduct this study was obtained from the University of South Carolina's Institutional Review Board (IRB). The CoSIK-C was uploaded to and disseminated via SurveyMonkey.com. An email with a link to the CoSIK-C was sent to the sample of program staff identified via the Think College Database. Respondents were offered an incentive to complete the survey by electing to be entered in a drawing to receive one of the following: (1) \$100 Amazon gift card, (1) \$50 Amazon gift card, or (2) \$25 Amazon gift cards. To increase the response rate, reminder emails were sent one week and three weeks after the initial email request for completion (Smith, 1997).

Data Analysis

Data collected via SurveyMonkey.com were converted to SPSS Statistical Software for analysis. The statistical analyses described below were used to answer the two research questions. Due to the exploratory nature of the research study, descriptive statistics were used to identify the type and frequency of supports being provided to build intimacy knowledge. In order

to identify how often professional development related to intimacy is provided to each type of PSE staff member, response data was analyzed to determine frequency of professional development being provided to staff members and the mean and standard deviation of the level of satisfaction of staff members related to the frequency of professional development being offered in this area.

RESULTS

Research Question 1: *How are PSE programs supporting college students with intellectual disability in building their intimacy knowledge?*

Frequency and context of support. Overall, the frequency and context in which support in building intimacy knowledge is provided to college students varied greatly. Fifteen percent of PSE programs never provide support in building students' general intimacy knowledge. A majority of programs (60.9%) provide support in building romantic relationship knowledge (RRK) proactively for all program participants. Forty percent of programs provide support in building knowledge of sexual activity knowledge (SAK) proactively for all students. Often, support is provided reactively, most often due to an individual's expressed interest in engaging in intimacy (50.6% RRK/47.1% SAK). Approximately one-third of PSE programs provide support in building intimacy knowledge due to a negative experience with intimacy (32.2% RRK/29.4% SAK).

Types of support. PSE programs are more likely to use services to build students' RRK as opposed to SAK (Table 2). Thirty-two percent of PSE programs do not offer support to build students' SAK and 18% do not provide support in building RRK. The service most frequently utilized by PSE programs in building either aspect of intimacy knowledge is the use of group courses consisting of only PSE program participants (46.4%). For both aspects of intimacy, PSE

programs also frequently utilized one-on-one sessions with full-time staff members (35% for RRK/33% for SAK) and dissemination of intimacy education materials (33% for RRK/29% for SAK). Programs offer other services for building RRK (10.3%) and SAK (7.1%), including workshops, computer programs, support groups, and information from local independent living centers.

Instructional practices. Within the services provided by PSE programs, the most common instructional practice PSE programs used to build intimacy knowledge is discussion (91.4%). Additional practices used by programs to teach intimacy include mixed gender courses (61.7%), the use of handouts and worksheets (54.3%), role-play (51.9%), lecture (49.4%), the use of media (48.2%), and single-gender courses (23.5). Other practices (12.4%) included guest presentations, clinic site visits, referral to a health center, the use of 3D models, and student presentations and interviews. Personal hygiene and social skills/cues related to dating were the topics covered most frequently by PSE programs, with 44% of programs addressing personal hygiene and 37% addressing social cues related to dating once or more per week. Topics that were never addressed at many programs include unplanned pregnancy (45%), biological and reproductive functioning (42%), sexual and gender identity (40%), and masturbation (59%) (see Table 3).

Resources. The most frequently utilized resources to support students to build romantic and sexual knowledge are those from community agencies (42% for RRK, 38% for SAK). Programs more frequently provide resources to build RRK (84%), compared to SAK (67%). Approximately one-third of programs use research-based curricula, program-based curricula, or resources from the IHE's student health center to build both RRK and SAK. Staff members who indicated that their PSE program uses resources from IHE health centers identified those

resources as counselors, sexual health educators, sexual assault awareness training, health fairs, therapy, online courses, preventative birth control, and STD testing and prevention (See Table 4).

Assessment of intimacy knowledge and interest. Almost half of PSE programs do not assess students' intimacy knowledge and level of interest related to engaging in romantic relationships or sexual activity. Those programs that do assess students' knowledge and level of interest are more likely to use informal assessment to measure RRK (38.8%) and SAK (33.7%). Few programs use formal assessment (4.7%, RRK/ 2.3% SAK). When asked to briefly describe the assessments being used to measure knowledge and level of interest within either aspect of intimacy, many methods were listed including assessments from specific intimacy curricula, informal interviews and discussion, one-on-one advising sessions, checklists, role-play, pre/post assessment, and questionnaires. Some respondents stated that while they currently do not measure participants' intimacy knowledge, they would like to start.

Research Question 2: *How often is professional development related to building students' intimacy knowledge provided to PSE program staff members?*

Professional development related to building students' intimacy knowledge is not provided to staff members at half of PSE programs (see Table 5). Peer mentors never receive professional development on intimacy education at 58% of PSE programs. Perception of the level of satisfaction with the amount of professional development offered in this area to both full-time staff and peer mentors is relatively comparable between those who expressed overall satisfaction (51.8% full-time, 47.5% peer mentors) or dissatisfaction (48.2% full-time, 52.5% peer mentors).

When provided with the opportunity to make recommendation on how PSE programs could improve or expand the continuum of support offered to students in building their intimacy knowledge, many replied by referencing that more training is needed. Some made more specific suggestions for what is needed such as, “online training modules,” “training by specialists in the field,” and one respondent suggested a social media platform for ideas, resources, and guidance so that programs could learn from each other based on what they each found to be effective. Others stated that professional development and training in this area wasn’t a priority. A few respondents indicated that, because of their status as faith-based institutions, they would not prioritize professional development in this area. Of the programs that provide dual-enrollment, some stated that dual-enrollment prevented them from broaching the topic because the LEA saw this as a liability. One respondent indicated that because they were not a residential program, they felt that they did not have time to address this topic because they were focused on using their limited time to provide effective instruction in broader areas. This was echoed by other respondents who stated that this topic was not one of priority given the primary focus of their program.

DISCUSSION

The findings of this study are important, as they provide a summary of how PSE programs are supporting students with intellectual disability to develop intimacy knowledge in college. Programs report variability in the frequency, type, and context of support provided in this area. Most PSE programs provide support in this area proactively for all students, however 15% of programs do not provide any support in building intimacy knowledge amongst their students. Programs are more likely to support the development of romantic relationship knowledge (RRK) than sexual activity knowledge (SAK). Further, half of PSE programs do not

assess students' level of intimacy knowledge and interest in engaging in intimacy. In order to build intimacy knowledge, PSE programs are most frequently utilizing group courses with other program participants and almost all programs used discussion as the main instructional method for intimacy education. Personal hygiene and social skills related to dating are the most frequently addressed topics amongst PSE programs, while topics such as unplanned pregnancy, reproduction, sexual and gender identity, and masturbation are never addressed in many programs. The most frequently used resource in building both types of intimacy knowledge is information from a community health agency.

When reflecting upon the typical college experience, most students are learning about sex from their male and female friends or from their own reading (Rutledge et al., 2011). Only 7.8% of college undergraduates reported learning about sex and intimacy from an instructor (Rutledge et al., 2011). While it may be commonplace for college students to learn about intimacy from peers or experience, many PSE program participants are likely interacting with peers in their program with a limited intimacy knowledge base, similar to their own. Even though college students typically do not talk to faculty and staff about sexual intimacy, programs may need to facilitate opportunities for these interactions to take place. The power of many college environments is the natural supports in place to inform and educate all students about intimacy and sexual behavior. Intimacy concepts certainly are prevalent across domains including employment (i.e. sexual harassment and relationships in the workplace) and academics (i.e. peer interactions and relationships in the classroom). Therefore, regardless if supporting students socially is within the scope of a program, intimacy is a topic that could be beneficial if addressed to some degree at all PSE programs.

Assessing students' needs and interests in learning about intimacy. Determining the right frequency, topics, and instructional methods to ensure that intimacy education is comprehensive and appropriate in this setting is determined by the unique needs and experiences of each student within the PSE program. Half of PSE programs do not assess student intimacy knowledge and interest, therefore half do not know what intimacy knowledge (or lack thereof) participants are bringing with them to college. Instruction and support may be occurring, but if programs are not assessing what students already know about intimacy, it is likely that this instruction is not as effective as it could be without an understanding of students' level of knowledge and interest in the topic (Thompson et al., 2016). In addition to informing instructional decisions for PSE administrators, assessing students' needs and interests would hopefully result in increasing students' self-awareness of their own intimacy needs.

Further, Think College Standards (Grigal et al., 2012b) necessitate a program of study and support that is reflective of student interest and that will lead to desired outcomes. This includes students' ability to direct their choice of coursework and experiences. Assessment can be used to identify the degree to which students would like to learn about intimacy, what they'd like to learn, and how best to provide this instruction. This data can be used to determine what is considered comprehensive and appropriate intimacy education for each student. Assessment is critical to understanding what students know, what they want to know, and a valuable method for creating a comfortable and effective environment for discussing and learning about intimacy topics (Thompson et al., 2016). Assessment data is critical for service providers supporting adults with intellectual disability in learning about intimacy (Thompson et al., 2016).

Comprehensive intimacy education for students with intellectual disability in college. Traditional comprehensive sexuality education includes multiple instructional practices

and topics (FoSE, 2019). The instructional practices most frequently used by PSE programs in building students' intimacy knowledge were discussion and group coursework with other students in the program. Although there are many ways to facilitate group discussions and group courses, more in-depth and individualized methods to convey information may be needed to support students in building their intimacy knowledge (Schaafsma et al., 2015). It may be difficult to discuss personal topics like sex and dating in a group setting, especially with peers. In addition, the use of discussion as an instructional practice does not guarantee retention when discussing a controversial topic such as intimacy (Pace, 2003). Topics that were never covered by almost half of all programs in the present study include unplanned pregnancy, biological and reproductive functioning, sexual and gender identity, and masturbation.

Intimacy education is often provided reactively to people with intellectual disability, which can increase the likelihood of experiencing negative consequences of intimacy such as unplanned pregnancy, STD contraction, and abuse (Gougeon, 2009). A majority of the PSE programs in this study provide support proactively for all students, yet one-fourth of PSE programs provide support reactively based on a students' negative experience with intimacy and 22% do not support the development of sexual activity knowledge. Although reactive support is expected if in the context of any negative sexual experience, reactive support alone will not provide young adults with intellectual disability with the knowledge, preparation, or protection they need. Individuals with intellectual disability may be prone to sexual abuse (Gougeon, 2009), therefore it is important for PSE programs to not wait until a negative experience with intimacy occurs before providing support in building this knowledge. Although programs cannot guarantee student safety, they must be proactive in providing information about intimacy so that students are aware of potential negative consequences, allowing them to make informed choices

regarding their own intimate lives while in college.

If PSE programs are preparing students for a truly independent and agentic future, they must consider the support that students may request in navigating this part of their lives. If a student expresses an interest in acquiring this knowledge, PSE programs should, per Think College Standards (Grigal et al., 2012b) assist them in identifying support from the program, on campus, or within the community. Adults with intellectual disability have the right to comprehensive sexuality education, but how this support is provided will vary based on the individualized needs and interest of the student, and resources within the programs.

Intimacy education professional development for PSE staff. Results of this study indicate that many staff members do not receive professional development in this area. Many disability service professionals do not feel comfortable or well-trained to provide intimacy education to individuals with intellectual disability (Evans et al., 2009). One hypothesis for why staff may not feel confident in providing this support is a lack of formal training or uncertainty in organizational guidelines related to teaching intimacy (Evans et al., 2009). Professional development opportunities can positively impact an instructor's willingness and ability to provide sexuality education (Ollis, 2010). All staff may not be provided this training for a variety of reasons, including other priorities for professional development within the program. Further, any staff member could receive intimacy education professional development and still lack confidence in providing support in this area, based on their own experiences. This is especially relevant to peer mentors, who are emerging adults themselves and experiencing their own shifting identity development. Whereas the use of peer mentors may be the most natural support a program could provide students, lack of experience and established intimate identity could hinder their effectiveness in providing support in this area.

Staff members would benefit from content specific professional development in order to develop confidence in supporting students in developing their intimacy knowledge (Evans et al., 2009). Not all programs have the resources to support having an intimacy expert on staff. A more feasible and universal method of supporting students does not require staff members to be intimacy experts. If intimacy education is not a program priority or within the scope of the purpose of program, staff members can still provide students with campus and community resources that they can access for more information on sex and dating. This would require professional development to make staff aware of the resources available to students and how to best support them in utilizing these resources. This concept is supported by Think College Standards that call for PSE programs to collaborate with IHE campus partners, including Health Centers (Grigal et al., 2012b).

Professional development on effective assessment of intimacy knowledge and interest would benefit staff members planning instruction and support in this area. Professional development on how to facilitate self-awareness of intimacy needs as well as how to create an environment in which students feel comfortable discussing such an intimate topic could promote confidence in students in expressing their desire to learn more.

Future research directions. The findings of this study should be interpreted with caution, as the 33% response rate suggests that those PSE program staff members who responded could have responded because of their interest or mastery of providing intimacy supports, and the other 66% may not have responded due to a lack of interest or effort invested in intimacy supports. Future research tapping a larger percentage of PSE staff members may help to address this concern. Additionally, services, instructional methods, and resources could be implemented or operationally defined in different ways. For example, there was no specification of the

duration of group courses or the types of professional development provided or the educational materials provided by community agencies or resources in building intimacy knowledge.

Additional research is needed to understand how to best support students in navigating intimacy in college. Examining how administrators assign levels of priority to instructional topics as well as where intimacy education falls on this scale of prioritization may contribute to the rationale for how frequently intimacy education support and professional development is offered by PSE programs. Additionally, identifying students' preferences for what they want to learn in relation to romantic relationships and sexual activity and how they would like to be supported in this area can inform program administrators' decisions on the frequency and type of support being provided.

Examining intimacy support provided by PSE programs to college to students with intellectual disability can help inform programmatic decision-making as to how to best support students in building intimacy knowledge. The results of this study indicate variability in the frequency, context, and types of support being offered by programs in this area. Adults with intellectual disability desire intimacy, likely lack intimacy knowledge typically gained in high school, and are living and/or learning in a college environment with higher degrees of autonomy. PSE programs can connect students with campus and community resources for learning more about intimacy, even if social engagement is not a primary focus of the program. Further, PSE program staff members would benefit from considering intimacy a universal topic that spans all programmatic domains and provide students with support accordingly. Intimacy exists in all facets of life and is a basic human right and need. It would be a disservice to assume that students with intellectual disability in college do not need support in some capacity in navigating intimate relationships, identity, and values. Whether provided directly by a PSE program or a

collaborative campus partner, supporting students in developing their intimacy knowledge is a significant component of developing sexual agency. It is imperative to discover new ways to support individuals in complex and important issues such as intimacy that respect their preferences, choices and comfort level.

References

- Arias, B., Ovejero, A., & Morentin, R. (2009). Love and emotional well-being in people with intellectual disabilities. *The Spanish Journal of Psychology, 12*(1), 204-216.
- Akrami, L., & Davudi, M. (2014). Comparison of behavioral and sexual problems between intellectually disabled and normal adolescent boys during puberty in Yazd, Iran. *Iranian Journal of Psychiatry and Behavioral Sciences, 8*(2), 68.
- Arnett, J. J. (2000). Emerging adulthood: A theory of development from the late teens through the twenties. *American Psychologist, 55*(5), 469.
- Barnard-Brak, L., Schmidt, M., Chesnut, S., Wei, T., & Richman, D. (2014). Predictors of access to sex education for children with intellectual disabilities in public schools. *Mental Retardation, 52*(2), 85-97.
- Birtchnell, J. (1997). Attachment in an interpersonal context. *British Journal of Medical Psychology, 70*(3), 265-279.
- Borawska-Charko, M., Rohleder, P., & Finlay, W. M. L. (2017). The sexual health knowledge of people with intellectual disabilities: A review. *Sexuality Research and Social Policy, 14*(4), 393-409.
- Butler, L. N., Sheppard-Jones, K., Whaley, B., Harrison, B., & Osness, M. (2016). Does participation in higher education make a difference in life outcomes for students with intellectual disability? *Journal of Vocational Rehabilitation, 44*(3), 295-298.
- Castelão, T., Campos, T., Torres, V. (2010). A new perspective of sexual orientation for adolescents that have mental retardation. *Sexologies 19*, 116.
- Dekker, A., Safi, M., Echteld, M. A., & Evenhuis, H. M. (2014). Sexuality and contraception in young people with mild intellectual disability; a qualitative study

- on the basis of 28 interviews. *Nederlands tijdschrift voor geneeskunde*, 158, A8010-A8010.
- Dukes, E., & McGuire, B. E. (2009). Enhancing capacity to make sexuality-related decisions in people with an intellectual disability. *Journal of Intellectual Disability Research*, 53(8), 727-734.
- Evans, N. J., Forney, D. S., Guido, F. M., Patton, L. D., & Renn, K. A. (2009). *Student development in college: Theory, research, and practice*. San Francisco: Jossey-Bass.
- Evans, D. S., McGuire, B. E., Healy, E., & Carley, S. N. (2009). Sexuality and personal relationships for people with an intellectual disability. Part II: Staff and family carer perspectives. *Journal of Intellectual Disability Research*, 53(11), 913-921.
- Future of Sex Education (2019). Youth health and rights in sex education. <http://www.futureofsexed.org/youthhealthrights.html>
- Gil-Llario, M. D., Morell-Mengual, V., Ballester-Arnal, R., & Díaz-Rodríguez, I. (2018). The experience of sexuality in adults with intellectual disability. *Journal of Intellectual Disability Research*, 62(1), 72-80.
- Gougeon, N. A. (2009). Sexuality education for students with intellectual disabilities, a critical pedagogical approach: outing the ignored curriculum. *Sex Education*, 9(3), 277-291.
- Graff, H. J., Moyher, R. E., Bair, J., Foster, C., Gorden, M. E., & Clem, J. (2018). Relationships and Sexuality: How is a Young Adult with an Intellectual Disability Supposed to Navigate?. *Sexuality and Disability*, 36(2), 175-183.
- Grigal, M., Hart, D., Papay, C., Smith, F., Domin, D. & Lazo, R. (2019). Year Four Annual

- Report of the TPSID Model Demonstration Projects (2018–2019). Boston, MA: University of Massachusetts Boston, Institute for Community Inclusion.
- Grigal, M., Hart, D., & Weir, C. (2012). A survey of postsecondary education programs for students with intellectual disabilities in the United States. *Journal of Policy and Practice in Intellectual Disabilities, 9*(4), 223-233.
- Grigal, M., Hart, D., & Weir, C., (2012b). Think College Standards Quality Indicators, and Benchmarks for Inclusive Higher Education. Boston, MA: University of Massachusetts Boston, Institute for Community Inclusion.
- Harlow, H. F. (1958). The nature of love. *American Psychologist, 13*(12), 673-685.
- Harris, J. C. (2006). *Intellectual disability: Understanding its development, causes, classification, evaluation, and treatment*. Oxford University Press.
- Isler, A., Tas, F., Beytut, D., & Conk, Z. (2009). Sexuality in adolescents with intellectual disabilities. *Sexuality and Disability, 27*(1), 27-34.
- Lechner, K. E., Garcia, C. M., Frerich, E. A., Lust, K., & Eisenberg, M. E. (2013). College students' sexual health: Personal responsibility or the responsibility of the college? *Journal of American College Health, 61*(1), 28-35.
- McDaniels, B., & Fleming, A. (2016). Sexuality education and intellectual disability: Time to address the challenge. *Sexuality and Disability, 34*(2), 215-225.
- McDaniels, B., & Fleming, A. (2018). Sexual health education: A missing piece in transition services for youth with intellectual and developmental disabilities? *Journal of Rehabilitation, 84*(3), 28-38.
- Miller, K. D., Schleien, S. J., White, A. L., & Harrington, L. (2018). "Letting go:" Parent perspectives on the outcomes of an inclusive postsecondary education experience

- for students with developmental disabilities. *Journal of Postsecondary Education, 31*(3), 267-285.
- Moss, B. F., & Schwebel, A. I. (1993). Defining intimacy in romantic relationships. *Family Relations, 42*(1), 31-37.
- Nasr, M., Cranston-Gingras, A., & Jang, S. E. (2015). Friendship Experiences of Participants in a University Based Transition Program. *International Journal of Whole Schooling, 11*(2), 1-15.
- National Conference of State Legislatures (2020). State policies on sex education in schools. <https://www.ncsl.org/research/health/state-policies-on-sex-education-in-schools.aspx>
- Newman, L., Wagner, M., Cameto, R., Knokey, A. M. (2009). The Post-High School Outcomes of Youth With Disabilities up to 4 Years After High School. A Report From the National Longitudinal Transition Study-2 (NLTS2) (NCSE 2009-3017). Menlo Park, CA: SRI International.
- Ollis, D. (2010). 'I haven't changed bigots but...': Reflections on the impact of teacher professional learning in sexuality education. *Sex Education, 10*(2), 217-230.
- Pace, D. (2003). Controlled fission: Teaching supercharged subjects. *College Teaching, 51*(2), 42-45.
- Plotner, A. J., & Marshall, K. J. (2015). Postsecondary education programs for students with an intellectual disability: Facilitators and barriers to implementation. *Intellectual and Developmental Disabilities, 53*(1), 58-69.
- Plotner, A. J., Marshall, K. J., Stinnett, C. V., & Teasley, K. (2018). Developing an inclusive model of postsecondary education for students with intellectual disability: Challenges and outcomes. In O'Brien, P., Bonati, M. L., Gadow, F., &

- Slee, R. (Eds.) *People with Intellectual Disability Experiencing University Life* (99-113). Brill Sense.
- Schaefer, M. T., & Olson, D. H. (1981). Assessing intimacy: The PAIR inventory. *Journal of Marital and Family Therapy*, 7(1), 47-60.
- Schaafsma, D., Stoffelen, J. M., Kok, G., & Curfs, L. M. (2013). Exploring the development of existing sex education programmes for people with intellectual disabilities: an intervention mapping approach. *Journal of Applied Research in Intellectual Disabilities*, 26(2), 157-166.
- Siebelink, E. M., de Jong, M. D., Taal, E., & Roelvink, L. (2006). Sexuality and people with intellectual disabilities: assessment of knowledge, attitudes, experiences, and needs. *Mental Retardation*, 44(4), 283-294.
- Smith, C. B. (1997). Casting the net: Surveying an Internet population. *Journal of Computer-Mediated Communication*, 3(1), Retrieved from <https://onlinelibrary.wiley.com/doi/full/10.1111/j.1083-6101.1997.tb00064.x>
- Thompson, V. R., Stancliffe, R. J., Broom, A., & Wilson, N. J. (2016). Clinicians' use of sexual knowledge assessment tools for people with intellectual disability. *Journal of Intellectual & Developmental Disability*, 41(3), 243-254.
- U.S. Department of Education (2015). *Transition and postsecondary programs for students with intellectual disabilities*. Retrieved from <https://www2.ed.gov/programs/tpsid/index.html?exp=0.when>
- Whirley, M. L., Gilson, C. B., & Gushanas, C. M. (2020). Postsecondary Education Programs on College Campuses Supporting Adults With Intellectual and Developmental Disabilities in

the Literature: A Scoping Review. *Career Development and Transition for Exceptional Individuals*, DOI: 10.1177/2165143420929655

Wolfe, P. S., Wertalik, J. L., Domire Monaco, S., Gardner, S., & Ruiz, S. (2019). Review of sociosexuality curricular content for individuals with developmental disabilities. *Focus on Autism and Other Developmental Disabilities*, 34(3), 153-162.

Yau, M. K. S., Ng, G. S. M., Lau, D. Y. K., Chan, K. S., & Chan, J. S. K. (2009). Exploring sexuality and sexual concerns of adult persons with intellectual disability in a cultural context. *The British Journal of Development Disabilities*, 55(109), 97-108.

Table 1

Program Demographics and Characteristics

Demographic Category	<i>n</i>	%
Number of Student Enrolled		
1-4	4	4.4
5-10	15	16.5
11-15	19	20.9
16-25	26	28.6
26-35	7	7.7
36+	20	22.0
Program Years in Existence		
< 1 year	2	2.2
1-2 years	11	12.1
3-4 years	17	18.7
5-7 years	19	20.9
8-10 years	20	22.0
> 10 years	22	24.2
Dual-Enrollment Status		
Dual-enrollment	23	25.6
Non dual-enrollment	67	74.4
Type of IHE		
Community college	24	25.5
4-year liberal arts college	9	9.6
4-year university	48	51.1
Trade/technical school	2	2.1
Other	11	11.7
Total Student Population of the IHE		
< 2,500	11	12.2
2,500-4,999	8	8.9
5,000-9,999	16	17.8
10,000-14,999	16	17.8
15,000-19,999	10	11.1
20,000-24,999	8	8.9
> 25,000	21	23.3

Table 1 cont'd

<i>Program Demographics and Characteristics</i>		
Characteristic Category	<i>n</i>	%
Residential Model		
Students live on campus with a roommate of their choosing, in a location of their choosing	19	21.4
Students live on campus, exclusively with other program participants in a designated location on campus	15	16.9
Students live in off-campus housing, exclusively with other program participants	4	4.5
Students live off-campus with a roommate of their choosing, in a location of their choosing, or with their families	51	57.3
Domains of Support		
Employment	86	94.5
Independent living	70	76.9
Self-determination	90	98.9
College course access	84	92.3
Social engagement	86	94.5
Other	17	18.7
Guardianship Requirement Policy		
Requirement for student to retain guardianship	8	8.8
No guardianship status requirement	83	91.2
Percentage of Students Who Retain Guardianship		
< 25%	13	14.4
25-50%	20	22.2
50-75%	24	26.7
> 75%	33	36.7
Frequency of Communication with Parents Regarding Social Engagement		
Never	8	8.8
Once	4	4.4
Annually	3	3.3
Once a semester	27	29.7
Monthly	27	29.7
Weekly	21	23.1
Multiple times per week	1	1.1

Note: Sample for each item ranged from 89-4

Table 2

Services Offered to Build Students' Intimacy Knowledge

Services by Intimacy Type	<i>n</i>	%
Romantic Relationships		
No services offered	16	18.4
Dissemination of intimacy educational materials (e.g., pamphlets, flyers, brochures)	29	33.3
One-on-one sessions with full-time program staff	30	34.5
One-on-one sessions with peer mentors	26	29.9
Group courses with other program participants	50	57.5
Group courses with other university students outside of the program	19	21.8
Other	9	10.3
Sexual Activity		
No services offered	27	32.1
Dissemination of intimacy educational materials (e.g., pamphlets, flyers, brochures)	24	28.6
One-on-one sessions with full-time program staff	28	33.3
One-on-one sessions with peer mentors	17	20.2
Group courses with other program participants	39	46.4
Group courses with other university students outside of the program	17	20.2
Other	6	7.1

Note: Romantic relationships n = 87, sexual activity n = 84

Table 3

Frequency of Intimacy Topic Coverage Within PSE Supports for Building Intimacy Knowledge

Topic	Frequency (n)/%						
	Never	Once	Yearly	1 x Sem	1 x Month	1 x Week	>1 x a Week
Personal hygiene	(8) 9.2	(7) 8.1	(5) 5.8	(17) 19.5	(12) 13.8	(24) 27.6	(14) 16.1
Preventing sexual abuse	(11) 12.6	(12) 13.8	(18) 20.7	(32) 36.8	(9) 10.3	(3) 3.5	(2) 2.3
Preventing sexually transmitted diseases and infections	(32) 36.8	(16) 18.4	(12) 13.8	(20) 23.0	(5) 5.8	(2) 2.3	(0) 0.0
Unplanned pregnancy	(39) 44.8	(14) 16.1	(10) 11.5	(19) 21.8	(3) 3.5	(2) 2.3	(0) 0.0
Biological reproductive functioning	(36) 41.9	(16) 18.6	(11) 12.8	(18) 20.9	(3) 3.5	(2) 2.3	(0) 0.0
Initiating romantic relationships	(13) 14.9	(10) 11.5	(10) 11.5	(23) 26.4	(16) 18.4	(11) 12.6	(4) 4.6
Social skills and cues related to dating	(7) 8.2	(6) 7.1	(10) 11.5	(17) 20.0	(14) 16.5	(21) 24.7	(10) 11.8
Self-advocacy within a romantic and sexual relationship	(14) 16.1	(6) 7.1	(11) 12.8	(19) 21.8	(18) 20.7	(12) 13.8	(7) 8.1
Sexual and gender identity	(35) 40.2	(14) 16.1	(9) 10.3	(16) 18.4	(8) 9.2	(5) 5.8	(0) 0.0
Masturbation	(51) 58.6	(11) 12.8	(5) 5.8	(12) 13.8	(5) 5.8	(3) 3.5	(0) 0.0
Sustaining lasting relationships and marriages	(24) 27.6	(9) 10.3	(13) 14.9	(22) 25.3	(12) 13.8	(5) 5.8	(2) 2.3

Note: Sample ranged from 85-87 by topic

Table 4

Resources Offered to Build Students' Intimacy Knowledge

Services by Intimacy Type	<i>n</i>	%
Romantic Relationships		
Unpaid peer mentors	19	22.4
Paid peer mentors	22	25.9
Research-based curriculum	27	31.8
Program-created curriculum	32	37.7
Resources from a community agency	36	42.4
Resources from the IHE's health center	29	34.1
No resources are used	14	16.5
Sexual Activity		
Unpaid peer mentors	11	13.4
Paid peer mentors	16	19.5
Research-based curriculum	24	29.3
Program-created curriculum	26	31.7
Resources from a community agency	31	37.8
Resources from the IHE's health center	28	34.2
No resources are used	27	32.9

Note: Romantic relationships n = 87, sexual activity n = 84

Table 5

Frequency of Intimacy Education Professional Development

Frequency of Professional Development by Staffing Type	<i>n</i>	%
Full-Time Staff		
Never	43	50.0
Once	12	14.0
Annually	19	22.1
Once a semester	9	10.5
Monthly	2	2.3
Weekly	1	1.2
Multiple times per week	0	0.0
Peer Mentors		
Never	47	58.0
Once	8	9.9
Annually	9	11.1

Table 5 cont'd

Frequency of Intimacy Education Professional Development

Frequency of Professional Development by Staffing Type	<i>n</i>	%
Peer Mentors		
Once a semester	14	17.3
Monthly	0	0.0
Weekly	2	2.5
Multiple times per week	1	1.2

Note: Full-time staff n = 86, peer mentors n= 81