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

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DEDICATION

This dissertation is dedicated to the young men and women with intellectual disability enrolled in college who, like their peers, are trying to figure out who they are and who they will be. May your voice be the most valued in the room. To those who support them along the way, may you always remember a person's life is so much more than where they will live and work.

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ABSTRACT

Adults with intellectual disability report the same relational and sexual intimacy needs as those without disability, yet experience barriers in accessing intimacy education and engaging in intimacy. Postsecondary education (PSE) programs for students with intellectual disability allow for college students to experience a higher level of autonomy in choice-making they may not have experienced in their family home. 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, intimacy education professional development opportunities for PSE staff members, and staff perceptions on factors that could influence whether students engage in intimacy or access intimacy education. Frequency of support, context in which support is provided, and types of resources and services used to build intimacy knowledge were identified and varied across programs. Half of the respondents indicated that their PSE program provides support in building students' intimacy knowledge two times per year or less, with 15% of programs not providing any support related to building intimacy knowledge. Contextually, support is most frequently provided proactively for all students, and one-fourth of PSE programs provide support reactively based on a student's negative experience with intimacy. Intimacy topics most frequently discussed include personal hygiene and social skills and cues related to dating, while topics such as unplanned pregnancy, biological and reproductive functioning, sexual and gender identity, and masturbation were not discussed in 40-50% of PSE programs. Half of PSE programs do

not offer intimacy education professional development to their staff members, yet almost two-thirds of respondents indicated that students in their PSE program consider learning about intimacy a priority. Additional staff perspectives on influential factors that could affect whether a student enrolled in the PSE program can access intimacy education or engage in intimacy are identified. Implications for practice and future research are provided.

TABLE OF CONTENTS

LIST OF TABLES

CHAPTER 1

INTRODUCTION

Background of the Study

Intellectual disability is characterized by the American Association on Intellectual and Developmental Disabilities (AAIDD) as an individual having "significant limitations in both intellectual functioning and in adaptive behavior, which covers many everyday social and practical skills" (AAIDD, 2018, para. 1). Individuals with intellectual disability may have support needs relative to conceptual skills such as language, math, reasoning, knowledge, and memory (American Psychiatric Association, 2013). Socially, an individual may need support in developing empathy, communicating interpersonally, and developing new relationships. Those with an intellectual disability may require support related to self-management, personal care, organization, and work-related tasks. Intellectual disability is diagnosed when an individual's intelligence quotient is approximately 70 or below, in addition to confirmation of the individual's inability to function conceptually, socially, and/or practically within their environment (APA, 2013).

Outcomes for young adults across all disability categories are poor compared to their peers without disability, including outcomes in postsecondary education, employment, and independent living (Newman, Wagner, Cameto, & Knokey, 2009). Only 60% of young adults with disabilities have ever enrolled in postsecondary education, compared to 67% of their peers without disability. Sixty percent of young adults with disabilities are employed outside of their home, compared to 66% of young

adults without disability who report being employed. Approximately 60% of young adults without disability live independently, while only 45% of young adults with disabilities live outside of their family home. Outcomes specific to young adults with intellectual disability are poor compared to other disability categories. In fact, 29% of young adults with intellectual disability indicate they've ever enrolled in postsecondary education, 39% are employed and 36% live independently (Newman et al., 2009).

Community-based transition (CBT) programs for students with intellectual disability have been perceived as ineffective in improving these outcomes (Neubert, Moon, & Grigal, 2002). The need to improve these outcomes through rigorous educational experiences has led to the creation of postsecondary education (PSE) programs for students with intellectual disability. Although the number of postsecondary education programs have grown within the past decade, more information is needed in order to understand to how they support students in their skill development across various domains of life, including academics, employment, independent living, self-determination, and social engagement.

Articles within this literature base primarily focus on program development or outcomes related to employment and independent living. Social engagement outcomes for young adults with intellectual disability are also poor compared to general disability outcomes. 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). Those articles that focus on social skill development focus largely on the development of platonic friendships. The purpose of this study is to examine the continuum of support provided by PSE programs in building students'

intimacy knowledge. Examining how PSE programs are supporting students in building their intimacy knowledge and the perceptions of PSE staff members will yield valuable information for administrators to consider when making programmatic decisions regarding support in this area.

Education of individuals with intellectual disability. Preparation for career and independent living for students with disabilities is mandated to begin at the age of 16 through the process of secondary transition (IDEA, 2004). The Individuals with Disabilities Education Act (IDEA, 2004) refers to secondary transition services as "a coordinated set of activities within a results-oriented process, meant to facilitate the transition to adult life by focusing on the development of skills related to postsecondary education, vocational education, integrated employment, adult education, adult services, independent living, and community participation," (IDEA 300.43, 2004). IDEA (2004) also stipulates that students should have the opportunity to be exposed to age-appropriate content with their non-disabled peers. Community-based transition programs prepare 18-21 year-olds with disabilities to build employment skills while still enrolled in their respective high school communities. These programs are often ineffective, and overtime, stakeholders have sought a more natural and effective transition experience via postsecondary education (Neubert, Moon, & Grigal, 2002).

Families and local education agencies recognized the potential benefits of a college experience, and initiated the creation of PSE programs for students with intellectual disability (Hart, Grigal, Sax, Martinez, & Will, 2006). Key legislative and funding initiatives have increased the number of these programs on college campuses. In an effort to develop model PSE programs across the country, the U.S. Department of

Education has awarded over $20,000,000 in Transition and Postsecondary Programs for Students with Intellectual Disabilities (TPSID) grants to support emerging comprehensive PSE programs (U.S. Department of Education, 2015). Increases in access, funding, and legislation have led to the creation of 265 PSE programs for students with intellectual disability across the country (Think College, 2019).

PSE programs for students with intellectual disability. Programs are housed within two and four year IHEs, as well as trade and technical schools (Grigal, Hart, & Weir, 2012). Most programs consist of services and supports related to five domains including academics, independent living, employment, self-determination, and social engagement (Grigal et al., 2012; Plotner, Marshall, VanHorn Stinnett, & Teasley, 2018). Models for housing vary from program to program. Some are residential (on-campus dorms or apartments) and others may require students to commute to campus. While most PSE programs focus on skill development in career, academics, and independent living access (Grigal et al., 2012), the acquisition of social skills and building interpersonal relationships are desired outcomes associated with attending a PSE program (Miller, Schleien, White, & Harrington, 2018). College is a time of personal development through exposure to new beliefs and experiences (Arnett, 2000; Evans, Forney, Guido, Patton, & Renn, 2009). Students attending a PSE program for people with intellectual disability 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).

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 while in college, through the acquisition of self-determination skills, risk-taking, and the application of learned experiences to achieving desired agency. One type of identity development that occurs in the late teens and early twenties is intimate identity or one's thoughts and beliefs specific to romantic relationships and sex (Arnett, 2000; Evans et al., 2009). Positive intimate relationships, including engaging in romantic relationships and sexual activity, contributes to positive emotional well-being and a higher quality of life for people with intellectual disability (Arias, Ovejero, & Morentin, 2009). According to a bi-annual survey conducted by the American College Health Association in the Spring of 2018, 47.5% of undergraduate college students reported being in a romantic relationship. In a period of thirty days, 68.4% percent of undergraduate students engaged in oral sex, 65.1% in vaginal intercourse, and 25.4% in anal intercourse. Many students reported not using a condom or protective barrier when engaging in oral sex (51%), vaginal intercourse (45.9%), and anal intercourse (32.2%) (American College Health Association, 2018). The need for all students on campus to have access to intimacy knowledge is critical for the health, safety, and well-being of all people living and learning on campus (Lechner, Garcia, Frerich, Lust, & Eisenberg, 2013).

Intimacy education for people with intellectual disability. Comprehensive sexuality education programs that address the physical, mental, emotional, and social dimensions of sexuality have proven to be effective in reducing sexual risk behaviors (Haberland & Rogow, 2014). Sexuality education programs for people with intellectual disability have been proven effective in building intimacy knowledge, however they are limited to certain topics (Gonzalvez et al., 2018) and lacked evidence that participants are

able to generalize intimacy knowledge to real-life scenarios (Schaafsma, Stoffelen, Kok, & Curfs, 2013). Abstinence education is the likely sexual health programming students encounter in high school (Treacy, Taylor, & Abernathy, 2018) if any, as 57% of students with intellectual disability never receive sexual health programming (Barnard-Brak et al., 2014). Even so, sexuality education is often provided reactively upon a student engaging in intimacy (Gougeon, 2009). Young adults with intellectual disability may utilize other sources of information and resources to learn about intimacy including the internet, magazines, leaflets, books, sexual health services, films, or college courses (Williams, Scott, & McKechanie, 2014). As a result, young adults with intellectual disability may be relying upon their own lived experiences to learn about intimate relationships and activities (Gougeon, 2009).

Barriers to accessing intimacy education or experiencing intimacy. Many barriers exist for people with intellectual disability when it comes to experiencing intimacy including negative self-perceptions, the negative perceptions of others, and a lack of intimacy knowledge (Sinclair, Unruh, Lindstrom, & Scanlon, 2015). Lack of intimacy knowledge amongst people with intellectual disability (Barnard-Brak et al., 2016; Borawska-Charko et al., 2016; Galea, Butler, Iacono, & Leighton, 2004) may result in a lack confidence or misunderstanding as to how to pursue fulfilling intimate desires. Self-perceptions of sexual identity are poor amongst people with intellectual disability; they may feel a lack of control over their own intimate decision-making and uncertainty as to how to access supports to achieve sexual agency (Sinclair et al., 2016). Oftentimes, they can be made to feel wrong for exploring their sexual identity due to having an intellectual disability (Dinwoodie, Greenhill, & Cookson, 2016). Factors such as lack of

privacy, limited finances, and lack of transportation limit the ability of individuals with intellectual disability to explore intimacy. Often the ability to establish intimate relationships is dependent upon the support and assistance of their immediate family members (Azzopardi-Lane & Callus, 2014).

Barriers to experiencing intimacy include the perception that people with intellectual disability are asexual, the lack of consensus amongst caregivers on which topics should be covered within sexuality education, and how much and how often parents (identified as the primary instructors on sexuality for their child) are actually addressing this topic (Sinclair et al., 2016). Caregivers often encourage friendships, but not intimate relationships, which is difficult when caregivers have full control over whether or not a young adult with intellectual disability experiences intimacy (Lofgren-Martenson, 2004). Despite expressing an interest in learning more about how to discuss and educate their child with intellectual disability on intimacy, many caregivers report feeling a lack of confidence and training in being able to provide intimacy education (Evans, McGuire, Healy, & Carley, 2009).

Resources for building intimacy knowledge. When caregivers don't provide intimacy knowledge, support and information must be accessed elsewhere (Williams et al., 2014), however people with intellectual disability lack the social network and resources to receive adequate intimacy information (Jahoda & Pownell, 2014). They are more likely to consult service staff or relatives other than parents on matters of intimacy (Jahoda & Pownell, 2014), and may also access information about sex and dating from the internet, magazines, leaflets, books, sexual health providers, films, or college courses (Williams et al., 2014). An IHE's health center is one example of a resource that may be

used in building students' intimacy knowledge in college. Approximately 70% of college campuses have a health center and many report various services related to sexual education and health (Habel, Coor, Beltran, Becasen, Pearson, & Dittus, 2018).

Need for the Study

Intimacy refers to a level of physical and emotional closeness experienced within a reciprocal relationship (Moss & Schwebel, 1993). PSE programs for students with intellectual disability address many outcomes to increase the quality of life of their participants (Grigal et al., 2012). Intimacy is an important aspect of life for people with intellectual disability, who express the same need for intimacy as those without disability (Castelao, Campos, & Torres, 2010; Siebelink et al., 2006; Yau, Ng, Lau, Chan & Chan, 2009). Many adults with intellectual disability report that they are sexually active or desire to be (Gil-Llario, Morrell-Mengual, Ballester-Arnal, & Diaz-Rodriguez, 2018), however almost half never receive sexuality education (Barnard-Brak, Schmidt, Chesnut, Wei & Richman, 2014; Isler, Tas, Beyut, & Conk, 2009). Because of this, adults with intellectual disability lack intimacy knowledge across a variety of topics (Borawska-Charko, Rohleder, & Finley, 2016). This makes people with intellectual disability more susceptible than their peers without disability to potentially negative outcomes associated with engaging in intimacy, which could include unplanned pregnancy, sexually transmitted disease (Dekker, Safi, van der Zon-van Welzenis, Echteld, & Evenhuis, 2014), or sexual abuse (Akrami & Davudi, 2014). Recent literature has had a primary focus on students with intellectual disability in college building friendships (Butler, Sheppard-Jones, Whaley, Harrison, & Osness, 2016; Nasr, Cranston-Gingras, & Jang, 2015). Only one study has examined the effectiveness of a secondary sexuality education

program for this population of students (Graff, Moyher, Bair, Foster, Gorden, & Clem, 2018).

Purpose of the Study

Young adults attending college are more likely to encounter opportunities for intimacy risk-taking and decision-making they would in their family home (Evans et al., 2009). College campuses naturally expose students to experiences they may not have had in high school, such as opportunities to engage in intimacy. The purpose of this study is to examine the continuum of support that PSE programs provide to build students' intimacy knowledge. Specifically, this study will use a survey disseminated to full-time, PSE program staff members to identify the frequency, types, and context of support provided to students in building their intimacy knowledge. Frequency and satisfaction levels of intimacy education professional development opportunities for program staff will also be examined. Finally, staff members' perceptions of several influential factors that may affect students' ability to engage in intimacy or access support in building their intimacy knowledge in college will be analyzed. Findings gleaned could help improve PSE policy and practices related to providing support and professional development related intimacy education. Three research questions will guide the study:

Research Questions

1. Which supports do PSE program staff members report offering to students to build their intimacy knowledge?
2. How often is professional development related to building students' intimacy knowledge provided to PSE program staff members?

3. What are PSE program staff members' perceptions of influential factors that may affect program students' ability to engage in intimacy or build their intimacy knowledge?

Definitions

Causal Agency Theory. An extension of the functional model of self-determination. Individuals must utilize self-determined behaviors to take action to achieve their own desires, while having the self-awareness and knowledge to be independent in overcoming obstacles and setbacks they may face (Shogren et al., 2015).

Dignity of risk. In line with the principle of normalization, people with disability should be afforded the same right to experience risk with the potential for positive outcome as those without disability (Perske, 1972).

Emerging adulthood. The development that occurs in the late teens through the mid to late twenties (Arnett, 2000).

Intellectual disability. The federal definition under IDEA states that intellectual disability "means significantly subaverage general intellectual functioning, existing concurrently with deficits in adaptive behavior and manifested during the developmental period, that adversely affects a child's educational performance [34 Code of Federal Regulations §300.7(c)(6)}].

Intimacy. A level of closeness, emotionally and physically, achieved within a reciprocal relationship (Moss & Schwebel, 1993).

Postsecondary education (PSE) program for students with intellectual disability. College programs for students with intellectual disability that serve students within an IHE setting (Grigal et al., 2012).

Romantic relationships. Experiencing a level of closeness, while being listened to, understood, and valued within a reciprocal, affectionate relationship based on love (Schaefer & Olson, 1981).

Self-determination. The ability of a person to be the causal agent in their own life (Wehmeyer, 1996).

Sexuality. "Sexuality is a central aspect of being human throughout life and encompasses sex, gender identities and roles, sexual orientation, eroticism, pleasure, intimacy and reproduction. Sexuality is experienced and expressed in thoughts, fantasies, desires, beliefs, attitudes, values, behaviours, practices, roles and relationships. While sexuality can include all of these dimensions, not all of them are always experienced or expressed. Sexuality is influenced by the interaction of biological, psychological, social, economic, political, cultural, ethical, legal, historical, religious and spiritual factors (World Health Organization, 2006, p. 4)

Sexual activity. The sexual aspect of intimacy where physical closeness results in engaging in sexual acts performed with another with the purpose of achieving sexual gratification (Schaefer & Olson, 1981).

Sexual agency. One's control over their own body and choices related to engaging in sex (Phillips, 2000).

Sexual health. "…a state of physical, emotional, mental and social well-being in relation to sexuality; it is not merely the absence of disease, dysfunction or infirmity. Sexual health requires a positive and respectful approach to sexuality and sexual relationships, as well as the possibility of having pleasurable and safe sexual experiences, free of coercion, discrimination and violence. For sexual health to be attained and

maintained, the sexual rights of all persons must be respected, protected and fulfilled" (World Health Organization, 2006, p. 4).

Student Development Theory. The theory that college attendance affects personal development in variety of ways, due to the exposure of new ideas, people, and programming (Evans et al., 2009).

CHAPTER 2

LITERATURE REVIEW

This study aims to examine the continuum of support used by PSE programs for students with intellectual disability in building participants' intimacy knowledge. Specifically, this exploratory study will identify the frequency, type, and context of supports provided to students in building their intimacy knowledge. The frequency of intimacy education professional development offered to PSE staff members will be identified, as well as level of satisfaction with the amount of professional development provided by the program in this area. Staff members' perceptions of influential factors that could affect students' ability to engage in intimacy or access intimacy education will also be identified. The following literature review provides the reader with a brief history of the education of individuals with intellectual disability, including the evolution of college access for students with intellectual disability and the characteristics of PSE programs. To aid the reader in understanding intimate identity development as it occurs in college, a review of self-determination and related concepts and how they relate to college success and better quality of life is provided.

In order to establish the need for examining this topic, a review of the research examining the intimacy needs, experiences, and knowledge of individuals with intellectual disability will be presented, as well as a review of the history and current status of intimacy education specific to this population. Barriers to individuals with intellectual disability experiencing intimacy and accessing intimacy education will be

reviewed. Available supports, including those specific to the college environment, will be discussed. Literature specific to how PSE programs are supporting students in the development of their intimacy knowledge will be provided and contributes to the rationale for the current study.

Education of Individuals with Intellectual Disability

In the mid-twentieth century, people with intellectual disability were frequently served in institutions (Harris, 2006). In the 1960s, at the insistence of newly-elected president John F. Kennedy, a national spotlight was placed on the rights of individuals with disability. During the same decade, Nirje (1969) presented the principle of normalization to the disability services field, which states that people with disability have the right to a life that mirrors that of any other person, to the fullest extent possible. Advancements in federally-supported, community-based programs and the perpetuation of the normalization principle led to the decline of institutionalism, thus increasing the number of students with disability receiving special education services in public school systems (Harris, 2006). Over the course of the late 20th century, several key pieces of education legislation including the Elementary and Secondary Education Act (ESEA), The Individuals with Disabilities Education Act (IDEA), and No Child Left Behind Act (NCLB) have contributed to the progression of quality in special education programming for students with intellectual disability, including those preparing for adult life after high school.

Secondary transition. By the late 20th century, an emphasis was placed on the inclusion of individuals with disability in the least restrictive environment, the utilization of evidence-based practices, and ensuring skill development for better postsecondary

outcomes for people with disability after graduation from high school. The process of preparing for adult life after high school is known as secondary transition. The process of secondary transition became a national priority in the 1980s (Will, 1984). In a position statement from the Office of Special Education and Rehabilitation Services (OSERS), Will (1984) first described transition as a bridge between the security of secondary education and the risks of adult life. In 1990, the reauthorization of IDEA defined secondary transition as "a coordinated set of activities for a student, designed within an outcome oriented process, which promotes movement from school to post-school activities, including post-secondary education, vocational training, integrated employment (including supported employment), continuing adult education, adult services, independent living or community participation" (Section 300.18). Despite an emphasis on preparing students for adult life, outcomes for students with intellectual disability are poor, with the lowest rates of postsecondary education and work compared to other disability categories (Migliore, Butterworth, & Hart, 2009). Historically, instruction provided to students with disability has been "non-functional, artificial, and inappropriate for their chronological age," (Brown, Branston, Hamre-Nietupski, Pumpian, Certo, & Gruenewald, 1979, p. 83), and is still an area of concern in modern inclusive classrooms (DeSimone & Parmar, 2006).

Graduation from high school typically occurs at or around age 18, however students with disability have the opportunity to remain in transition programs housed within local school districts until they are 21 years old to pursue additional community-based instruction (Neubert et al., 2002). These community-based transition (CBT) programs allow for students to experience inclusion by remaining in the school setting for

a part of the day while also being exposed to community work experiences to prepare them for full-time work after high school (Gaumer, Morningstar, & Clark, 2004). However few CBT programs utilize evidenced-based curricula in program development and LEA personnel are not familiar with program characteristics or standards (Gaumer et al., 2004). Given this information, it is not surprising that students who elect to graduate with their peers and continue in CBT programs are considered to have the greatest unmet needs (Neubert et al., 2002), resulting in the development of more effective and age-appropriate programs for students with intellectual disability in postsecondary education settings.

College access for people with intellectual disability. College is inherently a place of exclusivity, with the role of "college student" being one of value and respect that many young adults aspire to, including those with intellectual disability (Hart, Grigal, & Weir, 2010). Collegiate access for students with intellectual disability began with the Civil Rights Movement of the 1970s. This movement culminated in the passage of Section 504 of the Rehabilitation Act in 1973, requiring institutions of higher education (IHE) receiving federal funding to be responsible for providing equal educational opportunities for students with disability who meet qualification criteria (Paul, 2000). The Americans with Disabilities Act of 1990 increased physical access to IHE campuses by eliminating discrimination related to public sites, thus increasing the enrollment of individuals with disabilities (Paul, 2000). Finally, revisions to the Higher Education Opportunity Act in 2008 allowed people with intellectual disability to access federal financial aid to fund their postsecondary education. The expansion of PSE programs for students with intellectual disability was a movement started by families wanting more

effective and age appropriate options for their child after completing high school (Grigal & Neubert, 2004).

The US Department of Education (DOE) funded Transition and Postsecondary Programs for Students with Intellectual Disability (TPSID) in an effort to develop model programs across the country. Additionally, the DOE funded Think College, the national coordinating center for PSE programs. The mission of Think College is to develop and improve postsecondary options for people with intellectual disability and to support the 266 programs that exist nationwide (Think College, 2019). The goal of PSE programs may differ, but largely it is to improve adult outcomes such as employment, independent living, and social and community engagement of individuals with intellectual disability by having them learn and often live in a college setting (Grigal, Hart, & Weir, 2012). Students have the benefit of pursuing higher education specific to their career goals, while experiencing college life with the support necessary to navigate barriers related to these domains.

Miller, Schleien, White, and Harrington (2018) conducted a qualitative study where they interviewed parents of graduates and current students of a PSE program to determine why they pursued college options for their child, what they hoped their child would gain from attending college, and which gains, benefits, and outcomes resulted from attending college. Twenty-three parents participated in the interview process; 22 of whom were parents of current PSE program students and five who were parents to a graduate. Findings of this study indicate that many students are encouraged by seeing peers and siblings move onto the next phase of life. Parents express feelings of "sadness" that their child with an intellectual disability would not be able to have the same

transitional experience until they realized PSE programs existed (Miller et al., 2018).

In these interviews, parents express a desire for students to achieve positive outcomes related to independent living, social relationships, career skills and employment, and experience in the "real world" as a result of going to college (Miller et al., 2018). Experiencing college naturally exposes students to practicing more self-care and independence such as taking care of their own personal needs, planning and preparing their meals, problem-solving, and time-management. Parents state that had their student remained at home, it would have been difficult for them to learn these skills, given that their family members would continue in the role of caretaker. Post-secondary programs for students with intellectual disability are viewed as a step between high school and living independently in the community (Miller et al., 2018).

Parents also believe that the college environment is better suited to facilitating natural connections and social networks (Miller et al., 2018). There are many opportunities to be involved in a variety of ways such as inclusive classroom participation, joining clubs and organizations, and living on campus. By attending a PSE program, positive outcomes related to independent living, conversational skills, social life and friendships, campus and community involvement, happiness, and employment may be achieved (Miller et al., 2018). By having their child experiencing college via a PSE program for students with intellectual disability, parents reported they were are able to "let go," and grant their child more autonomy with confidence in the skills that the program is supporting them in developing. Through this process, parents are finally able to understand the full capabilities of their son or daughter to be an independent adult (Miller et al., 2018).

PSE program characteristics and domains. In 2012, Think College conducted a national survey of PSE programs for students with intellectual disability in an attempt to identify major program characteristics and domains. A majority of programs (51%) are housed within four year colleges or universities, but they also exist within two-year community colleges (40%) and trade/technical schools (10%), (Grigal et al., 2012). Students enrolled in PSE programs may be adult students who have exited high school special education services, students who are dually enrolled in high school and college, or a combination of both. Those who are dually-enrolled have yet to exit an LEA program, however IDEA funds are given to the PSE program to serve students in a college environment rather than in a high school based transition program. Programs have different standards for entrance, which could include the traditional application and placement testing process or consist of a separate entrance process. A majority of programs (71%) report the use of special entrance criteria (Grigal et al., 2012). These criteria include considerations of a students' ability to follow the code of conduct, level of safety skills, ability to independently navigate campus, possession of a record of immunizations, attainment of a high school credential, disability label/type, and IQ. Eighty percent of programs report that they assist students in the registration process. Other models for college advisement that programs may subscribe to include typical college registration and utilization of a traditional college advisor (Grigal et al., 2012).

Programs focus on the development of many different skills. The most frequently reported primary focus area is independent living/life skills, followed by employment, college course access, self-determination, and social skills (Grigal et al., 2012). There is a significant level of variability in the foci and services that programs may use to meet the

needs of students (Grigal et al., 2012). Below is a brief description of program domains and examples of supports programs may offer students within each domain.

Independent living. A majority (67%) of programs indicate that they have a residential component. Residential settings could include dorms, on-campus apartments, off-campus apartments, fraternity or sorority houses, and exclusive dorm settings for students enrolled in the PSE program. Services offered to students within this setting could include independent living skills training, 24-hour staff support, and paid roommates (Grigal et al., 2012). The goal of the residential component of a PSE program is to provide students with learning experiences that prepare them to live independently in the community and environment of their choice upon graduation (Plotner et al., 2018). Staff members may assist students in living independently while living in the same location on campus or practicing skills with students in their respective residence (Plotner et al., 2018).

Employment. A majority (81%) of programs indicate that employment is the main focus of their program. Attending college increases the probability of obtaining a career (Bureau of Labor Statistics, 2015), as students benefit from coursework aligned with their career interests and social experiences that are generalizable to many aspects of life (Plotner et al., 2018). Students work towards their career goals by gaining valuable experience in the community. Programs offer varying levels of support based on student need which could include job shadowing, situational assessment, person-centered career planning, job development, placement services, job coaching, transportation, and the facilitation of natural supports (Grigal et al., 2012). The goal of the employment component of a PSE program is to prepare students for competitive, community-based

employment upon graduation (Plotner et al., 2018).

Academics/College course access. Seventy-five percent of programs indicate that students receive a majority of their instruction in small group courses with their peers from the program. Students access college coursework in an auditing capacity at 57% of programs and in a credit-bearing capacity at 51% of programs. Varying levels of support may be offered in achieving academic goals, which could include the utilization of accommodations via the Office of Disability services, modified coursework, and academic coaching (Grigal et al., 2012).

Social skills. The skills necessary to interact with a variety of people on a college campus are built throughout a students' time with the program. These necessary social skills include daily interactions with peers, initiating and maintaining new friendships, communicating with faculty and staff, and engaging in the campus community through participation in clubs and organizations (Plotner et al., 2018). Social involvement on campus is directed by students' preferences and often occurs naturally as a product of being a college student. Programs may assist students in social skill development by encouraging the vocalization of their social wants and needs, facilitating the broadening of social networks by introducing them to new people on campus, encouraging their attendance at organizational fairs, and role-playing social scenarios (Plotner et al., 2018).

Self-determination. Learning skills necessary to act in a more self-determined manner occurs across program coursework and services (Plotner et al., 2018). Inherently, college requires individuals to act with more independence and experience personal growth and development (Evans et al., 2009). Students are required to make decisions frequently such as where to eat, what to do with their free time, whether or not they

should do their homework instead of going out with friends, or whether they should tell their parents about their new relationships. Being a college student in itself entails utilizing skills related to many aspects of self-determination and the development of these skills are refined via PSE programming (Plotner et al., 2018). Because of the applicability to all aspects of college life, self-determination is seen as critical to the success of students both during and after college.

The Role of Self-Determination in Identity Development While in College

Self-determined behavior (autonomous functioning, self-regulation, psychological empowerment, and self-realization) predicts higher quality of life for individuals with intellectual disability (Lachapelle et al., 2005). They are more likely to experience a better quality of life if they are exposed to a variety of opportunities available to them (Brown & Brown, 2009). In order to become familiar with these options and their associated outcomes, individuals should be exposed regularly to a variety of opportunities available to them within their respective environment. This level of exposure to many choices occurs more frequently in the college setting compared to the family home environment (Evans et al., 2009). People with intellectual disability traditionally have fewer choices than their non-disabled peers and are more likely to make everyday choices such as what to wear or eat, but are not as frequently given the opportunity to make larger life decisions such as those related to career and living (Stancliffe, 2001). A desire to make more choices in their own lives exists, yet people with intellectual disability have little control over the decision-making process (Stancliffe, 2001). However, college life requires a higher level of autonomy in choice-making and the development of these skills is critical to their success (Getzel & Thoma,

2008; Jameson, 2007).

In a focus group of 34 college students from various cultural backgrounds and disability categories, students were asked to elaborate on the skills necessary to remain in college and access needed supports. College students identify many key components of self-determination as being necessary for college success including problem-solving, self-awareness, goal-setting, and self-management (Getzel & Thoma, 2008). Self-determination is linked to positive success outcomes for college students with disability (Jameson, 2007). Jameson employed a mixed methods study with 48 participants with disability who attended a two-year community college to determine the effect of self-determination on experience and outcomes. College students with higher levels of self-determination are more likely to report more positive outcomes. Students who report higher levels of self-determination describe a more positive experience and higher levels of success as a college student than those with lower levels of self-determination.

College identity development of students with intellectual disability. *Self-determination*, within the field of disability services, refers to the ability for one to be the primary choice-maker in his or her own life without the influence of family members, peers, and service providers (Wehmeyer, 1996). In an adolescent environment such as high school, many choices are made with the support of family members and teachers. In college, the role of choice-maker shifts from parent to child (Evans et al., 2009). Choices may include taking risks. *Dignity of risk* is a related concept that refers to the basic human dignity of allowing all people to experience risk with possibility of positive outcomes (Perske, 1972). In lieu of a sheltered life, professionals and parents should empower people with disability with the knowledge to take these risks and understand

both the positive and negative consequences associated with their actions (Perske, 1972).

Emerging adulthood (Arnett, 2000) refers to the development that occurs in the late teens through the mid to late twenties. This time period coincides with the most frequent age demographic enrolled in undergraduate programs, according to the National Center of Education Statistics (2017). During emerging adulthood, many students transition to college, which requires a higher level of independence and autonomy (Arnett, 2000; Evans et al., 2009). A point of emphasis within emerging adulthood includes making independent decisions (Arnett, 2000). This phase of the life is characterized by "trying out" scenarios across all life domains while moving towards more definitive values and preferences (Arnett, 2000). *Student Development Theory* relates to the impact that attending college has on personal development (Evans et al., 2009). Emerging adults' exposure to different programming and people forces them to think beyond their own lived experiences (Evans et al., 2009). *Casual Agency Theory* (Shogren et al., 2015) states that it isn't enough to simply teach self-determination concepts. In order to achieve agency in one's own life, one must apply the concepts of self-determination that they have learned to volitional action, resulting in the achievement of results desired by the individual (Shogren et al., 2015). College is a unique environment in which students with intellectual disability are developing, learning, and applying their knowledge to real-life scenarios they encounter each day, simply by being a college student. The college experience is a complex and enlightening process of autonomous identity formation. Identity development that occurs during emerging adulthood, combined with the exposure that college campuses provide to new ideas and values, may result in the development or evolution of an individual's beliefs and their

ability to take action towards achieving their desires by taking necessary risks.

Intimate identity development in college. Engaging in intimacy is an example of risk-taking that one could engage in while at college. During this time period, emerging adults are exploring sex and dating more seriously and forming their identities and values related to intimacy (Arnett, 2000). This process of identity development includes the exploration of an individual's values, needs, and attitudes related to intimacy and sexual agency (Evans et al., 2009). Several inherent needs drive human development during emerging adulthood (Arnett, 2000). In the field of sociology and psychology, there is a consensus on what "drives" human beings with the five primary drives being hunger, thirst, elimination, pain, and sex (Harlow, 1958). Secondary drives include love and affection (Harlow, 1958). Specifically, who we choose to share our lives with to fulfill basic socio-emotional needs such as feeling loved and cared for and fulfilling sexual desire (Harlow, 1958) contribute to a higher level of intimacy, which is correlated with greater happiness and well-being (McAdams & Bryant, 1987).

The definition of intimacy within its respective literature base is complex and not always clear (Popovic, 2005; Moss & Schwebel, 1993; Yoo, Bartle-Haring, Day, & Gangamma, 2014). There are many types of intimacy, including emotional, social, sexual, intellectual, and recreational intimacy (Schaefer & Olson, 1981). Literature specific to intimacy for people with intellectual disability focuses on two types of intimacy: relational and sexual (Siebelink, do Jong, Taal, & Roelvink, 2006). This is supported by general intimacy literature, which identifies emotional and sexual intimacy as significant predictors of relationship satisfaction (Yoo et al., 2014). 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, as cited in Povic, 2005). Emotional intimacy refers to experiencing this level of closeness while being listened to, understood, and valued within a relationship (Schaefer & Olson, 1981). Sexual intimacy refers to engaging in sexual activity to gratify physical needs (Schaefer & Olson, 1981). For the purpose of this study, emotional intimacy within a romantic relationship will be encapsulated into the term "romantic relationship," while sexual intimacy will be referred to as "sexual activity." Both romantic relationships and sexual activity are represented by the general term "intimacy."

Risk-taking and intimacy. 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). The integration of students with intellectual disability into college campuses is not done without considerations of risk as a result of navigating more autonomy in choice-making. In examining issues, policies, and procedures related to the development of PSE programs on a college campus, dignity of risk must be considered amongst all stakeholders (Plotner & Marshall, 2015). The concept of risk must be presented with transparency to parents and students, despite perceived levels of independence. Parental involvement in students' decisions to engage in risk may be difficult to navigate. Federal privacy laws require students' written permission to discuss their life at college with their parents. For PSE programs, this transition from IEP-like parent participation in high school to a more autonomous college life is particularly difficult when the matter of guardianship is taken into account. Programs may have different policies on whether they accept students who are their own guardian versus

those whose parents retain guardianship, affecting the level of communication between program staff and parents on matters of risk-taking (Plotner & Marshall, 2015). Intimacy is a topic that many parents are hesitant to discuss with their child with intellectual disability (Evans, McGuire, Healy, and Carley, 2009), therefore this topic may be particularly difficult to navigate for PSE program staff. In order to understand how PSE programs address the topic of intimacy within their respective programs, we must first examine the intimacy needs and experiences of people with intellectual disability as well as their level of intimacy knowledge.

Intimacy in the Lives of People with Intellectual Disability

Myths specific to people with disability and intimacy may impact their self-esteem and motivation to express their need for intimacy (Brodwin & Fredrick, 2010). Some of these myths include people with disability being asexual, oversexed with uncontrollable urges, dependent and therefore needing protection, and that disability will "breed" more disability (Brodwin & Fredrick, 2010). Other societal misconceptions include the idea that people with disability are sexually inadequate, do not have the same biological functions as those without disability (i.e., ovulation, menstruation, conception, giving birth, having orgasms, getting erections, or ejaculation), lack social skills and judgement to be sexually safe, and that women with disability are sexually passive (Brodwin & Fredrick, 2010). The reality is that people with intellectual disability express the same need for relational and sexual intimacy as individuals without disability (Castelao et al., 2010; Yau et al., 2009). In fact, 84.2% of adults with intellectual disability report having had a sexual relationship with another person (Gil-Llario et al., 2018), however these adults still lack intimacy knowledge which makes them more

susceptible to negative outcomes than their peers without disability, such as unplanned pregnancy, sexually transmitted disease (Dekker et al., 2014), or abuse (Akrami & Davudi, 2014). This is largely due to the fact that almost half of adults with intellectual disability do not receive sexual education (Barnard-Brak, et al., 2014; Isler et al., 2009) and therefore may lack critical knowledge in this area.

These themes (intimacy needs and knowledge, intimacy education, and network of support for developing intimacy knowledge) are reflected within the literature pertaining to intimacy for adults with intellectual disability (Medina-Rico, Lopez-Ramos, and Quinonez, 2018) and contribute to the need of the current study. Medina-Rico and colleagues (2018) conducted a literature review of articles pertaining to the sexuality of individuals with intellectual disability. The authors searched four databases for peer-reviewed articles published within the past ten years and identified 898 references specific to this topic. Articles were then reviewed by title and abstract by two independent reviewers to identify those articles that contained relevant information specific to the sexuality of individuals with intellectual disability. They identified 38 full-text articles for full review.

Seven articles pertained to sexuality in adolescents with intellectual disability (Medina-Rico et al., 2018). Within this area, the review indicated that sexual interests of adolescents with intellectual disability do not differ from those without a disability (Castelao, et al., 2010), boys with intellectual disability had more behavioral problems like public masturbation and 7.69% of boys had experienced sexual abuse (Akrami & Davudi, 2014). Young people with intellectual disability are aware of the rules associated with appropriate sexual behavior, but they did not understand how sexual relationships

develop (Frawley & Wilson, 2016). More than half of young adults aged 15-20 years with intellectual disability had not received sex education and almost half have never broached this subject with their parents (Isler et al., 2009). Further, young adults with intellectual disability lack knowledge of mechanisms of sexual intercourse and contraceptives, which indicates a higher predisposition to unplanned pregnancy and sexually transmitted disease compared to those without intellectual disability (Dekker et al., 2014). This was evident in a study conducted by Shandra and Chowdhury (2012), who found that young women (ages 12-24) with intellectual disability have less knowledge of contraceptives and less use of them with a sexual partner than those without intellectual disability. In the same study, the authors found that young women with intellectual disability desired pregnancy with their first sexual encounter at a higher rate than those without intellectual disability. Young adults with intellectual disability were more likely to participate in atypical sexual practices due to environmental factors (Wilson, Parmenter, Stancliffe, & Shuttleworth, 2015).

Six studies within the literature review address adults with intellectual disability and their sexuality (Medina-Rico et al., 2018). Chou, Lu, and Pu (2015) found that adults with intellectual disability are limited in developing emotional relationships and a healthy sexual identity. Yau, Ng, Lau, Chan, and Chan (2009) found that adults with intellectual disability desire intimacy, yet feel insecure in their ability to pursue a long-term relationship. Other findings include the higher likelihood of exclusive heterosexuality, fear of first sexual intercourse, and fear of negative consequences for engaging in intimacy (Bernert & Ogletree 2013). Additionally, auto erotic behavior is higher in individuals with intellectual disability compared to those without disability (Kijak, 2013),

and lack of knowledge regarding laws against sexual abuse, consent, and right to marriage exists amongst this population of adults (O'Callahan & Murphy, 2007).

Ten studies address the importance of sex education for adults with intellectual disability (Medina-Rico et al., 2018). Between 53-57% of people with intellectual disability receive sex education, largely due to educators not feeling prepared to teach this topic and their misperception of age-appropriateness (Barnard-Brak, Schmidt, Chesnut, Wei, & Richman, 2014). Concepts such as consent and legal implications of abuse are taught to combat the prevalence of vulnerability and sexual abuse amongst this population (Calitz, 2011; Enow, Nagalingam, Singh, & Thatlitaya, 2015). People with intellectual disability lack sexual knowledge related to bodily function during intercourse, contraceptives, and sexually transmitted diseases (Leutar & Mihokovic, 2007), but understand body parts (Thompson, Stancliffe, Wilson, & Broom, 2016). Important aspects in delivering sex education to individuals with intellectual disability include identification of important problems in the community, an evaluation of instruction being provided (Schaafsma, Stoffelen, Kok, & Curfs 2013), sex education classes being provided in mixed group settings, and discussing topics such as safe sexuality and feelings related to sex (Swango-Wilson, 2011), while understanding sentimental relationships and bodily function (Lofgren-Martenson, 2012).

Four articles address sexual and gender identity (Medina-Rico et al., 2018). Both Dinwoodie and colleagues (2016) and Lofgren-Martenson (2009) identified that adults with intellectual disability rarely identify as anything other than heterosexual and attribute this to the low level of support that these individuals have in exploring their gender and sexual identity. One article produced findings that dispute this, as the authors

found that individuals with intellectual disability were aware of their sexuality from childhood and further develop their sexual identity in adulthood (Rushbrooke, Murray, & Townsend, 2014). Another article stated that males with intellectual disability felt a sense of diminished masculinity because they could not complete masculine actions such as playing sports or retaining independence (Wilson, Parmenter, & Townsend, 2014).

Lastly, Medina-Rico et al. (2018) identified eight articles that discussed the network of support that adults with intellectual disability use to discuss intimacy topics. Support networks can influence an individual's level of intimacy knowledge, quality of information they receive on this topic, and access to resources and information (Pownall, Jahoda, Hastings, & Kerr, 2011). It is important to include family members of individuals with intellectual disability in intimacy education (Healy et al., 2009). Disability service providers and medical staff often lack the training needed to deliver this information to consumers with intellectual disability (Lafferty, McConkey, & Simpson, 2012; Meaney-Tavares & Gavidia-Payne, 2012). McCarthy (2011) identified the lack of tools to assess an individual's sexuality knowledge. Despite a lack of training and professional development in this area, parents (especially mothers) express an interest in wanting to communicate this information to their child with intellectual disability (Pownall et al., 2012; Yildiz and Cavkaytar, 2016), however communication about sex can be difficult, given parents' perceptions that their child with intellectual disability is an 'eternal child,' (Parchomiuk, 2012). In subsequent sections, these themes identified by Medina-Rico et al. will be expanded upon to contribute to a thorough understanding of what individuals with intellectual disability have experienced and what they know in relation to intimacy in order to address how their needs are met through intimacy education.

Intimacy needs and experiences. Romantic relationships and the ability to engage in healthy sexual activity play a role in the quality of life and emotional well-being of people with intellectual disability (Arias, Overjero, & Morentin, 2009). Gil-Llario and colleagues (2018) confirmed that people with intellectual disability have the same intimacy needs as those without disability. They interviewed 360 people (180 females and males, respectively) between 19 and 55 years of age with both mild and moderate levels of intellectual disability. One third of participants lived in supervised housing, a third in a residential facility, and a third in their family home. A questionnaire evaluating sexual behavior, preventive behavior, and experience of sexual abuse was given to participants in the form of an interview conducted by the researchers. Almost all (97.8%) of participants indicate that they have been sexually attracted to someone before, 88.3% reported having sexual fantasies, and 96.4% report having had a steady romantic partner at some point in their lives (Gil-Llario et al., 2018).

About three-fourths of participants indicate that that would like to have a partner in the future and 87.8% stated they currently had feelings for someone at the time of the interview. Approximately 85% of participants state they have had a sexual relationship with another person before with the most frequently experienced sexual practices being kissing and petting (99.2%), vaginal intercourse (84.4%), and oral sex (80.3%), however only 41.4% report being fully sexually satisfied (Gil-Llario et al., 2018). Participants of both genders expressed experiencing abuse (9.4% of women; 2.8% of men). Of those women who were abused, 52.9% report that they trusted someone enough to tell them, with most telling an educator (57.1%) as opposed to a close family member (28.6%). Of note was the fact that upon disclosure, all report receiving the blame for their abuse (Gil-

Llario et al., 2018).

Siebelink and colleagues (2006) report similar findings on the intimacy experiences of individuals with intellectual disability. The researchers interviewed 76 people with intellectual disability living in a supported community in the Netherlands in order to identify their intimacy knowledge, attitudes, experiences, and needs. Clients had the right to access societal aspects of sexuality including prostitutes, a culturally and legally acceptable practice in the Netherlands. All participants were at least 18 years or older, had no known or expressed history of sexual abuse, and had the ability to participate in a verbal and visual interview. Questions asked of participants were accompanied by visual cues. Twenty-eight questions were included across four topics: sexual knowledge, sexual attitudes, sexual and relational experience, and sexual and relational needs. Participants had a positive attitude towards heterosexual acts, including kissing, hugging, and sexual intercourse and state that they had less sexual experiences compared to relational experiences, which were quite common. Men and women are similar in their reports on relational experience, but men report more types of sexual experiences than women, particularly as it relates to impersonal sexual experiences (Siebelink et al., 2006).

For sexual and relational needs, participants report conventional sexual needs such as kissing, intercourse, and masturbation and relational needs such as hugging and having a romantic partner. Men report more sexual needs than women. When asked which relational and sexual acts they would like to participate in with a romantic partner, a majority indicate three activities: hugging (66%), kissing (62%), and sexual intercourse (57%). Non-sexual, social acts include shopping (64%), going for a walk (63%), or going

dancing (22%) (Siebelink et al., 2006). People with intellectual disability demonstrate interest and experience in engaging in intimacy (Arias et al., 2009; Gil-Llario et al., 2018; Siebelink et al., 2006), yet the literature suggests these adults require more intimacy knowledge (Borawska-Charko et al., 2016).

Level of intimacy knowledge. Borawska-Charko and colleagues (2016) conducted a literature review to determine the sexual health knowledge of people with intellectual disability. The authors conducted a search of peer-reviewed articles across a variety of electronic databases. There was no specified publication date range. In total, 46 articles that were published, written in English, and presented original research on the level of sexuality knowledge of people with intellectual disability were included in the review. These articles represent qualitative and quantitative methodologies, represent countries from all over the world (primarily from North America and Europe), and vary in sample size from 4 to 300 participants. Most articles (42) represent either mixed or unspecified samples of individuals with mild intellectual disability. Overall, the authors found that sexual knowledge in people with intellectual disability is lacking and that the level of knowledge varied significantly based on topic. Studies represented four decades, yet sexuality knowledge for this population was consistently low across all decades despite advances in sexuality education (Borawska-Charko et al., 2016).

Individuals with intellectual disability have some sexual knowledge. Most (93%) understand that sex could result in pregnancy, while 76% know about the risk of STDs. More than half (59%) can recognize a picture of a condom and 51% are able to recognize a picture depicting an individual masturbating. There are no significant differences in sexual knowledge amongst people with intellectual disability when taking into account

age or gender (Siebelink et al., 2006).

In an effort to determine the level of intimacy knowledge of this population, Healy, McGuire, Evans, and Carley (2009) conducted focus groups with 32 people with intellectual disability. One group consisted of individuals aged 13-17 years, another 18-30 years, and the last aged 31+ years. Once divided by age, the groups were further divided by gender. Focus groups conducted by the researchers were used to acquire a better understanding of the general views regarding sex and relationships for people with intellectual disability, their experiences regarding sexuality and relationships, and their aspirations for their intimate lives. The results of this study were categorized based on four themes: personal relationships, personal relationships and the role of relatives, experiencing relationships within a disability service environment, and sex and related issues.

The theme of sex and sex related issues include masturbation, sexual intercourse, sex education, contraception/sexually transmitted diseases, privacy, rules, and their thoughts for the future. Across all age groups, many participants have an incorrect or incomplete understanding of what masturbation entails and its purpose. Members of the 13-17 age group express feeling that it is forbidden to have sex before marriage. In the upper age groups, most understood the concept of sexual anatomy and that nudity in public was unacceptable. Most participants under the age of 18 had poor knowledge in relation to preventative measure for pregnancy and STDs. Those in the 31+ group are able to refer to both condoms and birth control pills as a means of preventing pregnancy (Healy et al., 2009). Poor intimacy knowledge may contribute to negative outcomes such as unplanned pregnancy, contraction of sexually transmitted diseases (Dekker et al.,

2004) and abuse (Akrami & Davudi, 2014). There is a need for effective intimacy education for people with intellectual disability in order to prevent these negative outcomes and in turn increase intimacy satisfaction and overall quality of life.

Intimacy education. An organization called *Future of Sex Education* (FoSE), sponsored by the Sexuality Information and Education Council of the United States defines comprehensive sexuality education as a planned curriculum that addresses all dimensions of human sexuality (physical, mental, emotional, and social) in an age-appropriate manner. The purpose of these programs is to support students in improving their sexual health while preventing disease and reducing sexual risk behaviors (FoSE, 2019). Curricula should be taught by qualified instructors to address the following topics: anatomy, physiology, families, personal safety, healthy relationships, pregnancy and birth, STDs, contraceptives, sexual orientation, pregnancy options, and media literacy (FoSE, 2019). Comprehensive sexuality education programs are generally effective in reducing sexual risk behaviors (Haberland & Rogow, 2015). Topics of intimacy education identified as necessary and specific to people with intellectual disability have include hygiene, sexual abuse prevention, STD prevention, unplanned pregnancy, reproductive healthcare (Servais, 2006), sustaining lasting relationships and marriages (Swango-Wilson, 2011), biological and reproductive functioning, sexual identity, and self-advocacy (Wolfe & Blanchett, 2006). Instructional methods and strategies could include the use of videos, mixed gender classes, access for caregivers/parents (Swango-Wilson, 2011), photographs, handouts/worksheets, discussion, lecture, and role play (Blanchett & Wolfe, 2002).

The effectiveness of intimacy education. Schwartz and Robertson (2018) conducted a literature synthesis to determine the components of sexual education programs for adults with intellectual disability and the effects of these programs on their sexual knowledge. Articles included in this review were peer-reviewed, used an experimental, quasi-experimental, or single-subject design, evaluated the effects of sexuality education specific to a topic (i.e.- reproduction), and evaluated effect via measure of sexual knowledge. Articles excluded include those specific to the sexual education of sexual offenders and those evaluating the effects of sexual abuse on program effectiveness. Six studies from six different journals met all criteria.

Two studies had a single-subject, multiple baseline design (Dukes & Mcguire, 2009; Zyalla & Demtral, 1981) and four used a group design (Casper & Glidden, 2001; Hayashi, Arkida, & Ohashi, 2011; Mueser, Valenti-Hein, & Yarnold, 1987; Valenti-Hein, Yarnold, & Mueser, 1994). While all studies examined the effects of sex education programs on sexual knowledge, some targeted specific areas or skills related to sexual knowledge. The curricula used in all of the studies were difficult to compare due to lack of description and varied content. Topics addressed across all studies included sexual intercourse, functioning, and birth control. Four articles additionally included all of the following topics: biological identification, gender identification, pregnancy, pregnancy prevention, hygiene, and safe sex (Casper & Glidden, 2001; Dukes & McGuire, 2009; Hayashi et al., 2011; Zyalla & Demtral, 1981). Three covered protective behaviors and choice (Casper & Glidden, 2001; Dukes & McGuire, 2009; Hayashi et al., 2011). Hayashi et al. (2011) also addressed self-assertiveness, communication, first impressions, and domestic violence, while both Mueser et al. (1987) and Valteni-Hein et al. (1994)

addressed social interactions and dating skills. Instructional methods and strategies used included integrated games and demonstrations, group conversations, lectures (Hayashi et al., 2011), and role-play and group discussion (Mueser et al., 1987; Valenti-Hein et al., 1994). Materials included handouts and worksheets (Casper & Glidden, 2001; Dukes & McGuire, 2009), anatomically correct dolls (Dukes & McGuire, 2009; Zyalla & Demtral, 1981), drawings (Casper & Glidden, 2001; Dukes & McGuire, 2009), and other supplemental materials (Hayashi et al., 2011; Zyalla & Demtral, 1981). Programs varied in duration from six weeks to three months (Schwartz & Robertson, 2019).

Schwartz & Robertson (2019) identified several flaws in these studies including methodological issues and lack of treatment fidelity cross all studies. However the authors indicate that there is still enough evidence to suggest that sexual education programs increase participants' sexual knowledge and that the difference amongst format, context, and content suggest that sexual education programs are developed and provided based on the needs and interests of the participants. Most of the interventions were related to sexual prevention and restraint and all were specific to heteronormative intimacy. It would be beneficial to understand the values and experiences of those conducting the studies to understand how they may have contributed to the components of each intervention (Schwartz & Robertson, 2019).

Similarly, Gonzalvez and colleagues conducted a meta-analysis to examine the effectiveness of sexuality education programs for people with intellectual disability (Gonzalvez et al.,2018). Researchers conducted a search across four electronic databases for articles containing experimental studies on the effectiveness of sexuality education programs for people with intellectual disability, as measured by pre and posttest, which

included enough data to demonstrate effect. An initial database search produced 3826 records, with 42 specifically addressing the evaluation of a sex education program for people with intellectual disability. After reading all 42 articles, the researchers determined that eight met the criteria for inclusion. The purpose of this analysis was to analyze the characteristics of sex education programs for people with intellectual disability, identify the variability of results, and propose future lines of research relative to the topic.

The eight studies included for analysis were published between 1988 and 2017, spanning four decades. Participants ranged in age from 11 to 56 years. Half of the studies were specific to participants with mild intellectual disability, two with mild or moderate, one with mild, moderate and severe, and one study which did not clarify participants' level of intellectual disability. Three categories of intervention techniques were identified: (1) psychosocial techniques, (2) cognitive-behavior techniques, (3) and traditional educational techniques. The average intervention duration is nine sessions of one hour per week, where post assessment occur an average of six weeks after completion. Content addressed within the programs predominately includes social skills and decision-making, inappropriate sexual behavior, and sexual abuse and to a lesser extent included healthy sexual relations and managing fear and stress. Effectiveness is measured via global effect, as determined by posttest assessment scores across all studies. The global mean effect for all studies (d = -.64) indicates that overall, sex education programs for people with intellectual disability are effective for those in intervention groups within these experimental studies (Gonzalvez et al., 2018). Single gender courses, as compared to mixed gender courses, are more effective. IQ level of participants and the

country in which the study was conducted has no bearing on overall effectiveness of sex education programs, but level of training received by program instructors impact the effect size, indicating that those programs using instructors with higher levels of training are more effective (Gonzalvez et al., 2018).

Schaafsma et al., (2015) also conducted a systematic review of sex education programs for individual with intellectual disabilities with the intent to determine which methods can be used effectively. The literature search and selection consisted of a three phase search of publications from the past 30 years using the search terms "intellectual disability," "sexuality," and "education", resulting in a list of 838 articles for initial inclusion. The next step of review required researchers to narrow down publications using the following criteria: the topic of the article must be sexuality, the population must be people with intellectual disability, the article must address sex education, and must be written in English. A final content analysis of abstracts for the remaining 59 articles and validity checks by the researchers resulted in the inclusion of 20 articles for the review.

Each of the 20 identified studies were geared toward improving knowledge and attitudes related to sex for people with intellectual disability. Fifteen of the twenty articles stated specifically which methods they used to teach knowledge, skills, or improve attitudes related to sex. The researchers note that the descriptions of topics and methods were often very broad and generic and none included justification for why the methods and topics were chosen (Schaafsma et al., 2015). A majority of studies failed to indicated the goals of the program and there were no methods that were identified as being developed systematically or rooted in theory and evidence. In most studies, there was a discrepancy in the lack of reporting how methods were used and parameters for correct

use, therefore it is unknown whether the methods were implemented correctly. The findings of the 20 studies of sexual education for people with intellectual disability indicate that despite the broad and generic goals of programs, it is possible to increase sexual knowledge, attitudes, and skills, yet the generalization of skills to real-life scenarios was seldom achieved. These findings indicate that while sex education materials and interventions for people with intellectual disability do show the ability to improve knowledge and attitude, they lack evidence and theory and are not always effective in generalizing to real-life scenarios (Schaafsma et al., 2015).

The need for effective intimacy education. McDaniels and Flemming (2016) reviewed the literature to determine the appropriateness, need, and availability of effective sexuality education programs for people with intellectual disability. The authors reviewed ten social science databases for full-length articles related to sexuality education for people with intellectual disability published in English between 1995 and 2015 in the United States and western countries. Initially 130 articles were included for review, however these were narrowed to 92 after accounting for whether the articles addressed the consequences of inadequate sex education or whether they examined the effectiveness of sex education curricula specific to people with intellectual disability.

This review confirmed previous findings of the field, that sexual abuse amongst people with intellectual disability occurs more frequently compared to people without disability (McDaniels & Flemming, 2016). People with intellectual disability are four to eight times more likely to experience sexual abuse (Jones, Bellis, Wood, Highes, McCoy, Eckley, & Officer, 2012; Servais, 2006; Spencer, Devereux, Wallace, Sundrum, Shenov, Bacchus, & Logan, 2005; Sullivan & Knutson, 2000). Without appropriate sexual

education, those with intellectual disability have an increased risk of negative consequences associated with engaging in unhealthy sexual practices (Gougeon, 2009). McDaniels and Flemming (2016) also confirmed the lack of sexual knowledge amongst this population of adults (Galea et al., 2004; McCabe & Shrek, 1992; McGillivray, 1999; Murphy & O'Callahan, 2004).

Current approaches to intimacy education. The inclusion of students with intellectual disability into general sexuality education courses is not effective in meeting the needs of these students (Walker-Hirsch, 2007). In their literature review, McDaniels and Fleming (2016) cite the 2002 sex education curriculum review conducted by Wolfe and Blanchett. In this curriculum review of 12 curricula for students with intellectual disability recommended by the Sexuality Information Education Center of the United States, only five were created specifically for students within varying categories of disability and most dealt with very limited topics such as sexual abuse, relationships, and STD prevention (Wolfe & Blanchett, 2002). Another concern throughout the literature was 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 and Fleming, 2016). Lastly, intimacy education is often provided reactively upon a student engaging in sex, which increases the likelihood of misinformation, abuse, STDs, and behavioral issues (Gougeon, 2009).

Barriers to accessing intimacy education and experiencing intimacy. Sinclair and colleagues (2015) conducted a literature review of peer-reviewed articles published between 2000 and 2013 to determine the barriers that exist for people with intellectual and developmental disability in achieving sexual agency. Thirteen articles were identified

by the authors as meeting the criteria for being timely, peer-reviewed articles pertaining to the sexuality exploration of individuals with intellectual and developmental disability. Themes identified within the articles include perceptions of others about people with intellectual and developmental disability and their sexuality, perceptions of individuals with intellectual and developmental disability on their own sexuality, and the lack of knowledge that this population has regarding sexuality (Sinclair et al., 2015).

Perceptions of caregivers and service providers. Over half the articles pertained to caregiver and service provider misperceptions of the sexuality of individuals with intellectual and developmental disability. The first barrier identified within this theme is the idea that their son or daughter was asexual. The second barrier is a lack of consistency in which topics and instructional approaches are used in educating people with intellectual and developmental disability on sexuality. There is no consensus amongst service providers as to what should be taught and how it should be taught. The third barrier within this theme is that parents identify themselves as the primary instructors on sexuality, yet there is little data on how much and the quality of the sexuality instruction that is actually being provided (Sinclair et al., 2015). This confusion on whether to teach sexuality and the quality of this instruction may contribute to the confusion or lack of knowledge that individuals with intellectual disability have when exploring their sexuality.

Caregiver relationships have an impact on an individual's sexuality (Lofgren-Martenson, 2004). Lofgren-Martenson conducted 36 participant interviews and 14 observations from dances specifically for people with intellectual disability. Participants for observation included a group of young adults who attended social dances, as dances

are a common meeting place for young people and a controlled environment for observation. Participants with intellectual disability were selected for interviews based on whether they were brought up in a family environment. Family and staff members who participated in interviews were reflective of those whose clients and children attended said dances. Participants describe an environment at home that is highly controlled with much oversight. Staff and family members of youth often encourage friendships, but not intimate relationships. Because young adults with intellectual disability may express their sexuality in ways that caretakers are unfamiliar with, it often creates an "us" and "them" relationship where the caretaker has full access to the young adult's sexual experiences (Lofgren-Martenson, 2004).

Evans and colleagues (2009) sought to identify staff and family members' attitudes toward relationship and sexual autonomy of people with intellectual disability. They surveyed 208 staff and family members of people with intellectual disability. Each participant was mailed a questionnaire asking respondents to rate their attitudes and experiences related to discussion of sexuality for people with intellectual disability, education and training, the sexual rights of people with intellectual disability, and their views on relationships amongst people with intellectual disability. The questionnaire also included three hypothetical scenarios which addressed topics such as pregnancy, privacy, and intimacy.

Approximately one third (35%) of staff members and 20% of family members feel confident in providing intimacy education for their family member or consumer with intellectual disability (Evans et al., 2009). For those staff members who indicate they are not confident, 35% state that it is due to lack of training and qualifications, personal lack

of confidence in discussing such issues (35%), uncertainty in what their organization's guidelines were for having such conversations (29%), parental preference (16%), and other barriers to discussing intimacy (13%). Family members who weren't confident in having such discussions indicated that it was due to not knowing how to explain issues related to sexuality (29%), a lack of personal understanding of sexuality (20%), and a lack of their family member with intellectual disability's understanding of sexuality (12%) (Evans et al., 2009).

Most staff and family caretakers agree that all people with intellectual disability should be able to engage in non-intimate relationships and friendships with their male or female friends (Evans et al., 2009). There are differing opinions of capability of specific relationships based on respondent category and level of disability. For those with a mild intellectual disability, 26% of parents, 4% of siblings, and 87% of staff members feel individuals with intellectual disability are capable of friendship. Seventeen percent of parents, 9% of siblings, and 85% of staff members believe people with mild intellectual disability capable of non-intimate relationships (Evans et al., 2009). No family or siblings believe their family member with mild intellectual disability are capable of an intimate relationship, yet 55% of staff members believe them capable. Four percent of parents, no siblings, and 48% of staff members believe that people with mild intellectual disability are capable of marriage (Evans et al., 2009).

Staff members overseeing the development of clients feel that the person with intellectual disability should be involved in the decision-making process 79% of the time, while the family should be involved 73% of the time, and other staff members 70% of the time (Evans et al., 2009). Sixty-three percent of family members feel that they should be

involved in deciding which level of relationship was appropriate for their family member with intellectual disability, 58% feel that staff members should be involved, and only 20% feel that the individual with intellectual disability should be involved. One quarter of staff (25%) and family members (26%) are undecided in their beliefs that adults with intellectual disability should be unsupervised in relationships. Forty-two percent of staff members, but only 10% of family members feel that adults with intellectual disability should be left unsupervised if they wanted to do so. Sixty-nine percent of staff members feel that family members should not be informed about the relationships of adults with intellectual disability and 57% of parents agree. In regard to training, only 12% of staff members and 8% of family members have received training in discussing sexuality with adults with intellectual disability. Ninety-five percent of staff members and 55% of family members expressed an interest in receiving training in facilitating these conversations (Evans et al., 2009).

Perceptions of individuals regarding their own sexuality. Almost all articles within Sinclair's review touched upon the perceptions that individuals with intellectual disability have about their own sexuality. Barriers identified within this theme include feeling a lack of control over their own relationship and sexual-related decisions and a lack of understanding of how to engage in sexuality and access sexuality education (Sinclair et al., 2015). If individuals with intellectual and developmental disability feel as though they have no control over their intimate lives and no idea of where to start in terms of accessing the information that they need to achieve sexual agency, it is not surprising that their self-perceptions are poor.

Azzopardi-Lane and Callus (2014) recorded the meetings of a self-advocacy

group for people with intellectual disability who attended day centers and chose to discuss sexuality and relationships in Malta. Participants express feeling that because they have a disability that means that they can't be in a relationship. Society at large determines social norms related to sex and relationships, but people with disability are further limited by factors such as lack of privacy, limited finances, and reliance on others for support, particularly transportation. Because most participants live with their immediate families, they convey their feeling of being controlled by their own family's thoughts on whether they should be sexually active or dating. Participants feel the need to interact socially more often with people their own age. When exploring the idea of constructing their sexual selves, many feel embarrassed by their own sexuality, as there was no discussion that referred to engaging in sex because it brought pleasure (Azzopardi-Lane & Callus, 2014). For those individuals with intellectual disability who are exploring their sexual and gender identity, they can be made to feel wrong, confused, or fearful of discussing this topics with others (Dinwoodie et al., 2016).

Lack of sexuality knowledge. Five articles addressed the lack of knowledge that individuals have on sexuality. Galea and colleagues (2004) found that individuals with intellectual and developmental disability have poor scores on a sexuality assessment in understanding concepts on virtually all aspects of sexuality (Galea et al., 2004). This lack of knowledge was confirmed in two other studies (Cabe & Cummins, 1996; Swango-Wilson, 2011) and only one study (Dukes & McGuire, 2009) proved the effectiveness of a sexuality education intervention in increasing participants' capacity to make intimacy decisions (Sinclair et al., 2015).

Support for building intimacy knowledge for people with intellectual disability. Individuals with intellectual disability have a smaller social network and fewer sources for sexual information, compared to their peers without disability (Jahoda & Pownall, 2014). In a study of 30 young adults with intellectual disability and 30 young adults without disability, Jahoda and Pownell sought to identify sources of sexual information amongst youth with and without intellectual disability. Youth with intellectual disability are less likely to speak with family, friends, or doctors (Jahoda & Pownall, 2014). Young adults with disability receive knowledge of contraceptives and preventative practices most often from service staff (49.2%), relatives others than parents (33.6%), friends (10.3%), and parents (5.3%), (Gil-Llario et al., 2018). A third of young adults discuss sexuality with relatives other than their parents, 23.9% with educators, 21.1% with friends or companions, and 9% with other people. Most (89.4%) state that they wanted to talk about sexuality more frequently than they currently do (Gil-Llario et al., 2018).

Williams, Scott, and McKechanie (2014) conducted an exploratory interview study with the intent of identifying who young adults with intellectual disability talk to for relationship and sex advice, the sources of information they used in learning more about sexual health, their experience with sexual health services, and their perceptions on what sexual health services should be like. Thirty-four adults with intellectual disability, ranging in age from 16-35 answered a questionnaire in an interview setting. The questionnaire consisted of both open and closed questions aimed at determining sources of help, sources of information, experiences with sexual health services, and preferences for sexual health services.

A majority of students with intellectual disability indicate that talking to someone

about sex and relationships was not a priority in their life at the moment. However, in the event that they did need someone to talk to about relationships, that most consult their parents (n=21) and friends (n=20), while others indicate that they seek the advice of doctors (n=11) or support staff (n=10). For advice or information about sex, 16 state they consult with parents, 15 with doctors, 13 with friends, and 8 with their partners. Despite fears of embarrassment and reprimand, participants state that they would likely consult their parents due to their trustworthiness and experience. There is a general concern that sharing information with peers is inappropriate or that peers' limited experience prohibits their ability to give advice. Three participants indicate that they have no one at all to talk to about sex or relationships. Women prefer to speak to their mothers or a female general practitioner, while men don't express a preference in the gender of their doctor. Adults with intellectual disability express that they only seek out a doctor for medical reasons, not for advice. Some are hesitant to reach out to their doctor because they believe they are unsympathetic. Few participants feel that sexual health services were useful alternatives, given that it is difficult for them to understand their unique support needs.

A variety of sources of information about sex and relationships are accessed, including the internet (n=9), magazines (n=6), leaflets (n=8), books (n=6), sexual health services (n=7), TV (n=4), films (n=3), and college courses (n=2). Most participants express satisfaction with their sexual education, but feel they lack information related to the emotional side of sex and sexually transmitted diseases. Some stat that they feel they missed out on more comprehensive sexual education because they attended special schools specific to their disability and support needs. Few participants (15.6%) have utilized health services, but those who had utilized these services view the experience

favorably. Some participants express that they feel health services took them more seriously. A majority (59.4%) of participants feel that health services that can be accessed by both genders so that partners could attend together would be helpful. Many express a desire to utilize services where they feel that the staff was relaxed, friendly, helpful, and possess the ability to explain things clearly. A majority of participants (65.6%) indicate that they would like for a family or support staff member to accompany them when going to receive sexual health services (Williams, et al., 2014).

Many college campuses offer sexual health services and educational programming (Habel et al., 2018). About 70% of college campuses have a student health center. Most offer STI/STD treatment and diagnosis, contraceptive services, and sexual health education. This valuable campus resource also has established community agency partners to provide continuing and supplemental intimacy education for all students (Habel et al., 2018).

Current PSE program support. There are few studies that focus on PSE program participants' development of relationships. Two studies (Butler et al., 2016; Nasr et al., 2015) have components that focus on building friendships while in college. One study conducted by Graff et al. (2018) examined the effectiveness of a secondary sexuality education program called Positive Choices, being implemented in a postsecondary education environment. The site of the study was a 4 year PSE program of 55 students ages 18-27. The first intervention group consisted of 13 first year students in a human development course exclusively for program participants with subsequent intervention groups consisting of incoming freshmen in the same course for the next academic year. There was only one control group in the first year of the study, which consisted of 12

students in the second, third, and fourth year of the PSE program. All participants were individuals with intellectual disability or autism spectrum disorder. The Positive Choice curriculum consists of a teacher workbook complete with outlined objectives and goals, assessments, lessons plans, and extension activities for each topic. Student workbooks include fill-in-the-blank notes for each lesson as well as pictures and activities relevant to the given topic. Topics covered within the curriculum include relationships and self-awareness, maturation, the life cycle, sexual health, and 'being strong, staying safe.' These topics were each encapsulated into their own respective chapters and while each chapter included a summative assessment, the researchers chose to create their own unit assessments to be used as a pre/posttest measure of participants' knowledge. A *t* test was used to compare the assessment data of the intervention group to the control group. Results indicate a significant statistical effect in knowledge of relationships and self-awareness and maturation and moderate effect for knowledge of sexual health and 'being strong, staying safe' with the use of the Positive Choices curriculum. The control group showed no gains in knowledge in these areas. Chapter three, The Life Cycle, was not taught due to time constraints and was listed as a limitation. While their knowledge increased, participants still had many questions and wanted to continue to discuss these topics in and outside of class sessions, indicating a need for a more comprehensive intimacy education supports for this population of students.

Rationale for Current Study

College options for students with intellectual disability allow emerging adults to 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). The transition from high school to college also involves transition in thoughts regarding sexual freedom (Evans et al., 2009). High school tends to be an environment dependent upon the message of abstinence, whereas college campuses typically promote safe sex instead of no sex (Evans et al, 2009). High school provides a protected environment for students with disability. The college environment provides the perfect atmosphere for personal growth, but it also forces students to make choices daily that could impact their overall happiness and safety when it comes to engaging in intimate relationships. While the focus of many PSE programs may be to prepare students for employment after college, a large part of the experience is the inclusion in college culture. Students are living on campus, attending classes with their peers, going to sporting events and participating in clubs and organizations. Meeting new people and learning how to develop and maintain relationships- both platonic and romantic- is a large part of the college experience. Like many college students, students with intellectual disability are also exploring their own values related to intimate relationships. It is a time when males and females alike are thinking about the next phase of their life and who they're going to spend it with. Exploring sexual desire is an innate need (Harlow, 1958) and teaching students with intellectual disability to navigate emotional and sexual needs associated with intimate relationships is critical to better quality of life (Arias, Ovejero, & Morentin, 2009). 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 is to contribute to the literature base by identifying which supports are being provided to PSE students with intellectual disability in building their intimacy knowledge, how often and

what context they are being provided, the frequency of intimacy education professional development offered to PSE staff members, and PSE staff members' perceptions on influential factors that could affect whether a student could engage in intimacy or access intimacy education in college.

CHAPTER 3

METHOD

The purpose of this study is to examine the continuum of support offered by staff members of PSE programs for students with intellectual disability in supporting participants in building their intimacy knowledge. Specifically, the researcher examines the frequency and context in which staff members of PSE programs are providing supports (e.g., assessment, resources, and services) to build students' intimacy knowledge. This study also explores how often professional development related to supporting students in developing their intimacy knowledge is provided to PSE program staff members, as well as staff members' level of satisfaction with the amount of professional development being offered in this area. Additionally, the researcher examines PSE program staff members' perceptions of influential factors that may affect students' ability to engage in intimacy and build their intimacy knowledge. College students explore freedom in choice-making and sexual identity that they may not have had the opportunity and resources to explore in high school (Arnett, 2000; Evans et al., 2009). Sexual and relational needs exist for people with intellectual disability (Castelao et al., 2010; Gil-Llario et al., 2018; Yau et al., 2009) and they express an interest in learning more about intimacy (Gil-Llario et al., 2018). Thus a research study utilizing a survey was designed. The following research questions guided the study:

1. Which supports do PSE program staff members report offering to students to build their intimacy knowledge?

2. How often is professional development related to building students' intimacy knowledge provided to PSE program staff members?

3. What are PSE program staff members' perceptions of influential factors that may affect program students' ability to engage in intimacy and build their intimacy knowledge?

Participants

One program staff member who coordinates supports for students from each of the 265 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 phone number associated with the program. The researcher then contacted these programs via phone and asked for an email address of the staff member who coordinates or has knowledge of the day-to-day support offered to students. 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%. Initially, 68 responded to the survey request. Upon second request via email, 18 additional respondents completed the online survey. Respondents represented 36 states within the United States. Participants at their respective programs included directors, assistant directors, coordinators, leadership staff, general staff, manager, lecturer, instructor, transition specialist, co-founder, dean, senior regional director, and principal. Summary statistics regarding individual demographics are included in Table 3.1 below.

Table 3.1

Individual Demographics

Demographic Category	n	%
Gender		
Male	13	13.5
Female	83	86.5
Highest Level of Education		
High School/GED	1	1.0
Associates	0	0.0
Bachelors	15	15.6
Masters	56	58.3
Doctorate	24	25.0
Years of Experience with Current Program		
<1 year	8	8.3
1-2 years	18	18.8
3-4 years	31	32.3
5-7 years	12	12.5
7-10 years	12	12.5
>10 years	15	15.6
Demographic Category	n	%
Title		
Director	43	45.7
Assistant Director	6	6.4
Coordinator	30	31.9

Table 3.1 (continued)

Demographic Category	n	%
Title		
Leadership Staff	5	5.3
Other	10	10.6
Years in Role		
<1 year	13	13.5
1-2 years	22	22.9
3-4 years	24	25.0
5-7 years	15	15.6
7-10 years	6	6.3
>10 years	16	16.7

Note: n for each item ranged from 94-96

Program Demographics and Characteristics

Table 3.2 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. Intellectual disability represented the largest (76.9%) disability category represented amongst the majority of students within PSE programs. Other categories representing the majority of students enrolled include Autism Spectrum Disorder (17.6%), Multiple Disabilities (4.4%), and Other Health Impairment (1.1%). Table 3.3 provides the frequencies in which all disability categories are represented in the PSE program student population. Table 3.4 provides summary statistics of program characteristics residential model, domains of support, guardianship policy, and level of communication with parents/guardians regarding social engagement.

Table 3.2

Program Demographics

Demographic Category	*n*	%
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

Note: Sample for each item ranged from 89-94

Table 3.3

Frequency of Disability Category Representation in Student Population

Disability Category	*n*	%
Specific Learning Disability	56	61.5
Other Health Impairment	56	61.5
Autism Spectrum Disorder	87	95.6
Emotional Disturbance	24	26.4
Speech or Language Impairment	55	60.4
Visual Impairment	34	37.4
Deafness	14	15.4
Hearing Impairment	32	35.2
Deaf-Blindness	6	6.6
Orthopedic Impairment	25	27.5
Intellectual Disability	86	94.5
Traumatic Brain Injury	38	41.8
Multiple Disabilities	62	68.1

**n = 90*

Table 3.4

Program Characteristics

Characteristic Category	*n*	%
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

Table 3.4 (continued)

Characteristic Category	*n*	%
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 89-91

Instrument

Instrument development. The instrument was developed based on existing literature surrounding intimacy experiences, education for people with intellectual disability, and college student development. The connection of survey items to the literature is depicted in Appendix A (Table 3.5), which adds to the internal validity of the study (Johnson & Morgan, 2016). The instrument was reviewed by a group of experts which consisted of a current PSE program director, assistant director, and coordinator from one programs and a director from Think College, a national expert in PSE for students with intellectual disability. 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 that needed to be added was gathered via a survey feedback form created specifically for this instrument (see Appendix B). Expert feedback was used to add items that could contribute to identifying the understanding the supports being offered by programs, ensuring 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 consisting of five sections, was developed for the purpose of this study (see Appendix C for the full CoSIK-C). 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. Within 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, and the topics covered within these supports.

The fourth section of the CoSIK-C consists two items aimed at identifying both the frequency and level of satisfaction of professional development provided to staff members in the area of intimacy education. The fifth and final section of the CoSIK-C consists of four questions, one which requires respondents to indicate their level of agreement with 12 influential factors that may affect participants' ability to engage in

intimacy and access support to build their intimacy knowledge.

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 three research questions.

Research Question 1: *Which supports do PSE program staff members report offering to students to build their intimacy knowledge?*

In order to identify which supports are being offered by PSE program staff members to students to building their intimacy knowledge and how often and in what context these supports are being provided, the researcher examined the assessments, services, and resources used for this purpose. The supports being used by programs to build intimacy knowledge was determined via item-level analysis of Items 20, 21, 22, 24, 26, 28, and 29.

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

In order to identify how often professional development related to intimacy is provided to each type of PSE staff member, the researcher analyzed the response data for Items 31 and 32. The researcher calculated the 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.

Research Question 3: *What are PSE program staff members' perceptions of influential factors that may affect program students' ability to engage in intimacy and build their intimacy knowledge?*

Staff member perceptions of factors that may influence students' ability to experience intimacy and access intimacy education was identified by conducting an item-level analysis on Item 34 on the CoSIK-C. Descriptive statistics including mean and standard deviation for the level of agreement amongst staff members for each of the 12 factors were calculated.

CHAPTER 4

RESULTS

The purpose of this study was to examine the continuum of support offered by PSE programs for students with intellectual disability in building students' intimacy knowledge. The research questions used for this purpose are included below:

1. Which supports do PSE program staff members report offering to participants to build their intimacy knowledge?
2. How often is professional development related to building participants' intimacy knowledge provided to PSE program staff members?
3. What are PSE program staff members' perceptions of influential factors that may affect program participants' ability to engage in intimacy and build their intimacy knowledge?

Research Question 1: *Which supports are being offered by PSE program staff members to participants to build their intimacy knowledge?*

The full continuum of support to building intimacy knowledge amongst college students with intellectual disability was examined in order to answer this research question. The continuum of support that could be provided to students in this area includes assessment, services (including topics and instructional methods), and resources.

Frequency and context of support. Overall, the frequency and context in which support in building intimacy knowledge is provided to college students varied greatly (see Table 4.1). Fifteen percent of PSE programs never provide support in building

students' intimacy knowledge. Many programs address the topic of intimacy proactively. A majority of programs (60.9%) provide support in building romantic relationship knowledge proactively for all program participants. Forty percent of programs provide support in building knowledge of sexual activity proactively for all students. When support is provided reactively, it is most often due to an individual's expressed interest in engaging in intimacy. However, approximately one-third of PSE programs provide support in building intimacy knowledge due to a negative experience with intimacy (see Table 4.2). Most respondents (59.8%) indicated they were either satisfied or very satisfied with the continuum of support offered to participants in building their intimacy knowledge, while 40.2% indicated that they were either unsatisfied or very unsatisfied (see Table 4.3).

Table 4.1

Frequency of Support Provided to Build Students' Intimacy Knowledge

Frequency of Support	*n**	%
Never	13	14.9
Once	6	6.9
Annually	10	11.5
Once a semester	14	16.1
Monthly	11	12.6
Weekly	23	26.4
Multiple times per week	10	11.5

**n = 87*

Table 4.2

Context in Which Intimacy Support is Provided

Context of Support	Romantic Relationships	Sexual Activity
Support is not provided.	(8) 9.2%	(19) 22.4%
Support is provided proactively for all participants.	(53) 60.9%	(36) 42.4%

Support is provided for an individual reactively due to expressed interest in engaging in intimacy.	(44) 50.6%	(40) 47.1%
Support is provided for an individual reactively due to a positive experience with intimacy.	(24) 27.6%	(21) 24.7%
Support is provided for an individual reactively due to a negative experience with intimacy.	(28) 32.2%	(25) 29.4%

Note: Romantic relationships n = 87, sexual activity n = 85

Table 4.3

Staff Members' Level of Satisfaction with the Continuum of Support

Frequency of Support	*n**	%
Very unsatisfied	10	11.5
Unsatisfied	25	28.7
Satisfied	43	49.4
Very satisfied	9	10.3

**n = 87*

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 (see Table 4.4) Those programs that do assess students' knowledge and level of interest are more likely to use informal assessment to measure relationship (38.8%) and sexual (33.7%) knowledge. Few programs use formal assessment (4.7%, relationships/2.3% sex). 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 stated that while they currently do not measure participants' intimacy knowledge, they would like to start.

Table 4.4

Types of Assessments Used to Measure Student's Intimacy Knowledge

Type of Assessment	Romantic Relationships	Sexual Activity
No assessment	(37) 43.5%	(45) 52.3%
Informal assessment	(33) 38.8%	(29) 33.7%
Formal assessment	(4) 4.7%	(2) 2.3%
Both formal and informal assessment	(11) 12.9%	(10) 11.6%

Note: Romantic relationships n = 87, sexual activity n = 85

Services. PSE programs are more likely to use services to build students' romantic relationship knowledge as opposed to sexual knowledge. The most common service utilized by PSE programs in building either aspect of intimacy knowledge is the use of group courses consisting of only program participants (see Table 4.5). Thirty-three percent of programs disseminate relationship education materials such as pamphlets, brochures, or flyers, 34.5% provide one-on-one sessions with full-time staff members, and 29.9% provide one-on-one sessions with peer mentors. Twenty-eight percent disseminate sexual intimacy education materials such as pamphlets, brochures, or flyers, 33.3% provide one-on-one sessions with full-time staff members, and 20.25% provide one-on-one sessions with peer mentors. Programs offer other services for building romantic relationships (10.3%) and sexual activity (7.1%), including workshops, computer programs, support groups, and information from local independent living centers.

Table 4.5

Services Offered to Build Students' Intimacy Knowledge

Services by Intimacy Type	*n*	%
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

Instructional practices and topics within services. 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%) described by respondents include

Table 4.6

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

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 and cues related to dating are the topics covered most frequently by PSE programs, while unplanned pregnancy, biological and reproductive functioning, sexual and gender identity, and masturbation are never addressed in a majority of programs (see Table 4.6).

Resources. Resources most frequently resources used by PSE programs in supporting students to build romantic and sexual knowledge are those from community agencies. Programs more frequently provide resources to build relationship knowledge, compared to sexual knowledge (see Table 4.7). Approximately one-third of programs use research-based curricula, program-based curricula, or resources from the IHE's student health center. Staff members who indicated that their PSE program uses resources from IHE health centers identified those resources, including counselors, sexual health educators, sexual assault awareness training, health fairs, therapy, online courses, preventative birth control, and STD testing and prevention.

Table 4.7

Resources Offered to Build Students' Intimacy Knowledge

Services by Intimacy Type	*n*	%
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

Table 4.7 (continued)

Services by Intimacy Type	*n*	%
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

In summary, PSE programs provide support in building intimacy knowledge at various levels. These supports are most frequently provided proactively for all students and supports most often include group courses with other program participants. Within the services provided by programs to build intimacy knowledge, almost all programs use discussion as an instructional method for teaching intimacy topics. These topics most frequently include personal hygiene and social skills and cues related to dating. Resources from community health agencies are the most frequently used resources in building students' intimacy knowledge. Almost half of PSE programs to do not assess students' level of knowledge and interest in engaging in intimacy.

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 half of PSE program staff members (see Table 4.8). Half of PSE programs are not providing full-time staff with training in this area. 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 or dissatisfaction (see Table 4.9).

Table 4.8

Frequency of Intimacy Education Professional Development

Frequency of Professional Development by Staffing Type	*n*	%
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
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

Table 4.9

Level of Satisfaction with Intimacy Education Professional Development

Staffing Type	Level of Satisfaction			
	Very Unsatisfied	Unsatisfied	Satisfied	Very Satisfied
Full-time staff	(17) 19.5%	(25) 28.7%	(42) 48.3%	(3) 3.5%
Peer mentors	(16) 20.0%	(26) 32.5%	(36) 45.0%	(2) 2.5%

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 a faith-based institution, they would not prioritize professional development in this area. Others 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.

Professional development related to intimacy education is not provided to half of PSE staff members and half feel satisfied with the level of professional development offered in this area. Staff members express experiencing multiple barriers to program-facilitated intimacy education professional development. This includes a lack of time, low level of priority within the scope of the entire program, and liability concerns of LEAs for dual-enrollment programs.

Research Question 3: *What are PSE program staff members' perceptions of influential factors that may affect program participants' ability to engage in intimacy or build their intimacy knowledge?*

The mean of all 12 factors fell within a range of 1.98 and 3.25. The factor with the lowest mean was *The PSE program's philosophy on guardianship affects the participants*

ability to engage in intimacy (M=1.98). The factor with the highest mean was *PSE program staff members believe that students should be able to engage in intimacy, should they so desire* (M=3.25). PSE program staff members indicated a stronger level of agreement with five factors. A majority of PSE staff members disagree with the notion that the program's philosophy on guardianship affected students' ability to engage in or learn more about intimacy. They also disagreed that peer mentors are both trained and comfortable with providing intimacy education. A majority agree that students within their PSE programs would consider learning about intimacy a priority, yet most agree that students lack the confidence to express an interest in learning more about intimacy. A majority of PSE staff members agreed that all students should be able to engage in intimacy, should they desire to do so. Of note is the 10% of PSE staff members who disagreed with the idea that students should be able to engage in intimacy. For a summary of staff members' perceptions of influential factors that may affect program participants' ability to engage in intimacy or build intimacy knowledge, see Table 4.10 below.

Summary of Findings

The frequency and context of support provided by PSE programs in building students' intimacy knowledge varies greatly across programs. 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. Half of PSE programs do not access 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

Table 4.10

Staff Members' Level of Agreement With Influential Factors That May Affect Students' Ability to Engage in Intimacy or Build Their Intimacy Knowledge

Factor	Level of Agreement					
	Mean	SD	Strongly Disagree	Disagree	Agree	Strongly Agree
Students' parents are supportive of their son or daughter exploring intimacy while at college.	2.47	.80	(9) 10.3	(36) 41.4	(34) 39.1	(8) 9.2
Students' parents would expect the program to inform them if their son or daughter engages in intimacy.	2.51	.94	(13) 15.1	(30) 34.9	(29) 33.7	(14) 16.3
Students' parents would prefer to educate their son or daughter on aspects of intimacy.	2.57	.68	(6) 6.9	(28) 32.2	(50) 57.5	(3) 3.5
The PSE program encourages students' use of the campus health center to receive information and services related to intimacy.	2.70	.90	(8) 9.8	(25) 30.5	(33) 40.2	(16) 19.5
The PSE program provides effective supports related to intimacy.	2.49	.85	(11) 12.8	(31) 36.1	(35) 40.7	(9) 10.5

Table 4.10 (continued)

Factor	Level of Agreement					
	Mean	SD	Strongly Disagree	Disagree	Agree	Strongly Agree
The PSE program provides a continuum of support to build students' intimacy knowledge that is age appropriate for students in college.	2.60	.84	(9) 10.3	(28) 32.2	(39) 44.8	(11) 12.6
The PSE program's residential model allows for students to experience the privacy necessary to engage in intimacy, which they may not experience at home.	2.26	1.08	(24) 31.2	(22) 28.6	(18) 23.4	(13) 16.9
The PSE program's philosophy on guardianship affects participants' ability to engage in intimacy.	1.98	.86	(28) 33.7	(32) 38.6	(20) 24.1	(3) 3.6
PSE program staff members are trained to provide effective instruction and support related to intimacy.	2.35	.90	(19) 22.4	(22) 25.9	(39) 45.9	(5) 5.9

Table 4.10 (continued)

Factor	Mean	SD	Level of Agreement			
			Strongly Disagree	Disagree	Agree	Strongly Agree
PSE program staff members feel confident and comfortable in providing intimacy education.	2.49	.86	(12) 14.3	(27) 32.1	(37) 44.1	(8) 9.5
PSE program staff members believe that students should be able to engage in intimacy, should they so desire.	3.25	.71	(2) 2.4	(7) 8.4	(42) 50.6	(32) 38.6
PSE program peer mentors are trained to provide effective instruction and support related to intimacy.	2.17	.87	(21) 26.3	(27) 33.8	(29) 36.3	(3) 3.8
PSE program peer mentors that support students in social engagement, feel confident and comfortable in providing intimacy education.	2.19	.76	(14) 17.3	(41) 50.6	(23) 28.4	(3) 3.7

A majority of students in the PSE program lack confidence to express their interest in learning more about engaging in intimacy.	2.90	.74	(2) 2.4	(27) 25.0	(44) 52.4	(17) 20.2
A majority of students in the PSE program feel that learning about intimacy is not a priority.	2.25	.75	(13) 15.3	(21) 48.2	(28) 32.9	(3) 3.5

Note: Sample ranged from 77-87 by topic

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 a majority of programs. The most frequently used resources in building intimacy knowledge is information from a community health agency.

Half of PSE staff members never receive professional development related to intimacy education. A majority of PSE staff members agree that peer mentors lack the confidence and training to provide support in building intimacy knowledge, yet approximately 25% of programs use peer mentors to support students in building romantic relationship knowledge and 20% of programs use peer mentors to support students in building sexual knowledge. A majority of PSE staff members agree that students should be able to engage in intimacy should they choose to do so, yet a majority feel as though their students lack of the confidence in expressing their interest in learning more about intimacy. Additionally, most PSE staff members indicated that their students within their respective programs would consider learning about intimacy a priority. Most PSE staff members disagree with the notion that their program's philosophy on guardianship affects students' ability to engage in intimacy.

CHAPTER 5

DISCUSSION

The purpose of this study was to examine the supports provided by PSE programs for individuals with intellectual disability in building students' intimacy knowledge. The findings of this study indicate that the frequency, type, and context of support provided to students varied across programs. Similar variance was found in the frequency and satisfaction of intimacy education professional development for staff members, as well as staff members' perceptions of influential factors that could affect students' intimacy knowledge attainment or engagement. This discussion will reflect upon the frequency and context of support in building students' intimacy knowledge in relation to program philosophy and purpose. Additionally, ensuring comprehensive and individualized intimacy education and staff professional development will be discussed. Implications for practice, including intimacy education professional development for staff members, viewing intimacy as a basic human right and universal topic, the context of intimacy education, understanding of the expectations of stakeholders, and developing students' self-awareness and self-advocacy for their intimacy needs will be presented. Finally, research directions will be proposed in an effort to connect the findings of this study to future work necessary to understand how to best support students with intellectual disability in college in developing sexual agency.

Program purpose and philosophical effect on intimacy support. Both the purpose and philosophy of the PSE program may affect whether and how frequently

support is offered to students in building their intimacy knowledge. The frequency of support being provided to students varied across response options, as did the context in which the support was provided. Findings of this study indicate that one-third of PSE programs provide support in building students' intimacy knowledge once a year or less, with 15% of programs not supporting students at all in this area. In trying to provide the most authentic and rigorous experience for their students, PSE programs may try to mirror college life as much as possible (Plotner et al., 2018). Many college students receive intimacy education in high school, therefore instruction and support at the college level is less direct and regulated to a human sexuality class or program sponsored by the health center. These traditional resources build upon students' foundational intimacy knowledge, focusing more on application rather than initial acquisition. However, over half of students with intellectual disability do not receive intimacy education in high school and therefore are not entering college with the same foundational knowledge as their peers who did receive this instruction before arriving on campus (Barnard-Brak et al., 2009). If a program is attempting to subscribe to typicality, it would make sense that support is not provided frequently by the program itself.

There may also be an assumption from PSE program staff that intimacy education is provided by parents of college students. This is supported by the findings of the current study, which indicate that 60% of PSE staff members report that they believe that parents would prefer to educate their children on intimacy. However, this assumption is problematic, as parents express a lack of confidence in being able to teach their son or daughter about intimacy (Evans et al., 2009). Additionally, some parents may not address this issue due to their belief that their son or daughter do not need intimacy education, as

they believe they will eternally have a child-like state of mind (Parchomiuk, 2012).

Other factors that may prevent PSE programs from offering intimacy education include lack of prioritization from students, cultural expectations of faith-based institutions, and dual-enrollment status. In the current study, 36% of staff members report that they feel that a majority of their student body would not consider learning about intimacy a priority. If programs are assessing students' needs and interests multiple times throughout their college experience and staff do not believe intimacy is the priority, it is understandable that these programs are not providing frequent or any support in this area. Faith-based organizations that subscribe to certain cultural norms regarding sexual behavior may not provide support in this area for this reason. Dual-enrollment scenarios, where the PSE program is receiving funds to provide transition services in a college setting, may be bound by state or district policies regarding sexuality education. At present, only 27 states mandate sex education, with varying definitions and expectations for instruction (Guttmacher Institute, 2019). If programs receive funding from a district, they are likely to adhere to district policies which could include not providing support in this area.

Further, it should be noted that PSE programs may have different areas of focus. If the PSE program functions solely for the purpose of teaching and practicing employment related skills, intimacy education will not be a primary focus, therefore support would be minimal, if it exists at all. According to the demographic information for this study, approximately 95% of programs consider social engagement to be a primary focus area. Social engagement includes exploring and developing relationships (both platonic and romantic) and attending and engaging with clubs and organizations on

campus (Plotner et al., 2018). For these programs and others like them across the country, it would then make sense that direct support in building intimacy knowledge is not provided, because it is outside of the scope and purpose of the program. Although the results of this study indicate that most respondents feel as though students in their PSE program would consider intimacy a priority, others do not. Gathering information on the importance of intimacy knowledge directly from students, rather than staff, might lead to increased emphasis on intimacy knowledge in students' individual goals.

Ensuring comprehensive and individualized intimacy education. While standards for comprehensive sexuality education exist (FoSE, 2019), student preference for frequency, instructional methods, and topics can inform PSE program administrators' decisions on how to support students in building intimacy knowledge. 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 sexuality 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, Stancliffe, Broom, & Wilson, 2016). Specifically, assessment data is critical for service providers supporting adults with intellectual disability in learning about sexuality (Thompson et al., 2016). Determining the right frequency, topics, 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, 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 administrators, assessing students' needs and interests would hopefully result in increasing students' self-awareness of their own intimate needs.

Intimacy instructional methods and topics. 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. Further, 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.

Adults with intellectual disability are sexually active and require an understanding of biological and reproductive functioning, including the possibility of pregnancy, in order to prevent STD/STI contract and unplanned pregnancy (Dekker et al., 2014).

Almost 85% of adults with intellectual disability report having sexual relationships with others, yet birth control is only used by 40% of sexually active adults with intellectual disability (Gil-Llario et al., 2018). Approximately 37% of respondents indicated that their programs never address prevention of STDs, 41.9% never address biological and reproductive functioning, and 44.8% never address unplanned pregnancy.

The disparity between those who report being sexually active and those who report using a form of birth control indicates the importance of educating young adults with intellectual disability about biological and reproductive functioning and unplanned pregnancy.

Individuals with intellectual disability who identify as being gay, lesbian, bisexual, or transsexual report experiencing abuse and discrimination including verbal and physical abuse and threats of violence (Dinwoodie et al., 2016). They also report that adult services fail to meet their combined needs of being an individual with an intellectual disability and an individual who is gay, because these are two separate and unique, co-existing identities within an individual (Dinwoodie et al., 2016). Sexual identity exploration in college is common (Evans et al., 2009). PSE programs are uniquely situated to assist students in navigating their sexual and gender identity questions, yet 40.2% of respondents in the current study indicated that their programs never address this topic.

About 90% of adult men and women with intellectual disability have masturbated (Gil-Lario et al., 2018), yet 58.6% of respondents in the current study indicated that their programs never address this topic. People with disability state that masturbation assists them with understanding the positive effects of sexual release on their bodies, including

better mood and sleep, and less anxiety (Morales, Gauthier, Edwards & Courtois 2016). Masturbation has been noted as the most common sexual practice amongst individuals with disabilities (Diaz, Gil, Ballester, Morell, & Molero, 2014). Sexuality education reduces the likelihood of inappropriate sexual expression (Tarnai, 2006). Young adults with intellectual disability may feel uncertain on how to properly and privately masturbate to achieve desired sexual release. This knowledge could reduce the frequency of inappropriate sexual expression. Students are exploring their sexuality in various ways, yet PSE programs may only address certain aspects of intimacy. Programs may be missing the most important and relevant issues in the lives of college students.

Intimacy education professional development. Many disability service professionals do not feel comfortable or well-trained to provide intimacy education to individuals with intellectual disability (Evans et al., 2009). This is reflected in the findings of the current study, which indicate that half of full-time PSE staff members never receive intimacy education professional development. A quarter of programs use paid peer mentors to provide support in building intimacy knowledge, however PSE program staff members indicated that many peer mentors lack the confidence to support students in this area. Almost half of respondents reported that staff at their current PSE program have not been provided training on how to effectively instruct and support students in building their intimacy knowledge. Further, 46% reported that their full-time staff do not feel confident and comfortable in providing intimacy education. This is reflective of the findings of Evans and colleagues (2009), who found that two-thirds of direct service providers do not feel confident in providing intimacy education to adults with intellectual disability.

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). 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, given their own lived experiences. This is especially relevant to peer mentors, as they are still in emerging adulthood 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. Professional development opportunities can positively impact an instructor's willingness and ability to provide sexuality education (Ollis, 2010).

Implications for Practice

Professional development for building intimacy knowledge. From the current study, we know that the frequency, context, and type of intimacy education being provided varies by program. It is important for students to establish intimacy knowledge to avoid negative consequences of engaging in intimacy and programs address this need in different ways, depending upon the scope and purpose of the program. For those programs that do address social engagement, 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.

Both of these methods for supporting students require students to become more self-aware of their intimate needs and to advocate for support in working towards sexual agency. Professional development on effective assessment of intimacy knowledge and interest would benefit staff members planning instruction and support in this area. Findings of this study indicate that almost 75% of program staff report that they agree or strongly agree that students lack the confidence to express interest or learn more about intimacy. 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.

Viewing intimacy as a basic human right and universal topic. Approximately 90% of respondents in the current study reported that they feel as though a majority of their PSE program staff would agree that students should be able to engage in intimacy if they so desire, therefore 10.8% (n=9) of respondents disagree. One may consider that even one-tenth of professionals not feeling as though this is a basic human right is problematic. The idea that anyone should be prevented from experiencing desired intimacy is a human rights issue. In a joint position statement, AAIDD and The Arc affirm the right of individuals with intellectual disability to exercise choice regarding

their sexuality and sexual relationships (AAIDD, 2013). A majority of adults with intellectual disability report that they are currently sexually active and would like to talk about intimacy more (Gil-Llario, 2018). This finding indicates a need for PSE program staff members' understanding of intimate need and development amongst people with intellectual disability in college and the role it plays in their overall quality of life.

Context of intimacy education. Intimacy education is often provided reactively to people with intellectual disability (Gougeon, 2009), 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% don't support the development of sexual 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.

Understanding the expectations of students and parents. Approximately 84% of respondents in this study indicated that a staff member from their PSE program

communicates with parents regarding students' social engagement once a semester or more. Furthermore, PSE staff members at half of the programs believe parents aren't supportive of their son or daughter engaging in intimacy and believe they would expect to be informed if their child did engage in intimacy. The pressure of appeasing parents, especially those who are their son or daughter's legal guardian, may affect the level of support offered to students in this area. Parental preference could trump staff and student desire to increase intimacy knowledge, therefore it is necessary for all stakeholders to establish expectations for communication and support regarding intimacy. In practice, communication among all parties may be enhanced if students and their parents are aware of what the expectations are in terms of recognizing and supporting students' social and intimate experiences, including intimate risk-taking. Regardless of guardianship status, students must be made aware of and must agree to the frequency and topics of communication with their parents.

Supporting self-awareness and self-advocacy for intimacy needs. As students experience college and emerge into adulthood, preferences and beliefs change with the acquisition of new knowledge and exposure to new experiences through risk-taking (Arnett, 2000; Evans et al., 2009). However, this knowledge and evolving preference mean little if students are not self-aware and advocating for what they want to take action towards. Seventy-three percent of PSE staff members in this study feel that a majority of their students lack the confidence to express their interest in learning more about engaging in intimacy. Developing self-determination skills such as self-advocacy and self-awareness are critical to being able to take action towards learning about and experiencing intimacy. However, it is difficult to develop self-awareness within students

if they don't understand their own level of intimacy knowledge or are not afforded the dignity of risk in being able to learn from their own intimate experiences.

Limitations

The findings of this study should be interpreted with caution, because the 33% response rate suggests that those PSE program staff members who responded could have only responded given their interest or mastery of providing intimacy supports. Additionally, respondents consisted of PSE program staff members providing their perceptions on factors that could influence whether a student is engaging in intimacy or accessing intimacy education. Staff members may not be privy to the opportunities and experiences of students, their parents, and the perspectives of all PSE staff members collectively. Finally, 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 educational materials provided by community agencies or resources in building intimacy knowledge.

Future Research Directions

Additional research is needed to understand how to best support students in navigating intimacy in college. Program administrators assign a level of priority to instructional topics and associated programmatic support. 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. Finally, examining stakeholder expectations for communication regarding sexual risk-taking would contribute to rationale for the development of policies and procedures for discussing these matters with families, if necessary. Transparency regarding these policies are especially important in situations where family members have retained guardianship.

Conclusion

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. Over half of PSE program staff members believe that their students would consider learning about intimacy a priority. 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. Despite this, only half of PSE programs intimacy education provide professional development to their full-time staff members. Many staff members feel as though peer mentors working with students in the PSE program lack confidence and training to provide intimacy instruction, further emphasizing the needs for professional development for full-time staff.

Support in building students' intimacy knowledge is often provided proactively, however some programs are still providing this support reactively based on a students' negative experience with intimacy. PSE programs can connect students with campus and community resources for learning more about intimacy, even if this 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. Lastly, ten percent of PSE staff members believed that students with intellectual disability in college should not have the right to engage in intimacy, should they so desire. Intimacy is a basic human right and need. Staff members should consider how to approach the topic of engaging in intimacy with all stakeholders, especially parents who have guardianship of their son/daughter, so that all parties understand an individual's biological need for intimacy and the need to address this topic in a college environment.

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APPENDIX A

LITERATURE SUPPORTING INSTRUMENT DEVELOPMENT

Table A.1

Literature Supporting the Development of the CoSIK-C

Survey Item	Author(s), Year of Study
10. Is the PSE program a dual-enrollment program? Dual enrollment refers to the partnership between at least one local school district and at least one college or university where a student who has not yet graduated with a diploma or credential is receiving both high school and college credit for coursework completed at the college or university. The education provided by the college or university meets the qualifications for designation as transition services on a student's IEP, paid for with IDEA Part B funds.	Grigal & Hart, 2012; Grigal, Hart, and Weir, 2012; IDEA 2004
11. Which option best describes the type of institution of higher education (IHE) is your PSE program housed within?	Grigal & Hart, 2012; Grigal et al., 2012
13. Which disability category represents the majority of the program's participants?	Grigal & Hart, 2012; Grigal et al., 2012; IDEA 2004
14. Which disability categories represent your current participant population? Check all that apply:	Grigal & Hart, 2012; Grigal et al., 2012; IDEA 2004
15. Which option best describes the PSE program's residential support model?	Grigal & Hart, 2012; Grigal et al., 2012
16. To what extent does your PSE program staff provide support to students in the following domains?	Grigal & Hart, 2012; Grigal et al., 2012; Plotner, Marshall, VanHorn Stinnett, Teasley, 2018
17. Which option best describes the majority of your students' level of support needs related to the following domains?	Grigal & Hart, 2012; Grigal et al., 2012; Plotner et al., 2018
18. Are students who attend the PSE program required to retain their own guardianship?	Plotner & Marshall, 2015
19. Approximately what percentage of current students retain their own guardianship?	Plotner & Marshall, 2015
20. How often do PSE program staff members communicate with parents regarding students' social engagement?	Evans et al., 2009; Miller et al., 2018; Plotner & Marshall, 2015

Survey Item	Author(s), Year of Study
21. Please indicate your level of agreement with the following statement: Supports (e.g., general supervision, residential support, support in managing free time, funds, or transportation) acts as a barrier to students being able to privately engage in intimacy.	Lofgren-Martenson, 2004; Azzopardi-Lane & Callus, 2014; Barnard-Brak et al., 2014; Evans et al., 2009; Gill, 2015; Healy et al., 2009; Sinclair, Unruh, Lindstrom, and Scanlon, 2015
22. Select which types of assessments are in place to measure students' knowledge and interest in engaging in each aspect of intimacy.	Galea, Butler, Iacano, Leighton, 2004; McCabe, Cummins, and Deeks, 1999; Talbot & Langdon, 2006
23. Briefly describe the assessments used to measure students' knowledge related to engaging in both aspects of intimacy.	Galea et al., 2004; McCabe etal., 1999; Talbot & Langdon, 2006
24. Which resources does the PSE program use to build students' intimacy knowledge? Select all that apply for each aspect of intimacy	Barnard-Brak et al., 2014; Blanchett & Wolfe, 2002; Borawska-Charko et al., 2017; Dukes & McGuire, 2006; Gougeon, 2009; Isler et al., 2009; Lafferty et al., 2012
25. Briefly describe the resources that the PSE program uses to build participants' intimacy knowledge.	Barnard-Brak et al., 2014; Blanchett & Wolfe, 2002; Borawska-Charko et al., 2017; Dukes & McGuire, 2006; Gougeon, 2009; Isler et al., 2009; Lafferty et al., 2012
26. Which services do PSE program staff members use to building participants' knowledge related to each aspect of intimacy? Select all that apply	Evans et al., 2009; Grigal & Hart, 2012; Grigal et al., 2012 Lafferty et al., 2012; University of South Carolina- Student Health Services, n. d.
27. Briefly describe the services that your PSE program staff uses to build intimacy knowledge.	Evans et al., 2009; Grigal & Hart, 2012; Grigal et al., 2012; University of South Carolina- Student Health Services, n. d.
28. Which option best describes the context in which the PSE program provides support related to building participants' intimacy knowledge and interest in engaging in each aspect of intimacy?	Azzopardi-Lane & Callus, 2014; Barnard-Brak et al., 2014; Evans et al., 2009; Gill, 2015; Healy et al., 2009; Lofgren-Martenson, 2004; Sinclair et al., 2015

Survey Item	Author(s), Year of Study
29. Indicate your level of agreement with the following statement: PSE program staff members provide a continuum of support related to building intimacy knowledge that is age appropriate for students in college.	Brown, Branston, Hamre-Nietupski, Pumpian, Certo, Gruenewald, 1979
30. How often do PSE program staff, including peer mentors, provide support in building participants' intimacy knowledge and interest?	Azzopardi-Lane & Callus, 2014; Barnard-Brak et al., 2014; Evans et al., 2009; Gill, 2015; Healy et al., 2009; Lofgren-Martenson, 2004; Sinclair et al., 2015
31. How satisfied are you with the continuum of support provided by PSE program's staff members in building participants' intimacy knowledge?	Azzopardi-Lane & Callus, 2014; Barnard-Brak et al., 2014; Evans et al., 2009; Gill, 2015; Healy et al., 2009; Lofgren-Martenson, 2004; Sinclair et al., 2015
32. How often is professional development related to building students' intimacy knowledge provided to each type of staff member?	Evans et al., 2009; Lafferty et al., 2012; Treacy et al., 2018
33. How satisfied are you with the amount of professional development related to building students' intimacy knowledge offered to each type of staff member?	Evans et al., 2009; Lafferty et al., 2012; Treacy et al., 2018
34. Indicate the extent to which you agree with the following statements regarding influential factors that may impact students' ability to engage in intimacy or access support to build their intimacy knowledge.	
I believe that participants' parents are supportive of their son or daughter exploring intimacy while at college.	Evans et al., 2009; Miller, Schleien, White, and Harrington 2018; Plotner & Marshall, 2015
I believe that participants' parents expect the program to inform them if their son or daughter engages in intimacy.	Evans et al., 2009; Gill, 2015; Miller et al., 2018; Plotner & Marshall, 2015

Survey Item	Author(s), Year of Study
I believe that participants' parents prefer to educate their son or daughter on aspects of intimacy.	Lafferty et al., 2012; Treacy et al., 2018
I believe that the PSE program exists within a campus culture that promotes intimacy education (i.e., no policies related to premarital sex/relations, campus resources that subscribe to sexual health education rather than abstinence education).	Evans et al., 2009; Treacy, Taylor, and Abernathy, 2018
I believe that the PSE program encourages participants' use of the campus health center to receive information and services related to intimacy.	Evans et al., 2009; University of South Carolina-Student Health Services, n. d.
I believe that the PSE program provides effective supports related to intimacy.	Evans et al., 2009; Miller, Schleien, White, and Harrington 2018; Plotner & Marshall, 2015
I believe that the PSE program's residential model allows for students to experience the privacy necessary to engage in intimacy, which they may not experience at home.	Evans et al., 2009; Gill, 2015; Miller et al., 2018; Plotner & Marshall, 2015
I believe that the PSE program's philosophy on guardianship affects participants' ability to engage in intimacy.	Evans et al., 2009; Miller et al., 2018; Plotner & Marshall, 2015
I believe that staff members are trained to provide effective instruction and support related to intimacy.	Evans et al., 2009; Lafferty et al., 2012; Treacy et al., 2018
I believe that peer mentors are trained to provide effective instruction and support related to intimacy.	Evans et al., 2009; Lafferty et al., 2012; Treacy et al., 2018
I believe that program participants lack confidence in expressing their interest in learning more about engaging in intimacy.	Azzopardi-Lane & Callus, 2014; Barnard-Brak et al., 2014; Evans et al., 2009; Gill, 2015; Healy et al., 2009; Lofgren-Martenson, 2004; Sinclair et al., 2015

APPENDIX B

INSTRUMENT FEEDBACK FORM

Survey Feedback Form

Thank you for agreeing to review this instrument, the *Continuum of Support for Intimacy Knowledge in College for Students with Intellectual and Developmental Disability Survey,* or CoSIK-C. I will be utilizing this instrument in a study aimed at examining the continuum of support provided by postsecondary education (PSE) programs for students with intellectual and developmental disability in measuring interest and building participants' knowledge related to intimacy. If you have any questions, please contact me by phone (513)-465-0129 or e-mail stinnetc@email.sc.edu.

1. **Did the survey items adequately cover the full continuum of support that a PSE program could offer participants in building their intimacy knowledge?**

   Adequate 5 4 3 2 Inadequate 1

   Comments

2. **Were there any terms/wording in the survey that were unclear?**

   Comments

3. **Were there items that you felt were covered more than once?**

   Comments

1

4. **Were there any items on the survey that need to be deleted?**

   Comments

5. **Were there concepts that need to be added to the survey?**

   Comments

6. **Were there barriers and facilitators to accessing intimacy education or engaging in intimacy that weren't covered?**

7. **Please provide any other points of feedback that you feel would improve the survey.**

Thank you for your time and feedback!

*Please save the document in the following format "*CoSIK-C Feedback_[YOUR INITIALS]*" and send via email to stinnetc@email.sc.edu.*

APPENDIX C

CoSIK-C

Continuum of Support for Intimacy Knowledge in College (CoSIK-C) for Students with Intellectual and Developmental Disability

Hello!

Your assistance is needed in this study examining the continuum of support used by staff members of postsecondary education (PSE) programs for students with intellectual and developmental disability to build students' intimacy knowledge. The purposes of this study are to identify (1) how and in what context PSE program staff members are building students' intimacy knowledge and (2) how often professional development related to intimacy is provided to all staff members. Additionally this study will identify (3) PSE program staff members' perceptions of influential factors that may impact students' ability to engage in intimacy and/or receive support in building intimacy knowledge in college. This data will be used to inform PSE policy and practices related to intimacy education. This survey is anonymous and strictly voluntary. Your responses to the survey questions are completely confidential and will be released only as summaries in which individual answers cannot be identified.

You are invited to complete the CoSIK-C because you are a staff member of a PSE program with knowledge of supports provided to students in the area of social engagement. Only one staff member per program should complete this survey. Even if your program is not supporting students in building intimacy knowledge, your answers are valuable in understanding which factors may influence the programmatic decision to not provide support in this area. It will take approximately 25 minutes to complete this 36-item survey. There is no risk associated with completing this survey. Data derived from this survey will remain confidential and will only be released as summaries with no identifying personal or programmatic information. If at any time you feel uncomfortable, please do not complete the survey. Please include your email at the end of this survey to be entered into a drawing to win a $100, $50, or $25 Amazon Gift Card!

Thank you for your participation!

Chelsea VanHorn Stinnett
Doctoral Candidate, University of South Carolina
stinnetc@email.sc.edu

Continuum of Support for Intimacy Knowledge in College (CoSIK-C) for Students with Intellectual and Developmental Disability

Instructions

Please indicate your response by selecting the option(s) that best describe yourcurrent PSE program and students. For the purpose of this study, intimacy consists of two main components: romantic relationships and sexual activity. Romantic relationships refer to experiencing a level of

closeness, while being listened to, understood, and valued within a reciprocal, affectionate relationship based on love. Sexual activity refers to physical closeness, which results in engaging in sexual acts performed with another with the purpose of achieving sexual gratification.

Continuum of Support for Intimacy Knowledge in College (CoSIK-C) for Students with Intellectual and Developmental Disability

I. Individual Demographics

1. What is your gender?

- ○ Male
- ○ Female
- ○ Non-binary/third gender
- ○ Prefer not to say

Prefer to self describe as:

2. What is your highest level of education?

- ○ High school/GED
- ○ Associates degree
- ○ Bachelors degree
- ○ Masters degree
- ○ Doctorate degree

3. How many years of experience do you have working for your current PSE program?

- ○ Less than 1 year
- ○ 1-2 years
- ○ 3-4 years
- ○ 5-7 years
- ○ 7-10 years
- ○ More than 10 years

4. What is your title at the PSE program?

- ○ Director
- ○ Assistant Director
- ○ Coordinator
- ○ Leadership Staff
- ○ General Staff
- ○ Graduate Assistant

Other (please specify)

5. How many years of experience do you have in this role?

- ◯ Less than 1 year
- ◯ 1-2 years
- ◯ 3-4 years
- ◯ 5-7 years
- ◯ 7-10 years
- ◯ More than 10 years

Continuum of Support for Intimacy Knowledge in College (CoSIK-C) for Students with Intellectual and Developmental Disability

I. Program Demographics

6. What is the name of your PSE program? (This information will not be reported and will be used to ensure that only one staff member per program responds to the survey.)

7. What state is your PSE program located in?

8. How many students are currently enrolled in your PSE program?

- ◯ 1-4
- ◯ 5-10
- ◯ 11-15
- ◯ 16-25
- ◯ 26-35
- ◯ 36+

9. How many years has your PSE program existed?

- ◯ Less than a year
- ◯ 1-2 years
- ◯ 3-4 years
- ◯ 5-7 years
- ◯ 8-10 years
- ◯ More than 10 years

10. Is the PSE program a dual-enrollment program? Dual enrollment refers to the partnership between at least one local school district and at least one college or university where a student who has not yet graduated with a diploma or credential is receiving both high school and college credit for coursework completed at the college or university. The education provided by the college or university meets the qualifications for designation as transition services on a student's IEP, paid for with IDEA Part B funds.

- ◯ Yes
- ◯ No

11. Which option best describes the type of institution of higher education (IHE) that your PSE program housed within?

- ◯ Community college
- ◯ 4-year liberal arts college
- ◯ 4-year university
- ◯ Trade/technical school

Other (please specify)

12. What is the total student population of the IHE that your PSE program is housed within?

- ◯ Under 2,500
- ◯ 2,500-4,999
- ◯ 5,000-9,999
- ◯ 10,000-14,999
- ◯ 15,000-19,999
- ◯ 20,000-24,999
- ◯ 25,000 or more

13. Which disability category represents the **majority** of the PSE program's students?

- ◯ Intellectual Disability
- ◯ Specific Learning Disability
- ◯ Autism Spectrum Disorder
- ◯ Emotional Disturbance
- ◯ Speech or Language Impairment
- ◯ Visual Impairment
- ◯ Deafness
- ◯ Hearing Impairment
- ◯ Deaf-Blindness
- ◯ Orthopedic Impairment
- ◯ Traumatic Brain Injury
- ◯ Other Health Impairment
- ◯ Multiple Disabilities

14. Which disability categories are represented in the PSE program's student population? Select all that apply.

- [ ] Specific Learning Disability
- [ ] Other Health Impairment
- [ ] Autism Spectrum Disorder
- [ ] Emotional Disturbance
- [ ] Speech or Language Impairment
- [ ] Visual Impairment
- [ ] Deafness
- [ ] Hearing Impairment
- [ ] Deaf-Blindness
- [ ] Orthopedic Impairment
- [ ] Intellectual Disability
- [ ] Traumatic Brain Injury
- [ ] Multiple Disabilities

15. Which option **best** describes the residential model that a **majority** of students in the PSE program live in?

- ( ) Students live on campus with a roommate of their choosing, in a location of their choosing.
- ( ) Students live on campus, exclusively with other program participants in a designated location on campus.
- ( ) Students live in off-campus housing, exclusively with other program participants.
- ( ) Students live off-campus with a roommate of their choosing, in a location of their choosing, or with their families.

16. Please **select all** of the domains in which the PSE program offers support (assessment, services, resources) to students.

- [ ] Employment
- [ ] College course access
- [ ] Independent living
- [ ] Social Engagement
- [ ] Self-determination
- [ ] Other (please specify)

17. Are students who attend the PSE program required to retain their own guardianship?

- ◯ Yes
- ◯ No

18. Approximately what percentage of current students retain their own guardianship?

- ◯ Less than 25%
- ◯ 25-50%
- ◯ 50-75%
- ◯ More than 75%

19. Approximately how often do PSE program staff members communicate with parents regarding students' social engagement?

Never	Once	Annually	Once a semester	Monthly	Weekly	Multiple times per week
◯	◯	◯	◯	◯	◯	◯

Continuum of Support for Intimacy Knowledge in College (CoSIK-C) for Students with Intellectual and Developmental Disability

III. Continuum of Supports Related to Intimacy

For the purpose of this section of the survey, "continuum of support for building intimacy knowledge," refers to all supports that a program may offer including assessments, services, and resources.

20. How often do staff members provide support (assessment, services, resources) in building participants' intimacy knowledge to a **majority** of students in the PSE program?

Never	Once	Annually	Once a semester	Monthly	Weekly	Multiple times a week
◯	◯	◯	◯	◯	◯	◯

21. Which option(s) describe(s) the context in which the PSE program provides support related to building participants' intimacy knowledge and interest in engaging in each aspect of intimacy? **Please check all that apply.**

	Support is not provided	Support is provided proactively for all participants.	Support is provided for an individual, reactively due to expressed interest in engaging in intimacy.	Support is provided for an individual, reactively due to a positive experience with intimacy.	Support is provided for an individual, reactively due to a negative experience with intimacy.
Romantic relationships	☐	☐	☐	☐	☐
Sexual activity	☐	☐	☐	☐	☐

22. Select which types of **assessments** are in place to measure students' knowledge and interest in engaging in each aspect of intimacy.

	No assessment	Informal assessment	Formal assessment	Both formal and informal assessments
Romantic relationships	○	○	○	○
Sexual activity	○	○	○	○

23. Briefly describe the assessments used to measure students' knowledge related to engaging in both aspects of intimacy.

24. Which **services** do PSE program staff members use to building participants' knowledge related to each aspect of intimacy? Select all that apply.

	No services are offered	Dissemination of intimacy educational materials (e.g., pamphlets, flyers, brochures)	One-on-one sessions with full-time program staff	One-on-one sessions with peer mentors	Group courses with other program participants	Group courses with other university students outside of the program	Other
Romantic relationships	☐	☐	☐	☐	☐	☐	☐
Sexual activity	☐	☐	☐	☐	☐	☐	☐

25. If you selected "other," please describe the services that the PSE program uses to build students' intimacy knowledge.

26. Which **resources** does the PSE program use to build students' intimacy knowledge? Select all that apply for each aspect of intimacy.

	Unpaid peer mentors	Paid peer mentors	Research-based curriculum	Program-created curriculum	Resources from a community agency	Resources from the IHE's health center	No resources are used
Romantic relationships	☐	☐	☐	☐	☐	☐	☐
Sexual activity	☐	☐	☐	☐	☐	☐	☐

27. If the PSE program uses resources from the IHE's health center, please describe the resources that are provided.

28. Which **practices** are used within PSE program services (i.e., courses, sessions, dissemination of materials) to build students' intimacy knowledge? Check all that apply.

- ☐ The use of media, including photos and videos
- ☐ Mixed gender courses
- ☐ Single gender courses
- ☐ The use of handouts/worksheets
- ☐ Discussion
- ☐ Lecture
- ☐ Role-play
- ☐ Other (please specify)

29. How often are the following **topics** are covered with a **majority** of students **by PSE program staff members** when providing support to build students' intimacy knowledge?

	Never	Once	Annually	Once a semester	Monthly	Weekly	Multiple times each week
Personal hygiene	○	○	○	○	○	○	○
Preventing sexual abuse	○	○	○	○	○	○	○
Preventing sexually transmitted diseases and infections	○	○	○	○	○	○	○
Unplanned pregnancy	○	○	○	○	○	○	○
Biological and reproductive functioning	○	○	○	○	○	○	○
Initiating romantic relationships	○	○	○	○	○	○	○
Social skills and cues related to dating	○	○	○	○	○	○	○
Self-advocacy within a romantic and sexual relationship	○	○	○	○	○	○	○
Sexual and gender identity	○	○	○	○	○	○	○
Masturbation	○	○	○	○	○	○	○
Sustaining lasting relationships and marriages	○	○	○	○	○	○	○

30. How satisfied are you with the continuum of support provided by PSE program's staff members to build students' intimacy knowledge?

Very unsatisfied	Unsatisfied	Satisfied	Very satisfied
○	○	○	○

Continuum of Support for Intimacy Knowledge in College (CoSIK-C) for Students with Intellectual and Developmental Disability

V. Professional Development Related to Intimacy for PSE Staff Members

31. Approximately how often is professional development related to building students' intimacy knowledge provided to each type of staff member?

	Never	Once	Annually	Once a semester	Monthly	Weekly	Multiple times a week
Full-time staff	◯	◯	◯	◯	◯	◯	◯
Peer mentors	◯	◯	◯	◯	◯	◯	◯

32. How satisfied are you with the amount of professional development related to building students' intimacy knowledge offered to each type of staff member?

	Very Unsatisfied	Unsatisfied	Satisfied	Very Satisfied
Full-time staff	◯	◯	◯	◯
Peer mentor	◯	◯	◯	◯

Continuum of Support for Intimacy Knowledge in College (CoSIK-C) for Students with Intellectual and Developmental Disability

V. Influential Factors of Engaging in Intimacy and Accessing Support in College

33. Indicate the extent to which you agree with the following statements regarding influential factors that may impact students' ability to engage in intimacy or access support to build their intimacy knowledge.

	Strongly Disagree	Disagree	Agree	Strongly Agree
Students' parents are supportive of their son or daughter exploring intimacy while at college.	◯	◯	◯	◯
Students' parents would expect the program to inform them if their son or daughter engages in intimacy.	◯	◯	◯	◯
Students' parents would prefer to educate their son or daughter on aspects of intimacy.	◯	◯	◯	◯
The PSE program encourages participants' use of the campus health center to receive information and services related to intimacy.	◯	◯	◯	◯

	Strongly Disagree	Disagree	Agree	Strongly Agree
The PSE program provides effective supports related to intimacy.	○	○	○	○
The PSE program provides a continuum of support to build students' intimacy knowledge that is age appropriate for students in college.	○	○	○	○
The PSE program's residential model allows for students to experience the privacy necessary to engage in intimacy, which they may not experience at home.	○	○	○	○
The PSE program's philosophy on guardianship affects participants' ability to engage in intimacy.	○	○	○	○
PSE program staff members are trained to provide effective instruction and support related to intimacy.	○	○	○	○
PSE program staff members feel confident and comfortable in providing intimacy education.	○	○	○	○
PSE program staff members believe that students should be able to engage in intimacy, if they so desire.	○	○	○	○
PSE program peer mentors are trained to provide effective instruction and support related to intimacy.	○	○	○	○
PSE program peer mentors that support students in social engagement, feel confident and comfortable in providing intimacy education.	○	○	○	○
A majority of students in the PSE program lack confidence to express their interest in learning more about engaging in intimacy.	○	○	○	○

	Strongly Disagree	Disagree	Agree	Strongly Agree
A majority of students in the PSE program feel that learning about intimacy is not a priority.	○	○	○	○

34. Please provide your recommendations on how PSE programs could improve or expand the continuum of support offered to students in building their intimacy knowledge.

35. Please provide your email address if you'd like the chance to be entered in a drawing for a $100, $50, or $25 Amazon Gift Card!

36. Please indicate whether or not you'd be willing to participate in a follow up study regarding intimacy programming for PSE programs.

- ○ No
- ○ Yes, please contact me at the following email or phone number: