

## Let's Talk about Health: Engaging College Students with Intellectual and/or Developmental Disabilities and Support Staff in Conversations about Health and Wellness Needs

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### **Abstract:**

This study explored the health experiences and health promotion needs of college students with intellectual and/or developmental disabilities (IDD) through individual interviews with current college seniors (n = 5) and recent college graduates (n = 3) with IDD, and support staff (n = 9) within a Southeastern university's inclusive postsecondary education (IPSE) program. Interviews with college seniors and recent graduates with IDD involved photo elicitation and a que-sorting exercise. Interviews with IPSE program staff involved reactions to the que-sorting results of the interviewees with IDD. Thematic findings from current college seniors/recent college graduates with IDD and IPSE program staff are discussed.

**Keywords:** health | wellness | college students | intellectual and/or developmental disabilities | inclusive postsecondary education programs

### **Article:**

**\*\*\*Note: Full text of article below**

## Let's Talk about Health: Engaging College Students with Intellectual and/or Developmental Disabilities and Support Staff in Conversations about Health and Wellness Needs

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This study explored the health experiences and health promotion needs of college students with intellectual and/or developmental disabilities (IDD) through individual interviews with current college seniors and recent college graduates with IDD, as well as support staff within a Southeastern university's inclusive postsecondary education (IPSE) program. Interviews with college seniors and recent graduates with IDD involved photo elicitation and a Q-sorting exercise. Interviews with IPSE program staff involved reactions to the Q-sorting results of the interviewees with IDD. Thematic findings from current college seniors/recent college graduates with IDD and IPSE program staff are discussed.

*Keywords:* health, wellness, college students, intellectual and/or developmental disabilities, inclusive postsecondary education programs

It is estimated that approximately 7 to 8 million Americans have an intellectual and/or developmental disability (IDD; Karimi, 2016). Inequality, exclusion, and segregation are all terms that are common and familiar within the history of people with IDD (Fiorati & Elui, 2015; Duvdevany, 2002). While there have been several advances and accomplishments in regards to integration (Friedman, 2016) and inclusion (Bogenschutz et al., 2015; Lysaght et al., 2017) of individuals with IDD in the United States, this population remains a marginalized population (Special Olympics, 2009) and continues to experience a variety of disparities (Beange & Durvasula, 2001; Clarke & Wilson, 1999; Eastgate, 2011; Kerr et al., 1996; Leeder & Dominello, 2005; McCarthy, 2002).

Disability has been described as the nation's largest public health problem (Courtney-Long et al., 2015; Lollar, 2002). In this country, individuals with IDD experience a variety of health disparities in the areas of life expectancy, mortality, morbidity, and uptake of health promotion and disease prevention activities (Iezzoni, 2011; Ouellette-Kuntz et al., 2005). Research conducted within general healthcare practice has found that people with IDD have more than twice as many health-related problems when compared to people

without IDD who were enrolled in the same healthcare practice (Reichard et al., 2011; van Schrojenstein Lantman-de Valk et al., 2000). When compared to adults without IDD, adults with IDD experience a higher risk for chronic diseases, and are more likely to have low levels of physical activity, to consume foods with high-fat content, and to be overweight (Reichard et al., 2011; Draheim et al., 2002; Fujiura et al., 1997; Rogers et al., 1998; Yamaki, 2003; McGuire et al., 2007).

With these health disparities, there are noteworthy differences between integration and inclusion. Integration is understood as physically being present within a setting, group, or environment. In the case of a specific subset of individuals with IDD (i.e., college students with IDD), they are simply integrated into the college environment when they have physical access to campus, classes, events, etc. Inclusion goes beyond the concept of integration. Inclusion means involving people with disabilities in every aspect of social participation. It is something that must come from a desire to include people with disabilities in the activities of the community, family, friendships, and more (Disabled World Towards Tomorrow, 2014; National Service Inclusion Project, 1993).

All people with IDD, including college students with IDD, should be afforded equitable opportunities to achieve the highest attainable standard of health (Brooker et al., 2015). One researcher explains that all students in health care should be taught that having a disability is not incompatible with being healthy (Bickenbach, 2013). Since health is socially patterned, people who have more extensive social networks and who report feeling connected to their community tend to have better health (Health and Medicine, 2005). Research that has meaningfully included people with IDD through the use of participatory methods demonstrated that the social and emotional aspects of health are frequently mentioned and discussed by people with IDD (Jurkowski, Rivera, & Hammel, 2009). People with IDD are more exposed to social conditions that are associated with poor health outcomes (Graham, 2005). Therefore, it is necessary to consider the social determinants of health and availability of social opportunities for individuals with IDD (Fiorati & Elui, 2015; Duvdevany, 2002), along with other determinants of health. Social determinants of health include conditions in the places where people live, learn, work, and play, which affect a wide range of health risks and outcomes (Centers for Disease Control and Prevention, 2018). Additionally, there is a range of health and wellness issues that relate to transition into adulthood for individuals with IDD. For example, supportive services for individuals with IDD that are provided by various entities during secondary school are most often terminated or drastically decreased when the individual with IDD finishes their secondary education experience and reaches adulthood (Bottos et al., 2001).

In an effort to counter the inequality, exclusion, and segregation that has surrounded adults with IDD and adolescents with IDD for many years, inclusive postsecondary education (IPSE) programs have been developed. However, they are not positioned to focus on the overall health and wellbeing of college students with IDD. It is the intent that these IPSE programs create, expand, and/or enhance high-quality, inclusive higher education experiences to support positive outcomes for individuals with IDD. Currently there are more than 260 IPSE programs for students with IDD across the United States (Think College, 2017). These IPSE programs provide varying levels and combinations of person-centered planning, access to academic advising, residential support, employment

services, specialized support for families of students, and/or student support from peer mentors in the areas of academics, socialization, employment, independent living, and transportation. Not only are IPSE programs creating opportunities for students with IDD to attend college, receive support, and obtain credentials, the majority of these programs are committed to the continued expansion of access to higher education for individuals with IDD (Grigal et al., 2017).

Whereas the expansion of access to higher education for individuals with IDD is a promising strategy to diminish inequality, exclusion, and segregation, an important question persists: What are the health and wellness needs of college students with IDD? Considering what some refer to as the “college effect,” a phenomenon suggesting that once a student is on campus they become exposed to risky behaviors such as alcohol use, risky sexual behavior and experience-related negative consequences (e.g., injury, stress, diminished mental health), it is possible that the college effect is impacting college students with IDD in similar ways. Furthermore, the consequences that are associated with these and other common college health issues have potentially greater consequences for college students with IDD.

Although there is limited research that specifically provides a comprehensive understanding of the health of college students with IDD, evidence does suggest that health inequalities and disparities exist for adolescents and adults with IDD who are at the college age. Individuals with IDD are generally unfit, obese, and often suffer from high blood pressure (Leeder & Dominello, 2005). While these health issues are the focus of many community-based health promotion programs, individuals with IDD are rarely included or targeted (Leeder & Dominello, 2005). Individuals with IDD are often overlooked and receive less by way of routine immunizations, blood pressure checks, cervical and breast cancer screening programs, and healthy nutrition programs (Beange & Durvasula, 2001). Some of the common health challenges that were occurring on college campuses across the country in 2018 included STDs and HIV, as well as dating violence (American College Health Association, 2019). Individuals with IDD, much like other individuals, are sexual beings; however, sexual health education has been shown to be a vital but often neglected aspect of health care for individuals with IDD (Eastgate, 2011). Additionally, the development of mental health services for individuals with IDD is minimal due to a lack of recognition at the primary care level and insufficient numbers of trained professionals with specialized services (McCarthy, 2002). Finally, health behavior literature related to individuals with IDD and alcohol or drug use is lacking.

Individuals with IDD who are transitioning into college settings will likely experience some of the very same health challenges that are naturally created by the college environment. Additionally, whereas the amount of resources available to college students without IDD is vast, comparatively speaking, the health education and related support college students with IDD have access to and receive for health issues is relatively unknown.

The social model of disability (Fujimoto et al., 2014; Fiorati & Elui, 2015; Ravindran & Myers, 2012; Gilbert, 2004) was the theoretical model that guided this study. The social model of disability expresses that disability is an outcome of societal processes, rather than an outcome of a diagnosis, label, or disability in and of itself. Within this model,

societal structures, political power, organizational attitudes, and social relations all play an important role in having, experiencing, or being labeled as having a disability (Fujimoto et al., 2014; Fiorati & Elui, 2015). Researchers explain that all development, including disability, occurs within a socio-cultural context (Ravindran & Myers, 2012). Therefore, it is important to consider societal structures, power, attitudes, and relations that play a role in disability. The aim within the social model of disability is to accomplish social change in the structural relationships between people with and without disabilities (Gilbert, 2004). In other words, the social model of disability encourages society to recognize physical and social barriers that make life harder for people with disabilities and that contribute to people being “disabled” (Gilbert, 2004). Therefore, the goal within the social model of disability is to accomplish changes that reduce or eliminate physical and social barriers that contribute to a person being “disabled” (Gilbert, 2004). The social model of disability supports the necessity for this study to focus on the perceptions and lived experiences of college students and recent graduates with IDD, as well as the staff who provide support to these students. The social model of disability frames this study by shifting the focus away from the students’ disabilities and towards physical and social barriers that may be inhibiting meaningful inclusion and/or the highest possible attainment of holistic health and wellbeing.

In sum, there is a dearth of literature that comprehensively outlines the health inequities and disparities for college students with IDD on a college campus, as well as an incomplete understanding of the programming provided to this marginalized population. In order to best serve this population, a better understanding of their health experiences and the health promotion needs must be established. While using the social model of disability as a lens to view the larger problem, the physical and social barriers that impact and influence health experiences and health promotion needs of college students with IDD are of utmost importance. Therefore, the purpose of this study was to explore the health experiences and health promotion needs of college students with IDD through the utilization of individual interviews with current college seniors with IDD, recent college graduates with IDD, and support staff within the university’s IPSE program.

## **Methods**

### **Setting**

The IPSE program within this study offers a certificate program to college students with IDD at a university in the Southeastern United States. The IPSE program is a four-year certificate program of study offered by the Office of the Provost at the university. A nonprofit agency collaborates with the IPSE program to provide support to students outside of the classroom. At the time of this study, the IPSE program had 65 students enrolled, and 57 graduates.

Using an inclusive-individualized model, the IPSE program encourages students to meet student-learning objectives through individualized plans of study that incorporate coursework and other educational activities. With oversight from IPSE program staff, students receive both academic and advising supports as determined by each student’s college support plan. The students with IDD are fully included in campus life and access courses supportive of career and life goals, academic resources, on- and off-campus

student housing, and co-curricular activities. Students are included within campus clubs, campus ministries, campus activity boards, new student orientations and tours, intramural and club sports, sororities/fraternities, the student recreation center, intercollegiate sporting events, and more. The students with IDD live among the general university student body in either on-campus residential housing or in privately owned apartment complexes adjacent to the university campus. A combination of paid and non-paid supports, including those supports and resources that are available to any student on campus, assist students with IDD in having a comprehensive university experience that prepares them for life after graduation, and encourages the development of natural supports.

## Participants

Participants included current college seniors with IDD, recent college graduates with IDD, and IPSE program support staff. With these three types of participants, there were two distinct groupings of participants within this study: (1) students/graduates with IDD, and (2) IPSE program support staff. It was deemed as most appropriate to involve current college seniors with IDD and recent college graduates with IDD as participants due to the fact that these individuals had the most recent experience as college students. A gatekeeper was identified at the IPSE program, who supported the research team with purposeful recruitment through the use of recruitment emails and follow-up phone calls with participants with IDD, as needed. All participants provided informed consent before engaging in the study.

As illustrated in Table 1, the sample of individuals with IDD was equally represented by race/ethnicity. The sample of individuals with IDD included more current students (seniors) compared to graduates. The sample of individuals with IDD also included more females compared to males. The sample of IPSE program staff was equally represented by the various roles of staff within the IPSE program. This diverse representation added richness to the collected data. The sample of IPSE program staff included more males compared to females. The sample of IPSE program staff also included more white individuals compared to black individuals.

Table 1. *Sample Characteristics (N=17)*

Individuals with IDD ( <i>n</i> =8)	<i>n</i> (%)
Demographic	
Individuals with IDD	
Current student (senior)	5 (62.5)
Graduate	3 (37.5)
Sex of students and graduates with IDD	
Male	3 (37.5)
Female	5 (62.5)
Race/ethnicity of students and graduates with IDD	
White	4 (50)
Black	4 (50)

IPSE Program Staff ( <i>n</i> =9) Demographic	<i>n</i> (%)
Role of IPSE program staff	
Student Life Support Advisor & LRT/CTRS	1 (11.1)
Academic Life Support	1 (11.1)
Academic Life Support & Career Preparation	1 (11.1)
Residence Life Support & Student Life Support	1 (11.1)
Recruitment & Admissions	1 (11.1)
Student Life Support Advisor	1 (11.1)
Student Life Support Coordinator & LRT/CTRS	1 (11.1)
Family Support	1 (11.1)
Program Director	1 (11.1)
Sex of IPSE program staff	
Male	6 (66.7)
Female	3 (33.3)
Race/ethnicity of IPSE program staff	
White	6 (66.7)
Black	3 (33.3)

*\*Note.* IDD = intellectual and/or developmental disability, IPSE = inclusive postsecondary education, LRT/CTRS = licensed recreational therapist and certified therapeutic recreation specialist.

## Procedures & Measures

All study participants were purposefully recruited through the use of email and follow-up phone call communication for participants with IDD who preferred to communicate over the phone. A gatekeeper at the IPSE program provided contact information for all potential study participants who met the inclusion criteria. Inclusion criteria for participants with IDD included being a current senior at the university who was currently part of the IPSE program, or being a graduate of the university who was previously a part of the IPSE program. Inclusion criteria for participants without IDD included being a current employee of the IPSE program. The goal was to recruit eight college students or recent graduates with IDD and eight IPSE program staff. The recruited individuals who responded to the recruitment email first were subsequently included in the sample of participants. As a procedure for de-identifying the interview data, a list of pseudonyms were created and stored in a password-protected electronic file that was separate from the password-protected electronic file where the data was stored.

An individual, semi-structured interview was completed and audio-recorded with each participant. There were two rounds of interviews. Interviews with students and graduates with IDD were completed before interviews with IPSE program staff. All but one interview was completed in person in a private office on UNCG's campus. One interview with a

recent graduate with IDD was completed via WebEx. Interview questions for students and graduates with IDD and IPSE program staff are listed in Table 2.

Table 2. *Interview Questions for Students and Graduates with IDD and IPSE Program Staff*

<b>Interviews with Students and Graduates with IDD</b>	<b>Interviews with IPSE Program Staff</b>
As a current or recent college student with IDD, how do you define “health” in college?	As a support staff for college students with IDD, how do you define “health” for college students with IDD?
When thinking back to your own experiences in college, would you consider yourself to be a healthy college student? And, why?	When thinking back to your own experiences supporting college students with IDD, would you consider the students that you supported to be healthy? And, why?
When thinking back to your own experiences in college, was it hard or was it easy to stay healthy when you transitioned from being a high school student to being a college student? And, please explain why it was hard or easy to stay healthy.	When thinking back to your own experiences supporting college students with IDD, was it hard or was it easy for these students to stay healthy when they transitioned from being a high school student to being a college student? And, please explain why it was hard or easy for these students to stay healthy.
What did your experiences in college teach you about your own health and wellness?	From your perspective as a support staff, what did the college experience teach these students about their own health and wellness?
Are there any health topics that you wish you could have learned more about while in college?	From your perspective as a support staff, are there any health topics that you wish these students could have learned more about while in college?
Was there anything about the college environment that made it hard to stay healthy?	Was there anything about the college environment that made it hard for these students to stay healthy?



<p>If yes, please explain what made it hard to stay healthy.</p>	<p>If yes, please explain what made it hard for these students to stay healthy.</p>
<p>Was there anything about the college environment that made it easy to stay healthy? If yes, please explain what made it easy to stay healthy.</p>	<p>Was there anything about the college environment that made it easy for these students to stay healthy? If yes, please explain what made it easy for these students to stay healthy.</p>
<p>Did you have any supports or services at college with staying healthy? If yes, please explain these supports or services.</p>	<p>What are the supports or services for these students at college in regards to staying healthy? Please explain these supports or services.</p>
<p>Are there any supports or services at college with staying healthy that you did not have access to? If yes, please explain these supports or services.</p>	<p>What are the missing or inaccessible supports or services for these students at college in regards to staying healthy? Please explain these missing or inaccessible supports or services.</p>

At the end of each interview with students and graduates with IDD, a photo elicitation and Q-sorting exercise was implemented. Six photos representing six major topics of health and wellness for college students were printed and used during the photo elicitation and Q-sorting exercise (see Figure 1). The six topics were chosen based on literature that highlights common health and wellness topics and challenges among college students in the United States (Iliades, 2011). The six topics were (1) physical activity and exercise, (2) food choices, (3) drugs and alcohol, (4) sex, dating, and relationships, (5) mental health, and (6) socializing and leisure.

Figure 1. *Photos Used for Photo Elicitation*



For the photo elicitation activity, each photo was presented to the interviewee one at a time. After presenting each photo, a series of questions were asked about each (see Table 3).

Table 3. *Photo Elicitation Questions*

Photo Elicitation Questions Asked After Each Photo Was Presented
What do you see in this photograph?
What is happening in this photograph?
How does this relate to your experiences with health and wellness as a college student?
Why is (insert health and wellness topic) important for college students with IDD?
What would have made your experience with (insert health and wellness topic) in college even better?

After the photo elicitation activity was complete, the interviewee was asked to sort the photos in order of which topics they felt were most important for college students with IDD

to learn about while in college (i.e., 1 = most important; 6 = least important). After all interviews with students and graduates with IDD were complete, the Q-sorting results were organized and printed on paper.

An individual, semi-structured interview was then completed with the IPSE program staff (see Table 2 for interview questions). At the end of each interview, the interviewee was given time to review the de-identified Q-sorting results from each of the eight students/graduates with IDD that previously completed an interview. Each interviewee was then asked to describe their reactions to the Q-sorting results (i.e., Were they surprised?, Did they agree or disagree?, Why or why not?, Would they change anything?). The IPSE program staffs' reactions to the Q-sorting results were not analyzed separately. Instead, their reactions to the Q-sorting results were analyzed along with all other responses to interview questions. After all interviews were complete, audio-recordings were transcribed by a principal investigator and a graduate research assistant.

Specific trustworthiness measures were used to ensure credibility, dependability, and confirmability. Credibility was ensured through the collection of interview data from students and recent graduates with IDD, as well as IPSE program staff, which contributed to the richness of the data collected. Dependability was upheld due to the legitimacy of the methods used (i.e., photo elicitation and Q-sorting within interviews; Sort and Sift, Think and Shift analysis approach). Dependability subsequently increased the likelihood of generating similar findings if our study were repeated. Lastly, confirmability was ensured through the engagement of multiple researchers (i.e., principal investigator and two co-investigators) throughout all data collection and analysis procedures. The engagement of multiple researchers contributed to a reduction of bias.

## **Data Analyses**

Data was analyzed using an iterative process with constant comparison. Our analysis approach proceeded through the six core phases of the Sort and Sift, Think and Shift approach: data inventory, written reflection, reflective diagrams, categorization, bridging, and data presentation (Curry et al., 2006; Maietta, 2006). The three researchers immersed themselves in the data by individually and independently reviewing through each transcript and writing a memo to describe initial ideas and patterns that emerged from the data. The three researchers then came together to discuss the memos. As the memos were discussed, the three researchers worked together to create two visual maps to visually document the emerging themes from students and graduates with IDD, as well as IPSE program staff. The three researchers then reviewed through the data individually and independently to identify quotes that represented themes that were identified during the visual mapping process. While identifying quotes, new themes that emerged were documented. The three researchers met one final time to condense, collapse, combine, and refine thematic ideas and generate rich descriptions of final themes.

## **Results**

All results are organized by the interviews from which the results were generated (i.e., students and graduates with IDD vs. IPSE program staff; see Table 4).

Table 4. *Thematic Findings Organized by Students/Graduates with IDD vs. IPSE**Program Staff*

<b>Thematic Findings from Students/Graduates with IDD</b>	<b>Thematic Findings from IPSE Program Staff</b>
Fundamentals of Health in College	The Balancing Act: Respecting Independence and Implementing Strategies
Challenging Assumptions About Sex, Alcohol, and More	Independence: A Complex Combination of Challenges, Choices, and Decisions
Situational Decision Making	Students Need Experiential Learning
Social Connections and Natural Supports	Accessibility of Information, Opportunities, and Resources
Coping with Stress and Anxiety	Campus Resources Need Increased Awareness, Attitudinal Changes, and Inclusion Training

**Students and Graduates with IDD**

The five most prominent themes that emerged from the students' and graduates' with IDD interview data included the following: fundamentals of health in college; challenging assumptions about sex, alcohol, and more; situational decision making; social connections and natural supports; and coping with stress and anxiety.

*Fundamentals of health in college.*

Students and graduates with IDD discussed experiences and preferences that revealed an overall sense of awareness of the basic idea that the college environment and experience can ultimately affect the health and wellness of college students, and the ownership of personal responsibility. One participant explained, "Staying healthy in college can be hard. You're living by yourself, without your parents, and it's kind of like your ultimate responsibility of what you do or don't do to stay healthy" (current senior). Another participant explained, "It is all about making choices of how you want to stay healthy. The choices you make are important for your health" (recent graduate). Another participant explained, "Health in college is about different things... eating healthy, going to the doctor, managing your health, and making good choices every day" (current senior).

*Challenging assumptions about sex, alcohol, and more.*

Students and graduates with IDD revealed exposure to and/or participation in behaviors, activities, events, and more that involved romantic relationships, sexual activity, alcohol, and drugs. These students and graduates also discussed their experiences and preferences in a manner that was similar to and typical of a college student without IDD. One participant explained, "I dated a lot of guys over the years before I came to college. I was a virgin, until freshman year" (current senior). Another participant explained, "I go to parties with alcohol. You have to watch what you drink, and don't leave your drink unattended. Watch how much you drink, and make sure you have a friend that can get you home safely" (current senior).

*Situational decision making.*

Students and graduates with IDD shared information that revealed frequent exposure to situational decision making and the need for support with situational decision making in regard to various health and wellness topics (i.e., nutrition, life skills, alcohol and drugs, etc.). One participant explained, "There are a lot of unhealthy food options on campus, and only a few healthy food options on campus. Sometimes it is hard to make the right choice" (recent graduate). Another participant explained, "Your friends can pressure you to drink at parties, even if you don't want to. In the moment, you have to know your limits" (current senior).

*Social connections and natural supports.*

Students and graduates with IDD discussed experiences that revealed exposure to and/or a need for opportunities that involve the development of social connections and natural supports (i.e., spending time with and receiving support from peers who are not paid to work with them). One participant explained, "When you socialize, you get to meet new people and find common interests. That is important" (recent graduate). Another participant explained, "I met a friend at the gym my freshman year and he is really cool. We both love to work out, and we still work out together" (current senior). These students and graduates also discussed experiences that revealed the use of and/or need for skills that can lead to social connections and the development of natural supports. Another participant explained, "You have to get out there and be yourself. When I was a freshman, I wanted to join groups and build new friendships. Sometimes people need help with that" (current senior).

*Coping with stress and anxiety.*

Students and graduates with IDD described successful experiences coping with stress and anxiety in college, as well as some needs for learning coping strategies. One participant explained, "If you overwhelm yourself, you pretty much get to the point where you are out of control. You might need help when you feel this way" (recent graduate). Other participants explained, "When you are in college, you have to learn how to deal with stress on your own. That is really hard sometimes" (current senior), and "When I got

stressed in college, I would take a deep breath and sometimes take a break to do something fun and relaxing” (recent graduate).

Results of the Q-sorting exercise are presented in Table 5. A number was assigned to each photo based on the ranking provided by the participant for which health topics they felt were most important for students to learn about while in college (i.e., 1 = most important; 6 = least important). The numbers for each photo were summed, and the lowest total score represents the health topic that participants felt was most important for college students to learn about while in college. The highest score represents the health topic that participants felt was least important for college students to learn about while in college.

Table 5. *Q-Sorting Results*

	Food Choices	Physical Activity and Exercise	Socializing and Leisure	Mental Health	Sex, Dating, and Relationships	Drugs and Alcohol
Participant 1	2	1	6	4	5	3
Participant 2	2	1	3	5	4	6
Participant 3	5	2	1	3	4	6
Participant 4	2	3	1	5	4	6
Participant 5	1	4	2	5	3	6
Participant 6	2	3	6	4	5	1
Participant 7	1	2	4	3	5	6
Participant 8	5	6	4	2	3	1
<b>TOTAL</b>	<b>20</b>	<b>22</b>	<b>27</b>	<b>31</b>	<b>33</b>	<b>35</b>

### IPSE Program Staff

The five most prominent themes that emerged from the IPSE program staffs' interview data included the following: the balancing act: respecting independence and implementing strategies; independence: a complex combination of challenges, choices, and decisions; students need experiential learning; accessibility of information, opportunities, and resources; and campus resources need increased awareness, attitudinal changes, and inclusion training.

*The balancing act: respecting independence and implementing strategies.*

IPSE program staff discussed the struggles that students experience during and after their transition from high school (or another environment) to college as mostly being complicated by the changes in structure. The staff explained that there are several students who were used to a significant amount of organizational and structural strategies before they came to college. Organizational and structural strategies can include various types of schedules (e.g., electronic, hard copy, pictures), reminders, and organizational strategies that provide visual prompts. For example, one staff member explained, "Some students are used to having their parents direct their lives from the moment they wake up in the morning to the moment that they go to bed at night." For these students, there are automatic difficulties when they are living in an environment with no strategies, and much less or sometimes different types of organizational and structural characteristics. The staff also explained that it is important to consider the types of organizational and structural strategies that worked well for each student before they came to college. One staff member explained, "When we are in the interview process with potential students, we try to learn as much as we can about the strategies and types of structure that have worked well for them outside of the college environment." However, the staff explained that it is also important to appropriately disrupt organization and structure so that the student can develop adaptive skills for the random happenings of day-to-day life. After all, the staff did describe the importance of respecting the individuality of each student, and recognized the benefits of allowing the student to organically experience the independence that they so deeply value during their college experience. For example, one staff member explained:

I think college gives them a chance with being independent with their health and wellness. Because you don't have your parents there to tell you, you know, eat your meals, or follow your schedule, or take care of yourself. The college experience gives them a lot of experience with responsibility, which they need.

As each student is supported to develop adaptive skills for the random happenings of day-to-day life, their self-esteem and self-efficacy in their ability to live an independent life increases.

*Independence: a complex combination of challenges, choices, and decisions.*

IPSE program staff talked about the importance of each student's impactful experience with independence. There were several ideas that were revealed when talking about each student's experience with their newfound independence in the college environment. Staff revealed the importance of allowing students the space and opportunity to work through the decision-making process, and experience natural consequences. For example, one staff member explained:

I think this college experience is so important, because it provides that opportunity to come out of that protective environment... to experience the consequences of what it's like to eat a whole pizza in one sitting. You don't have your parents saying that you can only have two pieces.

Staff discussed the idea that some students are more motivated and empowered than other students, and this can affect several aspects of their overall health and wellness. For example, one staff member explained, "There are some students that really want to

be healthy and connect to resources on campus, like the gym. There are other students that are not as motivated and develop unhealthy habits during college.” Staff also discussed the need for opportunities where students can learn to better assess and understand consequences and risks, and practice situational decision-making in a variety of different health and wellness related areas of life (i.e., food, physical activity, social interactions, living with others). One staff member explained, “Natural consequences are so important for the students to learn from their mistakes. If a student is not respecting their roommate’s privacy and is not cleaning up after their self within shared living spaces, the roommate might get fed up and file a formal complaint with their dorm’s resident assistant. These natural consequences are important.”

*Students need experiential learning.*

IPSE program staff talked about a need for students to learn experientially, with techniques and strategies that involve real life situations. One area of health and wellness that staff expressed as an area of high experiential need for students was romantic relationships. One staff member explained, “Some students are coming into college with fewer past experiences and opportunities to really practice building and maintaining a romantic relationship.” Staff explained that students need to be able to learn from modeling and/or have the opportunity to practice different communication skills that are needed to initiate and engage in romantic relationships. The staff explained that most students want to experiment with romantic relationships while in college, but they are not experienced with romantic relationships.

*Accessibility of information, opportunities, and resources.*

Staff discussed the fact that there are a plethora of opportunities and resources on campus that relate to health and wellness. However, they explained an overall experience that is witnessed among students: The students are not aware of and/or do not access the opportunities and resources. For example, one staff member explained:

You can go to the student health center, you can get a lot of information about nutrition. The information is there. The question is, how can we come up with more effective strategies for getting students engaged with information that is already out there?

The staff discussed the importance of not only considering physical accessibility of opportunities and resources, but also the accessibility of information and materials that describe and market the opportunities and resources. One staff member explained, “There are some students that do not read well or can’t read at all. The printed or online materials that advertise resources with only written text create a barrier for these students.”

*Campus resources need increased awareness, attitudinal changes, and inclusion training.*

When discussing campus resources, the staff explained that there are needs present within the different campus entities that provide campus resources. For example, the staff discussed the need for mental health resources, as well as recreation and sports resources, on campus, to increase awareness of students with IDD, to clarify assumptions



and change attitudes about students with IDD, and to develop skills for including and serving students with IDD. One staff member explained:

I think it is important to address some of the attitudinal barriers that students may come up against on campus. The campus community as a whole should value inclusion. If the value for inclusion is not there, that often gets in the way of students being able to access some things on campus. Some staff within the campus community may also not have the training they need to know how to include and serve our students.

### Discussion

The findings from the Q-sorting portion of the individual interviews with students/graduates with IDD show that college students with IDD feel that maintaining fitness and nutrition are the most important health and wellness topics for students with IDD to learn about while in college. Due to challenges with situational decision-making and tendencies for some students to give in to impulsive instincts, making healthy food choices in an environment that includes a plethora of unhealthy food choices can prove to be quite difficult. The literature supports the importance of fitness and nutrition among college students with IDD, as it reveals that individuals with IDD are more likely to have low levels of physical activity, to consume foods with high-fat content, and to be overweight (Reichard et al., 2011; Draheim et al., 2002; Fujiura et al., 1997; Rogers et al., 1998; Yamaki, 2003; McGuire et al., 2007). When viewing the problem of a lack of fitness and nutrition from the perspective of the social model of disability, the IPSE program staff spoke about the variety of resources that the college campus provides in regard to nutrition and fitness. In the case of nutrition, IPSE program staff explained that students are not aware of and/or experience barriers in accessing these resources. In the case of fitness, IPSE program staff specifically shared the need for campus recreation to increase awareness, change attitudes, and receive inclusion training. Although the topics of fitness and nutrition were ranked as most important among students with IDD, IPSE program staff revealed important social barriers.

The findings also show that college students with IDD are challenging stereotypical beliefs around sex, dating, romantic relationships, drugs, and alcohol. Many people may believe that individuals with IDD are not sexual beings and/or should not engage in sex, dating, or romantic relationships. Many people also believe that individuals with IDD are not exposed to, do not have desires to engage in, and/or do not engage in activities involving alcohol and drugs. Current literature suggests that the majority of adults with IDD are sexually active or have strong intentions to become sexually active (McGillivray, 1999). Contrary to this information, research also indicates that individuals with IDD have been marginalized, oppressed, and left out of sexuality discussions, regardless of the fact that individuals with IDD are sexual beings with desires, needs, and challenges that specifically relate to their own sexuality (Winges-Yanez, 2014). Another problematic fact from the literature that further complicates the issue relates to sexual victimization of individuals with IDD. When compared to individuals without IDD, individuals with IDD are more likely to experience sexual victimization (Brown-Lavoie, et al., 2014). Other studies underscore the importance of individuals with IDD being considered as a population who are at risk for dangerous alcohol and drug use and, for some, may require the need for

smoking cessation programs (Singh et al., 2014; Taggart et al., 2006; Tracy & Hosken, 1997).

Additionally, it is important to note that findings from the Q-sorting activity with students and graduates with IDD revealed that the topics of (1) sex, dating, and relationships, and (2) drugs and alcohol were voted as the least important for students to learn about while in college. This finding is interesting, as it could be related to the students' and graduates' lack of knowledge with these "taboo" topics. We prompted the students and graduates to sort the health and wellness topics based on which topics they felt were most important for students to learn about while in college. These students and graduates may have based their judgments of importance and subsequent sorting on the topics that brought the most fond memories to mind and the topics for which they were most experienced. If a topic like sex, dating, and relationships or drugs and alcohol was viewed as "taboo" by the students, it is likely that they would be more inclined to sort it as being of lesser importance. When referring to the literature, it is important to note that a lack of interest in a topic like sex, dating, and relationships among individuals with IDD is most often due to a lack of exposure and/or feeling that these are "taboo" topics (McCabe, 1999). These findings are consistent with research showing that people with IDD demonstrate lower levels of sexual health knowledge (McCabe, 1999).

The findings show that social connections and natural supports are important to the overall health and wellness of college students with IDD. Other studies have recommended supports for college students with IDD that include customized programs to promote social communication competence, as well as full and meaningful inclusion programming on college campuses (Zager & Alpern, 2010). The findings also show that college students with IDD have needs in regard to learning to cope with stress and anxiety while in college. Researchers who have studied college students with a specific type of intellectual disability, autism spectrum disorder, have recommended the provision of interventions and support for the development of coping strategies, given the stressful and anxiety-provoking nature of college life (Cowen, 1988).

The findings show that supporting students with IDD as they transition from pre-college to college life is a balancing act that involves being respectful of independence, as well as implementation of strategies and supports. Additionally, the newfound independence of new college students with IDD involves a complex combination of challenges, choices, and decisions. Difficulty with transition experiences and worries around transition of individuals with IDD who are entering into college life are confirmed within the literature. The literature recommends the use of personalized approaches and customized programming that is based on the individual needs of each student (Zager & Alpern, 2010). IPSE program staff within this study spoke to the benefits of utilizing individualized and person-centered approaches to overcome challenges with transition.

The findings revealed a need for students to engage in experiential learning and to gain skills with situational decision making around various health and wellness topics. Research involving college students with IDD has recommended the development and implementation of personalized interventions that utilize experiential learning and situation decision making techniques to coach students with IDD in the various aspects

of student life and daily living (Van et al., 2015). Lastly, the findings revealed a need for increased awareness, attitudinal changes, and inclusion training within various campus-based resources and departments. Research involving college students with IDD has recommended the development and implementation of inclusion programming that promotes and provides full and meaningful inclusion on college campuses (Zager & Alpern, 2010). Additionally, researchers have made recommendations related to the development of programs aimed at increasing faculty and staff awareness about students with IDD at institutions of higher education (Cowen, 1988).

### **Limitations**

Despite the benefits, this study did have limitations. This study was limited by the restricted nature of the sampling strategy. We only sampled at one university. Our study was diverse in race of individuals with IDD. However, there were more females with IDD, more male IPSE program staff, and more white IPSE program staff in the study. Our study is not transferable beyond this one IPSE program at this one university, because it is not representative of students and graduates with IDD and staff in other IPSE programs at other universities. In spite of this limitation, this study does begin to pave the way for future work by revealing the lived experiences and thematic findings from college students and recent graduates with IDD, along with IPSE program staff. We believe there may have been a potential response and/or recall bias with students and graduates with IDD during the Q-sorting exercise. We prompted the students and graduates to sort the health and wellness topics based on which topics they felt were most important for students to learn about while in college. These students and graduates may have based their judgments of importance and subsequent sorting on the topics that brought the most fond memories to mind and the topics for which they were most experienced.

### **Conclusion**

Given that there are over 260 IPSE programs that specifically serve individuals with IDD across the United States, the number of students with IDD who are attending a college or university will most likely continue to increase. This article underscores important health and wellness needs of college students with IDD at one university. Based on the social model of disability, it is important to note that a large majority of the findings reveal important physical and social barriers to meaningful inclusion and/or attainment of the highest possible level of holistic health and wellbeing among college students with IDD. It is imperative that research on this unique population continues and that attention be given to establishing the etiology of health and wellness issues of college students with IDD in order to develop and implement evidence-based programming.

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