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Sexual Wellness Across Abilities: Reimagining Education for Adults with Disabilities

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Abstract

Many adults with Intellectual and Developmental Disabilities (IDDs) lack sexuality education and opportunities for personal expression. Because of this, a sexuality education curriculum was developed for Gateway's program, Without Walls. This program is specifically for adults with Intellectual Disabilities. This curriculum was delivered to 15 students ages 25 to 56. The purpose of this project is to bridge information for this population and make it more accessible. Especially with this group, there is a need for further discussion and a space to ask questions about social-emotional and sexual health. Over the course of 11 classes, the students reported having a better understanding of sexuality and how to care for their overall health. Because of this, the project met its expected outcomes of making the information more accessible and having a positive impact. Due to its success, continuing the program and incorporating staff training as well as other programs is recommended.

Keywords: Disability, sexuality education, sexual health, social-emotional health, healthy relationships

Agency & Communities Served

Gateway Center of Monterey County is a non-profit organization located in Pacific Grove. They service those with developmental disabilities and have a mission to, “fully support their individual rights and choices, and empower them to live full and productive lives with dignity and independence within the community” (Gateway Center, 2022, para. 1). The community that they primarily serve are those over the age of 18, specifically living in Monterey County. According to the U.S Census (n.d), there are 248,979 individuals ages 18 to 64 in Monterey County. Of that, 15,213 or 6.1% of them are classified as having a disability. The total population in Monterey County is 438,953 for comparison. Moving on to ethnicity, 51.2 % identify as White, 3.6% Black or African American, 1.9% American Indian and Alaska Native, 7.8% Asian, 1.1% Native Hawaiian and Other Pacific Islanders, 43.9% as another ethnicity. These statistics change when looking at those with a disability. In that population, 13.3% are White, 25.9% are Black or African American, 30.8% are American Indian and Alaska Native, 13.1% are Asian, and 5.4% identify with another ethnicity. As clearly noted, minority groups are more likely to be diagnosed with a disability in Monterey County.

There are several services being offered at this organization. To start, they have residential care that includes two Intermediate Care Facilities, also known as ICF One & Two. In addition, they have the Reindollar Care Home, which is a four-bedroom residential home with level 4 care. Moving on, they also offer supportive living and independent living services. Lastly, they have a few different day programs. There is the Community Adult Development Center (CADC), the Senior Day Program which is in both Pacific Grove and Salinas, and the Without Walls Program. Each addresses the overall need of developing physical, emotional, and practical

skills appropriate to the clientele, while also providing a safe environment to grow and create community.

Problem Model Background and Literature Review

Problem Statement

Individuals with Intellectual and Developmental Disabilities (IDDs) often face a significant deficit in comprehensive sexuality education and expression opportunities, leading to a range of impacts on their overall well-being. The National Conference of State Legislatures (2020) provides context for this issue by indicating that only 30 states in the U.S. mandate sex education be taught in public schools, and only 22 of those states require curricula to be medically accurate. Further, according to a policy brief written by Dr. Laura Graham Holmes and the Sexuality Information and Education Council of the United States (SIECUS), “\$2.2 billion of federal funding has been wasted on failed AOUM [abstinence-only-until-marriage] programs over the past three decades.” (2021, p. 17). They further state that, “[t]hese programs have been found to be ineffective in delaying sexual intercourse or additional sexual risk behaviors and utilize fear- and shame-based tactics that are often harmful to young people” (2021, p. 17). Due to the lack of mandated material, individuals with IDDs are often overlooked and/or not given the same educational opportunities. The prevailing lack of sexual education for this demographic perpetuates misconceptions, hinders self-advocacy, and contributes to the vulnerability of individuals with IDDs to abuse and exploitation, as outlined in the Problem Model in Figure 1.

There are widespread misconceptions when it comes to the sexuality of individuals with IDDs. Many, including caregivers, believe that they have no sexual needs, are eternal children, and that they have no interest in sex (American Psychological Association, 2017). Because of

overprotective measures such as exclusion from sexuality education, higher rates of exploitation and abuse among this population is a result. According to Disability Justice, “[a]pproximately 80% of women and 30% of men with developmental disabilities have been sexually assaulted - half of these women have been assaulted more than 10 times” (2023, para. 5). These limiting beliefs only further isolate this group and impede the development of healthy self-esteem and self-identity. Addressing this gap is not only a matter of equality and inclusion but also a step towards fostering a society that respects and values the autonomy of all its members.

Figure 1: Problem Model

Contributing Factors	Problem	Consequences
Lack of Inclusive Education Programs	Lack of sexuality education and expression for individuals with Intellectual and Developmental Disabilities (IDDs).	Limited Autonomy & Independence
Social Stigma & Stereotypes		Increased Vulnerability & Exploitation
Caregiver Overprotection		Risk to Sexual Health

Contributing Factors

Lack of Inclusive Education Programs

Individuals with IDD encounter barriers to accessing sexuality education that is adapted to their cognitive abilities and communication styles. Standard curricula often do not account for diverse learning needs, leaving this population without essential information about their bodies, relationships, and sexual health. Decision-making capacity, experience, and commensurate skills that are required in order to establish appropriate sexual boundaries and healthy relationships are often not considered when designing sexuality education programs. Because of this, “46% of people with Intellectual and Developmental Disabilities (IDDs) with low support needs... and 84% of those with high support needs don’t receive any sex education,” (Elevatus Training,

2021-A, para. 1). Generally speaking, using easy words and pictures is the most effective design of content when addressing accessibility. Knowing that the amount of information that is understood outweighs how much is given. Simplifying vocabulary and providing context for more difficult concepts are two easy ways of modifying information to make it more accessible (CHANGE, 2019). The current curriculum counteracts the effectiveness of holding these classes given that those with IDD's are continuously excluded from the conversation, even if they are included. Traditional sex education materials often use complex language and terminology that may be difficult for individuals with IDD's to understand. Concepts related to anatomy, reproductive health, and relationships may be presented in ways that are not accessible to them. In addition to overlooking a difference in skill sets, using euphemisms and vague expressions creates a learning environment that is inaccessible to students with IDD's (Boehning, 2006). It is crucial to recognize the diverse experiences within this community and provide inclusive, age-appropriate, and accessible sexuality education that empowers individuals with disabilities to make informed choices and lead fulfilling lives.

Students with disabilities are often asked to be excused from sex education classes, perpetuating a cycle of exclusion and neglect. Despite the importance of inclusive sexual health education, many educators and administrators fail to provide accommodations or tailored curriculum materials that address the specific needs of students with disabilities. In fact, according to Michielsen and Brockschmidt, students with IDD's, "needs may exceed those of their peers without disabilities due to disability-specific issues, such as learning how to deal with reduced privacy" (2020, para. 4). This practice not only deprives these students of vital information about their bodies, relationships, and sexuality but also reinforces harmful stereotypes and societal taboos surrounding disability and sex. By allowing students with

disabilities to opt out of sex education, educational institutions inadvertently perpetuate their marginalization, and deny them the opportunity to develop essential life skills for navigating healthy relationships and making informed decisions about their sexual health. This was proven in a study conducted through the Journal of School Health which found that, “[a]lmost two thirds of participants faced structural barriers; 45% were concerned about parent, student, or administrator response; and one quarter reported restrictive policies" (2013, para. 3). Instead of excusing these students, educators and policymakers must prioritize implementing inclusive and accessible sex education programs that cater to the diverse needs of all students, ensuring that every individual receives the knowledge and support necessary to lead safe, fulfilling lives.

Social Stigmas & Stereotypes

Social stigmas and stereotypes surrounding students with disabilities often intersect with the topic of sex education, creating significant barriers to their access to comprehensive sexual health information. Society frequently views individuals with disabilities through a lens of asexuality, infantilization, or as being incapable of engaging in romantic or sexual relationships. Comparatively, as found in a study conducted by Ward, Bosek, and Trimble (2010), 85% of individuals with IDD reported that romantic relationships were part of their lives since high school and their time spent with their partner was limited. They wanted more time with their current partners as well. These misconceptions lead to the assumption that students with disabilities do not need or cannot handle sex education, resulting in their exclusion from such programs.

Moreover, there is a pervasive belief that discussing sexuality with individuals who have disabilities is inappropriate or uncomfortable, further contributing to their marginalization. These stereotypes not only deny students with disabilities their right to information crucial for making

informed decisions about their bodies and relationships but also perpetuate their social isolation and reinforce harmful attitudes about disability and sexuality. As researched by Elevatus Training in 2021, “findings indicated that people with disabilities experience higher levels of loneliness, less perceived social support, and increased feelings of isolation than their non-disabled peers (2021-B, para. 15). To combat these stigmas and stereotypes, it is essential for educators and society as a whole to recognize the sexual agency and diverse experiences of individuals with disabilities and to ensure that they receive inclusive, empowering sex education that addresses their unique needs and experiences.

Caregiver Overprotection

Caregiver overprotection often presents a significant barrier to comprehensive sex education for individuals with disabilities. Well-intentioned caregivers may harbor fears and misconceptions about their loved one's ability to understand or safely navigate sexual relationships, leading them to shield them from discussions about sexuality altogether. As one study found, those with intellectual disabilities expressed feeling the need for approval from their family as they sought their permission before having a sexual relationship or getting married. They also were led to believe that this would not be allowed (Wit et al., 2021). This overprotection stems from a desire to keep individuals with disabilities safe, but it can ultimately deprive them of essential information and skills needed for autonomy and self-advocacy. By restricting access to sex education, caregivers inadvertently reinforce the perception of their loved ones as perpetual children, denying them the opportunity to develop healthy attitudes towards sexuality and relationships.

Furthermore, this overprotection may hinder the individual's ability to recognize and respond to instances of abuse or exploitation, leaving them more vulnerable. To address this

issue, caregivers must recognize the importance of fostering independence and self-determination in their loved ones, including providing access to inclusive and tailored sex education that empowers individuals with disabilities to make informed choices about their bodies and relationships. This would act as a preventative measure as well given that many families and caregivers discouraged being sexual as they were concerned about safety and/or pregnancy (Mayes et al. 2006). Collaboration with educators and support professionals can help caregivers navigate these conversations and ensure that their loved ones receive the necessary support and guidance.

Consequences

Limited Autonomy & Independence

Students with disabilities who do not receive comprehensive sex education often face limited autonomy and independence in navigating their sexual health and relationships. As discussed by the National Partnership for Women & Families, “Sex ed access is also intrinsically tied to dignity because it allows us to maintain a level of respect for our own bodies and own decisions about whether or how to explore and express our sexuality” (2021, pg. 4). Without access to information about consent, contraception, sexually transmitted infections, and healthy relationships, these individuals may struggle to make informed decisions about their bodies and personal boundaries. This lack of education can lead to increased vulnerability to exploitation, abuse, and unintended pregnancies.

Without the skills and knowledge gained through sex education, individuals with disabilities may face challenges in asserting their rights and desires in intimate relationships, perpetuating a cycle of dependence and disempowerment. As Weber and Kaufman suggests, this is because those with IDD’s “are more likely to have others help them with day-to-day necessities

such as bathing and dressing. This provides perpetrators... the opportunity to groom for abuse and to be in a private space with the person while their body is exposed” (2021, para. 5). To promote autonomy and independence for students with disabilities, it is crucial to provide them with inclusive and accessible sex education that equips them with the tools to advocate for their own sexual health and well-being. By empowering these individuals with the information and skills they need, society can support their right to autonomy and promote their ability to lead fulfilling and self-determined lives.

Increased Vulnerability & Exploitation

Adults with developmental disabilities often experience social isolation and are dependent on caregivers for their daily needs, making them more susceptible to abuse due to their vulnerability and limited opportunities to report abuse. Lacking the resources to report an incidence is a major contributing factor to why this population of people are at a much higher risk. They are expected to rely on others to report suspected abuse. Even when it is reported, law enforcement is rarely involved and the situation is handled as an employment matter (Disability Rights California, 2020). Furthermore, staff turnover rate is significant in many group homes and residential care facilities. There is an unspoken expectation that those with disabilities must trust everyone. In reality, they are very dependent on those who provide them care. They aid in intimate care such as dressing, bathing, and toileting. (Shapiro, 2018). Further, such few incidents of abuse are prosecuted that criminal background checks of care providers are insufficient (Disability Rights California, 2020). Without the understanding of what boundaries and behaviors are okay, the more risk of abuse there is.

Risk to Sexual Health

Individuals with disabilities face heightened risks to their sexual health when they do not receive comprehensive sex education. Without access to information about sexual health, consent, and healthy relationships, they may lack the knowledge and skills needed to make informed decisions about their bodies and sexuality. This lack of education leaves them vulnerable to exploitation, abuse, and sexually transmitted infections. Research suggests that sexually active middle and high school youth with cognitive disabilities are at greater risk of contracting an STI being that 26% of females with a cognitive disability reported an STI vs. 10% without a disability (Cheng, 2002). The same study found that nearly 40% of cognitively impaired teenage girls had become pregnant—more than double the 18% rate of teenage girls without a mental disability (Cheng, 2002). Not only this, but pregnancies among women with disabilities are 42% more likely to be unintended than pregnancies among women without disabilities (Signore et al., 2021). These statistics indicate the importance of having access to comprehensive sex education. Individuals with IDD are sexual beings and deserve to receive preventative information to protect their sexual health.

Additionally, without understanding their own sexual health needs, individuals with disabilities may struggle to access appropriate healthcare services and contraception, further exacerbating their risks. According to Elevatus Training, “only 6% of women with IDD received a Pap smear within the last 3 years compared to 70% of women without disabilities” (2022-B, para. 1). The absence of sex education perpetuates a cycle of ignorance and vulnerability, depriving individuals with disabilities of their right to sexual agency and increasing their likelihood of experiencing negative sexual outcomes. To mitigate these risks, it is essential to

prioritize inclusive sex education that addresses the unique needs of individuals with disabilities, empowering them to advocate for their own sexual health and well-being.

Project Description and Implementation Process

Project Description

The project that I pursued was implementing a program that regularly addresses social-emotional and sexual health topics. By attending training, I was able to facilitate classes on a regular basis while also developing my own curriculum tailored to the clients of Gateway. The initial training and certification process was January 17th to the 19th. After this, sexuality education classes were implemented weekly. This means the final one was held April 16, 2024. The deliverables of this project include a certificate relating to sexual health education for those with developmental disabilities, 11 classes for the clients, pre and post surveys to determine which topics to discuss and the overall success of each gathering, and a report discussing the findings.

Project Justification & Benefits

The primary purpose of this project is to provide necessary information to this community, given that they are most at risk of abuse and for not having received the information in the first place. Gateway should expect to see growth within each individual in terms of social-emotional development and sexual health knowledge. It also acts as a preventative measure given the high turnover rate of employees caring for them. The clients will feel more autonomy and gain a sense of empowerment, which is in line with the values of the organization. They will have better overall social-emotional skills and sexual health. They would be better equipped to face potential abusive situations and have the resources in the event that it were to happen.

Expected Outcomes & Assessment Plan

The expected outcomes of this project were to have all 15 students enrolled in the Without Walls Program attend 11 sexuality education courses. Given that the students had some introduction to these topics, there was an expectation that the knowledge they learned in this course would expand upon what they already knew, while also introducing new information. Each student was expected to have a better understanding of their social-emotional and sexual health as a result.

Pre and post surveys were given to the students as a way to measure the knowledge they gained from the classes. The survey questions were content based, measuring their knowledge. They were also given a survey addressing how the classes were taught. A phenomenological orientation format was used as a tool to help the students reflect on their experience with the classes they attended. This was intended to show how impactful the information was and how well the information was presented to them. A section for open comments was also provided for any additional feedback. The goal is to elicit a space where they can provide rich and descriptive feedback as well as share any experiences they might have had to provide ideas for future topics.

Implementation Process

This project was inspired by a previous intern's work. Knowing my interest in the subject, she suggested a workshop that would result in a certification of completion in sexuality education training for adults with IDD's. Bringing this idea to the executive director of Gateway led to the conversation of funding. I was able to assist with a grant through Autism Speaks which resulted in enough money to sign up for the workshop. I attended the training which was held from January 17th to the 19th. With this new knowledge, I taught 11 sexuality education classes to the students at the Without Walls program. I distributed a survey based on workshop content

to the students before the classes began, and after the workshops were completed. The curriculum outline is as follows: public versus private spaces, decision-making, types of relationships, moving from friend to partner, healthy relationships, sexual relationships, sexually transmitted infections, birth control methods, phases of the female cycle, caring for your body, and building intimacy. My approach is person-centered, so the classes would change depending on the experiences the students shared and the questions that they had. Throughout the following three months, I also met with the executive director of Gateway, the principal of the Pacific Grove Adult School, and the staff of the program to discuss how the content was being received and any other feedback to better tailor the following classes to the student's needs. A more detailed outline of this process can be referenced under Appendix A.

Project Results

The results of the project did address the initial issue discussed in the problem model above; there is a lack of sexuality education and expression for individuals with Intellectual and Developmental Disabilities (IDDs). This was proven by the results of the initial survey I provided the students. This only captured four of the students' knowledge given that the initial idea of these classes did not strike everyone's interest. This was mostly because they were still building a relationship with me. Despite the low number of surveys returned, I gathered helpful information that would outline the topics I would go on to discuss. As shown in Appendix B, 50% of the students thought that abuse can happen in any type of relationship. In addition, only 50% of students agreed that consent means both people have to say "yes" to sex without lies, pressure, or force. Prior to starting the classes, these were two topics I wanted to focus on. Once the classes began, more students were present and engaged in the material. There was clearly a need for these discussions, however it can be difficult to break the ice at first. During the first

meeting, I held an informal focus group where we discussed different topics that were of interest to the students. Through their questions during the classes I was able to shape my curriculum as well.

The post survey had more responses, and I was able to hold a more formal focus group to discuss the outcomes. The students all had positive responses to the topics and were wanting to continue holding the classes weekly. Comments such as, “I really enjoyed learning more and everything about this topic. Also to know what to do if you're in a relationship or also in a couple. This a really good thing and important things” and “I liked learning about safety” further suggest the importance of this education and discussions. Many of the students also shared that they are interested in or already in relationships, so the topics were able to be applied to the real situations happening in their lives.

As far as expected outcomes, all outcomes were met. My implementation plan went smoothly. The outside factors including moving program locations did not affect the success of the classes and ultimately offered more opportunities for connections to the material being taught.

Conclusion & Recommendations

In conclusion, this project was successful in addressing the problem of having a lack of sexuality education for individuals with IDD. A more inclusive education program was created while social stigmas and stereotypes were addressed. Due to the environment created, students felt safe enough to join the classes each week and be engaged in the discussions. As shown by the results outlined in Appendix B, the students learned more about themselves as well as how to be safe both in and out of relationships. This in turn reduced their risk of facing consequences such as exploitation, lack of autonomy, and harm to their sexual health. I recommend that

Gateway continues to develop curriculum pertaining to this topic as well as extending it to other programs. I would also recommend developing training material for staff so the clients of Gateway have more accessibility to resources. One way to improve this project is to have consistent times where the students meet as well as having an additional staff member available to help facilitate some of the discussions. Meeting beforehand to have these discussions would be beneficial as well. Lastly, incorporating more activities using poster boards and/or other interactive activities to further engage the students would help to better conceptualize the topics being discussed.

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Appendix A

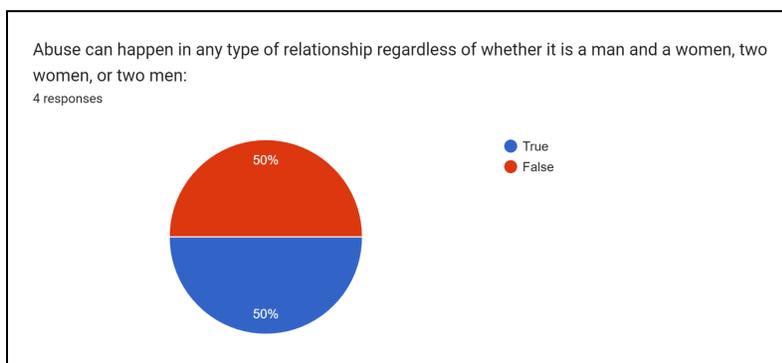
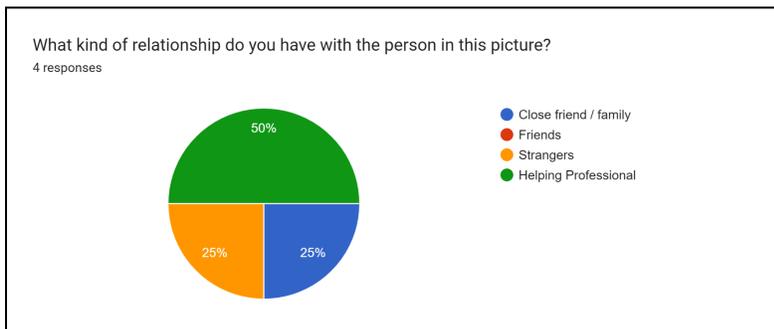
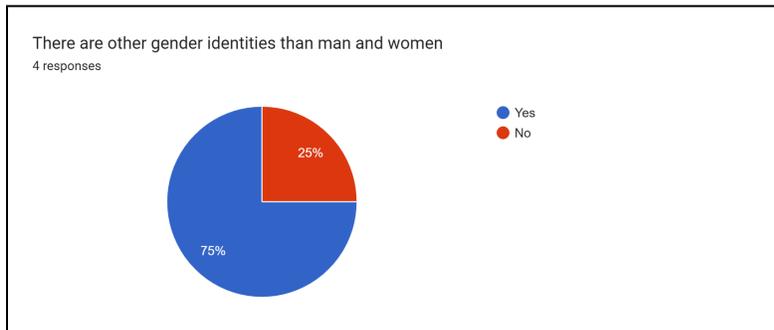
Project Implementation Plan

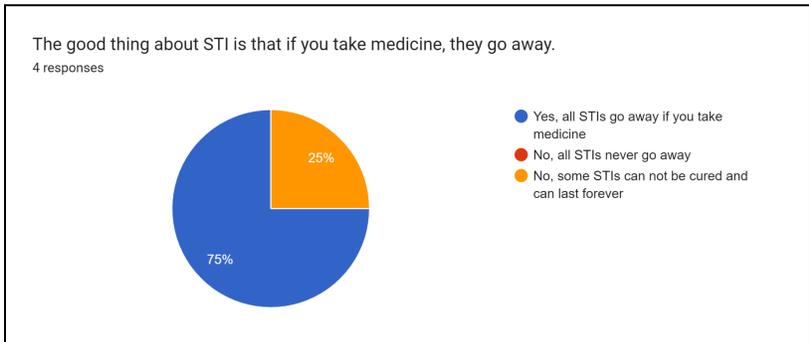
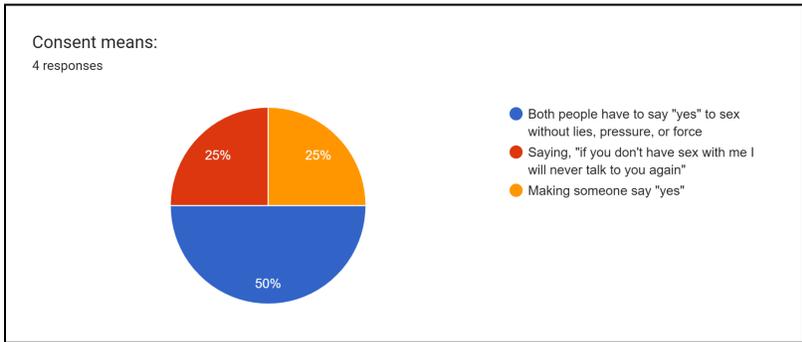
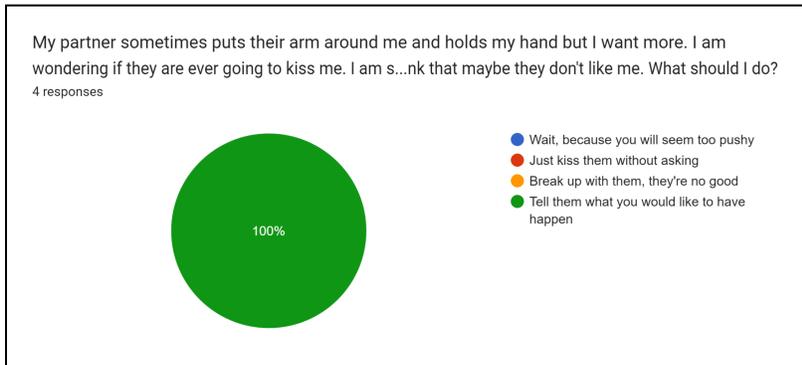
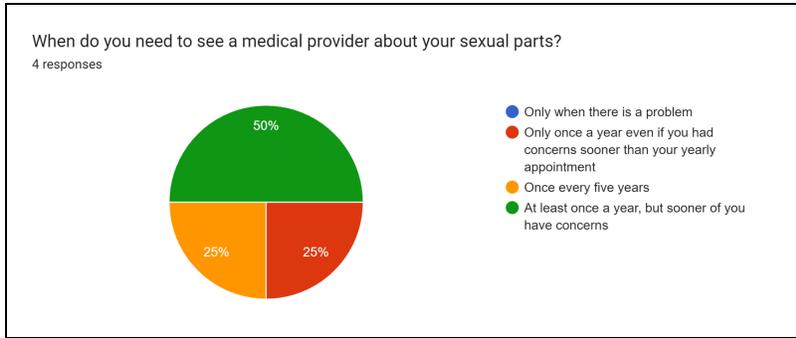
Tasks	Timeline/ Deadlines	Parties Involved	Materials/ Services Needed	Deliverables
Attend a Planning Meeting	July 17, 2023	Mentor and Intern	Meeting agenda and resources for notes	Decision of capstone project
Assist in Writing the Grant to Fund Project	October 5, 2023	Mentor and Intern	Access to login, writing resources, and feedback from mentor	Grant proposal
Attend Sexuality Training	January 17-19, 2024	Intern	Access to Zoom, Education curriculum, Materials for note taking	Certificate of Completion
Create Curriculum for each Class	February 20 - April 2, 2024	Intern	Training materials, laptop, google slides, mentor approval	Sexuality Education Class Curriculum
Create Pre & Post Surveys	By February 20, 2024	Mentor, Intern, and Sexuality Education Trainer	Google Forms, Dictionary	Survey
Teach Sexuality Classes	Every Tuesday Starting February 20 - April 2, 2024	Mentor, Agency Staff, Students, Intern	Classroom space, Computer Access, Google Slides	Sexuality Education Classes
Administer Post Surveys	April 2, 2024	Mentor, Intern, and Sexuality Education Trainer	Google Forms, Dictionary	Survey
Analyze Data	By April 19, 2024	Inten	Google Forms, Sheets, & Docs	Analyzed Data
Present Report to Agency	April 15, 2024	Mentor & Intern	Capstone report	Agency Approval of Report

Appendix B

Project Results

Initial Data





Post Session Evaluation

Students	A	B	C	D	E	F	G	H	I
I learned new information about relationships	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes
I learned new information about sexuality	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes
Was this training session useful and/or helpful to you	Yes	Yes	Yes	Yes	Yes	No	Yes	Yes	Yes
The presenter knew the topic and the information was interesting	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes
I learned how to stay safe in sexual relationships	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes
What did you like best? What did you like least? Other comments?	I really enjoyed learning more and everything about this topic. Also to know what to do if you're in a relationship or also in a couple. This a really good thing and important things.	I liked learning about safety.	I like the class, I learn about different sexuality	No	I really liked how open Damiana was! Because I am a very open person! I learned a lot of things	No	Blank	Blank	Blank