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**Angelique Bouthot** 

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# Self-Advocacy in the Exam Room: Tools and Techniques for Contraceptive Care

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School of Education and Social Policy at Merrimack College

2021

# MERRIMACK COLLEGE

# CAPSTONE PAPER SIGNATURE PAGE

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#### **Abstract**

Sexual and reproductive healthcare is fraught with both historic and current examples of oppression, systemic abuse, and injustice across gender, race, class, and ability. Still, high quality and responsive contraceptive care may provide numerous health benefits, the ability to prevent and plan pregnancies, and opportunities for exercising autonomy and greater educational and economic attainment. Many initiatives focus on quality improvement at the institutional or provider level, but these do not get to every institution or every provider. This project proposes an approach that reduces harm and maximizes benefit on an individual level while larger systemic changes occur. In a workshop utilizing an empowerment framework, this intervention situates an individual's care into its sociocultural and historical context. By providing space, tools, and techniques for identifying contraceptive care needs and building self-advocacy skills, all but one participant reported an increase in their comfort level advocating for themselves in healthcare settings after the workshop. This project provides evidence that people accessing contraceptive care may benefit greatly from self-advocacy skills-building practices that have been part of the disability community for decades. Tailored workshops for specific demographics may increase these benefits and expand the current field of research.

*Keywords*: sexual and reproductive health, contraception, birth control, reproductive violence, self-advocacy, empowerment, stratified reproduction

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# Self-Advocacy in the Exam Room: Tools for Navigating Contraceptive Care

The United States has a complicated relationship with sex and sexuality. Sensationalized sexuality sells many of the products and media we consume, but there are still strict expectations around gender roles, sexual pleasure, and sexual autonomy throughout much of this country (Rutter & Schwartz, 2011). Religions may condemn the use of many or all contraceptives and pregnancy prevention methods, often paired with restrictive sexuality expectations related to age, gender, sexual orientation, and marital status. This directly and indirectly impacts national policymaking related to funding for sexual and reproductive healthcare such as abortion access, Title X funding, and insurance coverage of contraception and birth services. The social group identities of an individual can also impact their ability to access care and the quality of the care they receive due to historical and current systemic oppression. Cisgender women often bear the burden of contraception as the person who can become pregnant from sex with reproductive potential (Rutter & Schwartz, 2011). Few contraceptive options exist for sperm-producing bodies. People with a uterus who do not identify as women may also face challenges in accessing care due to transphobia, lack of clinical knowledge, and implicit bias. Race and ethnicity can play a role in the exam room, as well—implicit bias from a provider can lead to coercive or dismissive contraception decisions, cultural assumptions are often made, and race may impact the power dynamic that already exists between a patient and care provider (Davis, 2003).

Contraceptive care is often a topic of political discourse. Contraceptive care intends to help someone who can become pregnant to prevent pregnancy, plan pregnancy spacing, manage menstrual symptoms and cycles, or treat health issues such as polycystic ovarian syndrome (PCOS), endometriosis, and others. Due to its connection to reproductive anatomy, sexual activity, and often womanhood, a slew of social forces impacts contraceptive care (Rutter &

Schwartz, 2011). Outside of a sexual and reproductive healthcare clinic or family planning provider, it may be considered non-essential. Unfortunately, patients may also feel the care they need is not prioritized or their desires are not considered in provider decisions. This dismissal or lack of prioritization is not new—it has grown out of profit-oriented healthcare, modern medical education, and historic precedent of inequality.

The history of sexual and reproductive healthcare, and contraception specifically, is laden with gross misuse of power and medical violence. For example, the birth control pill came out of unethical trials conducted in Puerto Rico, part of a decades long campaign of population control. These eugenicist actions caused individual harm, death, and generational trauma and impact to Puerto Rican people and their families (Davis, 2003). These issues have not been left in the past—as this project is in development, there are news reports of people detained by Immigration and Customs Enforcement (ICE) having their uteruses removed without their consent. This forced sterilization of marginalized groups is the latest incident in a consistent thread through our nation's history that continues to impact both the institutional delivery of care and individual care experiences.

This project aims to create a more just and effective healthcare experience within this current reality by bolstering self-advocacy skills in those accessing contraceptive care. This project situates the contraceptive care experience in a theoretical foundation of symbolic interactionism (Longmore, 1998) and feminist epistemology (Liao, 2006). In short, sexuality is socially constructed through interaction and this is evident in gendered sexuality, birth control, bodily autonomy, and in healthcare access and utilization (Rutter & Schwartz, 2011).

This intervention specifically addresses the exam room or appointment experience from the patient's perspective, which sets it apart from many current intervention models. Within the healthcare world, there are many quality improvement and justice-oriented training initiatives focused on improving care by impacting institutional practices and provider decisions.

Examples include patient-centered care, implicit bias training, non-coercive options counseling, and shared decision-making (Holt et al, 2020). These endeavors are necessary, as the larger systems must change for quality care to be widely accessible and affordable. As these quality improvement and equity- and justice-based changes occur, self-advocacy education such as this project can be taken outside of healthcare institutions and into our communities to make immediate impact.

The purpose of this project is to develop and evaluate resources and activities that empower participants as they navigate contraceptive care in (and out) of the exam room.

Utilizing an empowerment framework, the project assists participants in building their sense of self control to minimize stress and health issues (Carr, 2011). After the intervention, participants can develop their own reproductive life plan, articulate their contraceptive needs, practice self-advocacy skills, and utilize personalized tools and resources.

#### Literature Review

It is important to note that, while much of the research included in this review cites the experience of women, people who are not women use contraception. Any language not in direct reference to research, both in this literature review and the ensuing project, will reflect this reality. While transgender and nonbinary representation in research is growing, this is still an area rich for further investment.

To change the experience of contraceptive care, educators must first understand the practice and context of this care. Often referred to as birth control or even just "the pill," there

are many more options and reasons why people access contraceptive care than the pill and preventing pregnancy. Contraception may be broken into smaller and sometimes overlapping categories, such as hormonal prescriptions, non-hormonal methods, long-acting reversible contraception (LARC), barrier methods, behavioral methods, emergency contraception, and fertility awareness methods, among others. These may also be grouped together with protection methods, which are tools and techniques to reduce the risk of pregnancy and/or sexually transmitted infections (STIs) during a range of sexual activities, not just those with reproductive potential. People may choose a method based on ease of access, cost, provider suggestion or bias, recommendations from family and friends, advertising, positive or negative side effects, lifestyle fit, and a range of other factors (Bedsider, n.d.).

Guttmacher Institute, a national sexual and reproductive health research and advocacy organization, also provides context for contraceptive method selection: "Seventy-two percent of women who practice contraception currently use nonpermanent methods—primarily hormonal methods...IUDs and condoms. The rest rely on female (22%) or male (7%) sterilization" (2020a). Since 1982, the pill and female sterilization have remained the most popular methods. Dual use, which refers to the use of one method plus a barrier method, reduces risk of unintended pregnancy and sexually transmitted infections (STIs). Around 8% of women of reproductive age simultaneously use more than one contraceptive method, commonly partnering condoms with another method (Guttmacher, 2020a).

Guttmacher Institute (2020a) also shares information about the popularity of contraception in the United States, since over 99% of the women aged 15-44 who have ever had sex have used at least one contraceptive method and four out of five women who have had sex have used the pill. Guttmacher Institute (2020a) wrote, "There are 61 million U.S. women of

reproductive age (15–44). About 43 million of them (70%) are at risk of unintended pregnancy," meaning they are sexually active with activities that have reproductive potential, or the possibility of someone becoming pregnant (2020a). If someone has sex with reproductive potential during their fertile years and does not want to become pregnant, they may be using a pregnancy prevention method for around three decades of their life (2020a).

Contraceptive care access in the United States varies state to state. For example, access for minors ranges from some states offering providing all contraceptive options for any minors, to some states offering restricted access, to other states that only allow access for those who meet specific requirements such as being married, pregnant, a parent, a high school graduate, mature, and having a referral or experiencing a health hazard (Guttmacher Institute, 2020b).

Numerous policy reports present a clear picture: the future of contraception access is not stable because of consistent attacks on state and national levels. While some focus has been on contraceptive care specifically, broader sexual and reproductive health issues--including access to safe, legal abortion, funding for STI prevention services, and insurance coverage for gender-affirming care--are targeted by a litany of policies. While compiling this literature review, there is consistently new media coverage that confirms this. Mendez (2020) covered Texas Senator Ted Cruz's persistent and scientifically incorrect use of the phrase "abortion inducing drugs" when referencing birth control. This is not the first time this phrase has been used, or the first time anti-abortion rhetoric was used during policy discussion around contraception. This focus on the politicization of sex and sexual health, and not health needs and outcomes, impacts access to care (Rutter & Schwartz, 2011).

Across the country, millions have relied on healthcare coverage granted by the Affordable Care Act (ACA). The Trump administration steadily chipped away at this coverage

over its four years, especially in relation to contraceptive care. One example is the expanded definition of moral and religious objection exemptions for contraceptive coverage, which was outlined in 2017 and has been stuck in the Supreme Court (Sonfield, 2020). While insurance coverage for contraceptives is part of the ACA, these exemptions make it easier for an employer to refuse coverage.

Many states also have laws related to insurance coverage of contraceptive care. In response to threats to the ACA on the national political stage, the ACCESS bill (H.4009) was passed in Massachusetts in 2017. The ACCESS bill ensures co-pay free contraceptive coverage and the option to pick up 12 months of prescription contraception at a time (Planned Parenthood, 2017). At the time, Planned Parenthood Advocacy Fund of Massachusetts (2017) noted that "in Massachusetts, over 90 percent of voters believe contraception is a basic preventive service that should be affordable for everyone, and 81 percent support passage of a state law guaranteeing no-copay insurance coverage of contraception."

The Domestic Gag Rule was another blow to care access at the national level that had varying impacts across the country. Title X (pronounced "title 10") funding, a widely supported funding initiative enacted in the 1970s, grants federal funds to family planning providers across the country to deliver care to low-income and uninsured individuals at low or no cost. Almost 1,000 clinics received this funding in 2019 (Zolna et al., 2020). The gag rule restricts funding from any provider that would discuss, refer patients to, or provide abortions. Providers could either lose funding or provide biased and incomplete information to their patients. It is estimated that the resulting funding reductions to hundreds of providers across the country reduced their capacity by at least 46%, which translated to an impact on as many as 1.6 million patients (Zolna

et al., 2020). In April of 2021, the Biden Administration published a proposal to rescind the Title X gag rule (Dorf-Kamienny, 2021).

Policy provides critical context for examining relevant trends in contraceptive care, which include the decline in minors and young adults accessing care at publicly funded clinics and an increase in using insurance for contraceptive care (Frost & Lindberg, 2019). It is estimated that in 2016, 20.6 million women needed publicly supported contraception access (Frost et al., 2020). Trends gaining momentum in 2020 revolve around the provision of care via telehealth or telemedicine in response to the COVID-19 pandemic. Some innovative changes include waiving office visits for birth control renewals, mailing prescriptions, curbside care, changes in billing, and phone-only appointments (Keller & Dawson, 2020). There is also growing support behind hormonal contraception access over-the-counter, such as what currently exists with emergency contraception (ACOG Committee on Gynecologic Practice, 2019; Ibis Reproductive Health, 2019; Holt et al., 2020).

# Historical Perspective

To review literature on contraceptive care and not turn a critical eye to this field's deeply entrenched history of oppression would be irresponsible. Contraceptive care, and sexual and reproductive health more broadly, was largely built on the abuse, coercion, and eugenic treatment of marginalized groups. The American College of Obstetricians and Gynecologists (ACOG) has made public statements on the ethics of sterilization. While voluntary sterilization via tubal ligation or other means is a common contraceptive method by choice, forced sterilizations have also been part of U.S. history since its inception. Across the United States, Indigenous communities and people with disabilities often faced massive waves of statesanctioned sterilizations (Friedman et al., 2014) which is not well-known or widely taught

history outside of the field of reproductive health. It has been common for low-income women, Black and Brown communities, and people with disabilities to have their fertility targeted with forced sterilization or coercive contraceptive options counseling. At the same time, many white, middle-class women have trouble accessing desired sterilization procedures, sometimes needing spousal consent or to already have children for providers to be willing to provide sterilization (ACOG Committee on Ethics, 2017). It can also be difficult for people looking to access sterilization or hysterectomy as part of gender-affirming healthcare.

This is not just a historical phenomenon, either. Unnecessary and unexpected hysterectomies were so common in certain parts of the U.S. less than 60 years ago that there was a colloquialism, "Mississippi appendectomies." Even within the past 10 years, there have been numerous incidents of coercive sterilization or contraception decisions made for prisoners in exchange for shorter sentences (Moore, 2020). Moore (2020) also reported on the recent ICE sterilizations of immigrant detainees, connecting this to the long history of U.S. eugenic practices. This phenomenon of encouraging the fertility of some and oppressing the fertility of others is created through white supremacy and xenophobia and is termed "stratified reproduction" (ACOG Committee on Ethics, 2017; Holt et al., 2020). It favors the fertility of those with privilege (white, middle-class, able-bodied) and utilizes abusive practices to limit or entirely remove the fertility of marginalized groups, such as Black, Brown, and Indigenous people, immigrants, people with disabilities, and people experiencing poverty. Stratified reproduction has a range of manifestations, from eliminating fertility through forced sterilization to coercive contraceptive practices and targeted initiatives, such as those aimed at preventing teen pregnancy in specific demographic groups. This is all reproductive violence.

Just as policy plays a critical role in care access and health outcomes today, there are historical and modern examples of reproductive oppression via legal means. From 1873 to 1936, the Comstock Act made it illegal to provide birth control or birth control information across state lines due to anti-obscenity restrictions. These laws were designed to enforce chastity based on the persistent myth that if people are informed about contraceptives, they are more likely to engage in sex outside of marriage or sex with more than one partner. Many people were denied information and access to birth control, which negatively impacted their health, wellbeing, and autonomy. Margaret Sanger, the founder of Planned Parenthood, was instrumental in the court cases that eventually led to overturning the Comstock laws, making legal contraceptive use available to everyone (American Experience, n.d.). She was heavily involved in the opening of clinics, development of new birth control methods, and the birth control movement. However, she rightfully remains a controversial figure in the history of birth control as someone who worked with the eugenics movement and proliferated racist, classist, and ableist ideology. She has been widely celebrated in sexual and reproductive health spaces, with a growing body of people now moving from celebration to criticism and a realistic conversation around her legacy.

The birth control pill was FDA approved for contraceptive use in 1960, but it was approved after unethical and eugenicist trials. Some were in Worcester, Massachusetts at a state mental hospital while the most well-known were conducted in Puerto Rico as part of a decadeslong campaign of population control. The trial participants were largely unaware they were in a trial for a new drug and faced strong side effects from a concentration hormones much higher than has been prescribed in decades. Some researchers were openly eugenicist and, despite three participants dying during the trial, there was never an investigation. Some claim research standards were much lower 60 years ago and the researchers acted within standard practice at the

time (Vargas, 2017), but this provides the reader perspective for both ethical expectations then and current understanding of historical systemic oppression. The individual experiences of participants and their families, the communal impact on the island and culture of Puerto Rico, and the generational trauma from the erasure of these experiences continue to affect Puerto Rican people and other people of color to this day (Davis, 2003). In recent years, there have been frequent reports of coercive contraception counseling around long-acting reversible contraception (LARCs), meaning IUDs and implants, in Black and Brown communities and with young people (Holt et al., 2020). Historical issues of inequity and abuse continue to present themselves again and again in sexual and reproductive health settings.

# Self-Advocacy, Health Literacy, and Communication

Self-advocacy as a concept grew out of disability rights organizing and many groups or organizations may have their own specific definition. The National Deaf Center defined it as "the ability to articulate one's needs and make informed decisions about the support necessary to meet those needs" (National Deaf Center, 2020). This definition comes with four elements: "knowledge of self, knowledge of rights, communication skills, and leadership skills" (National Deaf Center, 2020). Friedman et al. note self-advocacy is based on self-determination, supported by the principles of freedom, support, authority, and responsibility (2014). A study searching for the meaning of sexual self-advocacy resulted in these themes: "knowing and respecting myself; respect for others; my choices; speaking up; respect my rights; getting information; and, healthy relationships," (Friedman et al., 2014, p. 520).

Self-advocacy is often outlined as a factor or skill related to health literacy (Hughes & Maiden, 2018). To consent to care, patients must fully understand their own needs as well as the risks and benefits of a procedure, prescription, or behavior and be able to communicate about it

effectively. Health literacy is a larger concept, defined by Netemeyer et al. (2020) as twodimensional:

Functional health literacy reflects a patient's basic reading and writing skills pertaining to comprehending health issues, as well as basic knowledge of health conditions.

Communicative health literacy refers to a patient's communication skills with regard to extracting information, deriving meaning, and using that information in interactions with health care practitioners. (p. 3)

Netemeyer et al. (2020) found that higher levels of patient anxiety are associated with fewer provider consultations and a lower rating of subjective personal wellbeing. Improving self-advocacy and lowering health anxiety could reduce improve these associations by encouraging more ownership of the healthcare experience.

Studies focused on communication in the exam room depict varied experiences. Giroldi et al. (2020) conducted a study in the Netherlands on how doctors determine if a patient is worried. While 70% of the participating general practitioners attempted to reassure their patients in the study, patient cues were identified as verbal, non-verbal, behavioral, or based on knowing the patient. Fröjd et al. (2007) also studied provider perception of patient cues, finding that doctors also used contextual factors and demographic clues when making decisions about providing additional information to their cancer patients. Providers should be adept at reading many patient cues, but leaving patient understanding up to provider cue recognition and possible implicit bias of contextual factors are clear opportunities for self-advocacy skills to improve care and reduce misunderstanding.

Models for decision-making may differ between specific providers, but Shay and Lafata (2014) endeavored to better understand what patients believe shared decision-making looks like

in practice. They conducted a study with primary care patients due for colorectal cancer screening and found that themes present in shared decision-making include mutual sharing of information, patient self-advocacy, patient-specific or personalized physician recommendation, and both parties being respectful and open-minded. Patients noted that self-advocacy must be exerted throughout the entire encounter, not just during the decision-making process, to have the best outcomes. Shay and Lafata (2014) also found that long-term doctor-patient relationships fostered these practices, which is not possible in all contraceptive care scenarios. In this study, 11 of the 23 respondents note that self-advocacy is necessary for shared decision-making, but the sample was also primarily female and white which may impact that finding.

Weitzman et al. (2004) reported that middle-aged and older Latino American women exhibited passive or indirect self-advocacy behaviors, such as finding a new doctor if they were dissatisfied. If they were involved in the healthcare experiences of their family members, however, they would exhibit direct advocacy for others. Ramos Salazar (2018) also found a relationship between self-advocacy and self-compassion, as they positively predicted patient satisfaction. An individual's relationship with the patient, whether it is themselves or a family member, impacts their advocacy behaviors.

Challenging healthcare scenarios present unique opportunities to exhibit self-advocacy. Zale et al. (2020) collected patient and provider perspectives on endometriosis, a painful uterine disorder. While one provider noted person-centered suggestions such as getting a second opinion or making sure a patient feels heard, numerous patients highlighted the importance of being their own advocate and navigating hostile and inflexible healthcare systems. This depicts one example of how provider and patient perspectives, and ideas about improving care practices, may or may not align.

# Connecting Shared Decision-Making and Contraceptive Care

Gonzalez et al. (2019) note that using contraceptive shared decision-making aids increases patient knowledge and satisfaction, preserves patient autonomy, and cultivates an informed and collaborative process. This results in better contraceptive outcomes. However, there are still quality issues with contraception decision-making aids, such as most not including reproductive life planning questions or presenting options in a hierarchy of effectiveness. For example, researchers reviewed popular aids from World Health Organization, Bedsider, Planned Parenthood, and others (Gonzalez et al. 2019). Their conclusion supported further study of patient-centered outcomes for adolescent and young adult patients, a key demographic using these aids and developing health literacy and self-advocacy skills. Edwards et al. (2016) evaluated a brief, personalized sexual health prevention program and found that learning about contraception methods increased knowledge and intent to use condoms in the future. While condoms are only one of many contraceptive methods, this does support changed sexual health behaviors after learning about various options. Both studies provide evidence that tailored sexual health education interventions with information about many possible methods can impact sexual health behaviors. However, they do not provide a best practice for ensuring patient satisfaction and that patients access the contraception that is the best for them and their lifestyle.

Holt et al. (2020) extol the efforts to expand access to contraception in high-quality and equitable ways over the past decade and are highly critical of the trend toward pushing long-acting reversible contraceptive methods (LARCs) on patients. Most public health initiatives and quality improvement endeavors focus on cost, provider, and policy barriers to LARC provision. This led to coercive marketing of LARCs as the most effective, and therefore the best, option for everyone. Framing contraceptive options more holistically, with a variety of factors that impact

what is best for each patient, is a critical piece of person-centered framework of care. Holt et al. (2020) cited the 2001 Institute of Medicine definition of "patient-centeredness": "Providing care that is respectful of, and responsive to, individual patient preferences, needs, and values and ensuring that patient values guide all clinical decisions" (p. S879). The authors propose a person-centered contraceptive care framework that centers a continuum of care: outreach and trust building, access, quality, and follow-up support (Holt et al., 2020, p. S880). Surrounding this continuum of care are community and family contexts, policy and health systems context, and historical, social, political, and economic contexts. This is notably like ecological systems theory, mirroring a nested approach to understanding how an individual navigates and experiences systems within community (Holt et al., 2020). Understanding social forces outside the exam room and how they may invisibly affect an individual healthcare appointment is vital for providers to encourage informed patient participation in decision-making.

Understanding the concepts around eugenics and stratified reproduction, as well as their deeply felt racist, classist, and ableist generational trauma, is necessary to improve contraceptive care in a socially just manner. Self-advocacy, health literacy, and shared decision-making practices cannot truly be cultivated without that understanding. "A patient-centered approach that focuses on the reproductive desires of an individual woman can mitigate some of the potentially negative effects of the larger social climate of race and class inequality in which health care is carried out" (ACOG Committee on Ethics, 2017). Note that ACOG chose the word *mitigate* and not *eliminate* or some other word to indicate that this is the panacea. True justice in sexual and reproductive healthcare would require something much larger than this, a radical reimagining of the field and larger social, cultural, and political contexts.

Theoretical Foundations: Socially Constructed Sexuality and Situated Knowledge

Considerable work supports the theory of socially constructed, or scripted, sexuality (Rutter & Schwartz, 2011; Seidman, 2010; Longmore, 1998). Seidman (2010) wrote:

Instead of understanding humans as being born sexual, they [John Gagnon and William Simon] argued that sexuality is socially learned. In the course of growing up, we are taught by society what feelings and desires count as sexual and what are the appropriate scripts for sexual behavior. Sexual scripts tell us where, when, and with whom (based on age, race, or class) we are supposed to have sex, and what it means when we do....sexuality is not an inborn property but a product of social labeling. (p. 26)

Much of Seidman's ensuing review of literature focuses on sexual orientation and behavior, but this applies to all aspects of sexuality--including access to healthcare related to sex.

Foucault also argued that sexuality is socially constructed, and for two main reasons—the rise of disciplinary control and an institutional duty to exert social control (Seidman, 2010). Sexuality is often considered deeply personal, a hidden truth or integral piece of identity, which is what makes it a powerful tool of control. Rutter and Schwartz (2011) provide sexual experimentation with multiple partners as an example of sexual control. It is seen as something that enhances masculinity and demeans femininity; men experience privilege and pleasure when pursuing multiple partners and women may lose their status as a "good" woman if they do so. This enforces rigidly gendered ideas about sexuality, with nuance across race and class. Socially constructed sexuality on individual and interpersonal levels plays out within larger socially constructed ideas about healthcare and birth control, such as stratified reproduction (ACOG Committee on Ethics, 2017; Holt et al., 2020).

The process through which these ideas about sex and sexuality are created is symbolic interactionism, or consistent learning and reinforcing of social rules through small acts and institutional expectations. Rutter and Schwartz (2011) write that:

When an adult tells a little girl "good girls don't do this," or when boys make fun of her

for wanting to be on the football team, or when she sees women joining a military school getting hazed and harassed, she is learning her society's rules of behavior. (p. 24)

They go on to discuss high heels, foot binding in China, and genitoplasty as examples of gender-based social control of sexuality, but this extends to beliefs around childbearing and contraception. Social norms and expectations around what it means for someone to use contraception, or certain types of contraception, may be more powerful than health needs. Rutter and Schwartz (2011) regularly remind the reader that sexuality is never entirely free from a social context, "No one escapes being influenced by their parents' and society's vision of what is sexually appropriate, and this goes beyond superficial compliance. It infiltrates our psyches, and even affects who we desire" (p. 27). This phenomenon's epistemology, understanding how those influences and desires are learned, is not always obvious or widely accepted as fact. These ideas may feel innate or "just the way things are."

The concept of situated knowledge is also helpful in understanding how sexuality and contraception can be understood from multiple perspectives. Haraway (1988) was the first person to use the term "situated knowledge" within feminist epistemology. McHugh (2015) reviews the iterations and evolution of the concept, acknowledging that all knowledge is discovered from a positional perspective. There is not one correct or true version of knowledge, but it varies in any given circumstance and in any and every position in that situation. Someone's position, or positionality, in a situation "consists of the complex unfolding resulting from one's

social, material, epistemological, gendered, lived bodily experience" (McHugh, 2015, p. 44). Someone's understanding of a situation is built from both their specific perspective and from collective social experiences. McHugh (2015) also posits that:

Dominant mainstream medical and scientific research methods are unsituated, not directed in their inquiry by the problems that need to be solved and they are interactionist. These practices are failing communities that are the most at risk due to poverty, race, gender, class, war, colonialism, and therefore those most in need of accurate knowledge about their lives to improve and protect their health. (p. 57)

This persistent issue, present throughout the history of sexual and reproductive health, can be addressed by providing accurate, unbiased information and opportunities to engaged in truly collaborative decision-making. It is from this person-centered perspective, where unique knowledge about contraceptive methods and personal needs and desires can be created in collaboration between patient and provider, that situated sexual and reproductive healthcare can flourish. Without the personal expertise of someone about their own needs, the clinical expertise of a healthcare provider, or their ability to share power and decision-making, this would not be possible.

# Theoretical Framework of Change: Empowerment Framework

Practical and applicable models of health education interventions that impact self-advocacy are plentiful. Selected examples include transition-of-care planning tip sheets for LGBTQ youth by Dykes and Thomas (2015), gamifying transitional readiness checklists for young people with long term conditions (Wilson & McDonagh, 2014), question prompt lists for surgical patients to use in provider conversations (Lim et al., 2011), self-advocacy activity and resource sheets for English-language learners (Singleton, 2001), consistent engagement with

sexual and gender minority peer advocates (Willging et al., 2018), patients watching or reading provider biographies before the healthcare encounter (Perrault, 2017), self-advocacy groups for people with intellectual disabilities (Anderson & Bigby, 2017), and the use of "health passports" with patients who have learning disabilities (Fish et al. 2017).

Within public health, empowerment education has been strongly linked to the works of Paolo Freire. Freire's work, often referred to as Freirian or popular education, centers the experience of marginalized people to learn, teach, and create more equal distribution of power. The popular education movement grew out of work at the Highlander Folk School that began in the 1930s, continued with Paulo Freire in the 1970s, and later and served as a foundational tool for many key figures in civil rights and social justice movements (Wiggins, 2011). Focused on recognizing and claiming power, this movement fostered empowerment education techniques that are now popular in U.S. public health literature, such as works by Wallerstein (2002) and others.

Wiggins (2011) crafted a three-dimensional model of empowerment that connects internal and individual empowerment to external organizational and community empowerment. She shares this definition of empowerment:

A philosophy and methodology that aims to construct a just society by creating settings in which people who have historically lacked power can discover and expand their knowledge and use it to eliminate societal inequities. It is grounded in two equally fundamental beliefs--first, that the current distribution of power and resources in the world is unjust, and second, that change is possible. (p. 358)

Wallerstein (2002) explores community empowerment as a protective factor, such as social capital and community capacity, and powerlessness as a core social determinant of health

disparities. Her work moves beyond individual empowerment in the common use of the word and turns toward social justice processes and outcomes.

Carr (2011) outlined a hypothetical model of empowerment education for African American grandmothers providing care for their grandchildren. While different in many ways from this project's focus on people accessing contraceptive care, this demographic may also feel powerlessness, especially those with low political or socioeconomic status. They could feel physically, mentally, and financially unprepared to provide fulltime caregiving with little institutional support. Carr's framework was created for this population and its unique intersection of oppression, but the main themes are transferable to other identities and social positions where empowerment can benefit the individual or collective. The five main phases are: "powerless position acknowledgement, awareness, participation, behavioral changes, and outcomes" (Carr, 2011, p. 3). Of note, the participation phase influences all the other concepts in this framework, both catalyzing and solidifying empowerment. Skills built during this phase include active listening, critical thinking, self-advocacy, and advocacy for others, which align with skills needed to improve contraceptive care experiences.

# Current Trends in Contraception Education and Training

Contraception education and training often focuses on the provider or the patient. Current topic trends for providers include shared decision-making, same-day access for all forms of contraception, better understanding patient pregnancy intentions, and expanding LARC access with insertion, removal, and best practices trainings (Holt et al., 2020). Current trends in education and training for patients differ greatly based on age, gender, race, class, location, and type of institution. Sex education in public and private K-12 schools varies widely by city, county, and state. In many cases, sexual health education in schools and community settings is

focused on risk reduction for unplanned pregnancy and sexually transmitted infections. Some provider approaches include providing resources to patients, such as brochures and contraceptive decision-making aids, but patients may feel rushed if at an appointment. There are several quizzes that people interested in contraceptive care can take online prior to a care appointment to better understand their options. Specific sexual self-advocacy education is often focused on people with disabilities, as a component of the larger self-advocacy movement (Friedman et al., 2014).

# Empowering People through Community Settings

Utilizing an empowerment framework within the context of contraceptive care access fills a currently unmet community need. In a society where sexuality and health are socially constructed, people accessing contraceptive care may feel powerless based on their social position and lack of expertise. Recognizing this position, growing in awareness, and participating more fully in shared decision-making normalizes sexual autonomy and self-advocacy. Creating supportive spaces for learning about sexual health and self-advocacy in community-based workshops, as opposed to within healthcare institutions, intentionally removes some historical power dynamics and distrust. Guiding participants through activities to discover their unique contraceptive needs allows them to create and develop what serves them instead of prescribing behaviors or contraceptive options.

# **Project Plan**

A two-hour virtual workshop intended to build self-advocacy skills in contraceptive care patients. The workshop structure will utilize an empowerment framework (Carr, 2011; Wallerstein, 2002; Wiggins, 2011) to develop self-advocacy skills. Content topics include the

historical context of contraceptive care, crafting a reproductive life plan, understanding their personal contraceptive dealbreakers and dealmakers, reviewing self-advocacy techniques for various stages of healthcare access, recognizing self-advocacy skills in healthcare settings, and resources related to care access. This information is delivered in various manners, through individual work, small groups, and interactive lecture. Participants will leave with some standard resources and referrals, as well as the unique results of their individual activities. While scheduled to be virtual, these content areas and activities could easily be adjusted for an inperson audience.

While this is a large-scale social issue, it is inspired and informed by personal experience. I am a sexuality educator and a person who uses contraception and accesses sexual and reproductive healthcare. My background in health promotion, community engagement, and sex education influence and support this work. Over years of discussing sexual health and contraceptive care with people in different settings across Massachusetts, persistent themes arose in participant questions: How do I know what's right for me? Which birth control is the best? Why didn't my doctor tell me about all these options? How do I work through what I know and don't know about sex, anatomy, and contraception? These questions, along with the many participants that shared myths, misunderstandings, and distrust of healthcare providers, inspired me to create a workshop to address these issues and empower contraceptive care seekers to advocate for themselves more effectively.

#### **Situation Statement**

Contraceptive care has a long history of coercion and abuse of marginalized groups across gender, race, ethnicity, social class, and ability. This negatively impacts the care

experience, the ability for patients to advocate for themselves effectively, and their experiences of sexuality and health outside an individual healthcare encounter.

#### **Define Your Goals**

My goals for engaging community in a virtual workshop include developing tools to facilitate understanding of the contraceptive care landscape, building individual self-advocacy skills, and empowering people to explore their sexual health needs and improve their contraceptive care experiences. To achieve these goals, there are three major objectives for those who participate. After this workshop, participants will be able to:

- Design and name their reproductive life plan and contraceptive needs
- Recognize and employ self-advocacy skills
- Utilize tools and resources when accessing contraceptive care

These allow participants to benefit personally from the workshop, and their evaluations will contribute to improving facilitation, activities, and resources for subsequent deliveries of the program.

# **Target Audience and Stakeholders**

The target audience for this project is any person interested in accessing contraceptive care. This is intentionally both broad and specific. It is broad in that it is not gendered or restricted to people of certain ages, demographics, or with certain anatomy. It is specific in that it is purposefully inclusive of identities that do not fit within the gender binary, which are often excluded in contraceptive care scenarios. Registration will not be limited by geography and the content is applicable to many different geographic regions, as resources will be provided after the workshop and can be tailored as needed. An accessibility note: the workshop will be

conducted in English via Zoom and will require navigating the Zoom platform and basic Google Suite access and proficiency.

Relevant stakeholders include the target audience and those who support them in their decision-making process, personally or professionally. This could include partners and families, those who work in sexual and reproductive health and in settings where contraceptive care is provided, and communities at large. These groups could all find the material useful, but the empowerment framework is specifically tailored for empowering an individual who is making these decisions for themselves. Much of the workshop is focused on reflection on personal needs.

# **Crafting a Clear Message**

According to the Guttmacher Institute (2020a), over 99% of the women aged 15-44 who have ever had sex have used at least one contraceptive method and 4 out of 5 women who have had sex have used the pill. Still, many people who access contraceptive care do not feel empowered to advocate for their sexual health, based on their knowledge of their options or their experiences accessing care and facing stigma, barriers, and oppression. This workshop will focus on empowering people to access contraceptive care on their own terms, reducing the impact of racist, sexist, ableist, and classist oppression that lingers in this field for the millions of patients who access it in the United States every year.

# **Incentives for Engagement**

Stakeholder: people interested in accessing contraceptive care

Incentive: resources, referrals, stronger self-advocacy skills, knowledge about contraception and the contraceptive care landscape, greater understanding of the social forces that impact contraceptive decisions

Stakeholder: providers of contraceptive care

Incentive: increased understanding of factors impacting patient experience and decisionmaking, better informed patients

Stakeholder: people and professionals that support others in accessing contraceptive care

Incentive: new understanding of social forces that impact decision-making, new
understanding of other perspectives, tools to utilize while supporting others

Stakeholder: general public

Incentive: general awareness of the personal, interpersonal, and institutional factors impacting contraception and contraception's place in the healthcare landscape

# **Identify Outreach Methods**

To attract the target audience, various outreach methods may be used. All methods will be supplemented with custom Canva graphics with event details and a link to more information and registration on a Google Form. I will share with work colleagues who specialize in sexualities and health, such as Planned Parenthood League of Massachusetts, JRI Health, The Institute for Sexual Education and Enlightenment, local domestic and sexual violence resource agencies, independent sex educators, and others. The event and graphics will be posted on both my personal social media and in sex and sexuality groups to which I belong. Pending registration numbers, I may boost social media posts to a specific demographic or geographic area but intend to garner registrations organically first.

# **Responsibilities Chart**

NAME	ORGANIZATION OR AFFILIATION	RESPONSIBILITIES	CONTACT INFORMATION
Angelique Bouthot	Merrimack College	Project Manager and Facilitator:  Research, plan, execute, and evaluate event.	bouthota@merrimack.edu
Dr. Melissa Nemon	Merrimack College	Capstone Advisor: Faculty support of the project.	nemonm@merrimack.edu
Cohort Classmates: Grace Chitam Cassie Peltola Morgan Prittie	Merrimack College	Breakout Room Hosts: Ensure that participants feel supported during introductions and group work, as well facilitate reporting back to the group.	
Various colleagues and personal connections		Material Reviewers: Provide feedback on workshop content from the perspective of a contraceptive care provider, gender diverse person accessing care, community member, etc. while in development.	

# **Tools/Measure to Assess Progress**

All participants will complete post-workshop evaluations to determine understanding of self-advocacy and contraception and provide feedback regarding workshop facilitation, content, and overall experience. During the workshop, participants will complete some independent and group activities that will allow for organic data collection, both by observations and notetaking as well as created content, such as Google Jamboard information. Other planned data collection

includes points related to event outreach, such as number of post clicks and shares, and the number of registrants and attendees. Possible avenues for future studies could include documenting some of the participant activities that are done individually, such as the reproductive life planning or dealmakers and dealbreakers chart.

# **Implementation Timeline**

December 2020	Create workshop materials (lesson plan, activities, resource lists, evaluation, etc.)
January 2021	Connect with material reviewers, as needed  Confirm date and time of workshop  Create registration form  Begin advertising and outreach
February 2021	Ensure all "day-of" materials are created, including Zoom link, Google docs, evaluation, etc.  Confirm breakout room hosts  Host a meeting of people involved in event, as needed
March 2021	Ensure hosts and participants have required materials in advance  Host workshop  Send any relevant follow up information to participants and thank-you notes, as needed  Evaluation of data
April 2021	Full capstone draft due
May 2021	Submit final capstone paper for publication in ScholarWorks  Capstone colloquium presentation

# **Logical Framework**

I will...

Facilitate a contraceptive care and self-advocacy building virtual workshop.

So that...

Participants better understand the contraceptive care landscape and their options in a historical context.

So that...

They can understand their personal healthcare needs and craft their reproductive life plan.

So that....

They are empowered to use self-advocacy skills to improve their own contraceptive care experiences. They are ready to access care when, where, and how they need it.

So that...

They feel empowered to use self-advocacy skills in and out of the exam room and in and out of their sexual lives.

# **Implementation Notes**

Sexual and reproductive health is not always easy to teach or discuss. Participants come into the room with their own ideas about sex, health, and taboo, but also often the experience of personal and generational oppression or trauma. Knowing this and incorporating a trauma-informed approach are two different things. Any facilitator should be prepared for a range of participant responses and be prepared to discuss them through a social justice lens.

# Methodology

Held in March of 2021, this online workshop connected people via Zoom to discuss self-advocacy and contraceptive care. It was two hours long and consisted of content delivery and interactive engagement.

# **Participants**

Recruitment was not limited to a geographic place or institution. Promotional materials were disseminated via email and social media to personal and professional networks in the weeks leading up to the event. It was shared by multiple organizations, including Partners in Contraceptive Choice & Knowledge and Warriors by BTFP (formerly Brock Turner for Prison), as well as groups at Merrimack College, such as the Merrimack Gender & Sexuality Alliance. Recruitment materials were shared in multiple closed Facebook groups, such as Queer Exchanges, a student and alumni page for the Institute for Sexuality Education and Enlightenment, the Merrimack College Community Engagement Program group, and some groups focused on kink and ethical nonmonogamy. Professional networks from prior employment in sexual health and community engagement in Central Massachusetts were heavily utilized.

This recruitment did not have a set demographic audience, beyond those who use or want to use contraception. This was intentionally inclusive of gender, sexual orientation, relationship styles, sexual activity, and experience with contraceptive care. An accessibility statement included the workshop being conducted in English and via Zoom, utilizing the Google Suite of products, and that participant experience would be best if participating via computer due to the planned activities.

#### **Materials**

In recruiting participants for this workshop, a registration link led to a Google Form (see Appendix A). This form asked for their name and pronouns, email, and how they heard about the event. To screen participants and prepare the facilitator for the possible participants, they were also asked to rate how comfortable they felt advocating for themselves in a healthcare setting on a scale from 1 to 5, with 5 being most comfortable. They were also asked if they were a person interested in accessing contraceptive care and learning more about it, as well as if they were okay with a workshop focused on contraception that touches on related social justice issues such as racism, sexism, and violence. An open response space was available if people had questions.

For this project, materials used include referenced sources and uniquely created tools, which can be found in the appendix. A facilitator agenda and script (see Appendix B) were created to improve flow of the workshop and were not shared with participants. Breakout room hosts received a simple agenda and additional directions for leading activities in advance of the workshop.

A few days before the workshop, participants received an email containing workshop details and a link to *A Brief and Incomplete History of Contraception and Reproductive Abuse in the US* (see Appendix C). This timeline was developed for this project on the website Padlet. It contains selected milestones in the history of contraceptive care, including positive and negative events. Viewers can scroll along the timeline and click on each event for more information or a link to a contraceptive history resource. Another participant email closer to the workshop date and time included the Zoom link and a *Participant Activity Packet* (see Appendix D) for use during the workshop.

As participants entered the Zoom room for the actual workshop event, they were encouraged to answer questions on a Jamboard, a Google suite product that mimics a white board with sticky notes. These questions included: 1. How have you learned about sex/sexuality? Did you have sex ed? What have you learned about birth control, good or bad? 2. What stood out when reviewing the history of contraception (birth control) and reproductive abuse? Did you learn anything new? 3. Do you ever use any tools to help you advocate for yourself in healthcare settings? Share examples, as you feel comfortable. These were to be referenced throughout the workshop.

Participants also had the opportunity to craft their own *Reproductive Life Plan* (see Appendix D). They did so by answering a series of questions focused on their pregnancy and family intentions, such as "Are you trying to become pregnant within the next year?" and "What would you do if you became pregnant?" These questions and others clarify their birth control needs before comparing different methods and were adapted from examples in the literature (Sanders, 2009).

The *Dealmakers and Dealbreakers* tool (see Appendix D) was created specifically for this workshop. Modeled after the popular sexuality and kink practice of creating a "Yes/No/Maybe" list of sexual activities, this tool had participants sort common contraceptive method traits into categories of "Yes, I want this," "I might want this or be okay with this," and "No, I do not want this." Examples of contraceptive method traits included: might improve acne, might cause heavier cramps, over 99% effective at pregnancy prevention, non-hormonal, take daily, must be removed by a healthcare provider, and permanent, among many others. Some of these traits were adapted from other examples in the field (Reed et al., n.d.). Because each participant had their own tool to work on, they could also change the color of each textbox,

highlight some or write notes, and even delete some traits or add their own. For example, if someone had tried a method in the past and it did not work for them, they could add the name of that method into the "No, I do not want this" category. This tool can be used for self-discovery and as a self-advocacy tool when visiting a provider. It can be printed or saved to show on a phone.

Contraceptive decision-making aids (see Appendix D) are common tools in sexual and reproductive healthcare clinics and there are many variations, from simple to complex. They are often organized by effectiveness at preventing pregnancy, although there some providers intend to change that standard. Several examples were shown to participants and their pros and cons were discussed.

Along with these tools, participants also received a follow-up email with additional materials. This included the Google Form *Evaluation Survey* shared at the end of the workshop (see Appendix E) and a custom *Self-Advocacy and Contraceptive Care Resources List* (see Appendix F). The resource list was hosted on a Google Doc in view only mode that had links to various websites. Resource categories included Sexuality and Contraception Info; History of Contraception, Birth Control, and Reproductive Violence; Healthcare Providers; Tools/Info about Self-Advocacy.

## **Procedure**

Recruitment began a few weeks before the event. Promotional materials were created on Canva which included information about the event, about the facilitator, and a Bitly link to the event registration. These materials were disseminated via email and social media to personal and professional networks, including sexual and reproductive health providers, social groups, and identity-based groups at Merrimack College and virtually. Professional networks from prior

employment in sexual health and community engagement in Central Massachusetts were heavily utilized. Sharing in one group or to one person often led to sharing with other groups, such as when a Clark University professor shared it with her classes.

After recruitment was complete, participants received one email with additional information about the workshop, including *A Brief and Incomplete History of Contraception and Reproductive Abuse* (see Appendix C) They received a second email the day before the event, intended as a reminder and to provide the Zoom link and the *Participant Activity Packet* (see Appendix D) that included the tools and activities for the workshop.

The event began with participants entering the Zoom room at 6 pm. As they settled in and we waited for additional participants, the Jamboard link and instructions were shared so participants could get into an activity while waiting. Once everyone was admitted to the room, I provided a quick introduction and started breakout rooms for participants to introduce themselves and craft working agreements for the group. Breakout room facilitators were confirmed in advance and provided additional context and instructions. They were instructed to ask everyone, "What do you need from everyone in this virtual room to get the most out of this event today? Is it reasonable that most or all of the group could maintain this?" Backup working agreements included "take space, make space," "manage yourself and your tech," and "what happens here stays here, what's learned here leaves here." Working agreements can be adjusted for the audience and delivery method.

After creating these in a small group setting, we brought them back to larger group to review and come to a group agreement. From there, I reviewed the agenda and objectives before beginning a lecturette. This presentation summarized some of the themes from *A Brief and Incomplete History of Contraception and Reproductive Abuse* (see Appendix C). Primarily, that

sexual and reproductive healthcare and contraception specifically can be wielded as a tool for oppression and leveraged as a tool for liberation. Some examples of oppression by identity were highlighted. This was followed by asking participants to list benefits of contraceptive care, from bodily autonomy and health benefits to unintended effects, such as cost savings from lightened or eliminated menses. The lecturette is closed out by sharing a picture of person-centered contraceptive care and defining self-advocacy. The intention of this section is to situate someone's individual experience of contraceptive care into the larger sociocultural and historical context of care. As sexuality and health are socially constructed over generations, this historical narrative informs someone's comfort advocating for themselves in healthcare settings.

We then began working with the three major tools of the workshop that focus directly on reproductive planning and contraception. First, we reviewed crafting a reproductive life plan (see Appendix D). After explaining the tool, participants were encouraged to shut their video off until they completed the questions on their own. Once complete, there was space to reflect and share with the group. Then we reviewed the *Dealmakers and Dealbreakers* tool (see Appendix D). Once everyone understood the instructions, they were moved into their earlier breakout rooms so they could work on their own exercises in small groups. In the breakout rooms, they could chat while working on this and ask any questions of the breakout host. The facilitator should hop between breakout rooms during this time, if possible.

When back in the main Zoom room together, I reviewed the tool's purpose to guide conversation. With this tool, it is important to remind participants that it is intended to point them in the right direction, but that not all combinations of contraceptive method traits exist in a currently available method. They may need to compromise on their selections as there are a finite number of methods, but this tool allows people to weigh what they may or may not want to

compromise. Including self-reflective activities was intentional, as literature review found self-advocacy and self-compassion to positively predict patient satisfaction (Ramos Salazar, 2018).

This conversation organically leads into reviewing contraceptive decision-making aids (see Appendix D), which cover the most common methods of birth control. A few aids were reviewed here, and future facilitators could pick some that are relevant for their specific population by literacy level, age, what is commonly used in their local health clinics, or another criterion.

Once these specific tools were discussed, the group took a quick break before moving onto other self-advocacy techniques. A short lecturette covered basic self-advocacy recommendations, such as conducting research, bringing an advocate or ally to appointments, taking notes and bringing written questions, tracking periods and birth control effects in a phone app, etc. These were organized by tools, activities, and skills for before, during, and after an appointment. As Shay and Lafata noted, self-advocacy should be exhibited throughout an entire encounter, not just while making decisions (2014). Demographic-specific techniques were also discussed, such as how to share pertinent gender, sexual orientation, or relationship style information with providers. As some healthcare institutions provide patient self-advocacy tools, some were described and shown. If conducted in the setting of a specific practice, the facilitator should include their specific recommendations for self-advocacy.

The last activity of the workshop was a breakout room discussion of two contraceptive care scenarios. Participants were asked to name self-advocacy skills or tools that could be used in each situation. Depending on time allowance, participants can have the option to complete this discussion in the larger group or in breakout rooms. They can also choose to discuss or roleplay using these self-advocacy techniques with each other.

Concluding the workshop, we moved into questions, where participants could ask about any of the content that was or was not covered during the planned activities. Participants were told they would get a follow up email with additional information and resources about self-advocacy and contraceptive care. While this resource list was created before the workshop, sending it out after the workshop allows it to be bolstered with any additional resources if specific questions arose during discussion. Once questions dwindled, a link to the evaluation on Google Forms was shared in the chat and a QR code to the survey remained onscreen. This link was also sent in the follow up email, in case participants left the workshop early or did not complete it during the allotted time.

#### Results

There were 25 registrations, 15 participants, and 11 evaluation survey responses. This survey was administered via Google Forms and included both qualitative and quantitative means of data collection (see Appendix E). No respondents were under 18 or in the 31–40-year-old age range. Three respondents (27.3%) identified themselves as 18-23, 5 respondents (45.5%) identified themselves as 24-30, and 3 respondents (27.3%) identified themselves as 41+ when asked their age (n=11). Of these respondents, 5 (45.5%) identified as Hispanic/Latino.a.x, 4 (36.4%) identified as Black/African American, 4 (36.4%) identified as white, no one identified as Asian, Native American/American Indian, Native Hawaiian/Pacific Islander, Middle Eastern/North African, or Other, while 1 (9.1%) selected Prefer Not to Say (n=11). Participants were able to select all race/ethnicity options that applied.

Figure 1: Self-Reported Participant Age

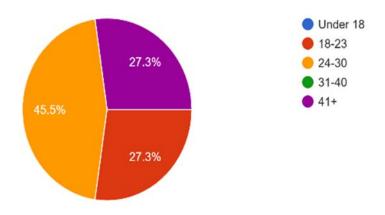
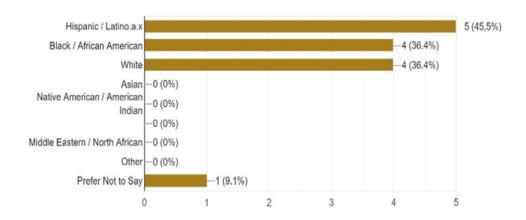


Figure 2: Self-Reported Participant Race/Ethnicity



Four participants (40%) selected that their sexual orientation was straight, 6 (60%) selected Bisexual/Pansexual, and no one selected Gay/Lesbian, Asexual, Queer, or Other (n=10). Gender Identity was an open response question and results were: 3 (27.3%) respondents wrote in "female," 2 (18.2%) wrote "Woman," 2 (18.2%) wrote "cis gender" or "cisgender," 2 (18.2%) wrote "cis woman" or "cisgender woman," 1 (9.1%) wrote "Female / Woman," and 1 (9.1%) wrote "NB" which can be understood as nonbinary in this context (n=11).

Figure 3: Self-Reported Participant Sexual Orientation

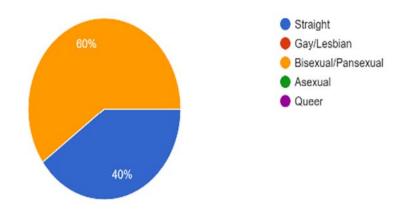
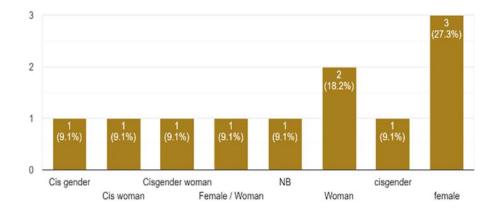


Figure 4: Self-Reported Participant Gender Identity by Open Response



In the evaluation survey, respondents were asked about the workshop and facilitator, how well objectives were achieved, if they intended to use the provided tools in the future, and to agree or disagree with statements about their learning. When asked to rank their agreement with the following statements, 10 of 10 respondents indicated that they "agree" or "strongly agree" that the facilitator was well-prepared and knowledgeable, that the facilitator managed the workshop well, and that the activities connected with the workshop content. Nine of 10 respondents indicated that they "agree" or "strongly agree" that the goals of the workshop were

clear to them, the content was applicable to their personal life or work, and the discussions reinforced the workshop content. One respondent chose "neutral" to rank their agreement with these three statements. Another respondent was excluded from these results as their answers on all statements were in direct opposition to their open-response answers and the feedback they provided during the event, indicating there may have been an error in their response.

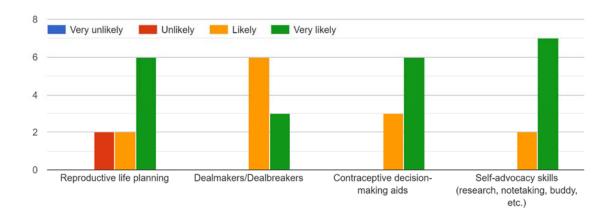
Respondents were also asked to rate how well objectives were achieved in this workshop. The most widely achieved objective was to recognize self-advocacy skills, to which 8 respondents felt they were able to do "very well," 1 felt they could do "adequately," and 1 felt they could do "fairly." When asked about employing self-advocacy skills in a healthcare setting, only 6 felt they were able to do so "very well" and 4 chose "fairly" or "adequately." For the questions with 11 respondents, 7 felt they were able to both design their reproductive life plan and utilize tools and resources when accessing contraceptive care "very well," and 4 felt they were able to do these activities "fairly" or "adequately." Identifying and naming personal contraceptive needs had the most respondents that selected they were only "fairly" able to achieve this activity (3 out of 11 respondents). When asked about utilizing tools and resources when accessing contraceptive care, 7 respondents felt they could do this "very well" and 4 felt they could do so "fairly" or "adequately" (n=11).

All respondents indicated they "agree" or "strongly agree" that they learned about new contraceptive methods, benefits, and/or side effects; learned about new self-advocacy skills for healthcare settings; will share some of this information with people they know; want to learn more about the content covered in this workshop; and better understand how contraceptive care is affected by things outside the exam room, such as individual experiences and systemic oppression. Of these responses, these had the most "strongly agree" responses, indicating

stronger results: sharing the information with others, wanting to learn more, and better understanding how contraceptive care is affected by external forces.

When asked about if they would use featured tools in the future, answers varied. General self-advocacy skills, such as research, notetaking, buddy, etc., are very likely to be used by the most respondents: 7 selected "very likely" and 2 selected "likely" (n=9). Contraceptive decision-making aids, available online or at healthcare providers, are "very likely" to be used by 6 respondents and "likely" to be used by 3 respondents (n=9). The dealmakers and dealbreakers tool created for this workshop had the least participants that selected "very likely" for future use: 3 chose this option and 6 chose "likely" (n=9). Reproductive life planning was the only tool that some respondents were unlikely to use: 2 indicated "unlikely," 2 indicated "likely," and 6 indicated "very likely" (n=10).

Figure 5: Participant Likelihood of Using Provided Tools in the Future



Participants were also asked to gauge their comfort level with advocating for themselves in healthcare settings, indicating their comfort level from 1 to 5 before and after the workshop with 5 being the most comfortable. For their estimate before the workshop, the average answer was 3, with 7 of 11 respondents (63.6%) choosing this answer. When asked to scale that same

feeling after the workshop, there was only 1 respondent who still chose 3. The new average, with a total of 10 respondents, was 4.3 and no respondents chose a 1 or 2. Most respondents, 5 of 10 (50%), chose to rate their comfort as a 4.

Figure 6: Participant Self-Reported Comfort with Self-Advocacy in Healthcare Settings, Before Workshop

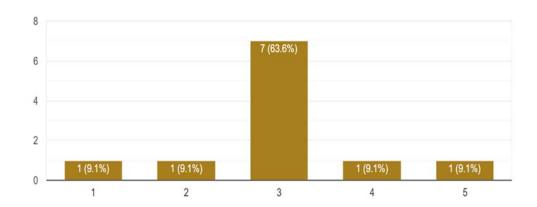
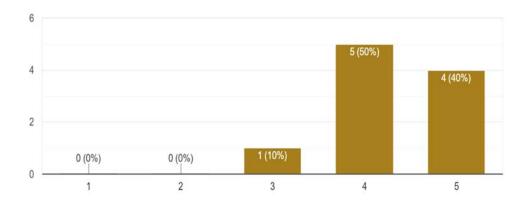


Figure 7: Participant Self-Reported Comfort with Self-Advocacy in Healthcare Settings, After Workshop



When asked about what was most impactful about the workshop or what could be improved, respondents could respond openly, and some consistent themes arose (n=9). One-third

(33.3%) of respondents found the reproductive life planning activity to be impactful and another 22.2% noted the materials and activities more generally. Two respondents (22.2%) noted their self-reflection and identification of their own needs, and a few individual respondents shared reflection-based impacts, such as learning some of their own birth control "dealbreakers" from an activity, better understanding the connection from social and historical context to comfort with self-advocacy, discussing how contraceptive needs differed amongst the participants, and reflecting on how few opportunities exist for education and connection around contraceptive care. Approximately 22.2% made mention of inclusive language or specific phrases used and another 22.2% mentioned how fun and engaging the workshop felt. For improvements, two respondents (22.2%) did not provide any feedback. Most common, 33.3% of respondents wanted more specific information about birth control methods, from specific traits to social and political context. 33.3% of participants wanted more time overall or more time for specific activities and 11.1% suggested a shorter workshop. Additionally, 22.2% suggested multiple workshops or a series, so people could be engaged for less time in a single workshop but spend more time on content overall. One comment worth mentioning was a desire for a stronger connection between the historical context and the current landscape of contraceptive care.

During the workshop, participants were asked to complete some activities. As people trickled into the Zoom room at the beginning of the event, there was a Google Jamboard link that was shared with the group. When asked, "How have you learned about sex/sexuality? Did you have sex ed? What have you learned about birth control, good or bad?" answer themes included birth control being both good and bad; learning about sex and birth control from sex ed, doctors, and family; having inaccurate, incomplete, or religiously based education and resources; and learning "the hard way" by living.

Enough time and support were not provided for participants to work their way through the other questions. One response for "What stood out when reviewing the history of contraception (birth control) and reproductive abuse? Did you learn anything new?" included an answer about being aware of this content due to a women's history class. Another question asked "Do you ever use any tools to help you advocate for yourself in healthcare settings? Share examples, as you feel comfortable." One answer said, "upfront boundaries, and asking questions when I need to."

The other activities included crafting working agreements and working through the various exercises in the *Participant Activity Packet* (see Appendix D). Most of these were completed individually, or semi-independently within small breakout groups. Completed activity packets are the property of participants and not accessible in this research. After completion of the Dealmakers and Dealbreakers activity, I asked what else could be on the list of birth control traits and characteristics. One person noted that money concerns were listed too many times, another mentioned religious consideration, and yet another mentioned greater comfort with Eastern versus Western medicine. For future workshops, reviewing and revising this list would be prudent, especially if it could be tailored for and with people from the population participating.

#### **Discussion**

This project was largely successful, with favorable outcomes and participant experiences. The results show that self-advocacy skills can be learned and bolstered via a workshop. When the post-workshop evaluation asked participants to rate their comfort with advocating for themselves in a healthcare setting before and after the workshop, the average answer increased

from 3 to 4.3, a 43.3% increase. All participants noted an increased comfort level, except for the one participant that rated themselves at the highest comfort level before and after the workshop.

Multiple participants spoke during the workshop or in their surveys about the value in having space to explore concepts like birth control, personal health needs, and the complex social forces that surround them both. I began this project because I suspected this due to anecdotal evidence, both in my own life and in years working in sexual health. This held true for some participants in this workshop.

Some participants desired more information about the contraceptive methods themselves. While all this workshop content could be part of comprehensive sexuality and health education, the desire for more contraceptive method information hints at the variation in participants' working knowledge of sexual health. Future workshops should either include more information about various contraceptive methods, provide scaffolding resources in advance of the event, or state that an intermediate knowledge of multiple methods is best for optimal experience. If possible, a needs assessment at the beginning of the workshop could flex workshop focus on different content areas based on participant knowledge and interest. As participant knowledge may vary, a flexible facilitator can ensure the workshop remains successful while meeting participants where they are in their understanding.

In reviewing some particular aspects of the study, some interesting results arise. For example, two participants noted they were unlikely to use reproductive life planning in the future (See Figure 5). When this data is informed by age, both respondents were 41+ and likely past making their reproductive life plan. They could still be likely to use other tools provided, as evidenced by their answers, as they use contraception for its other benefits or act as a resource for other people making contraceptive decisions. This point illustrates the number of

confounding variables that could be impacting the likelihood of a participant to utilize new selfadvocacy tools.

Some key elements feel critical to the success of the workshop. One was appropriately setting the stage, ensuring that people understood what would be covered in the workshop. If it were open access for anyone to join without pre-registration, participants may have felt unsafe, or an unsafe environment may have been created. Sending materials out in advance was helpful in ensuring participants were prepared, both personally and for the flow of the workshop.

Situating contraceptive care in the larger social, cultural, and political contexts was also integral to the core purpose of the workshop. This could be done in various ways and remain effective, but having it primarily as pre-work allowed participants to engage in as much reflection or investigation as felt right for them. During the workshop and in evaluations, participants noted reflection and the inclusive space of our workshop to be especially valuable. Should someone choose to alter or replace activities, including self-reflective activities and opportunities to engage with others in discussion are both necessary. Creating this space to reflect and process together is just as important as introducing new content.

## **Limitations of the Study**

The largest limitations to this study are those listed on the registration for this workshop: it was held in English, online via Zoom, and utilized multiple software applications. Everyone who attended was able to engage in this fully and I provided this information well in advance. If in person, people may have felt more comfortable sharing their own experiences with contraception or healthcare more generally. People may have also felt more comfortable sharing in a group where they knew all participants or if everyone shared a similar identity or experience.

There was clear sampling bias as recruitment was primarily through social media and personal network promotion. Several people who I did not know registered for the workshop, but I had met everyone who attended at least once in the past. Since I previously worked in sexual health, some of these participants had a higher-than-average comfort level and understanding of this topic. As I facilitated the entire workshop, a prior connection to me likely influenced participant responses. Promoting the workshop further in advance, using a more attractive title or branding, and creating promotion toolkits for individuals and organizations may have facilitated more registrations. Participants were also largely based in Massachusetts, so there may likely be regional influences in their experience of healthcare and self-advocacy.

As for the sample that did attend, it was a relatively small group. This was helpful in many ways, so people could have space to participate. However, that also means a small number of evaluation responses and a lack of diversity in identities. There were no participants in the 31-40 age range, and there were some past their reproductive age. Participants were predominantly bisexual/pansexual, with the remainder of participants identifying as straight. No participants identified as Native American, Asian, Native Hawaiian/Pacific Islander, or Middle Eastern/North African. There was only one person who did not identify as a woman, female, or cisgender. While this workshop did not have a large enough sample to create widely applicable results, these findings cannot be extended to transgender and nonbinary people who use contraception, people who are not straight or bisexual/pansexual, and people who identify as the missing racial and ethnic identities without further study. It was my intention to make this workshop inclusive for a broad range of people, however a more focused demographic could have increased attendance if people were interested because of a specific identity.

Within the workshop itself, some activities did not have enough time to be truly effective. For example, I had participants utilize a Google Jamboard as they got settled into the workshop space. I did not provide enough time or direction, as most did not participate in all of the questions. I also began asking closed-ended questions where people could raise their hands or use a Zoom reaction to indicate their answer as people were not actively engaging in open-ended questions. As many people are on video calls through much of their days at this point in 2021, another two hours in a workshop on a weeknight can be challenging. Including breakout rooms, background music, breaks, and ensuring being on video was optional was helpful to mitigate these challenges, but they did not eliminate "Zoom fatigue."

## **Implications for Future Studies**

Based on survey results and conversations with participants, there seems to exist a high need for self-advocacy focused education across sexual and reproductive experiences. Multiple surveys mentioned wanting more time to cover content or the creation of a series. In conversation after the workshop, other aspects of health came up: self-advocacy during birth or when accessing pregnancy options counseling. Expanding this work to include more dimensions of sexual and reproductive health is a clear next step. As there was sparse literature for self-advocacy and contraceptive care for a general population, this work could support further research.

This workshop did not recruit participants of a specific identity, but there is ample opportunity to do so in the future. This could allow for more targeted content about the way self-advocacy and healthcare intersects with race and culture, religion, gender identity, disability, class, etc. A workshop could also recruit participants based on other important factors about their health, such as if they are living with endometriosis, polycystic ovarian syndrome, or another

condition. Family and relationship structures that may also impact contraceptive decisions, such as already being a parent, single parenthood, or having multiple sexual and romantic relationships, could also inform a more tailored workshop environment and a specific research outcome.

The self-advocacy tools used in this workshop can be tested further. Some respondents indicated that they were unlikely to use the reproductive life planning tool. Based on the demographics of those respondents, it could be inferred that they have completed their reproductive life planning. Still, there could be confounding factors, such as the format or wording of the planning tool. The Dealmakers and Dealbreakers tool could also have lost the interest of some participants based on its format, but not its content. As the original design for an in-person workshop was to have laminated activity sheets or sticky notes instead of a virtual tool, a study or even focus group comparing multiple formats could inform educators and health practitioners in the future.

This project was an amalgam of personal and professional passions. To see participants recognize the value in this work and want more was validating and fortifying for continuing to work at the intersection of sexual and reproductive health and social justice. A major implication here is that this project is only one of many small activities in a larger area of study that requires further support, investment, and prioritization.

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# **Appendix A: Registration Survey**

# Self-Advocacy and Contraceptive Care Workshop

If you're still looking to join, send an email to bouthota@merrimack.edu

March 16th, 6-8 pm via Zoom

This free workshop is intended for people interested in contraceptive care (birth control) and learning about self-advocacy in healthcare settings. This space will be inclusive of various gender identities, sexual orientations, and relationship styles and will be conducted in English over Zoom and Google apps like Docs, Slides, and Jamboard-participants will have the best experience logging in from a computer. A Zoom link will be sent via email the day of the event.

If you have any questions or wonder if this is the workshop for you, please email Angelique at bouthota@merrimack.edu.

\* Required

1.	Name and Pronouns *
2.	Emai <b>l *</b>

3.	How did you hear about this event?
	Check all that apply.
	Social media
	Friend
	Email
	Flyer
	Other:
4.	Do you feel comfortable advocating for yourself in a healthcare setting? *
	Mark only one oval.
	1 2 3 4 5
	Not at all Yes, very much so
5.	Are you a person interested in accessing contraceptive care and learning more
	about it? *
	Mark only one oval.
	◯ Yas
	Yes
	No
	Unsure
6.	Care warning: This workshop will focus on contraceptive care (birth control), sexual
	health, and accessing healthcare. It will touch upon related social justice issues,
	such as racism, sexism, and violence. Is that okay with you? *
	Mark only one oval.
	Yes
	○ No

<i>'</i> .	Use this space if you have any questions in advance.

## Appendix B: Agenda and Script

## Agenda

- 6 pm: Intro (5 minutes)
  - o Jamboard
- 6:05 pm: Breakouts for Intros/Working Agreements (8 minutes)
  - Report out from shared google doc (5 minutes)
- 6:18 pm: Agenda/Objectives (3 minutes)
- 6:21 pm: Lecturette (20 minutes)
  - SRH and Oppression
  - SRH and Benefits
  - Self-Advocacy
- 6:41 pm: Self-Advocacy & Contraceptive Care Tools (25 minutes)
  - o Repro Life Plan (solo)
  - Decisionmaking Aids (group)
  - Dealmakers and Dealbreakers (in breakout room chats)
- 7:08 pm: Dance break!
- 7:11 pm: Self-Advocacy Techniques (25 minutes)
  - Self Advocacy Skills/ Tips and Tricks
  - Application of Content
    - (Extra Activity: Roleplays in breakout rooms if needed on time)
- 7:40 pm: Questions
- 7:45 pm: Evaluations
- 8:00 pm: End
- Email a few days before with timeline activity
  - Padlet link
- Email one day before with zoom link/activity packet

## Lesson Plan

- Pre-Class Action (5 minutes)
  - Welcome, refer to email, start "activity packet"
  - Change Zoom name to appear as you'd like, with pronouns
  - o Jamboard?
    - How have you learned about sex/sexuality? Did you have sex ed? What have you learned about birth control, good or bad?
    - What did you learn when reviewing the history of contraception (birth control) and reproductive abuse? Was anything surprising or shocking?
    - Do you ever use any tools to help you advocate for yourself in healthcare settings? Share examples, as you feel comfortable.
- 6:05 pm Breakout Rooms (10 minutes)
  - Personal Introduction
- SWITCH TO RIGHTS AND AGREEMENTS SLIDE
  - "Because we'll be talking about difficult things, I'm going to get us started with some breakout rooms to do introductions and come up with some working agreements. They might feel a little bit like classroom rules from when we were

kids, but I like to frame them as the rights and responsibilities that we all have to each other in this space. These are the things that we need to have in a space like this to have the most meaningful experience, like to respect each other or stay on mute when you're not talking. Be creative or think back to what has worked when you've been in other online spaces. You'll be in there for ...8? Minutes and will have a peer leader. These peer leaders are my gracious classmates who are just helping with the logistics--they are also participants in this workshop just like you so you are welcome to ask them questions about logistics knowing they may or may not know the answer to your content-based questions."

- (Breakout room hosts have directions to lead introductions and gather working agreements in a shared Google doc)
- WELCOME BACK SLIDE and then share working agreements Google doc
  - Read through agreements
  - "Can we all agree on these responsibilities together? Did we miss any?"
  - Awesome, let's hop into things!
- 6:18 WHY ARE WE HERE
  - Really quickly, here are the objectives for today, so you have an idea of what you'll be able to accomplish after our workshop.
  - The objectives are for you to be able to:
    - Design and name your reproductive life plan and contraceptive needs
    - Recognize and employ self-advocacy skills
    - Utilize tools and resources when accessing contraceptive care

#### • 6:21 TALKING ABOUT CARE

- "In order to do that, I want to talk about a couple things. You may have noticed that the materials for this workshop said "contraceptive care" and "birth control" over and over again. What's important is that we're talking about ways people prevent pregnancy. Contraceptive care is a little more accurate, but we tend to use birth control in social spaces a lot more often. I'm going to use them interchangeably today, and you can use whatever makes sense to you.
- I may also talk about "the exam room" or appointments. People can access birth control by going into a doctor's office or healthcare provider, as well as via telehealth, which is medical care over computer or phone. They can also use pregnancy prevention methods that are available without a healthcare provider.
- o I'm also going to be talking about people who want to prevent pregnancy or who can get pregnant, not just eisgender women or people assigned female at birth. That means I might also say things like "people who can become pregnant," "someone with a uterus," or things like "sex with reproductive potential" meaning that someone could get pregnant from that sexual activity. These are all ways that I recognize that sex, gender, and sexual orientation are not binary.
- Please stop me at any time to ask a question about a term I'm using. Are there any questions on that language before we hop in?"

## • SITUATING THE INDIVIDUAL

o "So let's jump into a little bit of the content. To make sense of why we need to learn about self-advocacy, we need to talk about how we are situated or our social positions. We access care in a sociocultural context, meaning that who we are,

- what we've experienced, and what is happening or has happened out in the world impacts our healthcare.
- We can also use this workshop as an example, too. I'm calling from land stolen from Indigenous Nipmuc people, and that has specific significance as we talk about reproductive oppression. I'm also a white, cisgender, queer woman. Those identities and experiences, and many others, inform what I bring into this workshop, and also how it feels to you all to have me talking about this work.
- As you saw in that timeline I sent out on Sunday and in this afternoon's email, birth control is complicated. It provides people with so many benefits, and has also been used as a tool for oppression. There are many good or beneficial things that have been and continue to be used as tools for oppression, like education or housing. Learning about this history and current trends can help people get what they need out of their healthcare, but it does not mean that every person using self-advocacy skills will have the same experience based on their social identities and the world they navigate."

## • THE PILL GENOCIDE OR LIBERATION

One of the events I included in the timeline was a reference to the complicated experiences of Black women during the civil rights era and the height of the birth control movement, specifically an essay published in *The Black Woman: An Anthology*. Author Toni Cade Bambara asked if the pill was a tool for genocide or liberation. A tool of oppression or a tool to practice freedom. A powerful question that is still asked today. This workshop is situated in that essay's position--that it can be both, that that is complicated and difficult, and each person should have the power to make their own reproductive health decisions."

## • IDENTITIES MATTER

- "Again, referring back to the timeline about birth control history, it looks like you had some different reactions. Here on this jamboard.....
- When I say things like "social position," I'm referencing some of these parts of our identity. Gender, race, disability status, class, immigration status, education level, age, sexual orientation. These all impact someone's everyday life and their access to high-quality healthcare.
- We saw examples of how birth control and sterilization has been used as a tool of oppression for people across all of these identities.
- It makes a lot of sense that people with these identities, or people who have seen
  these oppressive and violent events, would be skeptical or distrust the providers
  and the methods they use.
- I intentionally chose not to focus on a specific demographic group for this workshop so a wide range of people may find it useful. Still, I'm acutely aware of my position as a queer, cisgender white woman talking about contraception and I know that we could have a workshop about contraception intersecting with each one of these social identities and it could be a lot longer than two hours. I also want to note that things like the language someone does or does not speak, incarceration experience, surviving violence and trauma, having other conditions like endometriosis or PCOS, etc. These can also impact the type of experience someone can have accessing sexual and reproductive healthcare broadly and birth control specifically.

 But to go back to Toni Cade's question about the pill. Here we reviewed some of the examples of it used for oppression. How is it a tool for liberation? What are some benefits?"

# • BENEFITS

- o "Please either unmute or drop into the chat some of the benefits of contraception"
  - Conversation here about some of these:
    - Personally controlling repro: Impact on health, economics, educational attainment
    - Health benefits
    - Lifestyle benefits acne, periods
    - Preventing/planning pregnancy
    - Economic gains, Education, Health, Lifestyle preferences

## • A NEW MODEL

- o "So there is a newer image of contraceptive care that has become more and more popular in recent years. It's called "person-centered" meaning an individual is the focus, at the center of that sociocultural context I talked about earlier.
- This means an individual is respected as the expert on their own sexual and reproductive healthcare needs and they are working *with* a medical provider and their expertise to figure out what will work best for them.
- To be really effective in this model, or for people to get what they want out of providers who may not be as familiar with this model, people can practice selfadvocacy."

## • SELF-ADVOCACY

- o "This term grew out of disability rights organizing, around self-determination and autonomy. You can see here I have two definitions of self-advocacy. Can I have someone read each of them?
  - The action of representing oneself or one's views or interests. (I pulled that one straight off Google)
  - Self-advocacy is the ability to articulate one's needs & make informed decisions about the support necessary to meet those needs (This is from the National Deaf Center)
    - How to articulate, someone must also understand their own needs, have done the research to make informed decisions, and know about the type of support they need from care providers, their partners, or from other people in their lives

## • YOUR SELF-ADVOCACY

- "I want to share here that this is some data from the registration link, when I asked "Do you feel comfortable advocating for yourself in a healthcare setting?" None of us were on either end of the spectrum, of 1 being completely and totally and uncomfortable or 5 being the perfect example of comfortable and prepared self-advocacy.
- o I hope that after this workshop, you may go up a number or two."

# • SO...WHAT DOES THIS ALL MEAN?

"I'm almost always interested in working at problems from different angles.
 Many initiatives focused on improving these issues are aimed at the provider-implicit bias training, quality improvement, new models of care, policy around

- insurance coverage--and those are absolutely all things that have to happen. The institutions with power need to operate differently.
- O The focus of today is to recognize that these historical and current power dynamics exist, but we are not trying to change the system in this conversation. We as patients are not responsible for changing the system when we step into an exam room and are trying to get care. There are people doing that work, some of them are here in this conversation and I am grateful for it. In this space right now, we're going to focus on what people can do within these systems to improve their experiences in the short-term. So let's talk about hacking the system in the meantime....

#### • 6:41 LET'S START TALKING TOOLS

 "Alright everyone, let's take a deep breath. We're going to head into an activity to help us learn about our own needs before we even get to a healthcare appointment."

## • REPRO LIFE PLANNING

- "Raise your hand, either on video or by using the reactions at the bottom of the screen, if you've heard of the term reproductive life plan before.
- O It essentially means taking some time to figure out your personal pregnancy intentions. Often, one or two of these questions will be asked of people during a healthcare appt. Knowing the answers in advance can give you a head start and help you determine what types of methods you may want to use. Some people may be really quick with this activity, some people may take some time.
- O Because of that, I ask that you turn your cameras off for this, and open up the activity packet document I sent to you earlier today. Feel free to unmute or chat if you have a question. Type "done" in the chat when you're done and enjoy a smidge of free time if you're done early.
- You don't need to share what it was, but give me a hand raise if you learned something about yourself or your needs doing that activity.
- Great! This can be a good tool to talk about with a provider, or with family, partners, and your support network if you're actively planning or preventing pregnancy."

## • 6:48 CONTRACEPTIVE DECISION-MAKING AIDS

- Speaking of getting the conversation going, these next tools are usually used for that, too. I'm going to share my screen to go through these, but you can also follow along on your computer and activity packet if you'd prefer. We're going to cover a few of the many types of contraceptive decision-making aids. You may have seen some of these at doctors offices before, or when doing your own research on contraception.
  - Review options on screen and talk through pros and cons

## • 6:55 DEALMAKERS/DEALBREAKERS

o "Alright, for activity #2, we're going back into breakout rooms. Once inside, you can start working on your dealmakers & dealbreakers activity which is on the next page of your packet. You'll be taking common traits or side effects of birth control methods and moving them to make your own custom list of deal makers and breakers--You can have things you definitely want out of your method, something you're okay with having or not having, and things you definitely do

not want out of your method. I'll be hopping in and out of groups and you'll also have your peer leaders again. Does anyone have any questions before we get started?

- Welcome back everyone, how was that? "
- o "Did I miss anything?
  - Maybe religious needs or expectations?
  - This activity is really important because there is no one-size-fits-all method. People have different comfort levels with delivery, like a pill or implant, how the method works, like hormones or barrier methods, and side effects. Sometimes, there isn't a method that fits exactly what someone wants. A tool like this can help you play around with what's possible. You can also take a screenshot or open this on your phone to share with a provider and get the conversation going. "
- 7:08 DANCE BREAK
- 7:11 JAMBOARD SLIDE--SELF-ADVOCACY TOOLS
  - "Let's see what you all had to say about this earlier (refer to Jamboard).
  - Now let's dig into some tips and techniques for self-advocacy."
- PRE-APPOINTMENT
  - Understanding you/your needs
    - Do you need to see a provider? What type of provider? Are you planning to use a method that needs provider involvement, or do you want to use something like condoms? Are you and your partners up-to-date on other things like STI testing or preventive care?
  - Research--providers, contraceptive methods, etc.
    - Research can be important to find a high-quality provider, especially by aspects of your identity. Ask your friends, family, community members about clinicians who share your identity or are competent in providing care. If you're a Black woman and want a Black woman to be your care provider, you should be able to access that. If you're nonbinary and want to make sure someone will use your pronouns and understand your care needs, you deserve that. There are often online care directories for specific identities, from Black and Brown providers, to physically accessible care offices, to queer, kink, or polyamorous friendly providers, or those who specialize in certain conditions, like endometriosis and Polycystic ovarian syndrome.
    - Doing your research on contraceptive methods in advance can also make your conversations easier
  - Tracking period/symptoms
    - Asked at a doctor's appt, anything that's worrisome or a change from *your* normal
    - There are a lot of apps to help with this and there are some in the resource list I'll send out
  - Ouestions, beliefs/stories
    - These are the things that we learn about birth control from others. Wrangling some of those thoughts before you go in and get you organized get the answers you need

- Additional education (workshops)
  - I wouldn't be a sex educator if I didn't say you could go to other workshops
- Managing pre-appt. anxiety or worries
  - Some folks have reasonable anxiety around accessing care. Having a plan in place for what that means for you, whether it's having an escort or getting there early or treating yourself after, do what works for you
- Talk to others/practice
  - Talk with people you trust about their experiences, from what methods they chose to the types of questions their provider asked them during an appointment. Sometimes the uncertainty can be really overwhelming.

## • DURING APPOINTMENT

- Speak assertively
  - Remember, you are the expert in your experience and your body.
- Asking questions
  - This is a great time to use your phone or a note pad.
- Take notes of any answers, new questions, follow-up items, anything good/bad
  - When we're nervous, our short-term memory isn't always working at its best. Taking notes can help us remember things later on
- Name discomfort
  - If you're uncomfortable or nervous, you can say so. Your provider may take extra time to explain things, slow down, or ask clarifying questions.
- Hit pause
  - You don't have to leave with making a decision if it doesn't feel right. Check in with what you're feeling.
- Documentation
  - Documenting refusal—can be a tool when you want something and they don't agree with your decision or do not want to provide it to you.
  - Getting print copies of information, results, etc.
- Referrals
  - If you think you should see another provider about something, you can ask for it!
- Bring a buddy
  - This can mean your own buddy, or you can request a second person (usually a nurse or medical assistant) in the room with you.
  - Think of social identities for this again, and how that may be helpful to you.

## • AFTER APPOINTMENT

- Use your method consistently & correctly (Including Follow up)
  - If you left with a birth control method, use it correctly and consistently for it to be most effective.
  - Have a plan in place to stay on track, including any follow up care like STI testing, regular appts. For Depo provera shots, or annual appts. For prescription renewal.
- Keep tracking period, symptoms, other concerns
  - Your provider will keep asking these questions at each appt.

- Research methods more if needed
  - You can make a decision on your timeline.
- Stay in contact--portal, electronic medical record (EMR)
  - Use these to stay in contact or keep track of test results and bills.
- Find a new provider if you can/need one!
  - You have the right to high quality care with a competent and inclusive provider.
  - You also have the right to start or stop a method at any time, for any reason. If you got a method and want to stop using it, your provider may ask questions but they should support your decision. If they don't, like if they don't want to remove an IUD or an implant, find another provider.
- Leave feedback
  - Positive or negative, those annoying surveys do get back to individual providers and their practice managers. Did your provider do something awful? Let them know if you can. Did they do something really amazing and you want them to keep it up? Tell them that too!

## • OTHER GENERAL TIPS & TOOLS

- Q card/SOGI information
  - SOGI means sexual orientation and gender identity. There are some tools that exist where people can fill out a small card with details about themselves, like their pronouns, gender identity, and sexual orientation. Many intake forms are now being upgraded to include all of this information, but it's not true everywhere. If you don't have access to one of these tools, you can access them online or even make your own.
- Health history
  - It's important to really dig in on your health history so a provider can help you make the best decision for you. Things that might not seem related, like a history of smoking or migraines with impaired vision, can impact what method may work best for you
  - History of blood clots, high blood pressure, over the age of 35, smoker, migraines w/aura
- Patient advocacy tools from provider
  - Some providers even give you self-advocacy tools. Full disclosure here, friends, I used to work for Planned Parenthood League of Massachusetts. When I went in for my last appt a few weeks ago, these were in the waiting room. They have spaces for you to take notes before and during your appointment, and space to make a plan for the future.
  - Woo! What a ride! We are almost done here y'all.
  - Let's apply a few of these tips and techniques

# • APPLYING WHAT WE LEARNED

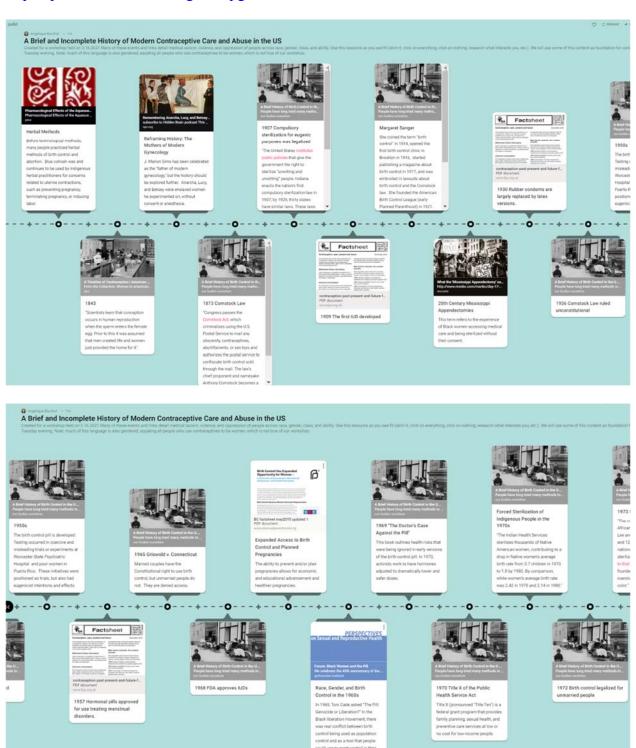
- For this next activity, we can do this in a Name self advocacy skills or tools that could be used in each situation. Role play a conversation between the person and provider.
- o "Jesse is 28 and they are going to the gynecologist for STI testing. While there, their doctor reminds them that their IUD is about to expire and begins talking about scheduling an appt. to insert another. Jesse is actually thinking about

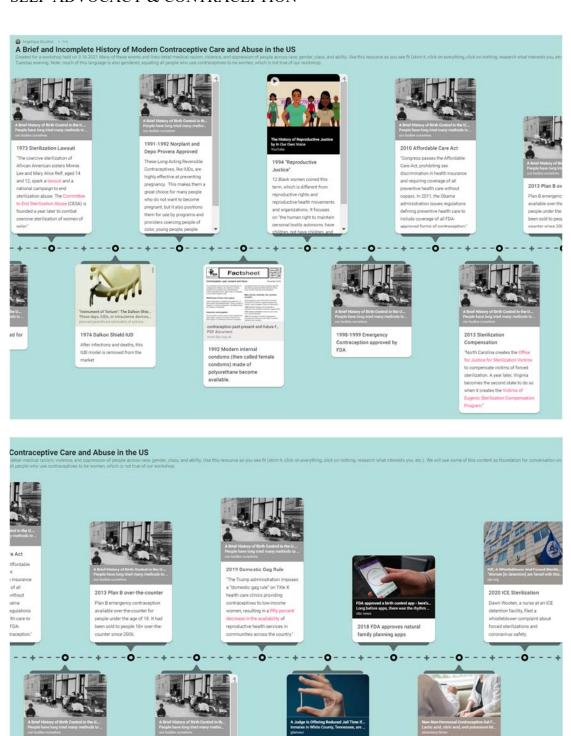
- stopping hormonal contraception all together and is feeling really uncomfortable at how it feels like a decision was being made for them."
- "Brielle is 18 and needs some form of pregnancy prevention. She has no idea where to start, and is headed to her local SRH clinic to learn more and find a free option--she's in school, working part time, and is concerned about how her family would react if they knew she was sexually active."
- 7:40 *QUESTIONS*
- 7:45 WHAT TO EXPECT
  - o Explain resource list and follow-up email
  - Ask folks to scan the QR code or follow the link in the chat to access the evaluation.
- THANK YOU

#### **Appendix C: Brief History Tool**

#### A Brief and Incomplete History of Modern Contraceptive Care and Abuse in the US

https://padlet.com/bouthota/gmzu7pg5vrutfw32





contraceptive gel FDA-

approved

reduced sentences for people who

were sterilized or got a long-acting contraceptive.

2014-2017 Religious Objections to Birth Control

"2014 The Supreme Court rules

in Burwell v. Hobby Lobby
Stores that employers with
religious objections can refuse
to cover contraception in their

health insurance plans. 2017 The Trump administration

Coverage

for Justice for Sterilization Victims

sterilization. A year later, Virginia becomes the second state to do so when it creates the Victims of

to compensate victims of forced

#### **Appendix D: Participant Activity Packet**



#### How This Works

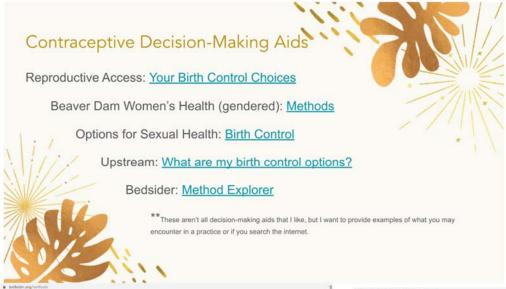
This is your activity packet--you can do whatever you want with it!

We'll go over directions for each of these activities as we move through the workshop.

### Activity #1 Reproductive Life Plan

Turn your camera off for this activity. Turn it back on once you're finished or type "done" in the chat. Either on a piece of paper or in this document, answer these questions:

- Are you planning a pregnancy within the next year? (This is a very common question at healthcare appointments.)
- Have you ever been pregnant? Do you ever want to become pregnant/become pregnant again? If yes, when?
- If you want to have children, how many? How many years apart do you plan to have your children?
- Are there situations in which these decisions could change? What are they?
- Are there any pieces of your personal or family health history that could impact these decisions?
- How do you plan to prevent pregnancy when you do not want to be pregnant?
- What will you do if you have an unplanned pregnancy?
- What can a doctor/healthcare provider do to help you with your plan?

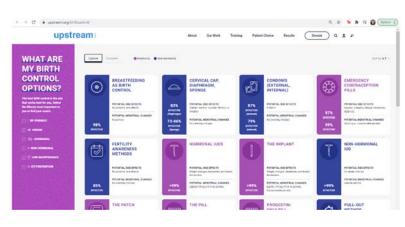












#### Activity #2 Dealmakers and Dealbreakers

List of traits if someone is doing this with a pen and paper:

- Might stop periods
- Hormone-free
- Safe for people who smoke
- Involves not having sex with reproductive potential during certain times of cycle
- Safe for people on gender-affirming hormone therapy (hint: all methods are!)
- Over 90% effective at preventing pregnancy Over 99% effective at preventing pregnancy
- Can be started/ stopped by you any time
- Must be inserted/removed by a healthcare provider
- Must be easy to access (no prescription, anyone can buy or
- Can reduce reproductive cancer risks
- Breast tenderness Reduces STI risk No cost/free

- Regulates periods/uterine bleeding
- Use a few times per year May cause vaginal irritation or infection

- Effective for long term use (years)
- Cost is not a major influence for me
- Must be used or maintained daily
- Is inserted into the body by a healthcare provider
- and stays there
- Use weekly
  Use only during sex with reproductive potential
  Requires prescription
- Is inserted into the vagina by you/requires you to
- touch your vulva/vagina Might lighten or make periods irregular
- May impact weight
- May cause heavier periods or cramping
- May decrease acne
- Must be discreet/hidden (if you need help, your provider may be able to help)
- May increase acne
- May cause headaches
- Requires partner collaboration

Add other things you've heard of, or even methods you've tried, to your list!



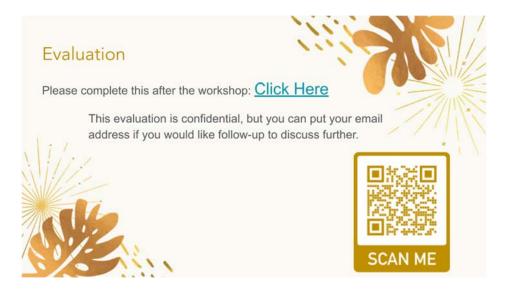
## Applying What We Learned

Name self advocacy skills or tools that could be used in each situation. Role play a conversation between the person and provider

"Jesse is 28 and they are going to the gynecologist for STI testing. While there, their doctor reminds them that their IUD is about to expire and begins talking about scheduling an appt. to insert another. Jesse is actually thinking about stopping hormonal contraception all together and is feeling really uncomfortable at how it feels like a decision was being made for them."

"Brielle is 18 and needs some form of pregnancy prevention. She has no idea where to start, and is headed to her local SRH clinic to learn more and find a free option--she's in school, working part time, and is concerned about how her family would react if they knew she was sexually active.







#### **Appendix E: Evaluation Survey**

# Self-Advocacy and Contraceptive Care Workshop Evaluation

Thank you for participating in today's workshop!

Please answer the following questions to help with the research portion of my graduate capstone at Merrimack College. Your answers are confidential and solely used for data collection purposes.

Thank you again for joining me today and taking these additional few minutes to help me gain insight on this workshop and your experience. Contact <a href="mailto:bouthota@merrimack.edu">bouthota@merrimack.edu</a> with any questions.

Please rank your agreement with the following statements.

Check all that apply.

	Strongly Disagree	Disagree	Neutra <b>l</b>	Agree	Strong <b>l</b> y Agree
The facilitator was well-prepared and knowledgeable.					
The facilitator managed the workshop well.					
The goals of the workshop were clear to me.					
The content was applicable to my personal life or work.					
The activities connected with the workshop content.					
The discussions reinforced the workshop content.					

	Not at all	Inadequately	Fairly	Adequately	Ver We
Design my reproductive life plan					
Identify and name my contraceptive needs					
Recognize se <b>l</b> f-advocacy skills					
Employ self-advocacy skills in a healthcare setting					
Utilize tools and resources when accessing contraceptive care					
workshop.	disagree	with the follow			
workshop. Check all that apply.			ving state Disagree	ments after	Strongl
Please rate how you agree or own workshop.  Check all that apply.  I learned about new contraceptive methods, benefits, and/or side ef	e	Strongly			Strongl
workshop.  Check all that apply.  I learned about new contraceptive	e fects.	Strongly			Strongl
Workshop.  Check all that apply.  I learned about new contraceptive methods, benefits, and/or side ef	e ffects. y skills	Strongly			Strongl
Workshop.  Check all that apply.  I learned about new contraceptive methods, benefits, and/or side effor healthcare settings.  I will share some of this information.	e ffects. y skills	Strongly			Strongl agree

2. How well were these objectives achieved? As a result of this workshop, I feel I am

4. How likely are you to use these tools in the future?

	Very unlike <b>l</b> y	Un <b>l</b> ike <b>l</b> y	Likely	Very likel
Reproductive life planning				
Dealmakers/Dealbreakers				
Contraceptive decision-making aids				
Self-advocacy skills (research, notetaking, buddy, etc.)				
in a healthcare setting?	ab <b>l</b> e were yo	ou with adv	ocating t	for you
BEFORE today's workshop, how comfort in a healthcare setting?  Mark only one oval.  1 2 3  Not at all comfortable	able were yo	ou with adv		for you
in a healthcare setting?  Mark only one oval.  1 2 3	4 5	Very com	fortab <b>j</b> e	
in a healthcare setting?  Mark only one oval.  1 2 3  Not at all comfortable   AFTER today's workshop, how comfortal	4 5	Very com	fortab <b>j</b> e	
in a healthcare setting?  Mark only one oval.  1 2 3  Not at all comfortable   AFTER today's workshop, how comfortal healthcare setting?	4 5	Very com	fortab <b>j</b> e	

7.	What was most impactful for you about today's workshop?
8.	How can this workshop be improved?
0.	
9.	What is your age?
	Mark only one oval.
	Under 18
	18-23
	24-30
	31-40
	41+

10.	What is your race/ethnicity? Select all that apply.
	Check all that apply.
	Hispanic / Latino.a.x
	Black / African American
	White
	Asian
	Native American / American Indian
	Native Hawaiian / Pacific Islander
	Middle Eastern / North African
	Other
	Prefer Not to Say
11.	What is your gender identity?
12.	What is your sexual orientation?
	Mark only one oval.
	Straight
	Gay/Lesbian
	Bisexual/Pansexual
	Asexual
	Queer
	Other:
13.	OPTIONAL: Provide your email if you are open to being contacted with follow up
	questions.

#### **Appendix F: Self-Advocacy and Contraceptive Care Resources**

#### **Sexuality and Contraception Info**

- Bedsider.org
- Reproductive Access: Your Birth Control Choices
- Upstream: What are my birth control options?
- Birth control and period apps--Spot On, Natural Cycles
- Period tracking apps--11 period apps, Spot On, Fitbit, iPhone Health, Apple watch, etc.
  - O Some people also keep a note on their phone with dates or use a calendar!
- Examples of Reproductive Life Plans
- Getting Contraception Online
- 7 Things to Know About Birth Control If You Are Transgender or Nonbinary
- Birth control coloring pages
- Women of Color Sexual Health Network Members Find a sex educator!
- Boston's Sex-Positive Newsletter by Pleasure Pie Find workshops!

#### History of Contraception, Birth Control, and Reproductive Violence

- Videos
  - o Black Women and Birth Control, A Complicated History
  - The Dark History of Forced Sterilization
  - The US medical system is still haunted by slavery
- Articles
  - A Timeline of Contraception
  - Past as Present: America's Sordid History of Medical Reproductive Abuse and Experimentation
  - The Bitter Pill: Harvard and the Dark History of Birth Control
  - Cade Bambara, Toni, ed. "The Pill: Genocide or Liberation? (1969) " In *The Black Woman: An Anthology*. Washington Square Press, 2005. ISBN: 9780743476973.

#### **Healthcare Providers**

- Your primary care, OB/GYN, or a referral from one of your providers!
- Planned Parenthood
- Find a Clinic (This resource isn't awesome, but I do like that it's a searchable resource hosted by a third party besides a search engine.)
- When Googling, watch out for crisis pregnancy centers
- Massachusetts-based

- ABCD, Health Imperatives, HealthQ, Planned Parenthood League of MA, Tapestry
- Many searchable databases are not well-funded or up-to-date. If possible, use these in addition to word-of-mouth or local group referrals, like those found on Queer Exchange Facebook pages or affinity-based groups.
  - <u>Black Women's Health/Finding a Provider</u> (this has scripts, which are another great self-advocacy prep tool)
  - o <u>TransCareSite.org</u>
  - Kink Aware Professionals

#### Tools/Info about Self-Advocacy

- Self-Advocacy (Disability and teen lens)
- <u>Self-Advocacy Toolkit</u> (Autism focus, great worksheets for anyone new to managing their own healthcare like making appts. and learning the process)
- LGBTQ Self-Advocacy
  - Q Card Project
- <u>Documenting Refusal</u>
- @eedie french shares about their health and appointment prep routine
- Tips/Techniques from workshop:



You can also Add me on LinkedIn or stay in touch via email!