

CONTRACEPTIVE JUSTICE

Policy and Community
Assessment Report

ACKNOWLEDGMENTS

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EverThrive IL works to improve the health of women, children, and families over the lifespan.

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I. EXECUTIVE SUMMARY

Illinois has been a leading champion for progressive policies related to sexual and reproductive health and rights not only in the Midwest, but across the United States. In just the last five years, Illinois expanded Medicaid, removed restrictions on abortion coverage in Medicaid, expanded protections for the rights of young people under the age of 18 in sexual and reproductive health services, and expanded coverage of contraceptives to include over-the-counter methods and dispensing of a 12-month extended supply.

In spite of the state's strong policy foundation, people in Illinois continue to experience significant barriers to their preferred method of contraception, often because of poor or inconsistent policy enforcement and implementation, challenges faced by health care professionals seeking to fulfill the guarantees of state policy, and misinformation or lack of clarity. People from marginalized communities face even more barriers to care that further fuel the inequities in health and health care. The Reproductive Justice movement requires an analysis of the history of reproductive oppression because we cannot understand the barriers related to access and rights and how they intersect without first understanding how those barriers were created. Many stories, experiences, and injustices were never recorded or validated and, in some cases, purposely erased from the narrative, however the fear and actual experiences of institutional violence continue to fuel distrust between people and communities and our health care system. Reproductive Justice seeks to repair the harm caused by institutions by addressing the roots of these injustices and ensuring they do not happen again.

EverThrive Illinois established a coalition of health care professionals, public health professionals, health educators, social service providers, consumer advocates, government officials, community members, funders, and other stakeholders that are actively engaged in efforts to provide or expand contraceptive care to guide the Contraceptive Justice Project in Illinois using a collective impact approach. The Contraceptive Justice Coalition employs the Reproductive Justice framework to inform and anchor our vision, research, strategies, and projects to increase access to all forms of contraception for all people and communities. By applying this framework to a contraceptive access project, we are able to advance the first community-driven contraceptive access project that is committed to using Reproductive Justice as the foundation and framework to move beyond access and work towards achieving justice.

To evaluate access to all forms of contraception for all people and communities, EverThrive IL with members of the Contraceptive Justice Coalition who participated in the Landscape Assessment Workgroup, facilitated a comprehensive assessment on the facilitators of and barriers to contraceptive access at the individual, community, health care professional and policy levels. EverThrive IL conducted the literature review and focus groups for the individual and community levels as well as the policy analysis. The Center for Interdisciplinary Inquiry & Innovation (Ci3) in Sexual and Reproductive Health at the University of Chicago facilitated the health care professional assessment, including a literature review and key informant interviews in a supplemental report. This landscape assessment revealed the barriers to comprehensive access to contraception that remain for all people, but especially people from communities that have been marginalized. It also revealed practices that facilitate and support comprehensive access, including information and education for people and communities about contraception and their rights, to sexual and reproductive health care, and support of efficient billing and reimbursement protocols for all methods of contraception, including switching or removing methods. The result of this landscape assessment is a series of recommendations to increase contraceptive access in Illinois, which will be considered and prioritized by the Contraceptive Justice Coalition as the focus of pilot and collaborative efforts moving forward.

Mission of the Contraceptive Justice Coalition

The Contraceptive Justice Coalition will increase access to all forms of contraception for all people and communities. We aim to do this by reducing unmet contraceptive need and addressing disparities in health and health care related to race, sex, gender, sexual orientation, age, income, ability, immigration status, primary language, and geographic location.

The Contraceptive Justice Coalition will:

- Honor the individual needs, values, and choices of each person while promoting the full range of contraceptive methods
- Facilitate meaningful community engagement and access through a feedback loop
- Build the capacity of local organizations and health care professionals
- Uplift innovative programs and strategies that are successfully meeting community and health care professional's needs

The Contraceptive Justice Coalition is comprised of health care professionals, public health professionals, health educators, social service providers, community-based organizations, consumer advocates, government officials, community members, funders, and other stakeholders that are actively engaged in efforts to provide or expand contraceptive care.

The Contraceptive Justice Coalition employs the Reproductive Justice framework to inform and anchor our vision, research, strategies, and projects.

The term “Reproductive Justice” originated in Chicago in 1994 by the Black Women’s Caucus of the Illinois Pro-Choice Alliance after attending a UN conference on population and development in Cairo, Egypt and Loretta Ross, a co-founder of SisterSong Women of Color Reproductive Justice Collective, was one of these women. Ross stated in her essay, *The Color of Choice: White Supremacy and Reproductive Justice*, that “Reproductive Justice can be described as reproductive rights embedded in a human rights and social justice framework” to protect every person’s right to:

- Decide if and when they will have a baby and the conditions under which they will give birth
- Decide if they will not have a baby and their options for preventing or ending a pregnancy
- Parent the children they already have with the necessary social supports in safe environments and healthy communities, and without fear of violence from individuals or the government

Definition of Contraceptive Justice and Guiding Values

EverThrive IL hosted a day-long Contraceptive Justice Symposium in April 2018 with more than 110 people in attendance to start a dialogue and lay the groundwork for the coalition moving forward. Our closing workshop centered around identifying ideological, institutional, interpersonal, and internalized barriers to contraception and developing shared language and meaning around what Contraceptive Justice could look like for the most marginalized communities at each level. For the purposes of our work and this report, we will focus on the institutional and interpersonal meanings of Contraceptive Justice we developed together.

In general, the following concepts were at the center of participants’ discussion of Contraceptive Justice at the institutional level:



And in discussion of Contraceptive Justice at the interpersonal level:



NOTE ABOUT LANGUAGE

Advocacy Meet Populations
Open-ended Questions
Health Care Justice
Training Dialogue Concerns

Using the definition of Reproductive Justice and the mission of the coalition, we define “Contraceptive Justice” as all people having the social, political, and economic power, rights, access, and resources to receive contraceptive and pregnancy prevention care that is:

- Person-centered
- Confidential
- Comprehensive
- Medically Accurate
- Developmentally Appropriate
- LGBTQQIA+ Affirming
- Accessible
- Trauma-Responsive
- Culturally and Linguistically Affirming
- Harm Reduction Grounded
- Pro-Choice
- Sex- and Body-Positive
- Challenging of Explicit and Implicit Bias, Shame, and Stigma

There is so much power in language, from expression and connection, to oppression and isolation. We acknowledge that much of the research presumes cisgender identities and does not include people who are transgender, gender expansive, and non-binary. The language used throughout this report is intended to be as accurate, inclusive, and affirming as possible while acknowledging that the research and data we are pulling from has used certain labels that we cannot change without misrepresenting the data. Transwomen are women and are therefore included whenever there is a general mention of “women” in this report. Identities as well as any identities that are presumed, such as the cissexist assumption that everyone’s gender identity aligns with the social constructs related to the sex they were assigned at birth, are made as explicit and accurate as possible.

Project Overview

To begin the landscape review, we conducted an assessment of federal, state, and local policies to understand how existing policies facilitate and impede access to contraception. A summary of policies reviewed and an analysis of findings is included in this report in *Section III, Analysis: Policies Influencing Contraceptive Justice*. To inform the analysis, we compiled a policy crosswalk comparing policies in Illinois with 10 other states across the U.S., and the District of Columbia, which is available as a digital supplement to this report.

We then conducted a review of the needs of people and communities, including a literature review and a series of focus groups. A summary of findings and analysis of literature pertaining to the needs of people and communities is included in this report in *Section IV, Literature Review: Unintended Pregnancy, Unmet Contraceptive Need, and Contraceptive Justice*, and the findings of the focus groups are included in *Section V, Focus Groups Regarding Contraceptive Access at the Individual and Community Level*. The literature review consists of an annotated bibliography, available as a supplement to this report, reviewing more than 100 peer-reviewed articles on people’s behaviors, attitudes, and barriers for access to and use of preferred contraceptive methods, summarized according to the identities and communities they represent.

Finally, the Center for Interdisciplinary Inquiry & Innovation (Ci3) in Sexual and Reproductive Health at the University of Chicago conducted a provider assessment literature review of more than 77 peer-reviewed articles synthesizing existing research on health care professional barriers and needs regarding contraceptive care for diverse populations, as well as lessons learned. Key informant interviews of providers at a range of health care sites and locations were also conducted for a deeper understanding of the behaviors, attitudes, barriers, and practical needs for local health care professionals. A report of findings from the health care professional’s literature review is available as a digital supplement to this report.

These three assessments together make up the Contraceptive Justice Landscape Assessment and inform the recommendations to advance Contraceptive Justice in Illinois, included in this report in *Section II*, the priority areas for capacity-building efforts, and the activities of the coalition.

II. RECOMMENDATIONS TO ADVANCE CONTRACEPTIVE JUSTICE IN ILLINOIS

The Contraceptive Justice Coalition seeks to increase access to all forms of contraception without barrier or delay and to reduce unmet contraceptive need, employing a Reproductive Justice lens. After rigorous review of existing literature and primary data collection, we believe that the following recommendations would advance Contraceptive Justice in Illinois. If these recommendations are enacted, in the long term, we would expect to see dramatic reductions in unmet contraceptive need and rates of unintended pregnancy that are mistimed or unwanted.

Recommendations for Supporting People and Communities

1. Help people find exceptional person-centered, high quality contraceptive care by developing a designation, in partnership between advocates and health care professionals, to identify, assess, and recognize individual health care professionals and health care facilities that are providing exceptional person-centered, high quality contraceptive care and publicize this information
2. Help people and communities feel better prepared to engage in conversations about their sexual and reproductive health, including with health care professionals, and address factors which might cause people to feel hesitant or distrustful of the health care system by:
 - a. Creating educational materials aligned with the values of Contraceptive Justice on the full range of contraceptive methods, including potential side effects to inform people and provide discussion tools to take into medical visits
 - b. Creating educational materials on people's rights to access care, including coverage mandates and processes; consent and confidentiality rights for all people, but especially young people; and freedom from discrimination
 - c. Creating tools for finding and selecting a health care professional who will provide comprehensive, person-centered care, including questions to ask when scheduling, scripts for talking to a health care professional about preferred contraception, etc.
 - d. Executing a broad public awareness campaign to increase knowledge among people about contraceptive methods, providers of high-quality care, and people's rights; including targeted outreach to marginalized communities to promote welcoming care
3. Ensure that language is affirming and inclusive for all people by working with health care professionals and communities to improve clinic forms, including intake forms and electronic health records (EHR)
4. Support and encourage social service provider engagement in sexual and reproductive health education and referrals to care for the people they work with, if desired by the person, by executing a broad educational campaign on sexual and reproductive health education, contraceptive methods, and people's rights for a range of social service providers
5. Support and encourage parent engagement in sexual and reproductive health care if, and only if, desired by the young person, by developing and disseminating curricula and resources to empower parents and young people to speak openly and honestly about sex and encourage conversations that are affirming, respectful, and accurate
6. To ensure people are satisfied and supported, health care professionals and facilities should conduct a follow up phone call or visit between three and six months after contraceptive counseling and method selection/placement to discuss whether they faced a barrier in accessing their contraception, whether they are still using the contraception or experiencing adverse side effects, answer any questions or concerns, and assess whether additional visits are needed

Recommendations for Supporting Health Care Professionals

7. Support health care professional efforts to offer the full range of contraceptive methods and stay up-to-date on new methods or best practices, especially if their practice is not focused on family planning, by:
 - a. Giving health care professionals standardized and centralized tools, apps, and resources with easy to access information on contraception
 - b. Offering trainings with continuing medical education (CME) and continuing education unit (CEU) credits, possibly state-mandated, on best practices in contraceptive care provision
 - c. Exploring peer-to-peer trainings, mentorship, and other opportunities to create networks among health care professionals who may feel isolated
 - d. Supporting access to in-person training, particularly for clinical training on long-acting reversible contraceptive (LARC) methods, and continued practice to help health care professionals feel comfortable and competent
8. Develop and facilitate training for a wide range of health care professionals, especially pediatricians and family medicine providers, on person-centered counseling and practices to support people pre- and post-pregnancy and pregnancy loss, which includes termination
 - a. Support health care professional engagement by offering CME and CEU credits
 - b. Support implementation through the development of tools, including scripts for providers to talk about contraception in a way that is consistent and respectful
9. Explore opportunities to offer financial incentives for health care professionals to carve out time for additional training opportunities, such as additional funding for clinics ensuring attendance or certification in particular topics and/or implementing a system of quality assurance, incentive, or recognition for those who implement best practices generally
10. Offer health care professional trainings with CME and CEU credits that help them identify their own biases and misperceptions and build competence to meet the needs of a diverse population
11. Develop and disseminate overviews and practice guidelines on relevant policies (e.g. Medicaid coverage, billing and coding)
12. Identify workarounds and pathways to care and coverage for patients receiving care at religious systems that limit contraceptive care and identify opportunities to support trainings for those educated in or working in religious health care settings
13. Support health care professionals as they seek to provide confidential care by:
 - a. Providing education on consent and confidentiality laws in Illinois
 - b. Strengthening policies and protocols for addressing confidentiality concerns, such as billing/coding, flagging confidential information in medical records, and disclosures of patient information

Recommendations for Policy Change

Illinois Administrative Recommendations

1. The Illinois Department of Health Care and Family Services (HFS) should:
 - a. Ensure reimbursement for contraceptive care, including counseling and follow up, is sufficient to incentivize the provision of high quality, person-centered care
 - b. Monitor Medicaid Managed Care Organizations (MCOs) to ensure access to the full range of contraceptive methods is provided and paid for without barrier or delay for all members; this includes reviewing utilization data, prescription drug formularies, medical device coverage, timely payment of

RECOMMENDATIONS

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- claims, and family planning policies and procedures
- c. Consider how the development and use of quality metrics, including pay for performance metrics, related to contraceptive care and sexual and reproductive health care could be improved or built upon to facilitate access and person-centered care
 - d. Identify and remove all barriers to sexual and reproductive health services, including the elimination of dispensation limits on hormonal contraception and removing administrative barriers that make it difficult for clinics to stock LARC
 - e. Partner with the Illinois Department of Public Health (IDPH) and the Illinois Department of Insurance (DOI) to develop and implement a statewide marketing campaign to educate people on their rights to access the full range to contraceptive methods without cost, regardless of insurance type
2. The Illinois State Board of Education (ISBE) should survey schools statewide to determine:
 - a. If they are implementing recommended sexual and reproductive health education curriculum
 - b. If they are conducting evaluations or have data on the impact of their sexual and reproductive health education
 - c. If the curriculum they are implementing is the best one for their student's needs
 - d. If they would benefit from technical assistance or other support from ISBE or other groups to better implement the state's sexual and reproductive health education requirements
 3. The Illinois Department of Insurance (DOI) should strongly enforce and clarify the state's comprehensive contraceptive coverage mandate (215 ILCS 5/356z.4) by:
 - a. Ensuring that adherence to the law is thoroughly evaluated at annual plan certification
 - b. Issuing guidance or rulemaking to clarify requirements related to coverage of over-the-counter methods without a doctor's prescription, as well as 12-month dispensation of hormonal contraceptives, and provide support to insurance companies as they work to implement these components of the law
 - c. Improve the system by which patients request a waiver for non-formulary contraception by encouraging use of a uniform waiver authorization tool and process by all private insurers and by publicizing that tool and process on DOI's website
 - d. Provide training and resources on contraceptive access laws, including the waiver process for non-formulary contraceptive and over the counter access, to pharmacists
 - e. Ensure that staff at the Office of Consumer Health Insurance who review and handle grievances and complaints are well informed on the state's contraceptive coverage requirements and the process for requesting a waiver for non-formulary contraception for all carriers
 4. The Illinois Department of Public Health (IDPH) should provide training and technical assistance and support to increase capacity of school-based health centers to provide all forms of contraception by addressing clinical and non-clinical barriers to care

Illinois Legislative Recommendations

5. Authorize a family planning state plan amendment to pay for family planning and sexual and reproductive health benefits to individuals who would not normally be covered under Medicaid, including those with incomes up to 300 percent of the federal poverty level, regardless of immigration status and regardless of sex assigned at birth or gender
6. Increase funding for Title X programs in Illinois using state-matched funds or by creating a state-run complimentary program

7. Require that all schools in Illinois teach comprehensive, age appropriate, medically accurate sexual and reproductive health education beginning in sixth grade
8. Expand Medicaid coverage for all people who are eligible as a result of pregnancy to a period of 12 months following delivery to increase access to sexual and reproductive health services and address maternal mortality and morbidity
9. Expand the comprehensive Contraceptive Coverage Act (215 ILCS 5/356z.4) to include no-cost coverage for external condoms
10. Allow for pharmacist prescribing of hormonal contraception to patients of all ages
11. Prohibit private insurance companies from generating and/or sending an Explanations of Benefits (EOB) when confidentiality from parents or partners are a concern for the patient
12. Strengthen the Consent by Minors to Medical Procedures Act (410 ILCS 210/) to prohibit health care professionals from sending information about sexual and reproductive health care received by a young person to their parents/guardians, including test results, without express written informed consent of the patient
13. Strengthen the Sexual Assault Survivors Emergency Treatment Act (410 ILCS 70/) to require dispensing of emergency contraception, if already available on site, to sexual assault survivors who request EC in a hospital or pediatric health care facility
14. Strengthen the Illinois Domestic Violence Act of 1986 (750 ILCS 60/) Article IV – Health Care Providers to:
 - a. Require and enforce routine screening for domestic violence in a hospital or other health care facility by any person who is licensed, certified or otherwise authorized by the law of this State to administer health care
 - b. Incorporate screening practices into licensing and training requirements of health care professionals or facilities
 - c. Acknowledge contraception as a safety planning tool and incorporate it as a part of the “immediate and adequate information regarding services available to victims of abuse” offered to a person suspected to be a victim

III. ANALYSIS: POLICIES INFLUENCING CONTRACEPTIVE JUSTICE

Illinois is a leading champion for progressive policies related to sexual and reproductive health and rights in the Midwest and across the United States. In recent years, a number of legislative victories have been particularly important in advancing access to sexual and reproductive health care. In 2017, the legislature removed restrictions of abortion coverage in Medicaid. In 2016, the state increased contraceptive access through the Comprehensive Contraceptive Coverage Act, which expanded private insurance coverage for all contraceptive methods and requires insurance companies to cover dispensing of a 12-month supply when desired. Just recently in 2019, the legislature passed the Reproductive Health Act (RHA) which updates Illinois' reproductive rights laws by repealing outdated and unconstitutional prohibitions on reproductive health care and regulates abortion like any other form of health care, an incredible victory in the current political climate where nine states have passed laws severely restricting access to abortion. Additionally, there are important municipal policies, like Chicago Public School's Sex Education Policy that mandates comprehensive sexual and reproductive health education that is developmentally appropriate and medically accurate be provided from kindergarten through 12th grade. According to the Local Reproductive Freedom Index, an initiative of the National Institute of Reproductive Health (NIRH) that evaluates the sexual and reproductive health, rights, and justice policies of 40 cities across the United States, Chicago scores four out of five stars with the average of these 40 cities being just two stars (52). While no city earned a perfect five out of five, only three cities scored 4.5 stars and they were Los Angeles, New York City, and San Francisco. Even so, Chicago achieves every recommended measure under the sections most relevant to contraception and unintended pregnancy, "Funding and Coverage for Reproductive Health Care," "Supporting Young People," and "Supporting Families."

In spite of the state's strong policy foundation, people in Illinois continue to experience significant barriers to their preferred method of contraception, often because of poor or inconsistent policy enforcement and implementation, challenges faced by health care professionals seeking to fulfill the guarantees of state policy, and misinformation or lack of clarity. People from marginalized communities face even more barriers to care that further fuel disparities in health and health care.

This Contraceptive Justice Policy Assessment evaluates the federal, state, and local policies in place as of May 2019 that have an impact on contraceptive access and identifies the gaps in coverage, implementation, and enforcement as well as harmful policies that create barriers, limit access, and contribute to disparities in health and health care. Our accompanying policy recommendations seek to fill those gaps; support implementation and enforcement; remove, or at least reduce, harmful policies; increase access; and address inequities in health and health care related to race, sex, gender, sexual orientation, age, income, ability, immigration status, primary language, and geographic location to achieve Contraceptive Justice for all.

State and Local Policy Analysis

[\(215 ILCS 5/356z.4\) Coverage for Contraceptives](#)

The Illinois Insurance Code requires all individual and group insurance, including health maintenance organization (HMO) policies, issued after 1/1/17 to provide coverage for all prescription and over-the-counter (OTC) contraceptive drugs, devices, and other products approved by the FDA, excluding external condoms, with no deductible, coinsurance, copayment, or other cost-sharing requirement, excluding coverage of vasectomy to the extent such coverage would disqualify a high-deductible health plan from eligibility for a health savings account pursuant to the federal Internal Revenue Code, 26 U.S.C. 223. Plans must also cover, without any cost-sharing:

- Dispensing of a 12-month supply of hormonal contraception at one time
- Voluntary sterilization procedures
- Comprehensive contraceptive counseling, services, and patient education
- Follow-up services related to the drugs, devices, products, and procedures covered here, including, but not limited to, management of side effects, counseling to support continuing or switching a method, and device insertion and removal

This Act, at the time of passage, was the most comprehensive contraceptive coverage law in the country and is much stronger and far reaching than the contraceptive coverage requirement of the Affordable Care Act (ACA). However, limitations of the law mean that gaps in coverage persist. If the FDA has approved therapeutic equivalent versions of a contraceptive drug or device, a policy is not required to include all therapeutic equivalent versions in its formulary, but is required to include at least one version and cover without cost-sharing. If one's health care professional recommends a particular service or item (approved by the FDA) based on medical necessity, the plan or issuer must cover that service or item without cost sharing and the plan must defer to the determination of the health care professional. This limitation on the formulary, at minimum, creates an extra, often confusing, step for patients seeking their preferred contraceptive method, and, at worst, removes the autonomy of the patient to freely choose their preferred contraceptive method, granting the power instead to the insurer or health care professional. External condoms are explicitly excluded from coverage requirements outlined in the law and coverage without any cost-sharing for vasectomies is limited to certain plan types (to maintain compliance with federal tax laws regarding health savings accounts). Religious and moral exemptions to contraceptive coverage from employers are not explicitly addressed in the law, allowing for the federal regulations on this issue to prevail.

[\(745 ILCS 70/\) Health Care Right of Conscience Act](#)

This Act protects the right of conscience of all persons, individually or collectively, who refuse to obtain, receive or accept, or who are engaged in the delivery of, arrangement for, or payment of health care services and medical care and prohibits all forms of discrimination, disqualification, coercion, disability or imposition of liability on those that refuse. It also requires that patients receive timely access to information and medically appropriate care, and requires a physician or other health care personnel to provide emergency medical care.

The law was amended in 2016 to require religiously affiliated facilities to inform patients in writing about health care professionals “who they reasonably believe” offer procedures that the institutions will not perform. The amendment requires health care facilities to adopt written access to care and information protocols that are designed to ensure that conscience-based objections do not cause impairment of a patients' health and explain how such objections will be addressed in a timely manner to facilitate patient health care services. When a facility or individual chooses not to offer a procedure due to their conscience-based objections, then the patient must be provided the requested health care service by others in the facility or be notified that the health care will not be provided and be referred, transferred or given the appropriate information. This amendment was an important step toward protecting access to care, and a major victory for advocates, though it does not perfectly preserve access to care, as people may still find that they need to overcome hurdles caused by religious refusals.

[\(410 ILCS 70/\) Sexual Assault Survivors Emergency Treatment Act](#)

This Act requires every hospital or approved pediatric health care facility providing services to sexual assault survivors to develop a protocol that ensures that each survivor of sexual assault will receive medically and factually accurate and written and oral information about emergency contraception (EC); the indications and contraindications and risks associated with the use of EC; and a description of how and when survivors may be provided EC at no cost upon the written order of a physician licensed to practice medicine in all its branches, a licensed advanced practice registered nurse, or a licensed physician assistant.

This Act acknowledges that each year more than 32,000 presumed ciswomen become pregnant in the U.S. as the result of rape with approximately 50 percent of these pregnancies ending in abortion and that the provision of emergency contraception in a timely manner can significantly reduce the risk of pregnancy

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and the trauma of rape. The law mandates the hospitals and health care facilities provide information about emergency contraception, including how and when it may be provided, but doesn't require the actual provision of emergency contraception. While the development of written policies and provision of information is important, failure or refusal of facilities to provide or prescribe emergency contraception can increase the risk of pregnancy and further traumatize the survivor.

[\(750 ILCS 60/\) Illinois Domestic Violence Act of 1986 Article IV](#)

This section of the Act states that any person who is licensed, certified or otherwise authorized by the law of this State to administer health care in the ordinary course of business or practice of a profession shall offer to a person suspected to be a victim of abuse immediate and adequate information regarding services available to victims of abuse.

While this section directs health care professionals to provide survivors of domestic violence with information regarding services available, there is no requirement for routine screenings to determine if someone is a survivor of domestic violence to begin with, nor does it include any requirements for training of health care professionals and facilities to be able to screen and refer effectively.

[\(405 ILCS 5/\) Mental Health and Developmental Disabilities Code](#)

This code deals with how people with disabilities are treated in residential facilities, but it fails to acknowledge the importance of providing sexual and reproductive health education to people as they enter these facilities in order to protect against abuse and coercion. Disability rights advocates have highlighted the need for an amendment to guarantee that people admitted to a development disability facility have access to sexual and reproductive health education, resources, and treatment planning to support their right to sexual expression.

[\(Public Act 100-0538\) Abortion - Various](#)

This Act concerning abortion removes a provision prohibiting the non-contributory portion of a program of health-benefits from including the expenses of obtaining an abortion; removes a provision excluding abortions or induced miscarriages or premature births from the list of services provided under the State's medical assistance program; removes language prohibiting the Department of Human Services from making grants to nonprofit agencies and organizations that use such grants to refer or counsel for, or perform, abortions. The Act provides that it is the intention of the General Assembly to reasonably regulate abortion in conformance with the legal standards set forth in the decisions of the United States Supreme Court of January 22, 1973. Finally, the Act removes language concerning the General Assembly's declaration that the unborn child is a human being from the time of conception and is, therefore, a legal person for purposes of the unborn child's right to life.

The passage of this law, often referred to as HB40, was a massive victory for sexual and reproductive health and justice. The Act protects and expands abortion access by removing language prohibiting the state's Medicaid program from covering abortion care and explicitly affirms that any sexual and reproductive health care that is legal in Illinois shall be covered under the Medicaid program, which insures more than three million people. The expansion of abortion coverage in Medicaid is incredibly important, but also requires significant administrative effort to implement on the part of both the state agency and abortion providers. Unfortunately, the Director of the state agency in 2018 refused to take necessary steps to implement the law. Governor JB Pritzker, in January of 2019, issued an executive order requiring the state to take the steps necessary to fully implement and enforce this law.

(410 ILCS 210/) Consent by Minors to Medical Procedures Act

This Act allows young people under the age of 18 (minors) to consent to the performance of a health care service by a physician licensed to practice medicine in all its branches, a chiropractic physician, a licensed optometrist, a licensed advanced practice nurse, or a licensed physician assistant if they are married, a parent, pregnant, or have consent of their parent or legal guardian. Further, all young people between the ages of 12 and 17 can access a range of sexual and reproductive health services without parental consent or notification including testing and treatment for sexually transmitted infections (STIs), pregnancy testing, pregnancy options counseling, and contraceptive counseling.

While health care professionals are not required to involve parents, they are asked to make a reasonable effort to encourage the young person to consent to parental involvement in STI testing and treatment if they believe that the family involvement will not be detrimental to the progress and care of the young person. The purpose of ensuring confidential sexual and reproductive health services for young people is to keep them safe, build trust, and remove any family barriers to the care.

(325 ILCS 10/) Birth Control Services to Minors Act

This Act allows doctors licensed in Illinois to practice medicine in all of its branches to provide contraceptive services and information to any young person under the age of 18 who is married, a parent, pregnant, has the consent of their parent or legal guardian, would have a serious health hazard created for them if they did not receive these services, or is referred for such services by a physician, clergyman or a Planned Parenthood agency.

Unfortunately, lack of clarity in the language contributes to the inconsistent application. A “serious health hazard” is not defined and therefore left to the discretion of health care professionals in Illinois, when it is clear that an unintended pregnancy that is also mistimed and/or unwanted can be a serious health hazard for anyone, regardless of age. Fear of familial violence due to pregnancy is also a serious health hazard and should be included in these conversations.

(750 ILCS 70/) Parental Notice of Abortion Act of 1995

This Act concerning families states that no person shall knowingly perform an abortion on a young person under the age of 18 or a person deemed incompetent, unless the physician or their agent has given at least 48 hours notice to an adult family member of the pregnant person under the age of 18 or a person deemed incompetent of their intention to perform the abortion. The exceptions to notification are that the:

- Young person under the age of 18 or a person deemed incompetent is accompanied by a person entitled to notice
- Notice is waived in writing by a person who is entitled to notice
- Attending physician certifies in the young person’s medical record that a medical emergency exists and there is insufficient time to provide the required notice
- Young person under the age of 18 declares in writing that they are a victim of sexual abuse, neglect, or physical abuse by an adult family member
- Young person under the age of 18 receives a judicial waiver of notice

This Act requires that a young person under the age of 18 seeking abortion care notify an adult family member at least 48 hours prior to their procedure. This was challenged in the Illinois courts and was not implemented until 2013. A privately funded initiative, the Judicial Bypass Project of the ACLU of Illinois, provides support to those young people seeking abortion care that do not wish to notify their families. While notification is not consent, in many cases the effects of notification can be the same as requiring parental consent in that the parent could physically prevent the young person from getting the procedure. Young people under the age of 18 have already been granted the “mature minor” status with the full authority to consent to health care services if they are married, a parent, or pregnant in both the Consent by Minors to Medical Procedures Act and the Birth Control Services to Minors Act without any requirement of notification and anyone seeking an abortion by definition must be pregnant. Forced parental involvement laws are one example of abortion restrictions that reinforce shame and stigma for all abortions under the guise of safety

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when in reality confidentiality promotes safety and encourages people to get the health care they need without fear. Young people who feel safe involving their families will involve them, and most do.

[\(410 ILCS 315/2e\) HPV-related prevention](#)

This Act states that all students who are entering sixth grade and their parents or legal guardians must be provided with written information about the link between human papillomavirus (HPV) and cervical, vulvar, vaginal, penile, anal, and oropharyngeal cancers for all people and the availability of HPV vaccine so that they may be protected before being exposed to the virus. The CDC's Vaccines for Children (VFC) program includes the HPV vaccine, and can provide vaccines for children between the ages of nine and 18 who are covered by Medicaid, Alaskan-Native or Native American children, and some underinsured or uninsured children.

This statute increases HPV vaccination rates by ensuring parents and young people receive accurate information about the vaccine. Previously, this information was only provided to parents of students assigned female at birth.

[\(105 ILCS 5/27-9.1\) Sex Education](#)

This Act states that if a school elects to teach sexual and reproductive health education in grades six through 12, it must be comprehensive, medically accurate, age appropriate, replicate or substantially incorporate evidence-based programs, and include information on contraception for both pregnancy prevention and prevention of sexually transmitted infections (STIs). Course material and instruction shall:

- Teach honor and respect for monogamous heterosexual marriage
- Place substantial emphasis on both abstinence, including abstinence until marriage, and contraception for the prevention of pregnancy and STIs among youth
- Stress that abstinence is the ensured method of avoiding unintended pregnancy, STIs, and HIV/AIDS
- Include a discussion of the possible emotional and psychological consequences of preadolescent and adolescent sexual intercourse and the consequences of unwanted adolescent pregnancy
- Stress that STIs are serious possible hazards of sexual intercourse
- Provide statistics based on the latest medical information citing the failure and success rates of condoms in preventing HIV/AIDS and other STIs
- Advise young people of the laws pertaining to their financial responsibility to children born in and out of wedlock

This Act was an important victory for improving the quality of sexual and reproductive health education in schools across the state and led to non-legislative victories, including the adoption of a mandatory sexual and reproductive health education policy in Chicago Public Schools. However, it is not a mandate to teach sexual and reproductive health education, meaning that access to this information continues to be unavailable to students based on where they live and attend school. Further, stressing abstinence and monogamous heterosexual marriage and discussing sexual activity only in the context of consequences reinforces shame and stigma for young people and young parents, but especially for young people who have experienced sexual assault. Finally, this Act does not have strong reporting or monitoring requirements, which has made it difficult to assess implementation and compliance.

[Chicago Public School Sex Education Policy](#)

This Chicago Public School (CPS) policy mandates comprehensive sexual and reproductive health education for all schools within the district, including charter and community schools, with mandatory minutes of instruction for kindergarten through 12th grade, and provides a foundation of knowledge and skills related

to human development, relationships, decision-making, abstinence, medically recommended contraception and disease prevention. At each grade level, the instructional program teaches developmentally appropriate, medically accurate information that builds on the knowledge and skills that were taught in the previous grades. Each school is required to have two trained instructors implement and report on the lessons delivered.

The two trained instructors, selected by the principal, are educators already teaching other subjects and therefore might not have capacity or interest in teaching comprehensive sexual and reproductive health education. They also might not be fully comfortable with all of the course materials or be able to effectively advocate for the purpose and benefits of comprehensive sexual and reproductive health education with parents. Furthermore, the course materials do not explicitly contain information about the sexual and reproductive health care rights that young people have or how they can advocate for themselves with their families and health care professionals for the health care they need.

Federal Policy Analysis

Patient Protection and Affordable Care Act

The Affordable Care Act (ACA) increased contraceptive access in two significant ways. First, it expanded access to health insurance for tens of millions of Americans, especially through Medicaid expansion. Second, the preventive services requirement of the ACA requires that the vast majority of insurance plans, public or private, provide coverage of a wide range of contraceptive methods for any reason.

Overall, as a result of the ACA, the proportion of people who can become pregnant between the ages of 15 and 44 without health insurance fell from 20 percent (12.5 million) in 2013 to 12 percent (7.5 million) in 2017, as calculated by the Guttmacher Institute, using data from the U.S. Census Bureau's American Community Survey. There was also a 38 percent drop in the proportion of people who can become pregnant between the ages of 15 and 44 with incomes at or below the federal poverty level who were uninsured and a 22 percent increase in the proportion covered by Medicaid.

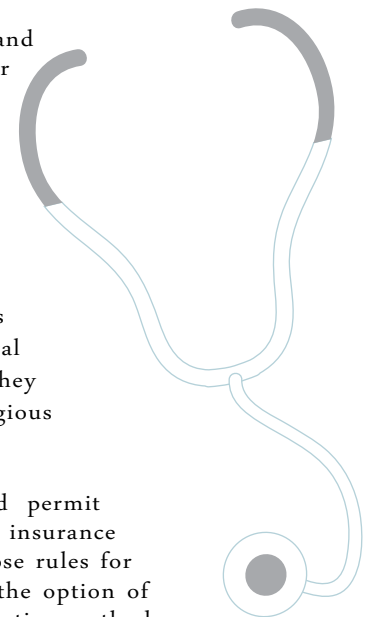
In spite of the existing challenges in meeting contraceptive need, regulatory and administrative changes to the ACA and family planning programs will further restrict access to contraceptive care nationwide. On November 7, 2018, two final rules were announced to allow for religious and moral exemptions to the ACA contraceptive coverage mandate:

- Religious exemptions for entities and individuals that have sincerely held religious beliefs against providing contraceptive services (or services that they consider to be abortifacients)
- Moral exemptions for nonprofit organizations, small and closely held businesses, as well as institutions of education, health insurance issuers serving exempt entities, and individuals that have non-religious moral convictions against providing contraceptive services (or services that they consider to be abortifacients) protections that are similar to the religious final rule's protections for religious organizations and businesses

The Obama Administration created rules for accommodation that would permit employers to object to offering contraception coverage, but require their insurance plans to pay for employees who wanted such coverage. While technically those rules for accommodation are still in place, they will now be completely voluntary at the option of the employer and give authority to the employer to choose which contraceptive methods they want to include or exclude.

Title X

The Title X National Family Planning Program, administered by the U.S. Department of Health and Human



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Services, Office of Population Affairs (OPA), is the only federal program dedicated solely to supporting the delivery of family planning and related preventive health care. The program is designed to provide contraceptive supplies and information to all who want and need them, with priority given to people from families with a low income. It is part of the Public Health Service Act that became law in 1970 to ensure that “no American woman should be denied access to family planning assistance because of her economic condition.” These crucial services include access to:

- Contraceptive education and counseling
- Contraceptive methods
- Breast and cervical cancer screening
- STI and HIV testing, referral, and prevention education
- Pregnancy testing and options counseling

The Trump Administration has also made changes to the regulations for the Title X program, made final in February 2019, that could seriously jeopardize care, resulting in the decline of comprehensive family planning clinics, services, and people getting the health care they need to achieve reproductive autonomy. This rule is being challenged in the courts and may not become effective.

The new rules for Title X would (24):

- Change the eligibility for funding from programs that offer comprehensive contraception services to those offering the rhythm method of contraception and abstinence, despite their lower rates of efficacy. The rule mandates counseling on “fertility awareness or natural family planning” (i.e., rhythm method) and “sexual risk reduction” (i.e., abstinence only)
- Eliminate the expectation that Title X organizations must comply with existing standards of quality family planning care written by HHS and CDC, including being able to provide clinical care
- Eliminate nondirective counseling on pregnancy options and prohibit abortion counseling and referrals
- Eliminate eligibility of funding for organizations providing abortions unless they are 100 percent physically and financially separate. The physical separation is likely to reduce the number of comprehensive family planning clinics, because the cost of maintaining two separate clinics will be prohibitive to many
- Require anyone with a positive pregnancy test to be referred to prenatal care, even if they do not want to continue the pregnancy
- Undermine the requirement of confidentiality for young people under the age of 18 seeking contraception and require documentation of why parents or guardians should not be involved

IV. LITERATURE REVIEW: UNINTENDED PREGNANCY, UNMET CONTRACEPTIVE NEED, AND CONTRACEPTIVE JUSTICE

Half of all unintended pregnancies—some 1.5 million annually—occur among people who use contraception; of these, nine in 10 result from inconsistent or incorrect method use, and only one in 10 from method failure (12). Guttmacher reported that 68 percent of people presumed to be ciswomen in the U.S. who are exposed to the potential for unintended pregnancy practice contraception consistently and correctly, therefore accounting for only five percent of unintended pregnancies (13). The remaining 32 percent of presumed ciswomen inconsistently using contraception, having long gaps in usage, or not using a method in the past year account for 95 percent of all unintended pregnancies. Unintended pregnancy is greatest for those not using any contraception or those using it inconsistently; therefore, the greatest impact on reducing unintended pregnancy that is mistimed or unwanted would come from supporting the 54 percent of people who are not using any method and the 41 percent of people using a method inconsistently.

According to the World Health Organization (WHO), family planning, “reduces the need for abortion, reinforces people’s rights to determine the number and spacing of their children, and prevents the deaths of mothers and children” (2). The primary reason people who can become pregnant in the U.S. give for using contraceptives are social and economic (3). One group of researchers asked more than 2,000 presumed ciswomen who were receiving services from a family planning clinic about their motivation for seeking contraceptive services. The responses that the majority of people gave were that access to contraception had “enabled them to take better care of themselves or their families, support themselves financially, complete their education, or get or keep a job” (3). Regardless of the reason, 99 percent of sexually active presumed ciswomen use contraception at some point in their lifetime (4).

It is important to note that not all unintended pregnancies are unwanted. Some are mistimed. Sometimes people knew they did not want to get pregnant and sometimes they were not sure. Relationships, health, employment, life goals, etc. can affect our intentions and desires, and can change over time. Sexual and reproductive health education and information can help people figure that out for themselves and informs them of the tools and resources that exist. Affirming and inclusive sexual and reproductive health care can help people access those tools and resources as their family planning desires and intentions become clearer or change across their lifespan. Our goal is to help people who are interested in contraception understand it, access it, and manage it in ways that are acceptable to them. To that end, our overall measure of success is a reduction in unmet contraceptive need.

Unmet contraceptive need has been traditionally understood as the gap between someone’s reproductive or pregnancy intention and their contraceptive behavior and is not currently tracked at a population level, though it is often cited as a critical public health indicator. Because ambivalence regarding reproductive or pregnancy intention is common for many people across many identities and having a solid pregnancy intention that you could act upon with the assistance of family planning services and contraception is a relatively new concept, we are proposing a more accurate definition of unmet contraceptive need as being the gap between someone’s contraceptive desires and their contraceptive behavior.

The effectiveness of any contraceptive method is directly impacted by how it is used. Typical use of contraception indeed differs from perfect use and can vary from person to person. Typical use is influenced by how someone understands the instructions, uses the method, and handles any problem that might come up. The most commonly used contraceptive methods in the United States are: oral contraceptive pills, tubal ligation, external condoms, and long-acting reversible contraception (LARC) (10). Perfect use of combination pills, progestin-only pills, the patch, and the ring are as effective as LARC with less than one percent chance of pregnancy. However, typical use of pills, patches, and rings can reduce their efficacy and increase the chance of pregnancy to nine percent (11). Typical use of these methods accounts for inconsistent use, including missing doses or pausing use, and switching a method without taking back-up precautions to prevent pregnancy. The efficacy of LARC methods barely decrease, if at all, with typical use, as they are

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long-acting once inserted and cannot be used inconsistently or discontinued without health care professional involvement. This can be a very helpful feature for people who are satisfied with the method and have no adverse side effects or change in pregnancy desires, but even so, LARC is not a permanent method and will need to be removed at some point.

The Contraceptive Justice literature review seeks to understand the factors that influence contraceptive access and use from the perspective of people and communities. In reviewing the existing literature on contraceptive access, this review assesses factors that act as facilitators and barriers to contraception for a wide range of patients, focusing on people from communities that are marginalized. This review employs the essential elements of the right to health as defined by the World Health Organization as a framework for this analysis. As such, findings are reported along the following dimensions: information access, economic access, physical access, non-discrimination, violence, and acceptability.

Information Access

Information access is facilitated by comprehensive sexual and reproductive health education in schools and up-to-date materials on all contraceptive methods that are medically accurate, age and developmentally appropriate, and take into account people's primary language and literacy levels.

The alarming reality is that only 24 states and the District of Columbia mandate sexual and reproductive health education and Illinois is not one of them. The law in Illinois states that if a school elects to teach sexual and reproductive health education in grades six through 12, it must be comprehensive, medically accurate, age-appropriate, replicate or substantially incorporate evidence-based programs, and include information on contraception for both pregnancy prevention and prevention of sexually transmitted infections (STIs).

Comprehensive and medically accurate information and education on sexual and reproductive health directly influences people's understanding of their bodies and how they can take care of them. It also ensures that people are not uninformed or misinformed about pregnancy, pregnancy prevention, and STI prevention, and prevents myths from being perpetuated, some of which we learn from our families and friends. A 2018 survey conducted by Healthline and Sexuality Information and Education Council of the U.S. (SIECUS), highlighted that only 33 percent of people between the ages of 18 and 29 reported having some kind of sexual and reproductive health education, with no data on if the information they received was comprehensive or medically accurate (5). The survey also showed that 25 percent of respondents believed that emergency contraception can cause an abortion, 34 percent believed taking emergency contraception can cause infertility, and a staggering 93 percent were unable to answer correctly how many days after sexual intercourse emergency contraception is effective.

The Society for Adolescent Health and Medicine (SAHM) published an updated position paper, as well as a comprehensive literature review on abstinence-only-until-marriage (AOUM) programs and their negative impact (6). John Santelli, MD, MPH, lead author of both publications, said, "The science is clear. Abstinence-only-until-marriage programs are not only ineffective in promoting healthy behaviors, they may also be harmful to many different groups of youth. As a nation, we must do better to ensure young people are safe and healthy." The research review found that AOUM programs (now sometimes referred to as Sexual Risk Avoidance programs):

- are not effective in delaying initiation of sexual intercourse or changing other health behaviors associated with reducing unintended pregnancy and STIs, such as increasing the use of contraception among sexually active youth
- may have negative impact on several groups of young people including LGBTQIA+ youth, sexually

- active youth, youth with a history of sexual abuse, and parenting youth
- reinforce damaging gender stereotypes
- censor lifesaving information about the prevention of pregnancy, HIV, and other STIs
- exclude accurate information about contraception
- undermine public health goals in the U.S. and globally

Promotion of these policies by the U.S. government has harmed other public health efforts, including family planning programs and HIV prevention abroad.

Lack of information, including misinformation, about sex, reproduction, and contraception contribute to the rate of unintended pregnancies even for people who are using contraception. For example, the efficacy of external condoms at preventing pregnancy goes from 98 percent effective with perfect use to 82 percent effective with typical use. This decline can be mostly attributed to a lack of knowledge on how to achieve perfect use. One study compared the correct usage of both internal and external condoms by people who received a condom demonstration only, a condom demonstration with materials and time to practice, and no session at all (7). As expected, the greatest change from baseline measures on condom use skills occurred with the demonstration and practice group, importantly, the group that received a condom demonstration only and the group that received no information at all did not have a statistical difference in correct usage. Youth who have had sexual and reproductive health education are more likely to use condoms the first time they have sexual intercourse, and more likely to use them consistently, than are youth who have not had formal sexual and reproductive health education (8). Similarly, another study found that, among college students, extensive practice was superior to demonstration and limited practice in teaching external condom use skills (9).

For young Latinx people who can become pregnant, there can be poor communication with health care professionals that contributes to lack of knowledge about and consistent use of contraception, dissatisfaction with contraceptive care because of language barriers and perceived cultural insensitivity (14, 15, 16, 17, 18). Lack of linguistically affirming sexual and reproductive health education and services remain a consistent barrier for those whose primary language is not English. Interpretation services are not always available or affordable to people, with many families relying on other family members or children to interpret. However, concerns around privacy and confidentiality of sexual and reproductive health issues can limit the family members that are safe, able, and comfortable to provide interpretation. It is important to note that inconsistent use is not always due to the fault or desire of the person. Lack of economic and physical access can make it difficult to use contraception consistently.

Economic Access

Economic access to contraception is facilitated by health insurance, including Medicaid, as well as publicly funded contraceptive services, like Title X. The Patient Protection and Affordable Care Act (ACA) advanced Reproductive Justice by prohibiting sex discrimination in health care and insurance, and providing a long-awaited expansion of health insurance and mandated coverage for contraceptives. Overall, the proportion of people who can become pregnant between the ages of 15 and 44 who were uninsured dropped by 41 percent between 2013 and 2017; the first four years of the ACA's major insurance expansions (19). There was also a 38 percent drop in the proportion of people who can become pregnant between the ages of 15 and 44 with incomes at or below the federal poverty level who were uninsured and a 22 percent increase in the proportion covered by Medicaid. In Illinois, as in most states, most people get their insurance via an employer sponsored plan (60% of people who can become pregnant between the ages of 15 and 49); Medicaid covers a smaller proportion of people who can get pregnant (19%), and 10 percent of people who can become pregnant are uninsured.

Despite the advances in insurance coverage made by the ACA, people of reproductive age who can get pregnant and live in poverty were still almost twice as likely to be uninsured in 2017 as people of reproductive age who can get pregnant overall (23). Other disparities in coverage also persist. Latinx people who can become pregnant between the ages of 15 and 44 were far more likely than white, Black, or Asian people of reproductive age who can get pregnant of the same age to be uninsured in 2017. Similarly, immigrant people of reproductive age who can get pregnant of the same age who are not citizens had more than three times

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the uninsured rate of people of reproductive age who can get pregnant who were born in the U.S. That gap grew wider between 2013 and 2017, likely because many immigrants are barred from eligibility for subsidized private coverage under the ACA and for Medicaid coverage. In fact, nearly half of noncitizen immigrant people who can become pregnant between the ages of 15 and 44 living at or below the poverty level remained uninsured in 2017. The disparities in coverage will widen if the proposed change to rules regarding the Public Charge Ground of Inadmissibility are finalized to include Medicaid and Medicare.

In 2014, 38.4 million people who can become pregnant in the U.S. needed contraceptive services and more than half of them, 20.2 million, were between the ages of 13 and 44 and in need of publicly funded contraceptive services (20). The Guttmacher Institute defines people in need of publicly funded contraceptive services as those who a) are younger than 20 or have a low-income (i.e., have a family income less than 250 percent of the federal poverty level) and b) are sexually active and able to become pregnant but do not want to become pregnant (21). In 2015, 6.2 million people who can become pregnant received publicly funded contraceptive services with 61 percent of those (or 3.8 million people who can become pregnant) receiving services from Title X programs. The remaining 2.4 million people who can become pregnant received contraceptive services from private doctors through Medicaid. With 20.2 million people who can become pregnant between the ages of 13 and 44 in need of publicly funded contraceptive services in 2014, and only 6.2 million people who can become pregnant actually receiving these services in 2015, there remain 14 million people who can become pregnant in the U.S. who did not receive the contraceptive care that they needed.

Publicly funded family planning programs similarly struggled to meet demand in Illinois. In 2014, 1.5 million presumed ciswomen in Illinois needed contraceptive services with 50 percent of that total (or 772,510) being ciswomen between the ages of 13 and 44 in need of publicly funded contraceptive services (22). Publicly supported family planning centers in Illinois provided services to 154,660 people who can become pregnant in 2014, meaning they only met 20 percent of the actual need. Across the United States, such centers met 26 percent of the need. Furthermore, the amount of federal funding Illinois received for Title X decreased by \$1,780,456, resulting in 6,726 fewer (6%) patients served from FY 2010 to FY 2016.

Regardless, publicly funded family planning centers in Illinois helped avert 37,400 unintended pregnancies in 2014, which could have resulted in 18,200 unplanned births and 13,500 abortions. In Illinois, 94 clinics received support from Title X in 2018 (22). They include 30 federally qualified health centers, 25 local health departments, 16 Planned Parenthood clinics, 10 Aunt Martha's health centers, six school-based health centers, three hospitals, two family planning health centers, and two other service sites. Centers supported by Title X provided contraceptive care to 86,830 people who can become pregnant in Illinois in 2014, making up 56 percent of all publicly funded contraceptive services in Illinois. In the absence of publicly funded family planning services, the number of unintended pregnancies and abortions in Illinois would be 29 percent higher (22).

Physical Access

Physical access takes into account location and scheduling and looks at transportation, hours of operation, as well as modifications to facilities to accommodate people with physical disabilities.

Currently more than 19 million people who can get pregnant live in contraceptive deserts, defined as counties where the number of public clinics offering the full range of methods is not sufficient to meet the needs of the county's number of people who can become pregnant and are eligible for publicly funded contraception; at least one clinic for every 1,000 person who can become pregnant and is in need of publicly funded

contraception. Within that group, more than three million people who can become pregnant live in counties without a single public clinic that offers a full range of contraceptive methods (25). In total, there are 105 counties in Illinois and 14 of those counties do not have a single publicly funded site offering contraception. Another six counties solely rely on Planned Parenthood for full-service family planning. Additionally, nearly three in 10 (29.5%) hospital beds in Illinois are bound by the limitations imposed by ethical and religious directives that prohibit providing, and many times even discussing, contraception, sterilization, and abortion even when the life or health of the pregnant person is at risk. Some people might not even know that their medical care will be limited until they are in a situation needing that care. Financial resources and access to transportation can allow for some people to seek out medical care elsewhere, but for many people that is not an option. Rural towns have fewer clinics offering walk-in appointments and availability on the weekends compared to urban areas and fewer health care professionals trained to provide IUDs (26). Nonmetropolitan hospitals and freestanding clinics were more likely to have parental notification policies in place and many followed multiple procedures to obtain consent (27).

People with disabilities can experience unique barriers to physical access related to transportation and health care facilities, and economic access related to income and employment, as well as barriers to information due to the lack of appropriate sexual and reproductive health education. In regard to understanding the physical access barriers that people with disabilities face, the literature is extremely limited. Studies reviewed were intentionally conducted in places that did not have physical impediments to participation for people with disabilities and therefore cannot show the impact of inaccessible clinics and health care facilities on the unmet contraceptive need for people with disabilities.

Non-discrimination

Non-discrimination allows equitable access to health care facilities, goods, and services to everyone regardless of race, sex, gender, sexual orientation, age, ability, and immigration status.

Discrimination poses a serious threat to sexual and reproductive health for many people and can show up as both explicit and implicit bias. Explicit is conscious bias while implicit bias is subconscious. Everyone has natural implicit and explicit cognitive bias as it is a part of being human and shapes our actions and attitudes. Given that implicit biases are present in all people, it is important that we all take intentional actions to acknowledge, address, eliminate, or counter bias. Explicit bias is often prevented by policies related to non-discrimination.

The Illinois Department of Public Health released its first Maternal Morbidity and Mortality Report in October 2018, highlighting that Black people who can become pregnant are six times as likely to die of a pregnancy-related condition as white people who can become pregnant and are three times as likely to die within a year of pregnancy as people who can become pregnant of any other race/ethnicity in Illinois (28). Medical causes of maternal mortality, such as hemorrhage, infection, cardiac conditions, or cancer, accounted for 75 percent of the maternal deaths for Black people who can become pregnant, 68 percent for Latinx people who can become pregnant, but only 42 percent for white people who can become pregnant.

According to the 2011 Pregnancy Risk Assessment Monitoring System (PRAMS) report, “about 42 percent of Illinois births result from unintended pregnancies. Place of residence, race/ethnicity, and age group all significantly affected the likelihood that a (presumed cis)woman’s recent birth resulted from an unintended pregnancy. Over two-thirds (67.5%) of births to Black (presumed cis)women resulted from unintended pregnancies, compared to about half of births to Hispanic (presumed cis)women, and one-third of births to White (presumed cis)women. Young mothers (<25 years old) were more than twice as likely to have a birth resulting from an unintended pregnancy than older (presumed cis)women.” (29). In 2011, the Guttmacher Institute released data that showed that even when taking income into account, unintended pregnancy rates are consistently higher for people of color who can become pregnant, but especially so for Black people who can become pregnant in the U.S. (30). Black people who can become pregnant with incomes ranging from 100 percent to 199 percent of the federal poverty level have an unintended pregnancy rate of 93 per 1,000 people who can become pregnant, while white people who can become pregnant experience 51 unintended pregnancies per 1,000 people who can become pregnant. For Black people who can become pregnant with

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incomes greater than 200 percent of the federal poverty level, the rate becomes 38 per 1,000 while the rate for white people who can become pregnant drops to 18 per 1,000.

A deeper look reveals disparities across health and health care related to race and ethnicity even when controlling for insurance status, income, age, and severity of conditions. The Institute of Medicine Committee on Understanding and Eliminating Racial and Ethnic Disparities in Health Care conducted a study assessing the potential sources of racial and ethnic disparities in care that are not otherwise attributable to access barriers at the request of Congress and published the book *Unequal Treatment: Confronting Racial and Ethnic Disparities in Health Care* (31). Disparities are found to arise from an historic and social context in which people of color received inferior health care, reflecting broader socioeconomic disadvantage and societal discrimination. When seen by a health care professional, people of color typically have been treated in segregated health care systems that today remain largely segmented by socioeconomic class. When differences in treatment attributable to insurance, access to care, health status, and other factors are eliminated, however, racial and ethnic health care disparities still remain. Factors related to people's needs and preferences, as well as the characteristics of health systems and the legal and regulatory contexts in which care is delivered, may explain some of the racial and ethnic differences in care that remain once access-related factors are controlled.

Some overarching themes from the patient annotated bibliography regarding race for Latinx and Black people, especially those in urban environments, highlight perceived cultural insensitivity and racial discrimination in contraceptive counseling and poor communication where they felt their preferred contraceptive choice was ignored for the health care professional's preferred method.

One central worry has been the role of bias in shaping contraceptive recommendations, a concern upheld in a trial documenting that health care professionals were in fact more likely to recommend intrauterine devices (IUDs) to people of color who can become pregnant with low income than white people who can become pregnant with low income. In the editorial "Beyond Coercion: Let Us Grapple With Bias", Melissa L. Gilliam, MD, MPH states, "Holding biases is natural. From an early age, to recognize friend from foe and identify potential threats, we learn to recognize patterns. Similarly, being a health care professional depends on recognizing patterns. Demographic, physical, and cultural clues help us make diagnoses, recognize distress, and tailor the treatment plan. Pattern recognition can also morph into preference. As a society, we privilege specific attributes pertaining to skin color, gender, age, religion, hair color, sexual orientation, and sexual identity. Possessing certain attributes can result in a positive bias or privilege. There is also negative bias that manifests as stereotype, prejudice, and even hatred (for others or even oneself). Although these biases often go unrecognized, they are perpetuated by people and also by systems, contributing to disparities in access to quality schools, safe neighborhoods, quality food, good transportation, and jobs. Similarly, societal biases affect how we provide medical care and, within that, family planning care." (32).

The vast majority of health care professionals are drawn to their disciplines out of feelings of compassion and a strong desire to heal. Data on the persistence of racial and ethnic discrimination in other sectors of American life are important, however, because they are likely to affect the clinical encounter and process of health care delivery in at least three ways:

- Experiences of discrimination, whether real or perceived, are experiences that people of color and people with marginalized identities are likely to bring to the clinical encounter, and are thereby likely to shape their expectations, attitudes, and behaviors toward health care professionals and health systems
- People of color and people with marginalized identities encountering health systems are likely to interact with many individuals in addition to health care professionals, such as administrative and clerical staff, who may be expected to mirror social attitudes and trends regarding race and ethnicity
- Health care professionals, like all other individuals, are likely influenced in their racial and ethnic attitudes by broader social trends

An essential component to building trust between the health care professional and person seeking care is the building of trust between health systems and communities that have been historically marginalized. This literature review shows that people's understanding and fear of certain historical injustices directly impact

the methods of contraception they feel are safe for them and even if they are willing to seek sexual and reproductive health care at all. This is where Reproductive Justice organizers can and have been building power by encouraging communities to take charge of their sexual and reproductive health care, and can continue to partner with reproductive health care professionals to build trust between communities and health care systems.

Violence

Being able to learn in inclusive and affirming spaces free of shame and stigma helps people take better care of themselves. It also allows for safety when discussing issues related to fear and violence. For example, youth leaders from the Illinois Caucus for Adolescent Health (ICAH), who focus on sexual health, rights, and identities in their organizing and educating work, consistently mentioned violence as a prevailing concern in their life. Violence inflicted by institutions and systems down to intimate partner and sexual violence, can impact everyone, but especially those with identities that experience multiple layers of intersecting oppression. It can feel incomplete to talk about bodies and health without acknowledging the harm and risk people have to navigate on a daily basis. It is important to clarify that we do not refer to people as “high-risk”, rather we acknowledge that they have to move through more situations that involve higher risks to their health and wellbeing.

For example, people experiencing domestic violence (DV), also referred to as intimate partner violence (IPV) and dating violence, are disproportionately exposed to the potential for unintended pregnancy and are less likely to use contraception with their partner at no fault of their own.

One survey of people who can become pregnant between the ages of 16 and 29 seeking family planning services showed that 53 percent reported physical and sexual violence from their partner, 19 percent reported experiencing pregnancy coercion, and 15 percent reported sabotage of their contraceptive method by their partner (33). Dating and domestic violence among sexually active high school students who can become pregnant was also related to increased exposure to unintended pregnancy (34). Sexual violence, reproductive coercion, and pregnancy coercion are components of the violence a person can experience that can lead to an unintended pregnancy. According to the American College of Obstetricians and Gynecologists (ACOG), reproductive coercion is a form of domestic violence where behavior concerning reproductive health is used to maintain power, control, and domination within a relationship. Behavior concerning reproductive health includes pregnancy pressure, pregnancy coercion, sabotage of contraception, and interference in receiving reproductive health care (53).

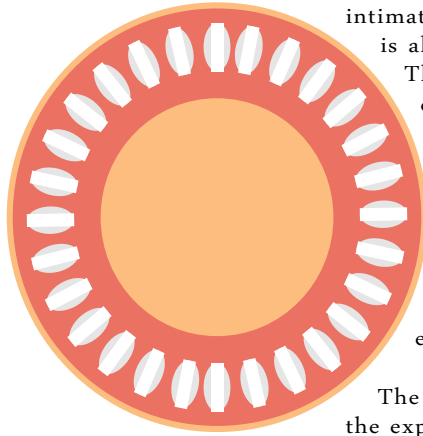
Additionally, pregnancy is not a protective factor against DV. People are at an increased risk of experiencing DV during pregnancy and/or the postpartum period, as well as an increase in severity of DV if abuse already existed. Homicide has been reported as a leading cause of maternal mortality, with the majority perpetrated by current or former intimate partners. Experiencing DV during pregnancy has also been associated with poor pregnancy weight gain, infection, anemia, tobacco use, stillbirth, pelvic fracture, placental abruption, fetal injury, preterm delivery, and low birth weight. People who experience DV around pregnancy are less likely to use contraception postpartum, even with prenatal contraceptive counseling, compared to those who do not experience DV (35).

People experiencing DV that have children feel that it is harder to leave because of concerns, pressures, and desires related to keeping their family together, issues of child custody and child support, and fear of stalking, retaliation, and the escalation of abuse. Harming and threatening to harm children is also an abusive tactic used to impose power and control and ensure obedience out of fear. In this way contraception can return bodily autonomy and facilitate being able to leave an abusive relationship. Sexual and reproductive health education that includes sexual violence prevention, such as information about healthy relationships and consent, and contraception, can reduce the impact of DV. Health care professionals can also reduce the impact of DV by screening their patients and discussing contraception, including emergency contraception, as a safety-planning tool.

The Centers for Disease Control (CDC) reports that more than one in three presumed ciswomen (35.6%)

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in the U.S. report having experienced rape, physical violence, and/or stalking by an intimate partner in their lifetime and one in four of those presumed ciswomen is also experiencing reproductive coercion (54).

That amounts to over half a million people experiencing reproductive coercion and DV just in Illinois. Since we do not know who is experiencing DV, we must be trauma informed and responsive in our conversations about contraception. Understanding whether or not a method needs to not be dependent on a partner, undetectable, and not affect menstruation can also contribute to more effective contraceptive counseling that can meet a person's contraceptive need, increase safety, and support their bodily autonomy. Having power can be described as having influence over the circumstances in your life and, in this way, contraception can be empowering for everyone, but especially those experiencing DV.

The reality of trauma is that it rarely occurs in isolation. Complex trauma, or the experience of multiple forms of trauma, has been documented by the CDC's Adverse Childhood Experiences (ACE) study as having negative physical and mental health outcomes. Some of the adverse childhood experiences that this study investigated are directly related to what children themselves experience, like abuse and neglect, while others are related to the household, such as witnessing DV. About two thirds of all adults in the U.S. have experienced at least one ACE of the 10 considered in the 1998 study and an ACE score of six or more can shorten an individual's lifespan by as much as 20 years. Another study found that people who can become pregnant who experienced four or more types of ACEs were 1.5 times more likely to have an unintended first pregnancy during adulthood than people who can become pregnant who did not experience any ACEs (36). In Illinois, 59 percent of adults reported at least one ACE and 14.2 percent reported four or more, with the highest rates among people who can become pregnant and Black and Latinx communities (37).

While research has provided some population specific insight, most people have more than one identity that can impact their access and experience. Kimberlé Crenshaw, a leading scholar of critical race theory, coined the term "intersectionality" in 1989 to describe how many of the experiences that women of color and Black women in particular face cannot be understood by analyzing the impact of gender and race separately (38). This is because the ways in which sexism and racism intersect have created barriers that are unique to Black women and women of color and, therefore, can only be fully understood with an intersectional analysis of oppression as opposed to a singular analysis. Crenshaw conducted research on how women of color generally and Black women, specifically, who were experiencing DV engaged with the justice system and social services. She concluded that not only do Black women and women of color experience sexism and gender-based violence differently than white women, but that both feminist and antiracist politics have, paradoxically, often helped to marginalize the issue of violence against Black women and women of color. For example, the desire to involve law enforcement in a DV situation is complicated for Black women due to fears of harm on the Black community as a whole and on themselves by law enforcement and not wanting to increase incarceration of Black people. Another example involving a 2017 survey showed that 78 percent of DV advocates reported that immigrant survivors of DV expressed concerns about contacting police and 62 percent of advocates observed an increase in the number of immigration-related questions that their agencies were receiving from immigrant survivors (39). Programs that put substantial emphasis on legal remedies to DV not only do not work for everyone, but also have the potential to expose someone to further harm. It is imperative to be responsive to concerns like these and use an intersectional analysis to go beyond good intentions and understand their impact.

Acceptability

Health care facilities, goods, services, and programs must respect medical ethics, respect the culture of individuals and their communities, and be sensitive to gender and lifecycle requirements. For contraception and sexuality, acceptability is an incredibly influential factor in use and continuation of a contraceptive method.

Sexual acceptability, or how methods influence a person's sexual experiences, can influence family planning preferences and practices. As discussed earlier, unmet contraceptive need is the gap between someone's contraceptive desires and contraceptive behavior and contributes to unintended pregnancies that are mistimed or unwanted. Unintended pregnancy is greatest for those not using any contraception or those using it inconsistently; therefore, the greatest impact on reducing unintended pregnancies that are mistimed or unwanted would come from reducing unmet contraceptive need by supporting the 54 percent of people not using any method and the 41 percent of people using a method inconsistently. High rates of contraceptive dissatisfaction, switching, and discontinuation demand new approaches to contraceptive acceptability and promotion.

This literature review revealed that side effects are a huge factor in whether or not someone used contraception at all or discontinues it for both adults and young people across identities. While it can be difficult to predict which side effects will impact someone enough to reconsider the method, helping people understand how to manage expected side effects and identify adverse side effects that require immediate care can alleviate concerns and facilitate contraceptive use and continuation. Concerns regarding side effects make up one aspect of the sexual acceptability of contraception, or how methods influence the user's sexual experiences, which can in turn influence preferences and practices. Aspects include macro factors (gender, social inequity, culture, and structure), relationship factors (vicarious experience and preferences of partner), and individual factors (sexual functioning, sexual preferences, such as spontaneity, pleasure, and the sexual aspects of side effects, like bleeding, mood changes, sexual identity, and pregnancy intentions). Currently, there are roughly 255 contraceptive drugs and devices approved by the FDA. While the large variety of methods could feel daunting to go through and understand on your own, contraceptive counseling that is comprehensive and person-centered supports people in finding a method that is best for them.

A small but growing body of work links pregnancy intentions to both sexuality and contraceptive behavior. People who can become pregnant that have clear desires to avoid pregnancy are likely to benefit from methods that help them feel secure about preventing conception. However, many people who can become pregnant are unclear or ambivalent about their pregnancy intentions, and some may feel happy about an unintended pregnancy, even if they were not trying to have a child (40). The number one reason people who became pregnant in Illinois gave for not using contraception even though they were not necessarily trying to get pregnant was that they would not mind if they got pregnant (41). In general, people who can become pregnant with ambivalent attitudes toward pregnancy have been found to use contraceptives less continuously and less effectively than those with a clearly defined, firm motivation to avoid pregnancy (42, 43, 44). The relationship between attitudes regarding contraception and pregnancy prevention for people who can become pregnant and their contraceptive behavior has also been investigated, and several theoretical models have been developed to explain these associations (45, 46, 47, 48). In addition, some empirical studies have addressed these issues. They typically measure the strength of the motivation to avoid pregnancy for people who can become pregnant—such as their reaction to the hypothetical situation of discovering they were pregnant (49, 50), their agreement with statements suggesting a fatalistic attitude toward becoming pregnant (42), whether and when they desire to have a child, and their attitudes toward conception with a specific partner (51).

Sometimes the reasons why people do not want to become pregnant and do not use contraception are ideological and experiential, stemming from beliefs and experiences they have had or are exposed to regarding sex, pregnancy, relationships, religion, and morality. A consistent theme from this literature review is that many people across practically every identity rely on, or are at least influenced by, vicarious experience to learn and make decisions about contraception. Being able to learn from people you trust and feel comfortable with are the basis of our support systems and can be the difference between learning about contraception and receiving the care that you want and not knowing what your options are or where to even start. For young people especially, having parents or family that make an effort to talk about bodies, healthy relationships, sex, and parenting facilitates getting and continuing the health care they need. We also know that not every family is safe or has the same beliefs, and that some young people choose to access care without family involvement because their family might prevent them from seeking care. Young people in Illinois between the ages of 12 and 17 have the right to consent to sexual and reproductive health services without any familial involvement, with some restrictions discussed in detail in the policy assessment, as a way to protect young people and encourage them to seek care.

V. FOCUS GROUPS

REGARDING CONTRACEPTIVE ACCESS AT THE INDIVIDUAL AND COMMUNITY LEVEL

In spring and winter of 2018, EverThrive IL conducted 10 focus groups across Illinois to learn about community beliefs, attitudes, and experiences accessing contraception. Participants offered feedback on their experiences with sexual and reproductive health education, family planning, health care professionals, and more. This report summarizes the feedback and insights from these focus group participants, framed through 12 recommendations:

Clinical Health Care Professionals

1. Give all people the full range of contraceptive options
2. Communicate clearly and with respect
3. Honor a person's contraceptive choice
4. Acknowledge and respect the range of a person's needs, including side effects
5. Partner with people to create a reproductive life plan
6. Ensure that non-clinical health care professionals are also respectful and person-centered

Sexual and Reproductive Health Education

7. All schools should have sexual and reproductive health education
8. Provide a youth-friendly and participatory space for conversation
9. Include conversations about sexual orientation and gender identity
10. Include conversations about healthy relationships

Family and Communities

11. Acknowledge and leverage peer relationships and other support systems
12. Include partners in conversations about contraception

This report serves as an initial foray into understanding the lived experiences of community members in relation to contraception and sexual and reproductive health. These recommendations have been woven into the comprehensive list of recommendations supporting people and communities in Section II and will inform the work of EverThrive IL and our partners as we work to achieve Contraceptive Justice across the state.

Methods and Demographics

EverThrive IL hosted 10 focus group conversations with a total of 74 participants. Two staff facilitated the focus groups using a conversation guide included here and staff also reviewed definitions and contraceptive methods to ensure a shared understanding and language. Focus group participants were paid a small stipend for their participation, EverThrive IL also provided food, compensation for transportation, and childcare. All participants signed confidentiality and non-disclosure statements.

- 56 (76%) participants were from Chicago, three (4%) were from the western suburbs of Chicago, five (7%) were from Rockford, two (3%) were from southern Illinois, three (4%) were from other Illinois suburbs, one (1%) was homeless, and three (4%) did not share their region
- 34 (46%) identified as ciswomen, two (3%) identified as cismen, eight (11%) identified as nonbinary/

gender fluid, two (3%) identified as transgender, one (1%) identified as unsure, and 27 (36%) did not share

- 19 (26%) participants identified as Black or African-American, 31 (42%) identified as Hispanic/Latinx, 17 (23%) identified as White or Caucasian, one identified as Native American (1%), four identified as multi-racial (5%), one identified as other (1%), and one (1%) did not share
- 19 (26%) were between the ages of 18 and 24, eight (11%) were between the ages of 25 and 29 age range, 10 (11%) were between the ages of 30 and 34, 11 (15%) were between the ages of 35 and 39, nine (12%) were between the ages of 40 and 44, three (4%) were between the ages of 45 and 49, seven (9%) were between the ages of 50 and 54, three (4%) were between the ages of 55 and 59, one (1%) was between the age of 60 and 64, and three people (4%) did not identify their age
- 45 (61%) had income below \$15,000/year, 18 (24%) had income between \$15,000 and \$30,000/year, four (9%) had income above \$30,000/year, and seven (9.45%) did not share their income
- 36 (49%) had health insurance, 34 (46%) were not insured, two (3%) were unsure of their insurance status, and two (3%) did not share their insurance status
- Three (4.05%) had previously been incarcerated, although incarceration history was not collected for 57 (77%) participants

These demographic indicators demonstrate the geographic, racial and ethnic, and age diversity represented in these focus groups. Despite the diversity represented across focus group participants, there are some gaps in representation and geographic limitations. All focus group participants had low-income which shed light on how medically underserved communities access contraception.

Clinical Health Care Professionals

1. Give all people the full range of contraceptive options

Some focus group participants shared that they did not receive comprehensive contraceptive counseling from health care professionals. Facilitators began each focus group by reviewing the formal names of contraceptive methods with participants. Participants were shocked to see the variety of methods and immediately shared that they did not receive this information from their health care professional(s). Most reported that providers only recommended between three and five contraceptive options, and that these were usually condoms, oral contraceptives, and the Depo Provera shot. One woman shared that her doctor did not provide any space for discussion regarding contraceptive options following the birth of her child: “After I had my baby, the doctor asked what birth control I was using and that’s it! I was never asked, did I like it? Did I want to explore other options? Nothing!” Another woman expressed how her options were restricted by stating that she was not given the option to use a long-acting reversible contraceptive method (LARC) until after she had given birth.

These experiences contrast starkly to another mother’s positive experience. She was educated on interconception health and all of her contraceptive options. She felt comfortable trying different contraceptive methods with the support of her doctor until she found the method that was best for her. This ultimately led to her “feeling in control of my body.” This example highlights how positive relationships with health care professionals can empower people.

2. Communicate clearly and with respect

Participants also emphasized the need for health care professionals to speak clearly and with respect when interacting with patients. Many reported feeling judged, dismissed, and confused, especially when their health care professionals used statistics and medical terms that they didn’t understand. One mother, who is in a polyamorous relationship with a partner who is transgender, shared feeling very uncomfortable talking about her sex life and how to protect herself and her partner. This fear of being judged and mistreated has prevented her, at times, from seeking the care and she and her partner need. Conversations with gender expansive people revealed that using gender inclusive language in intake forms and conversations, as well as, avoiding assumptions in the clinical setting about who people are having sex with would create a more comfortable

FOCUS GROUPS

(CONTINUED)

environment. For example, a participant recalled a visit with a gynecologist in which the physician was “not comfortable working with transgender people. I could tell they did not know what language to use, so I would jump in with the words and answer the question. But, they left space for me to do that and let me use words I’m familiar with.” This example emphasizes how respectful communication with de-gendered language can create an overall positive experience for patients.

For many, the context of the medical environment (long wait times and short visits) makes it even more difficult to advocate for oneself and slow the pace of the visit: “Wait time to see the doctor is long! By the time I get in (the exam room), the visit moves so fast, I forget what I wanted to ask. At the end, I’m so ready to go, because I was there forever.” Given this environment, it’s essential that health care professionals create a safe space that validates patient concerns and input.

3. Honor a person’s contraceptive choice

Some participants had health care professionals who honored and supported them when choosing a contraceptive method, while others did not. One mother shared that prior to education from her physician, she only knew about condoms and oral contraceptives. She discussed a broader array of methods with her health care professional, and ultimately chose oral contraceptives, which she had used before. She felt well-informed throughout the conversation and did not feel pressured to pick any particular method.

Other participants had strikingly different experiences and did feel pressured to choose one contraceptive method over another. Two participants—one from Southern Illinois and one from Chicago—shared that they each specifically asked for tubal ligations but were steered away from that option. As a result, each had multiple unplanned pregnancies. Another mother from Southern Illinois shared that, following the birth of her child, a physician administered the depo shot without her knowledge or consent. This health care professional assumed that, because this was her method of choice prior to her pregnancy, that she would want to use it again. The mother lost a significant amount of trust in her doctor and was disappointed because the depo shot is not recommended for use while breastfeeding. Another mother from the Western suburbs shared that, following the birth of her child, her health care professional suggested that she try an IUD. Ultimately, this mother did not feel comfortable with having a device in her uterus and chose the implant. She shared that this was uncomfortable as her health care professional had tried to steer her away from the implant due to “side effects.” Similarly, another participant shared that she was already using the depo shot and did not want to switch. However, her physician recommended an IUD because it was “personally better for her.” A high school student shared requesting an IUD from her health care professional, but she was steered away from this option because she had not previously given birth and the health care professional said it could “tamper with her cervix.” Lastly, a participant expressed that her physician always pushed contraception, even though she preferred to use condoms. She reported that her dislike for other methods stemmed from her belief that anything that was put into her body was a form of sterilization. Therefore, she did not always trust that her physician’s recommendations were in her best interest, a sentiment that was further exacerbated by the physician’s continued efforts to convince her to try a different method. A few other participants also expressed their concerns of “a hidden agenda” when physicians pushed contraception on them.

4. Acknowledge and respect the range of a person’s needs, including side effects

Focus group participants felt that health care professionals emphasized pregnancy prevention over people’s comfort and wellness. Namely, participants overwhelmingly felt that health care professionals did not prioritize the impact of side effects or honor the patient experience of side effects. One woman shared that she was unaware that the depo shot can have a negative impact on bone density until it became a medical issue. Another woman shared that her health care professional did not take her side effects seriously. Following her IUD insertion she experienced severe cramping and bleeding. Her health care professional was dismissive of her discomfort and said, “I told you there would be cramping.” She felt she had to fight to get it removed and did not feel heard or valued in the discussion. Another participant shared that while using Nexplanon, she experienced continuous bleeding for two years. However, she was homeless and uninsured, so she had

difficulty having it removed. She was so frustrated with the side effects of the method that she “thought about cutting it out [herself].” One person shared that she was started on birth control pills and experienced vomiting while taking them. She returned to her physician to switch methods but was instructed to continue taking the pills. Afterwards, she discontinued the pills and did not return to her health care professional. Thus, participants recommend that health care professionals review all potential side effects of contraceptive options with patients and remain flexible when patients do experience said side effects.

5. Partner with people to create a reproductive life plan

Many people shared that health care professionals did not take the opportunity to create a reproductive life plan either before or after a pregnancy. Most said that their health care professionals ensured that they had an effective method for preventing pregnancy, but they did not have conversations about when and if they wanted another child and, if so, how to prepare their bodies for pregnancy.

Participants also suggested that partners and spouses be part of the conversation surrounding contraceptive options and reproductive life planning. This would provide an opportunity to identify which method(s) would work best for them as a couple and help establish shared responsibility and accountability.

6. Ensure non-clinical health care professionals are also respectful and person-centered

Focus group participants used ancillary support services such as WIC, home visiting, and case management during their pregnancies and beyond. Thus, they emphasized the need for respect not only with clinicians, but also with these non-clinical professionals. Two women shared negative experiences at their local WIC clinics, where staff insensitively pressured them to “pick a birth control so you don’t have any more babies.” One mother was told, “if you keep getting pregnant and having babies you’re going to ruin your life.” This mother then felt apprehensive about sharing her plans to have another child. Thus, it is essential that any professionals who work with pregnant and parenting families are non-judgmental and put the family’s needs and desires first.

Sexual and Reproductive Health Education

7. All schools should have sexual and reproductive health education

Focus group participants all agreed that sexual and reproductive health education should be taught in all schools. Adult participants universally shared that they did not receive adequate sexual and reproductive health education. Youth participants said that sexual and reproductive health education should begin in elementary school so that students can understand their bodies and why and how they change. Students shared not understanding the importance of hygiene, which they believe is foundational to sexual and reproductive health education: “How you wash-up before puberty is totally different after puberty. You didn’t have those body odors before and need (to spend) more time (on yourself).” Students agreed that starting these conversations earlier will reduce embarrassment and shame, and empower students as they navigate relationships, sexuality, and their bodies.

8. Provide a youth-friendly and participatory space for conversation

Adult focus group participants almost universally shared feeling uncomfortable and shamed when learning about sex in schools. They felt the environment was not conducive to asking questions and delving into these important issues. Youth participants felt their sexual and reproductive health education was limited due to the discomfort of their teachers when discussing these topics with youth. These same youth credited EverThrive IL staff who work with them and create a comfortable space to discuss STIs, healthy relationships and violence, youth sexual and reproductive health rights, sexual identity, navigating resources, and healthy communication. Youth shared that this approach was both better and different than what they had traditionally experienced. Other young adults also shared positive experiences they had in receiving sexual and reproductive health education at the Illinois Caucus for Adolescent Health (ICAH). They liked that the education included conversations about pleasure, was inclusive of intersex anatomies and gender, provided information on all contraceptive methods, and provided opportunities to role-play how to talk to health care professionals

FOCUS GROUPS

(CONTINUED)

about sexual and reproductive health. One adult participant grew up in Denmark and shared that sexual and reproductive health education was taught with a comic book and that it was a “fun” class. This is a unique approach that highlights the need to make sexual and reproductive health education fun and accessible to youth.

Many mothers also discussed having age-appropriate conversations about a range of topics from inappropriate touching to safe sex with their children throughout their lifetimes. Although many agreed that these conversations were necessary, they often felt uncomfortable initiating them and deciding the appropriate age to do so. Other mothers discussed using the internet as a resource, as well. For example, a mother of a five-year-old son and daughter said, “I feel that they should get basic information and not to an extreme, because they have a phone and can access information, and it’s good to give them good information, instead of them obtaining wrong information online.” This highlights the importance of providing parents with resources so that they can also participate in creating a space for their children to learn about sexual and reproductive health.

Lastly, many people shared experiences of childhood sexual abuse, often perpetrated by family members including parents, cousins, siblings, grandparents, and other family members. Often times, these experiences resulted in feelings of shame and stigmatization: “I grew up with a sense of shame. I was a very curious three-year-old when a girl about six years old force me to have sex. I have always felt shame due to that. Even now I still feel embarrassed to talk about sex.” Given the high prevalence of childhood sexual abuse and the long-term adverse effects, it is essential that conversations with children and sexual and reproductive health education curricula are trauma-informed and do not perpetuate stigma.

9. Include conversations about sexual orientation and gender identity

Participants named needing a more comprehensive and open approach to sexual and reproductive health education, including conversations about sexual orientation and gender identity. One participant who is in a relationship with a partner who is transgender felt that educating youth on these issues earlier will reduce bias and increase empathy. Youth participants shared that the EverThrive IL sexual and reproductive health education sessions allowed them to ask questions and learn about the differences between sexual orientation and gender identity. They shared that students at their school have an array of sexual orientations and express their gender differently, but the school does not address this. Thus, they have taken it upon themselves to stand up for students who are being teased, bullied, or misunderstood. The participants of ICAH’s sexual and reproductive health education program also emphasized the importance of inclusivity: “I like that the education is for everybody. Typically, there is separation by gender or sex, but not at ICAH.”

10. Include conversations on healthy relationships

Both young and adult participants emphasized the need to include curriculum on healthy relationships. The participant who was raised in Denmark shared that sexual and reproductive health education teachers focused on the feelings of having a relationship and that sex is something special to enjoy with a partner you trust and love. In contrast, another mother shared that she had no idea sex could be enjoyable for the woman, as nobody discussed sex in the context of pleasure and enjoyment.

The participant raised in Denmark also shared that teachers emphasized that pregnancy prevention was the job of both partners in a sexual relationship. This is an inclusive approach that most of the other participants did not experience; rather they shared experiences of feeling like pregnancy prevention was squarely and solely on their shoulders.

The need for conversations about healthy relationships becomes more evident with the number of participants that shared a history of sexual abuse and domestic violence. One woman in particular recalled abuse and stigma after moving in with a man at the age of 13: “As soon as I moved in with him, he began hitting me. I would have to have sex with him, but he would always say he didn’t want to have a child. I didn’t have

a period at that time and really didn't know what it was with the exception that my father once had told me women bleed. I went back with family, but I was shunned and was told not to be around other children because I could hinder them since I had already had sex. I experienced so much stigma I went back to the abusive relationship and had a child at 13. He would leave for days at a time. I ended up having four children as a result of this man raping me." This example, and many others, emphasizes the need for discussions about how to navigate unhealthy relationships. Youth participants also shared how important conversations around healthy communication and healthy relationships are: "I really liked the communication session. We all need help in understanding what to say and how to say it. The role plays [we did in class] gave me time to think about what I want to say and practice turning someone down. It's not easy!" They also shared that it's important to educate young people on the signs of dating violence and how to navigate out of an unhealthy relationship.

Families and Communities

11. Acknowledge and leverage peer relationships and other support systems

Both adult and youth participants shared that they value their peers advice when choosing a contraceptive method. As previously mentioned, some participants felt judged and confused by their health care professionals and turned to friends to learn about their experiences with different contraceptive methods. All adult and youth participants shared soliciting input from friends before making a decision, as friends' experiences are "real" while a health care professional "might just be pushing a product." One participant who had received sexual and reproductive health education through ICAH expressed that they love that the program allows people to bring their friends with them to learn. Participants also shared that case managers, home visitors, and doulas are also considered trusted resources when engaging in family planning. Thus, it is important to consider the impact that both peer and other support relationships have when people make decisions about contraception.

12. Include partners in conversations about contraception

Participants felt that it is imperative to include men and other partners in conversations about contraception. Most participants felt that, although unfair, it is solely their responsibility to prevent pregnancy and protect themselves from STIs. One mother from the western suburbs of Chicago shared that she consulted her husband before choosing a contraceptive method because they make family planning decisions together. Thus, the assumption on the part of health care professionals (and others) that patients do not include partners in these conversations perpetuates the notion that people who can become pregnant should be and are solely responsible for this decision. It was therefore recommended that clinicians have family planning conversations with all partners when possible so that a decision regarding contraception is jointly made. There were a handful of people who can become pregnant who that said their partners were just as responsible for pregnancy and STI prevention, and shared that they are confident and comfortable communicating these expectations with their partner(s). By including partners in these conversations, health care professionals have the opportunity to help facilitate healthy relationships with open dialogue and communication.

Conclusion

This report highlights the improvements that can be made in clinical, school, and community settings to improve access to contraception and ensure Contraceptive Justice. Although many participants had positive experiences with health care professionals, teachers, friends, and other community members, there is still significant room for improvement. The unfortunate reality is that many adults and youth across Illinois are not equipped with medically accurate information about all contraceptive options. In addition, many have never received comprehensive and holistic sexual and reproductive health education. It is important that we remedy this while also leveraging informal peer and community networks where there is already commonality and trust.

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