

## Federal Sterilization Consent: A Summary of the Current Context and Recommendations for Change

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### Introduction

Sterilization is the most used contraceptive method among women aged 15-49 in the United States.<sup>1</sup> It is disproportionately used by people with (often intersecting) marginalized identities including those with low incomes, public or no insurance, lower education levels, and people of color.<sup>2</sup> Existing policies governing consent for federally-funded sterilization were enacted in the 1970s to protect people from coercive sterilization, and have not been updated since.<sup>3</sup> Current policy applies to people of all genders and requires that they be 21 years old, not be in the process of obtaining or seeking to obtain an abortion, complete a standardized consent form at least 30 days prior to the surgery, and use that form within 180 days of signing. A range of concerns about current policy exist, including that it potentially inhibits access to desired sterilization while not eliminating coercion.<sup>4,5,6</sup>

The [Coalition to Expand Contraceptive Access](#) (CECA) led a process to review existing research on federal sterilization consent policy, gather diverse stakeholder input, and consider the multifaceted issues involved. This process resulted in a set of recommended actions to better protect autonomy and increase access to care. This resource explains the context in which this work was conducted, describes the process undertaken, and summarizes current issues and recommended next steps. It can be used by a variety of stakeholders, including policymakers, healthcare providers, advocates, and researchers to inform their understanding of current sterilization consent policy and the need for reform, and to institute changes that will better protect autonomy and increase access to care.

### Overarching Themes

CECA's review of evidence and stakeholder input highlighted several overarching themes that informed the development of the recommended actions, detailed below:

- **Proposed changes to the federal sterilization consent form and process must balance ensuring access to desired sterilization while also preventing coercion.** People face multilevel barriers to accessing sterilization, stemming both from existing federal policies as well as larger issues in the healthcare system and beyond. While most research about sterilization is conducted among people who identify as women, policies apply to people of all genders, and the experiences of transgender and nonbinary people and people who identify as men should be considered as well.
- **Creating conditions that enable informed consent necessitates multi-level interventions.** The current consent process does not necessarily ensure informed decision making, as demonstrated by the high level of misinformation about sterilization among people who have already undergone the procedure. Informed consent is complex and layered, requiring interventions such as accessible and inclusive language and process, comprehensive sexuality education, provider training, transparency around policies and their rationale, and a broader centering of reproductive justice and a culture of respect in the healthcare setting.
- **Robust accountability mechanisms need to be implemented to address current and potential future harm.** This includes a comprehensive examination of who is accessing sterilization and why, as well as the quality and timeliness of counseling and care people are receiving.

## Historical Context and Contemporary Implications

Current regulations governing federally funded sterilization were instituted to address a legacy of sterilization abuses throughout the 20<sup>th</sup> century. Yet sterilization abuse is not a historical aberration; it is consistent with a longstanding, pervasive, and ongoing ideology of stratified reproduction, in which the reproduction and fertility of low-income people, people of color, people with disabilities, and others with marginalized identities are systematically devalued. Examples include:

- **In the early 1900s, many states passed eugenical legislation allowing involuntary sterilization of women deemed “unfit” to reproduce, which included the poor, the deaf, people of color, and those labeled as “feebleminded.”** Although tolerance for eugenic thinking waned mid-century, especially in response to reports of Nazi atrocities, which were grounded in eugenic ideology, coercive sterilization practices continued through the 1970s in the U.S. as part of poverty prevention tactics.<sup>3</sup> These sterilizations were financially supported by state and federal governments and occurred disproportionately among low-income women and women of color.<sup>3,7</sup> Patient and community activism exposed these abuses. For example, a group of women known as the Madrigal Ten, sued the University of Southern California and Los Angeles County General Hospital for nonconsensual sterilizations. The plaintiffs in this class-action suit were working-class women of Mexican origin who had been coerced into postpartum tubal ligations minutes or hours after undergoing cesarean deliveries. In response to a public outcry accusing the government of racist and classist application of family planning funds and programs, the U.S. Department of Health, Education, and Welfare developed strict regulations for federally funded sterilizations in an attempt to ensure informed and voluntary consent.<sup>8</sup>
- **Prisons and jails are environments that limit an individual’s autonomy and ability to make decisions.** Incarcerated individuals have reported being coerced into sterilization by prison healthcare practitioners and personnel, including being offered rewards for agreeing to the procedure or threatened with punishments for refusing.<sup>9</sup> Coercive sterilization in the carceral setting has been documented as recently as 2010.<sup>9</sup>
- **Current regulations governing federally funded sterilization do not apply in other contexts.** Some ethicists and researchers have argued that by hindering access to desired family planning services and treating publicly insured people differently than privately insured ones, federal regulations violate the ethical standards of beneficence, non-maleficence, justice, and autonomy.<sup>10,11</sup>

## Development Process

As part of their effort to update the federal sterilization consent process and policy, the Department of Health and Human Services (HHS) Office of Population Affairs (OPA) reviewed all comments submitted during the 2022 information collection request on consent for sterilization form comment period (0937-0166). OPA compiled a crosswalk summarizing all feedback and noting where there was broad agreement and where there was need for further knowledge-gathering, whether through stakeholder engagement or evidence review. This crosswalk indicated that consent form changes like improving readability, for example, are clear areas of consensus, while topics like extending the validity period require further exploration.

To build on the work already completed by OPA, CECA participated in or conducted the following activities between January and August 2023. In keeping with principles of sexual and reproductive health equity (SRHE), the work focused on engaging evidence and stakeholder perspectives to shape actionable recommendations:

- **Listening Session.** OPA and the HHS Office of Intergovernmental and External Affairs (IEA) convened a listening session with a diverse group of organizations with expertise in the topic of sterilization. The goal was to explore concerns related to publicly funded sterilization and ideas to advance the concurrent goals of safeguarding communities from abuse and facilitating access to sterilization when desired. CECA participated in this listening session.
- **Workgroup Meetings.** CECA then convened a workgroup of policy advocates, clinical experts and educators, researchers, community representatives, and other key stakeholders to explore the topics and suggestions raised in the listening session in more detail. In May and June of 2023, CECA gathered 19 thought leaders representing 16 organizations for two 90-minute meetings to consider specific issues with the federal sterilization consent form and process. (See **Appendix A** for a full list of Workgroup members and the CECA Conveners).
- **Center for American Progress (CAP) Disability Reproductive Health Coalition Discussions.** CECA also gathered feedback from the CAP Disability Reproductive Health Coalition, a group with deep expertise and lived experience in the disability justice and reproductive health, rights, and justice movements. This collaboration highlighted disability rights and justice organizations' perspectives on the community-specific issues that arise with the federal sterilization form and process.
- **Lived Experience Panels (LEPs).** CECA partnered with SisterLove and California Latinas for Reproductive Justice to host two LEPs, which are semi-structured discussions with community members intended to gather expert insights on a range of topics. CECA defines community as people who use or would like to use contraception and the people who help them access it, with a particular focus on people who experience barriers to receiving the care they want and have experienced mistreatment. During the LEPs, sixteen community members shared personal and community experiences with the federal sterilization consent process. Participants reported multilevel barriers to accessing sterilization, including provider-related issues (e.g., negative attitudes, overt deterrence, and difficulty locating a provider), cost and insurance issues, and the logistical challenges posed by waiting periods and consent requirements. They expressed confusion about the rationale of certain aspects of the policy, emphasized the importance of autonomy in health care decisions, and called for the government to disseminate clear and substantive information about sterilization as a health care option through trusted channels.

**Sexual and reproductive health equity (SRHE)** means that systems ensure that all people, across the range of age, gender, race, and other intersectional identities, have what they need to attain their highest level of sexual and reproductive health. This includes self-determining and achieving their reproductive goals. Government policy, healthcare systems, and other structures must value and support everyone fairly and justly.

## Recommended Areas of Change

There is a critical need to transform sterilization policy to meet the concurrent goals of ensuring informed decision making, facilitating fair and equitable access, and safeguarding against coercion and abuse. The following recommended areas of change are intended to improve states' and providers' ability to meet requirements and to better equip individuals considering sterilization to make informed decisions. The recommendations apply to people of all genders and to people seeking sterilization procedures for any indication.

### **1. Lower minimum age of consent**

Lowering the minimum age to consent for sterilization from 21 to 18 years old is a step toward honoring young people's autonomy, lowers barriers to care, and aligns with other healthcare processes, including reproductive healthcare, procedures, and services.<sup>12,13</sup> Beyond this immediate next step, the larger question of whether any age limit is needed should be explored. Input could be sought from states that have enacted lower sterilization age restrictions (e.g., Oregon), while recognizing the unique factors and policies at play in different states. Additional strategies, including provider resources, are needed to ensure increased access and appropriate care for young people, who often experience discrimination and stigma when seeking reproductive healthcare, including sterilization.<sup>6</sup>

### **2. Enable people to consent to sterilization when seeking to obtain or obtaining an abortion**

The current prohibition on consenting to sterilization when seeking to obtain or obtaining an abortion contributes to abortion stigma, and places greater barriers on people seeking abortion than on those giving birth.<sup>14</sup> It is essential to ensure that systematic and individual biases against people seeking abortion are removed to foster patient-centered care and true informed consent. With appropriate education, care, and counseling, people can consent to sterilization at the time of abortion, birth, or any other healthcare service.<sup>6</sup>

### **3. Extend the consent form validity period**

The federal sterilization consent form's current expiration period of 180 days means that for many people, their consent form has expired before they can get the care they desire.<sup>15</sup> This can constitute a significant burden, especially for individuals who are already facing financial, logistical, and emotional challenges in accessing sterilization. Individuals' reproductive goals can be fluid and circumstances can change, so some validity period can act as a prompt for ensuring that counseling and consent are current.<sup>16</sup> A one-year expiration period aligns more closely with processes for other procedures (e.g., general consent for treatment forms).

### **4. Shorten the mandatory waiting period**

The 30-day waiting period between an individual's signature on the consent form and the date upon which the sterilization is performed imposes a burden on patients seeking federally funded sterilization. This results in disproportionately more Medicaid beneficiaries not obtaining their desired sterilization.<sup>5,17</sup> Requesting sterilization too late in pregnancy, not having the form present at delivery, or delivering unexpectedly before the waiting period has elapsed are all documented barriers to postpartum sterilization.<sup>18,19,20</sup> Furthermore, many pregnant people covered by Medicaid who do not receive a desired sterilization in the immediate postpartum period may miss their window of opportunity, since pregnancy-related Medicaid eligibility often ends shortly after delivery.

While patients may express understanding of the rationale for a waiting period, a waiting period will not alone guarantee informed consent. Available evidence suggests that the federal consent form and 30-day waiting period have no significant impact on the decision-making process or comprehension among women with Medicaid, as compared to their privately insured counterparts.<sup>21</sup> Additional guidance would help with consistent and appropriate application of the waiting period. Reducing the waiting period can alleviate some of the challenges associated with a lengthy wait to receive care, while maintaining a safeguard to help prevent coercion.

### **5. Reassess and streamline data collection**

Data-collection efforts must balance not overly surveilling people with the need to understand trends and patterns. By all available reports, the data collected from the race/ethnicity designation question is not being used, and the question could be experienced as burdensome to those completing the form. There are more comprehensive ways to assess disparities through large national datasets. However, with additional contextual data (e.g., patient’s gender identity, age, level of education, socioeconomic status, and how long they knew they desired sterilization, etc.), this data could potentially be useful in helping to monitor for possible inequities and systematic issues. Currently, this data collection is not a valuable assessment of the risk of coercion, and incorrect interpretation of the data could detrimentally impact access. Research and additional stakeholder engagement is needed to determine the most accurate ways to collect, routinely analyze, and utilize relevant data to identify trends and areas for improvement.

#### **Ethnicity and Race Designation Question**

You are requested to supply the following information, but it is not required: (*Ethnicity and Race Designation*) (please check):

|  |  |
|--|--|
| <p><i>Ethnicity:</i></p> <p><input type="checkbox"/> Hispanic or Latino</p> <p><input type="checkbox"/> Not Hispanic or Latino</p> | <p><i>Race: (mark one or more):</i></p> <p><input type="checkbox"/> American Indian or Alaska Native</p> <p><input type="checkbox"/> Asian</p> <p><input type="checkbox"/> Black or African American</p> <p><input type="checkbox"/> Native Hawaiian or Other Pacific Islander</p> <p><input type="checkbox"/> White</p> |
|--|--|

### **6. Offer guidance on supported decision making**

Supported decision making (SDM) presumes that individuals with intellectual and developmental disabilities can make decisions but require assistance in making those decisions. SDM is the least restrictive option for those who desire some form of assistance that does not compromise their decision-making capabilities and offers opportunities to ensure that anyone making the decision to get sterilized is fully informed. The federal sterilization consent form should reflect SDM agreements as an option.<sup>22</sup> Recognizing SDM agreements is consistent with the regulatory requirements for informed consent. Intentional outreach to disability rights and justice experts is needed to create robust infrastructure to support meaningful and appropriate SDM implementation in the federal sterilization consent process.

### **Implementation Strategies**

The recommended changes described above should be accompanied by a vigorous re-evaluation of the consent form, process, and monitoring strategy, consistent with the values of equity and justice, and with an understanding of the specific populations impacted. The table below outlines recommendations for monitoring, research and evaluation, and dissemination of any regulatory changes. While federal government agencies like HHS will be responsible for many aspects of this implementation, broader coordination and collaboration will also be needed, including with state and local policymakers, healthcare providers and professional organizations, advocates, researchers, community-based organizations, and the public.

## Implementation Strategies

### Monitoring

- **Release available federal sterilization data** on a quicker timeframe.
- **Collect data on the volume of procedures with contextual data** such as changes in local policies impacting contraceptive access.
- **Oversample surveillance systems**, such as the [Pregnancy Risk Assessment Monitoring System \(PRAMS\)](#), [National Survey of Family Growth \(NSFG\)](#), to develop a reproductive coercion health care supplement.
- **Develop and implement a system to identify, track and discipline, or remove providers who are in violation of patients' civil rights.** This system should include a database of providers who have been reported for misconduct, as well as a process for investigating and verifying reports.
- **Collaborate with state Medicaid agencies and relevant stakeholders to develop a comprehensive guide** outlining the interpretations and implications of federal sterilization consent policies. Provide detailed guidance on how State Medicaid Officers can effectively implement and enforce sterilization consent requirements within their respective jurisdictions.

### Research and Evaluation

- **Review existing literature, research findings, and relevant data sources to identify current gaps** in knowledge regarding sterilization consent policies and practices. Prioritize the identified gaps based on their potential impacts related to informing policy reforms and improving patient care.
- **Create a formal and rapid assessment process** to gain insight into patients' experiences, during and/or after the mandatory waiting period.
- **Examine the system of care for people seeking sterilization**, including the policies, procedures, and resources that are available, and how they interact with each other, to identify the specific barriers people face, and to develop solutions that address these barriers at the system level. Implement continuous quality improvement efforts based on these findings.
- **Assess the effects of any policy changes**, including changes in the rates of people obtaining their desired sterilization, satisfaction about/experiences with sterilization (including regret), and other key metrics.

### Dissemination

- **Educate and train trainees and providers in women's health and other specialties** to ensure comprehension of sterilization, relevant context/background, and its intended outcomes.
- **Develop a comprehensive white paper** in collaboration with the National Academies of Sciences, Engineering, and Medicine or other prominent organizations to identify and better understand the complexities of sterilization consent policies. Disseminate the white paper widely to policymakers, healthcare providers, advocates, researchers, and the general public to inform understanding of and stimulate dialogue on sterilization consent reform.
- **Incorporate policy advocacy, personal narrative, and storytelling in public information campaigns** to destigmatize sterilization as a contraceptive option and share accurate information about the procedure and associated policies at community-based access points.
- **Conduct listening sessions with hospital leaders**, including professional associations and those in general counsel roles, to understand what guidance is needed to successfully implement new policies and procedures.
- **Collaborate with legal experts to draft legislative proposals** that address the identified gaps and weaknesses in the current sterilization consent statutory framework. Work closely with policymakers and advocacy groups to build support for the proposed legislative changes and advance their passage through the legislative process.



## Conclusion

Diverse stakeholders are eager for the sterilization consent form and process to be updated and recommend several actionable changes. Both government and non-government organizations should undertake comprehensive, recurring evaluation of this important topic.

Policies governing sterilization must be designed and examined through a reproductive justice lens, emphasizing bodily autonomy, meaningful access, and informed consent. Comprehensive data collection and analysis is needed to understand patterns and trends in sterilization, including the quality of care. Providers must be equipped to provide evidence-based, ethical, and equitable counseling, informed consent, and care to all patients considering sterilization. Implementing mechanisms for monitoring, evaluation, and accountability mechanisms can help to ensure that processes are patient-centered and just. In the long term, such efforts can help to advance better policies, improve individual and community experiences, and improve public trust in the healthcare system.

## APPENDIX A: WORKGROUP MEMBER NAMES AND AFFILIATIONS


| Workgroup Member      | Organization   |
|-----------------------|--|
| Aletha Akers          | Guttmacher Institute   |
| Ma'ayan Anafi         | National Women's Law Center                                    |
| Kavita Arora          | University of North Carolina at Chapel Hill School of Medicine |
| Clare Coleman         | National Family Planning and Reproductive Health Association   |
| Kelly Davis           | New Voices for Reproductive Justice                            |
| Cat Duffy             | National Health Law Program                                    |
| Emily Eckert          | Upstream USA   |
| Zsanai Epps           | Black Women's Health Imperative                                |
| Rachel Gandell Tetlow | American College of Obstetricians and Gynecologists            |
| David Inoue           | Japanese American Citizens League                              |
| Mia Ives-Rublee       | Center for American Progress Disability Justice Initiative     |
| Camille Kidd          | In Our Own Voice   |
| Dora Maradiaga        | Guttmacher Institute   |
| Sophie Mraz           | Planned Parenthood Federation of America                       |
| Jamila Perritt        | Physicians for Reproductive Health                             |
| Taylor Platt          | American College of Obstetricians and Gynecologists            |
| Carolyn Sufrin        | Johns Hopkins School of Medicine                               |
| Lauren Wallace        | National Women's Law Center                                    |
| Nikki Zite            | University of Tennessee Graduate School of Medicine            |

| CECA Conveners      |                    |
|---------------------|--------------------|
| Jamie Hart          | Executive Director |
| Lisa Stern          | Deputy Director    |
| Fajer Saeed Ebrahim | Senior Advisor     |
| Tanishia Smith      | Project Manager    |



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