

To:Ciara Davis, Policy Analyst, Office of Population AffairsJamille Fields Allsbrook, Senior Policy Advisor, Office of Population Affairs

From: CECA Conveners

- **RE:** Updated recommendations for updating the federal sterilization consent policy and process
- **Date:** August 10, 2023

Dear OPA Colleagues,

The <u>Coalition to Expand Contraceptive Access</u> (CECA) supports the Office of Population Affairs (OPA) efforts to update the form and process that govern how informed consent is conducted for all federally funded sterilization procedures in order to better protect patient autonomy and increase access to care. This letter delineates evidence- and stakeholder-based final recommendations to advance these goals.

# **INTRODUCTION**

Sterilization is currently the most used contraceptive method among women aged 15-49 in the United States.<sup>1</sup> It is disproportionately used by people with social disadvantages, including those with low incomes, public or no insurance, lower education levels, and people of color.<sup>2</sup> Existing policies were enacted in the 1970s to protect people from coercive sterilization<sup>3</sup>, and have not been updated since. Concerns with current policy include inhibiting access to desired sterilization while not eliminating coercion.<sup>4</sup>

CECA is a convener of committed partners working to ensure access to contraception as part of a broader vision to achieve sexual and reproductive health equity (SRHE). To augment OPA's information-gathering activities, CECA led two **expert workgroup meetings** to review evidence and consider federal sterilization issues and, where possible, suggest specific changes; **consulted** with the Center for American Progress (CAP) Disability Reproductive Health Care Coalition to gather feedback on Supported Decision-Making (SDM) and other potential recommendations; and conducted two **Lived Experience Panels (LEPs)** with community members to review evidence and give input on potential changes (see **Appendix B** for details). Several overarching themes emerged (**Exhibit 1**). 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.

## **Exhibit 1. Overarching Themes**

- 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. All policy changes must be grounded in SRHE. 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.
- It is the federal government's obligation to create conditions that enable informed consent. Informed consent is complex and layered, requiring interventions such as accessible and inclusive language and process, comprehensive sexuality education, provider training, clarity and 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 who is accessing sterilization and why, as well as the quality and timeliness of counseling and care people are receiving.

<sup>&</sup>lt;sup>1</sup> Daniels and Abma, "Current Contraceptive Status among Women Aged 15-49."

<sup>&</sup>lt;sup>2</sup> Borrero et al., "Race, Insurance Status, and Tubal Sterilization."

<sup>&</sup>lt;sup>3</sup> Stern, "STERILIZED in the Name of Public Health."

<sup>&</sup>lt;sup>4</sup> Borrero et al., "Medicaid Policy on Sterilization--Anachronistic or Still Relevant?"; Arora et al., "Medicaid and Fulfillment of Desired Postpartum Sterilization"; American College of Obstetricians and Gynecologists' Committee on Ethics, "Committee Opinion No. 695."



## RECOMMENDATIONS

The following recommendations are intended to support federal government efforts to: (1) improve states' and providers' ability to meet federal consent requirements; and (2) equip individuals considering sterilization to make informed decisions. The recommendations, highlighted in **Exhibit 2** and the text that follows, apply to people of all genders and to people seeking sterilization procedures for any indication. Sterilization should be presented as a reproductive health care option and discussed in a patient-centered shared decision-making frame.

### **Exhibit 2. Summary of Recommendations**

- 1. Lower the minimum age of consent from 21 to 18 years old.
- 2. Remove the prohibition on people consenting to sterilization when seeking to obtain or obtaining an abortion.
- 3. Change the consent form expiration period from 180 days to 365 days.
- 4. Change the required waiting period between an individual's signature on the consent form and the date upon which the sterilization is performed from 30 days to 72 hours.
- 5. Evaluate how to best collect and utilize race/ethnicity data.
- 6. Incorporate supported decision making into the federal sterilization consent process and provide needed resources for implementation.

## Recommendation 1: Lower the minimum age of consent from 21 to 18 years old.

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, including reproductive healthcare, procedures, and services.<sup>5</sup> Beyond this immediate next step, OPA should consider whether any age limit is needed. HHS could seek input 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>

# Recommendation 2: Remove the prohibition on people consenting to sterilization when seeking to obtain or obtaining an abortion.

The current prohibition contributes to abortion stigma, and places greater barriers on people seeking abortion than on those giving birth.<sup>7</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 health care.<sup>8</sup>

# **Recommendation 3: Change the consent form expiration period from 180 days to 365 days.**

The current expiration period means that for many people, their consent form has expired before they can get the care they desire.<sup>9</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>10</sup> A one-year expiration period aligns more closely with processes for other procedures (e.g., general consent for treatment forms).

<sup>&</sup>lt;sup>5</sup> Guttmacher Institute, "An Overview of Consent to Reproductive Health Services by Young People"; Centers for Disease Control and Prevention, "State Laws That Enable a Minor to Provide Informed Consent to Receive HIV and STD Services."

<sup>&</sup>lt;sup>6</sup> American College of Obstetricians and Gynecologists' Committee on Ethics, "Committee Opinion No. 695."

<sup>&</sup>lt;sup>7</sup> Borrero, Talabi, and Dehlendorf, "Confronting the Medical Community's Complicity in Marginalizing Abortion Care."

<sup>&</sup>lt;sup>8</sup> American College of Obstetricians and Gynecologists' Committee on Ethics, "Committee Opinion No. 695."

<sup>&</sup>lt;sup>9</sup> Russell et al., "Medicaid Sterilization Consent Forms."

<sup>&</sup>lt;sup>10</sup> Frederiksen et al., "Contraception in the United States: A Closer Look at Experiences, Preferences, and Coverage."



# Recommendation 4: Change the required waiting period between an individual's signature on the consent form and the date upon which the sterilization is performed from 30 days to 72 hours.

The 30-day waiting period imposes a burden on patients seeking federally funded sterilization, who are subject to this policy, while patients with private insurance are not, resulting in disproportionately more Medicaid beneficiaries not obtaining their desired sterilization.<sup>11</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>12</sup> Furthermore, the waiting period creates a gap in which patients could lose their Medicaid coverage, particularly postpartum. While patients may express understanding of the rationale for a waiting period, a waiting period will not alone guarantee informed consent. 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.

# Recommendation 5: Evaluate how to best collect and utilize race/ethnicity data.

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 (**Exhibit 3**) 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. HHS should conduct a literature review and stakeholder engagement to determine the most accurate ways to collect relevant data and routinely analyze and utilize that data to identify trends and areas for improvement.

## **Exhibit 3. Ethnicity and Race Designation Question**

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

#### Ethnicity:

Race: (mark one or more):

- American Indian or Alaska Native
- Not Hispanic or Latino

□ Hispanic or Latino

- Black or African American
- □ Native Hawaiian or Other Pacific Islander
- □ White

Asian

# Recommendation 6: Incorporate supported decision making into the federal sterilization consent process and provide needed resources for implementation.

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>13</sup> Recognizing SDM agreements is consistent with the regulatory requirements for informed consent. HHS should conduct intentional outreach to disability rights and justice experts to create robust infrastructure to support meaningful and appropriate SDM implementation in the federal sterilization consent process.

<sup>&</sup>lt;sup>11</sup> Arora et al., "Medicaid and Fulfillment of Postpartum Permanent Contraception Requests."; Arora et al., "Medicaid and Fulfillment of Desired Postpartum Sterilization."

<sup>&</sup>lt;sup>12</sup> Gilliam et al., "A Qualitative Study of Barriers to Postpartum Sterilization and Women's Attitudes toward Unfulfilled Sterilization Requests"; Potter et al., "Frustrated Demand for Sterilization among Low-Income Latinas in El Paso, Texas."

<sup>&</sup>lt;sup>13</sup> Duffy, "National Health Law Program Comments on Consent for Sterilization Form."



# MONITORING, EVALUATION, DISSEMINATION, AND IMPLEMENTATION

Stakeholders voiced concern that if informed consent is not prioritized in the wider sterilization and sexual and reproductive health context, discrete changes to the federal sterilization consent form and process may have little impact or even potentially increase coercive practices. The specific policy recommendations should be accompanied by a vigorous re-evaluation of the federal sterilization consent form, process, and monitoring strategy, consistent with the values of equity and justice, and with an understanding of the specific populations impacted. **Exhibit 4** outlines recommendations for monitoring, evaluation, dissemination, and implementation for HHS to consider while updating the federal consent form and process. While some of the recommendations can be implemented by OPA alone, many will require collaboration and coordination with other relevant agencies, such as the Centers for Medicare and Medicaid Services and the Office for Civil Rights.

## Exhibit 4. Monitoring, Evaluation, Dissemination, and Implementation Recommendations

Monitoring	<ul> <li>Release Medicaid sterilization data on a quicker timeframe.</li> <li>Collect data on the volume of procedures with contextual data such as changes in local policies impacting contraceptive access.</li> <li>Oversample the Pregnancy Risk Assessment Monitoring System (PRAMS), National Survey of Family Growth (NSFG), and/or other surveillance systems to develop a reproductive coercion health care supplement.</li> </ul>	
Evaluation	<ul> <li>Create a formal and rapid assessment process to gain insight into patients' experiences, either during the mandatory waiting period or after sterilization.</li> <li>Conduct a comprehensive examination of 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 that patients face, and to develop solutions that address these barriers at the system level. Implement continuous quality improvement efforts based on these findings.</li> <li>Assess the effects of any policy changes, including changes in the rates of people obtaining their desired sterilization, satisfaction about/experiences with sterilization (including potential regret), and other key metrics.</li> </ul>	
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. Incorporate policy advocacy, personal narrative, and storytelling in public information campaigns to destigmatize sterilization as a contraception option and share accurate information about the procedure and associated policies at community-based access points.	
Implementation	<ul> <li>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.</li> <li>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.</li> </ul>	



# CONCLUSION

Diverse stakeholders are eager for the federal government to enact needed changes to the sterilization consent form and process and recommend several immediately actionable changes. Additionally, OPA and its partners within and outside of government 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 the patterns and trends in sterilization, including the quality of counseling and of care. Providers must be trained to provide ethical and equitable counseling and care to all patients seeking sterilization. Implementing mechanisms for monitoring, evaluation, and accountability mechanisms can help to ensure that processes are patient-centered and just. While the recommendations in this report do not specifically address individuals in incarceration settings, stakeholders emphasized that the federal government must acknowledge and address the disproportionate and ongoing harm caused by sterilization practices in prisons and immigration detention facilities and consider how policy can protect incarcerated people.

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			
Name	Title		
Jamie Hart	Executive Director		
Lisa Stern	Deputy Director		
Fajer Saeed Ebrahim	Director of Partner Engagement		
Tanishia Smith	Project Manager		



# **APPENDIX B: STAKEHOLDER ENGAGEMENT APPROACH**

CECA's approach focused on gathering feedback across a broad and diverse range of stakeholders to identify what changes should be made, with the goals of: (1) improving states' and providers' ability to meet federal consent requirements; and (2) equipping individuals considering sterilization to make more informed decisions. CECA participated in or conducted the following activities to engage critical stakeholders with expertise in and lived experience with sterilization to develop the recommendations.

## **OPA Review of Public Comments**

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, for example, improving readability, are clear areas of consensus, while topics like extending the validity period require further exploration.

## **Listening Sessions**

In March of 2023, OPA and the Office of Intergovernmental and External Affairs (IEA) convened a listening session with a diverse group of organizations with expertise in the topic of sterilization to explore concerns related to publicly funded sterilization and ideas to advance the concurrent goals of safeguarding communities from abuse and facilitating access to permanent contraception when desired.

## **Workgroup Meetings**

Focused on the goal of providing stakeholder-informed recommendations to the federal sterilization consent form and process, CECA brought together a workgroup of policy advocates, clinical experts and educators, researchers, community representatives, and other key stakeholders, many of whom attended the listening session convened by the OPA and IEA. In May and June of 2023, CECA virtually convened 19 thought leaders representing 16 organizations for two 90-minute meetings to consider specific changes to the federal sterilization consent form and process as well as dissemination and implication considerations. (See **Appendix A** for a full list of Workgroup members and the CECA Conveners).

# Center for American Progress (CAP) Disability Reproductive Health Care Coalition Discussions

CECA also gathered feedback from the CAP Disability Reproductive Health Care Coalition, a group of members with deep expertise and lived experience in the disability justice and reproductive health, rights, and justice movements. Meeting monthly in April and May of 2023, this collaboration helped highlight disability rights and justice organizations' perspectives on the community-specific issues that arise with the federal sterilization form and process.

## Lived Experience Panels (LEPs)

Lived Experience Panels (LEPs) are semi-structured discussions with community members intended to gather valuable 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 in the past and/or the present. CECA partnered with SisterLove and California Latinas for Reproductive Justice to host two LEPs in July and August of 2023, where sixteen community members evaluated the evidence on potential changes to the federal sterilization form and process and gave input on potential changes. 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 general confusion as to the rationale of certain parts of the sterilization 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 existing trusted channels.



# **APPENDIX C: CITATIONS**

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