



**NATIONAL LATINA
INSTITUTE FOR
REPRODUCTIVE HEALTH**
Salud | Dignidad | Justicia

September 17th, 2018

The Honorable Alex Azar, Secretary
Department of Health and Human Services
U.S. Department of Health & Human Services
200 Independence Avenue, S.W.
Washington, D.C. 20201

Via email: Sherrette.funn@hhs.gov

Re: Information Collection Request on Consent for
Sterilization Form (0990–New–60D)

Dear Secretary Azar:

The National Latina Institute for Reproductive Health (NLIRH) thank the Department of Health and Human Services (HHS) for the opportunity to respond to its Agency Information Collection Request regarding the Consent for Sterilization Form (OMB No. 0937-0166) set to expire on December 31, 2018.

NLIRH is the only national reproductive justice organization dedicated to building Latina power to advance health, dignity, and justice for 28 million Latinas, their families, and communities in the United States through leadership development, community mobilization, policy advocacy, and strategic communications. NLIRH works to ensure that all Latinxs¹ are informed about all their options for safe, effective, and acceptable forms of contraception and family planning. NLIRH supports affordable, accessible, and quality contraception and counseling for all persons regardless of their age or gender identity.

We support the continued use of the Consent for Sterilization Form (“Form”) and offer the following comments to improve clarity and enhance the quality and utility of the information collected through the Form.

¹ NLIRH, conscious of the importance of gender equity in the production of educational materials utilizes gender-neutral terms throughout this document. “Latinx” is a term that challenges the gender binary in the Spanish language and embraces the diversity of genders that often are actively erased from spaces. Due to the limitations of data collection, we use “Latina(s)” or “women” where research only shows findings for cisgender women, including Latinas.

I. History of Sterilization in the Latinx Community and Necessity and Utility of the Information Collection

The consent requirement was created to protect people from coercive sterilization practices, especially women of color. Established by regulation, the Medicaid Consent for Sterilization policy was a much-needed protection against these practices.² It is important to note that any changes to the Form must comply with the underlying regulation that established the 30-day consent period and authorized the Form.³

The history of forced sterilization and practices that continue today, specifically of Latinxs, other women of color, immigrant women, women with low-incomes, and women with disabilities, demonstrates the need for sterilization consent practices, including the Form used for Medicaid-funded sterilization procedures, remain vital and necessary even as they could be improved.

The practice of sterilization abuse has historically tied to the eugenics movement. This movement sought to control the reproductive autonomy of individuals deemed “undesirable” by society—including persons incarcerated, persons with disabilities, individuals with low-incomes, and people of color. In the infamous 1927 case of *Buck v. Bell*, the Supreme Court upheld Virginia’s eugenic sterilization law, which forcibly sterilized thousands of “feeble-minded” or “morally delinquent” men and women, which has never been overturned.⁴

Sterilization abuse and its legacy have been disproportionately felt in Latinx communities and other communities of color in the United States. When the United States assumed governance of Puerto Rico in 1898, it established population control policies, arguing that overpopulation of Puerto Rico would lead to negative social and economic consequences⁵. These policies became codified when Law 116 was passed in 1937 and sterilization was soon made widely available in Puerto Rico at low cost through financial subsidies.⁶ This practice was closely tied with prevalent ideas about economic development.⁷ In Los Angeles, low income, immigrant, Mexican women were coercively sterilized during the late 1960s and early 1970s by medical practitioners who believed that “poor minority women in L.A. County were having too many babies.”⁸ Latinxs were at the forefront of organizing against forced and coerced sterilization and contraceptive abuse. Dr.

² 42 C.F.R. § 441.257.

³ An exception to the 30-day consent period exists in cases of premature delivery or emergency abdominal surgery. See 42 CFR § 441.253(d).

⁴ *Buck v Bell*, 274 U.S. 200 (1927)

⁵ Kathryn Kruse. *Our Bodies, Our Selves. History of Forced Sterilization and Current U.S. Abuses.* October 1, 2014. <http://www.ourbodiesourselves.org/health-info/forced-sterilization/>.

⁶ Kathryn Kruse. *Our Bodies, Our Selves. History of Forced Sterilization and Current U.S. Abuses.* October 1, 2014. <http://www.ourbodiesourselves.org/health-info/forced-sterilization/>.

⁷ Kathryn Kruse. *Our Bodies, Our Selves. History of Forced Sterilization and Current U.S. Abuses.* October 1, 2014. <http://www.ourbodiesourselves.org/health-info/forced-sterilization/>.

⁸ Alexandra Minna Stern *Sterilized in the Name of Public Health* 1134, 1135 <http://www.ncbi.nlm.nih.gov/pmc/articles/PMC1449330/>

Helen Rodriguez-Trias, a noted Puerto Rican activist, founded the Committee to End Sterilization Abuse (CESA) in the 1970s.⁹ The federal government adopted guidelines on sterilization informed by CESA and other advocates and included provisions such as mandating informed consent procedures.¹⁰

In other cases, Immigrant, Native American/American Indian, and women with low-incomes were threatened with deportation or the withholding of public benefits or health treatment, or the removal of their children if they did not consent to sterilization.¹¹ Between 1964 and 1981, approximately 65 percent of the women sterilized in North Carolina were African-American.¹² Indian Health Services coercively sterilized an estimated 25,000 Native American women by 1975 without their informed consent.¹³

Unfortunately, sterilization abuse has continued into the present day. Between 2006 and 2013, it was found that 39 percent of tubal ligations performed on women incarcerated in the California prison system were done without legal consent and many patients were women of color.¹⁴ In addition, transgender individuals may face coerced sterilization as state and local governments often require proof of surgical treatment to update identification credentials for transgender persons who desire that their identification reflects their gender identity.¹⁵ These requirements may necessitate surgeries which ends a transgender person's reproductive capacity.¹⁶

Medicaid provides critical health care coverage for the Latinx community. Hispanics account for 30 percent of Medicaid enrollees and more than one quarter (27 percent) of Latinas of reproductive age are enrolled in the Medicaid program¹⁷ and it is essential that this Form continues to protect

⁹ Kathryn Kruse. Our Bodies, Our Selves. History of Forced Sterilization and Current U.S. Abuses. October 1, 2014. <http://www.ourbodiesourselves.org/health-info/forced-sterilization/>.

¹⁰ Kathryn Kruse. Our Bodies, Our Selves. History of Forced Sterilization and Current U.S. Abuses. October 1, 2014. <http://www.ourbodiesourselves.org/health-info/forced-sterilization/>.

¹¹ See Sally J. Torpy, *Native American Women and Coerced Sterilization: On the Trail of Tears in the 1970s*, 24 AM. INDIAN CULTURE AND RESEARCH J., 1-22 (2000), https://www.law.berkeley.edu/php-programs/centers/crrj/zotero/loadfile.php?entity_key=QFDB5MW3. See also Elena Gutierrez, *Fertile Matters: The Politics Of Mexican-Origin Women's Reproduction*, Univ. of Texas Press (2009), at 44.

¹² Begos, Kevin, et al. April 15, 2003. *Against Their Will: North Carolina's Sterilization Program*. <http://againsttheirwill.journalnow.com>.

¹³ Jane Lawrence, *The Indian Health Service and the Sterilization of Native American Women*, 24.3 AM.Indian Quarterly 400, 406 available at <http://faculty.utep.edu/LinkClick.aspx?link=lawrence.pdf&tabid=19869&mid=71730>

¹⁴ Corey G. Johnson The Center for Investigative Reporting. June 19, 2014 *Female Prison Inmates sterilized illegally, California Audit Confirms* <http://cironline.org/reports/female-prison-inmates-sterilized-illegally-california-audit-confirms-6471>

¹⁵ See Laura Nixon *The Right to (Trans) Parent: A Reproductive Justice Approach to Reproductive Rights, Fertility, and Family-Building Issues Facing Transgender People* 20 William and Mary Journal of the Law 73 (2013) 84-89

¹⁶ See Laura Nixon *The Right to (Trans) Parent: A Reproductive Justice Approach to Reproductive Rights, Fertility, and Family-Building Issues Facing Transgender People* 20 William and Mary Journal of the Law 73 (2013) 84-89

¹⁷ Kaiser Family Foundation "Distribution of the Nonelderly with Medicaid by Race/Ethnicity." 2016. <https://www.kff.org/medicaid/stateindicator/distributionbyraceethnicity4/?currentTimeframe=0&sortModel=%7B%22colId%22:%22Location%22,%22sort%22:%22asc%22%7D>

against sterilization abuses. Medicaid is indispensable for ensuring that individuals have coverage for family planning, prenatal and pregnancy-related care, STI testing and treatment, preventative services, and other reproductive health services. Additionally 58 percent of Hispanic children rely on Medicaid and the Children’s Health Insurance Program (CHIP). This access to necessary care for otherwise uninsured individuals is vital in reducing health disparities for communities of color.

Policy and clinical efforts regarding unintended pregnancy and the promotion of contraceptive methods in communities of color must take into account this history so these efforts recognize the autonomy of individuals and are culturally competent. These efforts must give our communities the tools and resources needed to independently choose the contraception that is right for them. The Form used for Medicaid-funded sterilization procedures helps to create an environment where individuals can make these decisions free from coercion, bias, and stigma.

II. Ways to Improve Information Collection

42 C.F.R. § 441.258 defines the Form’s content, signature, and certification requirements for states to receive federal financial reimbursement for the procedure. Recent CMS guidance documents reinforced these consent requirements as a condition for federal reimbursement.¹⁸ While the need for the Form continues, the Form itself has remained unchanged for over 40 years.¹⁹ We offer the following recommendations to enhance the quality, utility, and clarity of the consent process for people with disabilities, individuals with limited English proficiency, LGBTQ individuals, and people with low literacy levels who want to undergo sterilization.

Changes to the Interpreter’s Statement

Individuals with limited English proficiency (LEP) and disabilities may also face barriers to understanding the Form. In 2013, LEP individuals were much more likely to be Latino or Asian than their English-proficient counterparts.²⁰ Additionally, Latinos comprised 63 percent of the LEP population, but accounted for only 12 percent of the English-proficient population.²¹

While the Form includes an interpreter’s statement, the text is confusing and inaccurate. For example, the interpreter statement includes the following declaration: “To the best of my knowledge and belief he/she understood this explanation.” This requirement falls well beyond the

¹⁸ CMS, Frequently Asked Questions Medicaid Family Planning Services and Supplies (Jan. 11, 2017), <https://www.medicaid.gov/federal-policy-guidance/downloads/faq11117.pdf>. See also CMS, Dear State Health Official Letter Re: Medicaid Family Planning Services and Supplies (June 14, 2016)(SHO #16-008), <https://www.medicaid.gov/federal-policy-guidance/downloads/sho16008.pdf>.

¹⁹ The “Consent to Sterilization” form was created in 1976 through regulation. Dana Block-Abraham, Kavita S. Arora, et al, *Medicaid Consent to Sterilization Forms: Historical, Practical, Ethical, and Advocacy Considerations*, 58 Clinical Ob. And Gyn. at 412, (June 2015).

²⁰ Jie Zong and Jeanne Batalova. “The Limited English Proficient Population in the United States.” Migration Policy Institute. July 8, 2015. <https://www.migrationpolicy.org/article/limited-english-proficient-population-united-states>

²¹ Jie Zong and Jeanne Batalova. “The Limited English Proficient Population in the United States.” Migration Policy Institute. July 8, 2015. <https://www.migrationpolicy.org/article/limited-english-proficient-population-united-states>

role of a language interpreter. According to the National Council on Interpreting in Health Care, an interpreter cannot speak to the level of understanding of a person for whom they interpret. Rather, an interpreter serves as a conduit handling language and can only attest that they accurately interpreted the information to the best of their knowledge and ability.²² This circumscribed role of an interpreter is further recognized by the two organizations that certify foreign language interpreters, the Certification Commission for Healthcare Interpreters and the National Board of Certification for Medical Interpreters. Both organizations test candidates to ensure their knowledge of the ethics and practice standards governing interpreters.²³ Asking an interpreter to attest that a patient understands a form or understands statements made by a medical provider seeking the patient's informed consent violates the ethics and standards of practice that an interpreter must follow.

The Interpreter's Statement also misuses the term "translated." Translation refers to the conversion of written text into a corresponding written text in a different language.²⁴ Translation involves different skills and abilities than interpretation, which is a process of understanding and analyzing a spoken or signed message and re-expressing that message faithfully, accurately, and objectively in another language, taking the cultural and social context into account.²⁵ There are several methods of interpreting, including sight translation, which involves an interpreter reading text in one language and delivering an oral rendition of the text in another language.

Further, the Form does not adequately address the accessibility needs of people with disabilities and should be inclusive of sign language and other communication methods. For example, individuals fluent in American Sign Language may have trouble reading written English due to differences in grammar structure. Other individuals may use simplified signs and will need an interpreter who works regularly with them and understands their modifications. Deaf Blind people will need tactile signs.

As such, we recommend HHS amend the interpreter statement to cover language interpreting in a foreign language, sign language, and other communication methods.

²² National Council on Interpreting in Health Care, *A National Code of Ethics for Interpreters in Healthcare* at 15 (2004), <http://www.ncihc.org/assets/documents/publications/NCIHC%20National%20Code%20of%20Ethics.pdf>.

²³ For more information, see Certification Commission for Healthcare Interpreters, <http://cchicertification.org/certifications/preparing/>; National Board of Certification for Medical Interpreters, <https://www.certifiedmedicalinterpreters.org/candidate-handbook>.

²⁴ Mara Youdelman, NHeLP, *What's in a Word? A Guide to Understanding Interpreting and Translation in Health Care* (2010), http://www.healthlaw.org/issues/health-disparities/whats-in-a-word-a-guide-to-understanding-interpreting-and-translation-in-health-care-full-guide#.W4_-hOhKjIU.

²⁵ Mara Youdelman, NHeLP, *What's in a Word? A Guide to Understanding Interpreting and Translation in Health Care* (2010), http://www.healthlaw.org/issues/health-disparities/whats-in-a-word-a-guide-to-understanding-interpreting-and-translation-in-health-care-full-guide#.W4_-hOhKjIU.

Current language: I have translated the information and advice presented orally to the individual to be sterilized by the person obtaining this consent. I have also read him/her the consent form in _____ language and explained its contents to him/her. To the best of my knowledge and belief he/she understood this explanation.

RECOMMENDATION: We recommend HHS revise the interpreter statement as follows:

I have accurately interpreted the information that was presented orally by the person obtaining this consent to the individual to be sterilized. As requested by the person obtaining consent, I have also:

__ sight translated the consent form into _____ (Specify Language) _____; or
__ interpreted a summary of the form into _____ (Specify Language) _____ or an alternative format as communicated by the person obtaining the consent to the individual to be sterilized.

Changes to Make the Form More Gender Inclusive

We recommend HHS amend the “he/she” pronouns used in the Form to more accurately reflect the nonbinary nature of gender identity. Gender identity and expression are fluid, and adopting more inclusive language will help enhance the utility and quality of the consent process for transgender, gender nonconforming, and gender non-binary individuals seeking sterilization. We recommend using the singular pronoun “they” and “their” in place of “he/she” and “his/her,” respectively.

Changes to Improve Readability

Studies have shown that the Form is difficult to read and understand.²⁶ The Form’s text is written at a ninth grade reading level, which exceeds the recommended level for patient education and informed consent materials.²⁷ The Form’s lack of readability is a serious concern because sterilization has life-altering consequences for the women who undergo the procedure. The NIH recently awarded a grant to support a research project that found that women of color and women with low-incomes were less likely to understand that sterilization is a permanent procedure.²⁸

Another study tested a low-literacy version of the Form and found improved understanding of the permanent nature of the procedure, the time limits associated with the form, and the availability of

²⁶ N.B. Zite & L.S. Wallace, *Medicaid-Title XIX Sterilization Consent Form: Is it Readable?*, 74 *CONTRACEPTION*, 180 (2016). See also Nikki B. Zite, Sandra J. Philipson, & Lorraine S. Wallace, *Consent to sterilization section of the Medicaid-Title XIX Form: Is it Understandable?*, 75 *CONTRACEPTION*, 256-260 (2007).

²⁷ N.B. Zite & L.S. Wallace, *Medicaid-Title XIX Sterilization Consent Form: Is it Readable?*, 74 *CONTRACEPTION*, 180 (2016). See also Nikki B. Zite, Sandra J. Philipson, & Lorraine S. Wallace, *Consent to sterilization section of the Medicaid-Title XIX Form: Is it Understandable?*, 75 *CONTRACEPTION*, 256-260 (2007).

²⁸ Wes Venteicher, *Sterilization Among Low-income Women Target of New Pitt study*, *TRIBUNE REVIEW* (Sept. 1, 2017), <https://triblive.com/local/alleggheny/12682263-74/sterilization-among-low-income-women-target-of-new-pitt-study>.

long-acting reversible contraceptive options which are as effective as sterilization.²⁹ When asked which form they preferred, an overwhelming majority (94%) of study participants preferred the low-literacy version.³⁰

In addition, we recommend HHS consider the font type, font size, line spacing, and column width of the Form to improve its overall visual readability. HHS should also consider accessibility requirements for individuals with disabilities when modifying the Form.

Technical Corrections

Finally, the Form contains some typos, grammatical errors, and inaccuracies that should be corrected:

Section	Current language	Explanation
Consent to Sterilization	“I will not lose any help or benefits from programs receiving Federal funds, such as Temporary Assistance for Needy Families (TANF) or Medicaid that I am now getting or for which I may become eligible.”	Some federally funded state Medicaid family planning expansion programs will not cover family planning services (such as STI/STD testing) after a sterilization procedure. ³¹
	“I, _____, hereby consent of my own free will to be sterilized ...”	Fill-in-the-blank should direct the patient to enter their name.
	“I am at least 21 years of age and was born on: <u> Date </u> ”	Fill-in-the blank should be clarified and direct the patient to enter “Date of Birth.” The sentence is also missing a period.

²⁹ N.B. Zite & L.S. Wallace, *Use of Low-literacy Informed Consent Form to Improve Women’s Understanding of Tubal Sterilization: A Randomized Controlled Trial*, 1117 *Ob Gyn.* 1160-66 (2011).

³⁰ N.B. Zite & L.S. Wallace, *Use of Low-literacy Informed Consent Form to Improve Women’s Understanding of Tubal Sterilization: A Randomized Controlled Trial*, 1117 *Ob Gyn.* 1160-66 (2011).

³¹ For example, Mississippi’s 1115 demonstration waiver for family planning services limits eligibility to “women and men, ages 13 through 44, *who are capable of reproducing*” (emphasis added). CMS, Approval Letter for Mississippi Family Planning Medicaid Waiver Section 1115 Demonstration 7 (Dec. 28, 2017), <https://www.medicare.gov/Medicare-CHIP-Program-Information/By-Topics/Waivers/1115/downloads/ms/ms-family-planning-medicare-expansion-project-ca.pdf>.

	“You are requested to supply the following information, but it is not required: (<i>Ethnicity and Race Designation</i>)(<i>please check</i>)”	The request for race/ethnicity should explain why the data is being collected, and reiterate the confidential nature of the information collection. We also recommend the inclusion of a fill-in-the-blank option. Also, the purpose of the text contained inside the first parenthetical (“Ethnicity and Race Designation”) is unclear, and should be struck. In addition, the text in the second parenthetical (“please check”) should be modified to allow the patient to check all of the race/ethnicity categories that apply.
	See comments above, under “Issues with the Interpreter’s Statement.”	See comments above, under “Issues with the Interpreter’s Statement.”
Interpreter’s Statement	“Before <u>_(Name of Individual)_</u> signed the consent form, I explained to him/her the nature of sterilization operation...”	Insert “the” before “sterilization operation.”
Statement of Person Obtaining Consent	Use of “him/her” and “he/she”	See comments above, under “Need for gender inclusive language.”

Given the long history and continuation of abusive and coercive sterilization practices in the U.S., NLIRH recommends that HHS revise the Form based on our suggestions. Our recommendations will improve states’ and providers’ ability to meet the regulation’s consent requirements, and equip Medicaid enrollees considering voluntary sterilization to make a more informed decision.

Thank you for the opportunity to comment. If you have any questions or need any additional information, please contact Nina Esperanza Serriane at the National Latina Institute for Reproductive Health at nina@latinainstitute.org.

Sincerely,

National Latina Institute for Reproductive Health