2019 Comments on behalf of Monica R. McLemore PhD, MPH, RN
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COMMITTEE ON ENERGY AND COMMERCE
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I am grateful to provide my clinical, scientific, and research expertise to the committee in written form to educate the committee about the importance of Title X, the federal family planning program, that serves low-income individuals – that was signed into law in 1970, by then President Richard Nixon. It is important to recognize that I have published evidence-based OpEds specific to this issue[1-2] and I include these writings as an official component of my written testimony. I will cite my work and the work of others to provide primary sources for the data I use in this testimony.

Positionality and Expertise

I have been a licensed registered nurse since 1993 and for most of my career I have worked clinically in facilities that have received Title X funding. This includes 18 years with my current clinical employer, Zuckerberg San Francisco General Hospital and Trauma Center; an additional combined 9 years at Planned Parenthood, Kaiser Permanente, and Stanford University Medical Center. I am an expert nurse in the provision of sexual and reproductive healthcare services. My skills include patient education and counseling, provision of contraception and abortion services, ultrasound, cardiac monitoring, procedural sedation, symptom management, telephone triage, and emotional and physical support. As a faculty member, I teach in courses such as Childbearing Families, Maternal Child Nursing, and Contraception in Primary Care – a pharmacology course for advanced practice clinicians. As a researcher I explore topics within sexual and reproductive healthcare provision, specific but not exclusive to nurses and patients' experiences of their care. I employ reproductive justice (RJ) as a theory and praxis to guide all of my work – a full definition of RJ is provided with other definitions I use throughout this written testimony.

Outline of Testimony

I have planned my oral testimony around three distinct themes and my written testimony mirrors that approach. These four categories are: 1) Impact on Public Health Goals, and more specifically why the proposed rule change is a direct violation of principles of reproductive justice; 2) The Professional and Ethical Responsibilities of Providers and the Confidentiality and Privacy Issue Caused by the Rule Change; and finally, 3) How the Rule Change Stymies Innovation & Increases Healthcare Costs. First, I plan to define terminology; next I present these themes; finally, I end with some resources that I believe are crucial to fully understand the potential impact of this rule change and to increase the knowledge of those involved in this investigation.

Definitions

- Where appropriate, I used gender neutral language to encompass the widest range of the public that we serve. People with the capacity for pregnancy is the preferred term I use for people who birth other humans.
- Reproductive Justice (RJ) is is simultaneously a theory, practice and a strategy that is grounded in four principles. Simply put, RJ posits that every person has the right to decide if and when to become pregnant and to determine the conditions under which they will birth and create families. Next, every person has the right to decide they will not become pregnant or have a baby and options for preventing or ending pregnancy are accessible and available. Third, individuals have the right parent children they already have with dignity and has the necessary social supports in safe environments and health communities without fear of violence from individuals or the government. Finally, individuals have the right to disassociate sex from reproduction and that health sexuality and pleasure are essential components to whole and full human life.[3]
- I use the World Health Organization's definition of Sexual and Reproductive Health: "Sexual health is an integral part of overall health, well-being and quality of life. It is a state of physical, emotional, mental and social well-being in relation to sexuality, and not merely the absence of disease, dysfunction or infirmity. Sexual health requires a positive and respectful approach to sexuality and sexual relationships, as well as the possibility of having pleasurable and safe sexual experiences, free of coercion, discrimination and violence. For sexual health to be attained and maintained, the sexual rights of all people must be respected, protected and fulfilled."[4]

I. Impact on Public Health Goals (and more specifically why the proposed rule change is a direct violation of principles of reproductive justice).

Ensuring all people of reproductive age can achieve their reproductive life goals is an essential component of public health. Additionally, Reproductive Justice (RJ) is essential to bodily autonomy, human rights principles, and existential liberation for all humans. Reproductive Justice (RJ) is is simultaneously a theory, practice and a strategy that is grounded in four principles. Simply put, RJ posits that every person has the right to decide if and when to

become pregnant and to determine the conditions under which they will birth and create families. Next, every person has the right to decide they will not become pregnant or have a baby and options for preventing or ending pregnancy are accessible and available. Third, individuals have the right parent children they already have with dignity and has the necessary social supports in safe environments and health communities without fear of violence from individuals or the government. Finally, individuals have the right to disassociate sex from reproduction and that health sexuality and pleasure are essential components to whole and full human life.[3] Therefore, academicians, activists, clinicians, researchers, and scholars, believe that Title X, like Title V are essential components to achieve reproductive justice.

There are currently 4,000 entities designated as Title X grantees and 40% are Planned Parenthood health facilities. Half of the people served at Title X clinics are people of color.[1] Nurses (nurse practitioners, nurse midwives and public health nurses) have been the mainstay of sexual and reproductive health care, including in Title X and Planned Parenthood centers, and provide crucial access for vulnerable and low-income populations.[5] These clinics also provide training for nursing and medical students — clinic closures will reduce the pipeline of appropriately trained clinicians.[1]

Additionally, federal funding for low-income individuals who seek family planning services affirms one of the most basic human rights – bodily autonomy. The right to bodily autonomy has been recognized in both life and death. One of the reasons why even when you are dead, informed consent is required for organ and tissue donation.[6]

Next, Title X grantees provide a wider range of services consistent with public health priorities that are aligned with, but not unique to family planning. Pregnancy spacing, allowing individuals to be as healthy as possible prior to becoming pregnant including preconception wellness are known interventions that impact preterm birth (born too soon) and infant mortality. Additionally, screening for sexually transmitted infections including HIV, and care of lesbian, gay, bisexual, transgender, queer, intersex, asexual, and agender individuals are priority areas for public health. It is already known that zip code impacts one's health more than their genetic code.[7] It is essential that poverty be addressed using a lifecourse approach[8] to ensure all people with the capacity for pregnancy be able to attain their person and reproductive life goals.

These rule changes force providers into an impossible choice: Will we care for the pregnant person in front of us and make a requested referral for abortion related services, or will we accept funds allowing us to care for thousands of others? The new rule also imposes cumbersome physical and financial demands on abortion providers who receive Title X funds, which further limit access to abortion care. The proposed changes to the rule are not about "paying for abortion"—rather, if directly asked for an abortion referral, providers would have to respond that as a Title X grantee, we cannot refer them, and we would be limited instead to providing a resource list of comprehensive providers without specifying whether they offer abortion services. **But this rule does mean that we cannot support our patients to make the best decision for themselves and their lives.**

II. The Professional and Ethical Responsibilities of Providers and the Confidentiality and Privacy Issues Associated with the Rule Change for Patients.

The new Title X rules proposed by the current administration means federally funded family planning clinics can no longer refer a patient for abortion and must maintain a "clear physical and financial separation" between services funded by the government and any organization that provides abortions or abortion referrals. This component of the proposed rule change is extremely concerning and problematic for two distinct reasons: 1) potential loss of privacy and confidentiality – including Health Insurance Portability and Accountability Act (HIPAA) of 1996; 2) the violation of informed consent.

Co-location of health services has been shown to be both cost effective and improve health outcomes. This has been particularly true in the context of comprehensive cancer services.[9] My use of oncology and cancer as an exemplar is not by accident. My dissertation entitled *An Evaluation of the Molecular Species of CA125 Across the Three Phases of the Menstrual Cycle* specifically examined the CA125 biomarker that is used to distinguish benign from malignant masses of the ovary and is used to monitor epithelial ovarian cancer. I published 5 manuscripts from this work.[10-14] It has long been understood that the tumor growth and development is biologically similar to pregnancy and that most of the pathways used at a molecular level are similar. A paradigm shift was developed in cancer research to understand that comprehensive and systems approaches would accelerate discoveries and reduce costs. The proposed rule change is inconsistent with this trend in other health services provision – and creates unnecessary and costly silos.

Additionally, comprehensive family planning services have been offered with abortion services and vice versa to center patient needs and reduce the undue burdens of multiple visits, additional costs for childcare, and transportation. If facilities are to develop "clear physical and financial" separation, for many Title X grantees this may mean creating separate physical clinic spaces and therefore inadvertently violating privacy. For example, in the clinical environment where I work, sending patients to different space for clinical services in and of itself could violate their rights to privacy – whether it's accessing a different unit, floor, space or building. Additionally, if different forms, paperwork, electronic health records or other documentation of care provided needs to be distinguished from other types of care, this creates unnecessary redundancy, cost, and other potential violation of privacy.

The proposed rule change violates the American Nurses Association's (ANA) Code of Ethics[15] that reads: "ANA has historically advocated for the healthcare needs of all patients, including services related to reproductive health. ANA believes that healthcare clients have the right to privacy and the right to make decisions about personal health care based on ***full information and without coercion***. Also, nurses have the right to refuse to participate in a particular case on ethical grounds. However, if a client's life is in jeopardy, nurses are obligated to provide for the client's safety and to avoid abandonment. This rule would clearly limit the capacity of nurses to provide fully informed consent."

Finally, the patient-provider relationship is inherently one of unequal power: The patient is seeking expertise, in many cases, from a person with the power to act as a gatekeeper. That power imbalance is often intensified by class, health literacy, race, sexual orientation and gender identity differences between providers and patients—with potentially catastrophic consequences.[2] The successful patient-provider relationship relies on trust: in state and federal regulations, in accrediting organizations and in the provider acting in partnership with the patient. The proposed rule changes to Title X destroys that fragile balance between power and trust.

All of the major U.S. nursing organizations (American Academy of Nursing, American Nurses Association, American College of Nurse-Midwives, Nurse Practitioners in Women's Health) have joined with other professional organizations (American Medical Association, American College of Obstetricians and Gynecologists, American Academy of Pediatrics, Society for Adolescent Health and Medicine) to denounce the proposed rules for placing providers in ethically compromising positions and threatening quality of care.[1]

III. How the Rule Change Stymies Innovation & Increases Healthcare Costs.

The expertise of Title X grantees cannot be replicated in any other healthcare entity that currently exists. This clinical expertise in non-directional counseling,[16] decisional assessment,[17] and shared decision-making[18] has been a true innovation in team-based care approaches. Led by nurses, counselors, medical assistants, physician assistants, midwives, and physicians, this expertise has the potential to be lost – after almost 50 years of cost-effective care. Particularly, when it is known that for every dollar spent on family planning save $5 to $7 in later healthcare and service costs.[19]

Title X clinics already adhere to standards for quality family planning[20] developed by the Centers for Disease Control and Prevention and the Office of Population Affairs. These new regulations do nothing to improve quality of care, access or cost. Instead, they will degrade quality and access while adding costs due to delayed or unavailable care. To best serve the public, rule changes should be based on evidence, the highest standards of care and improving the health of our nation; not political ideology.

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