

Jaime Miracle Deputy Director Senate Concurrent Resolution 14 Proponent Testimony Senate Health, Human Services, and Medicaid Committee June 24, 2020

Chairman Burke, Ranking Member Antonio, and members of the Senate Health, Human Services, and Medicaid Committee, my name is Jaime Miracle and I am the Deputy Director of NARAL Pro-Choice Ohio. I am sending in this written testimony in support of Senate Concurrent Resolution 14, to declare racism a public health crisis, on behalf of our more than 50,000 members and activists.

Thank you, Senators Craig and Williams, for introducing this critical resolution and to all of the activists and racial justice organizations who have been calling for this action for years for never giving up. You might ask, why is it important to be so specific and name racism as a public health crisis in Ohio. To be able to fully address a problem and propose solutions to fix a problem, you have to know what the problem is. For far too long, race has been seen as the risk factor, when in fact it is racism that is the root cause of all of the racial disparities we face in our state and across the nation. To those who ask, "Why now?" I ask you to look around. Look at the disparities our nation faces; COVID-19 infection rates and death rates for Black, indigenous, and people of color (BIPOC) that are much higher than their white counterparts; infant mortality and maternal mortality rates for Black Ohioans are several times greater than white Ohioans.

But these statistics barely scratch the surface of the centuries of inequities that BIPOC have experienced in the United States. Our entire government, our laws, our systems have been built on a foundation of racism and through the lens of white supremacy. This is why it is so critical that this resolution calls for a commitment to reviewing all portions of the Revised Code with a racial equity lens as well as reviewing all human resources, vendor selection, and grant management through this lens. Structural racism is defined as "a confluence of institutions, culture, history, ideology, and codified practices that generate and perpetuate inequity among racial and ethnic groups¹."

Racism is complex and multi-layered. It is not just the overt racist statements, but the covert assumptions and biases that happen every day to people of color. Racism is all around us, each and every day, and very often they go unnoticed and unchallenged by white people. It is because racism is so pervasive that we cannot just put a band-aid on the problem and wish it away. We must really examine the racist foundations of our policies and our work and rebuild systems from the ground up in order to be able to fulfill the promise Ohio should have for each of us — to be able to live healthy and happy lives free of discrimination no matter what your skin color is.

For example, just take the subject of sexual health and gynecology. Did you know that the so called "founder of modern gynecology" was a doctor named J. Marion Sims? Did you know that in the mid-1800's he became famous for his modernization of gynecological practices and surgeries by experimenting on enslaved Black women, often performing multiple surgeries on them without any anesthesia? Sims took advantage of their status as enslaved people to experiment on them and to perfect his methods, even purchasing one woman for the express purpose of experimenting on her. Lucy, Anarcha, and Betsey were three of his victims that we know of, but there were many

¹ Jones CP. Confronting institutionalized racism. Phylon 2002;50:7-22; https://www.jstor.org/stable/4149999?seq=1

² https://www.theatlantic.com/health/archive/2018/04/j-marion-sims/558248/

others we don't know anything about. Dr. Sims performed thirty surgeries on Anarcha alone, all without anesthesia.³ A ban on importing enslaved people took effect in 1808, meaning that the ability enslaved women to bear children was even more valuable. Ensuring enslaved people could reproduce was critical to continuing slave trading and the economy of the southern states.⁴ This practice continued from 1808 until June of 1865 when the news of the Emancipation Proclamation finally reached southern Texas, over two years after the end of slavery had been declared in the United States.

In 1932 the US Public Health Service, working with the Tuskegee Institute, began a decades long study into the "natural history of syphilis." The 399 Black men with syphilis in the study were being told that they were being treated for disease, but never received treatment, even after penicillin was accepted as the treatment of choice in 1945. The study was reaffirmed in 1969 by the CDC, with the support of the American Medical Association, and it wasn't until the first news articles came out critical of the program in 1972 that the study was finally halted.⁵

Continuing the legacy of a lack of ethics and medical standards when treating Black folks in the US, at Johns Hopkins Hospital in 1951, a woman named Henrietta Lacks walked into the hospital complaining of vaginal bleeding. Because of lack of access to health care, by the time Ms. Lacks walked into the hospital she had a large cancerous tumor on her cervix. Even with radium treatment for her tumor Ms. Lacks died on October 4, 1951 at the age of 31. She left behind a husband and five young children. What the Lacks family didn't know at the time was that some of her cancerous cells had been removed during a biopsy and were sent to a lab, where researchers celebrated because unlike every other cell Dr. George Gey had tried to culture Henrietta Lacks' cells thrived in culture, doubling every 24 hours.

Without her knowledge and without compensation, Henrietta Lacks' cells became known as the "HeLa" cell line and have been used to study the human genome, develop the polio vaccine, cloning, in vitro fertilization, and so much more. Her cells have been sold across the globe, all without any compensation to her family, and until recently without even being connected to her story. In fact, I worked in a lab with derivatives of these cells many years ago, not knowing anything about their history and how they were developed without the consent or knowledge of the Black woman they came from.

The emergence of birth control opened up a whole new era of racist practices and racist medical system. From the beginning, controlling birth was less about an individual person deciding to control their fertility and more about society determining who was fit to reproduce and who should be stopped from doing it. The US has a long history of forced sterilization of Black, indigenous, and people of color many times without the patient even knowing that they had been sterilized, other times as punishment for being poor. Instead of giving people the information about what was available and letting them decide for themselves, these decisions were made for individuals under the belief that society knew what was better for them than they did.

Author Dorothy Roberts explains in her book *Killing the Black Body: Race, Reproduction, and the Meaning of Liberty,* because of its history, "birth control became a means of controlling population, rather than a means of increasing women's reproductive autonomy. Birth control in America was defined from the movement's inception in terms of race and could never be properly understood

³ Ojunga, Durrenda (March 1993). <u>"The medical ethics of the 'Father of Gynaecology', Dr J Marion Sims"</u>. *Journal of Medical Ethics*. **19** (1): 28–31. doi:10.1136/jme.19.1.28

⁴ Wilma King, *Stolen Childhood: Slave Youth in Nineteenth-Century America* (Bloomington: Indiana University Press, 1995)

⁵ https://www.cdc.gov/tuskegee/timeline.htm

apart from race again." Unfortunately this racist history is still something that white-led reproductive health and rights organizations struggle with today. How do we acknowledge this racist history in the movement as we fight for individual bodily autonomy in 2020? How do we re-build systems of health care delivery structured from this racist history? It is only through naming it, continuously working on it, and rebuilding systems from the ground up that we will ever be able to begin to overcome this racist history. Strong declarations like SCR 14 will allow everyone to start unpacking the racist history of health care delivery and allow for everyone to finally access the care they deserve, on their terms, and in their communities. It is this form of health care delivery that we fight for each and every day at NARAL Pro-Choice Ohio.

Even the testing of the eventual birth control pill has racist origins. The first large scale human trials of the first birth control pills happened in the mid-1950's in a public housing project in Puerto Rico. Where patients were recruited to test the medication without telling them that they were essentially guinea pigs in testing the world's first birth control pill. Little was known about the drug's effects when human trials began. Enovid had been tested in rats and rabbits, but only a small sampling of human patients had taken the drug before the large-scale trial was launched. By the end of the trial as many as 1,500 women had taken the drug in Puerto Rico. Researchers knew they had an opportunity and they preyed on a population of poor, uneducated, and desperate population to conduct their trial. Doctors from the continental US descended on the rural town of Humacao at first to deliver their babies, but soon after were recruiting them to join the study.⁷

Three women in the trial died, but they didn't even perform autopsies to figure out if their deaths were linked to the drug. From its use in the US for other gynecological issues, we know that six women are known to have died from taking the medicine by 1962. The pills in this study were much higher doses than modern birth control pills that carry much less risk but are still known to cause blood clots in higher risk individuals. The study continued in Puerto Rico even after women in the continental United States complained about the side effects caused by the drug. They needed a population desperate enough to continue taking the pills even if it caused depression, headaches, and blood clots. In the words of one study participant, Delia Maestre, "Why didn't they let us make some decisions for ourselves? I have difficulty explaining that time to my own grown children. I have very mixed feelings about the entire thing."

You might be thinking as you read this that these stories are all in the past, that medical science has rules and procedures in place to stop these things from happening now. Yes, there are now rules on how you enroll subjects in research projects, rules about compensation, rules about informed consent. But that doesn't mean that racism doesn't still exist in the delivery of reproductive health care today. Our infant mortality rates and maternal mortality and morbidity rates in Ohio are some of the worst in the nation, and the racial disparities in these statistics are stark. Latinx women have the highest rate of severe maternal mortality (often referred to as a "near miss" by doctors referring to the fact that the patient could have died because of their condition). An average of 215 Latinx women experienced life-threatening health problems within a year of giving birth per 10,000 deliveries, compared to 124 per 10,000 deliveries for white women. Black women have the highest rate of pregnancy-related maternal mortality, with 42.8 deaths per 100,000 live births, compared to 13.0 deaths per 100,000 for white women. You can read more about this and other racial disparities in health in the NARAL Pro-Choice Ohio Foundation report, *The State of Choice*, authored by program and research manager Ashley Underwood and released earlier this month.⁹

⁶ Roberts, Dorothy, *Killing the Black Body: Race, Reproduction, and the Meaning of Liberty* (New York: Vintage Books, 1997)

⁷ https://www.chicagotribune.com/news/ct-xpm-2004-04-11-0404110509-story.html

⁸ https://www.washingtonpost.com/news/retropolis/wp/2017/05/09/guinea-pigs-or-pioneers-how-puerto-rican-women-were-used-to-test-the-birth-control-pill/

⁹ Underwood, Ashley, *State of Choice in Ohio.* NARAL Pro-Choice Ohio, released June 2020. https://prochoiceohio.org/state-choice-2020/

The reasons why these rates are higher are complicated, but one emerging factor is that doctors do not believe Black and Latinx women when they report pain or other complications following childbirth. Even tennis superstar Serena Williams experienced this when giving birth to her daughter. The day after her emergency c-section Serena Williams, who has a history of pulmonary embolism (a condition in which arteries in the lungs become blocked by a blood clot), noticed she was out of breath, a symptom of pulmonary embolism. She immediately told the nurses and said she needed a CT scan and IV heparin (a blood thinner) right away. The nurse blamed it on confusion because of her pain medication, but Serena Williams persisted. A doctor came and did a doppler scan and found nothing, but she continued to push for a CT scan which revealed that several blood clots were in her lungs. Coughing from the clots in her lungs caused her c-section wound to open, revealing additional bleeding in her abdomen. Several procedures later she was finally home, but unable to get out of bed for six weeks.¹⁰

If this happens to a world-famous tennis star, what do you think happens to a regular woman from down the street? Story after story exists of Black women not being trusted and heard. Sometimes BIPOC women like Serena Williams survive, but all too often these stories end with the death of the woman or of the baby when a family should be celebrating the new addition. Even in the neonatal intensive care unit (NICU), racial disparities exist. In a term often referred to by NICU personnel as "wimpy white boy syndrome," white babies are seen as more frail and needing more care than their Black counterparts. White babies frequently get more attention, more handling, and more care in the NICU as they struggle for their lives.¹¹

These issues are not just a problem for Black Ohioans. A 2005 National Healthcare Disparities Report indicated white patients receive better quality of care than 53% of Hispanic, 43% of African American, 38% of American Indian/Alaska Native, and 22% of Asian and Pacific Islander patients. In 2010 a follow up study showed no changes in racial health disparities of 30 of 41 quality core measures for Hispanics, 40 of 47 measures for African Americans, 13 of 19 measures for Asians, and 15 of 22 measures for American Indian of Alaska Natives compared with non-Hispanic whites. Additionally, most of the current reporting and research does not account for trans and non-binary people when talking about health disparities. People who are both BIPOC and trans or non-binary experience multiple systems of inequities in health care. Much more research must be done in this area to really see the intersections of race, ethnicity, sex, and gender.

Naming racism is a critical first step. We cannot even begin to address a system of oppression unless that system is defined. We have let the racist systems sit unchallenged for far too long. We must begin to dismantle the systems of racism in our government, in our communities, in our health care settings, and every other place where they exist. Now is the time for actions, not platitudes. Now is the time for real change — not trivial measures that make legislators feel good but don't really challenge racism in any real way. Now is the time to pass this resolution and begin the process for making Ohio's promise real for everyone who lives here, no matter their skin color. NARAL Pro-Choice Ohio stands ready to face these challenges and work with legislators to create this new reality.

¹⁰ https://www.vogue.com/article/serena-williams-vogue-cover-interview-february-2018

https://pediatrics.aappublications.org/content/140/3/e20170918

¹² Agency for Healthcare Research and Quality. National Healthcare Disparities Report. Rockville, MD: 2005. Available at: http://www.ahrq.gov/qual/nhdr05/fullreport/Index.htm

¹³ Agency for Healthcare Research and Quality. National Healthcare Disparities Report. Rockville, MD: 2010. Available at: http://www.ahrq.gov/qual/nhdr10/nhdr10.pdf