Reproductive Justice Principles for Federal Universal Health Care Reform

Thirty years ago, twelve Black women — Dr. Toni M. Bond Leonard, Reverend Alma Crawford, Evelyn S. Field, Terri James, Bisola Marignay, Cassandra McConnell, Cynthia Newbille, Loretta Ross, Elizabeth Terry, 'Able' Mable Thomas, Winnette P. Willis, and Kim Youngblood—gathered to discuss the Clinton administration's health care reform plan, which, similar to the white-led pro-choice and mainstream feminist movements, failed to address the unique struggles and voices of Black women and other marginalized groups. On August 16, 1994, the group, called Women of African Descent for Reproductive Justice, published a full-page letter to Congress in the *Washington Post* and *Roll Call* titled "Black Women on Health Care Reform." They demanded universal, comprehensive, and affordable health coverage and access with robust nondiscrimination protections for all. They expressed the urgent need for equitable access to all health services, including diagnostic, treatment, preventive, long-term care, mental health services, prescription drugs, and care for people with pre-existing conditions. They would "not endorse a health care reform system that does not cover the full range of reproductive services for all women—including abortion." They emphasized that the U.S. would not achieve these goals until Black women had meaningful representation in national, state, and local planning, review, and decision-making bodies. Nearly 850 Black women signed on.

Through that action, they forged a groundbreaking analytical, organizing, and movement-building framework rooted in intersectionality, human rights, and social justice. Reproductive justice (RJ) is the human right to bodily autonomy; to have children, not have children, and raise them in safe, healthy, and sustainable communities; and to live with dignity. Ultimately, RJ can only be achieved when all people have the economic, social, and political power and resources to make their own decisions about their bodies, health, sexuality, families, and reproduction.

While some progress has been made to advance RJ in health care, significant challenges remain. For example, Medicaid eligibility gaps in non-expansion states and for many immigrants persist. The last several years have marked backsliding in the fight for RJ in health care. In 2022, the Supreme Court of the United States ushered in another setback when it overturned the constitutional right to abortion in *Dobbs v. Jackson Women's Health Organization*. While that right was never enough to ensure access, especially for underrecognized and low-income communities due to barriers such as the Hyde Amendment, *Dobbs* has made things much worse. Gender-affirming care and vital preventive services such as pre-exposure prophylaxis (PreP) for HIV and contraceptives are also facing intensified attacks.

The Medicaid and Reproductive Justice Collaborative is comprised of Advocates for Youth, In Our Own Voice: National Black Women's Reproductive Justice Agenda, National Asian Pacific American Women's Forum, the National Health Law Program, the National Latina Institute for Reproductive Justice, and Unite for Reproductive & Gender Equity. Together, we have developed the following *Reproductive Justice Principles for Federal Universal Health Care Reform (Principles)* for policymakers and advocates. In honor of the RJ movement's thirtieth anniversary, our *Principles* aim to build upon the vision articulated by the Women of African Descent for Reproductive Justice in their 1994 letter to Congress, addressing persistent reproductive injustices in our health care system today. The Medicaid and Reproductive Justice Collaborative calls on Congress to prioritize the following RJ *Principles* in federal universal health care reform efforts:

1. **All people in the U.S. experience the human right to universal health care coverage and access, including access to culturally and linguistically appropriate sexual, reproductive, and gender-affirming health care.**

   Universal health care coverage means that everyone living in any U.S. state or territory should have access to health coverage and care that reflects the principles below, regardless of race, ethnicity, sex (including sex stereotypes, pregnancy or related conditions, sex characteristics including intersex traits, gender identity, sexual orientation, and sexual activity or behavior), national origin, immigration status or length of stay, migrant status, language, disability, age, income (including source of income or use of public benefits), fatphobia, or any combination thereof. This human right encompasses a comprehensive range of services necessary to support physical, mental, and social well-being. Under the international human rights framework, this unequivocally includes ensuring access to culturally and linguistically appropriate sexual, reproductive, and gender-affirming health care. By firmly establishing health care as a fundamental human right within the framework of RJ, we resolutely affirm the intrinsic dignity and worth of every individual.

2. **Underrecognized communities are equitably represented among policymakers.**

   Equitable representation at every level of health care, including policymaking, is essential to ensure that universal health care reform truly serves all communities, particularly those that have historically been marginalized and underrecognized. These communities must have equitable access to all institutions that hold power over people's health care. To achieve RJ in our health care system, we cannot entrust decisions solely to the communities that have benefited from longstanding systems of domination and oppression. We must invest in the leadership of policymakers and candidates from underrecognized communities in federal health policymaking bodies, such as Congress, the White House, and the U.S. Department of Health and Human Services. This includes Black, Latine, Indigenous, Asian American, Pacific Islander, and other people of color; Lesbian, Gay, Bisexual, Transgender, Queer, Intersex, Plus (LGBTQI+ people), im/migrants, people with limited English proficiency (LEP), disabled people, youth, individuals with lower socioeconomic status, and those who live at the intersections of multiple marginalized identities. We believe that lived experience with systemic inequities can provide invaluable insights and unique perspectives, as we recognize that the people closest to the problems are often closest to the solutions. Achieving participatory parity will help ensure that universal health care reform is grounded in the realities and needs of diverse communities, ensuring that their perspectives, concerns, and expertise are genuinely considered and integrated into policy discussions and decision-making and resulting in a more inclusive and responsive policymaking process.

3. **Underrecognized communities' concerns and vision guide reform throughout design, implementation, and evaluation.**

   Meaningful community engagement at every stage of the universal health care reform process (*e.g.,* design, implementation, evaluation, iteration) is crucial to ensure that we are working toward a more inclusive, effective, and equitable health care system that fosters RJ for all. Policymakers must prioritize centering the expertise and addressing the concerns of communities most impacted by systemic reproductive oppression, beginning with centering and deeply listening to underrecognized communities.

4. **All people are liberated from health care discrimination.**

   Achieving RJ requires liberation from discrimination or coercion. Historically and presently, underrecognized communities have faced heightened discrimination, bias, and neglect within our health care system. Reform must build and expand upon current nondiscrimination protections, such as those outlined in Section 1557 of the Affordable Care Act (ACA). This includes strengthening protections against discrimination by health care entities and professionals (e.g., all health insurance plans, all health-care providers and professionals, and all government agencies), including reproductive coercion and barriers to culturally and linguistically congruent care, based on race, ethnicity, sex (including sex stereotypes, pregnancy or related conditions including abortion, sex characteristics such as intersex traits, gender identity, sexual orientation, sexual activity or behavior), national origin, immigration status or length of stay, language, disability, age, income (including source of income and public benefits), fatphobia, or any combination thereof. Examples of discriminatory practices include, but are not limited to, reproductive coercion such as forced or coercive sterilization or other forms of contraception, barriers to contraception and abortion access, obstetric violence, inadequate pain management, and denials of culturally and linguistically congruent care based on any of the classes listed above. Equitable access necessitates halting these discriminatory practices and ensuring meaningful participation in health care programs and services for historically marginalized communities. Addressing these inequities demands targeted education and accountability for health care providers to enhance standards of care and eliminate bias.

5. **Coverage includes comprehensive benefits that meet all health care needs.**

   Universal health care reform must ensure access to the health care needs of all people living in the United States. Centering RJ in reform means eliminating benefit coverage gaps and providing coverage without any annual or lifetime limits. The current Medicaid program provides a current baseline to serving individuals with low-incomes and their unique needs. Thus, universal health care reform must ensure that those currently eligible for Medicaid and future enrollees with low incomes receive, at a minimum, the services they would receive through Medicaid. To achieve the principles of RJ, federal universal health care must include:

   - **Sexual, Reproductive, and Gender-Affirming Care Services:** Coverage must include full-spectrum sexual, reproductive, and gender-affirming health care, adhering to medical standards of care. Benefit packages must at least cover: abortion services; preventive services as currently recognized by the ACA (*e.g.,* contraception; STI and HIV preventive services such as PreP); full-spectrum doula services; pregnancy care (*e.g.,* midwifery care(including registered and community midwives); pelvic floor therapy); unbiased and medically accurate counseling; care for chronic sexual and reproductive health conditions (*e.g.,* viral load suppression for HIV); menstrual products; and gender-affirming care.

- **Early and Periodic Screening, Diagnostic, and Treatment (EPSDT) services:** Enrollees under age 21 must be eligible to receive Early and Periodic Screening, Diagnostic, and Treatment coverage at least as required currently under the Medicaid Act. This includes timely and appropriate medical screenings to detect, treat, or manage potential conditions. Medical screenings must be comprehensive and include: vision, dental, hearing, and medical services (*e.g.,* physical examination, immunization, laboratory testing, developmental history, and health education, including comprehensive and gender-affirming sexuality education). After screenings, providers must arrange for treatment of conditions.
- **Mental Health and Substance Use Disorder Services:** Benefits packages must include access to the full-spectrum of mental health and substance use disorder care (*e.g.,* psychotherapy, community-based support groups, peer support, access to essential medications, and a range of other coordinated services designed to support holistic and person-centered care).
- **Prescription Drugs:** Universal health care reform must work to lower the cost of prescription drugs and ensure that individuals have access to the medications they need. Reform must build on the protections for prescription drug pricing already present in the Medicaid and Medicare programs including: the ability to negotiate the price of prescription drugs with manufacturers and caps on copayments for prescription drugs. Prescription medications must be covered without copayments and without unnecessary barriers like prior authorization and step therapy for critical medications, including expanded access and coverage for over the counter contraceptives.
- **Long-Term Supports and Services (LTSS):** RJ includes the right to raise our families in safe and sustainable communities. To realize this right, universal health care reform must make LTSS, the daily living care that supports people with disabilities, available and affordable to all who need it. This must include home and community based services (HCBS). People should not have to leave their children, parents, partners, and communities to receive the care that they need, yet private plans and Medicare have excluded caregiver supports and home and community based services, including mental health services and supports. Additionally, Medicaid's current structure allows states to limit and cap access to HCBS in ways that they cannot for other services. Universal health care must include an entitlement to HCBS and bar requirements of institutionalization, family separation, or custody relinquishment. Reform must also incentivize a comprehensive provider network and address the home and community based workforce crisis. Ensuring that caregivers receive adequate wages and benefits is critical to achieving RJ.
- **Vision, hearing, and dental services:** Coverage must include vision, hearing, and dental services to help ensure the well-being of an individual. For example, dental coverage is a RJ imperative as poor oral health has been linked to complications such as low birthweight and preterm birth.
- **Whole-person care:** Reform must address the social and structural determinants of health and reproductive futures, such as access to culturally congruent food, economic and housing stability, comprehensive sexuality education, safe drinking water, and adequate sanitation. This can involve furthering whole-person care models that support care coordination between medical and social services without requiring coercing enrollees into participating or disclosing personal information in order to access health care. Reform must also include strategies to combat structural racism, ableism, sexism, classism, xenophobia, cisheteropatriarchy, and ageism.

6. **Health care is affordable for everyone.**

   Premiums, deductibles, copayments and cost-sharing requirements prevent meaningful access to health care services and should not exist for low-income people, including current Medicaid enrollees. Cost-sharing must also provide protections for people with disabilities, those with chronic conditions, and others who may have heightened health care needs. Any costs to accessing health care should be limited to those with the highest incomes and must be reasonable and predictable for both individuals and families.

7. **Health care is confidential for everyone.**

   To protect the right to bodily autonomy, all people , including minors, must be able to make confidential sexual and reproductive health care decisions, especially when seeking stigmatized services. Amidst the increasing criminalization of these vital services, individuals must be able to access care without fear of legal repercussions or immigration enforcement. Minors should have the right to access sexual, reproductive, and gender-affirming health care without parental or guardian consent or notification. Strengthening patient privacy protections is crucial to minimize the use and disclosure of protected health information and preempt the state laws that undermine these fundamental rights.

8. **People have uninterrupted access to care and can enforce their rights.**

   RJ requires robust enforcement mechanisms to protect individuals' rights. These must include:

   - **Court access and robust due process protections.** All people must be guaranteed robust due process protections and effective methods of redress to resolve barriers to health care such as denials, delays, or terminations of eligibility or benefits through a fair, accessible, and efficient administrative system. These protections must include: notice, including effective and linguistically appropriate written notice of decisions and the facts and legal bases used to reach them; hearing rights; continuation of benefits during a review of a termination, suspension, or reduction in coverage (aid pending). Medicaid's procedural protections, such as notice, hearing rights, and continuing aid pending review, should be used as a floor for reform.
   - **No one is denied health care, including sexual, reproductive, or gender-affirming health services, due to an institutional or individual provider's biases or personal beliefs about religion and morality.** Reform should include a right to receive immediate referrals if needed and to know whether network providers are religiously affiliated and what services these providers refuse to offer. If the services an enrollee needs are not available in-network due to religious restrictions, the enrollee should be able to immediately access those services out of network at no additional cost. In medical emergencies, including emergencies that require abortion as the necessary stabilizing treatment, the health and well-being of enrollees should override providers' beliefs.
   - **Public education and outreach.** For these due process mechanisms to be effective, reform must include public education funding to inform the public of their rights and provide them with the tools and access to understand and navigate the system. This includes access to a multitude of accessible resources both in person, on-demand, and telephonic in the language of the individual's choice.

Advocates for Youth (AFY) envisions a society in which all young people are valued, respected and treated with dignity; sexuality is accepted as a healthy part of being human; and youth sexual development is normalized and embraced.

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In Our Own Voice: National Black Women's Reproductive Justice Agenda (IOOV) is a national-state partnership focused on lifting up the voices of Black women leaders at the national and regional levels in our fight to secure Reproductive Justice for all women, girls, and gender-expansive individuals.

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The National Asian Pacific American Women's Forum (NAPAWF) builds collective power with AAPI women and girls so that we can have full agency over our lives, our families, and our communities.

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The National Health Law Program (NHeLP) is a public interest law firm working to advance access to quality health care and protect the legal rights of low-income and underserved communities.

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The National Latina Institute for Reproductive Justice (Latina Institute) fights for equal access to reproductive health for Latina/x communities because all of us should have the power to make informed decisions about our bodies, families, and futures.

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Unite for Reproductive & Gender Equity (URGE) envisions a liberated world where we can live with justice, love freely, express our gender and sexuality, and define and create families of our choosing.

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