

An **Advocate's Guide** to Reproductive and Sexual Health in the Medicaid Program (2nd Ed.)

2023 SUPPLEMENT





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Forward

In 2019, the National Health Law Program published its second edition of *An Advocate's Guide to Reproductive and Sexual Health* in the Medicaid Program ("Guide").¹ The purpose of the Guide is to familiarize readers with the basics of the Medicaid program and related health care safety net programs, and in particular to highlight features of the Medicaid program that support reproductive and sexual health.

In the years since, the legal and policy landscape for sexual and reproductive health, rights, and justice in the United States (U.S.) has altered considerably. In 2020, the COVID-19 pandemic upended access to care while also paving the way for policymakers to test new flexibilities, such as telehealth policies that helped address long-standing barriers to health access. Various COVID-era federal legislative packages expanded Medicaid eligibility to underserved populations. After President Biden took office in January 2021, his administration swiftly began the work of undoing the Trump administration's far-reaching actions to gut implementation of federal health care and civil rights laws. The Biden administration also prioritized countering the maternal mortality epidemic, with particular attention to expanding health insurance eligibility and quality improvement.

Anti-abortion politicians' long-standing efforts to pack the courts resulted in an array of harmful rulings on matters of reproductive and sexual health and justice. Most notably, in June 2022, the U.S. Supreme Court overturned the constitutional right to abortion in *Dobbs v. Women's Health Organization*.² This ruling not only harmed access to abortions, but pregnancy services, contraception, gender-affirming care, and related care for people with chronic conditions as well.

The 2023 Supplement ("Supplement") provides brief overviews of these and other developments. Advocates should reference the Guide alongside this Supplement to ensure that they access both key background information and the most current legal and policy analysis on issues of interest. In this Supplement, we offer new developments related to current sections of the Guide as well as additional sections on new issues. Updates to existing sections have the same section numbers as the corresponding sections in the Guide. If there are no updates, we skip over that section number and indicate that there

were no updates with an ellipsis (. . .). We enumerate new sections as if we inserted them at the end of existing sections in the *Guide*. The *Supplement* includes what we believe to be the most relevant updates from when we published the second edition of the *Guide* in 2019.

Note on Terminology

This *Supplement* uses gender inclusive language as much as possible in recognition of the variations in gender identity and expression in all communities. We have also tried to limit the use of the terms "woman" or "women" to instances when necessary to explain the Medicaid requirements for reproductive and sexual health services in conformity with the language used in the statute and regulations, and/or in conformity with cited research or data.

Acknowledgements

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Chapter I. Overview of the Medicaid Program

B. The Affordable Care Act and Medicaid Expansion

At the time of this writing, forty states and the District of Columbia have adopted Medicaid expansion. Lawmakers in the remaining ten states continue to withhold vital and often lifesaving health insurance coverage from people with low incomes. Black, Latine, or other people of color disproportionately fall into the resulting coverage gap.³ Two-thirds of uninsured women of reproductive age in the gap are people of color.⁴ One in three people in the gap are parents with children at home.⁵

The Medicaid coverage gap operates as an instrument of reproductive oppression for these populations.⁶ This is by design. Some anti-choice state lawmakers and advocates openly oppose Medicaid expansion in part because it would mean more people would have some, albeit extremely limited, abortion coverage. Non-expansion also withholds coverage for contraceptives; care for chronic conditions such as sickle cell disease and endometriosis, which can complicate fertility; disability services that help parents with children at home remain in their communities; and primary care services that address a wide range of needs. Some state lawmakers' refusals to expand Medicaid are driving the closure of maternity wards in rural hospitals amid a growing maternal mortality crisis that disproportionately affects Black and Indigenous people.8 Non-expansion also harms the health and development of the children of those in the Medicaid expansion coverage gap, as these outcomes depend "in part on their parents' health and [wellbeing]." In short, nonexpansion denies people in the coverage gap meaningful self-determination over their health, fertility, and reproductive futures.9 Expansion is a health and reproductive justice imperative.



Chapter II. Medicaid Eligibility

A. Coverage Categories

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4. Eligibility for Pregnancy Services

The American Rescue Plan Act of 2021 (ARPA) included a provision allowing states the option to file a State Plan Amendment (SPA) to extend pregnancy-related Medicaid coverage to roughly one year after the end of the pregnancy (*i.e.,* "the last day of the month in which the 12-month period (beginning on the last day of her pregnancy) ends"). Otherwise, the Medicaid Act only mandates that states provide pregnancy-related coverage until the end of the month in which the sixtieth day following the end of the pregnancy falls (anywhere from roughly 60-90 days, depending on when the pregnancy ends). The new option took effect on April 1, 2022 and is available to states for five years. As of this writing, thirty-five states and D.C. have implemented the one-year pregnancy-related Medicaid extension."

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C. Eligibility Based on Citizenship/Immigration Status

Section 208 of the Consolidated Appropriations Act of 2020 (CAA) expanded Medicaid eligibility to citizens of Micronesia, Marshall Islands, and Palau who reside in the U.S. pursuant to a Compact of Free Association (i.e., COFA migrants). Specifically, the CAA newly categorized COFA migrants as "qualified" immigrants for Medicaid eligibility purposes only. The CAA requires that states and DC provide full Medicaid coverage to COFA migrants without a five-year waiting period, provided they otherwise meet all other Medicaid eligibility requirements. The CAA also provides an option for U.S. territories to elect to provide full Medicaid benefits to COFA migrants. Some states also have policies and/or use their own funds to provide health coverage to additional groups of immigrants.



Chapter III. Section 1115 Demonstration Waivers

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B. Waivers Used to Limit Eligibility and Enrollment

1. Work Requirements

During the Trump administration, the U.S. Centers for Medicare & Medicaid Services (CMS) approved section 1115 waiver projects with work requirements in thirteen states. However, only one state—Arkansas—fully implemented work requirements. More than 18,000 Arkansans lost Medicaid coverage over the course of six months before the U.S. District Court for the District of Columbia vacated the approval of the project. The Court set aside the approval of similar projects in Kentucky and New Hampshire and the approval of work requirements in Michigan.

Shortly after President Biden took office, CMS withdrew its approval of work requirements in every state with an approval based on its determination that the requirements would not promote the objectives of the Medicaid program.¹⁹ Georgia, which had received approval to impose work requirements on a partial expansion population (adults with income up to 100% of Federal Poverty Level (FPL) not otherwise eligible for Medicaid), successfully challenged the rescission in court.²⁰ As a result, Georgia is the only state currently permitted to impose work requirements and began implementation on July 1, 2023.²¹

2. Lockout Periods

Currently, only two states (Michigan and Wisconsin) have an approved § 1115 project that includes a lockout penalty.²² The Michigan approval is the subject of ongoing litigation, which was on pause during the COVID-19 public health emergency.²³

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C. Waivers Used to Exclude Abortion Providers

In 2020, CMS approved the "Healthy Texas Women" project. With the approval, CMS permitted the State to cover family planning and other services for certain women with low incomes and to exclude providers that "perform or promote elective abortions or affiliate with entities that perform or promote elective

abortions" from participating in the project, undermining access to essential care.²⁴ The approval expires at the end of 2024. CMS has not acted on similar, pending requests from Tennessee or South Carolina.

D. Waivers Used to Limit Benefits and Increase Costs

1. Elimination of Vital Services

Medicaid's non-emergency medical transportation (NEMT) benefit helps beneficiaries with limited access to transportation access covered health care services, including sexual and reproductive health care. Several states, such as Indiana and Georgia, have approved projects that include a waiver of the requirement to provide NEMT.²⁵ In fact, a number of family planning expansion projects, discussed in § II.A.5 of the *Guide*, include a waiver of NEMT.

Notably, in 2020, Congress amended the Medicaid Act to make its NEMT requirement explicit.²⁶ Congress amended 42 U.S.C. § 1396u-7(a)(1) to require states to ensure that individuals enrolled in alternative benefit plans receive NEMT services.²⁷ With these changes, Congress expressed its clear intent that states cover NEMT, including for the Medicaid expansion population. Because of this change, and because eliminating NEMT is not experimental and runs counter to the objectives of Medicaid, CMS should no longer be approving waivers of NEMT.

2. Premiums and Cost-Sharing

In 2021, CMS denied Montana's and Arkansas's requests to continue imposing premiums on individuals in the expansion population based on its determination that "premiums can present a barrier to coverage," and thus, allowing states to charge premiums above those permitted by the Medicaid Act is "not likely to promote the objectives of Medicaid." CMS invoked similar reasoning when it withdrew its approval of Georgia's premiums. However, as described in § B.1 of this *Supplement*, Georgia successfully challenged the rescission, leaving the State free to impose premiums on its partial expansion population. Other states, including Indiana, Michigan, and Wisconsin, have § 1115 waivers that permit them to charge premiums to beneficiaries with household incomes below 150% of FPL. As also described above, Medicaid beneficiaries have challenged the Indiana and Michigan projects in court, but the cases were on pause during the COVID-19 public health emergency and the stays have continued at the agreement of the parties.

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F. Reduced Oversight and Monitoring

The 2017 guidance discussed in the *Guide* announced CMS's intent to "approve the extension of routine, successful, non-complex" § 1115 waivers for a period of up to ten years.³¹ After issuing the guidance, CMS extended a number of projects for ten years. Some of the projects met the criteria articulated in the

policy, while others did not.³² In any event, CMS should reconsider the 2017 policy and the subsequent ten-year approvals, which directly conflict with § 1115's statutory criteria.³³



Chapter IV: Reproductive and Sexual Health Services Under Medicaid

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C. Pregnancy Services

Doulas are non-medical professionals who provide social, emotional, physical, and informational support to people during pregnancy, childbirth, and the postpartum period, as well as during miscarriage, stillbirth, and abortion. Doulas provide individually tailored, culturally appropriate, and client-centered care and advocacy. A growing number of states are now implementing Medicaid coverage for doula care, recognizing the important role that doula support can play in positively affecting maternal and infant health, and reducing the impacts of racism and racial bias in health care.³⁴ At the time of his writing, more than half of all states are either actively providing Medicaid coverage for doula care, in the process of implementing such coverage, or taking some statewide action related or adjacent to Medicaid coverage for doula care.³⁵

D. Abortion

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4. State Funding of Abortion

As of April 2023, sixteen states use state funding to cover all abortions for Medicaid enrollees: Alaska, California, Connecticut, Delaware, Hawaii, Illinois, Maine, Massachusetts, Minnesota, Montana, New Jersey, New Mexico, New York, Oregon, Rhode Island, Washington.³⁶

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6. Telehealth Medicaid Abortion Services

Telehealth medication abortion (TMAB) generally refers to the use of telehealth for some or all of communications between a provider and a patient for abortion care, either synchronously through live video or telephonic exchanges or asynchronously through "store-and-forward" non-real-time interactions. Historically, telehealth service delivery of abortion services has been constrained by the U.S. Food and Drug Administration's (FDA) implementation

of a Risk Evaluation and Mitigation Strategy (REMS)—a drug safety program only implemented for "certain medications with serious safety concerns"—for mifepristone. In January 2023 (after previously implementing temporary flexibilities tied to the public health emergency around the REMS requirements), the FDA announced that it was permanently lifting the requirement that mifepristone be dispensed in-person and that the new mifepristone REMS would enable pharmacists become certified to dispense the medication. The FDA's decision to permanently lift the in-person dispensing requirement was long overdue as numerous studies have shown telehealth medication abortion (TMAB) to be extremely safe and advocates have called for these changes to remove a major federal barrier to telehealth service delivery.³⁷

While federal law limits Medicaid abortion coverage overall, the Medicaid Act does not differentiate between medication or procedural abortions for coverage purposes.³⁸ In fact, it requires states to cover all outpatient drugs from any manufacturer participating in the Medicaid Drug Rebate Program, since all fifty states and territories have chosen to participate in Medicaid's optional prescription drug benefit.³⁹ Danco Laboratories and GenBioPro, the manufacturers of mifepristone, each have a Medicaid rebate agreement in place, which means all states must cover mifepristone.⁴⁰ Medicaid coverage of TMAB varies widely from state to state, due to the wide latitude states maintain to determine telehealth coverage including what constitutes telehealth, eligible providers, eligible services for reimbursement, and reimbursement structures.⁴¹

7. Dobbs v. Jackson Women's Health Organization

When the Supreme Court issued its ruling in *Dobbs v. Jackson Women's Health Organization* in June 2022, it held that the Constitution does not confer a right to abortion and overturned longstanding precedent established in *Roe v. Wade and Planned Parenthood of Southeastern Pennsylvania v. Casey.*⁴² The decision opened the floodgates to pre-viability abortion bans and restrictions and many states moved swiftly to enforce abortion bans and restrictions that were already on the books, like trigger bans or antiquated pre-*Roe* laws, while others moved to pass new extreme bans. As of March 2023, at least thirteen states have either completely banned or severely restricted abortion access.⁴³ The abortion access landscape constantly shifts, as state restrictions go in and out of effect depending on the status of ongoing litigation. This has created tremendous uncertainty for both patients and providers.

However, other states have chosen to pursue policies that protect and expand abortion access for their residents and for people who are forced to travel from restrictive states in order to access care. For example, legislation in California created the California Reproductive Health Equity Program, an uncompensated care program that supports providers who offer free services to patients with low incomes and those that lack abortion coverage, including patients from out of state.⁴⁴

The Hyde amendment restricts federal funding for Medicaid abortion coverage. States are required to provide coverage when a pregnancy results from rape or incest, or when "a woman suffers from a physical disorder, physical injury, or physical illness, including a life-endangering physical condition caused by or arising from the pregnancy itself, that would, as certified by a physician, place the woman in danger of death unless an abortion is performed." Thus, even states that have almost entirely banned abortion must still provide coverage for Medicaid beneficiaries who seek an abortion that qualifies under one of Hyde's narrow exceptions.

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F. LGBTQI+ and Gender Affirming Care

Since 2019, Medicaid coverage of gender-affirming services has been a relatively active area of the law. In fact, multiple federal district courts have found that state policies categorically excluding Medicaid coverage of gender-affirming care violates the Constitution, § 1557 of the ACA (the law's nondiscrimination provision), and the Medicaid Act.⁴⁶ In the face of these decisions, Florida adopted a new Medicaid regulation prohibiting coverage of gender-affirming services.⁴⁷ Transgender Medicaid beneficiaries have challenged the regulation in court.⁴⁸

Florida and many other states have gone even further, launching unprecedented attacks on transgender and gender nonconforming (GNC) people, particularly youth. Many of these attacks focus on limiting access to health care for transgender and GNC people. For example, at least eleven states have banned or limited access to gender-affirming care for transgender and GNC youth.⁴⁹ Transgender and GNC young people, their parents, their health care providers, and/or the Department of Justice are challenging a number of these actions as unconstitutional.⁵⁰ For updated information about the regulations implementing § 1557 and the associated litigation, see § VI.B of this *Supplement*.

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H. Mental Health

In 2021, an estimated 57.8 million (more than one in five) adults in the U.S. had a mental health condition.⁵¹ Mental health conditions include depression, anxiety disorders, and serious psychological distress, among others. The prevalence of mental health conditions is higher among women, including Black, Indigenous, and other people of color, young adults, and the lesbian, gay, bisexual, transgender, queer, intersex, and gender-expansive (LGBTQI+) community.⁵² LGBTQI+ adults are more than twice as likely to experience mental health conditions compared to heterosexual adults and transgender individuals are nearly four times as likely to experience mental health conditions compared to cisgender individuals.⁵³ Women report more depressive symptoms than men and Black people, Latine people, and Asian people experience more symptoms

of depression than their white counterparts.⁵⁴ Postpartum depression affects one in eight new mothers and gender-expansive parents though the risk is significantly higher for mothers and gender-expansive parents of color.⁵⁵ In addition, prevalence of postpartum depression symptoms is higher among women who had participated in WIC during pregnancy, had Medicaid during their delivery, self-reported depression before or during pregnancy.⁵⁶

COVID-19 has increased the prevalence of anxiety and depression worldwide by approximately twenty-five percent.⁵⁷ In the U.S., about four in ten adults reported symptoms of anxiety and depression in 2021.⁵⁸ Further, overdose deaths and suicide deaths have increased disproportionately impacting Black, Indigenous, and other people of color.⁵⁹

I. Assisted Reproduction

Assisted reproduction refers to treatments, interventions, or procedures intended to cause or assist in causing pregnancy through means other than by sexual intercourse. Despite the growing use of assisted reproduction services in the United States, it remains primarily privately funded. Most health plans and programs, including Medicaid, exclude assisted reproduction from coverage or provide extremely limited coverage, putting assisted reproduction out of reach for people with low incomes. According to the Kaiser Family Foundation, New York is the first and only state Medicaid program to cover any fertility treatment.

Policies regarding assisted reproduction have a disproportionate impact on LGBTQI+ people; individuals with low incomes; non-partnered people; Black, Indigenous and other Women of Color; and individuals with disabilities As such, assisted reproduction must be approached using an intersectional lens and a reproductive justice approach that takes into account histories of injustice, racism, and discrimination. This approach must affirm the right to have a child, not to have a child, and to parent with dignity in healthy and safe environments. For more information about how Medicaid should cover assisted reproduction services, please visit NHeLP's *Principles on Assisted Reproduction*.⁶⁴



Chapter VI: Access to Care

A. Refusal Clauses/Religious Exemptions

If implemented, Trump-era regulations would have vastly expanded the application of federal health care refusal laws. They would have enabled providers to opt out of providing reproductive and sexual health services such as abortions and miscarriage management, sexual health services such as testosterone therapy, and preventive services for sexually transmitted infections, and disability services such as treatments for HIV, sickle cell disease, and endometriosis, disregarding evidence-based standards of care. 65 Fortunately, in November 2019, the U.S. District Court for the Southern District of New York struck down the Trump administration's regulations. 66 Consequently, the U.S. Department of Health and Human Services' (HHS) Office for Civil Rights (OCR) never implemented them. In January 2023, the Biden-Harris Administration's HHS OCR issued a notice of proposed rulemaking, "Safeguarding the Rights of Conscience as Protected by Federal Statutes." The proposed rule rescinds significant portions of the Trump-era rule that emboldened refusals of care, while leaving others in place.⁶⁷ At the time of this writing, we await the final rule.

B. Non-Discrimination Protections Under ACA § 1557

Since the Supreme Court's decision in *Dobbs*, we have seen a proliferation of sex-based and intersecting discrimination in health care. Beyond increasing abortion and miscarriage management refusals, some health insurers and pharmacies have denied or imposed burdensome restrictions on access to medications such as methotrexate, which is often used to treat autoimmune and other chronic conditions, on the basis that the medications could end, prevent, or cause complications in potential pregnancies.⁶⁸ Some pharmacies, such as CVS Health, have asked pharmacists to verify that patients will not use their prescriptions to end pregnancies.⁶⁹ Verification requirements regarding pregnancy status can unduly delay individuals' access to crucial and potentially life-saving care, compromising cancer treatment or subjecting people to painful and potentially dangerous flare-ups of chronic health conditions.⁷⁰ Outright refusals to fill prescriptions also cause undue delays in access to care and can particularly harm people who live in rural or other isolated communities with limited pharmacy options.

In July 2022, HHS OCR released guidance to retail pharmacies nationwide, reminding them of their obligation not to discriminate on the basis of race, color, national origin, sex, age, and disability in their programs and activities under a range of federal civil rights laws, including § 1557 of the ACA (the law's groundbreaking nondiscrimination provision). The guidance reiterated that pregnancy discrimination is a form of sex discrimination, and affirmed that discrimination based on current pregnancy, past pregnancy, potential or intended pregnancy, and medical conditions related to pregnancy or childbirth are all forms of unlawful sex discrimination. Furthermore, OCR provided examples of pharmacy refusals that may constitute discrimination on that basis, such as refusals to fill prescriptions for emergency contraception, mifepristone for miscarriage management, misoprostol for ulcers, or methotrexate for ectopic pregnancy or rheumatoid arthritis. OCR specifically declined to provide general guidance on application of the Church Amendments to pharmacy refusals, and stated that it will evaluate relevant situations on a case-by-case situation.

In August 2023, OCR published a new notice of proposed rulemaking on § 1557.72 Among other changes, the proposed rule seeks to restore a regulatory definition of sex discrimination that includes "discrimination on the basis of sex stereotypes; sex characteristics, including intersex traits; pregnancy or related conditions; sexual orientation; and gender identity." HHS also noted in the preamble that while the 2020 Final Rule did not define sex discrimination, the underlying self-implementing statute has always prohibited discrimination on the grounds prohibited under Title IX.74 These include discrimination related to pregnancy-related conditions, including childbirth, false pregnancy, termination of pregnancy, and recovery therefrom.75 These protections would also apply under the proposed rule. HHS also proposed to restore and improve upon a regulation from the 2016 final rule that clarifies covered entities' obligations to provide equal access to health programs and activities, including services, without sex discrimination.76 In addition, HHS proposed to clarify that § 1557's protections apply to health insurance and other health-related coverage.77

C. Language Access for People with Limited English Proficiency

HHS' proposed rule on § 1557 issued in August 2022 would reinstate some requirements for notices and taglines removed by the Trump-era final rule⁷⁸ and add other language access requirements, such as mandates that covered entities have specific language access procedures in place and train staff.⁷⁹

D. Public Charge and Immigration-Related Barriers and Fears

On September 9, 2022, the Department of Homeland Security U.S. Citizenship and Immigration Services (UCIS) issued a new final rule on the Public Charge Ground of Inadmissibility.⁸⁰ The final rule formally removed the Trump-era public charge rule and essentially codified the historical understanding of a "public charge" that was previously in place for decades under the agency's long standing 1999 Field Guidance, with some added protections and information.⁸¹ Under both the 1999 guidance and the 2022 final rule, it is safe for immigrants

and their families to use most health care, nutrition, and housing programs for which they qualify without adverse immigration consequences. Only those deemed likely to be primarily dependent on cash aid for income maintenance or long-term care at government expense could receive a denial on public charge grounds. DHS will apply the new rule to all adjustment of status applications that implicate the public charge test postmarked on or after December 23 that same year. For applications filed prior, DHS will apply the policy under the 1999 field guidance. At the start of 2023, Texas filed a new lawsuit challenging the invalidation of the Trump administration's public charge rule and the Biden administration's final rule.⁸² At the time of this writing, the Biden rule remains in effect.



Chapter VII. Other Reproductive and Sexual Health Programs

A. Title X

The HHS Office of Population Affairs (OPA) reported that in 2021, 1.7 million patients received Title X-supported services.83 This figure is well below the 4 million people served in 2018; OPA attributes the substantial decrease to the dual impacts of a devastating program rule implemented by the Trump administration in 2019 and the COVID-19 pandemic. The Biden administration's 2021 final rule on Title X lifted the harmful restrictions put in place by the Trump administration and reinstated program rules that governed the program prior to July 2019.84 In addition, the final rule requires that Title X projects provide a broad range of acceptable and effective medically approved family planning methods and services in a manner that is "client-centered, culturally and linguistically appropriate, inclusive, and trauma-informed; protects the dignity of the individual; and ensures equitable and quality service delivery consistent with nationally recognized standards of care."85 It restores pre-2019 requirements that projects offer pregnancy clients neutral, factual information; nondirective options counseling, including on abortion; and referral upon request, except on any option(s) for which the client indicates they do not want information or counseling.86 It clarifies that telehealth is an acceptable service delivery modality.87 It also revises HHS' criteria for evaluating grant applications, such as by adding a new criterion on an applicant's ability to advance health equity.88

There are currently seventy-eight grants across the country in the middle of a five-year project period ending in March 2027: fifty-three percent of grantees are state and local health departments, eleven percent are federally qualified health centers, twelve percent are Planned Parenthood affiliates, and twenty-five percent are other nonprofit agencies.⁸⁹ In fiscal year (FY) 2023, Congress appropriated \$286.5 million for Title X, the ninth year in a row of flat funding.⁹⁰ This funding allocation does not meet the need for publicly funded family planning services. This means that dozens of qualified applicants who could not receive funding in the March 2022 funding cycle remain unable to join the program.⁹¹ Biden's FY 2024 budget proposes \$512 million to Title X, which is still inadequate to fully fund the program, but would be a welcome increase.⁹²

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H. Ryan White

1. Increasing the Representation of People Living with HIV on Planning Councils

The Ryan White HIV/AIDS Program (RWHAP) Part A, serving metropolitan areas hit hard by the pandemic, must establish planning councils to identify priorities in the allocation of funds, and develop a comprehensive plan for the organization and delivery of HIV health and support services.⁹³ Priority setting and planning must be based upon the demographics of persons living with HIV/AIDS in the jurisdiction, the ongoing needs of the population, and availability of other governmental and non-governmental resources.⁹⁴ Moreover, planning councils by law must pay "particular attention to eliminating disparities in access and services among affected subpopulations and historically underserved communities." ⁹⁵

Planning council members are appointed through an open process by the Mayor or other chief elected official of the jurisdiction receiving Part A funds. Membership must include representatives from a broad array of providers, including public health and social services agencies, FQHCs and other community providers, substance use disorder treatment providers, hospital groups, and AIDS services and other community based organizations. Planning councils must also include representation by affected communities, including people living with HIV, members of a federally recognized Indian tribe as represented in the population, individuals co-infected with hepatitis B or C and historically underserved groups and subpopulations.

Federal law also requires that one-third of planning council members be clients who receive HIV services funded through the program and who are not employees, board members, or consultants employed by providers receiving funds. Advocates pushed for this provision to be added to the RWHAP to bring greater accountability in how funds are allocated and spent. Ryan White planning councils provide an important opportunity to ensure that program priorities and funding allocations reflect the real life experience of people living with HIV, their family members, and caregivers. The premise that people with HIV must be integrally involved in all decision-making affecting their lives dates back to *The Denver Principles*, first adopted in 1983, which hold, in part, that people with AIDS be involved at every level of decision-making and specifically serve on the boards of directors of provider organizations; [and] be included in all AIDS forums with equal credibility as other participants, to share their own experiences and knowledge.

2. Ryan White Program's role in the Ending the HIV Epidemic Initiative In 2019, the White House and U.S. Department of Health and Human Services launched the Ending the HIV Epidemic in the U.S initiative (Initiative). The initiative is designed to target HIV treatment and prevention resources to the forty-eight counties and seven states, plus the District of Columbia and San

Juan, Puerto Rico, that comprise more than half the new HIV diagnoses.¹⁰³

The RWHAP and the providers it funds play an important role in meeting a primary goal of the initiative, enrolling and retaining people with HIV in treatment. Four of the seven target states have not expanded Medicaid, while nearly half the target counties are in non-expansion states.¹⁰⁴ The RWHAP is, in some places, the main or only source of HIV care. Other aspects of the initiative include access to PreExposure Prophylaxis (PrEP), medication that reduces the chance for HIV infection by up to ninety-seven percent and approved more than ten years ago.¹⁰⁵ In 2021, the FDA approved an injectable form of PrEP, which lasts for two months, instead of a once-daily pill. 106 Increased access to no cost PrEP will help address inequities in HIV infection rates, especially among Black and Latine persons who experience high rates of new HIV infections, but low update of PrEP.¹⁰⁷

3. The Ryan White Program and Mpox

The Mpox epidemic disproportionately affected people with HIV both in the percentage of overall cases, and in more serious health harms, including fatalities.¹⁰⁸ With Mpox vaccine supplies limited, the Centers for Disease Control and Prevention prioritized people with HIV among other populations at high risk.¹⁰⁹ The HHS Health Resources Services Administration (HRSA) sought to distribute the Mpox vaccine to RWHAP recipients, which include people with HIV who are low-income and uninsured. 110 HRSA distributed the Jynneos vaccine to Part C dually funded Health Center Program providers that care for a significant number of men who have sex with men (MSM) and people who are transgender.¹¹¹



Appendix: Additional Resources

HHS Guidance and Federal Reports

- 1. HHS, Secretary's Report: Health Care Under Attack: An Action Plan to Protect and Strengthen Reproductive Care (Aug. 2022), https://www.hhs.gov/sites/default/files/hhs-report-reproductive-health.pdf.
- 2. CMS, Reinforcement of EMTALA Obligations Specific to Patients who are Pregnant or are Experiencing Pregnancy Loss (UPDATED July 2022) (Jul. 11, 2022), https://www.cms.gov/medicareprovider-enrollment-and-certificationsurveycertificationgeninfopolicy-and-memos-states-and/reinforcement-emtala-obligations-specific-patients-who-are-pregnant-or-are-experiencing-pregnancy-0.
- 3. HHS, Office for Civil Rights, HIPAA Privacy Rule and Disclosures of Information Relating to Reproductive Health Care (Jun. 29, 2022), https://www.hhs.gov/hipaa/for-professionals/privacy/guidance/phi-reproductive-health/index.html.
- 4. CMS, Dear State Health Official (Dec. 21, 2021) (SHO # 21-007) (guidance on 12-months postpartum coverage in Medicaid and doula care), https://www.medicaid.gov/federal-policy-guidance/downloads/sho21007.pdf.
- 5. HHS, Know Your Rights: Reproductive Health Care, https://reproductiverights.gov/ (last visited May 23, 2023).

NHeLP Resources

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