AMERICAN LUNG ASSOCIATION®

A COORDINATED ATTACK:

REDUCING PATIENT ACCESS TO CARE IN STATE MEDICAID PROGRAMS

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In 2017, high-profile attempts in Congress to compromise patients' access to quality and affordable healthcare by repealing the Affordable Care Act (ACA) dominated the headlines. Now, simultaneously, but with much less public scrutiny, the Administration and many states have been working to enact new and serious barriers to care in state Medicaid programs through the Section 1115 waiver process. This systematic attack on the Medicaid program jeopardizes access to care for hundreds of thousands of low-income patients with serious and chronic health conditions across the country.

Under Section 1115 of the Social Security Act, states can apply to establish a research and demonstration program that waives certain provisions of federal Medicaid law. According to the statute, these demonstrations must be designed to promote the objectives of the Medicaid program.[1] For example, waivers can be used to test new delivery and payment models or improve behavioral health services. Prior to the implementation of the ACA, these waivers were also used to expand coverage to otherwise ineligible populations.

THIS SYSTEMATIC ATTACK ON THE MEDICAID PROGRAM JEOPARDIZES ACCESS TO CARE FOR MILLIONS.

On March 14, 2017, the same day she was sworn in as Administrator of the Center for Medicare & Medicaid Services (CMS), Seema Verma and then Secretary of Health and Human Services (HHS) Tom Price issued a letter to every governor in the country inviting them to pursue changes to their states' Medicaid programs. The letter specifically mentioned a number of proposals that threaten patients' access to care, such as implementing so-called work and community engagement requirements, imposing enforceable premiums, waiving non-emergent transportation benefits, ending retroactive eligibility and charging copays for emergency room visits.[2] In January 2018, CMS issued more detailed guidance for state Medicaid directors specifically encouraging states to consider work and community engagement requirements as a condition of Medicaid coverage.[3] A list of policies that states have proposed through the 1115 waiver process that could have harmful implications for patients is included in the next section.

A major consequence of these proposals is that patients, including those with or at risk of lung disease, who need access to quality and affordable care to manage their medical conditions and stay healthy, will lose their healthcare coverage. Estimates suggest that thousands of individuals will lose coverage under these new

policies. In Kentucky, the state estimated that 95,000 people would lose their healthcare coverage over the demonstration period.[4] Additionally, a group of deans, department chairs, and scholars at leading academic institutions estimated that the coverage loss in Kentucky would actually be between 175,000 and 300,000 individuals.[5] As shown in Table 3, the populations most impacted are often very vulnerable populations that cannot afford a sudden gap in their healthcare coverage. For example, in Alabama, the waiver requesting a work requirement would apply to parents and caregivers making less than 18 percent of the federal poverty level ($312 per month for a family of three).[6]

States Failing to Include Mandated Budget Estimates

Some states have failed to provide the legally required budget neutrality estimates in their 1115 waiver proposals including information about how enrollment would change as a result of the proposals. These estimates inform the public and CMS on issues like the impact of 1115 waivers on coverage in the Medicaid program, which is vital to determine if the proposal will promote the objectives of the Medicaid program. Patient advocacy groups representing individuals facing serious, acute and chronic health conditions have sent letters to state officials in South Dakota and Michigan requesting that these estimates be made public.[7]

These proposals will increase the paperwork and administrative burden on patients, who will have to deal with onerous new reporting requirements. Battling administrative red tape in order to keep coverage should not take away from patients' or caregivers' focus on maintaining their or their family's health. Even when proposals exempt certain enrollees struggling with health conditions, patients will still have to provide documentation of their illness, creating opportunities for administrative error that could jeopardize coverage. It is already clear that these processes will be difficult for patients despite states' claims to the contrary. In Arkansas, for example, despite over 600,000 Arkansans (23 percent of the population) not having access to wired broadband services, Arkansas only allows hours worked and exemptions to be reported via an online portal.[8] After the first month of this requirement, over 7,000 Medicaid enrollees in Arkansas are in jeopardy of losing their health coverage because they have failed to report 80 hours of work in June via the online portal.[9]

States Spending Millions on Administrative Requirements, Not Patient Care

Administering these requirements will also be expensive for states. States such as Michigan, Pennsylvania, Kentucky, Tennessee and Virginia have estimated that setting up the administrative systems to track new requirements and to verify exemptions will cost tens of millions of dollars.[10] These costs would divert resources from Medicaid's core goal – providing health coverage to those without access to care.

Under this Administration, CMS has approved 1115 waivers or waiver amendments in six states – Arkansas, Indiana, Iowa, Kentucky, New Hampshire and Utah – that contain provisions that threaten patients' access to care. Eleven states have waivers submitted to CMS that are still pending a final decision. This report provides an overview of these proposals, the vulnerable populations that would be impacted, and the number of patients projected to lose coverage as a result of these policies.

Recommendations to Protect Patient Access to Care

To ensure Medicaid patients have access to quality and affordable healthcare, the American Lung Association urges the following:

- CMS should reject any 1115 waiver that would create additional barriers that limit patients' access to care in the Medicaid program, as well as to rescind the guidance inviting states to submit 1115 waivers including work requirements.
- In light of the U.S. District Court for the District of Columbia's recent decision[11] to block implementation of the Kentucky waiver, CMS should also suspend implementation of 1115 waivers containing any provisions that threaten access to healthcare coverage.
- Members of Congress should ask CMS to reject harmful 1115 waivers, protecting people in their states, and use their oversight authority to monitor the impact of these waivers on patients.
- Congress should also ask the Medicaid and CHIP Payment and Access Commission (MACPAC) to monitor monthly Medicaid enrollment among parents, other adults, and children in states implementing these waivers and report to Congress and the public on a quarterly basis.

Barriers Preventing Medicaid Patients' Access to Care – 1115 Waiver Provisions

Medicaid enrollees are a population with unique needs and characteristics. By definition, they are low-income, and in the states that have not expanded Medicaid, the non-disabled adults are very low-income. Policies that might not impact middle class families can have a profoundly negative impact on families that rely on Medicaid to access medical care. For example, research shows that copays as low as one to five dollars lead low-income families to reduce their use of necessary healthcare services.[12]

FACES OF MEDICAID

Standard Medicaid enrollees: Low-income parents and caregivers and low-income patients in long-term care.

Medicaid expansion enrollees: Adults, aged 19-64, with or without children, making less than $1,893/ month for a family of two.

Table 1: Monthly Family Income for Federal Poverty Level (FPL)[13]

Family Size	50%	100%	138%
One	$506	$1,012	$1,396
Two	$686	$1,372	$1,893
Four	$1,046	$2,092	$2,887

States have used 1115 Waivers to propose the following policies that are negatively impacting lung disease patients, patients at risk of lung disease and others who have serious or chronic conditions. Table 2 contains a list of policies proposed and approved by states or CMS.

Emergency Department Copayment

Some states are proposing to impose an additional copay for patients whenever they go to the Emergency Department (ED), or if the patient goes to the ED for a condition that was deemed non-emergent or did not require an admission. These policies discourage patients from seeking needed care. It is often difficult for a lay person to determine if chest pains are a heart attack, indigestion or a panic attack. Patients should not be required to make the judgement calls to determine if a condition is life-threatening or not.

Enrollment Limit

Enrollment limits set a cap on the number of individuals that can be enrolled in a Medicaid program. Some states are proposing to cap enrollment for specific groups of Medicaid eligible individuals. Capping enrollment would limit some patients' access to critical treatment when they need it most. For example, an asthma patient who tries to enroll in Medicaid but is denied coverage because the state has hit an enrollment cap could be unable to get the inhaler she needs to breathe.

Limiting EPSDT Benefits

Children receiving healthcare as part of the Medicaid program have special protections to ensure they get the appropriate treatment. The Early and Periotic Screening, Diagnostic and Treatment (EPSDT) benefit ensures children can access certain screenings, services or treatments that are medically necessary, even if they are not normally covered under a state's Medicaid program for adults. Some states are proposing to limit these benefits to children 18 and under, limiting the benefit for 19- and 20-year-olds. This limitation could reduce older children's access to needed healthcare services at a critical time in their development. For example, a 19-year-old asthma patient could lose access to services like allergen immunotherapy to control his or her asthma.

Limiting Medicaid Expansion Eligibility

Some states that have accepted the enhanced federal matching funds made available for Medicaid expansion under the Affordable Care Act have proposed rolling back Medicaid eligibility to 100 percent of the Federal Poverty Level while retaining the enhanced match. States argue that this population can be served by the

marketplace. While this may be true for some, state experience has shown that many will get lost in the transition.[14] Under any scenario, a rollback of Medicaid eligibility would reduce the number of people with comprehensive healthcare coverage. Some patients might be able to obtain other healthcare coverage, but Medicaid provides important services, such as non-emergency transportation benefits, and limits cost-sharing to help patients adhere to their treatment that coverage on the individual market does not provide. Most importantly, patients could be unable to afford other coverage and become uninsured, as marketplace coverage can still be too expensive for patients at lower incomes even with the advanced premium tax credits.

Monthly Premiums

Many states are using 1115 waivers to request and impose enforceable premiums, in some cases only for populations with incomes above 100 percent of the FPL and in other cases for populations with incomes below 100 percent of the FPL as well. Research is clear that charging premiums to low-income persons will result in a loss of coverage.[15] Patients could risk completely losing coverage or losing access to certain benefits for failure to pay.[16] Ending coverage for lung disease patients who cannot afford their premiums will negatively impact their prognosis and may result in less use of preventive and primary care and more costly treatment in the emergency room. For example, a patient with asthma could lose access to their controller medications or rescue inhaler and end up in the emergency department with an asthma attack.

Prescription Drug Access

Another proposal would change prescription drug coverage in Medicaid. Currently, all the states that chose to provide prescription drug coverage in their Medicaid programs participate in the Drug Rebate Program. This program allows states to take advantage of drug discounts from drug manufacturers, provided they cover all the manufacturers' drugs, with the exception of drugs on the exclusion list. One state, Massachusetts, requested additional authority to have a closed formulary and not cover certain drugs, as well as allow the state or managed care plan to only cover one drug per class, in an attempt to negotiate larger discounts. The state would set up an exceptions process to cover drugs outside of the formulary when medically necessary.[17]

This is incredibly problematic for lung disease patients in the Medicaid program. Unlike individuals who are privately insured, Medicaid enrollees do not have opportunity to shop around for a plan that covers the appropriate medications and treatments. Patients could therefore lose access to lifesaving treatments. For example, lung cancer patients need very individualized treatments based on their tumor type, but the necessary immunotherapy drug might not be covered under this proposal. Additionally, an exceptions process could be extremely difficult for patients, especially patients with low literacy, to navigate, again compromising access to care. On June 27, 2018, CMS rejected Massachusetts's proposal to limit prescription drug coverage in Medicaid.[18] Other states are still publicly contemplating similar requests.[19]

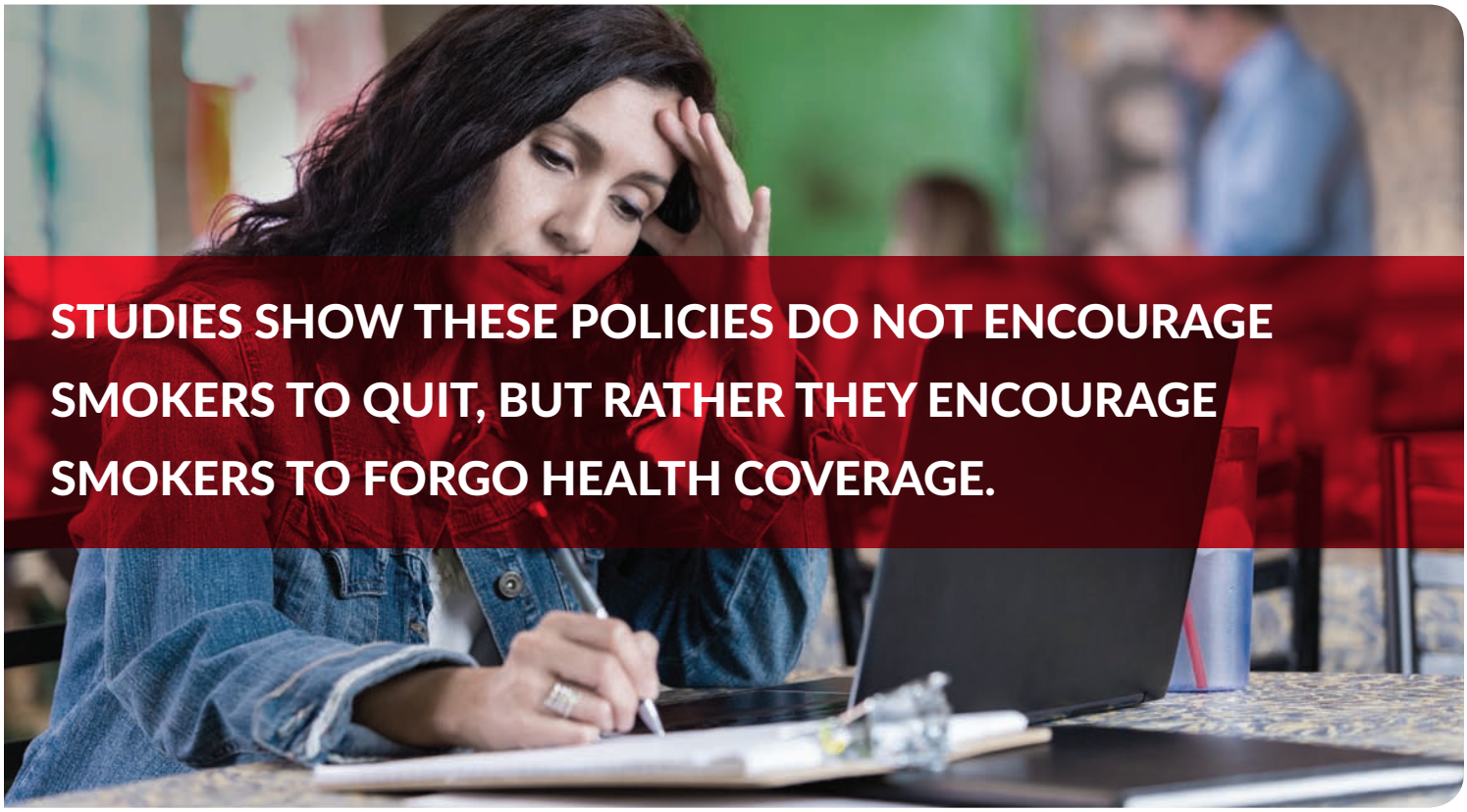
Removal of Non-Emergent Transportation Benefits
Some states are proposing to remove their non-emergent transportation benefits. This benefit helps Medicaid enrollees get transportation to their medical appointments so they can manage their conditions and stay healthy. Without this benefit, enrollees may forgo appointments due to lack of travel funds and delay getting needed care. This delay could also result in patients needing more expensive treatments at the ED in the future.

Removal of Retroactive Coverage
Medicaid programs are required to cover three months of retroactive coverage for Medicaid enrollees. This provision helps protect Medicaid enrollees from medical debt, including those who might have missed a re-enrollment, or those who didn't know they qualified for Medicaid until they got sick. Without this benefit, patients could face unaffordable healthcare bills or delay getting treatment when they need it.

Time Limits on Coverage
Time limit proposals would cap the number of months a person can be enrolled in a state's Medicaid program consecutively or impose a lifetime limit. Lung disease patients need access to continuous coverage, but this proposal could result in patients losing coverage at a critical point in their illness when they need it most. For example, a lung cancer patient could be forced out of the Medicaid program during the middle of chemotherapy and stop treatment because he is unable to obtain other affordable coverage.

Tobacco Surcharge

Quitting smoking is incredibly difficult. It can often take seven or more tries to quit permanently. Some states are proposing and implementing a tobacco surcharge or "non-smoker discount" as part of a broader healthy behavior or wellness program. Both have the same effect on patients – individuals who smoke have to pay more for health coverage than their counterparts who do not. Studies show these policies do not encourage smokers to quit, but rather they encourage smokers to forgo health coverage.[20] This policy would make health coverage too expensive for enrollees who need coverage and help quitting, leading more patients to potentially develop lung disease and other conditions linked to tobacco use and increasing the burden of tobacco-related diseases on the U.S. healthcare system.



Work Requirements

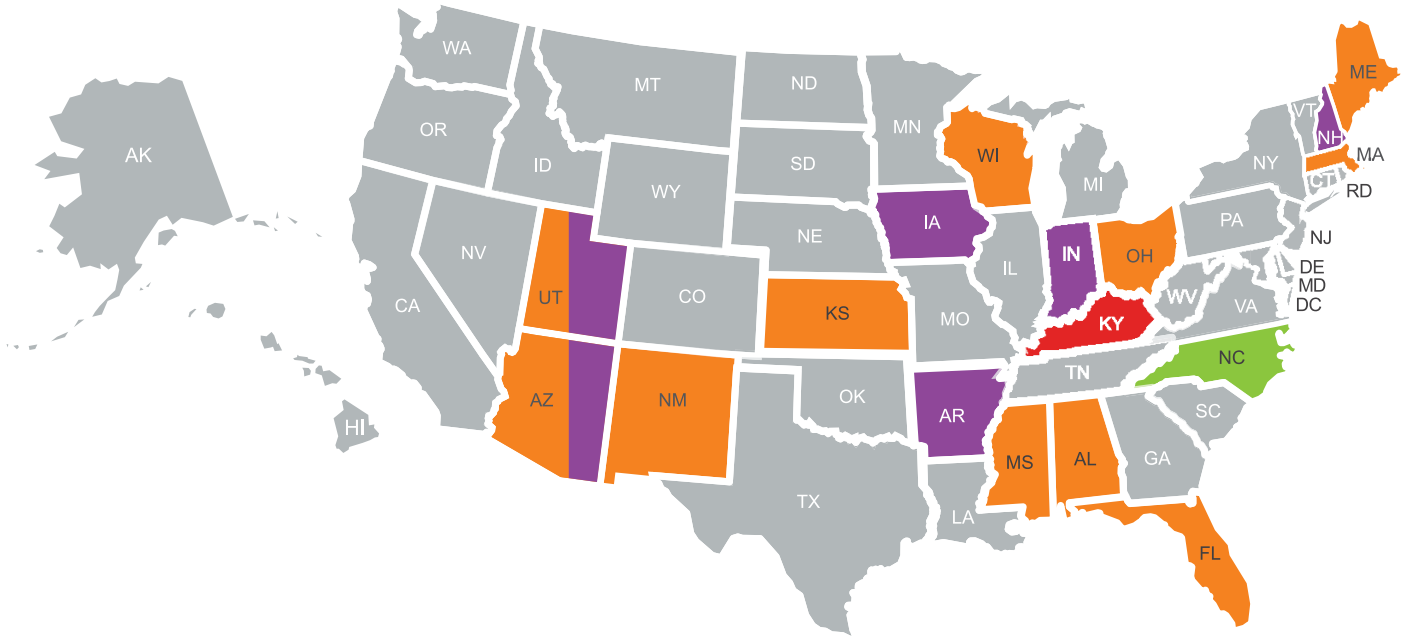
These requirements would end coverage for patients unless they prove that they work or volunteer a certain number of hours per week. These proposals would result in patients losing healthcare coverage. Research shows that expanding (not limiting) healthcare coverage through Medicaid leads to higher employment.[21] Another major consequence of this requirement would be to increase the administrative burden on all enrollees, regardless of whether or not they qualify for an exemption, as well as on state employees. Some states that have not expanded Medicaid are seeking to impose work requirements on very low-income parents. Such a policy targets the very poorest families in these states and could be harmful to children as well, as uninsured parents are more likely to have uninsured children, resulting in less access to care.[22] Battling administrative red tape in order to keep coverage should not take away from patients' or caregivers' focus on maintaining their or their family's health.

Table 2: Barriers to Coverage by State for Waivers Submitted to or Approved by CMS January 2017-June 2018

State	ED Copays	Enrollment Limits	Limited Expansion	Enforceable Premiums	Rx Drug Limits	Eligibility Time Limits	Removing Retroactive Coverage	Removing Non-Emergent Transportation Benefits	Limiting EPSDT	Tobacco Surcharge	Work Requirements
Alabama[23]											Proposed
Arizona[24,25,26]				Approved		Proposed	Proposed				Proposed
Arkansas[27,28]			Not Approved	Approved			Approved				Approved
Florida[29]							Proposed				
Indiana[30]	Approved			Approved			Approved	Approved		Approved	Approved
Iowa[31]	Approved						Approved	Approved			
Kansas[32,33]						Not Approved					Proposed
Kentucky[34]				Approved but currently blocked by U.S. District Court for the District of Columbia			Approved but currently blocked by U.S. District Court for the District of Columbia	Approved but currently blocked by U.S. District Court for the District of Columbia			Approved but currently blocked by U.S. District Court for the District of Columbia
Maine[35]	Proposed			Proposed		Proposed	Proposed				Proposed
Massachusetts[36]			Not Approved		Not Approved						
Mississippi[37]											Proposed
New Hampshire[38,39]							Approved				Approved
New Mexico[40]	Proposed			Proposed			Proposed		Proposed		
North Carolina[41]				Proposed							Proposed
Ohio[42]											Proposed
Utah[43,44]	Proposed	Proposed	Proposed			Proposed	Approved		Proposed		Proposed
Wisconsin[45]	Proposed			Proposed		Proposed				Proposed	Proposed

- Approved
- Proposed
- Not Approved
- Approved but currently blocked by U.S. District Court for the District of Columbia

Figure 1: States with 1115 Waivers that Put Coverage at Risk for Patients



- **States with proposed waivers that would put health coverage at risk for patients**
- **States with proposed waivers that risk patients' health coverage, conditional on expansion of the Medicaid program.**
- **States with an approved waiver that puts patients' health coverage at risk.**
- **States with an approved waiver that puts patients' health coverage at risk, but the waiver has been blocked by the U.S. District Court for the District of Columbia.**

States are only included in this map if they submitted an 1115 Waiver application (including amendments) to CMS or had a waiver application under review by CMS between January 1, 2017 and June 30, 2018.

Table 3: Population Targeted by State*

State	Population Targeted
Alabama Status: Pending	**Work Requirement:** Standard non-disabled Medicaid enrollees under the age of 60 (Parents with a dependent child, making 18 percent FPL or less)[46]
Arizona Status: Approved in Part, Pending in Part	**Work Requirement** (pending)**:** Both standard and Medicaid expansion non-disabled enrollees under the age of 55 **Time Limits** (pending)**:** Both standard and Medicaid expansion non-disabled enrollees **Removal of Retroactive Coverage** (pending)**:** Both standard and Medicaid expansion enrollees **Enforceable Premiums** (approved)**:** Enrollees between 100 and 138 percent FPL[47,48,49]
Arkansas Status: Approved in Part, Denied in Part	**Work Requirement** (approved)**:** Both standard and expansion non-disabled enrollees aged 19 to 49 years old with incomes up to and including 138 percent of FPL **Removal of Retroactive Coverage** (approved)**:** Both standard and Medicaid expansion non-disabled enrollees **Enforceable Premiums** (approved)**:** Enrollees between 100 and 138 percent FPL **Limiting eligibility to 100 percent FPL** (denied)**:** All enrollees[50]
Florida Status: Pending	**Removal of Retroactive Coverage:** All non-pregnant Medicaid enrollees aged 21 and older[51]
Indiana Status: Approved	**Work Requirement:** All members aged 19-59 **Enforceable Premiums:** Medicaid expansion enrollees with incomes over 100 percent of FPL **Tobacco Surcharge:** Medicaid expansion enrollees with incomes over 100 percent of FPL **Removal of Non-Emergent Transportation Benefits:** All non-pregnant, non-medically frail standard and Medicaid expansion enrollees **Co-Pay for Non-Emergent Use of Emergency Department:** All enrollees **Waiving Retroactive Coverage:** All non-pregnant standard and Medicaid expansion enrollees[52]
Iowa Status: Approved	**Co-Pay for Non-Emergent Use of Emergency Department:** All enrollees **Removal of Retroactive Coverage:** All non-pregnant standard and Medicaid expansion enrollees **Removal of Non-Emergent Transportation Benefits:** Medicaid expansion population (New Adult Population)[53]

Table 3: Population Targeted by State*

State	Population Targeted
Kansas Status: Pending (Denied in Part)	**Work Requirements** (pending)**:** Adults under the age of 65 **Lifetime Limits** (denied)**:** Adults under the age of 65[54]
Kentucky Status: Approved	**Work Requirement:** All adult enrollees **Removal of Non-Emergent Transportation Benefits:** Medicaid expansion population (New Adult Population) **Removal of Retroactive Coverage:** All Medicaid enrollees except former foster youth and pregnant women **Enforceable Premiums:** All Medicaid enrollees except medically frail, former foster youth and pregnant women[55]
Maine Status: Pending	**Work Requirement:** All enrollees **Enforceable Premiums:** All enrollees over 50 percent FPL except HIV Waiver enrollees **Removal of Retroactive Coverage:** All enrollees **Enhanced Cost-Sharing for Non-Emergent use of ED:** All enrollees **Lifetime Limits:** All enrollees[56]
Massachusetts Status: Approved in Part, Denied in Part	**Limiting eligibility to 100 percent FPL** (denied)**:** All enrollees **Prescription Drug Limits** (denied)**:** All enrollees[57]
Mississippi Status: Pending	**Work Requirements:** All non-disabled adults[58]
New Hampshire Status: Approved	**Work Requirements:** All non-disabled, non-pregnant adults, aged 19-64 **Retroactive Coverage:** Medicaid expansion population[59]
New Mexico Status: Pending	**Enforceable Premiums:** Medicaid expansion population above 100 percent FPL **Removal of Retroactive Coverage:** Medicaid expansion population above 100 percent FPL **Limiting EPSDT:** Individuals in the adult expansion population and the parent/caregiver categories aged 19 and 20 **Penalty for Non-Emergent use of ED:** All members[60]

Table 3: Population Targeted by State*

State	Population Targeted
North Carolina Status: Pending	**Work Requirement:** All enrollees not caring for a minor child, receiving active treatment, or the medically frail within 100 percent FPL **Premiums:** Enrollees above 50 percent FPL[61]
Ohio Status: Pending	**Work Requirement:** All enrollees under age 50.[62]
Utah Status: Partially Approved, Partially Pending	**Removing Retroactive Eligibility** (approved)**:** Non-disabled members 19-64 years old at or below 100 percent FPL **Work Requirements** (pending)**:** Primary Care Network enrollees under age 60 **Time Limits** (pending)**:** Primary Care Network enrollees and adults without dependent children **Penalty for Non-Emergent use of ED** (pending)**:** Parent/ Caretaker/ Relative Group (current eligibles) **Enrollment Caps** (pending)**:** Adults without dependent children, specifically the chronically homeless; individuals involved in the justice system and needing mental health or substance abuse treatment; and individuals needing substance use or mental health treatment **Limiting eligibility to 100 percent FPL** (pending): All enrollees **Limiting EPSDT** (pending)**:** Individuals aged 19 and 20 without dependent children[63,64]
Wisconsin Status: Pending	**Work Requirements:** Non-pregnant, childless adults, ages 19 to 64 years old, whose income does not exceed 100 percent FPL **Enforceable Premium:** Non-pregnant, childless adults, ages 19 to 64 years old, whose income does not exceed 100 percent FPL **Tobacco Surcharge:** Non-pregnant, childless adults, ages 19 to 64 years old, whose income does not exceed 100 percent FPL **Time Limit:** Non-pregnant, childless adults, ages 19 to 64 years old, whose income does not exceed 100 percent FPL **Penalty for Non-Emergent use of ED:** Non-pregnant, childless adults, ages 19 to 64 years old, whose income does not exceed 100 percent FPL[65]

*Information in the table is only included if a state submitted an 1115 Waiver application (including amendments) to CMS or was under review by CMS between January 1, 2017 and June 30, 2018.
Most states exempt certain subgroups from these requirements, based on age, disability or hardship.

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