I. INTRODUCTION

Premiums and cost sharing are two mechanisms by which individuals contribute to the cost of their healthcare. This issue brief reviews the literature on the impact of premiums and cost sharing on enrollment, service utilization, and health status. It focuses particularly on how the research consensus fits with the flexibility Medicaid law gives states to establish premiums and cost sharing and the proposals by some states to charge Medicaid beneficiaries even higher cost sharing and premiums.

The Medicaid Act gives participating states the option to impose cost sharing and premiums on program beneficiaries, with important limits and exemptions. These protections are supported by decades of research documenting the relationship between cost sharing and access to care. Starting with the RAND Health Insurance Experiment (“HIE”) in the 1970s, study after study demonstrates that increasing cost sharing reduces access to necessary services for low-income and chronically ill populations. Even slight increases in copayments can cause significant declines in utilization. Furthermore, numerous recent studies indicate that heightened premiums and cost sharing increase the risks of adverse health outcomes.

With regard to cost sharing, Congress has been generally protective of beneficiaries with family incomes at or below the Federal Poverty Level (“FPL”) and those who are

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1 Virginia Niehaus, NHeLP contract attorney, contributed significantly to the preparation of this paper.
2 Premiums are fees “paid for coverage of medical benefits for a defined benefit period” of time. Definitions of Health Insurance Terms, Bureau of Labor Statistics, http://www.bls.gov/ncs/ebs/sp/healthterms.pdf (last visited Feb. 25, 2014). Cost sharing is the portion of expenses for healthcare services and supplies not covered by the insurer that the patient must pay out-of-pocket. Types of cost sharing include deductibles, copayments, and coinsurance. A deductible is the amount a patient must pay out-of-pocket before the insurer covers any expenses during a given benefit period. Following payment of the deductible, most patients have copayments or coinsurance for the remainder of the coverage period. A copayment is a flat amount paid upon receipt of care, and coinsurance is a percentage amount paid upon receipt of care. Id. Health insurance policies also typically have an out-of-pocket maximum that caps total patient spending per benefit period. See Katherine Swartz, Robert Wood Johnson Found., Cost-Sharing: Effects on Spending and Outcomes 6 (2010), http://www.rwjf.org/content/dam/farm/reports/issue_briefs/2010/rwjf402103/subassets/rwjf402103_1.
3 42 U.S.C. §§ 1396o, 1396o-1.
4 See below, Section II.B.
5 Amal N. Trivedi et al., Increased Ambulatory Care Copayments and Hospitalizations among the Elderly, 362 New Eng. J. Med. 320 (2010); Amitabh Chandra et al., Patient Cost-Sharing and Hospitalization Offsets in the Elderly, 100 Am. Econ. Rev. 193 (2010); Bill J. Wright et al., The Impact of Increased Cost Sharing on Medicaid Enrollees, 24 Health Aff. 1106 (2005).
vulnerable, such as children, pregnant women, and the terminally ill. Nevertheless, Congress amended the Medicaid Act in 2005 to provide states with considerable flexibility to impose cost sharing on other population groups, particularly individuals above 100% FPL. In July 2013, the Centers for Medicare & Medicaid Services (“CMS”) finalized new regulations that implement the statutory changes. Among other things, the regulations slightly increase cost sharing maximums for medical services, prescription drugs, and non-emergency use of the emergency department (“ED”) and more than double the allowable cost sharing on “non-preferred” medications, but lower the maximum copay on inpatient care. In addition, a growing handful of states are seeking, and in some instances obtaining, permission from the federal government to impose premiums and cost sharing beyond the Medicaid limits. To execute these changes, the states rely on § 1115 of the Social Security Act, a provision that authorizes the Secretary of Health & Human Services (HHS) to waive certain provisions of the Medicaid Act to allow states to implement “experimental, pilot, or demonstration project[s].”

Section II of this brief reviews the literature assessing the effects of cost sharing and premiums. Section III then summarizes the premium and cost sharing permitted under Medicaid law and including demonstrations authorized under § 1115 of the Social Security Act. NHHeLP maintains an annotated bibliography of the cost sharing research available on request.

II. THE COST SHARING LITERATURE

A. Overview

Research over the last four decades has consistently concluded that the imposition of cost sharing on low-income and vulnerable populations reduces both necessary and unnecessary care and correlates with increased risk of poor health outcomes. The literature also finds current cost sharing policies do little to increase overall cost efficiency while their effect on the overall rate of growth in health care spending is complex, difficult to measure, and likely rather limited. Partly, this is because health expenditures are extremely concentrated in the sickest patients whose total expenses are little affected by cost sharing policies. Furthermore, health care utilization is strongly influenced by other factors not directly related to cost sharing, like provider

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6 See 42 U.S.C. § 1396o(a)(2). See also below, Table 2, at 24.
7 See 42 C.F.R. § 447.53(b).
8 42 U.S.C. § 1315(a).
10 Katherine Swartz, supra note 2, at 9-11.
11 A number of reasons lead to reduced responsiveness. First, once someone exceeds their out-of-pocket maximum, cost sharing no longer has any impact. Second, very expensive individuals have almost by definition already initiated care. Post-initiation expenditures are only modestly impacted by costs sharing. See Robert H. Brook et al., RAND Corp., The Health Insurance Experiment: A Classic RAND Study Speaks to the Current Health Care Reform Debate, at 2 (2006), http://www.rand.org/pubs/research_briefs/RB9174.html; See also Katherine Swartz, supra note 2, at 9.
norms, regional differences, and utilization management.\textsuperscript{12} However, cost sharing does shift healthcare costs. In the Medicaid program, costs shift from state and federal governments to low-income enrollees and, to some extent, their providers.\textsuperscript{13}

The RAND HIE, conducted from 1971 to 1986, remains the only long-term randomized experiment studying the impact of cost sharing on medical service utilization and health outcomes. Key findings from the study include that higher cost sharing reduced overall use of services and total health expenditures, but the reductions came from both essential and nonessential care in roughly equal proportions.\textsuperscript{14} And while the HIE generally found the cost sharing had no significant impact on most health outcomes, higher cost sharing correlated with worse outcomes in several areas for the poorest and sickest patients.\textsuperscript{15}

Taken as a whole, subsequent research overwhelmingly shows that heightened copayments hinder Medicaid beneficiaries’ access to medical services and prescription medications, while premiums make it harder for eligible individuals to enroll and maintain coverage.\textsuperscript{16} Increased cost sharing causes financial hardship, forcing difficult choices between health care and other basic necessities.\textsuperscript{17} Further, increased cost sharing can lead to adverse health outcomes, especially among individuals with chronic conditions and/or lower incomes.\textsuperscript{18} The general conclusions of the literature can be summarized as follows:

\textit{Cost sharing is an imprecise policy tool.} In its simplest expression, the dominant rationale for cost sharing is to reduce “moral hazard,” the tendency for comprehensively insured individuals to overuse services because they bear none of the costs for care at


\textsuperscript{15} Robert H. Brook et al., \textit{supra} note 11, at 3.

\textsuperscript{16} Leighton Ku & Victoria Wachino, \textit{supra} note 9.

\textsuperscript{17} Thomas M. Selden et al., \textit{Cost sharing in Medicaid and CHIP: How Does It Affect Out-of-Pocket Spending?} 28 Health Aff. W607 (online ed. 2009), http://content.healthaffairs.org/content/28/4/w607.

\textsuperscript{18} See e.g., Ku & Wachino, \textit{supra} note 9; Swartz, \textit{supra} note 2; Robyn Tamblyn et al., \textit{Adverse Events Associated with Prescription Drug Cost-Sharing Among Poor and Elderly}, 285 JAMA 421 (2001); Dana P. Goldman et al., \textit{Prescription Drug Cost Sharing: Associations with Medication and Medical Utilization and Spending and Health}, 298 JAMA 61 (2007).
the time they seek it.19 Indeed, the research generally finds that raising cost sharing on a targeted service typically reduces utilization of that service. Across-the-board cost sharing structures, like deductibles (where an individual pays a set amount before coverage begins) or standard copays for all services, typically result in similar across-the-board reductions in service use.20 That does not equate with more efficient use of health services, however, because people reduce both necessary (high-value) and unnecessary (low-value) care.21 Evidence and common sense also suggest that people with lower incomes and higher healthcare needs are disparately affected by cost sharing, and hence more likely to forgo necessary care.22

Cost sharing can be “penny-wise and pound foolish.”23 Delaying or reducing necessary drugs or services (e.g., preventive blood pressure medication) tends to increase the risk of negative health outcomes (e.g., a heart attack). Such adverse health outcomes can result in increased hospitalizations and other expensive services. In some cases, added costs can more than offset any savings due to cost sharing related service reductions.24

Cost sharing is not where the real money is. Cost sharing likely has a limited effect on total system-wide health spending, although it can significantly shift costs within the system.25 Sixty-four percent of all spending is concentrated in the top 10% of individuals (annual expenses above $6,444).26 Research suggests that cost sharing has little impact on overall expenses for such individuals, who are invariably already engaged with the healthcare system.27 The RAND HIE found that after an individual initiated care, the overall cost of an episode of care did not vary significantly across different levels of patient cost sharing.28 In such cases, “supply-side” practices such as utilization management (e.g., prior authorization, step therapy), professional norms of care, and regional care-giving traditions more strongly govern utilization, and thus expenditures.29

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19 Katherine Baicker & Dana Goldman, supra note 12, at 52-3.
20 Katherine Swartz, supra note 2, at 22.
24 See, for example, Amal N. Trivedi et al., supra note 5, at 327.
25 On cost shifting, see, for example, Amitabh Chandra et al., supra note 5, at 193-4.
27 Katherine Swartz, supra note 2, at 9; Dahlia K. Remler & Jessica Greene, supra note 21, at 306.
29 Katherine Swartz, supra note 2, at 9; Dahlia K. Remler & Jessica Greene, supra note 21, at 306.
The impact of cost sharing on behavior is “elastic.” That is, copays may have greater impact on the behavior of some populations than on others. Low-income individuals have qualified for Medicaid precisely because they have very limited income and, unlike individuals with more income, are not able to bear the costs of health care and other basic necessities, such as food and housing. Many cost sharing studies focus on individuals with employer-sponsored insurance, but such individuals generally have higher incomes and different underlying risk characteristics than individuals on Medicaid or older populations on Medicare. Medicaid and Medicare beneficiaries are more likely to have chronic conditions, require hospitalization or visit the emergency department. Cost sharing that reduces service use without impacting health outcomes in a relatively healthy, middle-income population can have quite a different impact on low-income, older or chronically ill populations.

Keeping these general features of cost sharing in mind, the following sections summarize more specific research findings in particular areas.

### B. Cost sharing and prescription drug utilization

Prescription drug utilization is the most widely studied aspect of cost sharing. Overwhelmingly, the literature finds that increased cost sharing decreases adherence to medication regimens. A recent meta-analysis of articles published between 1974 and 2008 found that 56 of 66 studies (85%) of cost sharing and medication adherence confirmed a significant inverse correlation. Other studies associate higher cost sharing with delayed initiation and/or discontinued use of prescription medications.

This general trend seems amplified in older and chronically ill populations, although limitations in research design make it difficult to isolate how much more. Goldman et al. showed that doubling copayments for a prototypical employer-sponsored health plan would reduce utilization, varying from 25% to 45%, across all measured classes of drugs for treating chronic conditions. In a similar study based on analysis of claims from roughly 275,000 retired employees of large employers, Solomon et al. found that doubling patients’ out-of-pocket expenses correlates with a sizeable and significant drop in the predicted percentage of patients initiating medications after a new diagnosis. This effect was most pronounced among newly diagnosed individuals.

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30 See for example, Paul T. Cheung et al., National Study of Barriers to Timely Primary Care and Emergency Department Utilization among Medicaid Beneficiaries, 60 Ann. Emergency Med. 4 (2012).
33 Dana P. Goldman et al., Pharmacy Benefits and the Use of Drugs by the Chronically Ill, 291 JAMA 2344 (2004). The prototypical plan is based on median estimated out-of-pocket costs across 52 health plans included in the data set. This would have copays $6/$12 for generic/brand name drug in Tier 1, and $12/$26 copays for Tier 2.
without a history of prior medication use. Huskamp et al. found that 16 to 32% of patients discontinued use of drugs to treat chronic conditions after their employers switched from a one-tier to a higher cost three-tier drug formulary (where certain non-preferred or brand name medications have increased cost sharing). Finally, after Georgia implemented medication copays of $2-$3, a cohort of Medicaid enrollees with cancer reduced prescription drug use by 16% relative to a control. Individuals with comorbidities reduced medication use by twice the amount of individuals with no comorbidities, while a control in nearby states with minimal or no copay increases saw individuals with comorbidities actually increase medication use.

A second branch of prescription drug research strongly links reduced medication adherence to poorer health outcomes, although the total impact is difficult to measure due to the relatively short duration of many studies and the lack of adequate control groups. That same Georgia Medicaid study found a slight but significant increase in emergency department visits (0.08% increased probability), and slightly higher total expenditures after the state implemented nominal copays. A 2001 study in Quebec, Canada, found that, after the province introduced medication cost sharing (25% coinsurance with $100 deductible and $200 annual maximum), welfare recipients reduced their use of essential drugs by 14%, which also correlated with an 88% increase in the occurrence of adverse events (such as hospitalizations or death) and a 78% increase in emergency department (ED) use. A more recent literature review found that 19 of the 25 studies that directly examined adherence and outcomes found increased cost sharing for prescription drugs raises the risk of adverse outcomes (such as increased adverse events, medical costs, hospital and nursing home admissions, or ED visits). Numerous other studies suggest savings due to decreased prescription drug utilization are offset, at least in part, by increases in the use of other services, such as hospitalizations and emergency care.

Finally, several recent studies have also linked decreased cost sharing with increased adherence and improved health outcomes. When patients discharged following myocardial infarction received a drug treatment regimen without cost sharing, adherence to discharge regimens increased by 31% to 41% while adverse outcomes decreased by 11%. Similarly, the elimination of copayments for ACE inhibitors/ARBs, beta-blockers, diabetes drugs, and statins decreased non-adherence by 7-14%.

34 Matthew D. Solomon et al., Cost Sharing and the Initiation of Drug Therapy for the Chronically Ill, 169 Archives Internal Med. 740 (2009).
35 Haiden A. Huskamp et al. (2003), supra note 32, at 2230.
37 Id.
38 Id.
39 Tamblyn, supra note 18; see also Ku & Wachino, supra note 9.
40 Michael T. Eaddy et al., supra note 31, at 45.
41 See Section II.E. below.
43 Michael Chernew et al., Impact of Decreasing Copayments on Medication Adherence within a Disease Management Environment, 27 Health Aff. 103 (2008).
## Value-Based Insurance Design: Smarter Cost Sharing?

A slightly more refined version of cost sharing, value-based insurance design (VBID), asks enrollees to pay relatively more for services with less apparent value, and less for “high value” services. Unfortunately, such systems are currently more theoretical than practical in public insurance. The most convincing evidence of effective VBID involves lowering or eliminating cost sharing on key preventive services and drugs, not on raising cost sharing on “low-value” services. In most studies, reducing cost sharing for treatments of certain chronic conditions improved care outcomes without adding significantly to overall costs. However, the “value” of a given treatment depends on when, where and for whom it is provided. Value varies relative to age, life history, clinical context and provider. An MRI may be superfluous for a headache, but if the individual has a history of dissected arteries it could be life-saving and essential. Assigning “value” in terms of efficacy and cost-effectiveness for given populations or individuals requires an extensive evidence base. Only limited clinical situations have achieved this threshold, such as reducing copays for anti-diabetics and anti-hypertensives for high risk groups. VBID, when limited to these clear cases, shows some promise.

The converse approach of raising cost sharing on “less effective” services is more problematic. Many services lack the clear evidence-base to target a specific group for higher cost sharing, and within that group, there may be individuals with a justified need for a given procedure. For example, if a plan charges higher cost sharing for hip replacement, will there be an exceptions process for an older woman with a broken hip who needs replacement surgery to stay out of a nursing home? How would such cases be decided when the evidence-base is less clear, and how much will “cost-effectiveness” weigh against clinical efficacy? How much administrative burden would an exceptions process generate and how accessible would it be?

Implementing a system to charge different beneficiaries different amounts for the same service based on a diagnosis or other risk factor increases plan complexity. This may add administrative costs, while enrollees might find such individualized cost sharing unfair or overly confusing. The VBID rationale relies on consumers to make accurate, cost conscious decisions about their health service utilization, but such context-driven cost sharing structures are more difficult to concisely explain. Not surprisingly, in practice, people facing complex plan designs may not be aware of VBID incentives built into their plan. Instead, they simply cut back on all services. For example, many High Deductible Health Plans cover preventive services before the deductible is met (a classic VBID structure), but studies show that a fifth to a third of enrollees in such plans report delaying preventive care due to the cost.

In short, making cost sharing “smarter” also makes it more difficult for consumers, providers, and administrators. While VBID is likely here to stay, the concept still has a long way to go before it realizes its policy goal of improving the efficiency of care delivery without adversely affecting access to necessary services.

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44 Niteesh Choudhry et al., *At Pitney Bowes, Value-Based Insurance Design Cut Copayments and Increased Drug Adherence*, 29 Health Aff. 1995 (2010); Michael E. Chernew et al., *supra* note 43; John F. Hoadley et al., *In Medicare Part D Plans, Low or Zero Copays and Other Features to Encourage the Use of Generic Statins Work, Could Save Billions*, 31 Health Aff. 2266 (2012);


46 *Id.*
C. Cost sharing and access to outpatient services

Multiple studies have demonstrated that increased cost sharing reduces utilization of a variety of outpatient services, including clinician visits, imaging tests, preventive care, and behavioral health services.\(^{48}\) For example, Ku et al.'s analysis of cost sharing in Utah’s Medicaid program found significant declines in various outpatient services and hospitalizations when the state implemented copays as low as $2 to $3.\(^ {49}\) As discussed below, although many studies do not differentiate between specific outpatient services, preventive services and behavioral health services deserve special attention.

Improving access to preventive services is a clarion call of public health policymakers. Better access to highly effective early intervention treatments can reduce costly complications and other adverse health outcomes.\(^ {50}\) However, these cost-effective services may also be more sensitive to cost sharing because, in the absence of acute symptoms, individuals may see them as less urgent. Indeed, increasing cost sharing on preventive services is associated with reduced utilization of these services in the literature.\(^ {51}\) Not surprisingly then, the Medicaid Act exempts certain preventive services from cost sharing and the ACA guarantees access to many recommended vaccinations and preventive services free of cost sharing in group health plans.\(^ {52}\) However, even with such exemptions, research raises concerns that without effective outreach enrollees may not know of the exemption and may as a result avoid or delay preventive care.\(^ {53}\)

The relatively few studies that focus on access to behavioral health services, including medications and provider visits, suggest such services may be particularly impacted by cost sharing, especially in the likelihood an individual will initiate or continue services. Historically, behavioral health services typically require higher out-of-pocket spending

\(^{47}\) Mary E. Reed et al., In Consumer-Directed Health Plans, A Majority of Patients Were Unaware of Free or Low-Cost Preventive Care, 31 Health Aff. 2641 (2012); Jeffrey Kullgren et al., Health Care Use and Decision Making Among Lower-Income Families in High-Deductible Health Plans, 170 Archive Internal Med. 1918 (2010).


\(^{50}\) Choudhry et al., supra note 44.

\(^{51}\) John Hsu et al., Unintended Consequences of Caps on Medicare Drug Benefits, 354 New Eng. J. Med. 2349 (2006); Trivedi et al, supra note 48; Geetesh Solanki et al., The Direct and Indirect Effects of Cost-Sharing on the Use of Preventive Services, 34 Health Services Res. 1331 (2000); Andrew J. Karter et al., Out-of-Pocket Costs and Diabetes Preventive Services, 26 Diabetes Care 2294 (2003); Dahlia K. Remler & Jessica Greene, supra note 21, at 301.

\(^{52}\) 42 U.S.C. 300gg-13(a), implementing ACA § 1001.

\(^{53}\) Mary E. Reed et al., supra note 47; Kullgren et al., supra note 47.
than general medical care. One study of retired Pennsylvania mineworkers and their dependents showed that after the introduction of $5 outpatient visit copays in 1978, overall outpatient visits declined by 23%, but participants reduced mental health visits by 40%. Simon et al. found that among a sample of primary care patients in a staff-model HMO in Washington, individuals in plans with $20 or $30 copayments for mental health visits were, respectively, 33% and 56% less likely to use the HMO’s mental health services than individuals with no cost sharing. A follow up study found a clear temporal correlation; in the year after plans instituted $20 copays the likelihood that an enrollee would use HMO mental health services decreased by roughly 15 to 20% across all levels of clinical need. Similarly, Stein et al.’s regression model of individuals with employer-sponsored insurance predicts a copayment of $30 will significantly increase the number of patients not receiving follow-up care (43%), while eliminating copays will decrease the number of patients without follow-up by 24%. More recently, Fishman et al. found reduced initiation of care for depression for individuals with unmet deductibles.

Notably, nearly all these studies drew from populations with employer-sponsored insurance, who generally have higher incomes than Medicaid beneficiaries. Evidence suggests that lower income individuals may respond similarly, even with only “nominal” copayments for behavioral health services. One multistate study of Medicaid claims data found generic copays of only $2 or $3 correlated with significantly lower adherence to medications for schizophrenia as compared with no copays. Hartung et al. found reduced adherence to antipsychotics and antidepressants (12% and 20%, respectively) after Oregon’s Medicaid program instituted copays for prescription drugs in 2003 ($2 generic; $3 brand name). Similarly, when Mississippi’s Medicaid program instituted new utilization management policies in 2002, including prescription caps and tripling copayments (from $1 to $3) for branded drugs, enrollees with schizophrenia were 5% less adherent to medications and 20% more likely to have a 90+ day gap without

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55 Jacqueline Wallen et al., Male-Female Differences in Mental Health Visits under Cost-Sharing, 21 Health Services Res. 341 (1986).


58 Bradley Stein et al., The Effect of Copayments on Drug and Alcohol Treatment Following Inpatient Detoxification under Managed Care, 51 Psychiatric Services 195 (2000).

59 Paul A. Fishman et al., Impact of Deductibles on Initiation and Continuation of Psychotherapy for Treatment of Depression, 47 Health Services Res. 1561 (2012).

60 Jonathan D. Brown et al., Medication Continuity among Medicaid Beneficiaries with Schizophrenia and Bipolar Disorder, 64 Psychiatric Services 878 (2013). A smaller cohort of beneficiaries with bipolar disorder also showed adherence reductions, but the small sample did not reach statistical significance.

The Mississippi study also found a suggestive 20% increase in mental health ED visits, although the sample was likely too small to expect a statistically significant difference.

D. Cost sharing and emergency department (ED) use

Emergency department care, one of the most frequently-cited drivers of health care costs, has become a major target for cost sharing policies intended to push enrollees to less expensive types of care. The stereotypical “frequent flyer” who uses the ED for every cough and sniffle has become a powerful, if erroneous, figure used to justify higher cost sharing on ED use. However, the meme of ED overutilization as a driver of wasteful spending is likely overblown. Largely, the steady increase in emergency care over the last two decades is attributable the ED’s evolving role as a “gatekeeper” and after hours treatment option with increasingly complex and comprehensive patient screening. This screening may be more expensive, but it aims to reduce unnecessary (and far more expensive) hospital admissions. Even with the increased utilization, EDs account for only 2% to 6% of all health expenditures, depending on the counting methodology. Inappropriate ED use constitutes no more than a tiny fraction of that small percentage. Meanwhile hospital care accounts for nearly a third of all costs.

Several studies of employer-sponsored insurance support the reasoning that higher ED cost sharing selectively reduces ED utilization for less urgent symptoms, possibly without significant increases in adverse health outcomes. For example, Wharam et al. found that when employers switch to high deductible health plans with substantial increases in patient out-of-pocket costs – on the order of hundreds of dollars per visit – ED use declined by 10% relative to controls. Low-severity repeat ED visits declined by 36% relative to controls. However, although the authors correctly claim that there is no significant decline in high-severity ED visits, the study’s sample size for such visits is so small that it would be nearly impossible to identify a statistically significant result. In fact, they do measure a 25% decline in high severity ED visits among enrollees with lower incomes (compared to a 1.3% decline for higher income enrollees). While not

63 In fact, while the most frequent users may account for a disproportionate share of ED expenditures, they are less likely to visit the ED with nonemergent symptoms. They are, in short, very sick. See John Billings & Maria C. Raven, Dispelling an Urban Legend: Frequent Emergency Department Users Have Substantial Burden of Disease, 32 Health Aff. 2099, 2103 (2013).
64 Arthur L. Kellermann et al., Emergency Care: Then, Now, and Next, 32 Health Aff. 2069 (2013).
66 For inpatient care costs, see Anne B. Martin et al., National Health Spending in 2012: Rate of Health Spending Growth Remained Low for the Fourth Consecutive Year, 33 Health Aff. 67, 70 (2014).
68 J. Frank Wharam et al., Emergency Department Use and Subsequent Hospitalizations among Members of a High-Deductible Health Plan, 297 JAMA 1093, 1097 (2007).
statistically significant, the findings suggest that increased copays may discourage unnecessary and necessary ED care, especially for low-income enrollees.\textsuperscript{69} Findings from an older major study of ED cost sharing in employer-sponsored insurance showed similar results, with significant reductions in urgent and less urgent visits.\textsuperscript{70}

However, these studies do not translate well to Medicaid. First, individuals in employer-sponsored plans earn more and have generally better health profiles than the Medicaid population. Second, cost sharing in these employer studies applies to all utilization of the ED. Medicaid law forbids cost sharing on ED use related to an emergency medical condition.\textsuperscript{71} Medicaid must include a screening process to evaluate the severity of symptoms as well as proper referral to actually accessible and available alternative Medicaid providers (keeping in mind that Medicaid beneficiaries cannot afford the up-front out-of-pocket costs care). The effectiveness of such a triage and referral system has little empirical support and may not be worth the administrative burden.\textsuperscript{72} One multi-state analysis found that requiring copayments for nonemergent ED use had no discernible effect on ED utilization (emergency or nonemergency) for Medicaid enrollees.\textsuperscript{73} Another study of ED copay increases in Alabama’s CHIP program, including a $20 surcharge for non-emergency ED use for some enrollees, found no reduction whatsoever in low-severity ED use.\textsuperscript{74}

Finally, one recent study shows that only about 10% of Medicaid ED visits are due to “nonurgent” symptoms, a rate on par with privately insured individuals.\textsuperscript{75} Although Medicaid beneficiaries typically use the ED more frequently, they are also more likely to have chronic disease or other health risks and experience emergencies because they face access barriers to primary care that correlate with higher ED use.\textsuperscript{76} Billings’ and Raven’s analysis of frequent ED users (3 or more visits per year) finds that such individuals are generally very sick and use the ED appropriately. The authors recommend screening to identify likely frequent users and then target specific case management services to reduce the likelihood that they will need emergency services going forward.\textsuperscript{77} The more effective policy to reduce ED use among Medicaid enrollees

\textsuperscript{69} Id, at 1098.
\textsuperscript{70} Joe V. Selby et al., supra note 67, at 638.
\textsuperscript{71} CMS defines an emergency medical condition as experiencing “acute symptoms of sufficient severity (including severe pain) that a prudent layperson, who possesses an average knowledge of health and medicine, could reasonably expect the absence of immediate medical attention” to seriously jeopardize or impair the individual’s health (or, in the case of a pregnant woman, her health or the health of her unborn child.) See 42 C.F.R. § 438.114.
\textsuperscript{72} Maryland abandoned a nonemergency ED copay for this reason. See Karoline Mortensen, Copayments Did Not Reduce Medicaid Enrollees’ Nonemergency Use of Emergency Departments, 29 Health Aff. 1643 (2010). See also below Section III.F.
\textsuperscript{73} Id.
\textsuperscript{74} David J. Becker et al., Co-payments and the Use of Emergency Department Services in the Children’s Health Insurance Program, 70 Med. Care Res. Rev. 514–529 (2013).
\textsuperscript{75} Anna S. Somers, Ellyn R. Boukus & Emily Carrier, Center for Studying Health System Change, Research Brief No. 23, Dispelling Myths About Emergency Department Use: Majority of Medicaid Visits Are For Urgent or More Serious Symptoms (2012).
\textsuperscript{76} Paul T. Cheung et al., supra note 29 (mentioning long wait times for primary care, limited clinic hours and lack of transportation to care).
\textsuperscript{77} John Billings & Maria C. Raven, supra note 63.
may be to eliminate barriers to primary care rather than increase cost sharing. In a recently released bulletin suggesting best practices to reduce unnecessary ED use, CMS cites effective strategies like expanding access to primary care or providing health homes for frequent ED users, but suggests that increased copays for nonemergency use are unproven and problematic to implement fairly.

**E. Offsetting costs, adverse events and evidence from the chronically ill**

One of the complicating factors of imposing cost sharing is its impact on use of substitutable or complementary medical services. In other words, findings show that increasing cost sharing in one area, such as pharmaceuticals, may reduce utilization and expenditures in that area while simultaneously increasing the frequency or intensity of service utilization in other areas, such as hospitalizations, that offset the cost savings.

Not all studies look for or find significant offsetting costs associated with higher cost sharing. Notably, the RAND HIE generally found that participants with higher cost sharing for outpatient visits had fewer hospitalizations. However, the HIE also found that health outcomes for low-income populations were worse in several areas. Furthermore, it did not include the elderly, who generally have higher rates of hospitalization. Measuring the impact of cost offsets can be challenging because the frequency of events like hospitalizations and ED visits is relatively low, and the incremental impact attributable to higher cost sharing may be difficult to detect without a large sample size and a multiple year study, especially among the nonelderly. However, because adverse events like hospitalizations are so serious and expensive, even a small increase is important and can quickly wipe out savings from reduced office visits or prescription drug use.

For these reasons, some of the best evidence for the impact of offsetting costs involves the elderly or individuals with chronic illness. Not only do such individuals face higher financial burden due to their health expenses, but they may be more likely to suffer adverse events due to poorer overall health status.

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78 For example, one program in Michigan identified hundreds of high frequency ED users and provided them with intensive case management and care coordination. A subsequent review of 300 participants found ED use declined by 64% after one year. Agency for Healthcare Research and Quality, *Coordinated, Intensive Medical, Social, and Behavioral Health Services Improve Outcomes and Reduce Utilization for Frequent Emergency Department Users* (2013) http://www.innovations.ahrq.gov/content.aspx?id=3866.


82 Robert H. Brook et al., *supra* note 11, at 3.

83 Amitabh Chandra, Jonathan Gruber, & Robin McKnight, *supra* note 5.
One of the most noted studies of the offset effect involved retired Medicare enrollees in the California Public Employees’ Retirement System. Chandra et al. found that increased copayments for clinician office visits and prescriptions induced significant declines in both office visits (17.5%) and in prescriptions filled, especially for drugs to treat chronic illness. However, these decreases correlated with a 6% increased risk of hospitalization. For the sickest beneficiaries, hospital spending increased by nearly $2 for every $1 saved. For all chronically ill individuals, 43% of savings realized by reduced medications and office visits were offset by increased hospital spending.

Another study of roughly 900,000 Medicare enrollees from 2001-2006 found that, overall, plans that increased copays had 19.8 fewer ambulatory visits per 100 enrollees as compared to controls that did not increase copays. However, the study population also experienced 2.2 more hospitalizations and 13.4 more annual inpatient hospital days per 100 enrollees. Based on the authors’ reasonable estimates for service costs and copays, the Medicare health plans with higher copays would save a bit more than $7,100 per 100 enrollees in outpatient services, but at the cost of $24,000 per 100 enrollees for increased hospitalization costs.

Similarly, an evaluation of Georgia’s Medicaid program found that after the state instituted $2-$3 medication copays in 2002, enrollees with cancer reduced their prescription drug use by 16% compared to similar Medicaid populations in two control states. This reduction corresponded to a slight but significant increase in ED visits and a $2,300-$3,500 relative increase in total treatment costs for enrollees with cancer.

Conversely, some studies show that reducing copays may actually save money. For example, Stuart et al. tracked diabetic Medicare recipients for three years and found that increased adherence to statins (for cholesterol) and RAAS-1 inhibitors (for high blood pressure) corresponded with reduced overall health expenditures. They estimated that the savings from a 10% increase in adherence more than paid for the added cost of the medications. Hoadley et al. similarly found that reducing or eliminating copays for generic statins would increase adherence and generate overall savings for Medicare.

These studies all reveal a substantial offset effect among the most vulnerable populations. Simply put, sicker people with higher expenses are more likely to ration care when their costs go up and also more likely to suffer the consequences.

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84 Id.
85 Amal N. Trivedi et al., supra note 5.
87 Id, at 846. Enrollees with comorbidities reduced prescriptions even more dramatically than patients with no comorbidities. Id.
88 Bruce Stuart et al., Does Medication Adherence Lower Medicare Spending among Beneficiaries with Diabetes?, 46 Health Services Res. 1180 (2011).
89 John F. Hoadley et al., supra note 44.
F. Impact of cost sharing on low-income populations

As income decreases, fixed dollar copayments and deductibles take up a significantly greater fraction of household income. Low-income individuals also face additional barriers to accessing care and maintaining coverage.90 Studies focusing on low-income populations consistently suggest that increased premiums and cost sharing have a substantial negative impact on prescription drug adherence, necessary service utilization, and maintenance of coverage.91 Low-income individuals have been found to self-ration, delay, or discontinue care because of cost sharing, even though they understand that those actions can have adverse health consequences.92

Two studies by Galbraith et al. found that families below 400% of FPL are more likely to experience increased financial burden due to cost sharing and to report delaying or foregoing care due to cost.93 Studies of Medicaid enrollees in Mississippi, Utah Massachusetts found that even low levels of cost sharing decrease medication adherence and result in delayed or foregone care.94 In Massachusetts, enrollees reported delaying or foregoing medications (30%), recommended tests (15%), specialist visits (14%), and dental care (42%) due to cost sharing.95 Also, as discussed earlier, a Canadian study found that, after Quebec imposed a 25% coinsurance on medications, welfare recipients reduced their use of essential drugs by 14%, while the relatively higher income elderly population reduced essential medications by only nine percent.96

Even minimal cost sharing can significantly degrade the financial health of low income families. One study estimated that over 12% of publicly insured children live in “high burden” families with health care expenses exceeding 10% of family income even before including the children’s insurance costs. Once researchers factored in small increases in premiums and cost sharing for the children’s public insurance, the proportion of children in high burden families increased to 15.7% overall, but fully 21% of children in families with incomes below poverty level.97 Thus, small increases in cost sharing for public insurance disproportionately impacted lower-income families.

95 Danny McCormick et al., supra note 94.
96 Tamblyn, supra note 18; see also Ku & Wachino, supra note 9.
97 Thomas M. Selden et al., supra note 17.
G. Impact of cost sharing and premiums on enrollment

A number of recently approved Medicaid expansion demonstrations will impose premiums or required monthly contributions on Medicaid enrollees under 150% FPL. Research and prior demonstration experience in various states suggest such premiums will significantly depress enrollment. For example, in 2003, Oregon increased sliding scale premiums and raised cost sharing for some adults in an existing Medicaid demonstration. Among the impacted population, enrollment dropped over 45% in the months after implementation. A number of other states, including Washington, Rhode Island, Maryland, Vermont and Utah also experienced substantial disenrollment after implementing premiums or enrollment fees on lower-income individuals in Medicaid or CHIP. 98 In response to such experiences, at least four states reconsidered, abandoned or ultimately discontinued policies to implement premiums in Medicaid or CHIP due to concerns about declining enrollment and adverse health consequences. 99

To measure the magnitude of the enrollment disincentive engendered by premiums, Ku and Coughlin compared premiums for low- to moderate income individuals in three states' public insurance programs. Their study estimated that charges of just 1% of family income reduce participation by approximately 15%. Premiums set at 3% of family income reduce total enrollment by roughly 50%. 100 These analyses together represent perhaps the strongest, most direct evidence that high out-of-pocket Medicaid expenses lead to adverse outcomes – in this case, qualified people avoid or leave the program.

H. Research conclusions

The extensive literature on cost sharing points to several consistent conclusions in terms of its potential impact on Medicaid:

- **Cost sharing, in practice, is not “smart.”** As currently structured, the mechanisms are too broad and imprecise to shape more efficient health seeking behavior or effectively reduce systemic health costs without negatively impacting beneficiaries’ health and financial well-being.

- **Increased cost sharing reduces utilization across many types of services.** In particular, cost sharing reduces adherence to medications, frequency of office visits, access to preventive services and utilization of mental health services.

- **Cost sharing substantially impacts individuals with lower incomes.** At lower incomes, even small copays substantially and significantly reduce access to needed care. The financial burden of cost sharing increases as household income decreases.

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99 Ku & Wachino, *supra* note 9. The states were VA, MD, CT, and WA.

• Decreased utilization due to cost sharing often increases the likelihood of adverse health events. Evidence is strongest that reduced prescription adherence increases adverse events. This effect seems to increase with age, poorer health status, and lower income.

• Cost sharing disproportionately impacts individuals with chronic illness and behavioral health conditions. These individuals have higher health expenses and face higher risk of adverse events. On top of that, cost sharing for behavioral health services and substance use disorders historically exceeds cost sharing for general medical care. Mental health parity laws aim to reduce such discrepancies.101

With this review of the research as a frame, the following section explains the flexibilities and the limitations authorized by federal Medicaid law, as well as several recent proposals by states to increase cost sharing beyond the federal limits.

III. MEDICAID PREMIUM AND COST SHARING LAWS

In the Medicaid Act, or Title XIX of the Social Security Act, Congress has enacted two separate provisions that give states fairly extensive flexibility to implement state Medicaid plans that include premiums and cost sharing.102 In addition, § 1115 of the Social Security Act authorizes the Secretary of HHS to allow states to implement experimental Medicaid projects, so long as they are consistent with the objectives of the Medicaid Act.103 These laws are discussed below.

A. The Medicaid Act Provisions

The first of the two Medicaid Act cost sharing provisions, 42 U.S.C. § 1396o, was enacted in 1982 and allows only limited cost sharing. Under § 1396o, premiums are generally prohibited, except on certain limited categories of individuals.104 States may impose only “nominal” deductibles, copayments, or similar charges on categorically needy and medically needy beneficiaries.105 A number of groups and services are exempt from cost sharing.106 Furthermore, providers are prohibited from denying care due to an individual’s inability to pay the cost sharing amount up front, a practice known as “mandatory” or “enforceable” cost sharing.107

In 2005, Congress enacted the second provision, 42 U.S.C. § 1396o-1, which greatly increases the state Medicaid plan options to impose premiums and significantly higher cost sharing on non-exempt groups of individuals with incomes above the federal

101 See supra, note 54.
103 42 U.S.C. § 1315(a).
104 Id at §§ 1396o(c), 1396o(d), 1396o(g), 1396o(i), 1396o-6(b). See National Health Law Program, The Advocate’s Guide to the Medicaid Program 4.12 Q (May 2011), available at www.healthlaw.org.
105 See 42 U.S.C. § 1396o(a)(3), (b)(3); 42 C.F.R. § 447.53.
106 42 U.S.C. § 1396o(a)(2), (b)(2), (j)(1); 42 C.F.R. § 447.53.
107 42 U.S.C. § 1396o(e).
poverty level. States may vary these premiums and copayments among such groups and services without regard to otherwise mandatory “comparability” requirements. Notably, the provision explicitly preserves the requirements that only “nominal” cost sharing may be imposed on individuals with family incomes at or below 100% FPL. Section 1396o-1 also allows states to require higher cost sharing for non-preferred prescription drugs and non-emergency use of the ED, and permits states to require individuals normally exempted from cost sharing to pay copays for these services. Furthermore, Congress rolled back the prohibition on “enforceable” cost sharing; states may permit this practice so long as the enrollee has income above 100% FPL and is not otherwise exempt from cost sharing.

CMS recently issued new regulations for Medicaid premiums and cost sharing. Effective January 1, 2014, the rule implements the statutory cost sharing provisions of §§ 1396o and o-1 within a single set of regulations. Previously, each cost sharing section of the Act had its own separate regulations. The following rules now apply:

B. Exemptions from premiums and cost sharing

From the beginning, Congress exempted certain vulnerable populations and key services from Medicaid premiums and cost sharing. The population exemptions, detailed in Table 2, comprise most children, Native Americans, pregnant women (except for services designated “not pregnancy related”), individuals in hospice care, women eligible through the Breast and Cervical Cancer Treatment Program, and individuals in institutions who retain only a small portion of income for personal needs. Congress also expressly exempted emergency services, pregnancy-related services, family planning services and supplies, and preventive services from cost sharing. CMS’ final regulations specify that the preventive services exemption must include, at a minimum, services that reflect the Bright Futures well-baby and well-child care and immunization guidelines set forth by the American Academy of Pediatrics. As suggested by the National Health Law Program in its comments to CMS, the final rules also exempt “provider-preventable” services, such as hospital-acquired conditions like serious pressure sores or infections from a catheter, or one of a group of “never events,” including surgical errors like operating on the wrong body part.

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109 Id. “Comparability” describes the general Medicaid requirement that medical assistance made available to one Medicaid beneficiary eligible under the state plan must be equal in amount, duration and scope to the medical assistance made available to other Medicaid beneficiaries. See 42 U.S.C. § 1396a(a)(10)(B), 42 C.F.R. § 440.240. Exceptions exist for certain populations, like children and adolescents, who have access to more robust services. See 42 C.F.R. § 440.250.
110 42 U.S.C. § 1396o-1(a)(2). Section 1396o permits only nominal cost sharing.
111 42 U.S.C. § 1396o-1(c), (e); 42 C.F.R. §§ 447.53, 54.
112 42 U.S.C. § 1396o-1(d)(2). The original prohibition is in 42 U.S.C. §1396o(e).
For institutionalized individuals who retain only a personal needs allowance, the exemption from Medicaid cost sharing does not mean they receive free care. These individuals already contribute the bulk of their monthly income to pay for their care, as any income left over beyond their own small allowance and an amount to cover the needs of their spouse and dependents goes to Medicaid to cover their expenses.\textsuperscript{116} This “share-of-cost” requirement means that many of these institutionalized individuals already pay care costs far beyond what would otherwise be allowed under Medicaid cost sharing. Furthermore, certain individuals who require an institutional level of care but live in the community under a Medicaid Home and Community-based Services (HCBS) waiver are also subject to “share-of-cost” requirements for the cost of their HCBS.\textsuperscript{117} The federal regulations give states the option to exempt individuals on such HCBS waivers from normal Medicaid cost sharing, even though states are required to exempt institutionalized individuals subject to share-of-cost. In states that do not elect this option, individuals in HCBS waivers may be subject to copays and cost sharing. The income they contribute to share-of-cost does not count toward the 5% aggregate cap on Medicaid cost sharing, described below in Section III.H.

\textbf{C. Maximum Nominal Limits}

Section 1396o of the Medicaid Act limits cost sharing to “nominal” amounts, as defined by HHS. The CMS regulations introduce significant changes to prior nominal cost sharing limits. Previously, CMS tied nominal cost sharing limits to the amount the agency pays for the service (see Table 1).\textsuperscript{118} Now, however, states may impose copays up to $4 for any nonexempt outpatient service, regardless of the agency’s cost.\textsuperscript{119}

Recall that copays as low as $2 to $3 can significantly reduce access to necessary services for lower-income Medicaid enrollees.\textsuperscript{120} For comparison, Medicare Part D allows copays of no more than $1.20 for generic drugs and $3.60 for brand name drugs for individuals below 100% FPL.\textsuperscript{121}

<table>
<thead>
<tr>
<th>2013 Tiered Nominal Limits (No longer applicable)</th>
<th>2014 Nominal Limits</th>
</tr>
</thead>
<tbody>
<tr>
<td>Maximum Copay</td>
<td>Cost of Service</td>
</tr>
<tr>
<td>$0.65</td>
<td>$10 or less</td>
</tr>
<tr>
<td>$1.30</td>
<td>$10.01 ≤ $25</td>
</tr>
<tr>
<td>$2.60</td>
<td>$25.01 ≤ $50</td>
</tr>
<tr>
<td>$3.90</td>
<td>$50.01 or more</td>
</tr>
</tbody>
</table>

\textsuperscript{116} 42 C.F.R. §§ 435.725, 733.-
\textsuperscript{117} Id. at §§ 435.726, 735.
\textsuperscript{119} 42 C.F.R. § 447.52(b). These limits will increase with inflation each fiscal year beginning Oct. 2015.
\textsuperscript{120} See above, Section II.F.
In addition, the new regulations redefine the nominal limit for certain specific services. CMS decreased the “nominal” cost sharing limit for inpatient services from 50% of the first day cost to a flat $75 maximum copay.\textsuperscript{122} On the other hand, the regulations more than double the maximum nominal limit for non-preferred prescription drugs, from $3.90 to $8. Of course, states opting to impose copayments do not have to set them at the maximum authorized amount.

**D. Higher cost sharing limits for individuals above poverty**

Section 1396o-1 allows states to charge higher cost sharing to individuals with income above 100% FPL. Generally, these limits are 10% of the agency’s cost for individuals between 101 and 150% FPL, and 20% of the agency’s cost of a service for those with incomes above 150% FPL. States may also target cost sharing to specific eligibility groups for individuals with incomes above federal poverty level.\textsuperscript{123} However, in the preamble to the final rule CMS maintains that it believes targeting by anything other than income or eligibility group will lead to discriminatory practices.\textsuperscript{124} States thus may not target cost sharing by delivery system, disease-type or chronic condition.\textsuperscript{125}

One exception is that in states that do not have fee-for-service payment rates, (presumably because all enrollees are under capitated managed care), no individual’s cost sharing may exceed nominal limits, regardless of her household income.\textsuperscript{126}

Few states have implemented higher cost sharing under this provision. According to a recent Kaiser Family Foundation report, in 2012 only Pennsylvania was actively seeking to implement higher cost sharing under § 1396o-1 authority targeted at children with disabilities whose income exceeded 200% FPL. The state later delayed its plans.\textsuperscript{127}

**E. Non-preferred Prescription Drugs**

The regulations increase cost sharing limits for certain prescription drugs. Under § 1396o-1, states may charge relatively higher cost sharing for “non-preferred” drugs within a drug class. For individuals below 150% FPL, non-preferred drug copays may not exceed nominal limits. However, states may impose cost sharing up to 20% of the agency’s cost for non-preferred drugs for enrollees above 150% FPL.\textsuperscript{128} In fiscal year


\textsuperscript{122} 42 C.F.R. § 447.52(b).

\textsuperscript{123} 42 C.F.R. § 447.52(d).

\textsuperscript{124} 78 Fed. Reg. 42273.

\textsuperscript{125} Id.

\textsuperscript{126} 42 C.F.R. § 447.52(b)(3). In a state with only a capitated payment system, there is no simple way to determine what the state agency’s cost would be for specific services.


\textsuperscript{128} 42 U.S.C. § 1396o-1(c).
2013, the nominal limit for all prescription drugs was $3.90. The new regulations redefine nominal to mean up to $4 for preferred drugs and up to $8 for non-preferred drugs. Importantly, the statute also allows states to apply this new “nominal” cost sharing for non-preferred drugs to individuals otherwise exempt from cost sharing.

States must also accommodate exceptions to the higher non-preferred copays if an individual’s provider determines a “non-preferred” medication for a given condition is medically necessary. More specifically, if the provider determines a “preferred” alternative for the same condition would be less effective or have adverse effects on the patient, the state agency must ensure that the patient’s copay for the non-preferred treatment is no more than the preferred drug copay.

**F. Non-emergency use of the emergency department (ED)**

The Medicaid Act exempts emergency medical services from cost sharing, but allows states to impose cost sharing on “nonemergency” use of the ED. The definition of “emergency use” is based on symptoms that a prudent layperson, with average health knowledge, might consider to seriously jeopardize or impair her health or bodily function without immediate medical attention. States have some latitude to define a “reasonable, clinically-based” methodology to identify nonemergency visits. Some states seek to apply a higher copayment or lower provider reimbursement based on an individual’s discharge diagnosis, but recent research shows that such claims-based algorithms cannot reliably identify nonemergency ED visits in individual cases and may violate the prudent layperson standard. Earlier attempts to accurately identify inappropriate ED use based on other methods, such as hospital triage systems and vital signs also showed considerable inconsistencies.

Moreover, before charging the nonemergency copay, an ED must first:

1. Appropriately screen the enrollee to determine that she does not require emergency medical services;
2. Determine an actually available and accessible non-emergency services provider who can provide the needed services in a timely manner with less cost sharing;

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129 Out-of-pocket Costs, supra note 118.
130 42 C.F.R. §§ 447.52(b), .53(b).
132 42 C.F.R. § 447.53(e).
133 42 C.F.R. §§ 447.51, 438.114; see supra note 71.
134 CMS, supra note 79, at 6. In the preamble to the recently finalized regulations, CMS acknowledges the difficulties of distinguishing “emergency” from “nonemergency” and notes that, after seeking comments on a feasible methodology, it received no recommendations. See 78 Fed. Reg 42278.
135 States that have passed or considered basing Medicaid ED payment on discharge diagnosis include TN, IA, NH, IL, and WA. See Maria C. Raven et al., Comparison of Presenting Complaint vs Discharge Diagnosis for Identifying “Nonemergency” Emergency Department Visits, 309 JAMA 1145, 1145-6 (2013).
137 This screening must be consistent with standards set forth in 42 C.F.R. § 489.24.
3. Inform the enrollee the copay required for nonemergency use of the ED; and

4. Provide the name and address of the alternative non-emergency services provider and a referral to coordinate scheduling for treatment.\footnote{42 C.F.R. § 447.54(d). These prerequisites have not changed substantially under the new rules, except for the addition of providing enrollees notice of the amount of cost sharing.}

Congress has introduced additional flexibility by allowing states to charge up to the agency’s full service cost for non-emergency use of the ED for an enrollee over 150% FPL, so long as the cost does not exceed the individual’s 5% aggregate cap.\footnote{42 U.S.C. § 1396o-1(e).} It also eliminated a requirement for a waiver to charge twice nominal amounts for individuals between 100 and 150% FPL.\footnote{42 U.S.C. § 1396o-1(e)(2)(A). Compare 42 U.S.C. §§ 1396o(a)(3), (b)(3).}

The regulations now allow states to charge as much as $8 for nonemergency ED use for enrollees up to 150% FPL without a waiver.\footnote{42 C.F.R. § 447.54(b).} As with non-preferred drugs, individuals otherwise exempt from cost sharing, while previously responsible for no more than $3.90 for nonemergency ED use, may now be charged up to $8 per visit.\footnote{42 C.F.R. § 447.54(c).}

**G. Premiums generally forbidden below 150% FPL**

Medicaid’s original cost sharing provision generally forbids premiums, save for a few eligibility categories. In particular, certain pregnant women, individuals qualifying as medically needy, children with disabilities who qualify through the Family Opportunities Act, and certain individuals with disabilities who qualify through work-related categories may be charged premiums under § 1396o.\footnote{42 U.S.C. § 1396o-1(d)(1).} States may also require premiums for families eligible for extended Transitional Medical Assistance.\footnote{See supra, note 143.} In 2005, Congress added state flexibility to charge premiums more generally.\footnote{42 U.S.C. § 1396o-1(e)(1).} However, this flexibility only applies to individuals with incomes above 150% FPL. The only groups below 150% FPL who may be charged premiums under the Medicaid Act are those few mentioned above who are not subject to the § 1396o prohibition.\footnote{See supra, note 143.} In addition, populations specifically exempted from cost sharing may not be charged premiums, and state Medicaid agencies may issue hardship exceptions to individuals within populations subject to premiums.\footnote{42 C.F.R. § 447.55(b)(1)-(4). For exemptions, see Table 2, at 24.}
States may terminate Medicaid eligibility for any individuals, except the medically needy, who fail to pay their premium for at least 60 days but may not impose additional consequences or penalties for failure to pay.\textsuperscript{148}

\textbf{H. The 5\% aggregate cap on Medicaid household cost sharing}

Federal Medicaid law protects individuals by establishing 5\% cap on a household’s Medicaid premiums and cost sharing, which states must apply on either a monthly or quarterly basis. Previously, only states that applied “alternative” cost sharing under § 1396o-1 had to track aggregate enrollee premiums and cost sharing and suspend copayments if the household reached the 5\% cap. CMS’ new regulations apply this important protection to all Medicaid enrollees.

\textbf{EXAMPLE: Applying the 5\% Aggregate Cap Monthly v. Quarterly}

The Medicaid Act allows states to apply the 5\% cap on a monthly or quarterly basis.\textsuperscript{149} And outside of what the law authorizes, some states have proposed using an annual cap.\textsuperscript{150} The time frame is critical, as health expenses tend to concentrate into a single month or quarter.\textsuperscript{151}

For example, Jane makes $1,000/month (104\% FPL) and has Medicaid coverage. In January she has an asthma attack and lands in the emergency room with a subsequent hospital stay. The total Medicaid bill comes to $5,000. The state Medicaid agency has decided to impose cost sharing that requires enrollees with her income to pay 10\% of the cost of the service, in Jane’s case $500.

If the state calculates the 5\% cap on a monthly basis, Jane hits the cap at $50 (5\% of $1,000 monthly income). If the state calculates quarterly, she will pay only $150 of the charge (3 x $50). But if the state applies the cap annually, Jane’s cost sharing cap will be $600 (12 x $50), and she will be responsible for the full $500 charge.

If a state’s cost sharing policies put any beneficiaries at risk of reaching the 5\% cap, Medicaid agencies must develop an effective mechanism to track families’ incurred

\textsuperscript{148} 42 C.F.R. § 447.55(b)(2), (5).
\textsuperscript{149} 42 U.S.C. § 1396o-1(b)(1)(B)(ii), (2)(A).
\textsuperscript{151} Selden et al., supra note 17, at w614. For families with children on public insurance, the average peak month accounts for 43\% of annual out-of-pocket spending, while the average peak quarter accounts for 58\% of annual spending.
Medicaid premiums and cost sharing “that does not rely on beneficiary documentation.”

Previously, many state Medicaid and CHIP agencies put the onus on families to track their own expenses, otherwise known as the shoebox method. State Medicaid agencies must also notify enrollees and providers when the aggregate cap is reached and establish a process for enrollees to request a recalculation of their limit due to a change in circumstances.

NOTE: All Medicaid premiums count towards the 5% aggregate household cost sharing cap. This differs from the Health Insurance Marketplace and most private insurance, where premiums do not count towards enrollees’ out-of-pocket maximum.

I. Enforceable cost sharing

The 2005 Congress introduced another flexibility feature, sometimes referred to as “enforceable” or “mandatory” cost sharing, whereby states may permit providers to deny services to enrollees who cannot afford the copay. However, “enforceable” cost sharing is limited to enrollees above 100% FPL who are not otherwise exempt from cost sharing. Moreover, the statute makes clear that individual providers may continue to reduce or waive cost sharing on a case-by-case basis.

This authorization is carefully crafted. Congress has placed responsibility for deciding whether to reduce or waive the cost sharing with the health care provider—specifically the provider who is directly treating and dealing with the patient. This legal requirement makes common sense. And, it is consistent with other aspects of the cost sharing law that require states (and their agents) to impose preferred drug cost sharing on non-preferred drugs if the prescribing physician determines that the individual needs the non-preferred drug.

According to a Kaiser Family Foundation report, only seven states allowed enforceable cost sharing on some eligibility group(s) in FY 2012.

Putting it all together, Table 2 summarizes Medicaid’s premium and cost sharing requirements.

152 42 C.F.R. § 447.56(f)(2).
153 Thomas M. Selden et al., supra note 17, at w608. The “shoebox” method refers to the practice of beneficiaries collecting paper cost sharing receipts in a shoebox as a means to track aggregate spending.
155 42 C.F.R. § 447.52(e).
156 See 42 U.S.C. § 1396o-1(c)(3).
157 The states were AZ, ID, KY, MS, NH, UT and WI. Additionally, CA, IL and ME planned to implement enforceable cost sharing in 2013. Vernon K. Smith et al., supra note 127, at 42.
Table 2. Rules for Medicaid Premium and Cost Sharing, January 2014

<table>
<thead>
<tr>
<th>Premiums</th>
<th>≤ 100% FPL</th>
<th>101% - 150% FPL</th>
<th>&gt;150% FPL</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Not allowed*</td>
<td>Not allowed*</td>
<td>Allowed</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Maximum Allowable Copayments</th>
<th>≤ 100% FPL</th>
<th>101% - 150% FPL</th>
<th>&gt;150% FPL</th>
</tr>
</thead>
<tbody>
<tr>
<td>Outpatient services</td>
<td>$4</td>
<td>10% of the service cost</td>
<td>20% of the service cost</td>
</tr>
<tr>
<td>Institutional services</td>
<td>Per admission, $75</td>
<td>Per admission, 10% of the total agency cost of stay</td>
<td>Per admission, 20% of the total cost of stay</td>
</tr>
<tr>
<td>Preferred drugs</td>
<td>$4</td>
<td>$4</td>
<td>$4</td>
</tr>
<tr>
<td>Non-preferred drugs#</td>
<td>$8 (nominal)</td>
<td>$8 (nominal)</td>
<td>20% agency cost of drug</td>
</tr>
<tr>
<td>Nonemergency use of ED#**</td>
<td>$8</td>
<td>$8</td>
<td>No limit*</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Aggregate cap</th>
<th>5% of household income calculated monthly or quarterly</th>
</tr>
</thead>
<tbody>
<tr>
<td>(cap includes all Medicaid premiums and cost sharing, state chooses periodicity)</td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Cost Sharing is enforceable?</th>
<th>No</th>
<th>Yes**</th>
<th>Yes**</th>
</tr>
</thead>
</table>

<table>
<thead>
<tr>
<th>Groups exempt from premiums and cost sharing</th>
</tr>
</thead>
<tbody>
<tr>
<td>• Mandatory eligible children under age 19 (§ 435.118), except for infants under age 1 with incomes above 133%</td>
</tr>
<tr>
<td>• Children in federally funded foster care</td>
</tr>
<tr>
<td>• Disabled children, except those eligible under the Family Opportunity Act with incomes above 150% FPL</td>
</tr>
<tr>
<td>• Persons in institutions who have only a personal needs allowance, and at state option, persons receiving HCBS who are subject to share-of-cost</td>
</tr>
<tr>
<td>• Women eligible through the Breast and Cervical Cancer Treatment Program</td>
</tr>
<tr>
<td>• Individuals receiving hospice care</td>
</tr>
<tr>
<td>• Indians who have ever been served through Indian Health Services programs</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Services exempt from cost sharing</th>
</tr>
</thead>
<tbody>
<tr>
<td>• Services furnished to pregnant women, including counseling and pharmacotherapy for cessation of tobacco use, unless identified in the state plan as not pregnancy-related</td>
</tr>
<tr>
<td>• Emergency services</td>
</tr>
<tr>
<td>• Provider-preventable services</td>
</tr>
<tr>
<td>• Family planning services and supplies</td>
</tr>
<tr>
<td>• Preventive services, including at least well-baby and well-child services and immunizations for children under 18, regardless of income##</td>
</tr>
</tbody>
</table>

* 42 U.S.C. § 1396o allows states to charge premiums on individuals below 150% FPL in certain eligibility categories. These include the Medically Needy, extended Transitional Medical Assistance, and several optional categories for people with disabilities. See also 42 C.F.R. § 447.55.

** Cost sharing is allowed only if the beneficiary has been screened and receives proper notice, with a referral to an actually available and accessible alternative provider.

# This cost sharing can also be applied to individuals normally exempt from cost sharing.

## States have the option to exempt additional preventive services from cost sharing. Preventive services recommended by the U.S. Preventive Services Task Force may not be subject to cost sharing in Alternative Benefit Plans, such as those available to adults in the ACA Medicaid expansion group.

† While the regulations set no federal limit, the 5% aggregate household cap still applies.

### Individuals normally exempt from cost sharing are not subject to enforceable cost sharing.
J. Section 1115 Demonstration Projects

Section 1115 of the Social Security Act (SSA) grants the Secretary of HHS the authority to approve "any experimental, pilot, or demonstration project which, in the judgment of the Secretary, is likely to assist in promoting the objectives of" the Medicaid Act. In so doing, “the Secretary may waive compliance with” certain Medicaid rules “to the extent and for the period he finds necessary to enable such State or States to carry out such a project.”

Section 1115 demonstration proposals must satisfy a number of requirements:

1. As noted, these projects must test experimental, demonstration ideas. Legislative history to § 1115 indicates that Congress authorized § 1115 demonstrations as limited scope projects to “test out new ideas and ways of dealing with the problems of public welfare recipients.” Congress expressed its intent that § 1115 demonstrations be time-limited and “usually cannot be statewide in operation.” HHS has previously recognized that, as conceived by Congress, these projects typically should include a detailed research methodology, often with control/study groups, and comprehensive evaluation.

2. The demonstration must be “likely to promote the objectives” of the Medicaid Act.

3. The Secretary may only waive provisions within 42 U.S.C. § 1396a (§ 1902 of the Social Security Act) to the extent necessary to carry out the project.

4. HHS has imposed requirements that demonstrations be budget neutral.

5. The § 1115 waiver process must be transparent and meaningfully engage stakeholders, including two 30-day public comment periods for new proposals or extensions (one to obtain and consider comments at the state level; one, at the national level).

Notably, federal courts have repeatedly found that the Secretary of HHS has acted illegally and arbitrarily by failing to adequately review state proposals for compliance with § 1115 standards, for example by failing to determine that a copayment proposal is testing anything new or different (i.e. that it is for an experimental or demonstration purpose). In one of these cases, Newton-Nations v. Betlach, the Ninth Circuit Court of

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158 42 U.S.C. § 1315(a).
159 Id. § 1315(a)(1).
161 Id.
162 E.g. Memorandum from David Ellwood, Bruce Vladeck, and Laurence Love, HHS, to HHS Secretary, at 2 (June 22, 1993) (on file with the author).
165 42 C.F.R. § 431 Subpart G.
166 Newton-Nations v. Betlach, 660 F.3d 370 (9th Cir. 2011); Wood v. Betlach, 922 F.Supp.2d 836 (D. Ariz. 2013); see also Beno v. Shalala, 30 F.3d 1057 (9th Cir. 1994)).
Appeals reviewed the Secretary’s approval of heightened and mandatory copayment on adults living below the federal poverty level and concluded:

There is no evidence that the Secretary made some judgment that the project has a research or a demonstration value…. Indeed, it is questionable whether the Secretary could have made such a finding. Plaintiffs' public health expert stated that “[o]ver the last 35 years, a number of studies have looked at the effects of cost sharing on the poor. Of all forms of cost sharing, copayments are the most heavily studied.” The administrative record contains no finding from the Secretary that Arizona’s demonstration project will actually demonstrate something different than the last 35–years’ worth of health policy research.\(^\text{167}\)

These cases have also consistently found that the Secretary of HHS cannot merely rely on statements made in the materials submitted by the state but must independently review the evidence in the waiver request to determine whether the § 1115 requirements are met.

Over the last 15 years, CMS has approved a number of § 1115 demonstrations that provided federal Medicaid funding to programs that included childless, nondisabled adults. These approvals have typically imposed premiums and/or cost sharing exceeding limits allowed states under the Medicaid Act. HHS’ justification rested on § 1115(a)(2).\(^\text{168}\) HHS reads this subsection of the Social Security Act to provide it with an independent “expenditure authority” to fund state projects that extend Medicaid to populations not otherwise eligible for Medicaid.\(^\text{169}\) In a decision that did not analyze the purported expenditure authority, the Ninth Circuit upheld a § 1115 project that imposed premiums and heightened copayments on adult, non-disabled enrollees. The court said the Medicaid Act’s copayment protections did not apply to this population because it was an “expansion population” of childless, nondisabled adults not described in the Medicaid Act.\(^\text{170}\) As of January 1, 2014, however, childless, nondisabled adults can no longer be considered an “expansion population” because they are described in the Medicaid Act as a mandatory coverage group (due to additions made by the Affordable Care Act).\(^\text{171}\)

\(^{167}\) Newton-Nations, 660 F.3d at 381 (internal quotations and citations omitted).

\(^{168}\) CMS, Dear State Medicaid Director (May 9, 2002). (SMDL #02-009) (including authorities in § 1115 template for Independence Plus programs.)

\(^{169}\) This statement is based on briefs filed by the Secretary of Health and Human Services in litigation on Portland Adventist Medical Ctr. v. Thompson, Spry v. Thompson, and Newton-Nations v. Betlach.

\(^{170}\) Spry v. Thompson, 487 F.3d 1272, 1275 (9th Cir. 2007).

K. Special waiver requirements for cost sharing

As noted above, HHS may exercise its authority under § 1115 to waive provisions of § 1396a for demonstration/experimental projects consistent with the objectives of the Medicaid Act. However, the cost sharing provisions of the Medicaid Act are not located in § 1396a, but in 42 U.S.C. § 1396o and 1396o-1. For purposes of a § 1115 demonstration project, the fact that these provisions are located outside § 1396a has serious consequences.

First and foremost, premium and/or cost sharing waivers should not be permitted through § 1115. Granted, § 1396a(a)(14) does mention cost sharing; however, when Congress amended the Medicaid Act in 1982 to move the substantive cost sharing provisions from § 1396a into § 1396o, it included mandatory language in § 1396o providing that “the state plan shall” implement premiums and cost sharing as set forth in that section and, in the legislative history to the provision, stated that it did not intend federal and state governments to continue to use the waiver authority to implement cost sharing.\(^{172}\) As a result, Congress has included a Medicaid cost sharing provision that imposes special requirements if a state wants to exercise cost sharing not authorized in the Medicaid Act. Section 1396o(f) provides that: “No deduction, cost sharing, or similar charge may be imposed under any waiver authority of the Secretary” until the proposal undergoes public notice and comment and meets five tightly circumscribed conditions:

- “[The demonstration] will test a unique and previously untested use of copayments,
- is limited to a period of not more than two years,
- will provide benefits to recipients of medical assistance which can reasonably be expected to be equivalent to the risks to the recipients,
- is based on a reasonable hypothesis which the demonstration is designed to test in a methodologically sound manner, including the use of control groups of similar recipients of medical assistance in the area, and
- is voluntary, or makes provision for assumption of liability for preventable damage to the health of recipients of medical assistance resulting from involuntary participation.” (Lettering removed). 42 U.S.C. § 1396o(f).

State and federal advocates’ input can play an important role in the § 1115 demonstration process, especially as CMS negotiates with states on what elements of a demonstration projects might be approvable. A strong political and policy argument exists to convince more states to accept Medicaid expansion, and many will utilize the § 1115 process to do so. Some advocates fear this pressure will lead CMS to accept

proposals that push the envelope on cost sharing limits, which would set a dangerous precedent for future administrations.

<table>
<thead>
<tr>
<th>Recent § 1115 Activity on Medicaid Premiums</th>
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<td>At the end of 2013, CMS approved several state demonstration proposals to expand Medicaid to adults up to 138% FPL. These Medicaid expansion proposals included policies that exceed the normal Medicaid rules for premiums.</td>
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Iowa’s demonstration requires individuals above 100% FPL to pay $10 monthly premiums, which will be waived for anyone who completes as yet undetermined wellness activities. Individuals who fall more than 60 days behind on their payments may face disenrollment. Enrollees with incomes between 50% and 100% FPL will pay $5 premiums – also waived on completion of healthy behavior goals – but may not be disenrolled for failure to pay.\(^\text{173}\)

The “Healthy Michigan” demonstration will charge premiums up to 2% of annual household income for adults between 100-133% FPL. Individuals under 100% FPL will contribute an amount equal to their average monthly copay.\(^\text{174}\) Failure to pay will not lead to disenrollment in either group, but other consequences may arise.

CMS approved these premium waivers without requiring the demonstrations implement the enhanced protections in § 1396o(f), apparently because the statutory language does not specifically mention premiums as a trigger for the added requirements. CMS did not approve other proposed cost sharing modifications in these demonstrations, such as applying the 5% aggregate cap annually or charging higher than nominal copays for nonemergency ED use.

IV. Conclusion

Over, the years, cost sharing and premiums have been heavily studied. The consistent and ever-expanding literature on cost sharing repeatedly demonstrates that premiums and cost sharing pose barriers to care for low-income and vulnerable populations while doing relatively little to improve the overall efficiency of the health care system.

In the Medicaid Act, Congress has included comprehensive regulation of cost sharing and premiums. The law provides states with a great deal of flexibility and options; however, Congress has set clear limits designed to protect Medicaid’s low-income and


vulnerable enrollees. And while the robust evidence-base actually supports lowering cost sharing and premiums in many cases, some states have obtained permission from the federal Medicaid agency to impose heightened and mandatory cost sharing on expansion populations of non-disabled adults who, prior to January 1, 2014, were not described in the Medicaid Act. However, with enactment of the ACA, Medicaid’s cost sharing and premium provisions clearly apply to all of the low-income population groups (including non-disabled adults) who are described in the Act. As Medicaid continues to evolve, the premium and cost sharing protections should be maintained or arguably strengthened. These protections are a clear objective of the Medicaid Act.