Despite the ongoing discussion about the pros and cons of the healthcare reform law enacted this year, it is here to stay. Healthcare reform consists of two laws: the Patient Protection and Affordable Care Act (Public Law 111-148) and the Health Care and Education Reconciliation Act (Public Law 111-152), together referred to as the Affordable Care Act (ACA). There are still many questions about what impact the ACA will have on the chronically ill, and to date, it’s apparent that out-of-pocket expenses still remain too high and reimbursement battles for high-cost medications such as immune globulin (IG) will continue. But, the law does have many positive far-reaching effects: It guarantees access to insurance, provides dependent coverage until age 26, provides coverage for essential health benefits, establishes caps on out-of-pocket expenses, eliminates lifetime caps, provides expanded access to Medicaid and standardizes the appeals process.

The Guaranteed Issue Provision

Under the ACA’s guaranteed issue provision, individuals are now guaranteed access to insurance without having to use a high-risk or a pre-existing condition insurance plan. Since Sep. 23, 2010, individual and group plans have been prohibited from imposing pre-existing condition exclusionary riders and outright coverage denials for children under age 19. Now, as of Jan. 1, all plans must guarantee policies to all applicants at any age regardless of health status or other factors. However, this guaranteed provision does not apply to grandfathered individual plans — those that were in existence as of March 23, 2010, when the ACA was enacted.¹

Insurers must also guarantee renewal of policies, except in certain circumstances. The ACA does not change existing federal law allowing insurers to refuse coverage or to renew individual policies if:
• the insurer stops offering a type of plan altogether (but the insurer must provide all customers under the canceled plan a chance to buy another).
• premiums are not paid at all, or if they are not paid on time.
• there is a case of fraud by the covered individual or group.
• the consumer moves out of the insurer’s geographic service area.

In addition, an insurer may discontinue offering all of its coverage in the individual market. But, if it does this, the insurer must notify state officials and enrollees at least 180 days in advance. And, it must discontinue and not renew all coverage in one or more markets and may not re-enter that market for five years.²

Also under the guaranteed issue provision, healthcare premiums must be offered at an averaged rate that does not necessarily reflect the actuarial risk, and the scope of coverage can’t be limited. For example, insurers must provide certain basic services, they cannot impose lifetime limits on coverage and they can’t unreasonably increase premium prices, even for those with a chronic illness. Premiums can only be rated higher on the basis of age or smoking status, and coverage can only be revoked for reasons of fraud or nonpayment.³

A downside to the guaranteed issue provision is that insurers have started to renegotiate their contracts with some healthcare providers to keep plans offered through the exchanges affordable for consumers. For instance, Blue Shield of California said it will include just 50 percent of the physicians and 75 percent of the hospitals in 2014 that it did in the 2013 individual plans. However, Blue Shield said it will offer exclusive provider organization plans (EPOs) for first-time buyers for a lower cost than other plans on the exchanges.⁴ These plans have a narrower base of in-network doctors, so chronically ill patients who need to ensure they have access to the specialists they now see, or to a new specialist, need to be sure those specialists are considered in-network; otherwise, the plan will not cover the costs of treatment.

**Dependent Coverage**

Children now have the option of staying on their parents’ insurance plan until age 26. This will particularly benefit those with chronic illness who are treated with high-cost medicines, eliminating the need to find a new plan that is in-network for their current physicians or the potential for possible reimbursement denial. Dependents do not have to be full-time students, claimed on their parents’ income tax or live with their parents, and they can be married (the spouse is not covered, just the child). A caution about this: Even though children can stay on their parents’ plans until age 26, health savings accounts cannot be used to pay for care of children between the ages of 24 and 26. The reason for this is the IRS rules are not in coordination with the ACA rules, and the IRS rules trump the ACA.⁵

**Essential Health Benefits**

As of Jan. 1, all individual health insurance plans must now provide coverage for a core package of healthcare services known as essential health benefits (EHB), regardless of the type of plan. Under the ACA, there are now four tiers of coverage for health insurance plans named for different metals. The tiers are differentiated based on their actuarial values, or the average percentage of healthcare expenses that will be paid by the plan: bronze pays 60 percent of healthcare expenses, silver pays 70 percent, gold pays 80 percent and platinum pays 90 percent. The more the plan pays toward healthcare expenses, the higher the monthly premium. However, fully insured large group plans, self-funded plans and grandfathered plans (those in existence on March 23, 2010) are not required to include an EHB package.

**As of Jan. 1, all individual health insurance plans must now provide coverage for a core package of healthcare services known as essential health benefits (EHB), regardless of the type of plan.**

EHB packages must cover, at a minimum, the following 10 general categories: ambulatory patient services, emergency services, hospitalization, laboratory services, maternity and newborn care, mental health services and addiction treatment, rehabilitative services and devices, pediatric services, prescription drugs, preventive and wellness services and

All health insurance marketplace plans and many other plans must also provide 100 percent coverage for certain preventive services, including abdominal aortic aneurysm, alcohol misuse screening and counseling, aspirin use to prevent cardiovascular disease, adult blood pressure screening, cholesterol screening for adults of certain ages and high-risk adults, colorectal cancer screening for adults over age 50, adult depression screening, type 2 diabetes screening, type 2 diabetes screening for adults with high blood pressure, diet counseling for adults at higher risk for chronic disease, HIV screening for individuals ages 15 to 65 and for other ages if the person is at increased risk, and adult immunization vaccines (hepatitis A, hepatitis B, herpes zoster, human papillomavirus, influenza, measles/ mumps/rubella, meningococcal, pneumococcal, tetanus/ diphtheria/pertussis and varicella). However, this applies only when these services are delivered by a network provider.

And, it is highly recommended that patients make a separate appointment for preventive services since a fee could be charged if a patient brings up a problem or symptom they might be having at the time and, therefore, the visit could be considered other than a preventive service visit.

Elimination of Lifetime Caps

Prior to the enactment of the ACA, many health plans set a dollar limit on yearly spending for covered benefits, as well as a set lifetime limit — a dollar limit on what the plan would spend for covered benefits during the entire time an individual was enrolled in the plan. After the limit was reached, individuals were responsible for paying the cost of all care exceeding those limits. As of Jan. 1, the ACA prohibits lifetime limits on most benefits in any health plan issued or renewed on or after Sept. 23, 2010. It also restricts and phases out the annual dollar limits on all job-related and individual plans issued after March 23, 2010. According to the law, no plans can set an annual dollar limit lower than:

- $750,000 for a plan year or policy year starting on or after Sept. 23, 2010, but before Sept. 23, 2011
- $1.25 million for a plan year or policy year starting on or after Sept. 23, 2011, but before Sept. 23, 2012
- $2 million for a plan year or policy year starting on or after Sept. 23, 2012, but before Jan. 1, 2014

No annual dollar limits are allowed on most covered benefits beginning Jan. 1, 2014.

However, there are some details to consider. While the ban on lifetime dollar limits for most covered benefits applies to every health plan — whether individual, family or through an employer — plans can set an annual dollar limit and lifetime dollar limit on spending for services not considered “essential.” And, some plans may be eligible for a waiver from the rules concerning annual dollar limits if it means there will be a significant decrease in benefits coverage or a significant increase in premiums.

Out-of-Pocket Expense Caps

Prior to the enactment of the ACA, out-of-pocket expense caps were very complicated and not so straightforward. To control costs and lower premiums, some health insurers adjusted their rules for out-of-pocket limits that shifted more of the cost of health onto the patient. They did this in several ways: by not crediting all of the patient’s expenses — including deductibles, copayments and coinsurance for drugs, tests and out-of-network care — toward the out-of-pocket maximum; by not paying 100 percent of healthcare costs after the patient reaches their out-of-pocket limit; and by creating separate out-of-pocket maximums for different parts of the health insurance coverage.

The ACA makes out-of-pocket maximums less complicated by requiring that deductibles, copays and coinsurance all get credited. It also places limits on how much the out-of-pocket maximum can be each year, after which the health plan must pay 100 percent of all costs. The maximum amount a consumer with single coverage will pay out-of-pocket in 2014 will generally be $6,350, while a family could pay up to $12,700. These totals include copayments and deductibles, but not premiums, and they apply only to plans that are not grandfathered under the law.

There’s a catch to this, though, and patients with high drug costs may find that limits don’t protect them yet. If health plans use more than one company to administer their benefits (and many do for major medical and pharmacy benefits), consumers may face separate caps or no cap on their pharmacy spending. According to the law, health plans with more than one benefits administrator don’t have to combine their tallies of members’ out-of-pocket spending into one total until 2015. Plans with no drug spending limit, which is the norm according to experts, don’t have to cap members’ out-of-pocket spending at all.

Even after the ACA provisions take effect, there are still some costs that patients will be responsible for paying after meeting the out-of-pocket maximum, including...
health insurance premiums, things that aren’t covered by the health plan (like cosmetic surgery), things the health plan decides aren’t medically necessary, and the balanced-bill portion of out-of-network healthcare expenses. If patients are receiving IG from an out-of-network provider, even with a letter of agreement, they could still be subject to balance billing and not subject to out-of-pocket maximums. Therefore, if using an out-of-network provider, even with a letter of agreement, patients should make sure to have something in writing from the provider that details the limitations of billing. This is because the letter of agreement only covers the payer and provider; it does not cover the patient.

The ACA has also created a health insurance subsidy that lowers the out-of-pocket maximum for patients with lower incomes. This subsidy is available only to individuals whose income is 100 percent to 250 percent of the federal poverty level (FPL), who have a silver-tiered health insurance plan through their state's health insurance exchange, who are married and file taxes jointly, who reside in the U.S. legally and who aren’t incarcerated. For those who qualify, the subsidy in 2014 is not more than $2,250 for an individual and $4,500 for a family whose income is between 100 percent and 200 percent of the FPL (a two-thirds reduction), and not more than $5,200 for an individual and $10,400 for a family whose income is between 200 percent and 250 percent of the FPL (a one-fifth reduction).

Access to Medicaid

The ACA calls for a nationwide expansion of Medicaid eligibility. Under the written law, nearly all U.S. citizens under age 65 with family incomes up to 133 percent of the FPL qualify for Medicaid under the expansion. Previously, the only individuals who qualified for Medicaid were children, pregnant women, parents, blind or disabled persons and the elderly, and they had to meet the financial test set by the state. Therefore, the ACA’s expansion of Medicaid will particularly benefit childless adults, who in more than 40 states could not qualify for Medicaid regardless of their income level, as well as low-income parents, who in more than 30 states didn’t qualify even if their children did.

Those with a chronic illness applying for disability face a two-year waiting period before Medicare will kick in, which previously meant they either had to find funds to get into a high-risk or pre-existing condition plan, get charity care or go without treatment until they could gain coverage again. Now, under the ACA, some patients will be able to receive Medicaid while they wait for Medicare coverage.

However, the Medicaid expansion was one of the major provisions at stake in the ACA cases decided by the Supreme Court in 2012. While the court upheld the Medicaid expansion, it limited the federal government’s ability to penalize states that don’t comply, thereby making it optional for states to expand Medicaid. It is predicted, though, that most states will eventually expand their programs, and the Congressional Budget Office predicts that 11 million Americans will gain coverage by 2022.

The ACA makes out-of-pocket maximums less complicated by requiring that deductibles, copays and coinsurance all get credited.

Standardized Appeals Process

For chronically ill patients who require high-cost medications to survive that are frequently denied reimbursement, the ACA has made the process of appealing an insurer’s decision about reimbursement more transparent, accountable and fair. Under the law, there are two stages of appeals to choose from to pursue if a claim is denied: an internal appeal and an external review. In most cases, the internal appeal must be made before an external review can be requested.

In an internal appeal, also known as a grievance procedure, the ACA requires insurers to adhere to a strict timeline and provide detailed and complete information for free about the reason for denying the claim. An insurer must provide notice of a decision to deny a claim within 72 hours for an urgent care claim, as determined by a doctor; 30 days for a non-urgent care claim submitted before the service is provided; 60 days for a non-urgent care claim submitted after the service is provided; and 24 hours for ongoing treatment that the insurer has approved, but is seeking to reduce or stop. Once a claim is denied, patients have 180 days to file an internal appeal. Most importantly for the
chronically ill, while an internal appeal is pending, the insurer cannot reduce or stop coverage for ongoing treatment. If at any time the insurer doesn’t fulfill its obligations, an external review can be filed.

**Patients whose situations are urgent can file an internal appeal and external review concurrently.**

An external review also can be filed after an internal appeal has been exhausted. An external review is an independent medical review of an insurer’s decision that a healthcare service is experimental, investigational or not medically necessary. The decision to rescind a policy is also subject to external review. Medical professionals from an independent review organization (IRO) with no connection to the health plan must conduct the review. And, the IRO must be a physician who specializes in the disease for which a claim was denied. For instance, for chronically ill patients who have a primary immunodeficiency, that would mean an immunologist must be part of the IRO.

Patients have four months to file an external review after notice that the internal appeal has been denied. Should the insurer determine that the claim is eligible for external review, it must provide information from the request to one of three contracted IROs assigned randomly.12

Patients whose situations are urgent can file an internal appeal and external review concurrently. A concurrent filing is eligible if any of the following conditions apply:

- The patient’s health or life may be in serious jeopardy, or the patient may not be able to regain maximum function if treatment is delayed while waiting for a decision.
- The health plan insurer’s decision concerns an admission, continued hospital stay, availability of care or healthcare service for which the patient received emergency services but have not yet been discharged from a facility.
- The patient’s treating physician believes that the experimental or investigational treatment requested would be less effective if not started right away.

The patient’s treating physician must certify in writing that any of the conditions apply to the patient’s case.13

**Gradual but Beneficial Change**

The gradual implementation of the ACA’s provisions are rapidly changing the healthcare system. The ACA’s goal is to improve access to and satisfaction with care, improve quality and outcomes of care and reduce total healthcare costs. It is not a solution for many of the issues that chronically ill patients face, especially with reimbursement and high out-of-pocket expenses, but in the long term, they should benefit from many of these changes.

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**References**