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# Realizing Health Reform's Potential

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## The Essential Health Benefits Provisions of the Affordable Care Act: Implications for People with Disabilities

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**Abstract:** In establishing minimum coverage standards for health insurance plans, the Affordable Care Act includes an “essential health benefits” statute that directs the U.S. Secretary of Health and Human Services not to make coverage decisions, determine reimbursement rates, establish incentive programs, or design benefits in ways that discriminate against individuals because of their age, disability, or expected length of life. This issue brief examines how this statute will help Americans with disabilities, who currently are subject to discrimination by insurers based on health status and health care need. The authors also discuss the complex issues involved in implementing the essential benefits provision and offer recommendations to federal policymakers for ensuring that people with disabilities receive the full insurance benefits to which they are entitled.



### Overview

When fully implemented in January 2014, the Patient Protection and Affordable Care Act (Affordable Care Act) will transform the health insurance market for people with disabilities, enabling them to secure access to more affordable coverage. Beyond the threshold issue of access, however, lies an equally important question: whether coverage will be appropriate to their health and health care needs or will leave them at risk for insufficient and ineffective care along with significant out-of-pocket financial exposure.

To avoid this, the Affordable Care Act breaks new ground by directly addressing the content of coverage through the concept of “essential health benefits.” The law establishes an essential health benefits framework in two distinct markets. The first is the market for qualified health plans sold through state health insurance exchanges to individuals and small-employer groups. The second

is the general market for individual and small-group health plans, whether sold as qualified health plans through state health insurance exchanges or outside of the state exchange structure in what might be thought of as a parallel, state-regulated market.

Whether sold inside or outside an exchange, plans sold in the individual and small-group markets will be regulated by the state within the same general rules, and will be available, if not marketed, to the same groups of individuals—namely those without employer-sponsored coverage and those who work for small employers. Embedded within this essential health benefits framework is a prohibition against coverage discrimination based on disability. (While there are other prohibited grounds for discriminating in the essential benefits statute, we focus on disability in this issue brief, because disabling conditions are emblematic of the types of higher health cost risks that in turn trigger insurers' exclusionary coverage practices.) How this nondiscrimination framework advances prior federal laws and will be implemented as part of essential health benefits policy can be expected to emerge as a central issue in the implementation of the reform law.

This issue brief examines the Affordable Care Act's essential health benefits statute and considers its provisions both separately and in relation to prior federal laws that address health insurance. We explore the concept of coverage discrimination and the various techniques of plan design and administration that can produce discriminatory effects against people with disabilities. We then examine how the reform law's essential benefits statute builds on existing federal laws that relate to health insurance and disability discrimination and discuss how implementation of the essential benefits statute might be approached.

## THE ESSENTIAL BENEFITS STATUTE

When fully implemented in 2014, the Affordable Care Act will establish a range of reforms under various federal laws that are intended to make insurance coverage fairer and more accessible to individuals with heightened health needs. Among other things, the law will:

- prohibit discrimination in coverage based on health status—that is, prohibit plans from denying coverage to individuals, and from utilizing varying health insurance premiums, based on factors other than family size, region, age, or whether the individual participates in wellness programs;
- bar the use of preexisting condition exclusions; guarantee the renewability of coverage;
- bar lifetime and annual limits on coverage;
- establish medical-loss ratio standards;
- prohibit cost-sharing for certain preventive services; and
- require coverage of routine patient costs associated with certain clinical trials.

These reforms alone will not ensure the adequacy of coverage in relation to health care need. Nor will they prevent insurers from designing coverage—including benefits, cost-sharing, and provider networks—in ways that attract and better serve healthier individuals with lower financial risks. Moreover, without provisions aimed at standardizing the content of coverage, it is very difficult for individuals and small-employer groups—the prime beneficiaries of the Affordable Care Act's market reforms—to make meaningful comparisons among coverage options. The need for some level of product standardization has long been recognized as a key element in making a health insurance market work.

For this reason, the law also broadly defines what benefits need to be covered through policies offered in the individual and small-group markets. Under the Public Health Service Act (PHSA) as amended by the Affordable Care Act, all insurers operating in the individual and small-group markets must cover an “essential health benefits” package.

The Affordable Care Act further directs that qualified health plans sold in state health insurance exchanges (including co-op plans) cover these essential health benefits.

## Exhibit 1. Essential Benefit Classes Covered by Qualified Health Plans Under the Affordable Care Act

- Ambulatory patient services
- Emergency services
- Hospitalization
- Maternity and newborn care
- Mental health and substance use disorder services
- Prescription drugs
- Rehabilitative and habilitative services and devices
- Laboratory services
- Preventive and wellness services
- Chronic disease management
- Pediatric services, including oral and vision care

Source: Authors' analysis of the Affordable Care Act.

The law also establishes cost-sharing limits with respect to the overall actuarial value of the plan, the total amount of cost-sharing to which individuals and families can be exposed, and the size of the annual deductible that must be met.

Finally, it amends the Employee Retirement Income Security Act (ERISA) to apply these provisions, codified in the PHS provisions to ERISA-governed employer groups.

The act exempts large-group health plans, as well as self-insured ERISA plans and ERISA-governed multiemployer welfare arrangements not subject to state insurance law, from the essential benefit requirements.

The term “essential health benefits” is defined as a series of broad benefit classes, with considerable discretion left to the Secretary of the U.S. Department of Health and Human Services (HHS) to further define the concept (Exhibit 1). Qualified health plans are not barred from offering additional benefits, and states may require that qualified health plans sold in state health insurance exchanges also cover state-mandated benefits.

Where a state mandate adds an entirely new benefit class to qualified health plans sold in exchanges, a state must pay the cost differential for coverage of these benefits.

How treatments subsumed within an essential benefit class will be treated when applied to exchange products has not yet been determined.

Although the essential benefits statute vests discretion in the HHS secretary, the law also sets boundaries on how she exercises that discretion, shown in Exhibit 2 and excerpted below. These boundaries consist of certain elements related to public notice and comment, inclusion of treatments and services falling within the essential health benefits package, consultation with the Secretary of Labor on establishing coverage parameters based on a Department of Labor survey of “typical” employer plans, and a series of “required elements for consideration.”<sup>1</sup>

Specifically, the law states that the HHS secretary must “ensure that such essential health benefits reflect an appropriate balance among the categories . . . so that benefits are not unduly weighted toward any category.”<sup>2</sup> Second, the secretary may “not make coverage decisions, determine reimbursement rates, establish incentive programs, or design benefits in ways that discriminate against individuals because of their age, disability, or expected length of life.”<sup>3</sup> Third, the secretary must take into account “the health care needs of diverse segments of the population, including women, children, persons with disabilities, and other groups.”<sup>4</sup> Fourth, the secretary must ensure that essential benefits “not be subject to denial to individuals against their wishes

## Exhibit 2. Parameters That Guide the HHS Secretary's Determination of an Essential Benefits Package

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**Benefit classes:** Certain classes of benefits must be represented in the essential benefits package.

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**Scope of benefits:** Essential health benefits must be equal in scope to benefits provided under a typical employer plan.

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**Certain elements must be considered:** Elements that must be considered include: the balance among benefit categories; nondiscrimination against individuals because of their age, disability, or expected length of life; the health care needs of diverse segments of the population; and the fact that benefits cannot be subject to denial on the basis of an individual's age or expected length of life or the individual's present or predicted disability, degree of medical dependency, or quality of life.

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**Cost-sharing:** The law includes broad limits on cost-sharing, including deductibles, coinsurance, copayments, or similar charges.

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**Utilization management:** The HHS secretary cannot prohibit a group health plan or health insurance issuer from carrying out commonly used utilization management techniques.

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Source: Authors' analysis of the Affordable Care Act.

on the basis of the individuals' age or expected length of life or the individuals' present or predicted disability, degree of medical dependency, or quality of life."<sup>5</sup>

The essential health benefits definition also addresses cost-sharing, defined as "deductibles, coinsurance, copayments or similar charges."<sup>6</sup> These provisions address both the limits on annual cost-sharing as well as how these limits will be applied in relation to a four-tier cost-sharing coverage structure. This structure ranges from "bronze" plans (covering 60 percent of the full actuarial value of benefits provided) to "platinum" plans (covering 90 percent of the full actuarial value). (A fifth level of coverage pertaining to catastrophic plans may be sold to individuals under age 30 or others who are certified by the exchanges as not having access to affordable coverage, as defined in the statute.<sup>7</sup>) The concept of a plan's actuarial value is defined as the level of coverage determined by the secretary based on the essential health benefits covered.<sup>8</sup>

The law also contains the following limitation on the HHS secretary's discretion to define an essential benefits package: "Notwithstanding any other provision of the . . . Act, nothing . . . shall be construed to prohibit (or authorize the Secretary of Health and Human Services to promulgate regulations that prohibit) a group health plan or health insurance issuer from carrying out utilization management techniques that are commonly used as of the date of enactment of this Act."<sup>9</sup> The term "utilization management techniques" is not defined.

Taken together, the Affordable Care Act's essential benefits provisions set out a multipronged decisional framework. First, they establish certain broad benefit classes that serve as anchors for the definition of an essential health benefits package. Second, they empower the HHS secretary, rather than health insurers, to define the essential benefits package, in consultation with the Labor secretary and on a nonreviewable basis ("as determined by the Secretary"). Third, the provisions peg the benefits to a "typical" employer plan while at the same time barring the HHS secretary from making coverage decisions, determining reimbursement rates, establishing incentive programs, or designing benefits in ways that discriminate on the basis of age, disability, or expected length of life. Finally, the law bars the secretary from prohibiting group health plans or health insurers from employing "utilization management techniques" that are "commonly" used, while leaving both terms undefined.

The essential health benefits framework raises important issues. To the extent that current "typical" coverage practices by group health plans discriminate on the basis of disability, the secretary nonetheless is obligated to ensure that such discriminatory practices are not carried over into the individual, small-employer group, and qualified health plan markets. But this provision raises the question of what "typical" employer practices consist of. Furthermore, how will the terms "coverage decisions," "reimbursement rates," "incentive programs," and "benefit design" be defined in terms of the provision that bars the secretary from using such

tools in ways that would discriminate against people on the basis of age, disability, or expected length of life. Finally, what are the “utilization management” techniques the secretary is barred from prohibiting?

## COVERAGE DESIGN AND UTILIZATION MANAGEMENT PRACTICES IN THE EMPLOYER GROUP MARKET

The starting point for determining how the essential health benefits package ultimately will be defined is the employer group market. It is thus useful to understand the techniques used by insurers operating in this market to manage costs and thereby limit their exposure to the financial risks associated with claims for coverage. To the extent that these techniques result in disability discrimination, the Affordable Care Act’s essential benefits framework can be expected to curtail or modify these practices.

Insurers’ strategies for managing risk are highly complex and extend well beyond simply offering a broader versus narrower range of benefit classes or instituting a prior authorization process for certain treatments. For example, how a particular benefit is defined may affect its availability in particular cases. Furthermore, within any covered benefit class there exist thousands of specific procedures that may or may not be covered. For example, a prescription drug formulary may exclude certain classes or types of drugs from coverage altogether. Provider networks may be designed to attract and enlist providers that treat lower-cost patients. Provider payment and incentive plans may encourage short-term treatment while discouraging longer-term interventions. Key terms that govern the availability of all benefits, such as “medical necessity” or “experimental,” also can affect whether coverage is available for a particular condition. The use of certain types of exclusionary terms, such as “educational” or “social,” can bar otherwise-available coverage.

Because the Affordable Care Act specifies that the HHS secretary utilize the “typical” employee health benefits plan as the starting point for determining the scope of the essential health benefits package, it is important to understand how discrimination against

people with disabilities and more advanced health needs can occur in such plans. In this context, the concept of discrimination is meant to denote practices that limit insurers’ cost exposure in the case of members with high health care needs. Because the Affordable Care Act’s market reform provisions effectively bar discrimination at the point of enrollment, efforts to constrain costs at the point of coverage and use become all the more important to understand.<sup>10</sup>

Insurers’ approaches to managing risk include: 1) techniques related to the design of benefits and coverage; and 2) techniques related to managing the utilization of covered benefits.<sup>11</sup> Coverage and benefit design techniques can limit or exclude coverage outright, much in the way that an annual dollar limit on the value of coverage would place a hard limit on coverage, regardless of need. Such techniques apply to all members enrolled in a particular plan and are intended to exclude certain types of coverage altogether, regardless of the characteristics of the individual who seeks care.<sup>12</sup> In effect, design features act as fixed limitations and restrictions on the “amount, level, extent or nature of benefits or coverage for similarly situated individuals enrolled under the plan.”<sup>13</sup> These types of limits cannot be challenged with medical evidence showing that more or different treatments are necessary; coverage is not available regardless of the merits of the claim.

The second set of coverage risk management techniques relates to utilization management, that is, techniques used by health insurers to manage the use of covered benefits in the case of individual patients.<sup>14</sup> In this regard, the Affordable Care Act requires the HHS secretary to recognize existing utilization management techniques in use at the time of passage, although such techniques presumably would be subject to the law’s broad nondiscrimination provisions.

The various types and range of coverage and benefit design limitation techniques, as well as utilization management techniques, can be found in the health insurance literature.<sup>15</sup> Another and perhaps even more useful source of evidence on these techniques is the large body of judicial case law involving appeals of benefit denials under ERISA and other laws governing health insurance and employee health benefits.<sup>16</sup>

Because the judicial record is comprehensive and public, it is possible to view with particularity the specific risk-avoidance techniques used by group health plans. While these cases do not shed light on the frequency with which certain types of claims are denied, the decisions provide understanding of the design and management techniques that are available to group health plans.

### **Benefit and Coverage Design Limitation Techniques**

One of the largest trends in care and cost management in recent years has been the use of benefit and coverage design to manage risk. Initially, in the late 1980s, insurers testing cost-containment strategies tended to use broadly crafted coverage documents coupled with individual patient management, such as prospective and concurrent utilization management procedures.<sup>17</sup> Eventually, this approach proved to be ineffective at containing costs. As a result, over the past two decades, far greater attention has been focused on the design of the plan documents that describe what is covered in order to tighten the coverage criteria and thereby exclude certain types of treatments and procedures. Design strategies also utilize financial techniques such as patient cost-sharing and payment incentives aimed at encouraging more efficient practices and care-seeking behavior.<sup>18</sup>

What sets plan design cost containment apart from utilization management efforts is that the denial of coverage is based on a specific limitation or exclusion that is not specific to an individual's health condition or treatment needs, and thus cannot be challenged. Under traditional employee health benefit plan principles and in the absence of specific legal requirements, employers that sponsor health plans are considered to have unlimited discretion to exclude coverage. By contrast, in cases involving patient-specific utilization management denials, the claim denial rests on a determination that a particular benefit is not necessary for a particular patient. The latter decision rests on medical evidence and factual issues at play, giving rise to appeals rights. But where a claim denial is based on an administrator's assertion that a particular benefit is excluded

altogether under the terms of a plan, the result is total exclusion regardless of individual circumstances, and no appeal can be mounted.<sup>19</sup>

**Coverage exclusions and limitations.** A claim denial can stem from an across-the-board coverage exclusion, embedded in the plan document, that excludes specific services and procedures in all cases. Exclusions can be expressed in durational or quantity limits (e.g., no more than 30 speech therapy sessions) or be tied to specific procedures or treatments. For example, prior to passage of the Women's Cancer Recovery Act of 1998, breast reconstruction following mastectomy was considered cosmetic and was routinely and explicitly excluded from coverage.<sup>20</sup>

Exclusions also can be condition- or diagnosis-based. For example, otherwise-covered speech and physical therapy might be excluded in cases in which the purpose of the treatment is to recover lost functioning or restore previous levels of functioning. In such a situation the "recover" limitation is embedded in the coverage definition itself (e.g., "speech therapy when needed to restore prior functioning") or in a broader medical necessity definition that defines medical necessity as existing only when a treatment has the potential to aid in recovery.<sup>21</sup>

In addition, coverage exclusions can be purpose-based. For example, an exclusion may be applied against coverage of otherwise-covered physical therapy where the insurer determines that the purpose of the therapy goes beyond clinical value and also will aid in broader health goals such as education or social and job-based functioning. This type of exclusion is sometimes applied when a child with developmental disabilities present at birth is receiving treatment that has clinical value as well as the added value of allowing the child to develop speaking and movement skills that ultimately can be expected to result in an overall improvement in health and functioning.<sup>22</sup> In those cases, an insurer may deny coverage because the therapy has an educational benefit, as well as a clinical benefit.

**Coverage and treatment guidelines incorporated into the plan's terms of coverage.** Health plans make extensive use of benefit and clinical guidelines to inform coverage decision-making. In some cases, the guidelines are used by an insurer to guide decisions but are not part of the plan documents themselves and thus do not bind a plan administrator to award or deny a benefit based on individual circumstances. In other cases, however, guidelines are incorporated into the plan documents as part of the coverage terms and thus create express limits on the types of treatments that can be covered. The guidelines express the full breadth and scope of treatment under the terms of the plan.<sup>23</sup> For example, medical management guidelines might specify coverage of long-term treatment for alcohol addiction only in situations in which short-term treatments have failed—thus barring the use of longer-term treatments even in situations in which a short-term treatment is clinically inappropriate, given a patient's underlying health condition.<sup>24</sup>

**Definitions of key benefit and coverage terms.** How plan documents define benefit classes can determine whether coverage is available. For example, where a plan's terms define speech therapy as therapy needed to recover lost speech or restore speech, the effect is to exclude coverage for a child or adult whose health condition can benefit from therapy but for whom prior functioning cannot be "restored." This type of example has particular resonance for children born with developmental disabilities and who need therapy to attain speech, or adults with muscular dystrophy who need therapy to maintain speech or avert the loss or deterioration of speech.<sup>25</sup> In both cases, the therapy is clinically indicated as an effective health intervention, but coverage is excluded because the intervention in the patient's case falls outside the terms of coverage.

In a similar vein are medical necessity definitions that apply to all covered treatments and procedures and that limit coverage to services that are required for the treatment of "illness, injury, diseased condition, or impairment."<sup>26</sup> Such a framework may exclude some conditions. For example, a "diseased

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condition" as a concept could be construed narrowly to exclude physical and mental health conditions that are not considered by clinical experts to be the product of a disease but are instead determined to be present at birth.

**Tiered cost-sharing.** Creating different levels, or tiers, of cost-sharing has gained popularity as a way to provide incentives for the appropriate use of care.<sup>27</sup> In tiered cost-sharing arrangements, higher-cost treatments and services (e.g., brand-name prescription drugs, a specific type of operation performed by an out-of-network surgeon) are subject to higher cost-sharing when, in the health plan's determination, a lower-cost treatment or in-network provider would provide equally effective treatment.<sup>28</sup> Similarly, cost-sharing may be reduced in cases in which adherence to a particular course of treatment (e.g., use of prescription drugs to control blood pressure) is consistent with sound clinical practice and good health outcomes.

Tiering decisions may be made on a case-by-case basis or may be subject to practice guidelines that are embedded in plan documents and coverage terms and therefore automatically place certain treatments and procedures on a higher tier.<sup>29</sup> Where the tiered arrangement is the result of a medical management decision specific to a particular patient, modification to consider whether the guidelines appropriately address

that patient's underlying condition may be possible. But where the tiered arrangement is the result of a guideline that is directly embedded into the terms of coverage, challenges are generally not possible.<sup>30</sup>

**Tiered provider networks.**<sup>31</sup> Early efforts by health plans to encourage patients to use efficient, high-quality providers involved a total exclusion of certain providers from networks, leaving patients completely uncovered for out-of-network care. In recent years, group health plans have moved to a more nuanced, value-based approach that involves the use of provider tiers. Providers who have been shown to have higher costs and/or worse outcomes, as measured by a health plan, may be subject to higher cost-sharing or excluded altogether. The lowest cost-sharing levels are required for health professionals who deliver high value. Depending on the methodology used to compare providers, tiering may or may not take into account whether providers treat patients with more extensive health needs and thus utilize more resources either in their own practices or through specialty care referral patterns. Furthermore, tiers may be determined based on practice measures that are designed for populations with health conditions (e.g., diabetes), but without considering patients whose health conditions are made more complex by the presence of underlying disabling conditions (e.g., diabetes and schizophrenia).<sup>32</sup>

**Provider payments.** Health plans give providers several different types of incentives to be parsimonious in their use of resources.<sup>33</sup> Incentives may take the form of a year-end bonus or a shared-savings plan. Incentive payments may be tied to a provider's overall consumption of resources and benefits (e.g., laboratory tests), and providers may be benchmarked against one another without taking into account their patient mix. Providers may be offered bonuses or case management fees to actively manage complex patients. To determine such incentive payments, health plans might compare the costs and outcomes for actual patients or, alternatively, might compare costs and outcomes for a provider's patient panel against established and normative

**The Affordable Care Act's essential benefit nondiscrimination provisions add new dimensions to prior federal laws regulating insurance and health plans and barring discrimination.**

benchmarks that may or may not reflect the actual health status of the provider's patients.

### Utilization Management Techniques

**Prospective and concurrent review.** Health plans have used prospective and concurrent review to control costs for decades. These processes are designed to control unnecessary utilization of covered but costly resources through advance or concurrent consideration of the medical necessity of the treatment or service under review. Central to the review process are: the substantive standards to assess the need for care; the strength of the clinical evidence considered; the application of clinical decision-making guidelines to particular treatments, as well as the quality and relevance of the guidelines to the case at hand; and the extent to which the reviewer takes into account the clinical evidence that is presented in relation to the case at hand.<sup>34</sup>

### Care coordination and care management.

An insurer or health plan may offer or require case management for certain types of conditions. In some cases, the service may be offered in addition to other covered services. Patients with particular conditions may be offered additional treatments and counseling, and their health and course of treatment may be closely monitored to measure improvement. In other cases, a disease management protocol may take on the qualities of an embedded practice guideline that restricts coverage to certain predefined treatments and charges higher cost-sharing for certain treatments. When implemented in this fashion, care management may operate

as an exclusive form of coverage for a particular illness or condition rather than as a process for tailoring covered benefits to individual needs.<sup>35</sup>

## HOW THE NONDISCRIMINATION PROVISIONS EXTEND EXISTING LAW

The Affordable Care Act's essential benefits nondiscrimination provisions break new ground in how to think about these common techniques of health benefit design and management—adding new dimensions to prior federal laws regulating insurance and health plans and barring discrimination. The nondiscrimination provisions have no real parallel in state insurance laws, which do not address discrimination in the content of coverage but instead tend to mandate specific treatments and procedures that otherwise were at risk for exclusion. For example, no state's insurance laws bar the use of a “recover” or “restore” medical necessity standard in the group health market, but as of 2010, 23 states have laws that require coverage for certain types of habilitation treatments aimed at promoting the overall health of children with autism.<sup>36</sup>

Although the nondiscrimination provisions are unprecedented in the context of coverage content, a number of federal laws offer important precedents.

### Federal Laws Regulating Insurance and Employee Health Benefit Plans

**HIPAA.** The Health Insurance Portability and Accountability Act of 1996 (HIPAA) provided the foundation for the Affordable Care Act's market reforms.<sup>37</sup> HIPAA was the first major attempt to use federal law to prevent insurers from discriminating against people with health conditions and disabilities. Amending the PHSA, ERISA, and the Internal Revenue Code in order to reach both state-regulated health insurance and self-insured health benefit plans, HIPAA bars discrimination based on health status at the point of enrollment and renewal. In effect, the new reform law builds on the HIPAA precedent, extending nondiscrimination prohibitions into the individual market and strengthening existing provisions in the

group market. But unlike the reform law, HIPAA does not address the problem of discrimination in the design and administration of coverage because it does not address the content of insurance itself.

**ERISA.** Other than having to abide by the HIPAA provisions, ERISA generally accords employers broad discretion in health benefit plan design and administration, regardless of whether the plan is fully insured (and thus also subject to applicable state laws) or self-insured (and thus exempt from state laws regulating insurance).<sup>38</sup> Thus, for example, although ERISA contains provisions barring discrimination against participants or beneficiaries who exercise their right to benefits, this prohibition has been held not to bar a group health plan from singling out a specific disability for express limitation or exclusion from coverage.<sup>39</sup>

There are important exceptions, however. For example, ERISA requires that certain individuals experiencing a “qualifying event,” including illness and job loss, be permitted to continue to buy group health coverage under their ERISA plans (a right popularly known as “COBRA”).<sup>40</sup> ERISA also bars exclusion from coverage of college students on a medically necessary leave of absence.<sup>41</sup>

Furthermore, ERISA has been amended to bar discrimination against certain types of patients in terms of the content of coverage. For example, ERISA prohibits group health plans from excluding coverage for reconstructive surgery to women with breast cancer or from covering only minimal hospital stays for pregnant women and newborns.<sup>42</sup> Perhaps most important in the context of discrimination, ERISA bars discrimination in coverage in the case of individuals with mental illness or substance use disorders, as discussed below.

**GINA.** The Genetic Non-Discrimination Act of 2008 (GINA) bars certain employer and insurer practices related to the use of genetic information, but nothing in GINA directly addresses content restrictions that might reduce or eliminate coverage for certain individuals with conditions tied to genetic traits.<sup>43</sup>

**Mental health and substance use disorder parity.** Mental health parity represents the most important law enacted to date that directly addresses discrimination in the design and administration of state-regulated health insurance and ERISA-governed employer-sponsored health benefit plans. The Mental Health Parity Act of 1996, revised and expanded by the Paul Wellstone and Pete Domenici Mental Health Parity and Addiction Equity Act of 2008, broadly addresses the problem of discrimination against mental illness and addiction disorders in both benefit design and plan administration.<sup>44</sup>

The original legislation addressed parity only in relation to annual and lifetime dollar limits on coverage; the 2008 amendments extend the concept of parity to reach a broad range of coverage limitations and exclusions. These amendments were further refined in implementing regulations released in 2010 by the Departments of Labor, Treasury, and HHS, which define parity in terms of quantitative treatment limits (i.e., the number of visits permitted) as well as “non-quantitative” treatment limits that “otherwise limit the scope or duration of benefits for treatment.”<sup>45</sup> These types of limits lie at the heart of modern benefit design and medical management systems; in particular, non-quantitative design and management techniques, which in some cases are expressly designed to constrain coverage to individuals with disabilities.

The 2010 parity regulations affect many of the health benefit design and management practices described above. For example, the regulations specify that discrimination may be present under the parity law when mental illness and addiction disorders are singled out by guidelines that restrict coverage to certain treatments, regardless of the medical evidence, even when no similar absolute limits apply to other conditions. The rules also clarify that parity can be violated through discriminatory medical necessity criteria that utilize more restrictive tests of necessity in the case of mental illness and through other design techniques such as tiered cost-sharing, tiered network arrangements, and utilization management procedures that are applied in a discriminatory fashion.<sup>46</sup>

The parity provisions thus offer an important precedent in approaching the essential benefits provisions of the Affordable Care Act. In the case of mental health parity, the federal agencies not only have directly addressed the range of plan design and administration practices, but have identified many types of practices that must be held to nondiscrimination standards, including specific benefit definitions, broad definitional terms such as medical necessity, the use of practice guidelines, and the use of provider network and cost-sharing tiers. These strategies are grouped together as nonquantitative in nature and set the framework of coverage itself, as well as how that coverage will be administered.

### Civil Rights Laws

The Affordable Care Act directly incorporates numerous civil rights laws into Title I.<sup>47</sup> Specifically, it provides that:

An individual shall not, on the ground prohibited under title VI of the Civil Rights Act of 1964, title IX of the Education Amendments of 1972, the Age Discrimination Act of 1975, or section 504 of the Rehabilitation Act of 1973, be excluded from participation in, be denied the benefits of, or be subjected to discrimination under any program or activity, any part of which is receiving federal financial assistance, including credits, subsidies, or contracts of insurance, or any program or activity that is administered by an Executive Agency or any entity established under this title.<sup>48</sup>

The provision thus incorporates federal civil rights laws applicable to federally assisted programs while also clarifying that these laws reach federally subsidized contracts of insurance such as qualified health plans that receive federal premium tax credits. By incorporating these laws into the Affordable Care Act, the general nondiscrimination provision further strengthens the core essential health benefit nondiscrimination statute but does not duplicate it, since civil rights laws barring discrimination against people with disabilities have been held not to reach the content of

coverage itself.<sup>49</sup> Preexisting nondiscrimination laws might be expected to reach insurance and health plan practices inside exchanges such as: sales, outreach, and marketing practices; the selection and deselection of health care providers; the accessibility of care and appeals procedures; and other issues related to access to covered benefits. But it is the essential benefits nondiscrimination provisions that affect the actual content of benefits and do so both in exchange markets as well as in the parallel market for individual and small-group products.

## DISCUSSION AND IMPLEMENTATION RECOMMENDATIONS

Implementation of the Affordable Care Act's essential benefits provisions and its prohibition against discrimination against individuals with disabilities will raise a number of complex issues.

### Defining Key Terms

An important first step of the implementation process is for the HHS secretary to define key terms in the essential benefits provisions. In addition to needing to define the scope of each class of essential benefits, the secretary must define such terms as “disability,” “coverage decisions,” “reimbursement rates,” “incentive programs,” and “benefit design.” Also to be further defined in designing the essential benefits package is how the secretary will “take into account” the health care needs of diverse populations, including people with disabilities. Furthermore, the secretary must define the law's prohibition against the denial of essential benefits based on individuals' “age or expected length of life” or “present or predicted disability, degree of medical dependency, or quality of life.” In defining key terms, the secretary presumably will look to existing laws and relevant industry practices. For example, existing laws related to coverage decisions made by group health plans or Medicare provide guidance on how clinical evidence should be weighed.

The single most important definitional matter may be the threshold question of whether prohibited discrimination on the basis of disability reaches both

intentional discrimination as well as de facto discrimination—practices that are neutral on their face but discriminatory in their impact. Because the Affordable Care Act specifically incorporates existing disability law, and because existing law reaches both intentional and de facto discrimination, the essential benefits nondiscrimination provisions should be interpreted in a fashion that parallels existing disability law. This means that the provisions should be interpreted as reaching not only intentional practices (such as a coverage standard that specifies the need for “recovery” before a claim will be allowed) but also de facto practices such as the use of facially neutral provider payment incentives that nonetheless discriminate because they are applied without consideration of a provider's underlying patients. For example, plans would no longer be permitted to intentionally exclude providers that have a special expertise in, and a disproportionate share of, patients with disabilities. In designing the nondiscrimination aspect of the essential benefits provisions, Congress clearly intended to reach matters of both plan design and administration practices, in order to ensure that plans do not discriminate by either intentional design or practical effect.

### Plan Design and Administration Practices

The nondiscrimination provisions require that the HHS secretary set the parameters under which insurers may operate in matters of both design and administration, including benefit design, coverage decisions, reimbursement rates, and incentive programs. The sweeping language of the nondiscrimination provision means that, as with the mental health parity rules, the secretary must address certain risk-avoidance techniques and strategies.

**Exclusionary coverage terms.** Health insurers and qualified health plans should be expected to adhere to nondiscriminatory coverage terms in order to avoid excluding otherwise covered treatments simply on the basis of a patient's underlying condition. The decision of whether a particular treatment or service is covered should turn solely on whether it is appropriate

to a patient's health condition—not whether it will enable restoration or recovery or have effects that transcend the purely clinical and go to overall health and ability to function. In the case of children and adults with disabilities, many treatments within the essential benefits classes are clinically justified not because they allow restoration or recovery but because they enable patients to attain good health, maintain their health, or avert the loss of functioning that could lead to a deterioration in health.

**Excluding coverage for treatments that show both clinical and health benefits.** The fact that a treatment may confer both clinical and broader health benefits should be irrelevant in deciding whether it is appropriate. Exclusions based on the broader health benefits conferred by a clinical intervention (such as the ability to learn, work, or engage in social activities) are enhancements of the clinical effects of treatments, not reasons to deny them.

**Guidelines and coverage design and decision-making.** Benefit and treatment guidelines are a staple in health plan design and plan administration, serving two purposes: 1) to set out coverage limits for certain conditions or for one or more benefit classes; and 2) to use as a nonbinding tool to aid coverage decision-making in specific cases. In both situations, the impact of the guideline may be to foreclose potentially covered treatments within an essential benefit class at a level and scope necessary to achieve an appropriate health result. Guidelines that contain restrictions based on whether treatments are intended to help in “recovery or restoration” would appear to fail under a nondiscrimination test, for the same reason that such limits are contrary to a nondiscrimination test when they appear as limitations in the coverage definitional sections of an insurance plan. Further, guidelines that place fixed limits on treatments may be inappropriate in situations in which the condition to which the guideline is applied is further complicated by the presence of an underlying disability. Thus the management of asthma, for example, may vary depending on

whether the patient also has an underlying condition such as major depression or diabetes.

Regardless of whether benefit and treatment guidelines are used to set binding coverage limits or merely to guide treatment decision-making, the question is whether the nondiscrimination provision in the essential benefits statute bars the use of the guideline to limit treatment when the effect of the guideline is to discriminate against certain health conditions. Such an exception is similar to the one that applies to coverage of outpatient prescription drugs under Medicare Part D, which permits individuals to appeal coverage denials on the ground of documented health care need and to submit evidence demonstrating the utility of treatments for a particular condition.<sup>50</sup>

**Across-the-board coverage limitations and exclusions.** Nothing in the Affordable Care Act prohibits the use of across-the-board limitations on coverage. While strict limits on the amount or duration of benefits work particular hardships on individuals with disabilities, the question is whether such limits are discriminatory. As long as the limits apply to all conditions and all treatments, discrimination per se is not the issue. However, the essential benefits statute requires the HHS secretary to consider the needs of people with disabilities in designing benefits and making coverage determinations. This might argue for an exceptions process to permit greater levels of coverage in cases in which relevant and reliable evidence demonstrate the health benefits of a treatment. Further, while across-the-board limitations and exclusions on an entire benefit class might not be discriminatory, exclusions that single out specific treatments used only for specific disabling conditions should be considered a form of discrimination.

**Tiered cost-sharing and provider networks.** Tiered cost-sharing and provider networks are increasingly common design features in health benefit plans. The use of tiering raises the question of the need for an evidence-based exception to plan design in cases where a tier would otherwise result in the denial

of appropriate treatment based on a health condition or where a specific provider should be treated as an in-network provider (with in-network payment rates and cost-sharing) in order to ensure the appropriate management of disabling conditions. In essence, the question is whether the nondiscrimination provision applicable to essential health benefits, when coupled with existing civil rights protections, requires that health plans modify provider network selection and tiering practices in order to protect against the threat of discrimination in access to equally effective care.

**Provider payment and incentive arrangements.** Existing laws aimed at curbing health care fraud and abuse prohibit incentive arrangements that induce health professionals to deny or withhold medically necessary treatment.<sup>51</sup> However, payment and incentive arrangements should not be benchmarked against normative performance with a healthy patient panel, but instead should be risk-adjusted to take into account patients with disabilities. As with tiered cost-sharing and provider networks, this consideration reflects not only the essential benefit nondiscrimination provision but also federal civil rights laws that require access to equally effective health care.

**Utilization management techniques.** In addition to addressing the problem of discrimination in all aspects of benefit and coverage design and practice, it is important to address potentially discriminatory utilization management processes. The Affordable Care Act preserves existing utilization management practices but does so under the broader nondiscrimination provisions of the essential benefits statute. As such, and as with the mental health parity regulations, medical management techniques that differentiate based on the nature of the condition or disability should be prohibited. Further, the nondiscrimination prohibition should be extended to the claims appeals process applicable to essential benefits plans in order to ensure that evidence specific to an individual's condition and treatment is always taken into account as part of the record.

Finally, of course, for the nondiscrimination statute to be meaningful, compliance must be measured and the terms of the law must be enforced. This means assurance that the nondiscrimination provisions and implementing standards are incorporated into and applied to all state insurance contracts governed by the essential benefits statute. In this way, the requirements of federal law will become an inherent part of the documents that create the plan and define the rights of covered individuals. Further, government enforcement standards developed for oversight of the individual and small-group market, as well as the exchange qualified health plan market, should be structured to measure plan adherence to nondiscrimination standards. This structure will necessitate a review of plan documents and coverage terms, as well as an assessment of plans' coverage determination, incentives, and payment practices.

## NOTES

- 1 P.L. 111-148 §1302(b)(1) and PPACA §§1302(a)(1) and (b)(2).
- 2 PPACA §1302(b)(4)(A).
- 3 PPACA §1302(b)(4)(B).
- 4 PPACA §1302(b)(4)(C).
- 5 PPACA §1304(b)(4)(D).
- 6 PPACA §1302(c)(3).
- 7 P.L. 111-148 §1302(e).
- 8 P.L. 111-148 §1302(d)(2).
- 9 PPACA §1565(d).
- 10 S. Rosenbaum, “Insurance Discrimination on the Basis of Health Status: An Overview of Discrimination Practices, Federal Law, and Federal Reform Options,” *The O’Neill Institute for National and Global Health Law* (2009).
- 11 R. Rosenblatt, S. Rosenbaum, and S. Law, *Law and the American Health Care System* (New York: Foundation Press, 1997), 139–42.
- 12 See discussion of coverage limits in *Kenseth v Dean Health Plan*, 610 F. 3d 452 (7th Cir., 2010), 464–65.
- 13 *Kenseth v Dean*, 610 F. 3d at 464. See also J. M. Yegian, “Conference Summary: Setting Priorities in Medical Care Through Benefit Design and Medical Management,” *Health Affairs* Web Exclusive, May 19, 2004, w4-300–w4-304.
- 14 Yegian, “Conference Summary,” 2004.
- 15 See, e.g., S. Rosenbaum, “New Directions for Health Insurance Design: Implications for Public Health Policy and Practice,” *Journal of Law, Medicine, and Ethics*, Winter 2003 31(4 Suppl.):94–103; J. S. Rosenbloom, ed., *The Handbook of Employee Benefits*, 5th ed. (New York: McGraw-Hill, 2001); J. M. Robinson, “Renewed Emphasis on Consumer Cost Sharing in Health Insurance Benefit Design,” *Health Affairs* Web Exclusive, March 20, 2002, w139–w154; Yegian, “Conference Summary,” 2004; C. L. Barry, J. R. Gabel, R. G. Frank et al., “Design of Mental Health Benefits: Still Unequal After All These Years,” *Health Affairs*, Sept./Oct. 2003 22(5):127–37; J. M. Robinson, “Consumer-Directed Health Insurance: The Next Generation,” *Health Affairs* Web Exclusive, Dec. 13, 2005, w5-583–w5-590; L. A. Bergthold, “Medical Necessity: Do We Need It?,” *Health Affairs*, Winter 1995 14(4):180–90.
- 16 ERISA §502(a)(1)(B), 29 U.S.C. §1132 (a)(1)(B) permits participants and beneficiaries to pursue legal actions in court to recover benefits due them under their ERISA plans. Thousands of cases involving appeals of benefit denials have been decided since ERISA’s passage in 1974. There is no single comprehensive study that analyzes all benefit denial cases.
- 17 Rosenblatt, Rosenbaum, and Law, *Law and the American Health Care System*, 1997, pp. 543–73.
- 18 J. M. Robinson and J. M. Yegian, “Medical Management After Managed Care,” *Health Affairs* Web Exclusive, May 19, 2004, w4-269–w4-280.
- 19 *Jones v. The Kodak Medical Assistance Plan*, 169 F.3d 1287 (10th Cir. 1999).
- 20 29 U.S.C. §1185b. See *Krauss v Oxford Health Plan* for a discussion of the Act, at 517 F. 3d 614 (2d Cir., 2008).
- 21 *Bedrick v. Travelers Insurance Company*, 93 F. 3d 149 (4th Cir., 1996).
- 22 See, e.g., *Mondry v. American Family Mutual Insurance Co.* 557 F. 3d 781 (7th Cir., 2009).
- 23 See, e.g., *Mondry v. American Family Mutual Insurance Co.*, op. cit.; *Jones v. The Kodak Medical Assistance Plan*, 169 F.3d 1287 (10th Cir. 1999).
- 24 See *Jones v. The Kodak Medical Assistance Plan*, op. cit.
- 25 See *Bedrick v. Travelers Ins. Co.*, op. cit.
- 26 Bergthold, “Medical Necessity,” 1995.
- 27 See, e.g., A. M. Fendrick, D. G. Smith, and M. E. Chernew, “Applying Value-Based Insurance Design to Low-Value Health Services,” *Health Affairs*, Nov. 2010 29(11):2017–21.
- 28 *Saltzman v Independence Blue Cross*, 2010 WL 2340182 (3d. Cir., 2010); See, e.g., *Krauss v Oxford Health Plan*, op. cit.
- 29 *Saltzman v Independence Blue Cross*, op. cit.
- 30 *Saltzman*, op. cit.

- <sup>31</sup> See Bloomberg News, “In New York, Insurer Settles Its Dispute on Payments,” *New York Times*, Feb. 4, 2009; E. Nakashima, “Doctors Rated But Can’t Get a Second Opinion; Inaccurate Data About Physicians’ Performance Can Harm Reputations,” *Washington Post*, July 25, 2007; A. B. Claiborne, J. R. Hesse, and D. T. Roble, “Legal Impediments to Implementing Value-Based Purchasing in Healthcare,” *American Journal of Law and Medicine*, 2009 35(4):442–504.
- <sup>32</sup> *Krauss v Oxford Health Plans*, op. cit.
- <sup>33</sup> *Pegram v Herdrich*, 530 U.S. 211 (2000); *Shea v. Esensten*, 107 F.3d 625 (8th Cir. 1997).
- <sup>34</sup> See, e.g., *Bedrick v Travelers Ins. Co.*, op. cit.; *Wickline v State of California*, 239 Cal. Rptr. 810 (1987).
- <sup>35</sup> G. P. Mays, M. Au, and G. Claxton, “Convergence and Dissonance: Evolution in Private-Sector Approaches to Care Coordination and Disease Management,” *Health Affairs*, Nov./Dec. 2007 26(6):1683–91.
- <sup>36</sup> National Conference of State Legislators, “Mandated Health Insurance Benefits and State Laws: Insurance Coverage for Autism,” available at: <http://www.ncsl.org/default.aspx?tabid=18246>.
- <sup>37</sup> P.L. 104-191 (104th Cong., 2d sess.).
- <sup>38</sup> *Metropolitan Life Insurance v Massachusetts* 471 U.S. 724 (1985); *Kentucky Association of Health Plans v Miller*, 538 U.S. 329 (2003).
- <sup>39</sup> *McGann v H and H Music Co.* 946 F. 2d 401 (5th Cir., 1991).
- <sup>40</sup> 29 U.S.C. §1161
- <sup>41</sup> 29 U.S.C. §1185c
- <sup>42</sup> The Women’s Health and Cancer Rights Act requires group plans that cover mastectomy surgeries to cover “breast reconstruction, prostheses, and other treatments to address the complications of all stages of a mastectomy.” The Newborns and Mothers Protection Act applies to state-regulated group plans and employer plans subject to the Pregnancy Discrimination Act. Under the law, covered plans must provide a minimum of 48 hours stay following a normal delivery, and 96 hours following a Caesarean section.
- <sup>43</sup> 29 U.S.C. 1182 (2010).
- <sup>44</sup> Paul Wellstone and Pete Domenici Mental Health Parity and Addiction Equity Act of 2008, P. L. 110-343 (2008) (amending 26 U.S.C. § 9812, 29 U.S.C. § 1185a, and 42 U.S.C. § 300gg-5).
- <sup>45</sup> 29 C.F.R. §2590.712(a).
- <sup>46</sup> 45 C.F.R. §146.136(c)(4).
- <sup>47</sup> PPACA §1557. Title I of PPACA contains the provisions related to insurance market reforms, individual and employer responsibility, tax credit subsidies, exchanges, essential benefits, and qualified health plans.
- <sup>48</sup> PPACA §1557.
- <sup>49</sup> See *Doe v. Mutual of Omaha Insurance Co.*, 179 F.3d 557 (7th Cir. 1999), cert. denied, 528 U.S. 1106 (2000) (The public accommodations provisions of the ADA do not reach the content of private health insurance); *Alexander v. Choate*, 469 U.S. 287 (1985) (Section 504 of the Rehabilitation Act does not reach the content of public health insurance)/
- <sup>50</sup> 42 U.S.C. §§ 1395w-104 (g)–(h) (2006); 42 C.F.R. § 423.578.
- <sup>51</sup> Social Security Act § 1128A(b), 42 U.S.C. § 1320a-7a(b) (2006).

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