

August 25, 2011

Secretary Kathleen Sebelius
U.S. Department of Health and Human Services
200 Independence Avenue, S.W.
Washington, D.C. 20201

Dear Secretary Sebelius:

The undersigned organizations represent a diverse array of organizations committed to access to quality health care for vulnerable and low-income communities. We write to you to emphasize the obligations of the Department of Health and Human Services (HHS) under the Affordable Care Act (ACA) to define the Essential Health Benefits (EHB) package and to create a set of coverage standards that conform with ACA provisions. HHS must provide clear direction to the states and the insurance industry, and establish a floor for benefits. To do less would violate the statute. In this letter we also make recommendations regarding the benefits that should be included in the essential health benefits package.

The Need for Strong Federal EHB Standards

Some officials from HHS have suggested that the Department is considering giving states and/or health plans significant discretion in defining the essential health benefits standard. Varying EHB standards would be bad for consumer health. We recognize there may be reasons to accommodate regional or local health interests, but the purpose of the Federal EHB standard is to set a national floor. That floor must represent the minimum package of benefits that consumers need to meet all of their health care needs, not a bare-boned set of ‘catastrophic coverage’ benefits. Regional or local considerations, by states and/or plans, should be relevant to decisions about providing *additional* coverage. The Federal EHB standard should set a strong national floor, but it is not a ceiling. States and plans are free to use their judgment about ways to expand benefits packages to improve upon the national standard or take into account local health needs. This is explicitly contemplated by the ACA, which allows states to add on to the Federally defined EHB.¹ But firm and comprehensive Federal EHB standards must be the starting point. As you know, in Medicaid, a robust listing of mandatory services has been critical to assuring an appropriate coverage floor for the particular groups who qualify for Medicaid, while at the same time offering federal service options that allow states to offer more.

The structure of the ACA also makes it critical that there be a strong Federal EHB standard in place since the EHB provision sets the boundary for state and plan flexibility that *already* exists under the law. For example, although the ACA sets new prohibitions on annual and lifetime limits, it provides flexibility for non-EHB services.² With no or an inadequately established

¹ACA § 1311(d)(3)(B). See also §1302(b)(5).

² See ACA §1001, creating Public Health Service Act § 2711.

national EHB package, the annual and lifetime limit prohibitions are eviscerated. Other areas of the ACA that also presume a national EHB standard could also be severely impacted, including actuarial coverage calculations,³ Basic Health benefits,⁴ and Medicaid benchmark coverage.⁵

The ACA Requires Federal Standards

As a legal matter, there is no authority in the ACA for delegating the EHB package to states (or health plans). The ACA explicitly and repeatedly requires the Secretary of HHS (Secretary) to develop standards, factoring a number of considerations (with emphasis added):

- In §1302(a): “...with respect to any health plan, coverage that ... provides for the essential health benefits defined by the Secretary...”
- In §1302(b)(1): “...the Secretary shall define the essential health benefits...”
- In §1302(b)(2)(A): “The Secretary shall ensure that the scope of the essential health benefits ... is equal to the scope of benefits provided under a typical employer plan, as determined by the Secretary. To inform this determination, the Secretary of Labor shall conduct a survey ... and provide a report on such survey to the Secretary.”
- In §1302(b)(2)(B): “In defining the essential health benefits ... the Secretary shall submit a report to the appropriate committees of Congress containing a certification from the Chief Actuary of the Centers for Medicare & Medicaid Services...”
- In §1302(b)(3): “In defining the essential health benefits ... the Secretary shall provide notice and an opportunity for public comment.”
- In §1302(b)(4): “In defining the essential health benefits ... the Secretary shall--”
 - “periodically review the essential health benefits ... and provide a report to Congress and the public...”
 - “periodically update the essential health benefits ... to address any gaps in access to coverage or changes in the evidence base the Secretary identifies in the review conducted...”

Nowhere does the ACA authorize states or health plans to define the EHB standard; nor does it authorize the Secretary to delegate that function. Elsewhere in the ACA, where Congress wanted states to have discretion, Congress specifically delegated rulemaking authority to states, Exchanges, and plans. But the plain language of the ACA’s definition of “Essential Health Benefits” at §1302(b) unequivocally states that “...the Secretary shall define the essential health benefits...” Congress clearly intended the Secretary of HHS, and not states nor plans, to develop EHB standards.

In addition, numerous provisions presume that the Secretary will establish one national EHB standard. These provisions are almost impossible to understand if the Secretary could delegate EHB defining authority. How could the Secretary provide notice and comment for potentially

³ ACA §1302(d)(2)(A).

⁴ ACA § 1331.

⁵ ACA § 2001(c), amending 42 U.S.C. 1396u–7(b).

hundreds of state and plan defined standards? How could she periodically review and report to Congress? And how could the Secretary update the EHB based on her review? Neither the letter nor the logic of the ACA sustains an interpretation that the Secretary can allow a local definition of the EHB standard.

The EHB Standard Should Prioritize Medical Need, Not Costs

We realize that the Institute of Medicine (IOM) and HHS have received numerous comments urging the use of a non-prescriptive EHB standard to keep the costs of health plans lower and prioritize “affordability.” While we understand the interest in “affordability,” we think making this a decisive priority is a serious mistake.

- The EHB standard should provide for the health care that consumers need, based on *medical* standards, not financial objectives.
- The population that this standard will impact includes many low-income and vulnerable individuals for whom regular health care services are a matter of life or death. This is not a “young invincible” population that can survive with limited scope insurance.
- A low EHB standard will lead to consumers living in poor health and deteriorating faster, especially among vulnerable populations. This will worsen existing health disparities.
- This will also result in consumers going without needed health care and entering the health system in more advanced stages of illness, needing more invasive, expensive health care treatment.
- Furthermore, the notion that a weak EHB package will promote “affordability” is myopic and ignores the reality for consumers. While it is true that a robust benefits package may slightly push up premiums, non-coverage of necessary services drives medical debt and bankruptcies that overwhelm consumers financially. A weak EHB package that leads to millions of *underinsured* Americans will generate financial hardship for consumers that dwarf the concern about marginal premium increases.
- Consumer recognition that the EHB package does not meet their full health care needs will erode support for the ACA and undermine the attempts to reform the health care system in this country.

The Essential Health Benefits Package

1. General Recommendations

With the implementation of the new health reform law, it is critical to ensure that private health care plans provide appropriate care for *all* populations, including diverse and low-income populations. The essential health benefits will be relevant to “qualified health plans” participating in the Exchanges, issuers in the individual and small group markets, Medicaid benchmark and benchmark-equivalent plans, and state Basic Health programs for low-income individuals not eligible for Medicaid.

Low-income and vulnerable populations have qualitatively different health care needs than the average health consumer. For example, low-income children need proactive developmental screening and interventions to make up for a host of socioeconomic, nutritional, and environmental factors which may hinder their development. Medicaid standards should be a model for developing the EHB package. For example, the Medicaid Early and Periodic Screening, Diagnostic and Treatment (EPSDT) service and principles should be the basis for the EHB package for children (see section on “services for children” below).

A robust EHB package is essential to ensure that consumers receive effective care. If consumers do not have access to a full range of appropriate medical services, predictably, they will suffer from deteriorating health status and require more invasive (and more costly) interventions later. This not only affects the individual person, but also impacts our productivity as a nation, and ultimately increases the cost of health care. Therefore, the coverage policy should be comprehensive and based on medical standards. Consumers should have access to the health services they need to stay healthy.

A clear and prescriptive Federal EHB policy will also make administration of Exchanges and other markets much easier. Vague Federal standards will lead to a host of problematic consequences – different benefits packages, confused consumers, confused payors, and significant administrative costs associated with coordinating different benefits and disputes about coverage policies. This also undermines some of the basic ACA objectives, such as developing a simple and navigable insurance market for consumers, and promoting health care systems that are unified as opposed to siloed. As Medicaid history has proven, loose Federal standards will also lead to local abuses requiring heavy Federal oversight, and more importantly, it can lead to serious health consequences for participants.

2. Preventive Services

Prevention is the foundation of an effective health care system, both in terms of health status and cost. In 2005, almost one in two adults had at least one chronic illness.⁶ Therefore preventive services can improve the length and quality of a person’s life and reduce the economic burden of disease.⁷ We strongly encourage regulations around the EHB to be prescriptive and aggressive in setting out preventive care requirements.

3. Services for Children

Ensuring a robust and comprehensive EHB package is critically important for children, especially those who are low-income and/or have special health care needs. Medicaid’s pediatric standard of coverage, EPSDT, should serve as the model for the scope and breadth of EHBs for children.

⁶ *The National Prevention Strategy*, National Prevention Council (June 2011), <http://www.healthcare.gov/center/councils/nphpphc/strategy/report.pdf>, at 11.

⁷ *Id.* at 51.

It is well established that low-income children are more likely to have poor health than other children.⁸ Low-income children have a higher prevalence of special health care needs and conditions such as obesity, asthma, and attention deficit hyperactivity disorder.⁹ Low-income children are at greater risk for extreme prematurity, oral health problems, elevated blood lead levels, and behavioral health problems, all of which can cause long-term disabilities and limitations.¹⁰ Moreover, children's health care needs are different from adults' and require a tailored benefits package. Given these complex and evolving needs and the significant number of low-income and special needs children who will be covered through the Exchanges, it is imperative that all participating plans offer a comprehensive EHB package for children.

EPSDT was developed specifically to meet the physical, emotional, and developmental needs of low-income children. Medicaid covers, for all children under the age of 21: medical screens according to a periodicity schedule, including a comprehensive health and developmental history, an unclothed physical exam, immunizations, lab tests, and health education; vision, hearing, and dental services; and the necessary treatments and services (consistent with the scope of benefits under the Medicaid Act, 42 U.S.C. 1396(d)(a)) to correct or ameliorate physical and mental illnesses.¹¹

Using EPSDT as a model for essential pediatric benefits will ensure that plans in the Exchanges are required to provide not only frequent screening and preventive measures,¹² but also comprehensive treatment to correct or ameliorate physical and mental conditions, including chronic diseases and developmental conditions. This coverage will differ from that of current private insurers that have a narrow definition of medical necessity, limited to services that diagnose or treat illnesses and are needed to restore normal functioning.¹³ In fact, a study in the *New England Journal of Medicine* found that children in private plans are more likely to be *underinsured* than their counterparts in public programs.

In addition to using Medicaid as a model, the Secretary should consider existing state laws that require coverage of certain services for children. For example, 16 states and District of

⁸ See, e.g., Leighton Ku et al., Center on Budget and Policy Priorities, *Improving Children's Health: A Chartbook About the Roles of Medicaid and SCHIP* (2d ed. 2007).

⁹ See, e.g., Sara Rosenbaum & Paul H. Wise, *Crossing the Medicaid-Private Insurance Divide: The Case of EPSDT*, 26 HEALTH AFFAIRS, 382-93 (2007); C. Bethel et al., *National, State and Local Disparities in Childhood Obesity*, 29 HEALTH AFFAIRS, 347-56 (2010).

¹⁰ See, e.g., The George Washington University, *Comparing EPSDT and Commercial Insurance Benefits* (September 2005); Clarisa Ramirez, *Toothaches more likely in minority, poor, special needs children, study finds*, Medill Reports Chicago, Nov. 4, 2010.

¹¹ 42 U.S.C. §§ 1396a(a)(10)(A), 1396a(a)(43), 1396d(a)(4)(B), 1396d(r). For further explanation, see, e.g., National Health Law Program, *Towards a Healthy Future: Medicaid Early and Periodic Screening, Diagnostic and Treatment Services for Poor Children and Youth* (Apr. 2003).

¹² Fortunately, the ACA § 1001 requires plans to cover, without cost-sharing, preventive care and screening for children as outlined in *Bright Futures*. This important requirement will help to ensure that children receive the most effective and up-to-date preventive interventions.

¹³ See, e.g., Rosenbaum & Wise, *supra* note 16, at 387-91.

Columbia mandate that insurers in the individual market cover services for autism.¹⁴ These laws should be assessed for possible incorporation into the EHB package. Including these state-mandated benefits in the EHB package would mean that states would not have to absorb any additional premium costs as a result of requiring coverage of these benefits in the Exchanges.¹⁵ At the very least, existing laws should be preserved because the establishment of Exchanges does not nullify the individual market outside the Exchanges.

Congress understood the heightened need for ensuring that the Exchanges adequately cover low-income children. The ACA requires the Secretary, in 2015, to review benefits and cost-sharing for children in the Exchanges and certify that they are at least comparable to benefits and cost sharing in CHIP.¹⁶ Considering that many states cover EPSDT benefits for children enrolled in CHIP (in addition to those enrolled in Medicaid), states will be better able to satisfy this requirement if they ensure a robust pediatric benefits package when initially setting up the Exchanges.¹⁷

4. Reproductive Health

All health plans should include comprehensive preventive care and services, maternity services (including routine and high-risk prenatal care, pregnancy-related counseling and care, labor and delivery services, postpartum services, and services for other conditions which may complicate pregnancy), all forms of FDA-approved contraceptive services, drugs and devices, permissibly covered abortion services, and counseling and treatment for sexually transmitted infections (STIs) and HIV/AIDS. Preventive care should also include the full range of preventive services for women identified through the rigorous IOM process. Additionally, reproductive health preventive services, including those identified by the IOM, should extend to men, where appropriate. Reproductive health is integral to both women's and men's health, and men should also be able to gain access to annual counseling and screening for STIs and HIV/AIDS, as well as all FDA-approved contraceptive methods (e.g., condoms), sterilization procedures, and family planning education and counseling.

Furthermore, as the Secretary of HHS considers how reproductive health services will be included within EHB packages, the following principles should be considered:

- Preventive and promotive health care services must be considered essential aspects of a benefits package, including for the prevention of unwanted pregnancy and the

¹⁴ Horner & Corlette, *supra* note 9, at 5.

¹⁵ The ACA provides that states may require additional benefits beyond the essential benefits package, but must assume any additional costs. ACA §§ 1311, 10104(e)(1).

¹⁶ ACA § 10203(c) (amending 42 U.S.C. § 1397ee (a)(3)(F)(iii)).

¹⁷ For example, 11 states and D.C. use their CHIP funds to expand their Medicaid program to cover more children. Donna Cohen Ross & Caryn Marks, Challenges of Providing Health Coverage for Children and Parents in a Recession: A 50 State Update on Eligibility Rules, Enrollment and Renewal Procedures, and Cost-Sharing Practices in Medicaid and SCHIP in 2009 (January 2009).

prevention of sexually transmitted infections. The services should encourage and promote participatory decision-making on the part of the enrollee seeking care.

- In the reproductive health context, it is the patient who must make the ultimate informed decision regarding which treatments and services are appropriate. Enrollees seeking reproductive health care must have access to all necessary information to make informed decisions regarding their health needs. Benefits should never be restricted based on considerations outside of evidence-based medical standards.
- Reproductive health services must respect the decisions and needs of enrollees, particularly those marginalized by society as a result of low income, racial or ethnic discrimination, disability, sexual orientation or identity, or low level of literacy. The EHB package must ensure that enrollees are guaranteed confidentiality and privacy in the health care context, and that they are provided with necessary and understandable information to help them make well-informed decisions.

5. Health Disparities

Racial, ethnic, and gender disparities

We applaud HHS' commitment to assess the impact of all policies and programs on racial and ethnic health disparities through its Disparities Action Plan released in April 2011.¹⁸ For all populations to have access to needed care as HHS' Disparities Action Plan contemplates, HHS must design a comprehensive EHB package that ensures that private health care plans will offer the appropriate level of care for *all* populations, including diverse and low-income communities.

Under the ACA, the Secretary of HHS is instructed to include the health needs of diverse populations, including women, children, people with disabilities and others.¹⁹ Therefore the EHB must include strong coverage of the services that these populations will disproportionately need to address their identified health disparities. Failure to do so would violate the statute.

HHS' Disparities Action Plan includes a strategy to reduce disparities in quality of health care in the Health Insurance Exchanges by using financial and non-financial incentives to promote activities. These activities may include "language services, community outreach, cultural competency training, health education, wellness promotion, and evidence-based approaches to manage chronic conditions."²⁰

Discrimination also plays a role in the creation of health disparities, therefore HHS must ensure that non-discrimination policies are included in the EHB standards.

¹⁸ *HHS Action Plan to Reduce Racial and Ethnic Health Disparities: A Nation Free of Disparities in Health and Health Care*, Department of Health and Human Services,

http://www.minorityhealth.hhs.gov/npa/files/Plans/HHS/HHS_Plan_complete.pdf

¹⁹ ACA § 1302(b)(4).

²⁰ *HHS Action Plan to Reduce Racial and Ethnic Health Disparities*, *supra* note 21, at 17.

Language Access

The Secretary of HHS should define the EHB package to include appropriate language access for individuals with limited English proficiency (LEP). Language services should be provided in conjunction with covered services so that LEP individuals can fully understand the services available to them and receive appropriate care. Over 25 million people (9% of the population) speak English less than “very well,” and for health care purposes may be considered LEP. Language and cultural barriers undermine access to quality health services, resulting in substandard or inappropriate care as a result of inaccurate or incomplete information. The following principles should be deemed essential:

- Interpreter and translator services should be a general requirement for all EHB packages and for all health plans offering the EHB package. Estimates have shown that, for HMOs, providing language services would cost approximately \$2.40 per person per year. EHB packages should ensure the ready availability of translated reprintable resources for hospitals and participating providers.
- Plans offering EHB should be encouraged to promote accurate communication between patients and providers, ensuring informed consent and protecting patient-provider confidentiality.

6. Mental Health, Behavioral Health, and Substance Abuse Services

The EHB standard will be critical to consumers in Exchanges and state Basic Health programs, many of whom will be just above the poverty line, and Medicaid expansion populations who will predominantly be below the poverty line. These populations have disproportionately high incidence of mental or behavioral illness and substance abuse (MH/BH/SA), and the historic failure of health care packages to provide services for these conditions has trapped many individuals in a cycle of medical underinsurance, gaps in treatment, decreased function, socioeconomic depression, and social stigma. The recent national efforts to pursue mental health “parity” in health coverage are a critical step in the process of breaking this cycle, and robust EHB coverage of MH/BH/SA services is essential to continue this progress. Furthermore, the ACA prohibits the Secretary from implementing a definition of EHB that discriminates “on the basis of ... the individuals’ present or predicted disability, degree of medical dependency, or quality of life.”²¹

The EHB standard must include robust coverage of screening and assessment for MH/BH/SA conditions. Failure to diagnose these conditions is prevalent, and it leads to millions of dollars of wasted health care spending (including for physical health care) that fails to achieve results due to the underlying, untreated MH/BH/SA condition. Co-occurrence of physical and mental health disorders will be common in the Exchange, Basic Health and Medicaid Expansion populations, and MH/BH/SA treatment is necessary for successful health care, physical and/or

²¹ ACA § 1302(b)(4)(D).

mental health. Failure to comprehensively identify and treat MH/BH/SA will undermine the ACA goal of promoting consumer-centered care and better coordinated medical care.

In addition, the EHB standard must include a robust package of treatment options, as this is critical to maintaining overall health. It is important to note that many states and health plans have had historically weak coverage of MH/BH/SA; therefore, strong national standards will be necessary to meet the needs of enrollees and comply with the parity requirements of the ACA and other laws.²²

To maximize effectiveness, a wide array of MH/BH/SA benefits should be available based on a range of acuity, disability, engagement levels and consumer preferences. The Substance Abuse and Mental Health Services Administration (SAMHSA) services continuum includes:

- Health Homes
- Prevention and Wellness Services
- Engagement Services
- Outpatient and Medication Assisted Treatment
- Community Supports and Recovery Services
- Intensive Support Services
- Other Living Supports
- Out of Home Residential Services
- Acute Intensive Services

Finally, one of the most critical aspects of mental health EHBs is the inclusion of rehabilitative and habilitative services and devices, appropriate pain management, and chronic disease management as categories of essential health benefits. These categories of benefits are critical to the ability of the private insurance system to meet the needs of people with disabilities and chronic conditions.

7. ADA Considerations

Although the Medicaid program covers only roughly one-sixth of the population, many studies estimate Medicaid pays over half of the national long-term care costs. While the EHB standard is not one designed to meet the needs of populations needing institutional care, to the extent the ACA will promote consumer-centered care in home or community settings, the EHB standard must begin to address home support needs, such as medical equipment and supplies and home health services. Failure to provide these services will lead to decreased quality of life and financial ruin for many. It will also continue the trend of long term acceleration of health care spending through increased institutionalization.

For many people with disabilities and chronic conditions, rehabilitative and habilitative services and devices are the most essential services and interventions. The rehabilitative and habilitative

²² See., e.g., Mental Health Parity and Addiction Equity Act of 2008 (MHPAEA) and the Mental Health Parity Act of 1996 (MHPA).

services and devices should include services that prevent the worsening of a disability or a related condition or prevent deterioration of function over time. Interventions such as skills training and other independent living services designed to restore or improve functioning are critical. In addition, a relatively small, simple, and inexpensive set of home support services would prevent countless unnecessary institutionalizations, and maximize the functional status, independence, and quality of life of enrollees. As a matter of law, the ADA requires that government health care standards implementing the EHB not discriminate against persons with disabilities, and providing benefits in a way in which persons with disabilities are disproportionately forced out of their home and community based setting is discriminatory under the law.

We consider it crucial, in consideration of consumer health, health care spending, and disability, to include rehabilitative and habilitative services and devices, and home support services within the EHB package.

8. Limitations on Coverage / Utilization Management

Health insurers implement a wide variety of utilization management techniques to “manage” access to services. Broadly defined, these may include: medical necessity requirements, prior authorization requirements, step therapy systems, quantity or frequency limits, co-payments, cost-sharing, and deductibles. Some of these techniques (such as medical necessity) may have useful clinical applications when carefully implemented. Others may only result in negative clinical consequences (for example, co-payments restrict access to care based on sensitivity to cost, and not based on any clinically rational criteria). What all of the utilization controls have in common is that they present significant barriers to consumers receiving needed care and can cause individuals to go without prescribed or needed care with negative health care and cost consequences.

We recommend HHS implement a simple two-part requirement to any such restrictions being applied to EHB packages.

- 1. Coverage limitation policies can only be based on verifiable and documented objective medical standards.** The standards should be based on medical criteria (such as the guidelines of the major relevant professional academies or provider associations, for example, American Academy of Pediatrics, American Congress of Obstetricians and Gynecologists, etc.) and not non-medical standards, such as insurance industry standards. Ultimately, a coverage limit should only be allowed if it is based on medical evidence and is not detrimental to the health care needs of enrollees.
- 2. Regardless of whether coverage limitations are sometimes permissible, there must be a simple, transparent exceptions process with established decision-making criteria and processes that allow enrollees access to all benefits based on the medical judgment of their provider.** This is currently reflected in the Medicaid Act policies and should be continued to EHBs. We believe this position makes the utmost sense: Managed care

organizations select high-quality providers to fill their restricted provider networks, and the ultimate arbiters of medical need should be these medical experts the plan has contracted with.

The EHB standard must include the full array of benefits within each category that is necessary to treat a condition; this means the standard of coverage should be based on necessary and appropriate care. Offering the full continuum of recommended treatment should be the goal of benefits packages, as opposed to limits based on fiscal concerns. Finally, out-of-pocket costs should not be used to create limitations for certain categories of services; for example, coverage of maternity services with very high out-of-pocket spending will essentially limit or foreclose access to these services for low-income consumers in the Exchanges.

Comments on Specific Coverage Limitation Techniques

Medical Necessity

Medical necessity should generally defer to the discretion of the treating physician and/or treatment team. The major advantage of this view of medical necessity is that it reduces the likelihood that determinations of insurance coverage for treatments will be cost-based or administratively burdensome. Assuming that managed care delivery systems will dominate the market; this approach makes all the more sense. That is because one of the primary responsibilities of the managed care organization is to contract with a highly qualified network of health care providers. Proper selection of networks sets the foundation for allowing deference to those network providers when health decisions are being made.

With this in mind, we suggest that:

- The decision of the treating provider should be given great weight and deference.
- When decisions are reviewed, the purpose of the review should be to determine:
 - Whether the treatment accords with professional standards of practice (these standards should be considered a baseline of professionally agreed-upon practices, generally based on large quantities of evidence from empirical studies (i.e. evidence based), but where such evidence is lacking due to the condition or unique nature of a patient's needs or illness, the standards should be based on a clinicians' experience in practice);
 - Whether it will be delivered in the safest and least intrusive manner;
 - Whether the treatment is medical in nature (meaning that the treatment is necessary as a result of an illness, condition, or disability); and
 - Whether there are equally effective treatments, services, and care that are actually available and accessible to the enrollee.

We also encourage an explicit understanding of medical necessity for children living at or below 400% FPL and children with special health care needs that is defined using the EPSDT standard, namely, whether the care and/or treatment are necessary to correct or ameliorate physical and mental illnesses.

Benefit/annual/lifetime limits

Limits on specific or total benefits should be minimal in the EHB package. Existing statutory restrictions on lifetime and annual benefit limits support the notion that fiscal or policy concerns should not impede a consumer's access to needed health services. These types of limits particularly harm individuals with disabilities and chronic illness, and will hamper the ACA's success in addressing poor treatment of chronic illness as a health care spending cost driver. Quality health care delivery requires that health care providers are able to provide information about all treatment options in accordance with the proper standards of care, based on the consumer's needs, and with the overall goal of maximizing wellness. We view the appropriate standard of medical care to be those practices that are medically necessary given the factors discussed above, with deference to the consumer's treating physician (and assuming informed consent and decision-making).

Other criteria and methods currently used by insurers to limit coverage

- *Quantitative limits* (e.g. no more than 5 physician visits per month)
- *Deeming a treatment experimental*: This practice can hinder access to accepted treatments that are rare
- *Improvement standard*
- *Cost-based criteria*: Cost-based benefits determinations often exclude necessary treatment services for consumers with rare or uncommon illnesses. While proper fiscal management is an important consideration for viability of health plans, solely cost-based benefits determinations inappropriately move the focus away from the promotion of health.

The major disadvantage of using these methods is that people with disabilities and chronic conditions can be left woefully underinsured.

9. Process Issues

Under the ACA, the Secretary of HHS must periodically review the essential health benefits and provide a publicly available report to Congress that includes an assessment: (1) whether enrollees are experiencing barriers to needed services, (2) whether services should be modified or updated to account for changes in medical evidence or scientific advancement, (3) addressing gaps in access, and (4) whether existing benefits need to be expanded or reduced and the impact on cost.²³

Our recommendations include the following:

Identifying barriers and gaps in access to care

²³ ACA § 1302(b)(4).

- Benefits packages should be regularly reviewed to ensure that certain populations or specific diseases or conditions are not adversely affected by the services or level of coverage offered in a particular plan and that covered benefits reflect the standard of care and current clinical approaches.
- The process for review of the EHB packages must be transparent, with mechanisms in place to allow for regular public review and comment. Once benefits packages are established, there should be ongoing mechanisms available to track access to health services and potential obstacles in accessing services due to coverage limitations or cost.
- Plans should be expected to report all denials of coverage and consumer complaints; HHS should have a system in place for monitoring these reports as well as the outcomes (appeals/overrides) to provide early warnings of what types of problems consumers are encountering.
- A system of regular surveys should be used with both quantitative rating and qualitative experience reporting to assist in determining whether enrollees are facing difficulty in accessing coverage due to cost, unlawful practices, or other barriers. These surveys should be standardized so they can be compared across plans.
- The Federal Employee Health Benefits program can be an instructive model in this context. This program conducts an annual survey of a random sample of plan members to assess satisfaction with plans. The indicators used include: overall plan satisfaction, getting needed care, speed of getting care, provider communication, customer service, claims processing, and plan information on costs. This information is publicly available to members so they can compare results across plans (generally surveys are only available for those plans with more than 500 subscribers).
- Current and innovative survey and reporting methods and designs should be utilized to ensure that information received is based on sound protocols and guidelines. Surveys must be tested with a variety of audiences, including low-income, LEP and vulnerable populations to ensure that comprehension and usability is maximized and the surveys are meaningful. All major stakeholders, including clinicians, administrators, and consumers should have an opportunity to provide feedback via the surveys.
- All information collected and reported should be made publicly available, with opportunities to provide comment, and no charge should be required to access this information.

Updating benefits package

- The Secretary of HHS should create a separate and independent advisory council to assist in reviewing and determining whether details of each benefits package meets the requirements specified in the ACA.
- There should be flexibility available to HHS and the advisory council to make recommendations as to how benefits packages can be modified to address identified gaps in access. Further, the council should have the authority to monitor changes and developments in medical evidence, and update the benefits package to reflect those changes in a timely manner.

Conclusion

In conclusion, we urge HHS to define the EHB package in a way that establishes a strong national floor for benefits. We believe this is consistent with promoting consumer health, and the legal requirements of the ACA. If you have any questions or need any further information, please contact Leonardo Cuello (202-289-7661) or Michelle Lilienfeld (310-736-1648), Staff Attorneys at the National Health Law Program.

Sincerely,

National Health Law Program (NHeLP)
Advantage Care Services
Advocacy Center (Louisiana)
AIDS Legal Council of Chicago
American Academy of Pediatrics
American Academy of Pediatrics, California
American Dental Education Association
American Medical Student Association
American Medical Women's Association
Asian & Pacific Islander American Health Forum
Asian Pacific American Legal Center, member of Asian American Center for Advancing Justice
Assistive Technology Law Center
Black Women for Wellness
California Black Women's Health Project
California Family Resource Association (CFRA)
California Latinas for Reproductive Justice
California Pan-Ethnic Health Network
California Partnership
California Primary Care Association
Center for Independence of the Disabled, NY
Center for Medicare Advocacy, Inc.
Center for Oral Health
Center for Women Policy Studies
Children Now
Children's Health Fund
The Children's Partnership
Children's Specialty Care Coalition
Commission on the Public's Health System
Community Health Councils
Community Legal Services, Inc.
Connecticut Legal Services, Inc.
Consumers for Affordable Health Care
Disability Rights California
Disability Rights Education and Defense Fund (DREDF)

Families USA
Feminist Women's Health Centers of California
Florida Legal Services, Inc.
Georgetown University Center for Children and Families
Greater Hartford Legal Aid, Inc.
Having Our Say
Health & Disability Advocates
Ibis Reproductive Health
Kentucky Equal Justice Center
L.A. Gay & Lesbian Center
Law Students for Reproductive Justice
Legal Services of Southern Piedmont
Maine Equal Justice Partners
Maryland Disability Law Center
Massachusetts Law Reform Institute, Inc.
Mental Health America
Michigan Consumers for Healthcare
National Center for Law and Economic Justice
National Center for Transgender Equality
National Council of Jewish Women
National Council of Jewish Women, California State Public Affairs
National Family Planning & Reproductive Health Association
National Latina Institute for Reproductive Health
National Nursing Centers Consortium
National Women's Health Network
New Haven Legal Assistance Association
New Mexico Center on Law and Poverty
New York Immigration Coalition
New Yorkers for Accessible Health Coverage
Northwest Health Law Advocates
Pennsylvania Health Access Network
Pennsylvania Health Law Project
PHI - Quality Care through Quality Jobs
Physicians for Reproductive Choice and Health
Pisgah Legal Services
Public Justice Center
Raising Women's Voices for the Health Care We Need
Religious Coalition for Reproductive Choice
Sargent Shriver National Center on Poverty Law
Southwest Women's Law Center
Summit Health Institute for Research and Education, Inc.
Virginia Poverty Law Center
Voices for America's Children
West Virginia Focus: Reproductive Education & Equality (WV FREE)

Women of Reform Judaism
Women's City Club of New York

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Deputy Administrator and Director
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