



**CONSORTIUM FOR CITIZENS
WITH DISABILITIES**

February 9, 2012

Steve Larsen
Director
Center for Consumer Information and Insurance Oversight
Centers for Medicare & Medicaid Services
U.S. Department of Health and Human Services

RE: Essential Health Benefits Bulletin

Dear Director Larsen:

The undersigned members of the Consortium for Citizens with Disabilities (CCD) appreciate the opportunity to comment on the Essential Health Benefits (EHB) bulletin released on December 16, 2011 and the supplementary material released on January 25, 2012.

CCD believes that the goal of health care reform should be to assure that all Americans, including people with disabilities and chronic conditions, have access to high quality, comprehensive, affordable health care that meets their individual needs and enables them to be healthy, functional, live as independently as possible, and participate in the community. For healthcare reform to work for individuals with disabilities, the Affordable Care Act's (ACA) mandated benefit categories and non-discrimination provisions must be the foundation of the essential health benefits package that all Americans in the individual and small group markets will depend upon starting in 2014.

CCD organizations were expecting the Department of Health and Human Services (HHS) to take the lead in defining in regulation the EHB package that states could implement with an appropriate degree of flexibility to account for state variation. Instead, HHS has proposed a "benchmark" process, patterned on the State Children's Health Insurance Program, that gives states tremendous flexibility to choose their EHB package with little federal oversight. The guidance requires states to augment the benchmark they select with coverage of the ten categories of benefits listed in the Affordable Care Act and also requires that states ensure their benchmark plan complies with the non-discrimination protections established in Section 1302(b) of the ACA. However, the guidance does not address the critical federal role in assessing whether the benchmark plans chosen by states comply with the ACA statute itself. The guidance offers no meaningful role for the federal government before significant federal dollars in the form of subsidies flow to the states through the health insurance exchanges.

CCD believes HHS must establish through binding regulation a primary role for the federal government in the oversight and enforcement, including evaluation, approval, ongoing monitoring, and updating, of the EHB package. Without such a federal role, CCD has serious concerns with the approach taken in the guidance. As currently written, the EHB guidance would lead to wide variation of EHB plans across the country, essentially nullifying the concept of a federal standard EHB package that every American could rely upon. Such variation would likely impact people with disabilities and chronic conditions disproportionately and result in EHB plans not meeting the needs of this population, contrary to the protections offered in the ACA statute itself. For this reason, CCD strongly supports HHS moving forward with enforceable, comprehensive regulations on the essential health benefits package that incorporate a strong federal role and meaningful implementation of the non-discrimination safeguards in Section 1302 as soon as practicable.

In addition, CCD believes that the EHB process moving forward must be based on transparency and consumer engagement. We applaud the release of supplemental data on January 25th by HHS, which provides a list of the largest small employer plans by enrollment. Due to the proprietary nature of plan benefit design, HHS was not able to release key information that the public needs to know in order to assess the adequacy of the process laid out in the EHB guidance. Health plans that have been identified in the supplemental HHS information should immediately make available plan details—including benefits covered, out-of-pocket limits and cost-sharing information on the Healthcare.gov website. In addition, stakeholders were only apprised of plan information on cost-sharing and actuarial value just days before the deadline for public comments on the EHB guidance. This is important information that impacts how effective the approach taken in the guidance will be. As such, HHS should accept public comment on the guidance well past the January 31st deadline in order to obtain meaningful input from consumers and other stakeholders.

It is vital that the EHB packages be adequate to cover people with disabilities in or entering the workforce, particularly in the small group market. Restrictive coverage definitions, impediments to early intervention, and arbitrary limitations on benefits unfairly restrict access to services and benefits that enable people with disabilities to remain in or enter the workforce and live independently. A benchmark benefit package that meets the needs of working people with disabilities will place less pressure on public programs such as Medicare and Medicaid, which under the current system, often serve as the insurer of last resort once a working person with a disability cannot continue to get access to the health benefits they need through their employer based plan.

The remainder of this letter offers a number of detailed recommendations from a disability perspective in response to the EHB bulletin.

Federal Oversight of the ACA EHB Package

As to federal oversight, it is clear that Congress intended for HHS to have a strong role in overseeing the definition, establishment and future changes of the essential health benefits package mandated through the ACA. (Public Law 111-148, Patient Protection and Affordable Care Act, Section 1302.) Toward that end, **it is critical that HHS establish an oversight**

process by which the federal government will approve each states' initial essential health benefits package as well as updates to those benefit packages as they are refined in the future. Without such federal oversight, the state-by-state process described in the bulletin will result in too much variation in the initial EHB packages, with some states providing inadequate coverage for people with disabilities and chronic conditions.

Without a process for government approval of initial EHB packages across the country—as well as updates to those packages on a periodic basis—private health plans would essentially be in control of the process of defining essential benefits. CCD believes that without federal oversight of the entire EHB process in each state (both the original and added covered benefits, as well as annual updates), there will be inconsistent and, in some cases, insufficient accountability on the issue of EHB compliance with the ACA's mandated benefit categories and non-discrimination protections. For instance, future regulations must establish that the HHS Secretary is responsible to ensure that each EHB benchmark plan:

- Reflects an appropriate balance among the categories described so that benefits are not unduly weighted toward any category;
- Does 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;
- Takes into account the health care needs of diverse segments of the population, including women, children, *persons with disabilities*, and other groups; and
- Ensures that health benefits established as essential are not subject to denial to individuals on the basis of the individuals' age or *expected length of life or of the individuals' present or predicted disability, degree of medical dependency, or quality of life.*

Coverage of the Ten ACA Benefit Categories

The guidance states that whatever benchmark plan is selected by the state, the package must be examined to ensure that the benefits in each of the ten categories are covered. If a plan does not cover each of these categories, it must add such benefits to the benchmark plan. However, the categories of benefits are so broad that there is great risk that coverage in the benchmark plans will be inadequate to meet the needs of plan enrollees. For instance, the guidance mentions that states will have to add “habilitation” benefits to their benchmark plans as most, if not all, private plans do not currently cover these benefits. This is fairly straightforward, but CCD believes that states should also be required to assess the adequacy of coverage in all benefit categories listed in the ACA to ensure that coverage is meaningful. For instance, just because a plan covers a certain number of visits of physical therapy does not mean it covers “rehabilitation services and devices”—an ACA mandated benefit category—such as occupational therapy, speech language pathology services, durable medical equipment, orthotic braces, prosthetic limbs, and rehabilitation services provided in a wide variety of inpatient and outpatient settings.

States should be required to conduct this analysis for all ACA-mandated benefit categories, assess the benchmark plan to ensure compliance with the non-discrimination provisions of ACA Section 1302(b), and seek approval from the HHS Secretary of that benchmark plan.

In addition, HHS should create and utilize an Advisory Board subject to the Federal Advisory Committee Act (FACA) as a regular and integral resource to provide input on initial federal approval of benchmark plans as well as updated benchmark plans in future years. Such a board would also help the HHS Secretary with benefit design considerations, obtain public feedback on benefit packages, and share information with all Americans, including people with disabilities and chronic conditions. The Board should include individuals with disabilities, family members, patients and caregivers, and providers. It should also include representatives of all disability groups – sensory, physical, mental and cognitive. The Advisory Board should have real ability to influence the decisions of the HHS Secretary on an ongoing basis.

The Secretary should establish a formal process to review, assess and approve initial and updated EHB plans in future years. EHB packages should be evaluated annually to identify patterns in order to encourage parity and compliance with the requirements listed in the ACA statute. **This process should be public, transparent, unbiased and should be established by formal regulation. It should allow for public comment and permit stakeholder input from patient and provider organizations and individuals.** Official comment periods should be offered for proposed changes to this process that allow for transparency and comment before implementation of any changes that would potentially reduce or limit access to established benefits. Finally, a clear, understandable and reasonable appeals mechanism should be established to ensure due process.

Substitution of Benefits

CCD recommends that HHS develop and enforce safeguards to ensure that allowing flexibility in the development of EHB plans does not undermine the nature of a consistent EHB package to which every American should have access. The Bulletin states that HHS is considering allowing substitutions both within and between EHB categories of care. However, the bulletin does not detail how substitution would work. Substitution at the individual patient level may be advantageous, for instance, in the case where a person needs a particular benefit that is not covered but, by substituting coverage for another benefit that may be covered but is more costly, the patient gets what they need at no greater expense to the health plan. If this is what is contemplated by the guidance, CCD recommends that HHS elaborate on this concept in a proposed rule and seek public comment.

If, however, the guidance would permit substitutions within and between benefit categories when the benchmark plan is being developed by the state, then CCD believes this form of substitution will undermine the non-discrimination standards set forth in the ACA and could result in inadequate coverage of one of the categories of care. HHS should reject the proposed approach of permitting states and insurers to substitute benefits within and between benchmark plan benefit categories, as such extensive plan flexibility could be used for risk selection purposes and is not consistent with the ACA. Health plans should not be permitted to adjust the benchmark plan benefits, except to add benefits or to possibly substitute benefits on an individual basis as described above.

HHS should specify what constitutes a plan that is “substantially equal” to a benchmark plan. The operational specifics of the definition of “substantially equal” will affect requirements seeking “appropriate balance among benefit categories” and the provision requiring non-discrimination based on age, disability, or expected length of life.

State Mandates

CCD commends HHS for providing a process for states to include their mandates in their EHB plans at federal expense, at least for an initial two-year period, and recommends that HHS offer more than one option for states to incorporate their mandates into their EHB package. Millions of Americans with disabilities and chronic conditions rely on existing state mandates to ensure access to quality health care, and failure to include state mandates in the EHB that protect these individuals could result in a net reduction of coverage that potentially jeopardizes their health and functional status. **CCD supports the federal subsidy to states to defray the cost of covering state mandates for a transitional two-year period.** Since State mandates are critical to protect vulnerable populations, CCD recommends the federal government consider extending this subsidy to states that select this option beyond the initial two-year period.

In addition, since states will be choosing a benchmark plan in advance of the coverage year, it should be clarified in regulation that the essential health benefits benchmark option must be updated to include new state mandates established after the benchmark option is chosen. For example, the bulletin proposes that states choose their benchmark plans in the third quarter of 2012. If between 2012 and 2014, a state passes a new mandate, then in 2014 that benchmark option must reflect the new mandate as consistent with current law.

Limitations, Medical Necessity, and Evidence Based Medicine

CCD believes that HHS should prohibit benchmark plans from using benefit-specific limitations (e.g., dollar or treatment frequency) and/or condition-based exclusions, as these can be used to discriminate against plan enrollees with disabilities and chronic conditions. These tactics can also subvert the intent of restrictions on lifetime and annual limitations. Different illnesses or injuries require different levels of medical intervention, treatment, or care, and arbitrary, unrealistic restrictions should be prohibited by the Secretary. If allowed, CCD recommends that any condition-based exclusion of benefits must be rigorously reviewed in order to determine whether the exclusion violates the requirements of the Americans with Disabilities Act of 1990, which prohibits disability-based distinctions in health insurance coverage. Such a finding by the Secretary should render these types of limitations null and void.

The focus of many benefits for people with disabilities is not to provide a cure or ultimately “fix” the condition—indeed such a “cure” is rarely an option—but rather to improve a patient’s quality of life by improving, maintaining or preventing deterioration of a patient’s capacity to function. **Medical necessity, therefore, should be coupled with a directive to apply it to a patient’s individual functional needs.** The term “medical necessity” must refer to what is medically necessary for a particular patient, and hence entails an individual assessment rather than a

general determination of what works in the ordinary case.” (See, Defining Medical Necessity, Janet L. Kaminski, Attorney <http://www.cga.ct.gov/2007/rpt/2007-r-0055.htm>)

CCD believes that evidence based medicine or comparative effectiveness research should be applied in a manner that does not lead to inappropriate restrictions in coverage of and access to therapies, treatments, medications, assistive devices and long term services and supports for people with disabilities and chronic illnesses. Many services and devices do not have a robust evidence base in the traditional sense, especially with respect to treatments for children, but allow persons with disabilities to be functional and live independent and fulfilling lives. A *lack* of medical evidence does not prove the service or device ineffective or unnecessary.

Rehabilitative and Habilitative Services and Devices

CCD recommends that HHS define in regulations the term “rehabilitation and habilitation services and devices” in the EHB package to explicitly include services that *maintain* as well as *improve* function, consistent with the definitions adopted by the National Association of Insurance Commissioners (NAIC) as well as those adopted by HHS in the proposed rule on the definition of medical and insurance terms for purposes of comparing health plans in the state exchanges. (See, 76 Fed. Reg. 52,442; 76 Fed. Reg. 52,475)

The definition of *habilitation* reads:

“Health care services that help a person keep, *learn* or improve skills and functioning for daily living. Examples include therapy for a child who isn’t walking or talking at the expected age. These services may include physical and occupational therapy, speech-language pathology and other services for people with disabilities in a variety of inpatient and/or outpatient settings.” (See, NAIC Glossary of Terms for the Affordable Care Act.) [Emphasis added.]

The definition of *rehabilitation* reads:

“Health care services that help a person keep, *get back* or improve skills and functioning for daily living that have been lost or impaired because a person was sick, hurt or disabled. These services may include physical and occupational therapy, speech-language pathology and psychiatric rehabilitation services in a variety of inpatient and/or outpatient settings.” (See, NAIC Glossary of Terms for the Affordable Care Act.) [Emphasis added.]

The concept of “keeping” or “maintaining” function is a critical one for people with disabilities and chronic conditions—particularly conditions whose severity progresses over time—and is often cited by health plans to deny services that are medically necessary and appropriate.

A review of the FEHB benefit design information released on January 25th suggests that these plans do, in fact, cover a fairly wide range of rehabilitative services and devices. This includes physical, occupational and speech therapies in a variety of settings, cognitive and psychiatric rehabilitation, durable medical equipment, prosthetic limbs, orthopedic braces, supplies, and in

some instances, vision and hearing aids as well as other rehabilitation items and services. The bulletin itself lists many of these services and devices as regularly covered. (See, Essential Health Benefits Bulletin page 4)

However, there are often arbitrary limitations and exclusions built into these and other private plans in this benefit category. The HHS Secretary must be responsible for assessing benchmark plans to ensure appropriate coverage of a full spectrum of rehabilitation and habilitation services and devices before federal subsidies start flowing to states.

As to the definition of “habilitative services and devices,” the guidance seeks public comment on two approaches to the process where states will add habilitation benefits to a selected benchmark plan. CCD recommends that states design their benchmark plans to cover habilitation services and devices in parity with rehabilitation services and devices. States should look to the definition of “habilitation” offered by the NAIC and augment this definition with consideration of habilitation services and devices provided under the Medicaid program which has significant experience with habilitation benefits. The reason for the functional deficit in a child or adult should not affect the services covered to maintain or improve functional status associated with that functional deficit.

Mental Health/Substance Abuse/Behavioral Health

CCD applauds HHS for reinforcing the Affordable Care Act's extension of the Paul Wellstone and Pete Domenici Mental Health Parity and Addictions Equity Act (MHPAEA) to the individual and small group market. **The Bulletin indicates that HHS intends parity to apply in the EHB context to coverage under the mental health, substance use disorder and behavioral health coverage category, and we strongly support this principle.** However, further guidance and regulation are particularly important because the Bulletin fails to comment on how medical necessity will be determined to limit coverage. **HHS should require plans to use medical criteria to make benefit determinations and disclose to consumers those medical criteria.**

The fact that the ACA specifically identifies as a mandated benefit the category of behavioral health services is a major advance in health coverage for people with disabilities such as autism, brain injury and other conditions. If benchmark plans do not currently cover behavioral health services, HHS should require it.

There is clear evidence that Congress intended "behavioral health" to include a variety of behavior analytic strategies, such as applied behavior analysis, that have demonstrated to be effective in teaching language, social, and behavior skills to individuals on the autism spectrum, individuals living with a brain injury or individuals with other disabilities. Behavioral health interventions will lead to more productive quality lives and may prevent the need for more restrictive and costly services. It is therefore essential that HHS include a definition of "behavioral health" that includes these critical components to address autism, other developmental disabilities and brain injury that results in behavior or mental health changes.

Chronic Disease Management, Prevention and Wellness for People with Disabilities

CCD also applauds the inclusion of chronic disease management, along with prevention and wellness, in the ten essential benefit categories of care. These services are critical to individuals living with disabilities – a population that experiences chronic illnesses at higher rates than the population at large. According to the Centers for Disease Control and Prevention (CDC), chronic diseases are “non-communicable illnesses that are prolonged in duration, do not resolve spontaneously, and are rarely cured completely.” Examples of chronic diseases include multiple sclerosis, epilepsy, brain injury, end stage renal disease, Alzheimer’s, Parkinson’s, arthritis and AIDS.

CCD believes that HHS should require chronic disease management to be person-centered and involve interdisciplinary care coordination. Individuals with chronic conditions should be treated in the least restrictive setting, including home and community based settings, and have access to coordinated primary and specialty care benefits. For many individuals with long term disabilities, the specialists become the focal point for that individual’s medical care, particularly when treatment is provided over a lifetime. Chronic disease management services should include education and training for patient self care, interdisciplinary medical team conferences and certain telephone or other remote services.

According to CDC, three-quarters of all of healthcare expenditures are for the treatment of chronic diseases. For example, people with SMI have higher rates of cardiovascular disease, diabetes, respiratory disease and infectious disease. (See: Parks, Svendsen, and Foti, editors. Morbidity and Mortality in People with Serious Mental Illness. Alexandria, VA: NASMHPD, 2006; Colton and Manderscheid, Preventing Chronic Disease. Atlanta, GA: CDC, 2006 - www.cdc.gov/pcd/issues/2006 ; and SAMHSA 10 x 10 Wellness Campaign - www.samhsa.gov)

To ensure healthcare costs are contained and individuals can live independent lives with chronic conditions, **HHS should require early intervention and appropriate care as necessary.** By treating chronic conditions early and appropriately, patients can prevent developing secondary conditions that require further medical treatment and added costs. For example, brain injury patients require intensive treatment over an extended period of time to regain and maintain function. Early intervention can shorten the treatment time, improve outcomes and prevent correlated conditions in the long term, thereby significantly decreasing long term health care costs. There are many other similar examples of chronic conditions and disabilities.

CCD believes that HHS should include comprehensive pain care as a critical aspect of treatment for chronic conditions. For individuals living with chronic conditions, the goal is to achieve as much pain relief as possible to permit the individual to function in their daily life —at work, at school, and in the family. Mental and behavioral health services are an integral part of comprehensive, interdisciplinary pain care for many patients with the most complex chronic pain conditions.

Prevention and wellness services are also critical for people with disabilities, many of whom have poorer overall health, have less access to effective health care, and have higher rates of smoking and physical inactivity than their non-disabled peers. [See: CDC, Disability and Health

Data and Statistics webpage - www.cdc.gov; CDC, Health Care Access and People with Disabilities webpage - www.cdc.gov; Armour, Campbell, Crews, Malarcher, Maurice, and Richard. "State Level Prevalance of Cigarette Smoking and Treatment Advice, By Disability Status. 2004 Prevention Chronic Disease (4) (4); CDC, Physical Activity Among Adults with a Disability, in MMWR Weekly (56) (39) 1021-1024; and AAHD, Health Promotion and Wellness for People with Disabilities: Fact Sheet. Rockville, MD: AAHD, April 2011 – www.aahd.us]

A growing number of children have chronic conditions that affect their development and require specialized attention in order to generate, maintain, and restore age-appropriate functioning. In addition, 20% of children with special health care needs are obese, compared to 15% of children without special health care needs. Obesity rates for adults with disabilities are 58% higher than adults without disabilities. Obesity increases the risk of heart disease, diabetes, cancers, and stroke. [See: Child and Adolescent Health Measurement Initiative. National Survey of Children's Health, 2007; CDC, Behavioral Risk Factor Surveillance System Survey (BRFSSS) data, 2008; and AAHD, Health Promotion and Wellness for People with Disabilities: Fact Sheet. Rockville, MD: AAHD, April 2011 – www.aahd.us]

Pediatric Care Including Oral and Vision Benefits

CCD strongly recommends that HHS clarify in regulations that the ACA mandates coverage of more than just pediatric oral and vision care. In contrast to the language in the Bulletin, the ACA requires the Secretary to set forth a category of services described as “pediatric services, *including* oral and vision care” (Public Law 111-148, Patient Protection and Affordable Care Act, Section 1302(b)(1)(J)) [emphasis added]. However, the Bulletin refers to this category of essential health benefits as solely oral and vision benefits and does not describe guidance for other pediatric benefits. Pediatric services that should be available to children under the benefit category of the EHB should include other medically necessary services that are often excluded in a private plan’s standard option, such as medically necessary developmental assessments, medically necessary physical, occupational, speech, and related therapies including maintenance therapy (without “recovery” requirements). **To help ensure adequate health insurance coverage for children, HHS should require States to reference Medicaid benefits when they establish and augment the EHB plans.** Private plans routinely exclude the types of treatments needed by children with long-term developmental disabilities.

Prescription Drug Benefits

CCD recommends that HHS require a Standard of two drugs per Therapeutic Class and adopt the Part D Patient Protection Clause. In the “Benefit Design Flexibility” section of the Bulletin, HHS proposes a standard for prescription drug benefits based on the Medicare Part D program. However, HHS is proposing a standard of only a single drug per therapeutic class – a dramatically lower standard that could result in 50% fewer covered drugs on plan formularies relative to Part D. The HHS Bulletin also states that the EHB will not integrate a key patient protection that currently exists in Part D for plan formularies – the requirement for plans to include on their formularies “all or substantially all” of the drugs in 6 specific therapeutic classes. This rule in Part D is a critical protection for various disability populations including individuals with HIV-AIDS, epilepsy, transplant patients and people with mental illness.

Thank you for considering our positions on this important set of issues. Please contact Peter Thomas or Theresa Morgan with any questions at 202-466-6550.

Sincerely,

ACCSES

American Academy of Pediatrics

American Academy of Physical Medicine and Rehabilitation

American Association of People with Disabilities

American Association on Health and Disability

American Medical Rehabilitation Providers Association

American Occupational Therapy Association

American Speech-Language-Hearing Association

Association of University Centers on Disabilities

Brain Injury Association of America

Bazelon Center for Mental Health Law

Dialysis Patient Citizens

Disability Rights Education and Defense Fund

Easter Seals

Epilepsy Foundation of America

Family Voices

Health & Disability Advocates

Mental Health America

National Alliance on Mental Illness

National Association of Councils on Developmental Disabilities

National Association of County Behavioral Health & Developmental Disability Directors

National Disability Rights Network

National Multiple Sclerosis Society

Paralyzed Veterans of America

Rehabilitation Engineering and Assistive Technology Society of North America

School Social Work Association of America

The Arc of the United States

United Cerebral Palsy

United Spinal Association