February 17, 2012

Steve Larsen, Director
Center for Consumer Information and Insurance Oversight
Centers for Medicare and Medicaid Services
U.S. Department of Health and Human Services
200 Independence Avenue, SW
Washington, DC 20201

Re: Comments on the Essential Health Benefits Bulletin Issued by CCIIO

Dear Director Larsen:

The Habilitation Benefits Coalition (HAB Coalition) appreciates the opportunity to comment on the Essential Health Benefits (EHB) Bulletin released on December 16, 2011 and the supplementary plan listing released in January. The HAB Coalition believes the federal government must have a strong leading role in the establishment and enforcement of the essential health benefits package and we strongly support HHS implementing the EHB through binding federal regulations. The HAB Coalition is a group of national nonprofit consumer and provider organizations focused on securing appropriate access to, and coverage of, habilitation benefits within the category known as "rehabilitative and habilitative services and devices" in the EHB package under the Patient Protection and Affordable Care Act (ACA), Section 1302.

Definition of Habilitation

Although the HHS Bulletin does not define habilitative services, we recommend that HHS incorporate in regulations the habilitation definition developed by the National Association of Insurance Commissioners (NAIC), and proposed by HHS in regulations defining medical and insurance terminology.[1] This definition should be augmented by the habilitative services and devices covered by Medicaid, which has consistently covered habilitation in a number of states and has years of experience administering a comprehensive habilitation benefit:

> NAIC: "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

[1] See, 76 Fed. Reg. 52,442; 76 Fed. Reg. 52,475

outpatient settings." See, NAIC Glossary of Terms for the Affordable Care Act.[2] [Emphasis added.]

Medicaid: "Services designed to assist individuals in acquiring, retaining and improving the self-help, socialization, and adaptive skills necessary to reside successfully in home and community based settings."[3] [Emphasis added.]

The HAB Coalition agrees with the EHB Bulletin where HHS explains that private health plans have limited experience with habilitation benefits. It is for this reason that a national definition of habilitation services and devices in federal regulations is so important. Such a definition would serve as a model for states to incorporate into their benchmark EHB plans. It is also important to note that the ACA statute specifically mandates coverage of both habilitative services *and devices* and, we believe, final regulatory guidance should make this clear. For instance, under the habilitation benefit category mandated in the ACA, we believe that private plans must cover an amount, duration, and scope of appropriate therapies as well as orthotic braces, prosthetic limbs, mobility devices, hearing and vision aids, and other devices that assist an individual to attain skills and functions not otherwise acquired since birth.

Maintenance of Function

The definition of habilitation should include *maintenance* of function, as included in the NAIC and Medicaid definitions, in addition to *attainment* and *improvement* of skills and functions. The fact that private health plans have limited experience in covering services that *maintain* function, as the EHB Bulletin discusses, is not a valid reason to restrict coverage of these services when the physician and the provider team deem these services reasonable and necessary. The outcomes of habilitative services tend to be cumulative. Habilitative services and devices can assist a person in achieving a new plateau of skills and functions that can form the basis for the accomplishment of a whole new set of functions once certain skills are attained and maintained over time. In the long term, the achievement of functional milestones through habilitation can lead to far greater function in later life, reducing potentially significant long-term health care costs for people with certain medical conditions. The HAB coalition does not endorse or interpret maintenance to imply a continuation of therapy for an unspecified duration of time, but rather the establishment of a safe and effective functional maintenance program that would prevent deterioration of a gained skill, in connection with a specific disease state.

HHS should also provide guidance on maintenance programs as they relate to progressive degenerative diseases. Under these circumstances, therapeutic service may be intermittently necessary to determine the need for assistive equipment and/or establish a program to maximize function.[4] Were the function to deteriorate, additional skilled treatment would again be necessary, and additional assistance may be required by the individual.

[2] NAIC Glossary of Terms for the Affordable Care Act. http://www.naic.org/documents/index_health_reform_glossary.pdf
[3] Social Security Act, Section 1915(c)(5)(A)
[4] NHIC, Corp. REF-EDO-0555. Version 1.0 07/06/2010.

HHS Must Define Habilitation Services and Devices as "Essential"

Congress intended the Affordable Care Act to incorporate habilitation coverage into the essential health benefits package issued in every state.[5] In addition to the legislative history, the ACA statute itself lists habilitation as an essential benefit as part of the category of "rehabilitative and habilitative services and devices." [Section 1302(b)(1)(G).] In addition, there are numerous legal protections in the ACA that are designated to ensure fairness and equity in the benefit design of the EHB package. These provisions include the prohibition against discrimination based on health status or disability [Section 1201 of the ACA], as well as the general nondiscrimination section of the law found at Section 1557 of the ACA. Given these legal parameters and the explicit statutory mandate to cover habilitative services and devices, an EHB regulation that does not appropriately designate habilitative services and devices through a federal standard that states can adopt in their benchmark packages would likely be in conflict with the letter and spirit of the ACA law.

We applaud HHS for statements in the Bulletin that instruct states to augment their benchmark plans with benefit categories listed in Section 1302 of the ACA, which includes rehabilitative and habilitative services and devices. We strongly support HHS's references in the EHB Bulletin to both the NAIC definition of habilitation and the definition found in the Medicaid statute. Using these definitions as States determine the amount, duration and scope of their habilitative services and devices benefit will help ensure a consistent national standard for coverage that allows for some degree of flexibility in terms of the mix of therapies, devices, and settings of care that are covered.

HHS Should Mandate That Plans Cover Habilitation at "Parity" with Rehabilitation

Although the typical employer plan may not include coverage of habilitation, both the Institute of Medicine in its recommendations and the EHB Bulletin recognize that essential benefits packages must be enhanced to include the list of mandated benefits in the ACA, including habilitation. While many insurance companies may not recognize habilitative services for health coverage, the same therapies, treatments, and devices are often covered under the *rehabilitation* benefit for people who have sustained an illness or injury.

The Bulletin seeks public comment on two options for states to determine their habilitation benefit. Under the first option, habilitative services would be offered at "parity" with rehabilitative services. In other words, a plan covering certain therapies for rehabilitation must cover those therapies for habilitation purposes at equal amount, duration and scope.[6] The second option is described as a transitional approach, where plans would decide which habilitation services to cover and would report on that coverage to HHS. HHS would then evaluate those decisions and further define habilitative services in the future.

The HAB Coalition strongly favors the first option, where habilitation services are covered at parity with rehabilitative services. The services and devices used in habilitation are often the same or similar as in rehabilitation, as are the professionals who provide these services, the

[5] Congressional Record, H1882 (March 21, 2010).
[6] See, p. 11 of the EHB Bulletin

settings in which the services and devices are provided, the individuals receiving the services, the functional deficits being addressed, and the improvement in functional outcomes that result from treatment. The only meaningful difference is the reason for the need for the service; whether a person needs to attain a function from the outset or regain a function lost to illness or injury. Habilitation services should be covered whenever rehabilitation services would be covered; when services and devices are necessary to address a functional deficit regardless of the date of onset of the condition that caused that functional deficit.

However, parity should not be interpreted to mean that the habilitation should be held to a coverage standard of "regaining" function that is sometimes applied to rehabilitation services. Habilitation services and devices are designed for people that have never attained certain skills and functions in the first place. In fact, the NAIC recognized this by separately defining "habilitation" and "rehabilitation" in the following manner:

- Habilitation: "Health care services that help a person keep, *learn* or improve skills and functioning for daily living;" (emphasis added) and

- Rehabilitation: "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." (emphasis added).

The definitions include the concepts of attaining (habilitation) or restoring (rehabilitation) function, as well as maintaining and improving function. HHS should adopt in the EHB regulations these definitions so that "parity" will lead to coverage of habilitation for individuals that need to attain, maintain or improve function, in line with coverage of rehabilitation for individuals that need to regain, maintain or improve function.

Cost Effectiveness of Habilitation Services and Devices

Current data demonstrate the low cost impact on premiums of including habilitative services in the EHB package. For example, the Council for Affordable Health Insurance estimates that habilitative service mandates cost <1% of the total premium costs in the states with habilitation mandates. [7] The State of Maryland found that expanding its habilitation mandate to individuals with congenital or genetic birth defects regardless of age would increase state plan expenditures by only 2%.[8] Additionally, five private insurance companies reported to the State of Virginia that coverage of habilitation services would only result in an increase in the total premium cost between 0.2 and 1%.[9] Research findings also indicate that long-term healthcare costs of individuals with congenital and genetic disorders and developmental disabilities can be curtailed through intensive and comprehensive habilitation treatment early in life.[10,11]

[7] Council for Affordable Healthcare Service. Health Insurance Mandates in the States 2009. http://wwww.cahi.org/cahi_contents/resources/pdf/HealthInsuranceMandates2009.pdf

[8] *Annual Mandated Health Insurance Services Evaluation.* Maryland Healthcare Commission. Published December 20, 2007. http://mhcc.maryland.gov/health_insurance/habilitative15_1501.pdf

[9] http://jlarc.state.va.us/meetings/MHIB/HabilBrf.pdf

[10] Montana Department of Public Health & Human Services – Developmental Disabilities Program. http://www.dphhs.mt.gov/dsd/ddp/autism.shtml. Updated January 21, 2011. Accessed November 21, 2011

Medical Necessity and Habilitation Benefits

The HAB Coalition urges HHS to establish federal criteria for using medical necessity definitions to make habilitation benefit coverage and limitation decisions. A congressional floor statement regarding the ACA calls attention to the importance of having an interpretation of medical necessity that is applicable to the category of rehabilitative and habilitative services and devices, including "items and services used to restore functional capacity, minimize limitations on physical and cognitive functions, and maintain or prevent deterioration of functioning." [Congressional Floor Statement of Congressman Pascrell on November 7, 2009, H12896]

Decisions about the medical necessity of habilitation should defer to the practitioner actually treating the patient and should only be overridden if there is evidence that such deference is not appropriate for the individual patient. In its report to HHS, the IOM states that medical necessity determinations should be used to ensure that each individual patient receives appropriate care. According to this report, medical necessity determinations are particularly important when every service cannot be categorized as an "inclusion" and "exclusion" service and patients can qualify for coverage of non-listed services by medical necessity review. [Page 5-23 of IOM Report.] In addition, the IOM Committee noted as a major issue that safeguards in the application of medical necessity may be needed, "particularly for special populations (e.g., children; individuals with disabilities, mental illness, or rare diseases) both in the definition of what medical necessity means and in monitoring its implementation."

In its conclusion, the IOM Committee also references the Stanford definition of medical necessity which states it is "a health intervention for the purpose of treating a medical condition (i.e., to *treat* meaning to prevent, diagnose, detect, treat, or palliate) or to *maintain or restore functional* ability." Suggested criteria for medical necessity are also provided by the Joseph P. Kennedy, Jr. Foundation's "Defining Medical Necessity – Strategies for Promoting Access to Quality Care"[12] and include the following:

- A covered service or item is medically necessary if it will do, or is reasonably expected to do, one or more of the following:
    - Reduce, correct, or ameliorate the physical, mental, developmental, or behavioral effects of an illness, condition, injury, or disability;
    - Assist the individual to achieve or maintain sufficient functional capacity to perform age-appropriate or developmentally appropriate daily activities.
- The determination of medical necessity must be made on an individual basis and must consider:
    - The functional capacity of the person and those capacities that are appropriate for persons of the same age or developmental level;
    - Available research findings, health care practice guidelines, and standards issued by professionally recognized organizations or government agencies.

[11] Francis, et. al. Arch Otolaryngol Head Neck Surg. 1999;125:499-505
[12] http://www.jhsph.edu/bin/o/g/cshcn-MedicalNecessity.pdf

- Final determinations must be made by a physician in concert with the following persons: the individual's primary care physician; a consultant with experience appropriate to the individual's age, disability, or chronic condition; and the individual and/or family.
- Medically necessary services must be delivered in a setting that is appropriate to the specific health needs of the individual.

Limitations on benefits of any kind should be based on the best available evidence and such decisions should be made by professionals with sufficient knowledge and expertise in the rehabilitative and habilitative field to render informed decisions. Evidence-based medicine or comparative effectiveness research is, and should continue to be, an important tool in helping patients and providers distinguish between the effectiveness of treatment options, but should be applied in a manner that does not lead to inappropriate restrictions in coverage of or access to habilitative services and devices.

HSS Should Establish a National Benefits Advisory Council

The HAB Coalition recommends that HHS develop an advisory board in order to assist the HHS Secretary in assessing, recommending approval or rejection, monitoring the EHB, and measuring how the packages are meeting the requirements of the ACA based on the best available evidence. HHS should create and utilize this Advisory Board subject to the Federal Advisory Committee Act (FACA) as a regular and integral resource to assist the Secretary in updating the EHB package. This advisory board could also provide input into design considerations, obtain feedback on benefit packages, and share information with all Americans, including people with disabilities.

The advisory board should include representatives from the disability community, members of state organizations, non-profit organizations, advocates, providers, and other important stakeholders. Additionally, as suggested in the IOM report, the HHS should use "the results of a periodic national public deliberative process to inform its recommendations around updates to the EHB."

We greatly appreciate your attention to our concerns and your interest in our participation in this process. Should you have further questions regarding this information, please contact Peter Thomas or Theresa Morgan, Habilitation Benefits Coalition staff, at 202-466-6550.

Sincerely,
(Organizations listed on next page)

ACCSES
American Academy of Pediatrics
American Association on Health and Disability
American Music Therapy Association
American Network of Community Options and Resources
American Occupational Therapy Association
American-Speech-Language-Hearing Association
American Therapeutic Recreation Association
Association of University Centers on Disabilities
Autism Speaks
Children's Hospital Association
Easter Seals
Family Voices
Hearing Loss Association of America
March of Dimes
The Arc of the United States