November 27, 2017

VIA ELECTRONIC SUBMISSION

Seema Verma
Administrator
Centers for Medicare and Medicaid Services
U.S. Department of Health and Human Services
Attention: CMS-9930-P
Mail Stop C4-26-05
7500 Security Boulevard
Baltimore, MD 21244-1850

RE: Public Comments on HHS Notice of Benefit and Payment Parameters for 2019 (RIN 0938-AT12)

Dear Administrator Verma:

The undersigned members of the Habilitation Benefits (HAB) Coalition appreciate the opportunity to comment on the proposed rule *HHS Notice of Benefit and Payment Parameters for 2019*[1] (the Proposed Rule).

The HAB Coalition is a group of national nonprofit consumer and clinical organizations focused on securing and maintaining 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.

The Proposed Rule sets forth benefit and payment parameters, provisions related to essential health benefits, qualified health plans, risk adjustment, and the operation of Federally-facilitated and State-based exchanges, as well as many other policies implementing the ACA. This comment letter will focus on key proposed provisions that relate to enrollees in need of habilitative services and devices, specifically rules related to essential health benefits (EHBs).

I. The Importance of Habilitative Services and Devices

Habilitative services and devices are necessary for individuals with many types of developmental, cognitive, physical and mental conditions that, in the absence of such services,

[1] Patient Protection and Affordable Care Act; HHS Notice of Benefit and Payment Parameters for 2019, 82 Fed. Reg. 51,052 (Nov. 2, 2017). Available at: https://www.gpo.gov/fdsys/pkg/FR-2017-11-02/pdf/2017-23599.pdf.

prevent individuals from acquiring certain skills and functions over the course of their lives, particularly in childhood. Habilitative services are closely related to rehabilitative services although there are key differences between the two. Whereas *rehabilitative services* are provided to help a person regain, maintain, or prevent deterioration of a skill that has been acquired but then lost or impaired due to illness, injury, or disabling condition, *habilitative services* are provided in order for a person to attain, maintain, or prevent deterioration of a skill or function *never learned or acquired* due to a disabling condition.

The only meaningful difference between habilitation and rehabilitation 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.

The types of habilitative services and devices include, but are not limited to, behavioral health services, recreational therapy, developmental pediatrics, psychiatric services, and psycho-social services provided in a variety of inpatient and/or outpatient settings. Habilitative and rehabilitative services:

- Improve long-term function and health status and improve the likelihood of independent living and quality of life;
- Halt or slow the progression of primary and secondary disabilities by maintaining function and preventing further deterioration of function;
- Enable persons with developmental, intellectual, physical or cognitive impairments to improve cognition and functioning through appropriate therapies and assistive devices;
- Speed recovery by achieving better outcomes and enhancing the likelihood of discharge from the hospital to one's home, increase lifespan, and help individuals attain a higher level of function post injury or illness; and
- Reduce the likelihood of relapse and readmission to the hospital, while facilitating return to work in appropriate circumstances.

The following vignettes demonstrate just a few examples of real-life instances where access to habilitation services and devices has maximized the health, function, and independence of those who have been able to access these services:

- *Cleft Palate.* Jessica is a 2-year-old child with a bilateral cleft palate that was surgically repaired at 11 months of age. She presented with speech sound production errors and excessive nasality that impaired her ability to communicate. Jessica's care is coordinated by a cleft palate/craniofacial team that includes a plastic surgeon, an orthodontist, a speech-language pathologist (SLP), a pediatrician, and additional providers. With appropriate speech language treatment, Jessica will learn techniques to improve her speech intelligibility, allowing her to communicate with others at an age-appropriate level. Professional collaboration with the craniofacial team and a coordinated care plan ensure that Jessica achieves maximum functional communication.

- *Muscular Dystrophy.* Adam is a 14-year-old boy with Duchenne Muscular Dystrophy. He has recently experienced a significant decrease in his trunk and arm strength. After conducting an occupational profile and evaluating Adam's current performance skills, the

occupational therapist adapted Adam's computer keyboard in order for him to continue to be able to use the computer and keyboard for schoolwork and entertainment. She teaches Adam compensatory strategies and modifies his silverware so that he may continue to feed himself without assistance, and teaches him and his family strategies for dressing with minimal assistance from his caregivers. The occupational therapist also teaches Adam stretches for his shoulders and upper arms to help maintain flexibility and prevent the development of muscle contractures. Finally, she teaches Adam new strategies for relieving pressure on his buttocks in his wheelchair, as he can no longer perform wheelchair pushups. She works with Adam to build these techniques into his daily routine so he does not forget, since forgetting could result in the development of additional pressure sores.

- *Cochlear Implants.* Raul was diagnosed with congenital hearing loss as a young child, but did not have access to hearing aids until age ten. He attended a school for the deaf and hard of hearing, and his primary language is American Sign Language. As an adult, Raul decided to undergo cochlear implant surgery and learn spoken language. He works with an audiologist and SLP on open-set speech recognition with amplification. The prognosis from the interdisciplinary cochlear implant team—based on Raul's motivation, progress in therapy, and use of lip-reading and technology—is fair for receptive language abilities. His cochlear implant and related new skills will assist him with communication in the workplace and community.

- *Down Syndrome*. Jill is a 5-month-old girl with Down syndrome (DS). Jill's parents were aware of the diagnosis before her birth, and they have always sought optimal care for her. Jill has had difficulty drinking from a bottle, and her physical therapist has worked with other health professionals to assist the parents with the feeding program best suited for her. The pediatric physical therapist has helped her family learn how to teach Jill to hold her head upright when she is supported when sitting, and how to teach Jill to roll over from her stomach to her back and from her back to her stomach. As Jill continues to develop during her early years of life, the physical therapist will encourage progression of motor activities such as crawling, walking, climbing stairs, and running. An orthotics (orthotic braces for the foot and ankle) assessment will be completed once Jill begins to initiate weight-bearing activities at 7-9 months. Infants with DS are at high risk for delayed standing due to low muscle tone and joint instability, which may result in foot deformity and lifelong mobility impairments. Therefore, an orthotics assessment will be particularly beneficial in her first year of life, to prevent future complications.

There is a compelling case for coverage of habilitative services and devices for persons in need of functional improvement due to disabling conditions. These services and devices are designed to maximize the functional capacity of the individual, which has profound implications on the ability to perform activities of daily living in the most independent manner possible. Habilitative services and devices are highly cost-effective and decrease downstream costs to the health care system for unnecessary disability and dependency.

II. Background on Habilitative Services and Devices under the ACA

Prior to the ACA, most health plans did not cover habilitative services and devices and only three States (Illinois, Maryland, and Oregon) had adopted a habilitative services mandate in the individual market. Not only did this dramatically impact access to and quality of care for children and adults in need of these services and devices, but a lack of coverage also contributed to significant downstream costs to the health care system for unnecessary disability and dependency. Therefore, coverage gains for habilitation services and devices were hard fought but necessary to meet the needs of a wide variety of children and adults with autism, cerebral palsy, congenital deficits, disabilities, and other chronic and progressive conditions.

The category of "rehabilitative and habilitative services and devices" was included in the ACA as an essential health benefit, one of ten essential categories of benefits that must be covered by ACA health plans. It is noteworthy that Congress chose to include a separate EHB category for rehabilitative and habilitative services and devices to specifically list in the statute in recognition of the important role the benefit plays in helping ensure that adults and children maximize their health, function, and become productive members of society.
In the February 2015 Notice of Benefit and Payment Parameters Final Rule,[2] the Centers for Medicare and Medicaid Services (CMS) defined "habilitation services and devices" as follows:

> "Habilitation services and devices—Cover health care services and devices that help a person keep, learn, or improve skills and functioning for daily living. Examples include therapy for a child who is not 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."

The inclusion in the ACA of the category of rehabilitative and habilitative services and devices was a major milestone for the disability community in that Congress recognized the importance of these benefits to improve the health and functioning of the American people. The federal coverage standard for habilitation benefits has been responsible for a dramatic increase in access to these important benefits for patients across the country.

III. EHB Benchmark Plan Design under the Proposed Rule

We appreciate CMS' intent in proposing measures that it believes will increase affordability of plan options and make private health insurance more accessible. However, the HAB Coalition has some specific concerns that are outlined below. These concerns involve the proposals to grant states additional flexibility and discretion in redesigning their EHB benchmark plans, as well as CMS's proposed change in the definition of a "typical employer plan." The HAB Coalition is concerned that granting States this additional flexibility may undercut the requirement that states provide benefits for diverse segments of the population, including persons with disabilities, as well as other ACA statutory requirements involving nondiscrimination in plan design. While the HAB Coalition shares CMS's goal of reducing the costs of health care,

[2] Patient Protection and Affordable Care Act; HHS Notice of Benefit and Payment Parameters for 2016, 80 Fed. Reg. 10,750, 10,871 (Feb. 27, 2015).

we emphasize that reducing coverage of habilitation services and devices in the short term may, in fact, produce long term health care cost increases.

In the Proposed Rule, CMS states that, starting in plan year 2019, States would be permitted to change their EHB benchmark plan annually by:

1. Selecting the EHB-benchmark plan that another State used for the 2017 plan year under § 156.100 and § 156.110;
2. Replacing one or more EHB categories of benefits under § 156.110(a) in its EHB benchmark plan used for the 2017 plan year with the same categories of benefits from another State's EHB-benchmark plan used for the 2017 plan year under § 156.100 and § 156.110; or
3. Otherwise selecting a set of benefits that would become the State's EHB benchmark plan, provided that the EHB benchmark plan does not exceed the generosity of the most generous of among a set of comparison plans.

CMS further states that, under this proposal, a state's EHB benchmark plan must be equal in scope of benefits to what is provided under a "typical employer plan." This requirement reflects the statutory requirement in the ACA that the scope of EHBs must be equal to the scope of benefits provided under a typical employer plan. CMS proposes to redefine a "typical employer plan" as "an employer plan within a product (as these terms are defined in § 144.103 of this subchapter) with substantial enrollment in the product of at least 5,000 enrollees sold in the small group or large group market, in one or more States, or a self-insured group health plan with substantial enrollment of at least 5,000 enrollees in one or more States."

Specific Concerns Regarding Each EHB Benchmark Plan Design Option in the Proposed Rule

The HAB Coalition believes that the habilitation benefit is simply too important to children and adults with disabilities and chronic conditions to give states the flexibility to possibly limit or otherwise cut these benefits in establishing new EHB benchmark plans. This is a statutory benefit that should be as uniform as possible throughout the country so that access to habilitation benefits does not depend on the state in which one resides.

With respect to the first and second proposed options that would allow States to substitute either their entire EHB benchmark plan with the plan of another State or would allow States to replace one or more EHB categories of benefits with that of another State, HAB is deeply concerned that States will exercise this option to select a more limited benefit package, rather than the current benefit standard in their state's benchmark plan. These decisions may be made without sufficient regard to those in need of habilitative services and devices in their State. We believe this would be contrary to quality of care and cost-saving principles.

With respect to the third option, which would essentially allow States to rewrite their own benchmark plans while imposing a limit on the benchmark plan's "generosity," the HAB Coalition is concerned that this would only contribute to a decrease in coverage of EHBs, particularly habilitative services and devices. By granting States expansive power to alter their EHB benchmark plans so dramatically every year, the Proposed Rule threatens any hope of

predictability of coverage for consumers from year-to-year and State-to-State. This will likely reduce quality of care and increase downstream costs due to a lack of predictability in coverage of these essential services and devices.

Furthermore, CMS's proposed definition of a "typical employer plan" would considerably weaken the EHBs and may result in states choosing a very limited plan from another state. As a result of the lack of constraints placed on what constitutes a "typical employer plan," states, by choosing a slimmer "typical" plan, could establish a benchmark plan that does not appropriately meet the health care needs of their populations. The HAB Coalition supports CMS's position that the definition of typical employer plans should be limited to plans that already cover all 10 EHB categories. Furthermore, a typical employer plan should have to be from a recent year, as well as be required to meet minimum value standards or not be an indemnity plan or a health reimbursement arrangement.

Statutory Requirements for EHB Coverage

Habilitative and rehabilitative services and devices are mandated as EHBs in Section 1302 of the ACA. It is critical that the regulations on EHB benchmark plans explicitly establish appropriate coverage of these benefits in a manner that is consistent with the statute and the needs of adults and children with disabilities and other conditions that require habilitation services and devices. Given the legal parameters in the ACA statute and the explicit statutory mandate to cover habilitative services while ensuring that benefit design not be discriminatory based on disability, an EHB regulation that does not ensure appropriate coverage of habilitative services and devices for the segment of the population that needs access to these services would be in conflict with the letter and the spirit of the law. These legal parameters also mean that people with disabilities and chronic conditions who need habilitative services and devices should not face unreasonably restrictive coverage policies or arbitrary constraints that hinder their ability to achieve results through appropriate treatment.

The HAB Coalition supports the preservation of the regulatory definition of habilitative services and devices and related interpretations that have been duly promulgated. We urge CMS to reemphasize the following requirements and principles to the States with regard to EHB benchmark plan design:

- The ACA statutory language requires the EHB package to include coverage of both habilitation services *and* devices.
- The uniform definition of habilitative *services* and *devices* serves as a minimum standard for covering habilitative services.
- Limitations in habilitation 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 habilitative field to render informed decisions.
- The extent of coverage of habilitative services and devices should at least be in parity with rehabilitative coverage and if service caps in benefits are employed, there must be separate caps for habilitation and rehabilitation benefits.

- Habilitative services and devices should be covered without arbitrary restrictions and caps that limit the effectiveness of the benefit and undercut the ACA's prohibition on lifetime and annual limits in benefits.
- Regardless of the diagnosis that leads to a functional deficit in an individual, the coverage and medical necessity determination for habilitative services and devices should be recommended based on clinical judgment of the effectiveness of the therapy, service, or device to address the deficit.
- Benefits cannot be defined in such a way as to exclude coverage for services based upon age, disability, or expected length of life—an explicit requirement included in the ACA.

Antidiscrimination Provisions of the ACA

Given historic patterns of discriminatory benefit plan design in the area of habilitative services and devices, we encourage CMS to preserve a federal role for monitoring whether States comply with the following key antidiscrimination portions of the ACA statute. As noted in the preamble of the Notice, the ACA requires that benefit design not discriminate against individuals because of their age or disability[3] and there are numerous legal protections in the ACA that are designed 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[4], as well as the general nondiscrimination section of the law found at Section 1557 of the ACA. Nondiscrimination provisions also include the requirement that the Secretary must ensure that essential benefits reflect an "appropriate balance" of benefits covered across categories[5], that there is parity across the categories of benefits[6], and that the Secretary must not make coverage decisions, determine reimbursement rates, establish incentive programs, or design benefits in ways that discriminate against individuals because of disability.[7]

Therefore, we are pleased that the Notice requires states to take into account the health care needs of diverse segments of the population, including children, persons with disabilities, and other groups as required under the ACA.[8] This language speaks directly to the need to include in the EHB package services and devices such as habilitation. The Secretary must also ensure that EHBs are not subject to denial to individuals against their wishes on the basis of the individual's present or predicted disability, degree of medical dependency, or quality of life.[9] The HAB Coalition urges CMS to reiterate these requirements with which States must comply when designing EHB benchmark plans and monitor states to ensure that any redesign on EHBs comply with these important provisions.

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[3] Patient Protection and Affordable Care Act, Pub. L. No. 111-148, § 1302(b)(4)(B) (2010).
[4] *Id.* § 1201.
[5] *Id.* § 1302(b)(4)(A).
[6] *Id.*
[7] *See id.* § 1302(b)(4)(B).
[8] *See id.* § 1302(b)(4)(C).
[9] *See id.* § 1302(b)(4)(D).

Impact on Health Care Costs

The HAB Coalition agrees that affordability of coverage must be a priority. However, we caution a reduction in coverage under EHBs is not likely to significantly reduce premium costs.[10] This is particularly true for coverage of habilitative and rehabilitative care, which accounts for just 2% of total premium dollars. In fact, reducing coverage of these services would not significantly decrease the cost of insurance packages overall, but would lead to very high increases in out-of-pocket costs for children, families, and adults who need this type of care. We remind CMS that affordability must be measured not only by the cost of premiums, but by the full cost to consumers, which includes the financial burden of paying out-of-pocket for uncovered, but medically necessary services.

Therefore, the HAB Coalition recommends that States should be required to track downstream costs when limiting coverage of these services and devices. This would ensure that any reduction in coverage designed to reduce short-term costs does not simply shift, and ultimately increase, costs to consumers in the long-term. We also urge CMS to require States to assess and continually monitor the impact on access to care for children and adults that need these services and devices.

The HAB Coalition shares CMS's goal of reducing the cost of premiums and empowering consumers in the marketplace. However, the HAB Coalition believes that the federal government must play a strong role in the enforcement of the EHB package, particularly when certain EHB benefits, such as habilitative services and devices, are not well understood and have been inconsistently provided by States. As discussed in this comment letter, habilitation services and devices are highly cost-effective and decrease downstream costs to the health care system and society at large for unnecessary disability and dependency. They are critical to the ability of children, in the long-term, and adults, in the shorter term to be contributing members of society. A reduction in coverage of these services would turn back the clock on children and adults with disabilities and chronic, progressive conditions and increase costs on the health care system as a whole.

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We greatly appreciate your attention to our concerns involving this important proposed rule. Should you have further questions regarding this information, please contact Peter Thomas or Leif Brierley, coordinators for the HAB Coalition, by e-mailing Peter.Thomas@PowersLaw.com or Leif.Brierley@PowersLaw.com, or by calling 202-466-6550.

Sincerely,

The Undersigned Members of the HAB Coalition
ACCSES
American Academy of Physical Medicine and Rehabilitation

[10] Linda J. Blumberg & John Holahan, *The Implications of Cutting Essential Health Benefits: An Analysis of Nongroup Insurance Premiums Under the ACA*, Robert Wood Johnson Foundation (July 2017), https://www.rwjf.org/content/dam/farm/reports/issue_briefs/2017/rwjf438507.

American Association of People with Disabilities
American Association on Health and Disability
American Cochlear Implant Alliance
American Heart Association/American Stroke Association
American Music Therapy Association
American Occupational Therapy Association
American Physical Therapy Association
American Speech-Language-Hearing Association
American Therapeutic Recreation Association
The Arc of the United States
Brain Injury Association of America
Children's Hospital Association
Christopher & Dana Reeve Foundation
Clinician Task Force
Family Voices
Lakeshore Foundation
United Spinal Association