



[Submitted Electronically]

March 3, 2017

Re: Access to Habilitation Services and Devices under ACA Replacement Legislation

Dear Member of Congress:

The undersigned organizations are writing as members of the Habilitation Benefits (HAB) Coalition to express our deep concern about repealing key provisions of the Affordable Care Act (ACA) without having consensus on a viable replacement plan that ensures consumers access to habilitation services and devices. Repealing the ACA without an appropriate replacement in the same legislation endangers access to—and coverage of—these critical services and devices relied on by millions of Americans with individual and family coverage under the private Marketplace plans as well as Medicaid enrollees in 32 states that have chosen to expand their programs. Coverage gains for habilitation services and devices have been hard fought and 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 HAB Coalition is a group of national nonprofit consumer and clinical organizations focused on securing appropriate access to, and coverage of, habilitation benefits within the Essential Health Benefits (EHB) category known as “rehabilitative and habilitative services and devices” under Section 1302 of the ACA. Americans needing habilitation services and devices rely on their health care coverage to acquire skills and functions never developed due to disability, and to maintain their health and function, and live as independently as possible. Often skills acquired through habilitation services and devices lead to breakthroughs in functional ability that would not have been possible without access to timely and appropriate habilitation benefits. This reduces long-term disability and dependency costs to society.

Prior to the ACA, few Americans even understood the meaning of habilitation services and devices, let alone the benefits habilitation brings to those in need. In fact, only three states had adopted a habilitative services mandate in the individual market (Illinois, Maryland, and Oregon). The ACA resulted in several victories for individuals in need of habilitation. To preserve these victories, we strongly advise the new Congress to preserve the definition of habilitation services and devices in any future health reform that serves as a replacement to the ACA.

I. Definition of Habilitation Services and Devices

The ACA created in statute the Essential Health Benefits (EHB) category of “rehabilitative and habilitative services and devices.” ACA, Section 1302 (b). In the February 2015 Benefit and Payment Parameters Final Rule, the Centers for Medicare and Medicaid Services (CMS) defined “habilitation services and devices” using the definition of “habilitation services” from the National Association of Insurance Commissioners’ *Glossary of Health Coverage and Medical Terms*¹ plus explicitly adding habilitation 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.”²

This definition is a floor for individual insurance plans sold under the ACA exchanges. It was also adopted by states that chose to expand their Medicaid programs. For the first time, this definition established a uniform, understandable federal definition of habilitation services and devices that became a standard for national insurance coverage. We stress that this definition is a floor for coverage and includes both habilitative *services* and habilitative *devices*. The services and devices covered by the habilitation benefit should not be limited to the therapies enumerated in the federal regulation which are listed as *examples* of covered benefits.

We understand that an element of the legislation that House Republicans are considering would have states determine their respective essential health benefits package beginning on January 1, 2020. The HAB Coalition supports the preservation of the EHB category of “rehabilitative and habilitative services and devices,” and the subsequent regulatory definition and related interpretations duly promulgated, as a federal standard of coverage for habilitation under any version of ACA replacement legislation. The HAB Coalition believes that adopting the uniform federal definition of habilitation services and devices minimizes the variability in benefits across states and uncertainty in coverage for children and adults in need of habilitation.

In addition to the regulatory definition cited above, examples of these types of services typically provided under this benefit include rehabilitation medicine, behavioral health services, recreational therapy, developmental pediatrics, psychiatric rehabilitation, and psycho-social services provided in a variety of inpatient and/or outpatient settings. These services should be provided based on the individual’s needs, prescribed in consultation with a clinician, and based on the assessment of an interdisciplinary team and resulting care plan.

II. Vignettes

The following vignettes help to demonstrate the value of habilitation:

¹ <https://www.cms.gov/CCIIO/resources/files/downloads/uniform-glossary-final.pdf>.

² <http://www.gpo.gov/fdsys/pkg/FR-2015-02-27/pdf/2015-03751.pdf>, at 10871.

Habilitation Services for Infants and Children

Hearing Screening

Consistent with the state mandate for infant hearing screening, Gavin received a newborn hearing screening test in the hospital 48 hours after he was born. The newborn hearing screening indicated a possible hearing loss, and according to the state protocol, he was referred for a repeat outpatient hearing screening. The results of the outpatient screening indicated the need for further testing; therefore, he was referred to a pediatric audiologist for a comprehensive diagnostic evaluation.

The results of the evaluation confirmed a moderate sensorineural hearing loss in both ears. The family chose an auditory/oral approach for speech and language development for Gavin. He was fitted with binaural hearing aids at three months of age and referred to the state Early Intervention (EI) program. The initial recommendations from EI were biweekly early intervention services provided by an audiologist and speech-language pathologist (SLP) in the home, beginning at four months of age that focus on parent education, auditory/listening skills, and language development.

After three years of consistent hearing aid use and regular habilitation treatment services, Gavin entered preschool with normal receptive and expressive language, on par with his hearing peers.

Cochlear Implants

Olivia was identified with a permanent, sensorineural severe-to-profound hearing loss at six months of age and currently wears hearing aids in both ears. Her family chose an auditory/oral communication approach. Olivia received a cochlear implant evaluation from an interdisciplinary team—including a surgeon, an audiologist, a speech-language pathologist (SLP), and a social worker—at a hospital three hours away from her home. An SLP has been providing habilitation services in the home since Olivia's hearing loss was diagnosed. The audiologist and SLP have been collaborating with the cochlear implant team on habilitative treatment and will continue to provide services locally to the family following the cochlear implantation. This professional collaboration will help the audiologist in programming the cochlear implant to maximize the hearing benefit. A collaborative plan of treatment is critical for developing speech and language skills following implantation.

Cleft Palate

Jessica is a two-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, an SLP, a pediatrician, and additional providers. The SLP assesses articulation, language, voice, and resonance and determines the presence of articulation deficits and nasal emission that requires speech-language treatment weekly. Treatment goals focus on correct articulatory placement to address sound errors, nasality of speech, and oral airflow. 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.

Stuttering Disorder

James is a seven-year-old child who has stuttered since he was in preschool. His speech deficits, blocks, and facial grimaces impact his ability to verbally express himself in school, at home, and during social interactions. His pediatrician referred James for a speech-language evaluation for stuttering and the increasing anxiety that James experiences when speaking. During the speech-language evaluation, the frequency, duration, and type of stuttering were measured and the presence of secondary behaviors, such as eye blinking, were identified by administering standardized fluency test measures. Treatment was recommended and will focus on developing strategies to improve speech through rate control, continuous phonation, easy onset of speech, and light articulatory contact. Reducing physical tension and desensitization strategies were also treatment goals to reduce speaking anxiety. With appropriate speech-language treatment, James can become a more fluent and confident speaker.

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 be able to continue 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.

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. She is scheduled for surgical repair of a congenital heart defect in the near future.

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. She is seen at home by several health care professionals. The pediatric physical therapist has helped the 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. The physical therapist includes games and toys with bright colors to stimulate Jill's interest, play, and hand skills. The therapist incorporates words and pictures with the treatment sessions to help Jill's language development.

The family has already asked for information about starting an infant treadmill walking program as soon as Jill has recovered from her surgery and can put weight on her feet to stand. The

therapist is using a large ball to encourage Jill to take some weight on her feet now. Jill is placed on her stomach on the ball, facing away from the therapist, and the ball is moved toward the therapist so that Jill's feet will take some weight against the therapist's body as the therapist holds her safely on the ball.

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 (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. An orthotics assessment is beneficial, in the first year of life, to prevent misalignment.

Habilitation Services for Adults

Multiple Sclerosis

A 47-year-old female with Multiple Sclerosis was referred to occupational therapy for self-management, specifically management of fall risk and fatigue. She reported having difficulty with household chores, specifically cleaning and ironing. She also reported becoming easily fatigued during the day. Intervention focused on identifying adaptive and compensatory strategies to assist her to learn how to self-pace her daily routines between demanding and non-demanding activities to conserve energy. She was able to continue her daily routines with improved energy and satisfaction.

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.

Conclusion

Each of these vignettes represent 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. The undersigned members of the HAB Coalition firmly believe that failing to replace the Affordable Care Act in a manner that would preserve access to habilitative services and devices would turn back the clock on children and adults with disabilities and chronic, progressive conditions. If Congress wishes to make changes to the ACA, the HAB Coalition advises that Congress first ensure that any replacement legislation meets the needs of people needing habilitation services and devices.

Thank you for your willingness to consider our views. Should you have further questions regarding this information, please contact Peter Thomas or Steve Postal, HAB Coalition coordinators, by emailing Peter.Thomas@powerslaw.com or Steve.Postal@powerslaw.com, or by calling 202-466-6550.

Sincerely,

ACCSES

American Academy of Pediatrics

American Academy of Physical Medicine and Rehabilitation

American Association on Health and Disability

American Cochlear Implant Alliance

American Occupational Therapy Association

American Music Therapy Association

American Network of Community Options and Resources

American Physical Therapy Association

American Speech-Language-Hearing Association

American Therapeutic Recreation Association

The Arc of the United States

Beckett Family Consulting

Brain Injury Association of America

Christopher & Dana Reeve Foundation

Easterseals

Family Voices

Hearing Loss Association of America

Lakeshore Foundation

Legal Action Center

National Association for the Advancement of Orthotics and Prosthetics

National Association for Rural Mental Health

National Association of County Behavioral Health & Developmental Disability Directors

National Stroke Association

Paralyzed Veterans of America

TASH

United Cerebral Palsy

United Spinal Association