



OPEN LETTER TO STATES ON DEFINING ESSENTIAL HEALTH BENEFITS PACKAGE

RE: TECHNICAL ASSISTANCE FOR STATES TO DESIGN ESSENTIAL HEALTH BENEFITS PACKAGES FOR "REHABILITATIVE AND HABILITATIVE SERVICES AND DEVICES"

Dear State Leaders Designing Essential Health Benefit Packages:

The undersigned members of the four coalitions that authored this paper, the Consortium for Citizens with Disabilities (CCD), the Habilitation Benefits (HAB) Coalition, the Coalition to Preserve Rehabilitation (CPR), and the Independence Through Enhancement of Medicare and Medicaid (ITEM) Coalition, appreciate this opportunity to provide state leadership with this joint guidance on the essential health benefits process. This technical assistance document focuses solely on the essential health benefit (EHB) category referred to in the Affordable Care Act as "rehabilitative and habilitative services and devices."

With the deadline for selection of a state benchmark benefits plan fast approaching, we hope you find this technical assistance useful in selection—as well as enhancement—of your states' essential health benefits package. We also hope you find this to be a useful resource as you refine your EHB package in the years to come.

The CCD, HAB, CPR and ITEM coalitions together represent the key national consumer and clinical organizations focused on healthcare policy from a disability and rehabilitation perspective. Many of these organizations have state and local affiliates. These national coalitions based in Washington, DC have worked hard over the past few years to ensure full and appropriate implementation of the Affordable Care Act's reforms at the federal and state levels with the ultimate goal of eliminating decision-making based on health status in the individual and small group markets, which disproportionately impacts people with disabilities and chronic conditions.

As you are well aware, Section 1302 of the Patient Protection and Affordable Care Act (ACA), Pub. L. 111-148, lists ten benefit categories that must be covered as essential—beginning in 2014—by new individual and small group plans. In advance of regulating the EHB package, the U.S. Department of Health and Human Services (DHHS) released guidance instructing states to

choose an existing plan as a benchmark for their EHB package. The HHS guidance directs states to enhance that plan where it does not adequately cover all 10 of the required benefit categories. Although a number of EHB categories listed in the ACA include services beneficial to people with disabilities and chronic conditions, such as mental and behavioral health services and chronic disease management, this Technical Assistance (TA) document focuses on a single category of benefits: “rehabilitative and habilitative services and devices.”

Rehabilitative and habilitative services and devices encompass a wide range of benefits critical to individuals with injuries, illnesses, disabilities and chronic conditions. These services and devices are provided by appropriately credentialed (licensed, accredited and certified) providers and suppliers. Rehabilitation and habilitation services and devices include, but are not limited to, rehabilitation physician and nursing services; physical therapy; occupational therapy; speech, language and hearing therapies; recreational therapy; music therapy and cognitive therapy for people with brain injuries and other conditions; psychiatric, behavioral and other developmental services and supports; durable medical equipment (DME), including complex rehabilitation technologies; orthotics and prosthetics; low vision aids; hearing aids and augmentative communication devices; and other assistive technologies and supplies.

These services and devices are provided in an array of settings, such as inpatient rehabilitation hospitals and other inpatient or transitional rehabilitation settings, outpatient therapy clinics, community provider offices, at a person’s home, and at various levels of intensity, duration and scope, depending on the severity of the condition and the functional impairment presented by the particular individual.

This TA is intended to aid your state in establishing an EHB package that appropriately covers rehabilitative and habilitative services and devices, consistent with the intent of the Affordable Care Act and guidance issued by DHHS. As such, we provide the following recommendations and guidance within this document:

- **Overview: the State’s Role in Defining Essential Health Benefits**
- **Explanations and Definitions of Rehabilitative and Habilitative Services and Devices Enhancing Benchmark Plan Coverage of Rehabilitative and Habilitative Services and Devices**
- **Incorporating State Mandates for Rehabilitative and Habilitative Services and Devices**
- **Establishing Limits on Rehabilitative and Habilitative Services and Devices**
- **Rehabilitative and Habilitative Services and Devices Evaluation Chart**

Thank you for your consideration. If you have any questions, please do not hesitate to contact Theresa Morgan, CCD Board Member, at Theresa.Morgan@ppsv.com. Ms. Morgan can direct your questions to our specialists on rehabilitation and habilitation services and devices.

Sincerely,

Adapted Physical Activity Council
American Academy of Orthotists
and Prosthetists
American Academy of Physical Medicine and
Rehabilitation
American Association for Homecare
American Association of People with Disabilities
American Association on Health and Disability
American Board for Certification in Orthotics,
Prosthetics, and Pedorthics
ACCSES
American Foundation for the Blind
American Medical Rehabilitation
Providers Association
American Music Therapy Association
American Network of Community Options
and Resources
American Occupational Therapy Association
American Orthotic and Prosthetic Association
American Speech-Language-Hearing Association
American Therapeutic Recreation Association
Amputee Coalition
American Congress of Rehabilitation Medicine
Association for Education and Rehabilitation
of the Blind and Visually Impaired
Association of Academic Physiatrists
Association of Assistive Technology Act Programs
Association of Rehabilitation Nurses
Association of University Centers
on Disabilities
Board of Certification/Accreditation,
International
Brain Injury Association of America

CARF, International
Center for Medicare Advocacy
Christopher & Dana Reeve Foundation
Disability Rights Education and Defense Fund
Easter Seals
Epilepsy Foundation
Family Voices
Families USA
Health & Disability Advocates
Hearing Loss Association of America
Institute for Educational Leadership
National Association of Councils on
Developmental Disabilities
National Association for the Advancement of
Orthotics and Prosthetics
National Health Law Program
National Association of State Head Injury
Administrators
National Coalition for Assistive and Rehab
Technology
National Disability Rights Network
National Down Syndrome Congress
National Down Syndrome Society
National Health Law Program
National Multiple Sclerosis Society
National Stroke Association
Paralyzed Veterans of America
Rehabilitation Engineering and Assistive
Technology Society of North America
Research Institute for Independent Living
The Arc of the United States
United Cerebral Palsy
United Spinal Association

I. Overview: The State's Role in Defining Essential Health Benefits

Section 1302 of the Patient Protection and Affordable Care Act (ACA), Pub. L. 111-148, lists ten benefit categories that must be covered as essential by new individual and small group plans beginning in 2014. The 10 benefit categories describe the “essential health benefits package,” which includes services essential for all Americans, including people with disabilities and chronic conditions. Some of these benefits are not consistently covered in current insurance market plans. States have the opportunity to greatly enhance health care insurance coverage for individuals with disabilities and chronic conditions by establishing essential health benefits packages that adequately and appropriately cover health care benefits, without discriminating against individuals based on health or disability status.

In advance of regulating the essential health benefits package, the U.S. Department of Health and Human Services released guidance in December 2011 instructing states to (a) choose an existing plan as a benchmark for their EHB package and (b) enhance that plan where it does not adequately cover all 10 of the federally required benefit categories.

In the parameters that HHS provides for choosing a benchmark package, States are given four options for their starting benchmark plan:

- (1) The largest plan by enrollment in any of the three largest small group insurance products in the State's small group market;
- (2) Any of the largest three State employee health benefit plans by enrollment;
- (3) Any of the largest three national FEHBP plan options by enrollment; or
- (4) The largest insured commercial non-Medicaid Health Maintenance Organization (HMO) operating in the State.

In May 2012, HHS also released a proposed rule [CMS-9965-P] that would establish data collection for health plans that represent potential EHB benchmarks in the States. Under the rule, the issuers of the three largest small group market plans in each State would be required to report to HHS information regarding all the health benefits in the plan, treatment limitations, drug coverage, and enrollment. This data will inform states and stakeholders of the details of commonly selected benchmark plans and aid states in both choosing and enhancing their EHB package. If states opt not to choose a benchmark plan, the default benchmark plan for that state will be the largest plan by enrollment in the State's small group market.

Once a state has selected a benchmark plan, it is required to “plus up” that package with benefits required under the ACA that may not be covered under the selected benchmark plan. For example, some individual and small group plans may not currently cover habilitation benefits or pediatric dental and vision benefits, but these benefits are explicitly required by the ACA to be included in EHB starting in 2014. The proposed data collection rule will aid states in determining the scope of coverage for the ten benefit categories and identify those benefits previously omitted from coverage by the plan. Additionally, the benefit limitation information provided by the plans will inform the state regarding compliance with the non-discrimination provisions of the ACA and help them to maintain a balance of coverage between the benefit categories.

It is important that states conduct a thorough review of the contents of their selected benchmark benefit package and consider adding coverage of benefits *in every category* required under the ACA, not just those categories (e.g., habilitation) where there is a total absence of coverage in the benchmark plan. For example, a health plan that has a hard coverage cap of 12 physical therapy visits, fails to cover occupational therapy, omits coverage in the inpatient rehabilitation hospital setting, has an unrealistically low dollar cap on durable medical equipment, and limits prosthetic limb care to one prosthesis per lifetime cannot be said to provide appropriate coverage for the category known under the ACA as “rehabilitative and habilitative services and devices.” Such a benefit design must be measured—among other things—against the non-discrimination protections in Section 1302(b)(4) of the ACA which prohibits discrimination in benefit design based on disability status and mandates that benefit coverage is appropriately balanced among the categories of covered benefits.

II. Explanation and Definitions of Benefits

For many people with disabilities and chronic conditions, rehabilitative and habilitative services and devices are equivalent to the provision of antibiotics to a person with an infection—both are essential medical interventions. Thus, this benefit category is an integral component of health care, especially for persons with disabilities and chronic conditions. This is perhaps one reason why Congress chose to include this benefit category as one of only ten categories in the ACA statute that are required to be covered. Congress intended the essential health benefits package to be more than a typical major medical, acute care health plan. By including coverage for rehabilitative and habilitative services and devices, Congress clearly signaled its intent to accommodate the health care needs of those with functional limitations following illness, injury, disability and chronic condition.

With respect to an individual with such a condition, rehabilitative and habilitative services and devices:

- Speed recovery by achieving better outcomes and enhancing the likelihood of discharge from the hospital to one’s home, living longer, and retaining a higher level of function post injury or illness;
- Improve long-term functional and health status and improve the likelihood of independent living and high quality of life;
- Reduce the likelihood of relapse and rehospitalization;
- Halt or slow the progression of primary and secondary disabilities by maintaining function and preventing further deterioration of function; and
- Facilitate return to work in appropriate circumstances.

For example, medically necessary rehabilitative and habilitative services and devices:

- Enable persons with spinal cord injuries to recover and regain functions through intensive rehabilitation services and the use of appropriate wheeled mobility;

- Enable persons born with congenital conditions or developmental disabilities to acquire skills and abilities through habilitation therapies and assistive devices;
- Enable amputees to walk, run, work and fully function using an artificial limb;
- Enable persons with a traumatic brain injury to improve cognition and functioning through appropriate therapies and assistive devices.

Essential rehabilitation and habilitation care must include services and devices that improve, maintain, and lessen the deterioration of a patient's functional status over a lifetime and on a treatment continuum. This implies coverage of a spectrum of rehabilitation care, from immediate post-operative, intensive, inpatient hospital rehabilitation to outpatient rehabilitation therapies provided in a variety of settings. It also includes, under the term "habilitation," ongoing, medically necessary, therapies provided to individuals with developmental disabilities and similar conditions who need habilitation therapies to achieve functions and skills never before acquired. These skills acquired through habilitation often serve as important developmental building blocks that lead to significant gains in function during the lifespan of the individual, thereby decreasing long term dependency costs.

Distinction Between Rehabilitation and Habilitation

An important difference between rehabilitation and habilitation services and devices is the fact that *habilitation* 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. *Rehabilitation* services and devices, on the other hand, are provided to help a person **regain**, maintain or prevent deterioration of a skill or function that has been acquired but then lost or impaired due to illness, injury, or disabling condition.

Examples of the comparison between rehabilitation (where the individual **regains**, maintains, or prevents deterioration of a function or skill) and habilitation (where the individual **attains**, maintains, or prevents deterioration of a function or skill) are as follows:

- A speech-language pathologist providing speech therapy to a 3-year old with autism who has never acquired the ability to speak would be considered habilitation but providing speech therapy to a 3-year old to regain speech after a traumatic brain injury would be considered rehabilitation.
- An occupational therapist teaching children who have had a stroke *in utero* or children or teaching adults with developmental disabilities the fine motor coordination required to groom and dress themselves is considered habilitation, whereas teaching children or adults who have had a stroke the fine motor skills required to re-learn how to groom and dress themselves would be rehabilitation.
- An orthotist or therapist fitting hand orthoses for a child or an adult with a congenital condition to correct hand deformities would be habilitation, while fitting orthoses for a child or adult who has had hand surgery for a torn tendon repair would be rehabilitation.

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 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. There is a compelling case for coverage of both rehabilitation and habilitation services and devices in persons in need of functional improvement due to disabling conditions. This case includes the fact that both habilitation and rehabilitation services and devices are highly cost-effective and decrease downstream costs to the health care system for unnecessary disability and dependency.

Definitions of Rehabilitation and Habilitation Services

The term “rehabilitative and habilitative services and devices” that appears in Section 1302 of the ACA refers to a broad category of benefits, and the term itself does not typically appear in private health plan documentation. Rather, most health plan benefit packages are more specific with respect to the benefits covered by this category. States should define “rehabilitation and habilitation services and devices” in legislation, regulation and guidance related to their benchmark plan consistent with the definitions adopted by the National Association of Insurance Commissioners (NAIC) which are the same as those adopted by HHS in its glossary of medical terms, required by the Affordable Care Act. (See, 76 Fed. Reg. 52,442; 76 Fed. Reg. 52,475.) Although these definitions are written for a lay audience and, therefore, are not technical, they offer a clear starting point for coverage. The definitions of this term used by the states should also be consistent with the Institute of Medicine’s recommendations that the Secretary look to state Medicaid programs as a guide for defining what is covered under the EHB’s habilitation benefit.

The NAIC 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 NAIC 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.]

In its report, the IOM states:

“The committee is guided by the unambiguous direction of Section 1302 to start with a commercial health insurance benefit; however, it suggests that the Secretary compare, in particular, how Medicaid plan benefits for habilitation and mental health and substance abuse services compare with commercial plans that currently include such services. For example, Maryland has requirements to cover habilitation services in children under age 19 in its small business standards for health insurance (Maryland Insurance Administration, 2009). On the basis of this review, the Secretary would add selected services to the preliminary list to fulfill the 10-category requirement.” IOM Report: Essential Benefits: Balancing Coverage and Cost, p. 5-3 (2011)

Based upon these references, we believe the definition of rehabilitation and habilitation should read:

"Rehabilitative services" means health care services and devices that are designed to assist individuals in improving or maintaining, partially or fully, skills and functioning for daily living. These services include, but are not limited to, physical therapy, occupational therapy, speech-language pathology and audiology, and psychiatric rehabilitation services in a variety of inpatient and/or outpatient settings.

"Habilitative services" means health care services and devices that are designed to assist individuals in acquiring, improving, or maintaining, partially or fully, skills and functioning for daily living. These services may include physical therapy, occupational therapy, speech-language pathology and audiology, and other services and devices for people with disabilities in a variety of inpatient and/or outpatient settings. Plans should use Medicaid coverage as a guide where there is a question of whether to cover specific habilitation benefits.

Rehabilitative and Habilitative Devices

Rehabilitative and habilitative devices include durable medical equipment (DME), orthotics, prosthetics, low vision aids, hearing aids, augmentative communication devices that aid in hearing and speech and other assistive technologies and supplies. States should define “rehabilitative and habilitative devices” to explicitly include devices that *maintain* as well as *improve* function, consistent with the definitions for rehabilitative and habilitative services 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)

Based on extensive analysis of multiple health care programs and plans, we believe:

The definition of ***Durable Medical Equipment (DME)*** should read:

Equipment and supplies ordered by a health care professional for everyday or extended use to improve, maintain or prevent the deterioration of an individual's functional ability. Examples of DME include, but are not limited to, manual and electric wheelchairs, oxygen equipment, canes, crutches, walkers, standing system chairs, blood testing supplies for people with diabetes, as well as supplies and equipment to support medically necessary devices.

The definition of ***Orthotics and Prosthetics*** should read:

"Orthotics and Prosthetics" are leg, arm, back, and neck braces, trusses, and artificial legs, arms, and eyes, and external breast prostheses incident to mastectomy resulting from breast cancer. Covered services include adjustments, repairs, and replacements required because of breakage, wear, loss, or a change in the patient's physical condition.

The definition of ***Prosthetic Devices*** should read:

"Prosthetic Devices" are devices that replace all or part of an internal body organ or all or part of the function of a permanently inoperative or malfunctioning internal body organ. Examples of prosthetic devices include joint replacements, colostomy care, and implanted breast prostheses incident to mastectomy resulting from breast cancer, cochlear implants, and osseointegrated implants to replace middle ear or cochlear function. Covered services include adjustments, repairs, and replacements required because of breakage, wear, loss, or a change in the patient's physical condition.

The definition of ***Low Vision Aids*** should read:

"Low Vision Aids" help correct for the partial loss of eyesight, making it possible for an individual with impaired vision to accomplish everyday tasks, including reading, writing, driving a car or recognizing faces. Examples of low vision aids include devices which magnify, reduce glare, add light or enlarge objects as to make them more visible.

The definition of ***Augmentative and Alternative Communication Devices (AACs)*** should read:

"Augmentative and Alternative Communication Devices" are specialized devices ordered by a health care professional which assist individuals with severe speech or language problems to supplement existing speech or replace speech that is not functional. Examples of AAC devices include, but are not limited to, picture and symbol communication boards and electronic devices.

The definition of ***Hearing Aids and Assistive Listening Devices*** should read:

"Hearing aids and Assistive Listening Devices" are medical devices which amplify sound and/or counter the negative effects of environmental acoustics and background noise to assist

individuals who have been diagnosed with a hearing loss by a physician and/or hearing health professional.

Additional Considerations Involving Coverage of Devices

In implementing the essential health benefits provisions of the ACA, it is important that policy-makers and regulators understand the differences between the types of rehabilitative and habilitative devices listed above. For instance, basic benefits such as orthotics and prosthetics (“O&P”) differ significantly from DME and should be treated differently for coverage purposes by health plans. It is not sufficient for only DME to be listed under rehabilitative and habilitative devices within the essential health benefits. There is abundant evidence that health plans often treat these benefits separately as they should, as does Medicare and other publically supported payers. Orthotics and prosthetics, as well as a number of the types of devices listed above, should be specifically enumerated under the definition of “devices” for the purposes of EHB packages in the states. There is compelling legislative history to support this position.

1. During passage of the ACA, House Education and Labor Committee Chairman George Miller stated on the floor of the House of Representatives:

“The term “rehabilitative and habilitative devices” includes durable medical equipment, prosthetics, orthotics, and related supplies... It is my expectation ‘prosthetics, orthotics, and related supplies’ will be defined separately from ‘durable medical equipment.’” (Congressional Record, H-1882, March 21, 2010.)

2. A February 2011 study conducted by the Society of Human Resource Management (“SHRM”) surveyed employers from across the United States to examine whether they offered coverage for O&P services and devices. SHRM received responses from 1,115 employers. The data showed that 70-75% of employers provide coverage for O&P.
3. All federally supported health programs include coverage of O&P care. Medicare Part B covers orthotics and prosthetics, including artificial limbs and eyes; braces for the arm, leg, back, and neck; and breast prostheses and related supplies following a mastectomy. All state Medicaid plans cover O&P care for children and many states cover this same benefit for adults. The Department of Defense and the Department of Veterans Affairs offer robust O&P coverage for returning service members and all veterans with injuries, disabilities, or other conditions requiring O&P care. The Federal Employee Health Benefits Program (“FEHBP”) covers O&P care under its standard and preferred benefit packages. DME is also covered under these plans but is covered under a separate benefit.

Appropriate DME and O&P care, as well as coverage of assistive devices defined herein, enable an individual to live a life of full function, self-sufficiency, and independence. Inclusion of these devices and related services in the essential health benefits package will determine whether insured persons have their needs met when confronted with an illness, injury, disability, or other health condition. Inclusion of these benefits will also allow an affected person to speed recovery, improve functioning, live more independently and return to work. Alternatively, a lack of coverage of these devices will lead to individuals being forced to pay out-of-pocket for needed

care, go without needed care, or ultimately exit the private market altogether with no choice but to enter the publicly supported programs such as Medicare and Medicaid, as many children, adults, and seniors with disabilities do today.

III. Enhancing State Benchmark Plans to Meet Essential Health Benefits Requirements

When establishing EHB packages, States must ensure that their plan's coverage decisions, reimbursement rates, incentive programs, and benefit design avoids discrimination against individuals because of, among other things, disability. [See Section 1302(b)(4)(B) of the ACA.] In addition, health benefits established as essential cannot be 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. [See Section 1302(b)(4)(D) of the ACA.]

Non-discrimination provisions under the ACA, as well as guidance from HHS, dictate that states enhance benchmark plans to adequately cover mandated essential health benefits, such as habilitation, which are not generally covered by existing individual and small group plans. In addition, states should ensure that plans are not arbitrarily restricting certain essential benefits, or covering them in a manner that is not balanced across the categories of covered benefits. [See Section 1302(b)(4) of the ACA.] This may be typical with rehabilitative services and devices that are disproportionately used by a specific population. For example, a restrictive limitation on the number of covered rehabilitation therapies for a joint replacement patient will likely be totally inadequate for a person who has sustained a moderate or severe traumatic brain injury. States must ensure that limitations they impose on certain benefits do not violate the non-discrimination provisions of the ACA by failing to accommodate the rehabilitative needs of persons with particularly disabling diagnoses or conditions.

States must also be careful not to discriminate against persons with certain conditions by limiting or omitting coverage for certain treatments that are only relevant to people with that particular condition. For example, failing to include coverage of dialysis treatments clearly discriminates against people with kidney failure. Failing to include coverage of prosthetic limbs discriminates against people with limb loss. States must develop certain process protections to ensure that they fully examine the final EHB package they adopt to ensure that it conforms to the letter and spirit of the Affordable Care Act. If, in fact, a state's EHB package does not comply with these ACA protections against discrimination based on—among other things—disability, then the HHS Secretary should reject that state's EHB plan and direct the state to amend its package before federal subsidies begin to flow to the Health Insurance Exchange effective in that state.

Finally, with respect to states that do not proactively adopt an EHB package but simply default to the state's largest small group insurance plan, it is critical that these states ensure that a relevant and appropriate state agency engage in the process of assessing that plan to ensure it covers all 10 categories of benefits required by the ACA. The state agency must also conduct the non-discrimination analysis discussed above. Even if the federally facilitated exchange implements that state's EHB package, the state must still be accountable to ensure that the EHB package complies with federal law. In the alternative, HHS, through the authority granted to the federally facilitated exchange, should have the responsibility to complete the EHB design process before permitting federal subsidies to flow into that state.

The Habilitation Benefit

Habilitation services and devices are appropriate for individuals with many types of developmental, cognitive, and mental conditions that, in the absence of such services, prevent them from acquiring certain skills and functions over the course of their lives, particularly in childhood. Many people are already familiar with a wide range of rehabilitation services and devices, such as therapies and supports, including physical therapy, occupational therapy, speech-language pathology and audiology services, and other services that improve function and support independent living within the community, as well as durable medical equipment, prosthetic limbs, orthopedic braces, and augmentative communication devices. Habilitation services are very similar to rehabilitation in this respect but are focused on those who have never attained certain skills due to disability, not on those who have lost the ability to perform certain skills or functions due to disability.

Two states—Illinois and Maryland—and the District of Columbia have specific health insurance mandates for coverage of habilitative services up to the age of 19. Maine and Washington also mandate coverage of habilitation services under an early developmental and neurodevelopmental mandate, and a number of state autism mandates include coverage for some habilitation services in addition to an array of other covered services. The Council for Affordable Health Insurance (http://www.cahi.org/cahi_contents/resources/pdf/HealthInsuranceMandates2009.pdf) estimates that habilitative services mandates cost <1% of the total premium costs in the states that have them. The state of Maryland found that its habilitation mandate (which covers individuals up to the age of nineteen) **costs 0.1% of the total premium cost** in the private insurance market, and expanding the mandate to individuals with congenital or genetic birth defects regardless of age would increase state plan expenditures by 2%. If habilitation benefits were provided until age 25, responses from four insurance carriers in the state suggest that premiums would increase between 0% and 1.1%.

Medicaid programs across the country generally have greater experience with the habilitation benefit than private insurance plans. The Medicaid statute, for instance, defines habilitation as:

“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.” Social Security Act, Section 1915(c)(5)(A)

While different states cover habilitation to different degrees, habilitation under Medicaid consists of an expansive range of skilled therapies, services, and devices provided by a wide variety of providers. Habilitation services in the Medicaid context are provided to people who would require the level of care provided in a hospital, a nursing facility, or intermediate care facility for people with intellectual disabilities or related conditions (primarily “intellectual disability,” cerebral palsy, epilepsy, and autism), but who, with habilitation services and devices, are able to live in home- and community-based settings. For children, Medicaid provides for comprehensive coverage of habilitative services under its Early and Periodic Screening, Diagnosis and Treatment (EPSDT) mandate.

The Congressional Record clearly signals Congress' intent in the form of Congressman George Miller's floor statement offered at the time of passage of the House bill. Congressman Miller, Chairman of the House Committee on Education and Labor, a committee with primary jurisdiction over the House health reform bill, explained that the term rehabilitative and habilitative services:

“...includes items and services used to restore functional capacity, minimize limitations on physical and cognitive functions, and maintain or prevent deterioration of functioning. Such services also include training of individuals with mental and physical disabilities to enhance functional development.” [Congressional Record, H1882 (March 21, 2010)].

Congressman Bill Pascrell, a co-chair of the Congressional Brain Injury Task Force, included similar comments in the Congressional Record during this same debate.

Coupled with the Medicaid analysis recommended by the IOM in defining habilitation, and considering Congressional intent, the NAIC definitions are important in establishing the foundation of an appropriate and affordable habilitation benefit under the EHB package that all small group and individual health plans both inside and outside of the State exchanges must cover beginning in 2014.

Coverage of Habilitation in “Parity” with Rehabilitation Benefits

The December 16, 2011 guidance issued by HHS suggests that states have two choices when determining the amount, duration, and scope of their habilitation benefit. One option is to simply cover whatever they believe is appropriate and HHS will review this level of coverage in the years to come. In our view, this is far too nebulous a standard to meet the ACA's mandate for coverage of habilitation benefits.

The other option available to the states is to cover habilitation on par with rehabilitation benefits. This is an attractive concept but the details must be examined. First, we support “parity” between rehabilitation coverage and habilitation coverage, but only insofar as parity relates to the availability of coverage of services to treat an underlying condition. In other words, the coverage of therapy services and devices to treat a functional deficit in a child or adult should not turn on whether the condition that led to that functional deficit was acquired before/near birth or was acquired after birth through illness, injury, or other reason. In this respect, availability of coverage of habilitation services to address a functional deficit should be on par with the availability of coverage of rehabilitation services. The underlying condition that causes the functional deficit should not impact coverage of services to address that deficit.

However, simply importing the limits and exclusions that may exist under a plan's rehabilitation benefit and applying those same limits and exclusions to the habilitation benefit would seriously undermine the ACA's habilitation mandate. Habilitation benefits are defined as services that help individuals attain functions and skills they never have had due to a disabling condition. This may entail major variations in amount, duration, and scope of needed services in comparison to the typical rehabilitation patient. Therefore, when assessing limits on habilitation coverage, states should consider habilitative services independently from rehabilitative services.

IV. Incorporating State Mandates for Rehabilitative and Habilitative Services and Devices

In 2014 and 2015, states that choose a benchmark plan subject to state benefit mandates—such as one of the states’ largest small group plans—will have those mandated benefits included in their EHB package and the federal government will subsidize the cost for this coverage. However, if a state chooses a benchmark plan that is not subject to state mandates, the state will be responsible for defraying the cost of these excess benefits.

HHS intends to evaluate the benchmark approach in 2016, and is expected to develop an approach that may exclude some State benefit mandates from inclusion in the State EHB package, unless the state agrees to pay for them. As such, a designation as a state mandate does not permanently qualify that benefit as an essential health benefit. To avoid disruption of benefit coverage in the future, states should strive to adopt EHB packages that already treat benefits they have found to be essential for their state residents—by mandating coverage of that benefit by law—as essential health benefits in their benchmark plan.

Individuals with disabilities and chronic conditions are rightly concerned with the prospect of losing coverage of very important services if state mandates are not incorporated as essential health benefits. The following examples are illustrative of other essential benefit mandates which also benefit people with disabilities.

- a) Autism Services: Thirty-two states mandate coverage of applied behavioral therapy for individuals with autism. Research findings indicate that long-term healthcare costs of individuals with congenital and genetic disorders and developmental disabilities can be curtailed through intensive and comprehensive treatment early in life. For example, in a study conducted using cost data from Pennsylvania, researchers estimate that early intensive behavioral intervention for children with autism could save from \$187,000 to \$203,000 per child for ages 3 through 22 years, and from \$656,000 to \$1,082,000 per child for ages 3 through 55 years. States should therefore ensure that applied behavioral therapy benefits are covered in their essential health benefits package.
- b) Orthotics and Prosthetics: There are over 2 million people in the United States with limb loss, according to the Amputee Coalition. The total number of persons who use orthotics is expected to reach 7.3 million by the year 2020 (See, American Academy of Orthotists and Prosthetists, “O&P Trends and Statistics.” *Available at* <http://www.opcareers.org/assets/pdf/TrendsFINAL.pdf>). While orthotics and prosthetics are covered by 70-75 percent of employer sponsored health plans, nineteen states have passed laws ensuring that people with limb loss have fair and appropriate access to prosthetic care under private insurance and seven states have included orthotics in those laws as well. These mandates have also been cost-effective, with little or no increase in premiums with their inclusion. For example, in Colorado, the data show that covering prosthetics in all private insurance plans subject to state law cost less than twelve cents per month. The data also demonstrate that when cost savings from avoidance of co-morbid conditions are factored into the

analysis, covering O&P actually saves the state more money than it costs. States should include prosthetics and orthotics in the definition of “rehabilitative and habilitative services and devices” in state law to ensure that these essential benefits are included in their state EHB plan after 2016.

- c) Hearing Aids: Nineteen states mandate coverage for hearing aids for children, and three states include coverage for adults. One state, Wisconsin, includes mandated coverage for children for hearing aids and cochlear implants. The National Institutes of Health has identified hearing loss and the importance of appropriate amplification as a significant health concern for the aging population and is offering research grants for innovative and affordable access to hearing aids. It has been long known that the early treatment of hearing loss in children supports language development, academic achievement, social development, and economic contribution. A study by the National Council on Aging (NCOA) found that people 50 and older with untreated hearing loss were more likely to report depression, anxiety, anger and frustration, emotional instability and paranoia, and were less likely to participate in organized social activities than those who wore hearing aids. The degree of depression and other emotional or mental health issues also increased with the severity of hearing loss. However, a study published in the *Archives of Gerontology and Geriatrics* found for a cohort of patients 65 and older, after three months of using a hearing aid, all patients showed significant improvement in their psychosocial and cognitive conditions. States should factor these data into their decisions in future years whether cover hearing aids if HHS does not regulate coverage into the EHB.

V. Establishing Limits on Rehabilitative and Habilitative Services and Devices

When evaluating the coverage limitations on and exclusions of rehabilitative and habilitative services and devices, states should ensure these decisions are evidence based and not arbitrarily imposed to reduce short term cost to the health plan. Section 1302(b)(4)(B) of the Affordable Care Act explicitly prohibits EHB coverage decisions and benefit designs that discriminate against individuals based on disability. Section 1302(b)(4)(D) further prohibits any service established as essential from being subject to denial based on disability.

States must carefully evaluate both quantitative and non-quantitative limits on services and devices to ensure such limits do not restrict access to essential health benefits and violate these nondiscrimination requirements of the ACA. Patient’s individual needs should be the foundation of coverage decisions. Additionally, states must ensure an appropriate balance of coverage between categories of benefits under the ACA, meaning that coverage for rehabilitative and habilitative benefits should be no more restrictive than other benefit categories in the state’s EHB package.

Nondiscrimination and Medical Necessity

The ACA does not require the HHS Secretary to establish a uniform definition of medical necessity but the nondiscrimination provisions mentioned above provide strong protections for people with disabilities and chronic conditions with respect to coverage of benefits under the

EHB. To ensure plan limits and coverage decisions are in compliance with the nondiscrimination requirements for the essential health benefits and do not restrict patients' access to evidence based, individualized care, states should consider the following:

- The focus of many benefits for people with disabilities and other chronic conditions is to improve a patient's health status through improvement in their ability to function in daily life. The focus is not on "curing" the condition but rather on enabling, improving, maintaining or preventing deterioration of a patient's capacity to function. Coverage decisions, therefore, must include consideration of an individual's functional needs.
- Coverage decisions must refer to the individualized care needs for a particular patient, and hence entail an individual assessment rather than a general determination of what works in the ordinary case. This is critical for people with disabilities whose conditions (or combinations of conditions) often affect individuals in very different ways. (See, *Defining Medical Necessity*, Janet L. Kaminski, Attorney <http://www.cga.ct.gov/2007/rpt/2007-r-0055.htm>.)
- 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. Use of the best evidence available should be the standard. A *lack* of Level I medical evidence does not prove the service or device ineffective or unnecessary. This is particularly important with treatments that address low prevalence conditions or conditions that are difficult to assess and treat, such as traumatic brain injury and other similar conditions.

Health plans should not use arbitrary visit limits or other limitations or exclusions to impede or intrude on the patient and physician relationship, interfere with communication regarding the treatment options between the patient and physician, prevent access to rehabilitation or habilitation altogether, or stop rehabilitation or habilitation prematurely.

The complex nature of disabilities and chronic diseases often leads to a wide breadth of treatment from a range of providers. Services are often considered appropriate as long as:

- Separate and distinct goals are documented in the treatment plans of physicians, nurses and therapists providing concurrent services;
- The specific services are non-overlapping; and
- Each discipline is providing some service that is unique to the expertise of that discipline and would not be reasonably expected to be provided by other disciplines.

States should review plans' proposed limits and exclusions to ensure coverage decisions focus on the individualized health care needs of each particular patient and comply with all nondiscrimination requirements set forth under the law. Evaluation of plans' limits and exclusions should consider more than just physical health but also a person's ability to function in his or her environment.

Health care interventions should enhance, maintain, and prevent deterioration of cognitive and physical functioning to enable individuals with disabilities and other chronic conditions to live as independently as possible, to attain and maintain employment, avoid homelessness, avoid medical indigence, reduce lifetime cost of care, reduce caregiver burden and attendant care requirements, improve overall health and quality of life, and participate in the community to the maximum extent of their abilities and capabilities. In addition, it is important to note that the rate of progress across time and developmental expectations for the growing child are also highly variable and specific to the individual. Recovery is often divergent qualitatively and quantitatively, and as such is not always predictable.

REHABILITATIVE AND HABILITATIVE SERVICES AND DEVICES EVALUATION CHART

The next few pages contain a simple chart intended to assist states in their evaluation and enhancement of benchmark plan coverage for rehabilitative and habilitative services and devices. The chart lists typical rehabilitative and habilitative benefits across the left side and coverage qualifiers across the top. With information about their benchmark plans, State leaders can complete the chart and use it to help assess the level of coverage for these benefits and identify necessary improvements to bring the plan into compliance with the ACA.

If you have any questions about the chart or other sections of the open letter, please contact Theresa Morgan, member of the CCD Board, at Theresa.Morgan@ppsv.com or 202-349-4243. Ms. Morgan can direct your questions to our coalition specialists on rehabilitation and habilitation services and devices.



REHABILITATIVE AND HABILITATIVE SERVICES AND DEVICES EVALUATION CHART

Benefit	Inpatient	Outpatient	Quantitative Limits	Non-Quantitative Limits	Minimum Stay	Exclusions
	Inpatient Benefit Covered or Not Covered?	Outpatient Benefit Covered or Not Covered?	Explain limits, if any	Describe Limits, if any (prior authorization, referral required)	If applies, please enter the Minimum Stay (in hours) as a whole number	Enter any Exclusions for this benefit
Rehabilitation Benefits						
Physician Services						
Inpatient Rehabilitation Hospital Services						
Rehabilitation Nursing Services						
Physical Therapy						
Occupational Therapy						
Speech-Language Pathology and Audiology						
Cognitive Therapy						

	Benefit	Inpatient	Outpatient	Quantitative Limits	Non-Quantitative Limit	Minimum Stay	Exclusions
	Psychiatric Rehabilitation						
	Recreational Therapy						
	Respiratory Therapy						
	Music Therapy						
	Orthotics and Prosthetics						
	Prosthetic Devices						
	Durable Medical Equipment						
	Low Vision Aids						
	Hearing Aids and Assistive Listening Devices						
	Augmentative Communication Devices						
	Other services and devices that are medically necessary and prescribed by a practitioner as part of a plan of care						

	Benefit	Inpatient	Outpatient	Quantitative Limits	Non-Quantitative Limit	Minimum Stay	Exclusions
		Inpatient Benefit Covered or Not Covered?	Outpatient Benefit Covered or Not Covered?	Explain limits, if any	Describe Limits, if any (prior authorization, referral required)	If applies, please enter the Minimum Stay (in hours) as a whole number	Enter any Exclusions for this benefit
Habilitation Benefits							
	Physician Services						
	Inpatient Hospital Services						
	Nursing Services						
	Physical Therapy						
	Occupational Therapy						
	Speech-Language Pathology and Audiology						
	Cognitive Therapy						
	Developmental Services						
	Recreational Therapy						
	Respiratory Therapy						
	Music Therapy						

	Benefit	Inpatient	Outpatient	Quantitative Limits	Non-Quantitative Limit	Minimum Stay	Exclusions
	Orthotics and Prosthetics						
	Prosthetic Devices						
	Durable Medical Equipment						
	Low Vision Aids						
	Hearing Aids and Assistive Listening Devices						
	Augmentative Communication Devices						
	Other services and devices that are medically necessary and prescribed by a healthcare practitioner as part of a plan of care						