Coverage of Habilitation Services and Devices in the Essential Benefits Package under the Affordable Care Act

I. Executive Summary

Habilitative and rehabilitative services and devices are mandated as essential health benefits ("EHB") in Section 1302 of the Patient Protection and Affordable Care Act (ACA), Pub. L. 111-148. It is critical that the regulations on the EHB package explicitly establish appropriate coverage of these benefits in a manner that is consistent with the intent of the statute and the needs of people with disabilities and other conditions that require habilitation services and devices.

In setting the EHB package, the Institute of Medicine (IOM) recently recommended that the HHS Secretary start with the benefit package of the typical small employer plan, add to it benefits listed in the ten categories of the law not otherwise covered by the small employer plan, including habilitation services and devices, and then balance that package against the nondiscrimination protections and an actuarial analysis to limit costs. In deciding which specific benefits to include under habilitation, the IOM recommended that the Secretary look to the Medicaid program as a guide.

The HAB Coalition supports this approach and further recommends that the HHS Secretary seriously consider the definition of habilitation services and devices developed by the National Association of Insurance Commissioners (NAIC). This definition, along with consideration of the types of habilitation services that Medicaid covers, would serve as a sound foundation on which to align a habilitation coverage standard under the EHB package. The HAB Coalition recommends that, once the foundation is laid, HHS continue to assess coverage of habilitation services and devices to ensure that children and adults are able to access the habilitation services and devices they need.

The extent of coverage of habilitation services and devices should at least be in parity with rehabilitation coverage. In other words, regardless of the diagnosis that leads to a functional deficit in an individual, the coverage and medical necessity determinations for rehabilitative and habilitative services and devices should be based on clinical judgments of the effectiveness of the therapy, service, or device to address the deficit. Such judgments should be made on a periodic basis to ensure the individual continues to benefit from the rehabilitative or habilitative intervention.

Limitations in benefits of any kind should be based on the best available evidence and such decisions should be made by professionals with sufficient knowledge and expertise in the rehabilitative and habilitative fields to render informed decisions. Services under the EHB should not be denied under private insurance in an instance where a child is also receiving certain habilitation services in an educational setting.

II. Habilitation Defined

Habilitation services 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 familiar with rehabilitation services and devices, which can include a wide range of services, therapies, devices and supports, including physical therapy, occupational therapy, speech-language pathology and audiology services, and other therapies that improve function and support independent living within the community, as well as durable medical equipment, prosthetic limbs, orthopedic braces, and augmentative communication devices.

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 that has been acquired but then lost or impaired due to illness, injury, or disabling condition.

NAIC recently recommended definitions for medical and insurance-related terms to the HHS Secretary. These definitions were subsequently published in a proposed rule that defines medical and insurance terminology for consistent application by consumers. See, 76 Fed. Reg. 52,442; 76 Fed. Reg. 52,475. Due to the inclusion of habilitation services in the statutory definition of the essential health benefits package under PPACA, NAIC separately defined habilitation from rehabilitation.

The definition of ***habilitation*** reads:

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

The definition of ***rehabilitation*** reads:

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

The Medicaid program 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 "mental retardation," 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.

Notably, the IOM recommends that the Secretary look to state Medicaid programs as a guide for defining what is covered under the EHB's habilitation benefit. Specifically, 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)

Along with the Medicaid analysis recommended by the IOM, these NAIC definitions are important in helping to establish the parameters 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. The HHS Secretary should ensure periodic review of the scope of the habilitation benefit in future years to ensure it is meeting the needs of people requiring these services and devices.

III. Examples of Differences Between Habilitation and Rehabilitation

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 had speech 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.

- A physical therapist providing a strength training program for an individual with a congenital spine condition to prevent osteoporosis and decline in function as they age is habilitation, while a strengthening program for individuals who recently acquired a spinal cord injury would be rehabilitation.

- An occupational therapist teaching children who have a stroke *in utero* or children or 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.

- A therapist or orthotist 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.

IV. Legislative History of the Habilitation Benefit

The category of "rehabilitative and habilitative services and devices" was included in every version of the ACA in every House and Senate Committee that considered the legislation, including the leadership bills that were compiled prior to floor action. At no time was an amendment offered or adopted to strike coverage of habilitation services and devices from the EHB package. The final version of the ACA ultimately included this category of benefits within a short list of other categories for a total of ten essential categories of benefits that must be covered. Out of all the categories that Congress could have chosen to specifically list in the statute, it chose rehabilitative and habilitative services and devices. This is highly significant legislative history and clearly evinces Congressional intent to ensure these benefits are covered in the EHB package.

Congressional intent is also recorded in the Congressional Record 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 as well. [Congressional Record, H12896 (November 7, 2009).]

Consistent with congressional intent, it is inappropriate to deny coverage to a person who that has never gained the capacity to speak at age-appropriate levels, or has a hearing loss, simply because they have never possessed the ability to speak and hear, and did not lose these functions through an accident or injury. The same is true for the child born with a disabling condition and concurrent deficits in physical and psycho-social functioning not attributable to an accident or injury. Like rehabilitation services, habilitation services 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.

It is arbitrary for insurance policies to cover medically necessary rehabilitative services for individuals with disorders that manifest in adulthood (e.g., Parkinson's disease) but not cover medically necessary habilitative services for individuals with disorders simply because they manifest in early childhood (e.g., speech and language disorders). Congressional intent and the plain statutory language of the ACA mandate that qualified health plans cover habilitation therapies, services and devices. ACA, Section 1302(b)(1)(G). ACA also requires that benefit design must not discriminate against individuals because of their age or disability. ACA, Section 1302(b)(4)(B). In addition, members of Congress have decades of experience with the term habilitation, in part, because of the use of this term within the Medicaid statute.

V. Legal Framework of Benefit within ACA and its Protections

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 [Section 1201 of the ACA], as well as the general nondiscrimination section of the law found at Section 1557 of ACA. These provisions also include the requirement that the Secretary must ensure that essential benefits reflect an "appropriate balance" of benefits covered across the categories [Section 1302(b)(4)(A) of the ACA], that there is parity across the categories of benefits [Section 1302(b)(4)(A) of the ACA], 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. [See Section 1302(b)(4)(B) of the ACA.]

Further, the Secretary must take into account the health care needs of diverse segments of the population, including children, persons with disabilities, and other groups. [See Section 1302(b)(4)(C) of the ACA.] This language seems to speak directly to the need to include in the EHB package services and devices such as habilitation. In addition, the Secretary must ensure that essential health benefits 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. [See Section 1302(b)(4)(D) of the ACA.]

Given these legal parameters 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 appropriately cover 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 ACA law. These legal parameters also mean that people with disabilities and chronic conditions who need rehabilitative and habilitative services and devices should not face

unreasonably restrictive coverage policies or arbitrary time constraints that hinder their ability to achieve results through appropriate treatment. The decision to cover rehabilitation services—where a person has lost a skill or function due to illness or injury—and not cover habilitation because the person has not yet acquired a skill or function due to a congenital or early acquired condition, is arbitrary and comparable to rejecting coverage due to a pre-existing condition, which is prohibited by the ACA.

Based on the legal framework of ACA and the law's many protections for people with disabilities and chronic conditions, an EHB regulation that entirely omits coverage of habilitation services and devices based on an unclear understanding of the level of coverage under the typical employer plan would be contrary to the ACA statute. The ACA's overarching goal is to eliminate discrimination in private insurance based on health status, to eliminate pre-existing condition exclusions, and to design a benefit package that, among other things, meets the needs of children and adults with disabilities.

The Institute of Medicine's report entitled "Essential Health Benefits: Balancing Coverage and Cost," explicitly recognizes the obligation of the HHS Secretary to look beyond the typical employer plan and add benefits to the EHB package that are listed in the statute but not commonly included in the typical small employer plan. In fact, the IOM report states that, "The committee concluded that the scope of benefits eligible for coverage should be guided by scientific evidence about which…treatments…are effective in improving or maintaining people's health and functioning." See IOM Report at 9-2.

The IOM makes numerous references in its report to the need to expand coverage to habilitation benefits. For instance, the IOM states:

> "Congress, however, sought to remediate what it saw as shortcomings in current coverage by pulling out certain categories to ensure that they were covered, such as maternity services, mental health and substance abuse disorder services, and habilitative services. Habilitative services are distinct from rehabilitation, in that it is designed to help a person first attain a particular function, versus restoring a function…While most of the broader categories of ACA are in typical plans, it is less clear whether habilitation, wellness and chronic disease management programs, and pediatric oral and vision are, and even if they are, what services are affected…Nonetheless, it appears the typical employer plan will have to be expanded to accommodate the 10 categories of care." IOM Report on Essential Benefits: Balancing Coverage and Cost, p. 81-82 (2011).

VI. The Department of Labor and IOM Reports

On April 15, 2011, the U.S. Department of Labor submitted a report to the Department of HHS entitled, "Selected Medical Benefits" in connection with the PPACA requirement that the EHB package be equal to the typical employer plan. The report was designed to inform the HHS Secretary as to the contents of a health benefit package offered by a typical employer. The report contained virtually no useful information on the extent to which employer plans cover habilitative benefits.

The shortcomings of this report are well established. The Department of Labor was limited to using its existing survey tool, the National Compensation Survey (NCS) administered by the Bureau of Labor Statistics (BLS). This survey does not ask specific questions about rehabilitation or habilitation coverage. Employers are not mandated to report information about their benefit packages and employers that do report are not required to submit data in a uniform manner. The survey, therefore, combines information about benefits at varying levels of detail, making comparisons between plans difficult.

The fact that the Department of Labor was not instructive on the level of habilitation coverage does not mean that employer plans do not cover habilitation benefits. Strong anecdotal information from provider and consumer groups suggest that while many plans arbitrarily deny coverage for these benefits and find loopholes to avert coverage, many plans do, in fact, cover these benefits in a variety of ways, either through the rehabilitation benefit, or through a "substitution" of benefits approach. Many times coverage turns on the effectiveness of the patient or patient's parent or advocate making a persistent case for coverage.

In contrast, the IOM report released in early October 2011 found that one group plan out of three that it surveyed did, in fact, provide coverage of habilitation services, particularly in states that have established habilitation benefit mandates such as the State of Maryland. Maryland includes habilitation coverage for children under 19 years of age with congenital or genetic birth defects in its Standard Health Benefit Plan Requirements for Small Businesses. In addition, habilitation services and devices are also covered in many instances under autism benefit provisions. Standard small business and individual plans offered by WellPoint Anthem Blue cover "habilitative services" and WellPoint explains the benefit in the following manner:

> "Habilitation: This is a broad category and there is likely to be variation in what an insurer defines as habilitative. We do not have a specific habilitation benefit or exclusion but we do have "habilitative" services that may be covered. We were defining habilitative care as a category that includes services such as:
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> 1) Early intervention;
> 2) Autism mandates (i.e. improving language skills);
> 3) Congenital defect mandates; and
> 4) Home health care services provided by a licensed home health agency (i.e. skilled nursing and physical therapy) not services such as meal preparation, bathing, and medication management.)" See, IOM Report, Essential Health Benefits: Balancing Coverage and Cost, Appendix C, page 21 (2011).

VII. State Mandates on Habilitation Services

Many states have recognized the importance of habilitation and passed legislation requiring private health insurance to provide these services. Of the 28 states that have enacted autism related benefit mandates, 14 states use the term "habilitative or rehabilitative care" in the state insurance statutes requiring coverage of benefits for individuals with autism spectrum disorders. In many of the states—including Illinois, Kentucky, Louisiana, Maine and New Mexico—the term "habilitation" is defined in terms such as:

> "any professional, counseling and guidance service and treatment program, including applied behavior analysis that is necessary to develop, maintain and restore to the maximum extent possible the function of an individual." See, e.g, 215 ILCS 5/356z.14(i)(3).

Many of these state statutes also require coverage of a broad list of therapies including occupational therapy, physical therapy, speech-language pathology services, and behavioral therapies to help individuals acquire and retain functions in order to live as independently as possible in the home and community.

As already stated, some states such as Maryland and Illinois have passed legislation requiring health plans to provide habilitation services to children with congenital, genetic or early acquired disorders under the age of 19. In these states, habilitation services are defined as occupational therapy, physical therapy, speech-language pathology services and other services prescribed by the treating physician to enable a child to enhance function. See, e.g., Md. INSURANCE Code Ann. § 15-835(a)(3).

VIII. Response to Arguments Against Coverage of Habilitation for Children with IEPs

An often cited reason for noncoverage of habilitation services and devices by private insurance plans in the current market is that children with disabling conditions can obtain access to habilitation services in the schools under the Individuals with Disabilities Education Act (IDEA). While habilitation services can be provided to children under an Individualized Education Plan (IEP) under IDEA, those services assist children with disabilities to *benefit from special education*. IDEA specifically prohibits coverage of "medical services," except for diagnostic and evaluation purposes. (See, Section 602 (26) of IDEA.) Private health plans should cover necessary habilitation services without regard to inclusion of habilitation services in a child's Individualized Education Plan.

IX. Recommendation for Habilitation Coverage under the EHB Package

Congress intended the ACA's essential health benefits package to meet the needs of individuals requiring rehabilitation and habilitation services and devices, and specifically included language in the law to this effect. However, ACA states that the EHB package should be equal to the "typical employer plan." This limitation must be balanced against the strong nondiscrimination protections for people with disabilities and chronic conditions in the statute, i.e., that benefit design must not discriminate against individuals because of their age or disability. ACA, Section 1302(b)(4)(B).

In setting the EHB package, the Institute of Medicine recently recommended that the HHS Secretary start with the benefit package of the typical *small* employer plan, add to it benefits listed in the ten categories of the law, including habilitation services and devices, and then balance that package against the nondiscrimination protections and an actuarial analysis to limit costs. In deciding which specific benefits to include under habilitation, the IOM recommended that the Secretary look to the Medicaid program as a guide.

The HAB Coalition supports this approach and further recommends that the HHS Secretary seriously consider the definition of habilitation services and devices developed by the National Association of Insurance Commissioners (NAIC). This definition, along with consideration of the types of habilitation services that Medicaid covers, would serve as a sound foundation on which to align a habilitation coverage standard under the EHB package. In the future, HHS should continue to assess coverage of habilitation services and devices to ensure that children and adults are able to access the habilitation services and devices they need.

The extent of coverage of habilitation services and devices should at least be in parity with rehabilitation coverage. In other words, regardless of the diagnosis that leads to a functional deficit in an individual, the coverage and medical necessity determination for rehabilitative and habilitative services and devices should be recommended based on clinical judgment of the effectiveness of the therapy, service, or device to address the deficit. Such judgments should be made on a periodic basis to ensure the individual continues to benefit from the rehabilitative or habilitative intervention.

Limitations in benefits of any kind should be based on the best available evidence and such decisions should be made by professionals with sufficient knowledge and expertise in the rehabilitative and habilitative fields to render informed decisions. Services under the EHB should not be denied under private insurance in an instance where a child is also receiving certain habilitation services in an educational setting. School-based services (typically covered under an Individualized Education Plan pursuant to the Individuals with Disabilities Education Act (IDEA), are designed to address deficits related to academic performance in children with disabling conditions. Habilitation services and devices should be provided by qualified, licensed, and certified/accredited providers and suppliers to help ensure quality care.

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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 EHB regulations must be consistent with Congressional intent and must secure the level of access to care that is embedded in the statute. These benefits are simply too important to the disability and chronic illness community to omit or inappropriately limit in establishing regulations to implement this section of the law.

The undersigned organizations comprise the Habilitation Benefits Coalition (the "HAB Coalition") which actively works with Congress, the Administration, and other stakeholders to secure appropriate coverage of the category of benefits known as "rehabilitative and habilitative services and devices" in the essential health benefit (EHB) package under the Patient Protection and Affordable Care Act (ACA), Section 1302.

The following members of the HAB Coalition endorse this position statement:

American Academy of Pediatrics
American Academy of Physical Medicine and Rehabilitation
American Association for Homecare
National Association of Children's Hospitals
American Association of People with Disabilities
American Association on Health and Disability
ACCSES
American Heart Association/American Stroke Association
American Music Therapy Association
American Network of Community Options and Resources
American Occupational Therapy Association
American Physical Therapy Association
American Speech-Language-Hearing Association
American Therapeutic Recreation Association
Association of University Centers on Disabilities
Autism Speaks
Brain Injury Association of America
Christopher & Dana Reeve Foundation
Easter Seals
Family Voices
Hearing Loss Association of America
March of Dimes
National Association of Councils on Developmental Disabilities
National Association for the Advancement of Orthotics and Prosthetics
National Association of County Behavioral Health & Developmental Disability Directors
National Down Syndrome Society
The Arc of the United States
United Cerebral Palsy

October 25, 2011

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