



**CONSORTIUM FOR CITIZENS  
WITH DISABILITIES**

**Institute of Medicine  
Committee on Development of the Essential Benefits Package  
Under the Affordable Care Act**

**Testimony of**

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**On behalf of**

**Consortium for Citizens with Disabilities  
Long Term Services and Supports and Health Task Forces**

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Thank you for this opportunity to testify to the Committee regarding the meaning of the term “habilitation” and the importance of habilitation services to the disability community as you move forward in your work on implementing the Affordable Care Act.

Habilitation services have been an important component of the Medicaid program for many years within the home and community-based services (HCBS) waiver and other community-based services programs. For this reason, the Medicaid definition provides a good starting point for an understanding of the purpose of habilitation services.

**Medicaid definition**

Medicaid defines habilitation services as services designed to assist participants in acquiring, retaining and improving the self-help, socialization, and adaptive skills necessary to reside successfully in home and community-based settings.

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 (“mentally retarded”) or related conditions (primarily cerebral palsy, epilepsy, and autism). (While the statutory language of “mentally retarded” has not yet been updated in the statute, we will use the preferred, updated term “intellectual disability”.)

These therapies, services or supports enable a person with a significant disability to acquire, retain, improve or prevent deterioration of activities of daily living (ADL) or instrumental activities of daily living (IADL) skills and function over time. The services and supports may be delivered by means of hands-on, cueing, or supervision. These services and supports may be needed across the age span. Habilitation therapies include occupational therapy, physical therapy, speech therapy, behavioral therapies, and other services and supports.

Providing habilitation services prevents costly institutionalization and enables people to function better in the community. Habilitation services are critical to the success of young children with disabilities who need to acquire essential skills to ensure successful development and learning and for adults to live independently in the community. The provision of habilitation services can also prevent frequent hospitalization or emergency room visits because people are maintaining their function. The range of habilitation services can include social skills training, communication skills, behavior management, medication management, nutritional guidance, and personal hygiene skills.

### **Specific examples of habilitation services**

A wide range of services, therapies and supports are examples of habilitation. Habilitation may include teaching basic social skills to someone who developed schizophrenia at an early age or teaching people with developmental disabilities how to administer their own medication safely and, where appropriate, teaching them what the side effects are of their medication and how to order their medication. Habilitation may also include teaching people about their rights to privacy; to use a phone; to ask their healthcare professionals questions and expect to get answers; and how to reliably report how they are feeling, assistance that is vital to address health issues so individuals with significant disabilities can live independently in the community.

### **Comparing habilitation and rehabilitation**

Unfortunately private health insurance often distinguishes between coverage of rehabilitation and habilitation not based on medical necessity or the essential nature of the therapy or service but based on whether the individual seeking the service is acquiring a skill or recovering a skill. There are many anecdotal examples of this unfair practice in which a service might be approved for rehabilitation purposes but not for habilitation.

- An occupational therapist teaching children or adults with developmental disabilities the fine motor coordination required to 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 dress themselves would be rehabilitation.
- A speech therapist 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.
- A physical therapist making splints for a child or an adult with a chronic condition, such as arthritis, to prevent hand deformities would be habilitation, while making splints for a child or adult who has had hand surgery for a torn tendon repair would be rehabilitation.

Children and adults with disabilities and significant health care needs require both habilitative and rehabilitative services and supports. The policy of insurers to deny coverage for habilitative services, supports, and therapies discriminates against many children and adults who need these services and denies access to medically necessary and appropriate interventions.

### **Congressional intent**

Congress clearly intended to include the habilitation services and supports used primarily by people with developmental disabilities as part of the essential benefits package. Members of Congress are familiar with the term from its use in the Social Security Act, specifically the Medicaid program. The category of “rehabilitative and habilitative services and devices”, as included in the Affordable Care Act, is a broad category of benefits, services, therapies, devices, and supports. Using the terms together indicates that acquiring and retaining function were also critical aspects of the benefit category. This is particularly important to the class of therapies that can be both habilitative (acquiring, retaining, and improving) and rehabilitative (maintaining and improving) depending on the needs of the individual.

Congressional intent involving the definition of the term “rehabilitation and habilitation services and devices” can be seen in a floor statement offered by Congressman George Miller, the Chairman of the House Committee on Education and Labor. He 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)]

Similarly, Congressman Pascrell, a co-chair of the Congressional Brain Injury Task Force, included the following in his House floor statement: “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 as a result of an illness, injury, disorder or other health

condition. Such services also include training of individuals with mental and physical disabilities to enhance functional development.” [Congressional Record, E462 (March 23, 2010)]:

These statements of Congressional intent reflect an evidence-based understanding of the medical necessity of rehabilitative and habilitative services for individuals with disabilities and chronic conditions. Evidence indicates the need to focus on services that are designed to assist people with disabilities acquire self-help, socialization, and adaptive skills, and to restore function, maintain functioning, as well as prevent deterioration in functioning.

### **NAIC**

The National Association of Insurance Commissioners (NAIC) recognized this approach when they adopted the language below to describe habilitation to consumers.

“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.”

### **State mandates**

Many states have recognized the importance of habilitation and passed legislation requiring private health insurance to provide these services. Of the 23 states that passed autism related mandates, 14 states used 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 the term is defined 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 (states include Illinois, Kansas, Kentucky, Louisiana, Maine and New Mexico). Many of these state statutes also require a broad list of therapies including occupational, physical, speech, and behavioral to be provided to help individuals acquire and retain function.

In addition, Illinois and Maryland 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 therapy and other services prescribed by the treating physician to enable a child to enhance function.

These state examples illustrate aspects of the gap in private health coverage that Congress addressed by including rehabilitative and habilitative services and devices in the essential benefits packets.

What constitutes the scope of the essential benefits package is a critical issue to people with disabilities and chronic conditions. It will determine whether insurance plans within the exchanges meet the needs of individuals confronted with an illness, injury, disability, or other health condition, or whether those persons will be forced to pay out-of-pocket for needed care or go without needed care.

On behalf of CCD, I appreciate the opportunity to provide comments today and look forward to working with you on this important task. I am happy to answer any questions.