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on the Determination of the Essential Benefits Package

under the Affordable Care Act.

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Members of the IOM Committee on Essential Benefits:

Thank you for the opportunity to testify on the important issue of defining criteria to assess the essential benefits package under the Affordable Care Act, particularly criteria for establishing the scope of covered services under the category of "rehabilitative and habilitative services and devices." I speak on behalf of the Consortium for Citizens with Disabilities (CCD) and I co-chair the Health Task Force of that national disability and rehabilitation coalition.

What constitutes the scope of the essential benefits package is a critical issue to people with disabilities and chronic conditions. It will determine whether insured persons have their needs met when confronted with an illness, injury, disability, or other health condition, allowing that person to speed recovery, improve functioning, live more independently and return to work; or whether that person will be forced to pay out-of-pocket for needed care, go without needed care, or ultimately, exit the private market altogether and have no choice but to enter the publicly supported programs such as Medicare and Medicaid, as many people with disabilities do today.

The essential benefits package must include benefits that address the *functional* needs of insured persons. In 1998, the President's Commission on Health Care Quality stated that, "The purpose of the health care system must be to continuously reduce the impact and burden of illness, injury, and *disability* and to improve the health and *functioning* of the people of the United States." For many people with health care challenges, rehabilitative and habilitative services and devices are equivalent to the provision of antibiotics to a person with an infection—both are essential medical interventions.

Essential benefits must clearly include trauma care, hospitalization, and physician services that save life and services like kidney dialysis and organ transplantation that sustain life. But they also must include services and devices that are necessary in the post-acute care environment. These services allow people to regain, maintain, and prevent deterioration of their ability to function, live as independently as possible, and participate in the community, whether they are children, adults or seniors.

For instance, I have two artificial legs as a result of a car accident long ago. My health status is very good, but I have a major functional limitation that is only addressed through good prosthetic limb care. If I did not have access to inpatient rehabilitation hospital care, outpatient therapy, and prosthetic limb care, I would be a very different person today. Millions of Americans are in this same position due to a wide variety of health conditions or disabilities and they are counting on the essential benefits package to meet their health and functional needs as well.

The contents of the essential benefits package will literally determine whether or not the Affordable Care Act (ACA) works for people with disabilities and chronic conditions. CCD would like to underscore several main points for the Committee's consideration:

1. **The Statute Requires Coverage of Rehabilitation:** Out of all the benefits Congress could have listed in the short list of categories in the ACA statute, "rehabilitative and habilitative services and devices" was specifically included. We view this as highly significant and the clearest form of Congressional intent that these benefits must be included in the essential benefits package. Whatever limitations exist in the statute, these benefits must be considered essential and covered by private health plans.

2. **The Statute Establishes Major Principles to Guide the Development of the Essential Benefits Package to Meet the Needs of People with Disabilities:** The ACA statute lists a number of essential benefits in addition to rehabilitation that are critical to people with disabilities and chronic conditions. Typical employer plans do not do a particularly good job of covering some of these benefits and that is probably why Congress felt compelled to list them specifically. The statute also requires:

    a. An "appropriate balance" among the ten categories of essential care. We view this, in part, as a prohibition of unreasonable restrictions and exclusions in one benefit category (e.g., rehabilitation) if similar restrictions are not placed on other categories;

    b. Benefit design that does not discriminate against, and takes into account the health care needs of, persons with disabilities. We view this language as a strong counterbalance to the general limitation regarding the typical employer plan. To ensure benefit designs are not discriminatory, the IOM should recommend criteria regarding risk adjustment. As part of this, health plans should be required to disclose severity-adjusted quality indicators of access, outcomes, consumer satisfaction and disenrollment rates.

    c. Essential 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. This is very powerful language that is designed to ensure that normative judgments about the quality of life of a person with a disability are not used against people with disabilities when setting the essential benefits package.

3. **Principles, Criteria, and Methods Need to be Designed to Ensure that Essential Benefits Meet the Intent of the Statute:** The statutory language itself is a strong framework for an appropriate essential benefits package. But the Secretary should meet with relevant stakeholders, establish opportunities for testimony and public comment from interest groups, and issue a proposed and final rule. The Secretary should be required to certify that the benefit package meets the statutory requirements.

More importantly, the Secretary should establish a public, transparent process to advise HHS on the contents of the package. We recommend the appointment by the President of a formal Advisory Committee organized under the Federal Advisory Committee Act (FACA) to help effectuate the statute. This would include stakeholder representation on the Committee itself (including people with disabilities and their providers) as well as holding open public meetings and opportunities for the public to testify and provide comment. The committee would also recommend whether the Secretary should certify the essential benefits package.

This FACA committee should also play a key role in updating the benefit package by establishing a formal process to entertain specific requests for benefits coverage. The benefit package should be updated and recertified annually to reflect changes in the evidence base as well as new and emerging treatments, and proposed and final rules should be issued.

4. **Defining the Category of "Rehabilitative and Habilitative Services and Devices":** The term, "rehabilitative and habilitative services and devices" is rarely used in private health plans' benefit packages. This term was created by Congress to describe a category of care that was intended to be considered essential. Most of these benefits are routinely covered by public programs and many private plans.

   Congress clearly intended this category of benefits to be included in the essential benefit package because they included it in the statute. There are no committee reports to further indicate what Congress specifically meant by this category but there is important legislative history in the form of two floor statements delivered at the time the House passed the final bills. I have attached both statements to this testimony for your review, one from Chairman George Miller (D-CA) and one from Congressman Bill Pascrell (D-NJ) focusing on brain injury and the importance of cognitive rehabilitation. Both statements are completely consistent with CCD's view on essential benefits.

   The term "rehabilitation and habilitation services and devices" means:

   a. Rehabilitation therapies provided from a continuum of accredited programs and treatment settings based on intensity of service that help improve, maintain, and prevent deterioration of function. (Settings include inpatient rehabilitation hospitals, LTACHs, SNFs, long term residential transitional rehabilitation programs, outpatient therapy, home care, and community based programs.);

   b. Habilitation therapies are services or supports that 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 functions over time; and

c. Durable medical equipment, prosthetic limbs, orthopedic braces, and other assistive technologies to reduce functional deficits in mobility, communication, hearing and vision.

As to medical necessity, these services should be directed by a physician in consultation with the rehabilitation team and the patient, should be provided at a level of intensity to meet the individual's needs, and should not be arbitrarily limited or denied. The need for continued rehabilitation or habilitation treatment should be reassessed on a periodic basis and limits or denials should be based on an individual assessment rather than a general determination of what works in the ordinary case. Complex or advanced technologies, prosthetics, orthotics, and durable medical equipment should be covered if they are reasonable and necessary to meet the functional needs of the individual and are consistent with contemporary medical practice.

5. **Department of Labor's Assessment of the Typical Employer Plan:** CCD is concerned that the Department of Labor's efforts to identify the contents of the "typical employer plan" may fall short in terms of a number of important benefit categories listed in the statute. We understand that the Department has no funding to perform a specific benefits survey of employers but is relying on its annual employer survey results. There are several problems with this approach. Employers are not obligated to report what they offer in their benefit packages, there are no standardized formats that employers use to report data to the Department, and there are no questions requesting data on a number of categories listed in the ACA, including the rehabilitation category. The IOM, and the HHS Secretary, must take this lack of reliable data into account when determining the impact the "typical employer plan" limitation will have on the meaning of the essential benefits package.

6. **Value of Rehab in a Reformed Health Insurance System:** CCD believes that the IOM should consider the new set of insurance rules that will accompany the essential benefits package as it makes recommendations to the HHS Secretary. Under the current private insurance system, there is a strong incentive for private payers to "constructively discharge" enrollees who have significant health care needs by denying benefits, restricting and limiting care, and dramatically increasing premiums, especially in the individual market. This leaves these individuals with no choice but to enroll in Medicare or Medicaid. In this environment, the incentive is to limit therapy services to an arbitrary number of visits, place unrealistic caps on durable medical equipment, and limit prosthetic limbs to one per lifetime.

Under the new insurance rules of guaranteed issue and renewal, no lifetime or annual caps, and reasonable premiums, private plans will have a much greater incentive to provide early and intensive rehabilitative and habilitative services and devices and continue these services until they maximize the person's function. In many instances, this will be the cost-effective option in order to reduce more expensive, longer term services necessary to address functional deficits that were not adequately addressed up front. The IOM should consider this new set of incentives and reflect this in its recommendations to the HHS Secretary as to essential benefits.

Again, the definition of the essential benefits package is critical to ensure that individuals with disabilities and chronic conditions are able to receive the care they need to maximize their health, functional skills, independence, and participation in society. On behalf of the disability and rehabilitation community represented by the CCD Health Task Force, thank you for the opportunity to testify today on this very important issue.