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VIA ELECTRONIC SUBMISSION

Adam Block
Team Leader on Essential Health Benefits and Actuarial Value Working Group
Center for Consumer Information and Insurance Oversight
Centers for Medicare & Medicaid Services
U.S. Department of Health and Human Services

RE: Proposed Rule CMS-9965-P – Patient Protection and Affordable Care Act; Data Collection to Support Standards Related to Essential Health Benefits; Recognition of Entities for the Accreditation of Qualified Health Plans

Dear Mr. Block:

The undersigned members of the Consortium for Citizens with Disabilities (CCD) appreciate the opportunity to comment on the proposed rule “**Patient Protection and Affordable Care Act; Data Collection to Support Standards Related to Essential Health Benefits; Recognition of Entities for the Accreditation of Qualified Health Plans**” [CMS-9965-P] and the corresponding materials in the Paperwork Reduction Act (PRA) notice released on June 1, 2012.

CCD believes that the goal of health care reform should be to assure that all Americans, including people with disabilities and chronic conditions, have access to high quality, comprehensive, affordable health care that meets their individual needs and enables them to be healthy, functional, live as independently as possible, and participate in the community. For healthcare reform to work for individuals with disabilities, the Affordable Care Act’s (ACA) mandated benefit categories and non-discrimination provisions must be the foundation of the essential health benefits package that all Americans in the individual and small group markets will depend upon starting in 2014.

It is vital that the EHB packages be adequate to cover people with disabilities who are currently in or entering the workforce, particularly in the small group market. Restrictive coverage definitions, impediments to early intervention, and arbitrary limitations on benefits unfairly restrict access to services and benefits that enable people with disabilities to remain in or enter the workforce and live independently. A benchmark benefit package that meets the needs of working people with disabilities will place less pressure on public programs such as Medicare and Medicaid, which under the current system, often serve as the insurer of last resort once a

working person with a disability cannot continue to get access to the health benefits they need through their employer based plan.

Below are our detailed recommendations in regard to the proposed rule from a disability perspective.

1. HHS Should Detail Additional Services under Required Information (§156.120(b))

In 156.120(b) of the proposed rule, CMS proposes that certain plan issuers submit “certain benefit and enrollment information” to the Department of Health and Human Services (HHS). Since States, Exchanges and insurers will potentially use this information to “define, evaluate and provide the EHB” at the state level. CCD believes it is critical that the submitted data and descriptions encompass all services necessary for the treatment and support of individuals with disabilities and chronic conditions to be covered in the essential health benefits packages, such as rehabilitative and habilitative services, kidney dialysis and kidney care services, and mental health services.

Rehabilitative and Habilitative Services

CCD commends the inclusion of “habilitation services” as one of the listed services within the essential health benefits template (Appendix H3) accompanying the regulation in a Paperwork Reduction Act (PRA) notice. We support detailed collection of plan data on: (1) the “habilitative” benefits that are covered; (2) any specific quantitative, non-quantitative or other limits placed on habilitation benefits coverage and (3) any specific “exclusions” related to the benefit. This information will inform states, stakeholders, and plans as whether EHB package requirements are met or need to be enhanced to meet the non-discrimination standards of the ACA.

“Habilitation benefits” cover a broad array of services and settings and these should be detailed in order to ensure that data collection is adequately comprehensive for this essential benefit, which is often misunderstood or ill defined. Therefore, **CCD recommends that HHS insert the National Association of Insurance Commissioners’ definition of Habilitation Services in the data collection chart and add sub-rows specifying benefits that commonly fall under this benefit category (and that are included in the NAIC definition).** We also recommend the addition of a column to the chart that specifies the settings in which these services are covered.

Additionally, CCD recommends that there should be further definition and delineation provided by HHS between “rehabilitation” and “habilitation” services to ensure clarity about their differences.

The HHS Glossary of Terms [CMS-9982-F] published on February 14, 2012 defines habilitation as follows:

“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.” [Emphasis added.]

The HHS Glossary of Terms definition rehabilitation as follows:

“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.” [Emphasis added.]

In addition, to delineate the differences of services for rehabilitation and habilitation, CCD recommends altering the chart (Appendix H3) in the final rule to read in the following manner:

Benefit		Covered Inpatient	Covered Outpatient	Benefit Description
Habilitation Services and Devices				Health care services that help a person keep, <i>learn</i> or improve skills and functioning for daily living.
	Physical Therapy			
	Occupational Therapy			
	Speech-Language Pathology and Audiology			
	Developmental Services			
	Other Therapies and services that are medically necessary and prescribed by a physician as part of a plan of care			
	Durable Medical Equipment, prosthetics, orthotics, supplies and prosthetic devices (e.g., hearing aids, vision aids)			
Rehabilitation Services and Devices				Health care services that help a person keep, <i>get back</i> or improve skills and functioning for daily living that have been lost or impaired because a

				person was sick, hurt or disabled.
	Physical Therapy			
	Occupational Therapy			
	Speech-Language Pathology and Audiology			
	Psychiatric Rehabilitation			
	Other therapies and services that are medically necessary and prescribed by a physician as part of a plan of care			
	Durable medical equipment, prosthetics, orthotics, supplies and prosthetic devices (e.g., hearing aids, vision aids)			

Orthotics and Prosthetics

In implementing the essential health benefits provisions of the ACA, it is important that policy-makers and regulators understand basic benefits such as orthotics and prosthetics (O&P). Appropriate O&P care can mean the difference between a life of disability and dependency and a life of full function, self-sufficiency, and independence. O&P care benefits millions of people in America and aid in speedy recovery, improved functioning, independent living, and avoidance of secondary conditions.

CCD believes it is insufficient that only Durable Medical Equipment (DME) is listed under “rehabilitative and habilitative devices” within the essential health benefits template (Appendix H3 of the PRA notice). **We strongly recommend that “orthotics and prosthetics” also be explicitly listed in the essential health benefits template, separately from DME.**

The difference between DME and orthotics and prosthetics lies in the detail necessary for proper, specialized fitting. While the majority of DME items are largely product or commodity-based, orthotics and prosthetics entails a high level of clinical service by educated and trained practitioners who design, fabricate and fit custom orthoses and prostheses. House Education and Labor Committee Chairman George Miller has acknowledged Congress’ intent to include prosthetics and orthotics in the new health care law’s essential benefits package under the term “rehabilitation and habilitation services and devices,” but separately from DME. He said: **“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).

If benchmark plans are permitted to specifically limit certain benefits in material ways, such limitations and/or exclusions must:

- Be based on the best available evidence;
- Comply with all of the non-discrimination protections of the ACA;
- NOT be arbitrary in nature;
- NOT discriminate against patients based on their disability status; and,
- Be balanced with limitations or exclusions in other aspects of plan design.

End-Stage Renal Disease (ESRD) and Kidney Services

For individuals with ESRD, dialysis services and treatments are essential benefits. Dialysis care restores productive, high quality and sustainable life to the patient and interrupts the onset of diseases that could result in death. As the data collection will help inform states' essential benefit packages and these services save and sustain life, CCD strongly recommends "kidney dialysis and kidney related care" be included in the 45 benefit categories for which data will be collected using Appendix H3 of the PRA notice.

2. HHS Should Expand Data Collection Requirements to Include Additional Insurer Products, including Medicaid (§156.120(c))

The proposed rule (§156.120(b)) and the Paperwork Reduction Act (PRA) notice require the three largest small employer health insurance products in each state to report coverage data for services within the ACA's ten Essential Health Benefits (EHB) categories. Although HHS released a list of the largest three small group market products by State in January 2012, many consumer groups and other stakeholders requested more detailed information on the coverage and benefit limits, especially with regard to health benefits that are not consistently covered. These include benefits such as pediatric vision and oral care, habilitation, mental health benefits, behavioral health services, and chronic disease management services—all of which are listed in the ACA statute as essential categories of benefits and all of which are critical to the disability and chronic illness communities.

CCD applauds HHS for requiring data submission on potential benchmark plans, but we are concerned that the data collection is limited to only one of the four benchmark options available per state, and that these small employer plans will not adequately reflect all of the benefits included in the ten ACA-mandated categories of essential health benefits.

The proposed regulation do not specify how HHS and states are to develop benefits for which there is little to no data from the small employer plans. (Habilitation benefits are a prime example of this.) Some of ACA-mandated benefits may be covered by the other benchmark options—but some may not. To foster the creation of the needed data baseline on such benefits, **CCD recommends that the final rule require collection of information from a broader range of insurer products. This would provide a more comprehensive basis for comparing coverage of ACA-mandated EHB benefits under the small employer plans and how well the typical employer plan is actually reflected.**

In the case of pediatric vision and oral care, habilitation, mental health benefits, behavioral health services, and chronic disease management services, the relative lack of information on coverage in private plans places a premium on other sources to help fill this information gap. In some cases, such as the habilitation coverage and mental health services, many states' Medicaid programs consists of a wide range of skilled therapies, services, and devices provided by a variety of providers. Habilitation services in the Medicaid context are typically 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.

Notably, in their report to HHS, the Institute of Medicine recommended 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 in its report to the HHS Secretary:

“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)

CCD recommends that HHS, states and Exchanges look to the NAIC definitions and the Medicaid definition as key benchmarks for establishing the parameters of essential health benefits that are currently inconsistently covered in the small group market. In addition to detailing this process, HHS should stipulate in its final regulation the ongoing data requirements that will ensure periodic review of the scope of these benefit in future years.

3. HHS Should Add “Medical Necessity” to Information that Plans Provide (§156.120(c))

In 156.120(b) of the rule, CMS proposes that certain plan issuers submit “certain benefit and enrollment information” to HHS. Since HHS proposes to have states, Exchanges and insurers use this information to “define, evaluate and provide the EHB,” **CCD strongly recommends that CMS requires plans to provide information about their medical necessity definition and determinations process, in addition to benefit and enrollment information.**

Decisions about the medical necessity of services, especially those for people with disabilities and chronic conditions, should defer to the practitioner actually treating the patient and should only be overridden if there is evidence that such deference is not appropriate for the individual

patient. In its report to HHS, the IOM states that medical necessity determinations should be used to ensure that each individual patient receives appropriate care. According to this report, medical necessity determinations are particularly important when every service cannot be categorized as an “inclusion” and “exclusion” service and patients can qualify for coverage of non-listed services by medical necessity review. [Page 5-23 of IOM Report.]

Since plan information on certain services (pediatric vision and oral care, habilitation, mental health benefits, behavioral health services, and chronic disease management services) is either limited or inconsistent, and states are reporting difficulty in defining the scope of these benefits, consideration of coverage of non-listed benefits through a medical necessity process is critical. In addition, the IOM Report noted as a major issue that safeguards in the application of medical necessity may be needed, “particularly for special populations (e.g., children, individuals with disabilities, mental illness, or rare diseases) both in the definition of what medical necessity means and in monitoring its implementation.”

4. Ensure Accreditation Entities Use Quality Measures (§ 156.275)

The proposed rule acknowledges that the National Committee for Quality Assurance (NCQA) and the Utilization Review Accrediting Commission (URAC) are recognized as accrediting entities on an interim basis, and that a criteria-based review process will be adopted through future rulemaking. Further, the proposed rule acknowledges that URAC does not currently include clinical quality measures or patient experience ratings on a standardized Consumer Assessment of Healthcare Providers and Systems (CAHPS) survey in its accreditation standards for health plans. According to the URAC whitepaper noted in the notice, URAC’s Health Plan version 7.0 meets all PPACA requirements, including “flexible reporting” of clinical performance standards. The whitepaper also states that the requirements ensure transparency and that the definition of what is meant by “flexible reporting” should be included with the release of this version of URAC’s accreditation.

CCD believes that clinical measures should specifically capture people with disabilities and chronic conditions. This capacity is noticeably absent from the current accrediting entities. **Consideration for future organizations that will accredit health plans should also include standards for clinical quality measures that address the needs of people with disabilities and chronic conditions.** Measures of the end users’ experience with the services provided should also be included as a priority. In addition, specification is needed to define the process for provider credentialing and the standards that will be used to assure network adequacy and patient access to critical services for people with disabilities and chronic conditions.

The following areas should be addressed in the accreditation process:

- Inclusion of the end users’ evaluation of the services provided and their quality of life beyond that represented by more generic quality indicators;
- Explicit allowance of additional levels of accreditation to permit provider programs targeted to specific populations to achieve specialty recognition, such as brain injury programs, autism programs, and others; and,

- Network adequacy to ensure that patients have timely and convenient access to a range of appropriate services, number of providers, and physical accessibility to treatment.

5. Data Collection Elements Do Not Limit EHB

In the proposed regulation and PRA notice, the EHB data collection process outlined by HHS limits the data to a relatively short list of 45 benefits. This list is linked to the HHS publication of the Summary of Benefits and Coverage regulation (CMS-9982-F) that defines a number of benefit and insurance terms in layperson's language. The publication was illustrative and was not intended to serve as a notice of the official contents of the essential health benefits package nor convey that the 45 benefits were an exhaustive list of those EHB benefits to be included in Exchange plans.

The ten categories of benefits delineated in the ACA include more services and devices than are detailed in the benefits template proposed under this rule (along with the accompanying documents), such as orthotics and prosthetics, kidney dialysis, and kidney related services. Since the collection and evaluation of data for every service will initially be cumbersome, especially considering the path HHS chose to permit 50 different state EHB packages, **CCD recommends that HHS clarify in the final regulation that the benefits template in no way limits or defines the final essential health benefits packages.**

The EHB Template will prove to be a useful document for purposes of comparing small group plans within various states, but it is quite limited for purposes of defining a minimum benefits package since it omits many benefits that are currently covered in the typical employer plan (such as orthotics, prosthetics, kidney dialysis and transplants). **CCD recommends that HHS explicitly prohibit plans from narrowing current coverage to only the 45 benefits in Appendix H3 if such coverage is already more robust.** Without this instruction, it is possible that small group and individual plans in the reformed market could act to reduce current coverage, directly contradicting the spirit and purpose of the ACA.

6. States Should Report Mandated Benefit Information (Appendix H4)

In Appendix H4 of the PRA notice, HHS asks states to voluntarily submit state mandated benefit information when selecting their EHB plan. Since the federal government will subsidize all benefits for which the state has mandated coverage for a two-year period if the states choose a small group plan, it is likely states will be attracted to selecting one of these plans as the benchmark. However, very little detailed information is known about the scope and breadth of numerous services (orthotics, prosthetics, kidney dialysis, pediatric oral and vision care, and mental health services) under these private plans, and the proposed rule does not include data collection that will capture this information.

To best capture this information, **CCD recommends that states be required to report their mandates for these services to HHS.** If state mandated benefit information is not available and HHS does not require the collection of data on these benefits in the small group plans, other benchmark options, such as the FEHB plans, should be used as the benchmark for these benefits in state EHB packages.

7. Federal Oversight of States' EHB Packages

It is clear that Congress intended for HHS to have a strong role in overseeing the definition, establishment and future changes of the essential health benefits package mandated through the ACA. (Public Law 111-148, Patient Protection and Affordable Care Act, Section 1302.) State EHB packages can result in too much variation in the initial EHB packages, with some states providing inadequate coverage for people with disabilities and chronic conditions. **Therefore CCD strongly recommends that HHS establish through regulation a primary federal oversight role in the evaluation and approval of States' EHB packages.** In the proposed regulation, HHS released a template for States to report their chosen benchmark plan (Appendix H4) and the plan details. We applaud the Federal role in this process and encourage HHS to require States to obtain approval of the EHB package from the HHS Secretary before receiving federal subsidies to help cover essential health benefits. Any enhancements to the benchmark plan should be reviewed by HHS to ensure adequate, non-discriminatory coverage of essential benefits.

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Thank you for considering our recommendations on this important set of issues. Please contact CCD Health Task Force co-chairs Peter Thomas at 202-466-6550 or Julie Ward 202-783-2229 with any questions.

Sincerely,

The CCD Health Task Force