December 22, 2014

Centers for Medicare & Medicaid Services
Department of Health and Human Services
Attention: CMS–9944–P
P.O. Box 8016
Baltimore, Maryland 21244–8016

Re: Notice of Benefit and Payment Parameters for 2016 (CMS-9944–P)

Dear Administrator Tavenner:

As organizations dedicated to the health of children and families, we write to comment on CMS’s proposed Notice of Benefit and Payment Parameters for 2016. These comments pertain to the sections of the Notice on essential health benefits. The EHBs are a vital protection included in the Affordable Care Act (ACA) and we urge you to strengthen them so that they can better assure children in covered plans can access the services they need to grow up healthy.

**RECOMMENDATION:** EHB regulations should establish a broader definition of pediatric services that includes the full range of services children need for healthy development. The definition should be based either on the benefits provided in a state’s CHIP plan in 2014 or on the American Academy of Pediatrics’[Scope of Health Care Benefits for Children](https://www.aap.org/en-us/advocacy-and-policy/aap-health-initiatives/health-care-reform/scope-of-health-care-benefits-for-children.pdf). Any services provided by CHIP or included in the Scope of Health Care Benefits but not included in a state’s benchmark plan should be supplemented so that the plan fully covers pediatric services.

**DISCUSSION:** We must reiterate our concern that the current benchmark approach for determining the EHBs does not ensure children and youth have access to a comprehensive set of benefits that meets their needs. We recommend that pediatric services be defined more broadly to include more services that children need and that EHB regulations ensure that QHPs provide those services.

Numerous studies show that, to date, the process for defining EHBs has failed to assure that pediatric services are covered for children enrolled in individual and small group market plans. The small group plans that largely serve as the EHB benchmarks were not developed with adequate consideration of children’s needs, unlike Medicaid’s Early and Periodic Screening, Diagnosis, and Treatment benefit standard and the benefits in state CHIP plans. We believe that HHS should revise the EHB development and enforcement process to ensure that plans cover the pediatric services that children need without discriminatory limits. These services include, among others, hearing and vision services and devices, outpatient therapies, habilitative services and devices, and pediatric dental benefits.

Because of their continuous growth and development, children’s need for comprehensive benefits is particularly acute. Children are not little adults and need a set of health care benefits that is distinct from that provided to adults. Failure to
ensure an adequate scope and design of benefits for children can result in life-long health consequences that generate extensive and avoidable costs. The EHB package should assure affordable access to care for the vast majority of relatively healthy children and, at the same time, protect families from excessive costs when children have serious and/or chronic health needs.

Congress recognized children’s distinct needs by including ‘pediatric services’ as one of the ten categories required by the ACA to be included in EHBs. Our view is that by including pediatric services as a distinct category, Congress intended that children receive an additional set of benefits beyond that provided in the other nine categories.

A complete definition of pediatric services would include more than just oral and vision care. As they develop, children also need developmental assessments and screenings as well as preventive and supportive services to ensure they have the tools to maintain and/or improve their overall health into adulthood. Additionally, a segment of children suffer from chronic conditions that affect their development and require specific services in order to generate, maintain, and restore age-appropriate functioning. These services include, for example, audiology screenings and hardware, durable medical equipment, special therapies (physical, speech and occupational), education, counseling, and services such as anticipatory guidance, nutritional counseling, and treatment of pediatric obesity. Furthermore, children also often need services with greater frequency and intensity than adults, so certain benefit limits (for instance, limits on numbers of visits, etc.) established for adults may be inappropriate for children. The pediatric services category under the law was intended to include this broad and comprehensive set of services.

The benchmark selections that define today’s EHBs are almost exclusively small-employer plans. These plans were designed to address the health care needs of adults, with little to no consideration of the health care needs of children. For children with chronic conditions, these small group plans are particularly inadequate. For example, many plans only cover intermittent, short-term home health care. In some instances, plans only cover a few hours each day with a limit on the total number of visits each year even though many children with special needs may require ongoing and long-term home health care. In addition, the benchmark small group plans often only cover equipment that serves a therapeutic purpose in the treatment of an illness or injury. As a result, children with chronic conditions who require a customized wheelchair as they grow could be denied coverage for that equipment. Many children and families who face serious and long-term medical challenges also need case management and coordination services. However, those services are typically not covered by private insurance and thus not included in benchmark plans.

Unlike the EHB benchmark plans, the benefits in state CHIP plans were developed specifically to provide pediatric services to children. States frequently choose a robust package of benefits for the low- and moderate-income children covered by CHIP: 38 states use Medicaid or Medicaid-based benefits for some or all of their
CHIP enrollees, according to a recent study. Medicaid’s Early and Periodic Screening, Diagnosis, and Treatment benefit standard is intended to assure that children receive all the services they need to maintain and improve health as they grow and develop.

Recent studies of current EHBs reveal many gaps in pediatric services, especially when compared to the benefits offered by state CHIP plans. A recent report by the Wakely Consulting Group found that qualified health plans (QHPs) cover fewer of the benefits particularly relevant to children’s health and well-being than do CHIP plans (e.g. hearing services, autism services, habilitation, pediatric dental and vision, etc.). Furthermore, if and when such benefits are covered by QHPs, there tend to be more limits imposed. CHIP also frequently provides children with the enabling services they need to have meaningful access to medically necessary treatments. Some CHIP plans cover services like translation and non-emergency transportation, while Wakely found no QHPs that cover these services.

Further, the Wakely comparison found that 82% of CHIP plans cover child-specific benefits, sometimes with limits. Only 52% of EHB benchmark plans offer the same level of coverage. For instance, 95% of CHIP plans cover medically necessary audiology exams with no limits, but only 37% of EHB benchmark plans do so. In addition, CHIP covers hearing aids with or without some sort of limit in 95% of the states included in the Wakely analysis, while EHB benchmark plans offer that coverage in only 55% of those states.

Wakely’s review of child-specific services also provides a closer look at pediatric benefits in specific states:

- In Iowa, CHIP covers hearing aids (1 per ear/36 months) but there is no coverage for hearing aids in the state’s EHB benchmark plan. We know that as children grow, they will frequently outgrow their hearing aids and need new ones. However, the cost to families for these medically necessary devices when insurance coverage is inadequate can be in the thousands of dollars.
- In Colorado, a child who is covered by CHIP has unlimited coverage for medically necessary speech, occupational, and physical therapy from birth to the age of three. These are the critical years for learning to speak, walk, and develop fine motor skills. However, the EHB benchmark plan in Colorado limits these services to 20 visits per year per type of therapy. A child who needs speech therapy three times a week would exhaust this benefit in less than two months.
- In Florida, Applied Behavioral Analysis (ABA) services for treatment of autism are covered under CHIP but are not covered under the EHB benchmark plan.

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1Georgetown University Center for Children and Families and National Academy for State Health Policy, Benefits and Cost Sharing in Separate CHIP Programs, May 2014.
In Indiana, CHIP covers 50 visits per year per type of therapy for outpatient speech, occupational and physical therapy to ensure that children’s developmental needs are met. However, the state’s EHB benchmark plan offers only 20 visits per type of therapy.

Children with serious conditions, such as spina bifida, cerebral palsy or neurodevelopmental disabilities, require multiple therapies throughout their lifetime. Arbitrary limits on the number of visits to those therapies threaten their access to necessary services that will assist these children to achieve and maintain their highest level of functioning.

State Selection of Benchmark (§ 156.100)

RECOMMENDATION: States should have the opportunity to update their benchmark plan selections, but should have wider authority to supplement benefits when the benchmark plan does not sufficiently cover all EHB categories, in particular pediatric services and habilitation services and devices.

DISCUSSION: We support the proposal to provide states with an opportunity to choose a new EHB benchmark plan. However, as outlined above, states should also supplement those benchmark plans to assure full coverage of pediatric services. They should also be required to use the proposed definition for habilitation services and devices as recommended below.

We believe the updated benchmark selection should go into effect as soon as possible so that children and other consumers can benefit from greater benefit protections. While the proposal indicates plan year 2017 as the first with a new benchmark in effect, we urge CMS to make every effort to put the new benchmarks into place for plan year 2016.

RECOMMENDATION: States should be required to update their benchmark plan choice through an open process that considers public input.

DISCUSSION: States should be required to choose their benchmark plans through a transparent process that includes active efforts to gather public comments. Federal regulations should require that health care consumers and their representatives have the opportunity to weigh in as states consider their EHB benchmark choices.

Provision of EHB (§ 156.115)

RECOMMENDATION: Use the proposed definition of habilitative services for plans in all states and include the definition in regulation. If this recommendation is not adopted and the federal definition does not apply in all states, clarify that states must develop an EHB-compliant definition, even if the state’s benchmark plan includes some coverage for habilitative services.
DISCUSSION: We are extremely pleased that the Notice includes a uniform definition of habilitative services in §156.115(a)(5) and eliminates the provision that allows plans subject to the EHBs to determine the scope of habilitative services in their plans. We urge HHS to adopt a uniform definition as proposed in the Notice, but offer some revisions and recommendations to further strengthen the definition, services covered, and its application in the states.

First, we agree that the definition from the National Association of Insurance Commissioners (NAIC) Glossary of Health Coverage and Medical Terms is an appropriate way to establish the parameters of this benefit. However, we strongly urge HHS to add references in the definition to habilitative “devices,” as well as “services.” Not only does the addition of “devices” comport with the language in the Affordable Care Act (ACA), which includes both habilitative services and devices in its list of EHB categories, but devices are a critical component of habilitation. Habilitative devices, such as durable medical equipment (e.g., wheelchairs), orthotics, prosthetics, low vision aids, hearing aids, augmentative communication devices that aid in hearing and speech, and other assistive technologies and supplies are a critical component of the habilitative benefit, enabling children to function at the highest level possible.

Second, we urge CMS to require all states to adopt the proposed uniform definition, as modified above, as a minimum standard for issuers in their state. Furthermore, the uniform definition should be included, as revised, in regulation rather than in the preamble of the Notice, as is currently proposed, to ensure that it is implemented.

The federal definition should apply to all plans, rather than only to plans in those states where the base-benchmark does not cover habilitative services and the state has not offered its own definition, as proposed in § 156.115(a)(5). As noted in the preamble to this Notice, the level and scope of coverage of habilitation varies even when a state’s benchmark includes habilitative coverage. In some states, the coverage is quite good because the state has adopted a definition of habilitation that is very robust. In those states where there is an existing definition of habilitative services and devices that is more comprehensive than the proposed uniform definition, the state definition should take precedent under the final regulation. However, in many states, in the absence of a minimum standard definition of habilitative services and devices, coverage for habilitative services and devices is minimal. The adoption of a uniform minimum standard definition will help ensure that the intent of the habilitative services EHB is met and that all children have access to these services, regardless of where they live.

We strongly believe the federal definition should serve as a minimum. But if the federal definition is not applied as a floor for all plans, regulations should require states to establish their own comparable definition of habilitative services, even when the state’s chosen benchmark includes some habilitative services. The current
45 CFR 156.110(f) allows states to define habilitative services only "If the base-benchmark plan does not include coverage for habilitative services." In 23 states, benchmark plans include some habilitative services, but there is no state definition of the category. As noted above, the absence of an adequate definition of habilitative services has led to minimal coverage in this category in some states. CMS should clarify that either a state’s or the federal definition of habilitative services must be the standard, not the benchmark plan’s definition. We suggest adding to the regulation the language from the preamble:

“If the State does not supplement missing habilitative services or does not supplement in an EHB-compliant manner, issuers should cover habilitative services as defined in § 156.115(a)(5)(i).”

In addition, we believe that a certain minimum set of basic habilitative services and devices should be identified in regulation for illustrative purposes to ensure that issuers are providing access to the benefit as intended. Without a minimum set of identified services, there is no mechanism for HHS or the state to disapprove a plan’s habilitative services benefit when it is not adequate to meet beneficiaries’ needs. At the same time, we caution that any list of services and devices set forth for plans should not be considered to be exhaustive. The habilitative services benefit should include, but not be limited to, physical and occupational therapy, speech-language pathology, behavioral health services, audiology, rehabilitation medicine, and developmental pediatrics. Habilitative devices should include, but not be limited to, durable medical equipment (e.g., wheelchairs and related accessories), orthotics, prosthetics, low vision aids, hearing aids, augmentative communication devices that aid in hearing and speech, and other assistive technologies and supplies. For children, it is especially critical that there be no arbitrary restrictions on the coverage or replacement of devices. As they grow or their skills develop, children will need frequent replacements of devices, such as wheelchairs, glasses, auditory aids, orthotics, prosthetics, and augmentative communications devices.

A federal standard for habilitative services and devices that all states and issuers must meet, along with an end to age restrictions and arbitrary limits, will help ensure that all children, regardless of their health condition or disability, have the chance to meet their full potential.

Finally, we encourage HHS to consider a requirement that plans establish an exceptions process for individuals who need habilitative services that exceed a plan’s coverage. The Office of Personnel Management encouraged issuers to adopt such a process in its 2015 Call Letter to Issuers in the Multi-state Plan Program. While an exceptions process must not replace access to a full scope of habilitative services, a clearly delineated and simple appeals procedure must be available for families when a particular service is in dispute for any reason. We also encourage HHS to require plans to track requests for exceptions and their outcomes and report that information to HHS.

**Age Limit for Pediatric Services (156.115(a)(6))**
**RECOMMENDATION:** Raise the age limit for pediatric services to 21 years.

**DISCUSSION:** We reiterate the recommendations made in a joint letter to CMS on the 2012 proposed EHB standards that the age limit for the “pediatric services” category be raised from 19 to 21. The higher age limit would align with existing standards under Medicaid and CHIP for pediatric benefits, match the upper age for premium rating for children, and help ensure continuity of coverage for those children who will transition between Exchange and public coverage. Furthermore, children with life-long and chronic or complex conditions often continue to be cared for by their pediatric provider beyond the age of 19. In many instances, such as the care for a patient with cystic fibrosis, the pediatric provider has the expertise that an adult provider may lack to appropriately care for that patient.

**Non-discrimination (156.125)**

**RECOMMENDATION:** Codify the preamble’s clarification on discrimination based on age.

**DISCUSSION:** We appreciate and support the inclusion in the proposed rule’s preamble of the clarification that “age limits are discriminatory when applied to services that have been found clinically effective at all ages.” We urge CMS to include this in the regulations at 45 CFR 156.125. All stakeholders, including consumers, state regulators, and health insurers, will have a better understanding of the department’s interpretation of discrimination if the concept is defined in regulation rather than in a combination of guidance and Federal Register proposals. We further encourage CMS to engage in active enforcement of this provision—if plans are filed with discriminatory age limits, they should not be certified for sale. Because consumers may not be aware of the protections the ACA affords or why benefits are being denied, CMS and state regulators should not rely on consumer complaints to identify non-compliant plans.

Thank you for your careful consideration of these recommendations.

Sincerely,

American Academy of Pediatrics
Children’s Defense Fund
First Focus
Georgetown University Center for Children and Families
National Association of Pediatric Nurse Practitioners