

October 16, 2014

The Honorable Sylvia Burwell  
Secretary of the Department of Health and Human Services  
200 Independence Ave SW  
Washington, DC 20201

Dear Secretary Burwell:

As organizations dedicated to the health of children and families, we write to inform the Department's approach to revisions to the essential health benefits (EHBs) requirements for 2016.

The EHBs are a vital protection included in the Affordable Care Act (ACA). They help assure consumers that the health plans they purchase in the individual and small group markets will cover the health services they and their families need. However, we are concerned that the current benchmark approach for determining the EHB does not ensure children and youth have access to a comprehensive set of benefits that meets their needs. Therefore, it is critical that, when the Department refines its approach to EHBs, children are a top priority.

As a broad range of consumer groups have urged as a principle for all EHBs, the Department's revision of its approach to pediatric services should not be constrained by cost concerns. Rather, the Department should work to identify whether pediatric services offered as EHBs meet the requirements of the ACA and address identified gaps in coverage without considering overall cost.

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.

We recommend that HHS accomplish this goal by:

- Requiring states to use their current CHIP benefits as of 2014 as the benchmark for pediatric services
- Reviewing plans for inclusion of pediatric services and non-discrimination based on age
- Providing a definition of habilitative services and devices that meets children's developmental needs; and
- Taking steps to ensure children can access their EHB dental benefits.

## **Pediatric Services Include More than Oral and Vision Care**

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. We reiterate our view 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. Those additional benefits include, but are not limited to, oral and vision care. The ACA's legislative history makes it clear that oral and vision care were added to supplement other pediatric services provided under the category, not to limit pediatric services to 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. However the current benchmark approach has failed to ensure that children can access medically necessary services regardless of where they live.

## **EHBs Exclude Many Necessary Pediatric 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.

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.<sup>1</sup> 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.

Children with serious conditions, such as spina bifida, cerebral palsy or neuro-development 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.

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

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<sup>1</sup>Georgetown University Center for Children and Families and National Academy for State Health Policy, [Benefits and Cost Sharing in Separate CHIP Programs](#), May 2014.

- 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.
- 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.

Another recent study confirms the results of Wakely's analysis. The [National Alliance to Advance Adolescent Health](#) compared CHIP benefits and those offered in the second-lowest cost qualified health plan in five states. It found:

CHIP plans are far more likely to offer dental services, hearing aids and cochlear implants, residential treatment for mental health and substance abuse conditions, family therapy, and private duty nursing. In addition, CHIP plans in three of the five states provide more generous coverage for ancillary therapies and home- and community-based care than qualified health plans do. . . . These benefit differences would have their most significant impact on children and adolescents with special health care needs.

### **Assuring the Inclusion of Pediatric Services**

Due to the gaps in pediatric services in EHBs identified in the Wakely report and other research, we believe that HHS must immediately take steps to improve the benefit for children. We recommend two complementary changes: 1) Requiring states to use their CHIP benefits to serve as the benchmark for all pediatric services, not only oral and vision care. 2) Prohibiting benefit limitations in EHB packages that explicitly exclude pediatric services or discriminate based on age or health status.

#### *Using CHIP as a Benchmark*

Because CHIP was developed specifically to provide pediatric services, CMS should require a state's CHIP plan to serve as a benchmark for the 'pediatric services' category of EHB. Requiring states to do so would ensure a better benefit package for children based on their unique health care needs. It would also ensure a

smoother transition for children who may move back and forth between individual or small group market plans and CHIP coverage. The CHIP benchmark plan should be the CHIP plan (Medicaid expansion or separate CHIP plan) that is in effect for 2014.

### *Filling Gaps in Pediatric Services*

Federal and state officials must take a more active role in assuring that plans meet the requirements of the ACA.

The ACA makes several references intended to protect children's access to needed services. Section 1302(b)(4)(B) obligates the Secretary in the following way: "the Secretary shall...(B) not...design benefits in ways that discriminate against individuals because of their age." Section 1302(b)(4)(C) sets forth another required element of consideration: "the Secretary shall...(C) take into account the health care needs of diverse segments of the population, including women, children, persons with disabilities, and other groups." Section 1302(b)(4)(D) sets forth the last relevant required element of consideration: "the Secretary shall...(D) ensure that health benefits established as essential not be subject to denial to individuals against their wishes on the basis of the individuals' age."

Review of the EHB benchmark summaries posted to the CCIIO website reveals that these protections have been violated in many instances. For example:

- Utah's benchmark plan provides eye exams and eyeglasses starting at age 5, not for younger children.
- Maine's benchmark plan offers autism assessments only up to age 5, not for older children.
- Massachusetts' benchmark plan excludes coverage for chiropractic services for individuals under age 16.

Clearly, heightened scrutiny of plan provisions is needed before plans are certified for sale in a state's individual or small group market or in a marketplace. The review should seek to identify plan provisions that exclude pediatric services, discriminate based on age, or fail to cover all of the preventive services and developmental screenings required under Public Health Service Act Section 2713. Specific discriminatory provisions would include:

- Limits on treatment based on the patient's age that are not grounded in reasonable medical evidence. For example, Utah's eye exam limitation noted above.
- Exclusions of specific pediatric services. For example, many EHB benchmark plans exclude all treatments intended to reduce weight. Treatments to address pediatric obesity are vital pediatric services that must be included for children.

As noted above, if the state is not already using CHIP benefits as the benchmark for children, reviewers could use the state's CHIP benefits to determine which pediatric

services are included or excluded from the EHB benchmark. Alternatively, they could employ the American Academy of Pediatrics' [Scope of Health Care Benefits for Children](#). When such limits or exclusions are identified, plans should be required to supplement benefits to assure that pediatric services are provided as the ACA intends.

Although states share in the responsibility for approving health plans, HHS has a responsibility to establish and enforce EHB rules that implement the ACA's protections. The department should require these reviews of non-discriminatory coverage of pediatric services to be completed and documented by state insurance regulators or complete the reviews itself. Either way, documentation of these reviews should be available to the public so that families and stakeholders can be confident that plans are meeting the pediatric services requirement.

### **Fulfilling the Habilitative Services and Devices Requirement**

The habilitative services benefit under the EHB is of particular importance to children, particularly children with special health care needs. However, the flexibility afforded to states and issuers under the February 25, 2013, final EHB rule<sup>2</sup> includes inadequate protections for children who need access to a range of services to enable them to acquire, improve, or retain a skill or level of functioning. In order to fulfill the ACA's requirement that habilitative services and devices are a part of the EHBs, the Department should:

- Establish a defined set of habilitative services and devices that must be included in every plan that is subject to the EHB requirement; and
- Prohibit age restrictions and arbitrary limits on these services and devices, such as number of visits per year. Instead, the amount, duration, and scope of these benefits should be based on medical necessity.

A preliminary analysis<sup>3</sup> of QHP rehabilitation and habilitation coverage and limitations in the 2014 plan year shows that habilitative services are not easily accessible or sufficient in many states. For example:

- Rehabilitation, habilitation, physical therapy, and occupational therapy visit limits are often combined, which can reduce the number of needed therapy visits available to a child.
- Applied behavior analysis services for autism-spectrum disorders are sometimes included in the habilitation benefit, potentially to the exclusion of other habilitative services.
- Fewer than 10% of plans clearly identify all of the following: covered therapies, visit limits, and the applicability of the deductible.

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<sup>2</sup> Department of Health and Human Services. 45 CFR Parts 147, 155, and 156.

<sup>3</sup> Preliminary analysis of QHP Summaries of Benefits and Coverage by the American Occupational Therapy Association

- More than half of plans do not specify which therapies are covered under the rehabilitation and habilitation benefits.

In addition to highlighting inadequacies in currently-offered habilitation benefits, the analysis also demonstrates the need for more careful oversight to ensure that QHPs are both complying with current requirements and providing adequate information about what they cover.

A standard definition of habilitative services will help ensure that health plans provide adequate coverage for these important services for children who suffer from a condition that might otherwise prevent skills development and functioning. HHS should require states and plans to adopt the definition put forth by the National Association of Insurance Commissioners (NAIC), which was included in the Department's proposed regulations defining medical and insurance terminology.<sup>4</sup> According to the NAIC definition, habilitative services are: "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." (NAIC Glossary of Terms for the Affordable Care Act.)

The habilitation benefit must not be subject to age restrictions or arbitrary limits, such as number of visits per year, which are typical in rehabilitative services packages. Some children will need habilitative services or devices only for a short time, while others will need them on an ongoing basis to ensure that hard-earned skills are not lost. In the case of children with cerebral palsy, for example, extended therapies may be necessary so their muscles function as well as possible. Receiving sufficient habilitative services that helps the child acquire, improve, or retain a skill or level of functioning that they did not previously possess can mean the difference between talking and not talking, walking and not walking, or needing special education and being able to join a regular classroom.

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.

### **Making Pediatric Dental Benefits Part of the EHBs, as Intended**

HHS's decision to allow states to supplement pediatric dental benefits with a state's CHIP dental benefits or the federal employee's dental plan provides a strong basis for defining this important benefit. As it reviews its EHB approach, however, the Department should consider not only the adequacy of benefit definitions, but whether the EHB approach is having the intended effect of assuring access to

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<sup>4</sup> See 76 Fed. Reg. 52,442; 76 Fed. Reg. 52,475.

needed services. Because relatively few children have access to dental benefits in their QHP, HHS should revise its policies with regard to this benefit.

First, not every state has chosen to use CHIP or the FEDVIP plan as the benchmark for its pediatric dental benefits. Utah's EHB benchmark, as described in CCIIO's summary, seems to include x-rays, cleanings, and sealants only — excluding fillings for cavities or any other restorative services that many children need. An approach to setting EHBs that allows such a limited benefit is not one that serves children's needs nor meets the ACA's requirement to provide "pediatric services, including oral and vision care."

Second, available data suggest that relatively few children in QHPs have access to pediatric dental benefits. The [American Dental Association reported](#) that, across federally-facilitated marketplaces and California's marketplace, the take-up rate for children of stand-alone dental plans stood at 15.8% for 2014. Some additional children may access dental benefits that are embedded in qualified health plans, but their availability varies by state and data on enrollment in these plans are largely unavailable. On average across FFM, only 34% of QHPs offer embedded pediatric dental benefits, and in 15 FFM states, 20% or fewer of QHPs do so.<sup>5</sup>

As it works to improve its approach to EHBs, the Department must work to make pediatric dental benefits a reality for more children. It should explore ways to incentivize qualified health plans to offer pediatric dental benefits with reasonable cost sharing, including low deductibles for dental benefits separate from medical spending deductibles. And it should improve the provision of detailed dental benefit information to consumers. Further, the Department should seek to educate state insurance regulators and marketplace officials on their authority to make improvements to pediatric dental delivery, including developing standard plan designs, establishing robust certification requirements, applying relevant consumer protections, and establishing requirements for families to purchase pediatric dental benefits.

Thank you for considering the needs of children as you revise and improve the Department's approach to the EHB. We look forward to continuing to work with you to ensure that children have access to comprehensive benefits as envisioned under the ACA. We will be in touch to schedule further consultation with Department staff. Please contact Joe Tuschner ([joe.tuschner@georgetown.edu](mailto:joe.tuschner@georgetown.edu)) with any questions regarding these recommendations.

Sincerely,

Advocates for Children and Youth  
American Academy of Pediatrics

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<sup>5</sup> Colin Reusch, "[Greater transparency needed on dental coverage provided by health plans](#)," Children's Dental Health Project, March 2014.



American Association on Health and Disability  
American Occupational Therapy Association  
American Speech-Language-Hearing Association  
American Therapeutic Recreation Association  
Association for Ambulatory Behavioral Healthcare  
Association of Maternal and Child Health Programs  
Brain Injury Association of America  
Children's Defense Fund  
Children's Dental Health Project  
Children's Hospital Association  
Christopher and Dana Reeve Foundation  
Community Access National Network  
Community Catalyst  
First Focus  
Georgetown University Center for Children and Families  
Health Care For All – Massachusetts  
March of Dimes  
Maryland Citizens' Health Initiative Education Fund, Inc.  
Maryland Women's Coalition for Health Care Reform  
National Alliance on Mental Illness  
National Association of County Behavioral Health & Developmental Disability  
Directors  
National Association of Pediatric Nurse Practitioners  
National Multiple Sclerosis Society  
United Cerebral Palsy  
United Spinal Association  
West Virginia Focus: Reproductive Education & Equality

C: Michael Adelberg, CCIIO Exchange Policy and Operations Group