November 19, 2015

The Honorable Sylvia Matthews Burwell
Secretary
US Department of Health and Human Services
Hubert H. Humphrey Building
200 Independence Avenue, SW
Washington, DC 20101

The Honorable Josh Koskinen
Commissioner
US Department of the Treasury
US Internal Revenue Service
1111 Constitution Ave NW #5480
Washington, DC 20224

The Honorable Thomas Perez
Secretary
US Department of Labor
200 Constitution Avenue, NW
Washington, DC 20210

Re: Child health advocates’ priority regulatory improvements to ACA implementation for pediatric populations

Dear Secretaries Burwell and Perez and Commissioner Koskinen:

As organizations that share a strong commitment to the health of our nation’s children, we have appreciated the opportunity to comment on the various regulations the Department of Health and Human Services (HHS), Internal Revenue Service (IRS), and the Department of Labor (DOL) have promulgated to implement the Affordable Care Act (ACA). The ACA has led to vast improvements in health care coverage, access, and quality for families throughout the nation. Nevertheless, the undersigned organizations respectfully urge further action to ensure that ACA implementation meets the unique health care needs of children from infancy to adulthood, as well as pregnant women. In particular, we are most concerned that the implementation of standards related to essential health benefits, network adequacy, affordability, and pregnancy as a qualifying life event have not fulfilled the ACA’s promise that all individuals will have access to timely and appropriate care.

We have provided your agencies with input via formal regulatory comment letters, informal staff-level discussions, and in-person leadership level meetings on priorities for children’s and pregnant women’s health coverage and access since the beginning of the debate on the ACA and throughout the implementation process. While we deeply appreciate the instances in which your agencies have agreed with our requests, much remains to be done to mold the ACA to work best for children and pregnant women. We, therefore, ask that you review our recommendations, which we believe will result in important advancements for children’s health. We also are sending you a companion letter today for consideration regarding the 2016 regulatory agenda.

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1 Most recently, for instance, HHS adopted a federal definition for habilitative services and devices and agreed to propose to “degroup” children’s hospitals from other hospital types for purposes of enforcing essential community provider (ECP) requirements.
Essential Health Benefits (EHBs). First, we urge HHS to re-examine the implementation of the pediatric services category of EHBs to ensure that it covers the full range of services that a child might need. As you know, the tenth category of EHB is “pediatric services including oral and vision care.” As we have argued, this benefit should not be limited to oral and vision care, and would be best defined with reference to Medicaid’s Early and Periodic Screening Diagnosis and Treatment (EPSDT) benefit. EPSDT guarantees coverage for all medically necessary pediatric services. According to the Centers for Medicare and Medicaid Services (CMS), EPSDT is designed to assure that individual children get the health care they need when they need it – the right care to the right child at the right time in the right setting. A federal standard for medical necessity for children should be developed to ensure consistency in interpretation, expectations, and needed services across states to more systematically ensure children’s healthy growth and development. Children deserve access to the full scope of benefits essential for their healthy growth and development, and this requires their own medical necessity standard. As the next best alternative, we have suggested in prior communications that HHS define EHBs using services from states’ 2014 Children’s Health Insurance Program (CHIP) plan.

Children are continuously growing and developing and their coverage must provide the full range of benefits and providers necessary to meet their unique health needs. Children need, require and receive different health services than adults. The current benchmark approach to implementing the EHBs allows states to effectively design their own benefit standards. Unfortunately, in doing so, no state chose to address the unique developmental needs of children beyond oral and vision services. Children deserve access to the full scope of benefits essential for their healthy growth and development, and in the context of medical necessity, would greatly benefit from their own standard.

Second, we applaud HHS on the establishment of a uniform federal definition of habilitative services and devices and separate limits for habilitative and rehabilitative services if limits on these services are imposed. These regulatory changes are an important step toward ensuring that

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4 E.g., Letter from children’s health advocates to Kevin Counihan, Director & Marketplace Chief Executive Officer, Center for Consumer Information and Insurance Oversight (Sept. 30, 2015) (on file with author); Letter from children’s health advocates to Marilyn Tavenner, Administrator, Centers for Medicare and Medicaid Services (De. 22, 2014) (on file with author); Letter from children’s health advocates to Marilyn Tavenner, Acting Administrator, Centers for Medicare and Medicaid Services, & Gary Cohen, Director, Center for Consumer Information and Insurance Oversight (De. 26, 2012) (on file with author); Letter from children’s health advocates to Marilyn Tavenner, Acting Administrator, Centers for Medicare & Medicaid Services (Sept. 4, 2012) (on file with author).
5 CMS-9980-F; CMS-9944-F
6 Aimee Grace, et al., The ACA’s Pediatric Essential Health Benefit Has Resulted in a State-By-State Patchwork of Coverage with Exclusions, 33 Health Affairs 2136 (Dec. 2014), http://content.healthaffairs.org/content/33/12/2136.abstract.
8 Anne Rossier Markus & Kristina D. West, Defining and Determining Medical Necessity in Medicaid Managed Care, 134 Pediatrics 516 (Sept. 2014), http://pediatrics.aappublications.org/content/134/3/516; Letter from children’s health advocates to Steve Larsen, Director, Center for Consumer Information and Insurance Oversight (June 18, 2012) (on file with author).
Children and Youth with Special Health Care Needs (CYSHCN) can achieve and maintain function at the highest level possible. However, to adequately implement this EHB category, we believe that a minimum set of covered services and devices must be delineated in rulemaking. Absent this specificity, we have documented problematic gaps in coverage that do not meet children’s developmental needs.\(^9\) In addition, we urge you to prohibit arbitrary limits on visits or scope or cost-sharing requirements that are more restrictive than those for other benefit categories. These restrictions can impede a child’s access to services and devices that foster healthy development. For example, children will need regular replacements of devices, such as wheelchairs, glasses, auditory aids, and prosthetics as they grow and develop.

**The “Family-” or “Kid Glitch.”** One of the biggest concerns for child health and family advocates since the ACA passed is the test created to determine affordability of employer-sponsored insurance (ESI). In implementing the ACA, the IRS interpreted the law to the serious detriment of children and families.\(^10\) The IRS created the “family” or “kid glitch” when it defined ‘affordable’ coverage based only on the cost of individual coverage rather than the significantly higher cost of family coverage.

As you know, families are only eligible for financial assistance to purchase Marketplace plans if they meet the income thresholds and do not have access to “affordable” ESI. Because of this interpretation of affordability, an estimated 460,000 children, and between two and four million Americans overall, are expected to remain uninsured because they will not qualify for financial assistance and the cost of health insurance will be too high.\(^11\) Accordingly, we urge the IRS to re-examine its interpretation with the following in mind: the statute includes specific parameters for the determination of affordability stating that the determination of affordability “shall be made by reference to the required contribution of the employee,” which has been interpreted by the IRS to mean “the required contribution of the employee for coverage of family members.” The IRS regulations apply this special rule for purposes of applying the individual penalty but ignore it for the purposes of determining eligibility for premium tax credits for dependents lacking access to reasonably priced employer coverage. We strongly urge the IRS to apply this rule to the affordability test so that more children and their families can access quality, affordable health care.

**Network Adequacy.** Network adequacy refers to whether health plans provide enrollees with timely access to a sufficient number of in-network providers for covered services. Child health advocates have repeatedly argued to HHS that network adequacy rules should include specific provisions for pediatric care because different providers treat children than adults. Therefore, we are extremely pleased that HHS intends to propose stronger requirements for qualified health plan (QHP) contracting with children’s hospital essential community providers (ECPs) in upcoming rulemaking. We look forward to working with you to finalize these requirements to ensure that QHPs contract with at least one children’s hospital ECP in their service area so vulnerable children have access to the specialty care they provide.

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\(^9\) Sept. 15, 2015 Letter to Kevin Counihan, Director & Marketplace Chief Executive Officer, Center for Consumer Information and Insurance Oversight Re: Proposed 2017 Essential Health Benefits Benchmark Plans

\(^10\) See TD 9590.

At the same time, we respectfully highlight prior child advocates’ comments to HHS that specific network adequacy standards should be developed for children. Children are a special population because the providers of their care are different than those for adults. In particular, CYSHCN have specific needs to access pediatric specialty and subspecialty care, such as that provided by pediatric subspecialists, pediatric surgical specialists, and children’s hospitals, in order to address their particular health conditions.

Pediatric network adequacy standards must assure that all children and pregnant women, regardless of their health status, have timely access to appropriate in-network providers with the training and expertise to meet their unique needs. QHP networks must be capable of providing pediatric and obstetric services for all levels of complexity, including for rare conditions, without administrative or cost barriers for children and families. Out-of-network arrangements should be used only as an exception for extremely rare services or when timely access to the type of provider a child needs cannot be ensured. In the rare circumstance when a child must use an out-of-network provider, that child must not be penalized by the health plan. As we have stated in the past, we believe that QHPs should not be permitted to impose out-of-network cost-sharing if the most appropriate specialist for a child is not in the plan’s network or is not available in a timely fashion.

We understand that HHS has been monitoring the development of network adequacy standards by the National Association of Insurance Commissioners (NAIC) to determine the applicability of those standards to the Marketplaces. While the NAIC standards include some promising provisions, they do not go far enough to ensure that children and pregnant women have access to the full range of in-network providers with the training and expertise to meet their unique needs. Specifically, the NAIC model standards do not require plans to meet a broad set of objective pediatric-specific measures that are developed with the input of experts in pediatric health care or to include a full range of in-network primary, specialty, tertiary, and quaternary pediatric providers in the lowest cost-sharing tier when the plan utilizes tiered networks. Furthermore, the NAIC standards do not include adequate provisions for oversight of, and information dissemination regarding, both narrow and tiered networks, many of which seem to be designed on the basis of cost, rather than quality. We refer you to our companion letter with recommendations for the 2016 regulatory agenda for our specific concerns regarding the NAIC model standards. We also refer you to the consensus document, “Safeguarding Access to Medically Complex Care for Children by Requiring Health Plans and Exchanges to Develop Adequate Provider Networks,” which articulates the full range of principles that must be addressed in network standards.

Pregnancy as a Qualifying Life Event. While the ACA has significantly expanded access to health insurance for millions of Americans, many women of childbearing age remain uninsured

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13 A young child is developing rapidly and a wait of a few months may have a significant impact on the effectiveness of treatment.
or underinsured. For women who become pregnant, this lack of coverage and access to needed benefits can have a measurable impact on the health of their pregnancies and infants. Prenatal care should begin in early pregnancy for all women, but uninsured women receive far fewer prenatal services than their insured counterparts. They often do not receive important prenatal services (such as those recommended by the American College of Obstetricians and Gynecologists, March of Dimes, AAP, and the U.S. Preventive Services Task Force, among many others) until much later in their pregnancies than insured women do, and they also report greater difficulty in obtaining needed care. Existing regulations do not allow any women, including pregnant women, to enroll in Marketplace coverage outside of an open enrollment period, creating a gap in coverage. However, a solution exists: organizations, including ours, have repeatedly urged HHS to deem pregnancy to be a “qualifying life event” that would trigger a special enrollment period, allowing a pregnant woman to select a plan in the Marketplace to obtain coverage for medically necessary prenatal services. We were deeply disappointed that HHS has declined to date to designate pregnancy as a qualifying life event to address this gap in coverage, and we urge you in the strongest terms to reconsider this decision.

We commend HHS, IRS, and DOL for your ongoing efforts to expand coverage and access and to provide families with timely, accurate, and comprehensive information about their health plans. Your work has helped millions of children and families benefit from quality, affordable health care. We look forward to working with you to maintain and expand high quality coverage and access so that children and pregnant women receive the care they need and deserve. Thank you for your attention to our concerns. If you have any questions regarding these or other issues related to implementation of the ACA in the context of pediatrics, please contact Robert Hall (RHall@aap.org) with the American Academy of Pediatrics.

Sincerely,

Academic Pediatric Association
American Academy of Pediatrics
American Congress of Obstetricians and Gynecologists
American Pediatric Society
Association of Medical School Pediatric Department Chairs
Autism Speaks
Children’s Defense Fund
Children’s Dental Health Project
Children’s Hospital Association
Family Voices
First Focus
March of Dimes
National Association of Pediatric Nurse Practitioners

National Health Law Program
National Hispanic Medical Association
Pediatric Policy Council
Society for Pediatric Research

cc:

Kevin Counihan, Director & Marketplace Chief Executive Officer
Center for Consumer Information & Insurance Oversight

Jeanne Lambrew, Deputy Assistant to the President
White House

Andy Slavitt, Acting Administrator
Center for Medicare & Medicaid Services