

August 27, 2010

The Honorable Kathleen Sebelius  
Secretary  
U.S. Department of Health and Human Services  
200 Independence Avenue, S.W.  
Washington, DC 20201

The Honorable Timothy Geithner  
Secretary  
U.S. Department of the Treasury  
1500 Pennsylvania Avenue, N.W.  
Washington, D.C. 20220

The Honorable Hilda Solis  
Secretary  
U.S. Department of Labor  
200 Constitution Avenue, N.W.  
Washington, D.C. 20210

RE: Comments on Interim Final Rules Relating to Patient's Bill of Rights' Provisions (OCIIO-9994-IFC)

Dear Secretaries Sebelius, Geithner and Solis:

The undersigned organizations representing child health advocates, pediatricians, and hospitals appreciate the opportunity to comment on the interim final rule released June 22, 2010, pertaining to the patient protection provisions in the Patient Protection and Affordable Care Act (ACA). We commend the Departments of Treasury, Health and Human Services, and Labor (the Departments) in issuing regulations that provide strong safeguards for families in obtaining and utilizing health insurance for themselves and their children.

Nevertheless, we ask that you consider modifying the final rule in very specific areas to ensure that the needs of children are adequately addressed in relation to pre-existing condition exclusions, lifetime and annual limits, and patient choice of pediatrician and utilization of emergency services.

**Limitations on Pre-Existing Condition Exclusions for Children**

The interim final rule includes an important new reform that will make it easier for children who have pre-existing health conditions to obtain health insurance, and as a result, will likely increase access to health care and reduce financial strain on families. As you are aware, this provision is estimated to help at least 162,000 children get coverage they otherwise would not have, including those who are now uninsured and others who have insurance with benefit carve outs and pre-existing condition exclusionary periods. We are particularly pleased that the rules clarify that group or non-grandfathered individual health plans are prohibited from both excluding coverage of specific benefits associated with a preexisting condition for any period of time and from denying coverage to a child based on a preexisting condition. However, in order to strengthen the rules for children and families, we urge you to consider the following critical improvements to the final rule.

- Include excessive waiting periods (those longer than 90 days) in the definition of pre-existing condition exclusions so that these children will not continue to face delays in access to coverage.
- Prohibit unreasonable premium increases and/or excessive premiums for families with children with pre-existing conditions.

We also are very concerned about the advisory that was released following the interim final rule that allows health insurers to establish “open enrollment” periods for child-only plans. While we understand your desire to encourage insurers to continue to offer child-only plans, we believe this policy will make it much more difficult for families to obtain coverage for their children when they most need it. We urge you to issue a revised regulation that would include strong protections for children in the four areas discussed below when a plan establishes an “open enrollment” policy.

First, we ask that you to establish an unlimited initial enrollment period of at least one year, so that families have time to learn about the options available to them under the new law and enroll in the plan that best meets their needs. We encourage you to consider Massachusetts’ plan for phasing in open enrollment as a model for minimizing the negative impact on families that need care the most.

Second, we ask that regulations specify that beyond the initial enrollment period that insurers must ensure that open enrollment periods are available to families at least once a year during a standardized time period (such as October – December), that the period(s) last at least for 90 days, and that insurers fully advertise the availability of coverage during these open enrollment periods. Establishing these standards will ensure that there is consistency across plans to better enable families to access coverage. In fact, without such uniformity, it will be incredibly difficult, if not impossible, for families to navigate when and where they can enroll their child into the different plans available in their state.

Third, it is critical that families are given the opportunity to enroll their children into these plans when certain life events occur. We urge you to require plans to provide special enrollment opportunities for families experiencing a “qualifying event,” such as the birth or adoption of a child or a child’s loss of coverage (whether through a parent’s employer, Medicaid/CHIP, COBRA, etc.). At a minimum, we ask that the Health Insurance Portability and Accountability Act’s (HIPAA) provisions related to special enrollments be applied, with special consideration for how the requirements relate to children. For example, HIPAA specifies that a termination of employer contribution will trigger a special enrollment. For purposes of child only plans, this provision should apply to instances when an employer eliminates contributions toward dependent coverage. And fourth, since an open enrollment period makes it even more critical for families to stay enrolled in these plans, we ask that the regulations clarify the new procedures that insurers must undertake prior to dropping a child from coverage in a child-only plan.

Without these protections, insurers can make arbitrary decisions about enrollment in child-only plans making it difficult for families, especially those with sick children, to access coverage. This is contrary to the intent of the ACA and the prohibition on applying pre-existing condition exclusions for children.

**Lifetime and Annual Limits**

We strongly support the prohibition on lifetime and annual benefit limits which apply to both group and individual plans. For families with children with special health care needs, this is one of the most significant changes that health care reform offers and one that will enable these families to access the ongoing care that their children require. Additionally, we understand that plans may have lifetime or annual benefit limits on non-essential health benefits and anticipate additional guidance restricting the extent to which these limits can be applied.

Our primary concern, however, is centered on the schedule for phasing out annual limits, which begin with proposed limits of \$750,000 for plan or policy years until September 23, 2011, \$1.25 million until September 23, 2012, and \$2 million until January 1, 2014. While plans apply annual limits less frequently than lifetime limits, families with children, especially those with special health care needs, can quickly hit these limits, oftentimes with devastating consequences. Anecdotal evidence from the families we work with illustrate that parents whose children experience complications at birth can often exceed \$2 million in costs even before their newborns leave the hospital. Other parents are forced to make drastic decisions such as putting off chemotherapy for their ailing children because of the fear of exceeding \$2 million in spending within one year. While we understand that the proposed annual limits are “minimums . . . [and] plans may use higher annual limits or impose no limits” it is has been our experience that once a minimum is established, it typically becomes the standard. The starting \$750,000 threshold is much too low and we urge you to raise the initial annual limits to dollar amounts that are more likely to meet the needs of children and families, with an initial limit at or exceeding \$1.25 million. At the same time, we urge you to require that families be notified when they are approaching the annual limit and that they are informed of other coverage options available for their children, including Medicaid and CHIP.

Additionally, health plans often impose non-dollar limits on families, such as limits on days in the hospital, number of doctor visits, and drug refills. We urge you to issue a final rule that clarifies that limits on the duration and scope of coverage fall under the general ban on lifetime and annual limits under the ACA. Without such a clarification, we are concerned that insurance companies will simply replace their current dollar limits with annual or lifetime service limits, thus nullifying the effects of these important consumer protections.

Furthermore, we are concerned that the regulations allow for the establishment of “a program under which the requirements relating to restricted annual limits may be waived if compliance with these interim final regulations would result in a significant decrease in access to benefits or a significant increase in premiums.” In order to ensure that children are not unfairly denied access to health care, it is critically important that the needs of children, especially those with special health care needs, be addressed as you develop guidelines on this waiver process.

**Patient Protections**

We support the new rule that requires plans to allow a parent/guardian to designate a participating pediatrician as their child’s primary care provider. This is an important provision for children as regular pediatric care has been proven to improve child health outcomes, avert preventable health care costs, and limit delays in care. To ensure that this provision is most effective for families we ask that you make two additions to the final rule. First, the rule should stipulate that plans educate their members about this new option, including providing members with an updated list of pediatricians in the network. Second, pediatric subspecialists should be included in the definition

of pediatricians that can be designated as a primary care provider. For some children with serious chronic conditions, pediatric subspecialists (such as pediatric oncologists) oftentimes provide children with their routine and ongoing care and families should be afforded the ability to designate them as the primary care provider.

The rule that requires plans providing emergency services to eliminate the need for prior authorizations, even when the services are out-of-network, is extremely important for children. Children need access to emergency departments that are appropriate for them. Prohibiting plans from imposing administrative requirements or limitations on benefits for out-of-network emergency services that are more restrictive than those that apply if the family stays within network will encourage families of children with special health care needs to seek the emergency care most appropriate for their child. Therefore, we ask that the final rule clarify that children's hospitals be included in this important protection.

In closing, we urge the Departments to look closely at ways to ensure successful monitoring and enforcement of each of these important provisions for children so that the promise of health reform for them will be realized. Current insurance monitoring and enforcement rules are largely reliant on states and identification of issues by consumers. However, with the number of changes that insurers will be required to make under the ACA, we believe that there must also be a clear federal role in monitoring and enforcing plan compliance.

Thank you very much for your attention to the views of our organizations and the needs of children in your consideration of the final rule.

Sincerely,

American Academy of Pediatrics

Children's Defense Fund

Family Voices

First Focus

Georgetown University Center for Children and Families

March of Dimes

National Association of Children's Hospitals and Related Institutions

Voices for America's Children