

August 26, 2010

Jim Mayhew
Office of Consumer Information and Insurance Oversight
U.S. Department of Health and Human Services
P.O. Box 8016
Baltimore, MD 21244-1850

Attention: OCIIO-9994-IFC

Dear Mr. Mayhew:

On behalf of First Focus, I appreciate the opportunity to comment on the Interim Final Rule (IFR) “Requirements for Group Health Plans and Health Insurance Issuers under the Patient Protection and Affordable Care Act (PPACA) Relating to Pre-Existing Condition Exclusions, Lifetime and Annual Limits, Rescissions, and Patient Protections” (45 CFR Parts 144, 146, and 147). First Focus is a bipartisan children’s advocacy organization dedicated to making children and families a priority in federal policy and budget decisions. Our core mission is to ensure that all of our nation’s children are able to get the health care services they need and deserve.

First and foremost, First Focus applauds the provisions of the IFR that prohibit insurers from unfairly denying patients access to coverage, services, or providers when they are needed most. While we understand the importance of ensuring the adequacy of risk pools, for too long insurers have gone too far in denying coverage for those who are or who become sick by rescinding or capping coverage, limiting access to providers, increasing premiums and making coverage unaffordable, among other practices. This IFR goes a long way toward leveling the playing field for all consumers. We are particularly heartened that these reforms will be effective for children under 19 beginning on September 23, 2010.

We would like to offer specific comments in the following five areas:

Pre-Existing Conditions: First Focus offers its full support for the provisions of the IFR which prevent insurers from imposing any pre-existing condition exclusions on enrollees under the age of 19 for plan years beginning on or after September 23, 2010. This requirement extends to all individuals, regardless of age, for plan years beginning on or after January 1, 2014. No child who was born with spina bifida or a congenital heart defect, or who develops autism, juvenile diabetes, cancer, or any other illness should face discrimination either at the point of enrollment or following enrollment. For the protection of patients and consumers, we urge the Administration to develop clear guidelines defining the term “pre-existing condition” to prevent continued gamesmanship by the insurance industry and to ensure that coverage is available for children when they need it. Along these lines, we are also concerned that the IFR may allow insurers to impose excessively long

waiting periods for children with pre-existing conditions. This issue also must be addressed by the Administration.

Rescissions: First Focus also appreciates that the IFR addresses the rescission practices that have become commonplace among insurers which allow retroactive denials of coverage. Rescissions are perhaps the most pernicious of the unsavory practices perpetrated by insurance companies. An investigation by the House Subcommittee on Oversight and Investigation earlier this year showed that the three of the largest insurance providers in America had rescinded 20,000 policies in the years from 2003-2007 in California alone, saving an estimated \$300 million. The investigation discovered that insurers actually rewarded employees for canceling the coverage of sick patients. We are heartened that the IFR makes it clear that these despicable practices are no longer permissible.

In addition, we are pleased that the IFR makes it clear that coverage must continue while an appeal is in process. To ensure a fair and comprehensive appeals process, we urge the Administration to set in place a second-level external review outside of any internal medical review to allow the law and the facts of a particular denial to be considered on behalf of the consumer.

Annual and Lifetime Limits: First Focus appreciates the acknowledgement in the IFR that lifetime and annual limits have posed significant barriers to care for scores of Americans with private coverage. While we understand the importance of maintaining stability in the insurance marketplace and your efforts to establish a glidepath to improve on the current practices, we are concerned that the new limits set out in the IFR are insufficient to ensure the continuation of coverage for families who are managing a child's serious illness. In particular, we have heard from our partners who advocate on behalf of children with special health care needs that the first-year \$750,000 limit is simply not enough to cover the care that is necessary for their children. Whether it is newborns being treated in the NICU-setting or children with severe long-term developmental, mental, and physical disabilities, the costs of providing care to this relatively small population are exorbitant. We urge the Administration to revise the regulation on annual limits to accommodate the needs of this population.

We also request that the Administration extend the IFR to address not only dollar-amount coverage limits, but also efforts by insurers to cap the number of services a patient is able to receive. This is especially important for children who may require additional services over a compressed time frame to treat developmental health issues.

Finally, we urge the Administration to ensure that parents and families receive timely notification regarding lifetime and annual limit requirements, including notification when they are approaching their limits. As important, we also urge you to ensure that families who lose coverage as a result of these limits are informed that they may be eligible for coverage under Medicaid, often the provider of last resort, and to provide information about how to apply for coverage.

Provider Choice: First Focus applauds the IFR for guaranteeing that parents are able to elect a pediatrician as the primary care provider for their children. While this practice is becoming more and more commonplace, the clarification in the IFR will may make it easier for some parents to get the care that is most appropriate for their children. To strengthen the reach of this provision, we urge the Administration also to require health plans to maintain a current list of the providers that are included in their networks, including each provider's specialty area. This would be a significant improvement for consumers who often must make numerous calls to hunt down so-called "participating providers" and to glean those which are in the specialty areas they need for themselves or for their children.

Recent Administration Guidance on Open Enrollment Periods and the Availability of Child-Only Coverage: We also wanted to take this opportunity to comment on the guidance issued by the Administration on July 27, 2010, which clarifies that insurance companies have the authority to establish open enrollment periods for children with pre-existing conditions who seek coverage through child-only plans.

As stated previously, First Focus recognizes that in order for reform to be successful the insurance marketplace must be healthy and strong. While we support efforts to prevent adverse selection on the parts of both insurers and the insured, we urge the Administration to set in place safeguards to prevent the insurance industry from continuing to game the system to deny coverage for children with pre-existing conditions. Along these lines, we urge the Administration to issue further guidance to protect coverage for children with pre-existing conditions during the September 23, 2010-January 1, 2014 interval, including the following:

- Guidelines to ensure an appropriate duration for open enrollment periods;
- A comprehensive list of qualifying events for which children would be eligible to enroll in coverage outside of the open enrollment;
- A clear definition of the illnesses and conditions that qualify as a "pre-existing condition";
- Clarification that if a family with a child that has a pre-existing condition has a qualifying event which forces a change in coverage they will not have to wait for the open enrollment period before the child can be enrolled.

We recognize that addressing these issues before the reformed health care system is up and running in 2014 presents some challenges. To the extent that some of these children and families may have no choice but to enroll in coverage through the newly-established state high-risk pools, we urge the Administration to ensure that child-only coverage is available in each state, and that children who lose coverage as a result of a pre-existing condition should not be subject to any waiting periods to enroll in a high-risk pool.

We are grateful for the opportunity to comment on this important policy for our children. Continued action and vigilance must be taken in order to ensure that children reap the benefits and promise of health reform, including protections from current private insurance market practices designed to limit coverage for sick children.

We applaud the Administration for all of its efforts to improve access to care for everyone in America and for leading the charge on many of these reforms by beginning with our children. We would be happy to provide any additional information you may require.

Sincerely,

A handwritten signature in blue ink that reads "Bruce Lesley". The signature is written in a cursive style with a prominent "B" and "L".

Bruce Lesley
President