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Statewide Parent Advocacy Network, Inc.  
*Empowered Families: Educated, Engaged, Effective!*

**Family Voices-NJ Comments on the Pre-Existing Condition Insurance Plan Program; Interim Final Rule  
Submitted September 27, 2010**

Thank you for the opportunity to comment on the Pre-Existing Condition Insurance Plan Program: Interim Final Rule. Family Voices is a national network that advocates on behalf of children with special healthcare needs and works to “keep families at the center of children’s healthcare” (birth to age 26). Our NJ Chapter is housed at the Statewide Parent Advocacy Network (SPAN), NJ’s federally designated Parent Training and Information Center, Family-to-Family Health Information Center, and chapter of the Federation of Families for Children’s Mental Health. The NJ Coordinator also serves in a voluntary capacity as the NJ Caregiver Community Action Network representative for the National Family Caregivers Association for caregivers across the lifespan, as well as volunteering for the local and state chapter of the National Alliance on Mental Illness.

**Supplementary Information**

**I. Background**

*A. General*

We understand that there are currently 35 state high risk pools covering 200,000 individuals. We also understand that there is guaranteed issue in 7 states and that 2 states prohibit health status consideration in setting premiums. Further, we note that while plans for children will prohibit pre-existing condition exclusions starting September 23, 2010, that for adults this will take effect in 2014. This regulation focuses on the temporary Federal program in effect until 2014 for those who have pre-existing conditions and are uninsured.

*B. Overview*

We understand that HHS will establish (either directly or through contracts with States or non-profits) a temporary high risk health insurance program. This program will be known as PCIP Pre-Existing Condition Insurance Plan program, to distinguish it from

existing state high risk pools which can continue to operate. The PCIP will remain in place until the exchanges are established in 2014. Again, we understand that this regulation only applies to the PCIP.

## **II. Provisions of the Interim Final Rule**

### *A. General Provisions*

We understand that the definition of pre-existing condition applies to a PCIP by prohibiting “impos[ing] any preexisting condition exclusion...and is separate from the ‘guidelines’ that determine pre-existing condition status...for purposes of eligibility for enrollment in a PCIP.” This is because state laws vary in defining pre-existing conditions so the definition being used is that in the group market under HIPAA as well as the ACA which prohibits denials of coverage. Therefore the definition means “denial of coverage, or limitations or exclusion of benefits, based on the fact that the individual denied coverage or benefits had a health condition...This would include exclusions... from a condition identified via a pre-enrollment questionnaire or physical examination, or the review of medical records...”

### *B. PCIP Program Administration*

Again we understand that HHS will establish a temporary high risk program directly or through contracts with states or non-profits.

### *B. [sic C]. Eligibility and Enrollment (Subpart C)*

We understand that these requirements are consistent with the ACA for enrollment and disenrollment. We note, however, our strong opposition to making health reform coverage limited to only citizens or those immigrants who are “lawfully present,” as it is both inhumane and contrary to positive public health policy to deny health coverage to undocumented immigrants.

### Eligibility for the PCIP Program

The eligibility criteria are: citizen or lawfully present, no creditable coverage for 6 months, pre-existing condition, and state residency in the PCIP service area.

### Eligibility Conditioned on Citizenship and Immigration Status

We understand that PCIP eligibility is limited to citizens, nationals, and those lawfully present consistent with CHIP. For states that do not have online systems, the program may require documentation that establishes citizenship or immigration status, which we suggest should be standardized nationally.

### Eligibility Based on a 6-Month Period Without Insurance Coverage

We understand that creditable coverage is defined as group health plans, Medicare Part A or B, Medicaid/CHIP, TRICARE, Indian Health Service, state high risk pool, Federal Employee Health Benefits, public health including Veteran's Administration, and Peace Corps. This also includes coverage provided to former employees/retirees, spouses/former spouses, and dependent children under COBRA. We agree that if an individual already satisfied the 6 month limit and moves to another state, they would still be eligible. We look forward to forthcoming guidance on infants less than 6 months old with consideration of the mother's plan, current practices regarding newborns, and anti-dumping rules. We would not, however, consider birth defects to be considered pre-existing conditions.

### Eligibility Based on Having a Pre-Existing Condition

We understand that this criterion is based on documentation of: insurer refusal of coverage based on health status, individual insurance but only with a rider, medical/health condition specified by the state, and "other criteria as defined by the PCIP. We are concerned about the listing of health conditions established by states and would recommend either a federal listing or minimum standard. We strongly agree however with allowing states that have high risk pools or guaranteed issue to continue.

### Eligibility for a PCIP Conditioned on Residing in the Plan's Service Area

We agree that the eligible individual must reside in the state of the PCIP's service area. However, we strongly disagree that this should only apply to the 50 states but not territories. The ACA does cover territories and we would expect the PCIP to follow suit.

### Enrollment and Disenrollment Process

We agree that for states with existing high risk pools, the enrollment policies should be allowed to continue but only if they are "consistent with the statute". Further the PCIP must allow continued enrollment except if the individual moves outside the service area, obtains other coverage, or the PCIP program is terminated. We agree that there must be sufficient notice of nonpayment prior to disenrollment. We understand that there will be additional guidance in cases of fraud. We agree that if the individual moves they should be allowed to re-enroll immediately, and would like to add in the case of PCIP program termination that the individual also be allowed to immediately enroll in another PCIP without waiting 6 months. We agree with the enrollment deadline of the 15<sup>th</sup> for the effective date of the following month. We also understand that consideration must be given to enrollment management such as capacity limits, premium adjustments etc. but strongly disagree with "phased-in [delayed] enrollment" as this regulation states later that enrollment is immediate. Individuals with pre-existing conditions cannot afford, both in terms of finances and health outcomes, to delay treatment. We would also suggest protections against inappropriate rescissions of policies for these vulnerable individuals.

### *Benefits (Subpart D)*

We understand that this will be based on the forthcoming essential health benefits under ACA. We also agree that it should be consistent with listings from existing high risk pools.

### Excluded Services

We agree that this should be consistent with the FEHBP (Federal Employees Health Benefits Program). We understand that abortion is only covered in cases of rape, incest, or if the life of the mother is in jeopardy, but note our opposition to this restriction.

### Pre-Existing Condition Exclusions

We understand this is an expansion of HIPAA, and under the ACA there is prohibition on any pre-existing condition exclusions for both group and individual plans on January 1, 2014. We agree that the definition means “any limitation or exclusion of benefits based on the fact that the condition was present before the date of enrollment”. We strongly support the prohibition on PCIPs from “imposing any type of coverage waiting period upon eligible individuals”. This is why we opposed the delayed enrollment in the previous section above.

### Premiums and Cost Sharing

Under NAIC, high risk pools “determine a standard risk rate by considering the premium rates charged by other insurers...” The definition of standard risk rate includes: determination by the state high risk pool, “reasonable actuarial techniques”, and reflects anticipated claims. However while existing high risk pool premiums average 105-250% of the standard rate in the individual market, this regulation requires the PCIP to be at the standard rate. This means that premiums may not exceed 100% of the standard individual rate, which we strongly support. There will be variation as some states “require that insurers issue all applicants a policy or offer coverage at a community rate” so the standard individual rate may be higher in some areas.

### Premium Variation

We understand under ACA that there will be rates that can vary by age (not greater than 4 to 1) effective January 1, 2014. However “no such requirement exists for the PCIP program”. So we agree that it should be consistent with the forthcoming requirements.

### Limits on Enrollee Costs

We agree that the “issuer’s share...cannot be less than 65 percent”. We also agree that the out-of-pocket costs cannot exceed the Internal Revenue Code (\$5,960 for 2010). The out-of-pocket definition includes the deductible, and other annual expenses (except premiums), and that this limit is for in-network providers only.

## Access to Services

We agree that the PCIP may have a network of providers as long as there is “sufficient number and range of services...reasonably available”. We would also require provider offices to have physical accessibility for people with disabilities. We strongly agree that emergency room services can be out of network if the “enrollee had a reasonable concern that failure to obtain immediate treatment could present a serious risk...[or] services were required to assess whether a condition requiring immediate attention exists.” While generally based on a “reasonable person” standard, persons with cognitive or other disabilities should not be penalized if they use emergency room services even if a “reasonable person” with average cognitive ability or without other disabilities would not use emergency room services in the same circumstances.

### *E. Oversight (Subpart E)*

## Appeals Procedures

We strongly agree that this should apply to both benefits and eligibility, including determinations if the individual is a citizen, national, or lawfully present. The regulations state that there must be “timely redetermination” and “timely second-level appeal...by an independent entity”. We would suggest timeframes for both the initial and external appeal. We agree that this requirement could be satisfied under existing state law, a new review process under a state PCIP, or by an independent contractor. We would also suggest an expedited review for urgent care.

## Fraud, Waste, and Abuse

We understand that anti-fraud measures would include prevention and even payment recovery. We would suggest that there should be either a dollar limit or timeframe for retroactive billing. We also agree that there should be oversight in cases where “an individual may have been discouraged from enrolling...”

## Preventing Insurer Dumping

We are concerned that there is currently an incentive to single out high risk enrollees to “disenroll from their coverage and obtain coverage in PCIPs”. We strongly agree that, for “dumping” enrollees, the Secretary may bill the plan for medical expenses as well as refer to state/federal authorities for other enforcement. In addition, nothing in this regulation prevents states from “applying or enforcing this section”. We look forward to the additional guidance on public programs.

### *F. Funding (Subpart F)*

## Use of Funds

We understand that the ACA funded \$5,000,000,000 for the PCIP. Typically the funding for state high risk pools goes towards health expenses and administrative costs. We agree that this funding should not be used for any other expenses, including those associated with existing high risk plans. We further agree that a maximum of 10% should go towards administrative costs. These costs will include startup, materials and outreach, claims/appeals, fraud, and services such as a customer service line.

## Initial Allocation of Funds

We agree with the initial allotment in keeping with the methodology to set limits under CHIP. This formula will consider state population, number of uninsured, ages under 65, and geographic health costs. We agree that this will not penalize states attempting to reduce the uninsured. The formula, like CHIP, will hold “15 percent of the cost factor constant, while 85 percent reflects how each State’s average wage compares to the U.S. average”. This is especially important for states like NJ which has a high cost of living compared to states in other geographic parts of the country.

## Reallocation of Funds

We agree that spending will be based on “actual enrollment and cost experience of PCIPs”. The regulation thus allows for reallocation of funding as appropriate.

## Insufficient Funds

We agree that if HHS estimates for the high risk pool is less than the actual amount of expenses, there should be allowance for adjustments.

## *G. Relationship to Existing Laws*

### Relationship to Other Federal Health Insurance Regulation

We understand the some provisions also cover the same areas such as premiums, out-of-pocket costs, and pre-existing conditions. However, they do not apply to the PCIP because “high risk pools do not meet the definition of a group health plan...”

## Maintenance of Effort

We strongly agree that for states to participate in the PCIP, they cannot reduce amounts spent for existing state high risk pools. This disallows cost-shifting. This will also limit eligibility to the uninsured, not those in existing pools. We agree that this could be met by either “maintaining...the total amount or total per capita amount of State funding for...an existing high risk pool”. This could also be done by maintaining “the same formula for providing funding for a State high risk pool, or establishing an altered formula that the Secretary determines will not reduce the total funds expended on the

existing high risk pool”. We strongly support that HHS “shall take appropriate action, such as terminating the PCIP contract, against any State that fails to maintain funding levels for existing State high risk pools”.

#### Relation to State Laws

We agree that state laws that “might otherwise apply to...a PCIP program, are pre-empted, with the exception of...licensing or solvency”.

#### *H. Transition to Exchanges*

#### End of PCIP Coverage

This plan shall end January 1, 2014 when the new affordable coverage becomes available. We agree that contracts “will remain in effect to provide for appropriate contractual close out periods, but coverage of claims...will extend only...through December 31, 2013”.

#### Transition to the Exchanges

We understand the HHS will “develop procedures to transition PCIP enrollees to the Exchanges...to ensure there a no lapses in coverage”. We look forward to reviewing and commenting upon the transition procedures.

### **III. Response to Comments**

We understand that due to the “large number of public comments” the Department can’t respond to them individually. We look forward to the preamble of the “subsequent document” in which the Department “will respond to the comments”.

### **IV. Waiver of Proposed Rulemaking**

We strongly agree with the Department’s determination that “it is impracticable and contrary to the public interest to engage in full notice and comment rulemaking before putting these regulations into effect, and that it is in the public interest to promulgate interim final regulations.” However, we encourage widespread notice of the interim final regulations as soon as practicable and development of a process that allows for robust public input, including regional opportunities to hear concerns and recommendations from families and individuals.

### **V. Collection of Information Requirements**

We understand that the Department is seeking input on “the need for information collection, accuracy of the agency’s estimate...quality, utility, and clarity of the information,...minimize the burden of collection”.

#### *A. ICRs Regarding Proposal Process*

We understand that proposals can come from a State or non-profit. We agree that if States do not apply, HHS may outreach to non-profits. Non-profits may also submit directly to HHS. We agree with the estimate of the proposal development and information collection to be a burden of “684 hours to compile”.

#### *B. ICRs Regarding Eligibility*

We understand that documentation of proof of pre-existing conditions for enrollees can be done electronically or by hard copy. We agree that will be approximately 100,000 enrollees, at 30 minutes each, for an hour burden of 50,000 hours. In 2011 and after, we agree with the estimate of 50,000 enrollees per year, for an hour burden of 25,000 hours.

#### *C. ICRs Regarding Enrollment and Disenrollment Process*

We agree that enrollment/disenrollment “is a one-time burden that was included in the 684 burden hour”. We understand that “any State or entity selected to administer the PCIP program may later decide it is in the best interest of their State to propose amendments to the previously agreed upon contract”. We agree that this will take “24 hours per contractor...annual burden...is 1224 hours at a cost of \$28,152”. We would suggest any amendments however must meet the current minimum requirements in states with existing high risk pools so as not to undermine the process and maintenance of effort.

#### *D. ICRs Regarding Access to Services*

We understand that PCIPs must specify networks and assure sufficient numbers. We agree that “the burden associated with these requirements is included in the 684 burden hour estimate”. We also agree that possible amendments would have the same estimated burden (24 hrs./contractor, 1224 total hours, \$28,152) as above.

#### *E. ICRs Regarding Appeals Procedures*

We understand that the PCIP must list the minimum requirements with regards to appeals. We agree that “these requirements are included in the 684 burden hour estimate” and that proposed amendments would be the same hours/costs as the previous 2 sections.

#### *F. ICRs Regarding Fraud, Waste, and Abuse*

We agree with the Department’s estimate that this will take 4 hours per month per State, for an annual burden of “2448 hours at a cost of \$56,304”.

### *G. ICRs Regarding Preventing Insurer Dumping*

We strongly agree that plans who are “discouraging high-risk individuals” need to be identified. We agree that this will take PCIPs 8 hours per month per state for an annual burden of “4896 hours at a cost of \$110,160”.

### *H. ICRs Regarding Use of Funds*

We understand that funds must be used exclusively for claims and administrative costs. We agree that this will take PCIPs 16 hours per month per state, for an annual burden of “9792 hours at a cost of \$323,136”.

### *I. ICRs Regarding Maintenance of Effort*

We understand the existing high risk pools may not use this funding. We agree that “burden associated with this one-time requirement is included in the 684 burden hour estimate”.

## **VI. Regulatory Impact Analysis**

### *A. Summary and Need for Regulatory Action*

We agree that this will “provide the opportunity for coverage to individuals who cannot otherwise obtain insurance”. We strongly agree that this will “yield a meaningful increase in equity”.

### *B. Executive Order*

We agree that this regulation is “economically significant” (...annual effect on the economy of \$100 million in any one year)”.

#### a. Estimated Number of Affected Individuals

We understand that there are 35 existing high risk pools serving 200,000 individuals and 4 million uninsured individuals with health conditions. Yet impact estimates are difficult because existing pools don’t require 6 month wait, the new program prohibits “benefit carve-outs...which 30 State programs employ”, 8 states exceed the PCIP out-of-pocket limits, PCIP premiums are lower than states, 15 states have no pools, and there isn’t a numerical relationship between the uninsured and the state high risk pool. That said, we understand that several studies (200,000 per year vs. 375,000 in 2010, vs. 175,000 uninsured) results in a range of 200,000-400,000. Even the lowest estimate would “double the number of Americans with pre-existing conditions insured...”

### c. [sic b.] Benefits

We agree that this will reduce morbidity and lower mortality rates. We agree this will also decrease emergency care and hospitalizations, and result in lowering costs. It will increase worker productivity and help offset uncompensated care. Research has shown that “mortality risks for uninsured individuals...were 25 percent higher”. The uninsured avoided health care utilization so illnesses are more serious and costly. This regulation will help financial strain as 60% of bankruptcies are due to medical debt. With better health outcomes, productivity improves due to less absenteeism. Uncompensated care will be shifted to the “privately insured”.

### d. Costs and Transfers

It is estimated that the “Federal share of total costs could be...35 to 40 percent of total spending”. We agree with the Department’s estimate for administrative costs to be \$1.9 million, and this includes “State administrative costs incurred... [that] may be paid for by Federal and premium funds”.

## **VII. Other Sections**

### *Regulatory Alternatives*

We appreciate that the Department considered “some form of guidance” but agree “it is in the best interest...to establish this program through the rulemaking process”. We also appreciate that the Department “considered regulatory alternatives for program design, and often referred to the design features in existing State high risk pools and...CHIP”. We appreciate that the Department considered uniform eligibility but preferred to take into account existing programs.

### *Regulatory Flexibility Act*

We agree that “States and individuals are not included in the definition of ‘small entity’” so that these rules “will not have significant impact on a substantial number of small entities”.

### *Unfunded Mandates Reform Act*

As “there is no automatic enrollment or requirement to join”, we agree that “these regulations do not impose an unfunded mandate on the private sector”.

### *Federalism*

As these regulations “do not impose any direct costs on State or local governments”, we agree that these rules will not have significant federalism implications.

Lastly we would like to comment on definitions and benefits details at the end of the document.

## **Definitions**

The definition “lawfully present” still excludes immigrants who are here for less than five years. It is unfortunate that undocumented immigrants receive no coverage, but at a minimum, all immigrants who are here with documentation should be eligible.

## **Benefits**

We were pleased to see that benefits were fairly comprehensive but would include dental, hearing, and vision services. We were pleased to see mental health listed (item 3). We are concerned that several benefits may need to be clearly defined. Although preexisting condition exclusions go into effect for children September 23, 2010, we would suggest clarification for any child enrollees who may still be eligible for this new federal plan for whatever reason, or transitioning from pediatric to adult care and may thus be covered under a PCIP. Item 5 is “non-custodial skilled nursing services” and item 6 is “home health services”. These must specifically include children as many times we’ve heard about denials of nursing for children as “custodial”. A child with a trach or vent doesn’t need a babysitter, they need a nurse. Item 7 is “durable medical equipment and supplies”. Again these must specifically have parameters for children. We have heard of denials for wheelchairs for children who have grown “because they already got one”. We have also heard of incontinence supplies denied for children, yet there are children who are past the typical developmental age for diapers who may still need these supplies, perhaps lifelong. We would also include medical supplies such as life-sustaining tube feeding formulae, caloric supplements for growth disorders, and food thickeners for swallowing/choking problems, as some insurers deny these as “nutritional supplements like vitamins”. Item 9 is “physical therapy services (occupational...physical...speech therapy)”. Again this must be clarified as a covered benefit for children due to medical necessity and not denied as “educational or developmental”. We’ve heard of physical therapy denied for a child with spina bifida or speech for a hearing impaired child, because “you can’t prove he’d ever be able to walk (or talk in the second instance)” in the first place. How are children going to get these skills without therapy? We were pleased however to see prescription coverage (item 12) as essential, as those who forgo medications end up with more frequent hospitalization. We were extremely pleased to see preventive care (item 13) as wellness initiatives, such as the pediatric Bright Futures guidelines, reduce morbidity and mortality by improving health outcomes.

## **General Comments**

Nowhere in the document did we see mention of cultural competency, medical home, and health literacy addressed. Care must be given in a culturally competent manner for best health outcomes. New Jersey was the first state to pass a statewide mandate for cultural competency training for healthcare providers (see

[www.state.nj.us/lps/ca/bme/press/cultural.htm](http://www.state.nj.us/lps/ca/bme/press/cultural.htm) ), which should be mandated nationally. AT&T language lines and IBM computer translation programs can assist in communicating with patients in other languages by phone and email. Further, health literacy is the single largest barrier to healthcare access. Latest estimates indicate that 1 in 7 adults, or 32 million Americans, can't read the instructions on a medication bottle. The costs of healthcare literacy are high, besides the human factor of poor health outcomes. The University of Connecticut study showed that \$106-238 billion is lost every year on healthcare costs due to poor communication between patients and providers. Lastly, we would urge all plans to utilize the patient centered medical home model (see [www.medicalhomeinfo.org](http://www.medicalhomeinfo.org)) and shared decision-making (see [www.healthdialog.com](http://www.healthdialog.com)) for both cost effectiveness and better health outcomes.

As the Family-to-Family Health Information Center in NJ, we work with families and professionals to help them collaborate to improve health care access and quality for children with special healthcare needs. Thank you again for the opportunity to comment on the Interim Final Rule for the Pre-Existing Condition Insurance Plan Program.

Sincerely,

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**Our Mission: To empower families and inform and involve professionals and other individuals interested in the healthy development and educational rights of children, to enable all children to become fully participating and contributing members of our communities and society.**