



FAMILY VOICES STATEMENT ON THE PATIENT PROTECTION AND AFFORDABLE CARE ACT

Family Voices is an organization of families whose children have special health care needs. Its mission is to achieve family-centered care for all children and youth with special health care needs and/or disabilities.

Family Voices is very pleased that the Patient Protection and Affordable Care Act has become the law of the land. We also support the Health Care and Education Affordability Reconciliation Act now pending in the Senate.

The new law makes a number of improvements in our nation's health care system for children and youth with special health care needs (CYSHCN) and disabilities. These include several benefits that would take effect within the next six months, including:

- Elimination of lifetime benefit caps and a prohibition against rescinding coverage when someone get sick.

Example 1: A premature baby is in hospital for many months and has been diagnosed with multiple health issues. Due to the length of stay in the hospital, the family is near reaching its lifetime maximum for the child. With the elimination of lifetime caps, the family will not have to worry whether child will be able to continue to receive medical treatment.

Example 2: A family has had coverage for several years. Their teenage child is injured and needs expensive rehabilitation. The insurance company suddenly rescinds the policy, claiming that the family had failed to disclose that the child had the pre-existing condition of acne, and therefore the policy is invalid. The new law prohibits such cancellation of policies, absent intentional fraud on the part of the insured.

- A prohibition against denying children coverage for treatment of pre-existing conditions. (By 2014, no one can be denied access to insurance or coverage for treatment related to a pre-existing condition; HHS intends to clarify by regulation that, six months from the bill's passage, children will have access to insurance regardless of pre-existing conditions.)

Example 1: Sally, age 7, has cerebral palsy and is in need of a baclofen pump to assist with spasticity. Prior to the law's passage, the insurance company could have denied this due to her pre-existing condition of cerebral palsy. With passage of the law, this should no longer happen.

Example 2: A 6-month old is discovered to have a congenital heart defect. The insurance company refuses to cover necessary surgery because the defect is considered a pre-existing condition. This would be prohibited under the new law.

Example 3: Laurie has Down Syndrome. Once the regulations are issued to clarify that children cannot be denied insurance policies due to pre-existing conditions, Laurie's family will be able to add her to their plan.

- The establishment of a national high-risk pool for those who have been uninsured due to pre-existing conditions (until 2014 when insurance can be purchased on “Exchanges”).

Example: Christina, a self-employed young adult, age 28, has been unable to get insurance due to her Type 1 diabetes. If she has been uninsured for at least six months, she can get coverage through a high-risk pool that will be established within the 90 days from the signing of the bill.

- A requirement that young adults be permitted to stay on their parents' insurance policies until age 26, unless they have an offer of employer coverage.

Example: Sam is a 19-year old with spina bifida. He has a job working at a computer center which he love, but the job offers no insurance benefits. Under the new law, Sam can stay on his parents insurance until he is 26 years old.

- No-cost preventive care for children in new insurance plans (excluding ERISA plans), based on the “Bright Futures” recommendations of the Maternal and Child Health Bureau and the American Academy of Pediatrics.

Example: Children will be able to receive comprehensive preventive care, including developmental screenings, at no-cost.

- Extension of funding for Family-to-Family Health Information Centers (see below).

Other important provisions, to take effect in 2014, include:

- Expansion of the Medicaid program to *all* individuals with incomes up to 133% of the federal poverty level. (Currently, states cannot receive federal Medicaid funds for covering childless adults.)
- Elimination of all pre-existing condition exclusions (i.e., guaranteed issue of insurance), and a prohibition on premium variations based on health status. (This will eliminate discrimination against individuals with pre-existing conditions.)
- Elimination of annual benefit caps.

Example: Jack has required extensive hospitalization for multiple heart surgeries in his first year of life, exceeding the annual limit her insurance company will pay on his behalf. Under the new law, there will be no arbitrary annual limits, so Jack's family will not have to pay out-of-pocket for the balance of his expenses that year.

- A loan repayment program aimed at reducing shortages of pediatric subspecialists, including non-physician providers of mental and behavioral health care, and substance abuse prevention and treatment services.
- Incentives for more community-based long-term care in Medicaid, and establishment of a public long-term care insurance program (the CLASS Act).

- Support for establishment of medical home models.
- Significant increases in funding for prevention and wellness efforts, and the development of the public health infrastructure.
- Authorization of a new program to support school-based health centers and provision of \$200 million for immediate construction of such centers.
- Provisions to improve the oral health of children. (Inclusion of oral health care among the benefits required of insurance plans offered through state “Exchanges,” with no charge for preventive pediatric oral health services.)

Family-to-Family Health Information Centers. Family Voices is also very pleased with the provision to extend funding for Family-to-Family Health Information Centers (F2F HICs). These statewide, family-run centers were slated to lose all funding in May. With enactment of this law, F2F HICs will be able to continue their invaluable help to families whose children have special health care needs and disabilities. The 51 centers throughout the country provide information and assistance in securing health care and health care financing for the complex health needs of CYSHCN. The new law provides the current level of funding for F2F HICs (\$5 million nationally, divided among the 51 centers) through FY 2012.

NOTE: This is a preliminary summary. The new law is over 2,400 pages long, and there will be many regulations issued to implement it. We will provide further analysis and information as it becomes available. More detailed information can be found on the following websites:

Summary of National Health Care Reform Legislation And Reconciliation Amendment Changes
(Community Catalyst)

http://www.communitycatalyst.org/doc_store/publications/PPACA_Bill_&_Amendment_Summary_3.23.10.pdf

What Health Reform Means for Maternal and Child Health (AMCHP)

<http://www.amchp.org/Advocacy/health-reform/Documents/Senate%20Bill%20-%20MCH%20Highlights%203%2022%2010.pdf>

Key Medicaid, CHIP, and Low-Income Provisions in the Health Care Reform Package

(Center for Children and Families, Georgetown University Health Policy Institute)

<http://ccf.georgetown.edu/index/cms-filesystem-action?file=ccf%20publications/health%20reform/health%20reform%20package%20final.pdf>

Immediate Benefits of the Health Care Reform Package -- the Patient Protection and Affordable Care Act and the Health Care and Education Reconciliation Act (Senate Democratic Policy Committee)

<http://dpc.senate.gov/healthreformbill/healthbill64.pdf>

Health Care Reform Implementation Timeline (Kaiser Family Foundation)

<http://www.kff.org/healthreform/8060.cfm>

Oral health provisions (Children’s Dental Health Project)

<http://www.cdhp.org/system/files/FINAL%20HCR%20Senate%20Bill%20Summary%20-%203%2023%2010.pdf>