

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, and also supports 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). These include several benefits that would take effect within the first year, including:

- ✚ Elimination of lifetime benefit caps.
- ✚ A prohibition against denying coverage for treatment of pre-existing conditions for children who have insurance.
- ✚ The establishment of state high-risk pools for those who have been uninsured due to pre-existing conditions.
- ✚ A requirement that young adults be permitted to stay on their parents' insurance policies until age 26.

Other important provisions include:

- ✚ Expansion of the Medicaid program to individuals with incomes up to 133% of the federal poverty level.
- ✚ Elimination of all pre-existing condition exclusions (guaranteed issue), and prohibition on premium variations based on health status.
- ✚ Elimination of annual benefit caps.
- ✚ No-cost preventive care and developmental screenings for children.
- ✚ Provisions to increase the supply of pediatric sub-specialists.
- ✚ Incentives for more community-based long-term care in Medicaid.
- ✚ Support for establishment of medical home models.

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. 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) through FY 2012.