

Senate Health Care Bill Will Hurt Children/Youth with Special Health Care Needs and Their Families

Family Voices urges Senators to oppose the “Better Care Reconciliation Act.” Rather than ensuring “better care,” this bill will threaten the health of millions of children and youth with special health care needs and the well-being of their families in order to offset tax cuts for the country’s wealthiest individuals and corporations.

As an organization of and for families of children and youth with special health care needs, we appreciate the attempt to protect vulnerable children through a “carve out” from Medicaid per capita caps. Unfortunately, this provision will not provide the needed protections for children and youth with special needs. These cuts will hurt *all* children, including the “blind and disabled” children exempted from the caps.

Medicaid caps in any form will compel states to limit eligibility, cut coverage of services, medications, and supplies, and/or reduce payments to providers. Children with special health care needs will be disproportionately affected by these cuts. States may eliminate or reduce services provided under optional “Katie Beckett” waivers, which enable medically fragile children to live at home with their families rather than in nursing homes. Reductions in provider payments will also affect children with special health care needs disproportionately, as they rely on numerous specialists who may stop taking Medicaid patients if reimbursement is reduced.

The Medicaid caps and cuts in the House bill, made even worse in the Senate bill, constitute a fundamental change to a 52-year-old program that is the backbone of children’s health care coverage. These cuts to Medicaid, unrelated to the Affordable Care Act, should not even be considered without extensive expert hearings, comprehensive analyses, and the opportunity for widespread public input.

Children with special health care needs and their families will also be hurt by the bill’s elimination of the prohibition of annual and lifetime coverage limits and the caps on out-of-pocket spending. These provisions in current law protect families from extreme medical debt and bankruptcy. If states are permitted to waive Essential Health Benefits, these important protections will be severely undermined, *even for many people with employer-sponsored insurance.*

Before casting their votes on this legislation, we ask lawmakers to listen to families and providers to understand its very grave consequences for children and youth with special health care needs and others whose health and well-being depend on Medicaid and current health care protections.

About Family Voices

[Family Voices](#) is a national, nonprofit, family-led organization promoting quality health care for all children and youth, particularly those with special health care needs. Working with family leaders and professional partners at the local, state, regional, and national levels since 1992, Family Voices has brought a respected family perspective to improving health care programs and policies and ensuring that health care systems include, listen to, and honor the voices of families.