



HEALTH CARE REFORM AND CHILDREN WITH SPECIAL HEALTH CARE NEEDS

Family Voices is a national organization of families with children and youth with special health care needs (CYSHCN). Through our national network, we provide families with tools to make informed decisions, advocate for improved public and private health care policies, build effective partnerships between professionals and families, and serve as a trusted resource on health care.

Family Voices recommends that the following policies be part of national health care reform.

- ***Benefits must be comprehensive, flexible and continuous to address the unique and special health care needs of these children.***
 - Medicaid, including Early, Periodic Screening, Diagnosis and Treatment (EPSDT), should be preserved and strengthened given its unique and critical role in providing high-quality health care coverage for CYSHCN.
 - The Family Opportunity Act (FOA) Medicaid Buy-In program ("wrap around") should be strengthened by eliminating income limits and utilizing a progressive sliding scale for premiums. States should be given incentives to establish buy-in programs so that this benefit is available in every state.
 - Pre-existing condition exclusions should be eliminated.
 - There should be seamless transition without gaps in coverage in order to limit administrative burden on families when CYSHCN change insurers due to eligibility for Medicaid, changes in family employment status, etc.
 - Benefits must include health promotion and preventive care as recommended by *Bright Futures*.^{*} These benefits are important for children with special health care needs and disabilities in order to lessen or prevent secondary disability and to promote lifelong health.

- ***Health care must be affordable for families.***
 - No family should face unlimited or onerous health care costs. Affordability standards must take into account all out-of-pocket costs (premiums, co-pays, deductibles, coinsurance, costs of uncovered health care services, etc.)
 - Annual and lifetime caps on insurance coverage should be eliminated.
 - There should not be premium differences based on health status or utilization of services.
 - There should be a progressive sliding scale for premiums and a maximum percent of income that families must pay for care that takes in to account aggregated expenses of all out-of-pocket costs as listed above.

- ***The health system must be family-centered, community-based, coordinated, and quality-conscious.***
 - Every child should have a medical home that engages with families to coordinate care.
 - Families should have access to clear information about their child's special health care needs and how to navigate the health system including community services, new information technologies such as Health Information Technology (HIT) and health care financing. The Family-to-Family Health Information Centers provide a model for this kind of cost-effective family support.
 - There should be pediatric quality of care standards that address CYSHCN that are developed and implemented with family input, applied to both Medicaid and other health insurance plans and that are effective in promoting a high-performing health system.
 - There should be adequate provider reimbursement in Medicaid and other health care coverage plans to assure adequate access to needed pediatric specialists and other health care providers.
 - Health care reform must strengthen current systems of oversight and accountability for state run programs serving children with special health care needs. This would include State Title V MCH programs.

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