

APPENDIX: SELECTED RESOURCES



TITLE V AND MEDICAID/CHIP COLLABORATION

The following resource is from the U.S. Department of Health and Human Services, Health Resources and Services Administration, Maternal and Child Health Bureau:

EPSTD—Title V MCH Program Interagency Collaboration <https://mchb.hrsa.gov/programs-impact/early-periodic-screening-diagnosis-treatment>

Strategies for Changing State Medicaid Policy to Improve Services to Children with Medical Complexity https://ciswh.org/resources/medicaid_policy_strategies/

Paths to Financial Sustainability for Comprehensive Pediatric Complex Care Programs <https://ciswh.org/resources/paths-sustainability-complex-care/>

MEDICAID/CHIP DATA FOR YOUR STATE

Catalyst Center State-at-a-glance Chartbook on Coverage and Financing of Care for CYSHCN <https://chartbook.ciswh.org/>

Federal Medical Assistance Percentage (FMAP) for Medicaid and Multiplier <https://www.kff.org/medicaid/state-indicator/federal-matching-rate-and-multiplier/>

Federal and State Share of Medicaid Spending <https://www.kff.org/medicaid/state-indicator/federalstate-share-of-spending/>

Distribution of Medicaid Enrollees by Enrollment Group <https://www.kff.org/medicaid/state-indicator/distribution-of-medicaid-enrollees-by-enrollment-group/>

State Medicaid and CHIP Waiver and Demonstration Programs <https://www.medicaid.gov/medicaid/section-1115-demo/demonstration-and-waiver-list/index.html>

Children's Medicaid/CHIP Participation Rates, <https://www.kff.org/medicaid/state-indicator/medicaidchip-child-participation-rates/>

Medicaid and CHIP Income Eligibility Limits for Children as a Percent of the Federal Poverty Level, <https://www.kff.org/health-reform/state-indicator/medicaid-and-chip-income-eligibility-limits-for-children-as-a-percent-of-the-federal-poverty-level/>

Separate Children's Health Insurance Program (CHIP) Income Eligibility Limits for Children, 2000-2022 <https://www.kff.org/medicaid/state-indicator/separate-childrens-health-insurance-program-chip-income-eligibility-limits-for-children/>

All 50 States and D.C. CHIP Fact Sheets for all years, from the National Academy for State Health Policy <https://nashp.org/all-50-states-and-washington-d-c-chip-fact-sheets-for-all-years/>

THE AFFORDABLE CARE ACT (ACA)

The Patient Protection and Affordable Care Act of 2010 (Public Law 111-148).

Full text of the legislation: <http://docs.house.gov/energycommerce/ppacacon.pdf>

The Affordable Care Act and Children with Special Health Care Needs: An Analysis and Steps for State Policymakers, developed by the National Academy for State Health Policy (NASHP) for the Catalyst Center <https://ciswh.org/resources/the-affordable-care-act-and-children-with-special-health-care-needs-an-analysis-and-steps-for-state-policymakers/>

The Affordable Care Act: A Side-by-Side Comparison of Major Provisions and the Implications for Children and Youth with Special Health Care Needs, from the Catalyst Center <https://ciswh.org/resources/the-affordable-care-act-a-side-by-side-comparison/>

Health Care Transformation section of the Catalyst Center website <https://ciswh.org/projects/the-catalyst-center/health-care-transformation/>

Association of Maternal Child Health Programs. Promoting Coverage, Current Initiatives. <https://amchp.org/promoting-coverage-current-initiatives/#tabs1>

Find Coverage for Your Family at InsureKidsNow.gov. Use this resource to find state- specific information about Medicaid and CHIP programs. <https://www.insurekidsnow.gov/coverage/index.html>

MEDICAID ELIGIBILITY DETERMINATIONS

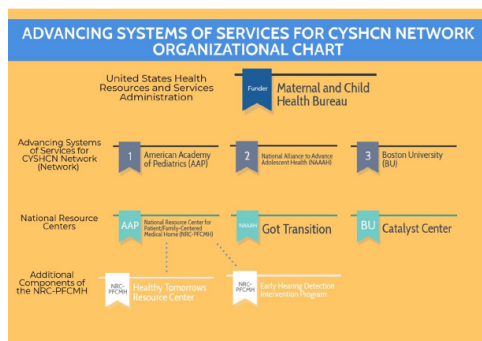
Medicaid Eligibility Determinations, Applications, and Online Accounts, <https://www.kff.org/health-reform/state-indicator/features-of-online-and-telephone-medicaid-applications/>

STREAMLINED ENROLLMENT & RENEWAL PRACTICES

State Adoption of Presumptive Eligibility for Eligible Individuals Enrolling in Medicaid/CHIP <https://www.kff.org/health-reform/state-indicator/presumptive-eligibility-in-medicaid-chip/>

State Adoption of 12-Month Continuous Eligibility for Children's Medicaid and CHIP <https://www.kff.org/health-reform/state-indicator/state-adoption-of-12-month-continuous-eligibility-for-childrens-medicaid-and-chip/>

THE MATERNAL AND CHILD HEALTH BUREAU-FUNDED NATIONAL CENTERS SERVING CSHCN



The Advancing Systems of Services for CYSHCN Network was established in 2018. The Network's goal is to improve the health and well-being of children and youth with special health care needs (CYSHCN) and their families by establishing a network of centers that focus on three core health system components: access to the patient/family-centered medical home, transition into adult health care systems, and continuous and adequate health care coverage. As the Network, the **Catalyst Center**, the **National Resource Center for Patient/Family-Centered Medical Home (NRC-PFCMH)**, and **Got Transition** collaborate to support state Title V programs, family leadership organizations, health care providers, and other stakeholders. In addition to the activities of the Network, each national center continues to provide its own technical assistance and training on topics specific to its area of expertise.



Family Voices Leadership in Family and Professional Partnerships (LFPP) is dedicated to providing leadership in helping families and professionals partner together in decision-making by providing technical assistance to the Family- to-Family Health Information Centers (F2F HICs), Family Voices State Affiliate Organizations and other family leaders in the states and partnering with other stakeholders to improve family engagement at all levels of health care from direct patient care to program design and policymaking. <https://familyvoices.org/lfpp/>



The National Coordinating Center for the Regional Genetics Networks (NCC) works with the seven Regional Genetics Networks and the National Genetics Education and Family Support Center to improve access to genetic services for underserved populations. They develop resources related to education on genetics and genetics policy, workforce development, and raising awareness about public health genetics. <https://nccrcg.org/>

PARTNERSHIP AND COLLABORATION



Leadership in Family and Professional Partnerships

Family Voices. Family Voices is a national organization with state affiliate organizations (SAOs) dedicated to achieving culturally competent, accessible, affordable family-centered care for children and youth with special health care needs. Veteran family members provide information and support, train other family members for leadership positions on the local, state and federal levels and advocate for policies that promote high-quality, community-based services and supports for CYSHCN. <http://www.familyvoices.org>



Data Resource Center for Child and Adolescent Health (DRC). The mission of the DRC is to take the voices of parents, gathered through the National Survey of Children's Health (NSCH) and share the results through this free online resource. Easy access to children's health data allows researchers, policymakers, family advocates and consumers to work together to promote a higher quality health care system for children, youth and families. <http://www.childhealthdata.org>



National Academy for State Health Policy (NASHP) is an independent academy of state health policymakers. They are dedicated to helping states achieve excellence in health policy and practice. NASHP provides a forum for constructive, nonpartisan work across branches and agencies of state government on critical health issues facing states. <http://www.nashp.org>