



CRISS CONFERENCE:

“The Devil is in the Details”

Family Voices of CA

- **Statewide collaborative of locally-based parent run centers, working to ensure quality health care for CYSHCN**
- **State Affiliate of Family Voices National**
- **CA's federally funded Family-to-Family-Health-Information-Center, providing statewide support to families of CYSHCN**

FVCA MISSION

- **Grow and support the capacity of parent-run centers**
- **Provide families information and support to make informed decisions about the health care of their CSHCN**
- **Present opportunities for parent centers and families to advocate for improved public and private policies**
- **Build partnerships between professionals and families**
- **Serve as a vital resource on health care**

COVERED CALIFORNIA

- Means Health Insurance for “All”
- Is designed with primary goal to expand health coverage for the general population

What about Children and Youth with Special Health Care Needs?



WHAT DO WE KNOW?

- **Families can no longer be denied health coverage because of a child's pre-existing condition**
- **11% of CA children have an identified special health care need**
- **Creating a comprehensive, quality system of care for CSHCN is one of the most challenging areas for DHCS**
- **It is critical for policymakers, researchers and advocacy organizations to monitor the many issues important to CSHCN**

INADEQUATE COVERAGE for CSHCN

- **Non-covered benefits**
- **Limitations in duration and scope**
- **Annual or lifetime limits**
- **Excessive out of pocket expenses or children not receiving the care they need**

BURDEN FOR FAMILIES

Out-of-pocket cost liabilities if the family is not eligible for subsidies (e.g. premium tax credits or reduced cost sharing):

- **Premiums**
- **Co-payments**
- **Co-insurance**
- **Deductibles**
- **Uncovered services**

ACCESSING THE RIGHT CARE IS KEY

Do plan networks include the pediatric specialists that CSHCN need?



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WHAT IS THE SYSTEM SUPPOSED TO LOOK LIKE FOR CSHCN?

**MCHB: Healthy People 2020 National
Health Objectives**

Six Critical Systems Outcomes

(1) FAMILY/PROFESSIONAL PARTNERSHIP AT ALL LEVELS OF DECISION MAKING



(2) ACCESS TO COORDINATED COMPREHENSIVE CARE WITHIN A MEDICAL HOME



(3) IMPROVE ACCESS TO MENTAL HEALTH SERVICES



(4) ACCESS TO ADEQUATE PRIVATE AND/OR PUBLIC INSURANCE TO PAY FOR NEEDED SERVICES



(5) EARLY AND CONTINUOUS SCREENING FOR SPECIAL HEALTH NEEDS



(6) YOUTH TRANSITION TO ADULT HEALTH CARE, WORK, AND INDEPENDENCE



FVCA: www.familyvoicesofca.org

Lucile Packard Foundation for Children's Health: <http://lpfch.org>

CRISS: www.CRISS-CA.org

National Health Law Program:

<http://www.healthlaw.org/issues/california/health-reform>

Catalyst Center: <http://hdwg.org/catalyst/publications/aca>

National Center for Family Professional Partnerships:

<http://www.fv-ncfpp.org>

Family Voices: <http://www.familyvoices.org/states>

California Children's Hospital Association: <http://www.ccha.org>

Disability Navigator Resource Collaborative:

<http://www.nationaldisabilitynavigator.org/state/ca>

THANK YOU FOR YOUR TIME

