

## Strategies

- 1. Build Relationships with Legislators and local Policy Makers:** To keep Legislators informed about how families of children with special health care needs are impacted by various budget proposals, FVCA will assist members in developing relationships with Legislators and legislative staff. FVCA will post information and materials families can use in communications with Legislators and local officials on the FVCA website.
- 2. Provide Education and Outreach to Families, Professionals and Policy Makers:** Many families of children with special health care needs and the professionals who work with them may be unaware of the impact of cuts contained in the 2009-10 Budget Agreement and may not know where to turn for information that will help them understand the ballot measures. FVCA will collaborate with professional and advocacy groups and use their listserves, websites and newsletters to disseminate the information about the proposed cuts and ballot measures. Families of children with special health care needs have powerful voices and are effective communicating about their children. FVCA will encourage families to input their stories into the electronic “Story Bank” maintained on the FVCA website. Stories will be used to help “paint a picture” of the real lives of families of children with special health care needs. The Story Bank will also be used to identify families interested in talking with the media, policymakers, and other groups. FVCA will explore using You-tube and Facebook as venues for outreach and information sharing and other electronic media.
- 3. Provide a Forum for Reviewing and Providing Feedback on Special Projects:** The federal Family Opportunity Act (FOA), signed into law in 2005, allows states to draw down significant federal matching dollars. Families making under 300% of the Federal Poverty Level and whose children meet the Supplemental Security Income (SSI) disability criteria can purchase Medicaid either as their only source of coverage or as a supplement to private insurance to offset the tremendous medical expenses they incur in caring for their children with special health care needs. The Catalyst Center, funded by the federal Maternal and Child Health Bureau, can calculate costs to states of implementing the FOA. FVCA can explore the viability of implementing the FOA in California.
- 4. Promote Collaboration on Behalf of Children and Families with Special Health Care Needs:** The safety net for families of children with special health care needs is made up of health care providers, insurers, public and private agencies, organizations, programs and services. As cuts occur in multiple service strands, that safety net very quickly unravels. It is important to work together on behalf of our mutual goals. FVCA will actively seek opportunities to work collaboratively with other entities to support mutual goals and ensure that the services and supports so critical to families of children with special health care needs do not disappear.

**Available Resources:** A number of useful resources were distributed at the Health Summit. Visit our website for: 2009-2010 Budget Items Affecting Families of Children with Special Health Care Needs; Tools for building relationships with legislators (including talking points, tips, California budget background and procedures).

# FAMILY VOICES of CALIFORNIA

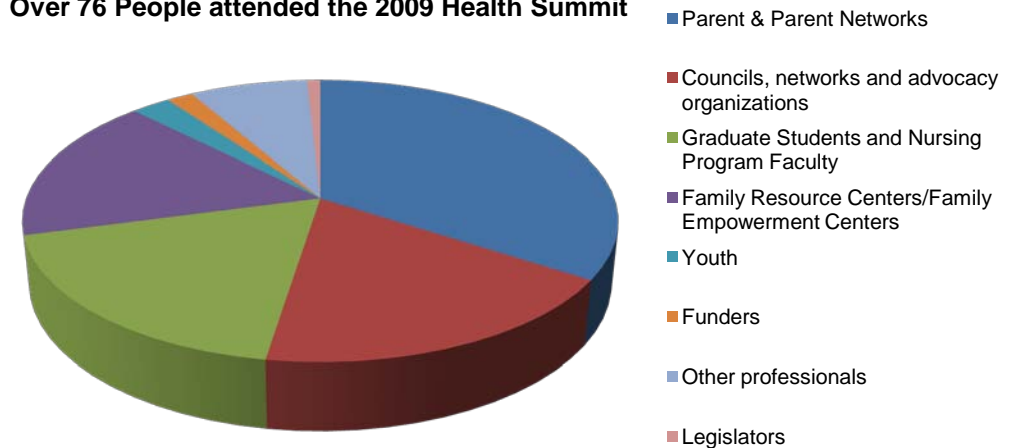
## “We Can Do It” VII

### Highlights of the March 2009 Health Summit

#### Background

On March 10, 2009 Family Voices of California held its seventh statewide Health Summit, bringing together families, advocates, advocacy organizations, state agency representatives, health policy advocates, funders, parent and youth networks, nursing students, doctors, nonprofits, coalitions, and legislative representatives. The Summit focused on identifying budget issues in California significantly affecting children with special health care needs and developing strategies to ensure that families in California are able to access family-centered, affordable care. This report summarizes the challenges identified by the group and the strategies developed to address these challenges.

#### Over 76 People attended the 2009 Health Summit



For more information, contact Family Voices of California  
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## Challenges

### *Access to Appropriate and Affordable Care/Services*

- **California's Budget Deficit, Low Revenue and Rising Unemployment:** California is facing an unprecedented budget deficit of an estimated exceed \$42 billion between January 2009 and June 30, 2010. While there are many underlying causes, the immediate culprit is the national and global economic meltdown. California's revenue is considerably lower than expected (\$14.5 billion lower in 2008-2009, and \$16.3 billion lower in 2009-10). Demand is rising for health and human services programs as state residents lose jobs, health coverage, and value in their retirement and investment funds.
- **Hole in the Safety Net:** This budget crisis follows years of budget deficits, resulting in substantial prior cuts to services and programs. California's safety net of services for children with special health care needs has an enormous hole in it.
- **State Budget May Continue to Change:** The 2009-10 budget agreement was developed behind closed doors without input from affected groups or programs. It relies on a combination of reductions, increased revenues, new borrowing, funds expected as a result of the economic recovery bill, new borrowing, and expected revenue from May 2009 Propositions voters have yet to approve.
- **Cuts to Regional Centers:** The current budget reduces funding to the Regional Centers by \$100 million. This reduction comes on top of "Cost Containment Measures" that have been imposed for the past six years, during which time the population served by the State's Regional Centers has consistently increased owing to immigration and skyrocketing rates of autism (from 1 in 2,500 births in the 1970s to 1 in 150 births today). Regional Centers serve approximately 227,000 individuals with developmental disabilities each year.
- **Redirecting First 5 Funds:** California voters are being asked to help solve the budget crisis by redirecting funds designated (and approved by voters) for the purpose of providing community-based mental health services and prevention and early intervention services for children birth to age 5. Proposition 1D will redirect \$268 million (about 50% of total funding) annually from First 5 Commissions to the state General Fund for five years beginning July 1, 2009. Since the tobacco tax is a declining revenue source, the percentage diverted to the general fund is expected to reach 65 percent within the five years.
- **Restrictions on First 5 commission funds:** Proposition 1D would also change what First 5 commissions can fund, requiring revenue to be used for "direct services" only. It is highly questionable whether many existing First 5 programs would fall under this category: providing health insurance, recruitment/training of dentists and other professionals to meet pediatric health and dental needs, training for preschool teachers and providers, and other preventative programs that leverage funds and coordinate services for young children.
- **Medi-Cal Provider Reimbursement Rate Cuts:** Cuts to Medi-Cal provider reimbursement rates have greatly reduced the number of doctors and specialists available to serve children with special health care needs, especially in rural communities. Families are unable to find the specialists and sub-specialists their children need and are forced to travel several hours, often waiting several months to gain access to care. Low provider reimbursement rates results in the inability to recruit and retain pediatric specialists in California. CSHCN are increasingly utilizing Emergency Rooms and are at increased risk of serious complications owing to the increased lack of access to essential specialists and sub-specialists.
- **Approval Process for Budget:** In order to pass a budget in California, two-thirds of the California Legislature must vote to approve the budget, rather than a simple majority (California is one of only three states with this requirement). This has made it increasingly difficult to negotiate a budget, as a small group of legislators has the power to stall budget agreements.
- **IHSS Provider Rate Cuts:** In Home Support Services (IHSS) are far less expensive than institutional care. IHSS contributes to the ability of families to keep their children with special health care needs at home rather than in institutions. Proposed cuts in provider pay make it increasingly difficult for families to make ends meet and provide the care their children need.