



“We Can Do It” IV

Highlights of the March 2005 Conference

Background

On March 16, 2005 Family Voices held its fourth statewide Health Summit, bringing together families, advocates, state agency representatives, health policy advocates, legislative representatives, providers and insurers to reflect on the progress made in implementing the strategies developed at the previous Health Summits and to discuss new and continuing challenges/barriers facing families. This report summarizes the challenges identified and the strategies developed to address the challenges.

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Challenges

(Summit participants identified the following challenges)

Access to Appropriate Care/Services

- California is facing a budget deficit resulting in massive proposed cuts to health care services for a third consecutive year.
- Term limits and redistricting have resulted in the election of a large number of new legislators who are not aware of the issues that affect families of children with special health care needs, or understand the systems and programs those children use.
- The Administration's proposal to redesign Medi-Cal, in order to save an estimated 5% in costs over time, includes the mandatory enrollment of the aged, blind and disabled in Medi-Cal managed care and the institution of premiums. Managed care may not be suitable for catastrophic/chronically ill children who need to access appropriate pediatric care in a timely manner. Children with special health care needs may be at increased risk of serious complications if services are delayed as families negotiate with the managed care plan for the needed services.
- Families may lose access to specialists and sub-specialists knowledgeable about their children's unique medical needs and to providers their children currently see, if the providers are not members of the managed care plan provider network that their child is required to enroll in. Currently, many families travel out of county to gain access to specialty care centers and other necessary services not available in their area. They may lose this option under managed care, which seeks to keep enrollees within the network.
- As part of the redesign, those county Medi-Cal managed care plans where California Children's Services (CCS) is rolled into the managed care plan may be allowed to expand into adjoining counties and roll the CCS program in the new county into the managed care plan. This may impact the ability of chronically/critically ill CCS eligible children to access the pediatric sub-specialists and specialty care centers available in other areas of the state and require families to negotiate for the CCS services their children are eligible for, creating critical delays in service.
- Insufficient planning for implementing the enrollment of children with special health care needs in Medi-Cal managed care on such a large scale and the lack of critical input from families and providers concerning the unique needs of this population may lead to a system that does not meet the needs of these children and their families.
- Many families rely on services from multiple systems such as In Home Support Services (IHSS), CCS, and Medi-Cal. Proposed cuts and redesigns of programs will impact their ability to care for their child.

Access to Affordable Care

- Imposition of Medi-Cal premiums would result in twenty percent (over 100,000) of children, parents, seniors and people with disabilities losing coverage due to their inability to pay the premiums. Procedures to deal with non-payment of premiums and subsequent dis-enrolling, and re-enrolling will need to be developed. Administrative costs associated with the implementation of premiums may exceed the premium amount collected.
- Families may go to emergency rooms to access care for their seriously ill children if Medi-Cal coverage has lapsed due to non-payment of premiums. Children with special health care needs will be at increased risk of serious complications or death due to lack of access in a timely manner to the specialists and sub-specialists knowledgeable about their child's medical needs.

- Proposals to lower the IHSS provider wage to \$6.75 per hour will make the already daunting task of finding an in home care provider even more difficult. Few non-family providers will choose to take on the task of caring for a child with special health care needs when an identical, or higher wage, can be earned at a job with fewer demands. Lack of qualified in home providers may require parents to quit jobs to provide the care their child needs.
- Many families are stretched financially and may not be able to supplement the cut in wages for the IHSS providers they need. Inability to find qualified providers to help care for their children may force families to institutionalize their children, with the state required by law to pay 100% of the high cost of institutionalization.
- The budget proposes to eliminate the state cost of living adjustment (COLA) of 4.6% and withhold the federal COLA of 2.5% for Supplemental Social Security/State Supplementary Program (SSI/SSP) grants. SSI/SSP grant levels would remain frozen at April 2005 levels until January 2007. Future COLAs would be based on the April 2005 level. Families of children with special needs impacted by this proposal may not be able to afford the care their children need.
- Many families may be impacted by more than one of the budget “cost shifting” proposals (Medi-Cal premiums, IHSS wage cuts, elimination of the 2006 COLAs), which would increase out of pocket costs for already financially stretched families, placing increased stress on their ability to care for their children with special health care needs.
- The Administration’s proposal for hospital financing shifts financial risk from the state to the counties, and does not keep up with the projected inflation in health care costs. Hospitals are unsure of funding that will be available for providing medical services and for growth, which may lead to closures impacting access to care for children with special health care needs.

Strategies for Improvement

(Summit participants agreed on the following strategies)

1. Collect a bank of family stories with pictures/videos of their children and family

Parents of children with special needs have powerful voices and are effective at communicating about their children. Families can provide the human face and story of their children. They should be encouraged to talk about their children, explain their children's unique needs and how they have worked to coordinate and organize care to meet their children's needs. They are the critical voices that should be heard. A bank of stories would be a valuable resource to educate legislators, policymakers, administrators and the public concerning the unique needs of children with special health care needs.

2. Build personal relationships with legislators

Term limits and redistricting have resulted in a large number of new legislators who need to be educated about the needs of children with special health care needs and the issues that affect them and their families. Families across the state should visit legislators and attend hearings with their children to provide education. Invitations should be extended to legislators and their staffs to visit programs that serve families of children with special health care needs. This will help legislators understand the programs serving children with special health care needs and gain first hand knowledge of the impact of cuts to these programs on children and their families. Legislators need to be challenged to do the right thing for families.

3. Build working relationships with policy makers to ensure the needs of CSHCN are addressed

Families should meet with the Director of the Department of Health Services (DHS) to make sure that the unique needs of families of children with special health care needs are understood and work with the department to ensure that programs created address these needs. Families should be at the table working with DHS and managed care plans to help create a system that provides

flexibility for families, access in a timely fashion to providers and specialty care centers with the experience and expertise in the unique needs of these children, and provides the option for families to enroll and dis-enroll their children if their child's needs are not being met. Families can provide invaluable information to DHS and plans to help create a system that works.

4. Gather data and research on the actual cost savings of proposed budget cuts

Families, advocates and providers should gather data and research that exists in California about the impacts of administrative proposals on budget cuts, data and research that exists in other states that have tried similar proposals, and information about various program efficiencies non-governmental agencies have proposed in order to cut costs. Kaiser Family Foundation, California Budget Project, Western Center on Law and Poverty, and the National Health Law Program are some of the resources that should be looked at for data and information. This information should be provided to budget committees, legislators and the administration to help inform them about whether the proposals will actually save money or increase costs in the long run.

5. Maintain current hourly wage of In Home Support Services (IHSS) providers

The In Home Support Services (IHSS) program is a cost effective program with low administrative overhead, since parents do most of the work by locating and training providers. The program allows families to keep their children at home and out of costly institutions the state would be required to pay for. Past increases in hourly IHSS wages have led to greater stability and less turnover of IHSS workers, essential for consistent quality care for children with special needs. Families, providers and advocates should promote the maintenance of the current hourly wage for IHSS providers. Families should write legislators to let them know what will happen to their families if they are unable to find IHSS providers due to the proposed hourly wage cut and how costly it will be to the state if families are forced to institutionalize their children.