

May 20, 2010

VIA FAX & EMAIL (916-319-2199, 916-323-8386)

The Honorable Mark Leno, Chair  
Senate Budget Subcommittee #3 on Health and Human Services  
State Capitol  
Sacramento, CA 95814

Dear Senator Leno:

On behalf of Family Voices of California, representing 964,167 children and youth with special health care needs in California, we are writing to express our strong opposition and grave concerns with several proposals included in the Governor's May Revision of the Budget.

**1. Co-pays/Cost Sharing for children in Medi-Cal and California Children's Services (CCS), including elimination of over-the-counter drugs, nutritional supplements and placing maximum benefits caps, and caps on prescriptions – OPPOSE.**

The Governor's proposal would result in babies and children in the Medi-Cal and CCS programs being charged co-pays for physician visits, dental visits, clinic visits, pharmacy, ER and hospitalization. This proposal would also result in the elimination of needed over-the-counter drugs and nutritional supplements, compromised access to durable medical supplies, prescriptions and doctor visits. Capping doctor visits to ten per year poses a serious challenge and threat to children and youth with special health care needs. The Administration would need to obtain a federal waiver in order to charge children co-pays since this would violate current federal law. This proposal would impact children with cancer, congenital heart disease, cystic fibrosis, diabetes and many other serious, life-threatening conditions.

Faced with large annual co-pays, this would jeopardize access to lower-cost, timely medical care for children and youth with special health care needs. **Children and youth with special health care needs are counting on you! Without your help, these families will be forced to make heartbreaking choices between the financial stability of their family and the health of their child.** In the end, this will not save the state money, as reducing access to care by making it more expensive for families ultimately costs the state more money (49% or \$10 billion was spent on hospital readmissions in 2005).

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*The following stories come from families across California and illustrate the potential co-pays families will face:*

“Sophie” has cerebral palsy (moderate mixed athetoid/spastic diplegia) and cortical visual impairment. Every year, Sophie needs the following medical visits:

- Neonatologist (2-3 times a year)
- Pediatrician (2 times a year)
- Optometrist (1-2 times a year)
- Ophthalmologist (every 6 weeks initially, then every 3 months)
- Special needs dentist (2 times a year)
- Neurologist (2 times a year)
- Orthopedist (2 times a year)
- Developmental pediatrician (once a year)
- One hospitalization (eye surgery, 3 days IP)
- 6 trips to the ER

**Total annual co-pay for Sophie: \$650.00**

“Liam” is a child with athetoid cerebral palsy, reflux, asthma and epilepsy. Every year, Liam needs the following medications/doctor visits:

Medications (analysis assumes \$5 co-pay every 30 days/drug)

- 2 for epilepsy
- 3 for reflux
- 3 for asthma/allergy

Physician visits

- Pediatrician (2 visits a year)
- Orthopedist (2 visits a year)
- Neurologist (2 visits a year)
- Physiatrist (2 visits a year)
- Gastroenterologist (3 visits a year)
- Neuro-Ophthalmologist (1 visit a year)

Sick Visits (6-8 per year)

Hospitalizations (3-4 per year starting in ER)

**Total annual co-pay for Liam: \$1,570**

## 2. Proposed Reduction of Radiologist Rates – OPPOSE

## 3. Mandate for Seniors and Persons with Disabilities mandated into Medi-Cal Managed Care – OPPOSE

This proposal is a result of discussions (and a stakeholder group) focused solely on the adult population. The approximate 75,000 children statewide in disability-related Medi-Cal codes who are not enrolled in managed care plans should not be mandated into managed care. The state has a responsibility to convene an appropriate stakeholder group to address this population of children. **The specific needs of these children have not been and must be considered.** The increasing survival of children and youth with special health care needs into adulthood has resulted in a growing number of young adults with disabilities who are already unable to access appropriate health care, given a shortage of providers and services. **With no available evidence that traditional managed care plans are capable of providing appropriate health care for those with special health care needs, neither adults nor children should be mandated into**

managed care unless and until it is shown to be effective for this vulnerable population.

**4. Healthy Families – Increase in Premiums and co-pays – OPPOSE**

The proposed increases are too high for this low-income population and will result in more children being priced out of the program and left uninsured, potentially violating the Maintenance of Effort provision in the national health care reform bill. This would result in loss of vision coverage for children and higher premiums for low-income families (from \$24 to \$42 per child per month). **These cost increases would disproportionately impact families whose children have serious and complex health conditions.**

**5. Proposed suspension of AB 3632 mandate – OPPOSE**

AB 3632 mandates counties to provide mental health services to children who need them in order to succeed at school. **By shifting this responsibility to schools, this reduction will negatively impact children’s access to mental health services in unanticipated ways.**

**6. Proposed elimination of CalWORKS – OPPOSE**

Since this proposal would have eliminated an essential safety net for children and families, **Family Voices of California expresses its sincerest thanks to the Assembly Budget Subcommittee for yesterday’s action to reject this portion of the Governor’s proposal.**

In addition, the Administration has released draft Budget Trailer Bill Language relating to the implementation of the 1115 Medicaid Waiver, raising significant concerns for children and youth with special health care needs. Family Voices of California would like to express our intense disappointment with the Administration’s proposals. **Systems serving children with life threatening and complex conditions must strive to avoid prioritizing money over the quality of life of a child.** The Administration’s proposals undermine a child’s ability to access family-centered medical care, education and information, undermining the state’s responsibility to ensure timely and appropriate medical care for this vulnerable population.

**Families in California urge you to first “Do No Harm”: Proceed cautiously in implementing substantial changes in health care delivery for children and youth with special health care needs, including implementing the 1115 waiver.**

Sincerely,



**Juno Duenas**  
Executive Director, Support for Families  
Lead agency for Family Voices of California



**Tara Chaffee Robinson**  
Manager, Family Voices of California

Cc: The Honorable Members of Senate Budget Subcommittee #3  
The Honorable Members of Assembly Budget Subcommittee  
Denise Ducheny, Chair of Senate Budget Committee  
Diane Van Maren, Senate Budget & Fiscal Review Committee