



As noted throughout this report, California's budget situation has resulted in major cuts to a number of programs that serve children and youth, including those with special health care needs. While the situation is fluid and not all details are known, certain budget impacts are clear for health and developmental programs that are fundamental to the care of CYSHCN.

### Healthy Families Program

State budget cuts resulted in a \$195 million shortfall in this program. On August 13, 2009, the First 5 California Commission voted to commit \$81.4 million to support premiums and other costs for children from birth through age five enrolled in the program. At the same time, MRMIB agreed that, in addition to the enrollment freeze implemented in July, 2009, it would begin disenrolling children from Healthy Families in order to address the remaining budget shortfall, effective October 1, 2009. MRMIB agreed to some protections for particularly vulnerable children in the program, determining that those children who are enrolled in both Healthy Families and CCS and whose families have incomes over \$40,000 per year (i.e., those children who are deemed financially eligible for CCS because they are enrolled in Healthy Families) would not be disenrolled from the Healthy Families program. This decision is important for CYSHCN; without this exemption and if these children lose their Healthy Families coverage, they also lose their CCS coverage.

As noted earlier in this report, funding was restored for the current fiscal year through the combination of state First 5 funds, a temporary provider tax on Medi-Cal managed care plans (and the federal matching funds it will draw), and increased premiums and co-pays for families. However, this funding solution will sunset in 2010, leaving the program vulnerable once more to the state's budget deficits.

### Regional Centers/Early Start Program

There have been three separate major cuts to services affecting children with developmental concerns, particularly children from birth to age three:

- A 3% reduction in overall regional center spending, followed by a \$100 million reduction, to be implemented through approaches developed via a statewide stakeholder process (finalized in budget agreement, February 20, 2009);

- A \$234 million reduction in DDS spending, including but not limited to regional centers; once again, a statewide stakeholder process including community forums and solicited comments was charged with recommending areas for program cuts to meet the funding reductions (finalized in budget agreement, July 24, 2009); and
- The Governor’s veto of an additional \$50 million, specific to the Early Start program for children from birth to age three with or at risk for developmental delays or disabilities (finalized in Governor’s veto message, July 28, 2009).

These cuts follow several years of budget reductions to regional center operations and to vendor rates and are expected to have a profound impact on access to care, particularly for young children at risk for or with developmental delay. Major budget-driven changes include:

- Early Start eligibility for toddlers age 24 months or older who were “at risk” of a developmental delay has been eliminated. Toddlers who are “developmentally delayed” and age 24 months or older will be eligible for entry to the Early Start program only if they have a 50% or greater delay in one domain or 33% or greater delay in two domains, a change from the current threshold of 33% in one domain regardless of age. These changes in eligibility will mean a loss of early intervention services for children who do not meet the new eligibility test.
- Elimination of eligibility for Early Start services for all “at-risk” infants and toddlers, including babies who were premature or with low birth weight, was proposed by Governor Schwarzenegger’s administration. In its place, a new prevention program has been authorized to provide specific services to these infants and toddlers as well as to several other categories of young children who also lost eligibility for Early Start. This new “prevention program,” which began October 1, 2009, includes “intake and assessment, case management, and referral to appropriate generic resources,” but other details are not yet available. This new program has a capped budget and so will not be an entitlement for infants and toddlers. The reduction in Early Start eligibility coupled with a new prevention program with limited funding may mean the loss of access to early intervention services for thousands of young children in the state.
- The Governor’s veto message included an additional reduction of \$50 million in funding for the Early Start program and urged that these funds be provided by the First 5 Commission. There is no indication yet whether and to what extent First 5 might replace this reduction and what specific steps will be taken to meet the additional reduction in the event that all or part of the reduction is enforced. This additional reduction in the Early Start budget could have profound impact on the program’s ability to serve even those children eligible under the new program criteria.

## **Medi-Cal Program**

The budget agreement cuts overall state funding for Medi-Cal by \$1.3 billion in unspecified reductions. (The budget assumes receipt of an additional \$1 billion in federal funds; if received, this would reduce Medi-Cal cuts to \$323 million.) While still unknown, cuts could resurrect past proposals such as requiring quarterly Medi-Cal certification for children and adults and implementation of premiums and co-pays. The Administration is also seeking major administrative changes to Medi-Cal that include mandatory enrollment in Medi-Cal managed care plans of adults and children in Medi-Cal disability aid codes; a move that would affect approximately 50,000 children and youth with disabilities.

## **In-Home Supportive Services**

The budget agreement included a major reduction of domestic services for IHSS enrollees based on their “functional level,” limiting services to only those recipients with very severe disabilities. The Governor further reduced funding for IHSS, resulting in even more restrictive eligibility criteria for domestic and related services. It is not yet known how many or which children and youth will be affected by these reductions.

## **California Children’s Services**

The state and county CCS programs have absorbed major budget reductions over the past year. At the local level this has resulted in the loss of CCS case management staff, social workers, and parent health liaison contracts; increased time for eligibility determinations and service authorizations; and reduction of many family-centered care activities such as standardized transition planning. In addition, the Department of Health Care Services has launched a project to analyze and make recommendations for potentially major changes in the CCS program; a significant redesign of the program would be built into planning for a federal waiver due for submission in 2010.

In this climate of severe budget reductions, program rollbacks, and state proposals for major overhaul of long-standing programs, it is especially critical that there are clear standards for the treatment of children and youth with special health care needs, against which proposals for change can be measured. For this reason, the authors strongly recommend two steps:

1. The state must commit to achieving the federal MCHB Core Performance Measures, which lay out nationally accepted goals for the care of CYSHCN and the system that serves them. The state should set clear operational criteria for achievement of each measure, and state progress should be evaluated and reported publicly on a regular basis. In this way there are measurable criteria for state performance that can be compared over time as well as compared with progress other states have made toward achieving core performance measures. The authors believe that commitment to and achievement of these measures would result in design of a better organized

and more usable system for children and families and ultimately could reduce the contradictions, gaps, and overlaps that bedevil families and providers and often result in additional costs to the system as a whole.

2. The state must commit to basic principles of care for CYSHCN in any major change of the health care system that serves them. These principles, which have been accepted by several groups of providers and families in California, include the following:
  - Families and youth must have access to ongoing information, education, and support in order to be an informed and effective partner in the care of their children and themselves.
  - All health care delivery to children, particularly children and youth with special health care needs, should be based on and flow from their medical and related needs. The medical necessity definition and standards-of-care for all children, including CYSHCN, should reflect sound pediatric principles and address children’s health, developmental, social, and behavioral needs.
  - Children should have access to medically, developmentally, and behaviorally appropriate care regardless of their geographic region. County-based systems of care that limit access to pediatric and/or other appropriate providers are not acceptable for CYSHCN. Children should retain access to regionalized pediatric health care systems such as CCS-approved neonatal, pediatric intensive care, and other pediatric care.
  - CYSHCN should have clearly identified medical homes, including primary care providers, access to pediatric subspecialists, and care coordination. Families should be recognized and supported as central to the organization and coordination of their children’s care, and should have the ability to exercise choice in selecting providers that meet pediatric credentialing standards.
  - Provider networks should include all pediatric subspecialties, pediatric hospitals, child-appropriate durable medical equipment (DME) and other supply vendors, and other pediatric-appropriate services. Providers should meet clearly established standards for credentialing that reflect pediatric training and experience.
  - The benefits package for children should be broad and representative of children’s needs, including appropriate medical, dental, developmental, behavioral, and rehabilitative services; pharmaceuticals; DME and medical supplies; and ancillary services. Care coordination should be a recognized component of service delivery to CYSHCN. The federal EPSDT benefit and medical necessity definition should serve as the model for care of children and youth.
  - Financing of health care delivery to CYSHCN should recognize their special needs, and children’s access to health care should not be hindered by inadequate reimbursement to providers. Fee-for-service systems

should reimburse at rates that reflect actual costs of care, and reimbursement should include the capacity to cover pediatric services beyond typical medical care (e.g., office visits), such as care coordination. Capitated systems should have rates that are risk-adjusted to reflect actual costs of care, and include additional services such as care coordination. Capitated systems should not include risk to providers (thus removing financial disincentives to provision of necessary care) and should avoid full risk to plans through strategies such as reinsurance or risk-sharing with the state (such as the current CCS carve-out).

Drawing on these past experiences, the authors believe that proposals that further achievement of the MCHB Core Performance Measures and meet core principles for health care delivery to CYSHCN stand the best chance of building a true system of quality care for vulnerable children and youth. California is indeed at a crossroads, with difficult decisions ahead and perhaps a “perfect storm,” putting our most vulnerable population at risk. It is clear that to address what past reports have recommended and to address the strategies outlined in this report, we must also garner the political will to make this systemic change.