e-Newsletter with a Focus on Children with Special Health Care Needs in California

Volume 1, Issue 4 April 2007

CACSHCNEWS

State Children's Health Insurance Program (SCHIP)

- Study on States' SCHIP Enrollment Cap
- Study on SCHIP Enrollment Effects on CSHCN

Article Highlights Lessons from States on SCHIP Enrollment Caps

"[State Children's Health Insurance Program] enrollment caps resulted in quick cost savings and, largely because of this, were lifted by the states relatively quickly," state the authors of an article published in the January-February 2007 issue of Health Affairs. In response to a national recession, struggling state and local economies, and increased public spending demands, most states have trimmed a broad range of programs, including the State Children's Health Insurance Program (SCHIP). The article presents the experiences of 7 of the 39 states with separate (as opposed to Medicaid expansion) programs that capped enrollment during the 2001-2003 recession.

The study was conducted as part of an evaluation of the Robert Wood Johnson Foundation's Covering Kids and Families (CKF) initiative to support outreach, simplification, and coordination activities in child-enrollment efforts in more than 140 community-based projects in 45 states and the District of Columbia. Telephone interviews were conducted in October and November 2004 with SCHIP and CKF grant directors in each of the seven states that enacted enrollment caps (Alabama, Colorado, Florida, Maryland, Montana, North Carolina, and Utah). Informants were asked to discuss the factors that led to the enactment and lifting of caps, policies that were adopted to manage implementation, caps' impact on SCHIP enrollment and other aspects of the program, and strategies to mitigate caps' negative effects. The existing literature on enrollment caps was reviewed, and administrative data were obtained to document enrollment trends.

Authors' findings:

- Three states enacted enrollment caps in 2001 at the outset of the recession; four states capped enrollment between July and November 2003 at the height of the recession.

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CA**CSHCN**EWS is produced by a consortium whose members work toward the common goal of improving systems of care for children with special health care needs in California:

- California Children's Services Medical Branch
- Los Angeles Partnership for Special Needs Children (LAPSNC)
- Family Voices of California (FVCA)
- Children's Regional Integrated Service System (CRISS) Project
- USC University Center for Excellence in Developmental Disabilities (UCEDD) at Childrens Hospital Los Angeles

If you...

- would like to contribute news items, please submit via email: **ngarro@ucla.edu**
- have any questions about this newsletter, please contact Kathryn Smith, MN, RN: **kasmith@chla.usc.edu**

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Next Issue Date:
July 2007

(Continued – States' Lessons from SCHIP Enrollment Cap)

- With the exception of Montana, all states lifted their enrollment caps within 1 year of enactment.
- While caps were in place, total enrollment dropped by an aggregate 15% in the six states that capped and then reopened enrollment. Rates of attrition ranged from 6% in Florida and Maryland to 29% in North Carolina.
- Only simplified renewal was observed to reduce rates of enrollment attrition; neither maintaining a waiting list nor modifying cost-sharing policies had an effect on enrollment attrition or recovery.
- Informants described their reluctance to conduct outreach while programs were capped. However, agencies adjusted messages and strategies to emphasize renewal or applications for Medicaid. States and CKF grantees were eager to promote coverage once caps were lifted.
- Enrollment caps caused confusion for parents (e.g., fear that SCHIP had been entirely closed was widespread). However, rapid enrollment recovery in most states after caps were lifted and during open periods suggests that SCHIP still represents a needed and desirable product to parents.
- Rates of retention among SCHIP enrollees improved during and after caps.

The authors conclude that "perhaps the lessons learned by the states studied here can help others design policies that minimize the negative impacts on vulnerable children." (MCH Alert, 1/26/07)

Hill I, Courtot B, Sullivan J. 2007. Coping with SCHIP enrollment caps: Lessons from seven states' experiences. Health Affairs 26(1):258-268. Abstract available at http://content.healthaffairs.org/cgi/content/abstract/26/1/258?etoc.

Study Finds Improved Health Care Among CSHCN after Enrollment in State Children's Health Insurance

"These findings extend our prior work to demonstrate that for special-needs children who enrolled onto SCHIP, access and quality of care improved after enrollment," state the authors of an article published in the January-February 2007 issue of Ambulatory Pediatrics. Despite evidence that the State Children's Health Insurance Program (SCHIP) improves care for the general population of children, few studies have assessed whether children with special health care needs (CSHCN) experience similar benefits. The article discusses findings from an assessment of the impact of New York's SCHIP on access and quality of care among CSHCN.

The study was part of a larger evaluation of CSHCN who enrolled in New York's SCHIP between 2001 and 2002. New York's SCHIP administrative files were analyzed to identify new enrollees, from which a stratified random sample of new enrollees was selected from four geographic regions, three age groups, and three racial and ethnic groups (based on parent self-report). Parents were interviewed shortly after enrollment (baseline) and again 13 months after enrollment (follow-up).

Before-after cohort analyses were conducted to assess the following: (1) demographic and health characteristics of SCHIP enrollees with special health care needs, (2) health care measures before and after enrollment in SCHIP by prior insurance and by type of special health care needs, (3) parent rating of the quality of medical care, and (4) reasons for unmet health care need before and after enrollment in SCHIP. To assess secular trends, baseline measures for the study group were also compared to baseline measures for a comparison group that enrolled 1 year later.

Authors' findings:

- At baseline, 454 (17%) of 2,644 children were identified as CSHCN; 398 (88%) of 454 CSHCN completed the follow-up interview and made up the analytical group.
- Most of the CSHCN had been enrolled in SCHIP for more than 9 months.
- Among CSHCN with physical conditions, improvements after SCHIP were noted for those having a usual source of health care (USC), having unmet needs for prescription medications, and having all or most visits to the USC.

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- Improvements were noted regardless of prior insurance status or type of chronic condition.
- Although unmet health care need declined after enrollment in SCHIP, it remained relatively high even during enrollment. The number of parents citing reasons for unmet needs related to costs or to health insurance (e.g., "costs too much" or "didn't have health insurance") declined markedly after enrollment in SCHIP, whereas the number citing reasons related to access to health care or to family factors (e.g., transportation or language) remained about the same after enrollment.

One measure of successful care for CSHCN, as outlined by the Maternal and Child Health Bureau, is having adequate private or public insurance to pay for needed services. "Our study suggests," the authors conclude, "that SCHIP improved health care for CSHCN by changing the pattern of health services for CSHCN to greater reliance on the USC." (MCH Alert, 2/23/07)

Szilagyi PG, Shone LP, Klein JD, et al. 2007. Improved health care among children with special health care needs after enrollment in the State Children's Health Insurance Program. Ambulatory Pediatrics 7(1):10-17. Abstract available at http://www.ambulatorypediatrics.org/article/PIIS1530156706002097/abstract.

Calendar of Events

May 2007

2 — **Keeping Depression a Secret is Dangerous - With Proper Treatment, Recovery Can Lead to a Healthy, Fulfilling Life — Los Angeles** (http://www.lanterman.org/training/Flyers/BureauofJewish_EducationofGreaterLA_20062007_brochure.pdf)

3–4 — **Institute for Healthcare Advancement's Sixth Annual Health Literacy Conference: Health Literacy and Chronic Illness Management — Anaheim** (http://www.iha4health.org/)

7–9 — **California WIC 15th Annual Conference "Get Health California: The WIC Connection"** – San Jose (http://www.calwic.org/spring_conference.aspx)

12–13 — **17th Annual People First Self-Advocacy Conference – Mission Valley** (**http://www.sandiegopeoplefirst.com/index.php?module=pagemaster&PAGE_user_op=view_page&PAGE_id=32&MMN_position=21:21**)

14–16 — **4th Annual Nutrition and Health State of the Science and Clinical Applications** – San Diego (http://integrativemedicine.arizona.edu/conf/pdf/07Nutbro.pdf)

15–16 — **Twentieth Annual National Maternal and Child Health Leadership Conference – St. Charles, IL** (http://www.uic.edu/sph/mch/includes/documents/Final%20Brochure%202007.pdf)

16–17 — **14th Annual Family Support Conference: Everybody Ready = School Success — Pittsburg, PA** (http://www.education.pitt.edu/ocd/training/FamilySupportConference2007STD.pdf)

16–18 — **California Mental Health Advocates for Children and Youth (CMHACY) 2007 – Pacific Grove** (http://www.cmhacy.org/2007-conference-regform.html)

17–20 — **Advances In Pediatrics: 18th Annual Las Vegas Postgraduate Pediatrics Meeting – Las Vegas** (http://www.aapca2.org/FutureEvents/LasVegas_May_2007/Vegasbrochure.pdf)

18 — **Fussy Babies, Caring Parents – Los Angeles (for information, contact Maureen Maki: mmaki@chla.usc.edu)**

18–20 — **Essential Topics in Pediatrics 2007: Exploring the Developmental Spectrum – San Diego** (http://cme.ucsd.edu/pediatrics2007/)

19 — **Pediatric Clinical Update – Shell Beach** (http://www.lpch.org/CMECourses/cmePediatric ClinicalUpdateSlo.html)

23–26 — **Family Voices 15th Anniversary Gala Celebration & National Conference — Washington, D.C.** (http://www.familyvoices.org/info/nc/index.php)

26–28 — **What's In the News: Best Practices in Pediatric Medicine – Monterey** (http://www.aapca1.org/Meetings/May%202007%20CME%20Brochure.pdf)

31–Jun 1 — **Building on Family Strengths - Effective Services for ALL: Strategies to Promote Mental Health and Thriving for Underserved Children and Families — Portland, OR** (http://www.rtc.pdx.edu/)

Policy Center Releases Second Report on Innovative Approaches for Improving Pediatric Subspecialty Care

Promising State and Regional Approaches for Extending Access to Pediatric Subspecialty Care and Coordination with Primary Care presents 13 examples of exemplary efforts to extend the geographic reach of pediatric subspecialty care and to enhance the capacity of pediatric health professionals to identify and manage chronic conditions. The report is the second in a series of promising practices reports prepared by the Federal Expert Work Group on Pediatric Subspecialty Capacity, convened by the Maternal and Child Health Policy Resource Center with support from the Maternal and Child Health Bureau. The report is divided into three sections. The first section describes the rationale for strengthening state and regional networks of pediatric subspecialty care within the context of the medical home and the major barriers affecting the expansion of state and regional pediatric specialty systems linked with primary care. The second section contains descriptions of 13 promising state and regional pediatric delivery networks. The third section identifies promising features of state and regional pediatric subspecialty arrangements. The report is available at http://www.mchpolicy.org/practice/documents/StateandRegionalPromisingPractices.pdf. (MCH Alert, 12/15/06)

Report: Recommendations for Enhancing Developmental Care Linkages in Communities, States, and Nationwide

Beyond Referral: Pediatric Care Linkages to Improve Developmental Health reviews the current state of pediatric linkages for developmental care, emphasizing the important role of pediatric health professionals in providing developmental care and linking children to needed services and resources within the broader community. The report, published by the Commonwealth Fund, focuses primarily on how pediatric practices "connect" young children and their families to developmental services and supports, whether within the practice setting or beyond. Topics include the context in which pediatric developmental care and linkage takes place, working definitions and a typology for describing linkage strategies, key linkage strategies used by exemplary practices and programs, and recommendations and next steps for improved linkages. The report is available at http://www.cmwf.org/usr_doc/Fine_beyondreferralpediatriccarelinkagesimprovedevelhlt_976.pdf. (MCH Alert, 1/13/07)

Calendar of Events (continued)

May 2007 (continued)

31–Jun 1 — **First 5 Statewide Conference – Garden Grove** (http://www.f5ac.org/event_detail.asp?id=&cid=0&eid=649)

31–Jun 2 — **40th Annual Advances and Controversies in Clinical Pediatrics – San Francisco** (http://www.ucsfcme.com/2007/MPD07001.pdf)

June 2007

1 — **How Does It Feel? A First Hand Experience of a Sensory Processing Disorder – Los Angeles** (http://www.idaofcal.org/Images/firsthand.pdf)

7 — **The 2007 Pediatric Trauma Critical Care Conference – Los Angeles** (http://www.childrenshospitalla.org/body.cfm?id=1081)

9 — **Innovative Approaches: Treatment for People With Developmental Disabilities & Psychiatric Disorders 6th Annual Conference – Santa Monica** (http://www.lanterman.org/training/Flyers/2007_Tarjan_Semel_DDS_DualDiagConference.doc)

15 — **Maintaining Compassion and Avoiding Burnout! CRISS Mid-year Workshop – Oakland** (for more information, contact Mara McGrath: **mkmcgrath1254@aol.com**)

23-29 — **Pediatrics in the Islands …Clinical Pearls – Maui, HI** (http://www.aapca2.org/FutureEvents/untitled/ScheduleofEvents2006-2007Mail.htm)

28–30 — **15th Annual Pediatric Update and Pre-Conference – Palo Alto** (http://www.lpch.org/CMECourses/cme15thAnnual_PediatricUpdate.html)

29 — **Occupation Therapy Strategies for Birth to Five Year Olds – Los Angeles** (for information, contact Maureen Maki: **mmaki@chla.usc.edu**)

29–Jul 1 — **AAP/ ACOP Future of Pediatrics Conference – Orlando, FL** (https://www.aap.org/commpeds/)

July 2007

12–14 — **2007 National Childhood Apraxia of Speech Conference – Anaheim** (http://www.apraxiakids.org/site/c.chKMI0PIIsE/b.2278609k.B66F/2007_Apraxia_Conference_Information_Page.htm)

12–15 — **23rd Annual Conference on Marfan Syndrome and Related Disorders – Palo Alto** (http://www.marfan.org/nmf/files/Conf_07_Brochure.pdf)

27–29 — **8th International Charge Syndrome Conference – Costa Mesa** (http://www.chargesyndrome.org/files/2007-conference-registration-form.pdf)

August 2007

18–19 — **"Back to School" Autism/Aspergers Conference — Pasadena** (http://www.autism-conferences.com/index.html)

Journal Supplement Highlights Findings from the National Survey of Children's Health

The February 2007 supplement to *Pediatrics* heralds new findings from the 2003 National Survey of Children's Health (NSCH), a random-digit-dial survey of more than 100,000 children considered to have special needs designed to provide national- and state-level estimates for a variety of physical, emotional, and behavioral child health indicators. The supplement, sponsored by the Maternal and Child Health Bureau, contains 15 articles prepared by multidisciplinary teams of academics, collaborations of state maternal and child health staff and university faculty, and teams of researchers working across federal agencies. The articles highlight unique aspects of the NSCH, providing a sense of the breadth and depth of information available from the survey as well as its analytical potential. A final commentary focuses on where to concentrate efforts to improve children's health and plans for future rounds of the survey. The supplement will be available to subscribers at http://pediatrics.aappublications.org/supplpage.shtml. More information about the NSCH is available at http://www.cdc.gov/nchs/slaits.htm and http://mchb.hrsa.gov/programs/dataepi. (MCH Alert, 2/2/07)

Curriculum Focuses on Ensuring Access to Oral Health Services for Young Children with Special Health Care Needs

Special Care: An Oral Health Professional's Guide to Serving Young Children with Special Health Care Needs is a Web-based continuing education (CE) course that provides oral health professionals (dentists, dental hygienists, and dental assistants) with information to ensure that young children with special health care needs have access to health-promotion and disease-prevention services that address their unique oral health needs in a comprehensive, family-centered, and community-based manner. The Web-based curriculum was prepared by the National Maternal and Child Oral Health Resource Center at Georgetown University and designed by the Center for Advanced Distance Education at the University of Illinois at Chicago with support from the Maternal and Child Health Bureau. Topics include (1) an overview of children with special health care needs and oral health, (2) the provision of optimal oral health care, (3) oral health supervision, (4) oral disease prevention, and (5) behavior management. Four CE credits through the Indian Health Service or through the American Dental Hygienists' Association will be awarded upon successful completion of the course.

The course is free of charge and is available at http://www.mchoralhealth.org/SpecialCare. (MCH Alert 2/16/07)

Announcements

Update on KASA Youth Panel

The CA KASA youth panel is going strong. So far there have been two face-to-face meetings and two conference calls. All have been well attended.

Currently the panel is working on creating a survey for California youth aged 14-24 who have chronic medical issues or disabilities. Their goal is to assess how youth feel about how their medical needs are being met and what they know about transition from pediatric medical services to adult medical services. A draft survey was created during our last meeting and is now in the review process. This has been a very new experience in decision making, consensus building, and critical thinking for the panelists. They have discovered that creating a brief survey (their main requisite for anything sent to folks their age) that is at the same time comprehensive enough to collect all the information they want from the survey, is a bigger job than it seemed.

There are presently 14 members on the panel and all but two live north of Monterey. We would like to have more members from Southern California and the Central Valley. The panel has good gender representation and we have a translator who works with us if a member is mono-lingual in Spanish. The members have various disabilities. Ideally we would like to recruit additional young people who would bring geographic and ethnic diversity to the group; however, we are open to hearing from all young people who would like to participate. For more information or an application, please email Judith Lesner (Youth Facilitator) at **MAVENno1@aol.com**.

New Website for the California Medical Home Project & Los Angeles Medical Home Project

Effectively immediately, the California/Los Angeles Medical Home websites can be found at http://mchneighborhood.ichp.ufl.edu/medicalhomela/. Please **DELETE** www.medicalhomela. org from any favorites lists, etc.

AT NETWORK PROJECT - Expanding Resources for Assistive Technology

The AT Network, a statewide non-profit organization dedicated to expanding accessibility to assistive technologies, operates a toll free information and referral line answering questions on assistive devices and services including identification and referral to assistive technology evaluation, and

Report Examines Role of Medicaid in Addressing Six High Cost Populations

The Foundation's Kaiser Commission on Medicaid and the Uninsured (KCMU) released a new report, Profiles of Medicaid's High Cost Populations [http://www.kff.org/medicaid/7565.cfm], which examines the role that Medicaid plays in addressing six populations with serious health needs resulting in high costs. For each population profiled (preterm birth babies, foster care children, individuals with spinal cord and traumatic brain injuries, individuals with mental illness, individuals with intellectual and developmental disabilities, and people with Alzheimer's disease), the report describes the condition and the need for services and supports, as well as the role of Medicaid in meeting those needs. Profiles of six real people with these conditions are included with descriptions of model programs or cutting edge practices designed to meet the health needs of these individuals. The new report highlights Medicaid's role in anchoring care for individuals with exceptional needs.

With recent policy debates about the future of Medicaid, KCMU has issued several publications [http://www.kff.org/medicaid/medicaidlongtermcare.cfm] in recent months that address key policy issues when examining Medicaid's role for high cost populations who typically rely on Medicaid for both acute and long-term care services (LTC). In addition to the new report profiling high cost populations, a recent analysis of Medicaid spending on people using LTC services shows more than half (52 percent) of all Medicaid spending goes towards their LTC and acute care services. The report underscores the need for reform strategies to address overall health needs of these very sick beneficiaries and not just focus on their long-term care use.

For further information on these publications or issues, please contact us at kcmu@kff.org .
(Kaiser Family Foundation, 12/20/06)

Medicaid Update: Final Report of the Medicaid Commission

In May 2005 the Secretary of the Department of Health and Human Services, Michael O. Leavitt, established a Medicaid Commission to advise the Secretary on ways to modernize the Medicaid program so that it can provide high-quality health care to its beneficiaries in a financially sustainable way. On December 29, 2006 the Commission issued its final report, which can be found at http://aspe.hhs.gov/medicaid/122906rpt.pdf. (TATRA Center, 1/5/07)

Announcements (continued)

funding sources. In February, the network launched a new website that features extensive information and referral resources. Trainings, both online and in person, are also offered on a variety of topics related to assistive technology.

In July 2006, The Alliance for Technology Access (ATA) became the manager of the AT Network. ATA, a national leader in the field of assistive technology for children and adults with disabilities for the past 20 years, is now working in close collaboration with the 29 California Centers for Independent Living. Working in partnership with a diverse group of state agencies, including CCS, the goal of ATA is to expand the scope of the Network to include families and underserved communities across the state. Contact information: 800-390-2699 / 800-900-0706 TTY / www.atnet.org / info@atnet.org.

Champions for Inclusive Communities (formerly Champions for Progress)

Last spring, the new center Champions for Inclusive Communities (ChamptionsInC) was created to replace Champions for Progress, the National State Leadership Center for CYSHCN. Also funded through MCHB-DSCSHN, the focus is a shift from state leadership development to achieving Performance Measure 5: *Services are organized so families of CYSHCN can use them easily and are satisfied with the services they receive.* This new direction involves taking the partnership activities that were made possible with state CYSHCN programs down to the community level. Information on the ChampionsforProgress.org website has been transferred to the new web site at http://www.championsinc.org.

As part of its information dissemination, the center will issue a bi-weekly electronic newsletter that will include several regular features:

- Interviews with key organizations and programs that support community development;
- Promising Practices for implementing community-based programs and systems;
- Up-to-date Evidence-Based Practice at the community level;
- Information on National Organizations & Foundations that support community-based efforts;
- Periodic updates on the Community Tool Box designed to support the activities of community teams and coalitions.

To subscribe to the newsletter, go to http://www.championsinc.org/main/newsletter.cfm?CFID=454385&CFTOKEN=78160324.

Multiple Health Care Proposals Introduced in Sacramento

Multiple proposals to expand health coverage have been introduced in Sacramento, from the all-inclusive single payer proposal by Sheila Kuehl vetoed by the Governor last year to a Republican plan to expand tax credits and Health Savings Accounts. All the plans include key concepts such as shared responsibility and expanded access to coverage; several are "Pay or Play" models in which employers are required to spend a certain percentage of their payroll for employee health insurance or pay a fee to the state. Almost all proposals are still vague and awaiting details. The major proposals include:

Governor's Health Care Proposal — Still a ten-page outline and not incorporated into a bill, the proposal is a mandatory enrollment model similar to that enacted last year in Massachusetts. As a Family Voices summary notes, the plan would require all individuals in the state to have some kind of health insurance coverage, whether through public programs like Medi-Cal or Healthy Families, through subsidized participation in an insurance purchasing pool, or through unsubsidized private coverage via employers or individual purchase (via "Pay or Play"). The proposal lacks details on almost all elements, including financing. (See below for more details on this proposal's potential impact on children with special health care needs.)

SB 870 (Kuehl) — Senator Sheila Kuehl has reintroduced her single payer bill, with the same bill number, from last year. Last year's version passed both the Senate and Assembly but was vetoed, as expected, by the Governor. Under this plan the state would establish a statewide, single payer model universal health care system to be administered by a newly created state commission. The bill would require the new system to be implemented in approximately four years. Once implemented, the new statewide system would replace all health insurance plans and policies currently marketed in the state for coverage of the services that now would be provided by the state program. A staff model system such as Kaiser could continue to function as an integrated medical group but not as a health plan. The plan includes a broad arrange of benefits.

SB 48 (Perata) — State Senate President Don Perata has introduced SB 48 with his own health coverage plan. This proposal, still in its early stages, would create a system under which all legal resident adults who work in the state and their dependents would be required to have a minimum health coverage policy (with "minimum benefits" to be determined by MRMIB, the agency that administers the Healthy Families and several other insurance programs). The proposal would enforce "Pay or Play" for all employers with at least ten employees. Legal resident working adults and all children, regardless of their documentation status, would be covered up to 300% of the Federal Poverty Level (FPL) by either Medi-Cal or Healthy Families.

Republican "Cal CARE" Plan — State Republicans have introduced a plan dubbed "Cal CARE" that would expand access to coverage through such strategies as tax credits, easier access to Health Savings Accounts (HSAs), reallocation of First Five funds to child health care initiatives, and permission for hospitals to offer preventive services-only coverage for access to primary care at hospital or community clinics.

(Continued next page)

Impacts of the 2007/ 2008 Budget Proposals and the New "Health Care Proposal" on Children with Special Health Care Needs — Presented by Family Voices of California

On January 10, 2007, Governor Schwarzenegger released his proposed budget for fiscal year 2007-2008. On January 8, 2007, the Governor also released a proposal for providing health coverage for all Californians. The Governor's "Health Care Proposal" seeks to create an "accessible, efficient, and affordable health care system that promotes a healthier California through prevention and wellness and universality of coverage." Funding for the Health Care Proposal is not included in the Governor's budget proposal. More information is needed to determine the cost of the plan and the impacts on state budget.

Both the budget proposal and the Health Care Proposal in their current form will have a direct impact on families of children with special health care needs and should be watched closely.

(Continued on page 9)

(Continued – Multiple Health Care Proposals)

Special Areas of Concern for Children with Special Health Care Needs

Several of the proposals reviewed on the previous page propose expansion of the Healthy Families program and either explicitly would move children from Medi-Cal to Healthy Families or appear to imply that the programs are interchangeable for children. The Governor's proposal, for example, would set a "bright line" for Medi-Cal eligibility for children at 100% of FPL, or $20,650 per year for a family of four, and would reduce eligibility for the program for children from birth to age six, shifting approximately 680,000 children from Medi-Cal to Healthy Families. Below are specific concerns raised by proposals that would lower eligibility for Medi-Cal or shift children from Medi-Cal to Healthy Families:

- Healthy Families is not a federal entitlement program; its existence and funding are not assured and must be reauthorized periodically. (In fact, the federal State Children's Health Insurance Program, or SCHIP, must be reauthorized by Congress this year and adequate financing for the program is a major health policy issue.) In contrast, Medicaid is a federally created entitlement program and must be made available to all children who meet its eligibility criteria. There are obvious risks in moving children, particularly children with complex medical conditions, from an entitlement program to one that exists at the pleasure of the President and Congress and that faces periodic reauthorizations.
- The Healthy Families Program benefit package does not meet Medicaid standards for children. SCHIP/Healthy Families was designed as a basic coverage program for essentially healthy children whose parents are unable to obtain or afford employer-based or individually purchased coverage. In contrast, the Medicaid program includes the federally established EPSDT mandate that guarantees eligible children access to all medically necessary services that are federally approved for Medicaid, even if the individual state does not currently provide that benefit. Many children with special health care needs use Medi-Cal and EPSDT for services that are vital to their care, and their access to these services could be imperiled by their transfer to Healthy Families.
- The Medicaid program includes several waivers that provide comprehensive medical care in the home or community for children with very complex medical conditions who otherwise would require care in some kind of institutional setting such as a hospital or nursing facility. The population of children shifted from Medi-Cal to Healthy Families will include children in these waiver programs (such as Katie Beckett/TEFRA waivers) whose families have incomes over 100% of FPL. The Healthy Families benefit package cannot possibly meet these children's extraordinary medical and nursing needs.
- There will be an increased financial burden for families with incomes above 100% of FPL who would be shifted from full-scope Medi-Cal, which has no premiums or co-pays for children, to Healthy Families, which does require premiums and co-pays. Healthy Families cost-sharing requirements include monthly premiums for insurance, with a maximum of $45 per family per month, and co-pays for many services, with a maximum of $250 per family per 12-month period. These costs may not seem onerous to people with professional salaries, but could be prohibitive for families living with incomes just over 100% of FPL (i.e. $20,000 for a family of four). Several studies indicate that families of children with special health care needs typically incur many uncovered expenses in accessing health care for their children, such as transportation to numerous medical appointments and out-of-pocket payments for special equipment and supplies.

- The shift to Healthy Families would move children from a mix of fee-for-service Medi-Cal and heavily regulated Medi-Cal managed care programs into a program that is exclusively capitated managed care, with extensive participation of commercial HMOs. Many families of children with special needs have invested time in constructing their own network of providers for their children, and these networks could be disrupted if children are transferred to the Healthy Families Program. Healthy Families plans have their own plan networks that may limit access to providers outside the individual county and may include few pediatric specialists. The lack of access to pediatric specialists already has been identified by researchers as a problem for Healthy Families plans statewide.

Policy-makers and advocates should consider the potential negative consequences of making major changes in children's current health care programs and ensure that in our zeal to reform our current system and expand coverage, we do not inadvertently reduce children's access to the health care they need.

For more information on federal or state issues, contact Laurie Soman at 510-540-8293 or **LSoman6708 @aol.com**.

(Continued — Impacts of the 2007 /2008 Budget Proposals)

The following represents information about the Governor's budget proposals and the Health Care Proposal that may impact children with special health care needs.

See the article on pages 7-8 for more information on the potential impact of the Governor's proposal and other state health care proposals on children in CA.

Governor's Budget Proposals

Reduction of Funding for CalWorks

- **Restrict Safety Net Grants to Children After Parent Reaches 60 month Time Limit**

  Current: Adults receive cash assistance for 60 months but children continue to receive cash assistance as long as the family meets eligibility requirements and is working.

  Proposal: Provide safety net benefits to children only if parents work sufficient hours to meet federal work requirements after 60 months.

- **Impose Full Family Sanctions**

  Current: When adult fails to meet CalWORKS requirements, the family's grant is reduced by the amount attributable to the adult. Cash aid is continued to children.

  Proposal: Eliminate entire grant to family for the adult who does not comply for 90 days.

- **Eliminate Grants to Children of CalWorks Ineligible Parents, Including U.S. Citizen Children of Undocumented Immigrants**

  Current: These children are currently eligible for CalWorks, but their parents cannot receive assistance.

  Proposal: Terminate cash assistance after 60 months.

- **Suspend CalWorks Cost of Living Adjustment (COLA) for a Third Consecutive Year**

  Current: Grant for a family of 3 is $723 per month.

  Proposal: Suspend the 4.2% COLA that increases the grant to $753 per month.

Cap State's Participation in In-Home Support Services (IHSS)

- **Freeze State's Share of Cost for IHSS Wages and Benefits**

  Current: IHSS workers hourly wage is set to increase from $11.10 per hour to $12.10 per hour during 2007-08.

  Proposal: Freeze the state's contribution to IHSS worker wages and benefits. State funded wages will freeze at $11.10 pr hour. Any increases in wages and benefits after January 10, 2007 would need to be funded by counties.

Information was drawn from the California Budget Project, *Governor Releases Proposed 2007-08 Budget* (http://cbp.org/pdfs/2007/070110_gov proposed-budget.pdf), Senate Committee on Budget & Fiscal Review's *Quick Summary of the Governor's Budget Proposal* (http://www.senate. ca.gov/ftp/SEN/COMMITTEE/STANDING/BFR/_home/ 2007quicksummarycomp.pdf), & Governor's Budget Summary: *Health and Human Services* (http://www.ebudget. ca.gov/pdf/BudgetSummary/HealthandHumanServices.pdf).

LAO Analysis of the 2004-05 Budget Bill

To access the Legislative Analyst's Office *Analysis* and *Perspective & Issues*, go to http://www.lao.ca.gov/analysis.aspx?year=2007&chap=0&toc=4.

(Continued next page)

Governor's Health Care Proposals

The Governor's proposal to provide health care coverage for all California's uninsured calls for "shared responsibility" from individuals, employers, providers, health care insurers, and public programs. The following represents key elements of the Governor's Health Care Proposal. Again, costs, funding and many details for specific proposals need to be clarified.

Requires all individuals to carry a minimum level* of coverage (individual mandate)

- Families and/or individuals above 250% of the Federal Poverty Level (FPL) $41,500 for a family of 3, would either carry insurance through their employer or purchase insurance in the market.
- Families and/or individuals below 250% of the FPL would be required to enroll in public programs, receive subsidized coverage through a state purchasing pool, or be covered through employment.

* *Minimum coverage requirement is a health plan with $5,000 deductible and maximum out-of pocket costs of $7,500 per person and $10,000 per family. Estimated monthly premiums would be $100 or less per month for an individual and $200 or less per month for a couple.*

- Children with family incomes below 300% of FPL, $49,800 for a family of 3, would be covered by Medi-Cal or Healthy Families regardless of their immigration status.
- Legal resident adults with incomes below 100% of FPL ($9,800 for an individual with no children) would be covered by Medi-Cal.
- Legal resident adults with incomes between 100 - 250% FPL ($9,800 - $24,500 for an individual) would be eligible for subsidized private health coverage. Benefits would not include dental or vision benefits.
- Families and individuals with incomes between:
  - 100 - 150% FPL would pay premiums equal to 3% of their income **
  - 151- 200% FPL would pay premiums equal to 4% of income **
  - 201- 250% FPL would pay premiums equal to 6% of income **

** *Individuals and families may also be required to pay premiums for their children in Health Families as well as deductibles, etc.*

- Children with incomes above 100% FPL currently enrolled in Medi-Cal would be moved into Healthy Families.

Requires heath insurers to issue health insurance

- Coverage must be guaranteed to individuals and families regardless of age or pre-existing conditions.
- Insurers will have limits on the amount they can charge for coverage based on age or health status.

Requires employers with 10 or more workers to provide coverage for employees or pay a fee to the state equal to 4% of their payroll tax

Information was drawn from the *Governor's Health Care Proposal*: http://gov.ca.gov/pdf/press/Governors_HC_ Proposal.pdf, and the California Budget Projects: *Governor Releases Proposed 2007-08 Budget:* http://cbp.org/pdfs/2007/070110_govproposedbudget.pdf

Access to affordable and comprehensive health care has become a concern for most Californians, with health care costs continuing to rise at a rate out pacing inflation. The administration's efforts to bring stakeholders to the table to discuss providing health care coverage for all Californians is an important step. We do, however, have several concerns with the proposed plan including:

- Moving children currently covered by Medi-Cal into Healthy Families may cause the loss of important benefits provided under Medi-Cal's EPSDT benefits program for children.
- Lowering the federal poverty levels currently being used in California that determine eligibility for public programs will force many families struggling financially into higher cost insurance coverage.
- Many families may find it too expensive to go to the doctor for care because of the cost of premiums, added co-pays, and high deductibles.

Family Voices of California will continue to be involved in the budget process and discussions on the health care proposal and strongly encourage all families to stay informed. Important decisions will be made that impact many California families. Policy makers need to hear from parents and professionals. Go to the following websites to find out who your elected officials are and how to contact them:

http://supportforfamilies.org/legislative/index.html

http://www.votesmart.org/index.htm

President's Proposed Federal Budget Would Slash Medicaid and Reduce SCHIP Coverage

On February 5, 2007, President Bush released his proposed federal budget for Federal Fiscal Year 2008, which begins October 1, 2007. The proposal recommends major cuts in Medicaid and inadequate funding for the State Children's Health Insurance Program (SCHIP), known in California as the Healthy Families Program.

The 2008 budget proposes cutting the Medicaid program by almost $26 billion over five years, primarily through changing program rules and shifting costs for certain services and program management to the states. California stands to lose up to $2 billion in federal Medicaid funds if this cut is enacted. Medi-Cal, California's Medicaid program, covers more than 6 million people, including 3.4 million children, and is the main source of health coverage for many children with special health care needs.

The legislation authorizing SCHIP expires this year and the program must be reauthorized. Virtually all health care analysts agree that SCHIP has made a profound difference in increasing access to health care for uninsured children, and reauthorization was expected to provide an opportunity to strengthen and expand the program-- perhaps to address the approximately 7 million American children who are eligible for SCHIP or Medicaid but not yet enrolled. The President's budget would reauthorize the program for another five years, through 2012, but would provide only $5 billion above SCHIP's current base funding over that five-year period. Children's health advocates maintain that the program needs an additional $15 billion just to maintain current SCHIP enrollment levels-- about 6 million children nationally and almost 800,000 in California. Seventeen states already have or will run out of SCHIP funds this year. Families USA estimates that states will need from $50-60 billion over the next five years to enroll all eligible children, including the 7 million not currently enrolled.

In addition, the President's proposal discusses "refocusing" the program on low-income children with family incomes below 200% of the Federal Poverty Level (incomes below $41,300 for a family of four). Fifteen states, including California, serve children above 200% of FPL in their SCHIP programs. Our Healthy Families Program, for example, enrolls children in families with incomes up to 250% of FPL (i.e. below $51,625 for a family of four). Reducing the SCHIP income level would be a giant step backward for children's health and result in the loss of health coverage for hundreds of thousands of children.

The proposed cuts in both Medicaid and SCHIP fly in the face of numerous proposals at both state and federal levels to expand coverage to more uninsured people, particularly children. Child advocates have mobilized to oppose the Medicaid cuts and to support reauthorization and full funding of SCHIP. For information on the budget proposal and status of SCHIP reauthorization, see the Families USA website: www.familiesusa.org.

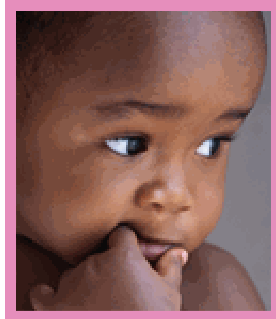
Information from Families USA, Commonwealth Fund, California HealthCare Foundation, and American Public Health Association.

UPDATE

Senate Finance Committee Chairman Max Baucus (Montana) announced that he will seek the $50 billion in new funding over the next five years required to fully fund SCHIP as part of its reauthorization this year. Baucus has made SCHIP reauthorization the Finance panel's top health priority for the year and said Congress must act before the program's authorization and funding expire Sept. 30. To access Senator Baucus' press release, go to http://www.senate.gov/~finance/press/Bpress/2007press/prb030607a.pdf.

Authors Assess the Feasibility of Expanding Mental Health Services for Young Children

"This quality-improvement study . . . demonstrates the feasibility of providing infant and preschool mental health interventions and the practicability of training mental health staff to identify and treat the mental health needs of a population heretofore underserved, with an emphasis on supporting the parent-child relationship," write the authors of an article published in the February 2007 issue of the Journal of the American Academy of Child and Adolescent Psychiatry. Preschool-age children are underserved by the public mental health system despite the growing awareness of the prevalence of mental health concerns in infants and young children and recognition that early parent-child relationship dysfunction may lead to psychopathological symptoms in later childhood or adolescence. Even when behavior and emotional problems are identified in infants and preschool-age children, trained practitioners and appropriate interventions are usually lacking. This article reports on a quality-improvement project carried out as part of an infant-preschool family mental health initiative in eight California county mental health programs. The eight participating counties had differing program characteristics and culturally diverse populations. All counties served infants and children with multiple environmental and parental risk factors. The goal of this initiative included training mental health professionals to provide relationship-based services to infants and children from birth through age 5 referred for mental health symptoms and to their families, and increasing the number of children serviced in this age group. State-level training was provided for at least 582 participants, and county-level training was provided for 5,425 participants.



Participating infants and children (N=388) were screened with the Mental Health Screening Tool (MHST) California Institute of Health (2000), which was developed to identify very young children needing mental health services. The mean age of the children was 34-35 months. Children received treatment that included relationship-based, dyadic techniques as a result of the training and supervision provided by the initiative.

Authors' findings:

- The children and their families were characteristic of county mental health populations in

(Continued on next page)

Resources

Spanish Versions of Bright Futures Developmental Tools Available

What to Expect & When to Seek Help: Bright Futures Developmental Tools for Families and Providers, now available in Spanish, are designed to help families and service providers from a range of disciplines support the healthy social and emotional development of children and adolescents. The tools are based on B*right Futures in Practice: Mental Health* and were developed through a partnership between Bright Futures at Georgetown University and the National Technical Assistance Center for Children's Mental Health, with support from the Child, Adolescent and Family Branch, Center for Mental Health Services, Substance Abuse and Mental Health Services Administration. Four of the tools, each of which is designed to address a specific developmental stage (infancy, early childhood, middle childhood, and adolescence), provide information about healthy child development and parenting and offer guidance on when, where, and how to seek help from local, state, or national resources. A tool to help service providers locate community-based services for families and create a referral network is also included.

The tools are available at http://www.brightfutures.org/tools . (MCH Alert, 1/13/07)

Updated: Child Advocacy Primer

This updated primer is targeted at child advocates, both veterans and newcomers, who are working to make a difference in the lives of children. It is intended to be an introduction to key advocacy skills, so that those who are new to the field can refer to it in their work. However, it is hoped that even experienced advocates will find that the materials and strategies used by their colleagues provide innovative approaches and ideas for their work.

To access the PDF document, go to http://www.voices.org/primer.

Kaiser Family Foundation: State Medicaid Fact Sheets

To compare your state's Medicaid program and the population it serves to other states and the nation, visit Kaiser's interactive online State Medicaid Fact Sheets tool. Go to http://www.kff.org/mfs/index.jsp. (TATRA Center, 12/19/06)

in California: culturally diverse and largely low income with multiple child, family, and environmental risk factors.

- At posttest, MHST and risk-assessment scores were significantly lower.
- At posttest, global assessment of function scores and parent support were significantly higher.
- Most parents reported high levels of satisfaction with the quality of service and the help they received.

The authors conclude that "expanding infant-family and early mental health services could enhance the well-being of at-risk children and has been shown to be cost-effective in the long run." (MCH Alert, 2/9/07)

Knapp PK, Ammen S, Arstein-Kerslake C, et al. 2007. Feasibility of expanding services for very young children in the public mental health setting. Journal of the American Academy of Child and Adolescent Psychiatry 46(2):152-161. Abstract available at http://www.jaacap.com/pt/re/jaacap/abstract.00004583-200702000-00003.htm.

New Data on Autism Spectrum Disorders

Prevalence of the Autism Spectrum Disorders in Multiple Areas of the United States, Surveillance Years 2000 and 2002, discusses findings on autism spectrum disorders (ASDs) prevalence recently reported by the Autism and Developmental Disabilities Monitoring (ADDM) Network. The fact sheet draws from two ADDM Network reports published in the February 9, 2007, issue of the Morbidity and Mortality Weekly Report (MMWR) Surveillance Summaries. The studies evaluated the prevalence of ASDs over several time points and compared the number of children with ASDs in different areas or groups of people.

The fact sheet is available at http://www.cdc.gov/od/oc/media/pressrel/2007/f070208.htm. The February 9, 2007, issue of Morbidity and Mortality Weekly Report Surveillance Summaries is available at http://www.cdc.gov/mmwr/PDF/ss/ss5601.pdf. (MCH Alert, 2/23/07)

Resources (continued)

The Painted Turtle — Camp for Children with Life-Threatening Illnesses

The Painted Turtle is the only multi-disease medical-specialty camp and family care center on the West Coast. Through week-long, illness-specific, summer sessions, and fall and spring family weekends, the camp provides life-transforming experiences to California children who have chronic and life-threatening illnesses.

For seriously ill children, The Painted Turtle is an oasis of fun, respite, and education. While at camp, they build confidence and self-esteem, learn crucial medical self-care skills, make friends, and have lots of fun. Expert medical care is provided 24/7 in the on-site "Well Shell," the camp's medical center.

The Painted Turtle allows seriously ill children to be more than patients; it enables them to be "regular" kids. Camp days are filled with swimming, boating and fishing, arts and crafts, singing, dancing, and so much more. All camp buildings are universally accessible, and all activities are designed to support campers' physical and psycho-social needs. The Painted Turtle is *free of charge* for all children.

For more information see www.thepaintedturtle.org, or contact Margaret Davis at: **margaretd@thepaintedturtle.org** or 661-724-1768 x 202.

Knowledge Path: Asthma in Children and Adolescents

The MCH Library released a new edition of *Knowledge Path: Asthma in Children and Adolescents*. This electronic guide presents a selection of current, high-quality resources about asthma in children and adolescents and the impact of asthma on homes, schools, and communities. The knowledge path also identifies tools for staying abreast of new developments in pediatric asthma research. Separate sections identify asthma information for families, information about asthma and environmental triggers, and resources about asthma management in school. The knowledge path is intended for use by health professionals, program administrators, policymakers, educators, community activists, and families. View the path online at http://www.mchlibrary.info/KnowledgePaths/kp_asthma.html . Knowledge paths on other maternal and child health topics are available at http://mchlibrary.info/KnowledgePaths/index.html.

Aging Out of Early and Periodic Screening, Diagnostic and Treatment (EPSDT): Issues for Young Adults with Disabilities

Early and Periodic Screening, Diagnostic, and Treatment (EPSDT) coverage offered through the Medicaid program has played an important and unique role for low-income children with disabilities. This Issue Brief from the Henry J. Kaiser Family Foundation discusses the implications for youth with disabilities when they become adults and lose their EPSDT benefits and how recent changes to the Deficit Reduction Act give states an opportunity to increase the availability of services that allow people with disabilities to lead as normal a life as possible as they move into adulthood. Available in PDF (14 pages, 490 KB). To access the brief, go to http://www.kff.org/medicaid/7491.cfm.

New Policy Brief from NCSL

The National Conference of State Legislators (NCSL) has issued a Policy Brief entitled, "A Difficult Passage: Helping Youth with Mental Health Needs Transition into Adulthood." Developed by NCSL and the National Collaborative on Workforce and Disability for Youth (NCWD/Youth), the Brief discusses current state strategies for improving outcomes for youth with mental health needs, and offers additional policy recommendations. This Brief is a prelude to a forthcoming NCWD/Youth publication entitled "Tunnels and Cliffs: A Guide for Workforce Development Practitioners and Policymakers Serving Youth with Mental Health Needs." It is available online at http://www.ncsl.org/programs/health/forum/youthmentalneeds.htm. (TATRA Center, 12/8/06)

DOJ Published Guidance on ADA Compliance

The U.S. Department of Justice is preparing guidance material for use by state and local governments in complying with the ADA. The "ADA Best Practices Tool Kit" provides guidance on identifying barriers to access in government programs, services, activities, and facilities and how to correct them. The first installment, released in December, provides an overview of the ADA and relevant regulations. A second section covers notice and grievance procedures and includes a compliance checklist and sample notices and policies. The information is posted on DOJ's website at www.usdoj.gov/crt/ada/pcatoolkit/abouttoolkit.htm. Additional installments will be posted throughout the year as they become available. (TATRA Center, 2/27/07)

Barriers to Employment for U.S. Latinos with Disabilities

A report conducted by Proyecto Visión titled "Latinos with Disabilities in the United States: Understanding and Addressing Barriers to Employment" examines the unique obstacles that Latinos with disabilities encounter in employment and offers suggestions to overcome these barriers. Specifically, the report suggests improving vocational rehabilitation programs, reconsidering the disability community's approach to Latinos, integrating individuals with disabilities into the Latino community, and increasing the overall visibility level of Latino leaders with disabilities. The full report can be found at http://www.proyectovision.net/report.html. (TATRA Center, 1/23/07)

To access previous issues of CACSHCNEWS, please visit http://uscucedd.org.