



CACSHCNEWS

Assuring Better Child Development (ABCD) Screening Academy

California 2007/2008

The National Academy for State Health Policy (NASHP) has selected 18 states, including California, along with Puerto Rico and the District of Columbia, to participate in a 15-month national consortium to improve early identification of young children with developmental problems. Public-private partnerships in each state will improve policy and clinical practice so that children's developmental and behavioral disorders are identified and treated at as early an age as possible. The consortium is being administered from May 2007-August 2008 by NASHP, with funding support from The Commonwealth Fund.

Although there is no funding for direct service, the 20 teams will receive technical assistance to integrate valid and standardized tools of children's development into preventive health care practice. Use of these instruments has been found to in-

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The Medical Home Project at UCLA

The Medical Home Project at UCLA was established in the resident-run Pediatric Continuity Clinic at the Mattel Children's Hospital at UCLA in 2003. The project has three basic elements.

- A working model of care delivery based on the American Academy of Pediatrics' definition of the Medical Home, namely accessible, family-centered, continuous, comprehensive, coordinated, compassionate, and culturally competent care for children with special health care needs and their families.
- A Medical Home curriculum integrated into the pediatric resident training program at the Mattel Children's Hospital at UCLA.
- Medical Home health services research consisting of prospective data collection for Children with special health care needs related to access to care, medical resource utilization and patient satisfaction. Research efforts are also directed at determining methodologies for measuring outcome improvements and enhancing the processes which optimize care coordination.

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CACSHCNEWS 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:

- ◆ Department of Health Care Services, Children's Medical Services 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

To receive CACSHCNEWS, please send an email message to ycasillas@chla.usc.edu with "CACSHCNEWS" in the subject line.

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Patients are seen by resident pediatricians during visits staffed by the regular teaching pediatric faculty. The Medical Home patients are encouraged to identify themselves as belonging to the Medical Home. Four benefits accrue to Medical Home Patients that are not available to other continuity patients: 1) patients are scheduled for a 60 minute initial Medical Home clinical and social evaluation; 2) patients receive 40 minute follow up appointments which are twice the length of the standard visit; 3) patients are assigned a bilingual “Family Liaison” skilled at coordinating follow-up appointments and procedures; 4) patients receive a family notebook called the *All about Me Binder* which includes copies of the patient’s medical records, physician names and contact information, as well as a list of the patient’s medicines. A distinctive Medical Home identifier appears on the binder.

The goal of the Medical Home Project at UCLA is to provide care to our children with special health care needs consistent with the AAP’s medical home model. Because these children have multiple complex diagnoses requiring management by various specialists, their care is often difficult to coordinate. The UCLA Medical Home is helping make this effort easier and better. As a result, our residents become comfortable and experienced with taking care of pediatric patients with complicated medical problems. The program is funded by grant support from the Healthy Tomorrows Partnership for Children, a partnership between the American Academy of Pediatrics and the Maternal and Child Health Bureau. Additional funding has been provided by the Skirball Foundation.

In 2005, the Medical Home added a half-time dedicated pediatrician who serves as Medical Director and staffs most *medical home* general pediatric visits. A parent advisory group meets once a month to provide parent input and to allow parents to share experiences regarding their children. Recently completed research suggests that the Medical Home is reducing both Emergency Department visits and hospital days for our patients. Discussions with the Parent Advisory Group suggest that the biggest benefit of the program is empowering parents to act as effective team members when interacting with the medical system. For more information, contact Leslie Rabbitt at LRabbitt@mednet.ucla.edu.

crease identification of young children with or at risk for cognitive, social, emotional, and developmental problems and thus increase access to early intervention services. Each team will include the state’s Medicaid program and other public agencies, along with child health physician associations, other clinicians, and nonprofit organizations.

California

In California, the Maternal, Child and Adolescent Health (MCAH) Branch of the California Department of Public Health (CDPH), which houses the federal Early Childhood Comprehensive Systems (ECCS) grant, will take the lead. Janet Hill, the ECCS Director, will work with the remaining members of the Core Leadership Team: Dr. Richard Sun of Medi-Cal; a pediatrician representing the American Academy of Pediatrics; Kris Perry, the Executive Director of the California Children and Families Commission; and Maggie Petersen, of the Children’s Medical Services Branch. Dr. Sun, as one of the Co-Principal Investigators for the 2004-2007 ABCD* II projects, is able to help the team apply the lessons learned from the BEST-PCP**. The Team met in late May to develop the project and the work plan will be finalized in July. For more information, please contact Janet Hill at jhill@dhs.ca.gov.

Jurisdictions Selected for the Consortium

Alaska, Alabama, Arkansas, California, Connecticut, Delaware, the District of Columbia, Kansas, Maryland, Maine, Michigan, Minnesota, Montana, New Jersey, New York, Ohio, Oregon, Puerto Rico, Virginia, and Wisconsin.

About the ABCD Initiative

Since 2000, the ABCD Initiative, administered by NASHP and funded by The Commonwealth Fund, has helped eight states create models of service delivery and financing to improve the delivery of early child development services. The program focuses particularly on preventive care of children whose health care is covered by state health care programs, especially Medicaid.

* For more information on the ABCD Initiative, go to http://www.nashp.org/catdisp_page.cfm?LID=2A78988D-5310-11D6-BCF00A0CC558925.

** For more information on ABCD II project, BEST-PCP, go to http://www.nashp.org/docdisp_page.cfm?LID=C9C5006C-F477-499B-902ACBDB9CC70B6B.

State Adds Cystic Fibrosis Test to Newborn Screening

California this month will add a test for cystic fibrosis to the state's newborn screening program, the *Contra Costa Times* (http://www.contracostatimes.com/search/cj_6312251) reports. The goal is to enable physicians to begin treatment immediately and reduce damage to the lungs, digestive tract and other organs. Karen Hardy, director of pediatric pulmonology at Children's Hospital Oakland, said an early diagnosis allows physicians to begin treating vitamin deficiencies in newborns with the disease. Out of 540,000 births in California each year, 92 infants are expected to have cystic fibrosis. The new screening test within the first month of its use should identify 85 of those infants. Fred Lorey, acting chief of the state's genetic disease screening program, said that nearly all infants with cystic fibrosis should be diagnosed within a few weeks of birth. Infants with the disease who are not identified by the test could later be diagnosed because of the presence of a condition called meconium ileus, which is a serious obstruction of the small intestine. Tests for cystic fibrosis that many other states use detect only the genetic mutations that are most common in white infants, according to the *Times*. Lorey said that during the past two years, state officials and cystic fibrosis experts in California have conducted research to identify common mutations in African Americans and Hispanics. The result is a more comprehensive screening process than most other states (*Contra Costa Times*, 7/6/07, as cited in California HealthLine, 7/06/07).



California Splits Health Department to Increase Focus on Public Health Threats

California is establishing a dedicated Department of Public Health to enhance the state's ability to combat chronic disease, respond to disasters, and address environmental health under legislation that took effect on July 1, the *Fremont Argus* (http://www.insidebayarea.com/argus/localnews/cj_6288272) reports. Sponsored by state Sen. Deborah Ortiz (D-Sacramento), the measure calls for the state to split its Department of Health Services into a Department of Health and a Department of Public Health. While the Department of Health will oversee Medi-Cal and address issues such as health information technology and patient safety, the Department of Public Health will oversee state efforts related to bioterrorism, infectious disease outbreaks, chronic illness, and other public health threats. In addition, public health officials will manage the state's public health lab in Richmond and California's \$500,000 emergency mobile lab, which was purchased with federal homeland security grants.

While officials have not earmarked any additional funding for the newly-formed public health department, they say current events, including heightened concern over a potential flu pandemic or terrorist attack, underscore the need for a dedicated agency that can effectively prioritize and address public health threats (Kleffman, *Fremont Argus*, 7/3/07, as cited in *RWJF News Digest*, 7/06/07).

New Chart Book Highlights the Essentials of Medi-Cal

The main source of health insurance for one in six Californians, Medi-Cal is the nation's largest Medicaid program covering 6.6 million people. Medi-Cal pays for nearly half of all births in the state, two-thirds of nursing home residents, and brings in more than \$20 billion in federal funds to California's health care providers.

The third edition of *Medi-Cal Facts and Figures: A Look at California's Medicaid Program* provides the essential elements of this massive program, including new information on enrollment, benefits and cost sharing, program spending, and cost drivers. It also features key trends and comparisons with other states, describes the important role that Medi-Cal serves in California's health care system, and examines several challenges facing the program. Among the findings presented in this chart book:

- Following several years of rapid growth due to eli-

gibility expansions in the late 1990s, Medi-Cal enrollment has remained steady at 6.6 million beneficiaries for the past four years.

- Medi-Cal now spends more on community-based long term care than on care in nursing homes and other facility-based long term care.
- Ten percent of Medi-Cal beneficiaries account for over 80 percent of fee-for-service expenditures.
- Three in four of these high-cost beneficiaries are seniors and people with disabilities.
- California spends almost 30 percent less per beneficiary than the national average; however, because a higher proportion of the state's residents are enrolled in Medicaid, California spends 9 percent less per resident than the national average.

To view the complete chart book, go to <http://www.chcf.org/topics/medi-cal/index.cfm?itemID=21659>. (California Health Care Foundation, 5/31/07).

**California Department of Health Services
Health Care Surge Planning**

Attacks from a biological, chemical, or radiological agent, a natural event, or emerging diseases will impose significant demands on California's healthcare system. During these crises, healthcare systems will have to convert quickly from their current patient capacity to "surge capacity", the maximum patient load a healthcare system can handle. Surge capacity is defined by the Agency for Healthcare Research and Quality (AHRQ) as: "A healthcare system's ability to expand quickly beyond normal services to meet an increased demand for medical care in the event of bioterrorism or other large-scale public health emergencies."

Converting to surge capacity is a daunting task. Hospitals and other medical care providers must be prepared to receive and treat large numbers of patients, requiring sufficient staff, ventilators, oxygen, medications, vaccines, personal protective equipment, and other supplies. In addition, the healthcare sector must address the special needs of vulnerable groups such as children, the elderly, and persons with disabilities. Essential hospital services such as food, water, and electricity must be continuously available, and care providers must be able to effectively communicate with public health, emergency medical services and other regional support services.

The 2006-07 State budget awarded \$214 million to build surge capacity including the purchase of the state's share of antiviral medications (3.7 million courses), 2400 ventilators, 50 million disposable respirators to protect healthcare workers from air-borne infectious agents, three 200-bed mobile field hospitals, and supplies and equipment for 21,000 alternate care site beds; the development of standards and guidelines for healthcare delivery during surge events; and updating hospital emergency and infection control regulations.

In December 2005, the California Department of Health Services (CDHS)* established a Surge Capacity Data Workgroup to collect consistent preparedness data from its local health care provider partners. In February 2006, CDHS conducted a statewide assessment of surge capacity based on standardized definitions. CDHS measured current surge capacity against federal Health Resources and Services Administration (HRSA) benchmarks for a moderate event and against a model pandemic influenza scenario using the Centers for Disease Control and Prevention (CDC) FluSurge

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Basic Principles in Approaching Health Care Reform for Children with Special Health Care Needs



In response to administrative and legislative health care reform proposals, Family Voices of California worked with advocates from across the state to develop "Basic Principles in Approaching Health Care Reform for Children with Special Health Care Needs." The principles have been distributed to the administration, key legislators, policy advocates, families and providers to ensure that children with special health care needs are part of the health care reform discussion.

The primary principle in approaching current or future health care reform plans proposed this year is that they first do no harm – i.e., no proposal should reduce or impede the access to appropriate pediatric health care that children with special health care needs currently have. At the same time, the health care reform efforts also provide opportunities to address existing problems of access to care, low reimbursement rates for providers, and other financial and systemic barriers to medically necessary care.

In California the Medi-Cal and CCS programs are the most comprehensive health care programs available to children with special health care needs and access to these programs must be protected for these children. In order to achieve this overarching goal, we recommend that all health care reform proposals meet the following basic principles:

- 1] Proposals must maintain or improve existing income eligibility levels for children's access to Medi-Cal:
 - Proposals should ensure that, at minimum, Medi-Cal continues to cover all currently eligible income levels based on percentage of Federal Poverty Level.
 - Proposals should maintain access to Medi-Cal for all special populations that currently are eligible, including but not limited to enrollees institutionally deemed under waiver programs.

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2.0 software. This is a spreadsheet-based model that provides hospital administrators and public health officials with estimates of the surge in demand for hospital-based services during the next influenza pandemic. An analysis of gaps in service was completed. CDHS proposed a \$400 million (state funds) Surge Initiative to diminish surge gaps for both moderate and catastrophic events.

In determining the standards to measure whether California has adequate surge capacity, CDHS and Emergency Medical Services Agency (EMSA) considered the following: federal benchmarks established by the National Bioterrorism Hospital Preparedness Program (NBHPP) administered by HRSA, guidance from CDC, current medical literature, and advice and consultation with the CDHS Joint Advisory Committee on Public Health Preparedness (JAC).

CDHS contracted with PricewaterhouseCoopers, in a project to address this challenge. The goal of this project was to provide:

- 1] *A standards and guidelines manual* that addresses the existing statutes and regulations that currently govern the standards of care, and identifies those that may be flexed or waived during a declared emergency;
- 2] *Operational tools* to guide healthcare planners in the adoption and implementation of new temporary standards; and
- 3] *A training curriculum* to support the planning and preparation for optimal surge response.

In January 2007, stakeholders were invited to participate in Collaborative Design Sessions. At these multi-day working sessions held in late February and early March, participants identified the complex issues and gaps in current preparedness efforts with regard to the various aspects of surge planning. The sessions used five different representative patients in three different scenarios, nuclear explosion, major earthquake, and pandemic influenza, to identify all possible issues to be addressed related to surge.

The 2,500 issues identified in the Collaborative Design Sessions were consolidated to 150 core issues. Eight work groups were identified with 150 core issues assigned to each work group. In preparation for work group meetings, CDHS and PwC conducted background research on existing regulatory requirements to provide a foundation for the development of standards and guidelines and, with technical experts and a small group of representative stakeholders, prepared a first draft of project deliverables for discussion by work groups. The eight work groups were Declarations and Triggers; Funding Sources; Existing Facilities; Alternate Care Sites; Personnel; Supplies, Pharmaceuticals, and Equipment; Administrative; and Population Rights. Each work group met for a full day in early May.



After the workgroup meetings, draft summaries were developed and posted on the web site for participant and other stakeholder input. This information was collected by PwC and CDHS. Draft deliverable documents were posted on the website on June 5, 2007, for final participant and stakeholder review, due June 12, 2007. The final products are *Standards and Guidelines Manual*, *Operational Tools*, and *Training Tools*. The intended audience is executives, legal counsel, compliance directors, risk management, department managers and supervisors, physicians, nurses, and allied health staff.

* As of July 1, 2007, California Department of Health Services (CDHS) is reorganized. Its programs continue under the Department of Health Care Services (DHCS) and the California Department of Public Health (CDPH).



Report Highlights Progress Toward Meeting Healthy People 2010 Maternal, Infant, and Child Health Objectives

Healthy People 2010 Midcourse Review: Maternal, Infant and Child Health highlights results from an assessment of progress toward achieving the Healthy People (HP) 2010 maternal, infant, and child health goals and objectives through the first half of the decade. The purpose of the midcourse review, which was led by the Centers for Disease Control and Prevention and the Health Resources and Services Administration, is to assess data trends; consider new science and available data; and, if appropriate, revise the objectives to ensure that HP 2010 remains current, accurate, and relevant to public health priorities. Topics include modifications to objectives and sub-objectives, progress toward Healthy People 2010 targets, progress toward elimination of health disparities, opportunities and challenges, and emerging issues. References and related objectives from other focus areas are also included. The report is available at <http://www.healthypeople.gov/data/midcourse/pdf/FA16.pdf>. (MCH Alert, 4/2/07)



- Proposals should ensure that earned income disregards for the purposes of Aged/Blind/Disabled-linked Medi-Cal eligibility continue to be treated as they currently are and that, at minimum, income eligibility levels are maintained at current levels for children with ABD-linked Medi-Cal coverage.
- 2] Proposals must maintain or improve on the existing benefit structure and guarantee for children's access to health services under Medi-Cal:
 - Proposals should ensure that current federal requirements for the Early Periodic Screening Diagnostic Treatment (EPSDT) benefit remain in place.
 - Proposals should at a minimum maintain the current benefit structure and package for all Medi-Cal children. A tiered benefit structure for Medi-Cal children that would limit or reduce services is not acceptable.
 - 3] Proposals should ensure that children maintain their access to pediatric and safety net providers, including regionalized pediatric health care systems for neonatal, pediatric intensive, and other pediatric care; pediatric sub-specialties; child-appropriate durable medical equipment and other supply vendors; and other pediatric appropriate services.
 - 4] Providers serving children with special health care needs must continue to meet established CCS standards for credentialing that reflect pediatric training and experience.
 - 5] Proposals should ensure that the CCS carve-out remains intact. Proposals also should address the need to update income eligibility for the program beyond the current income ceiling, set in 1982, in order to ensure that underinsured and uninsured children obtain access to necessary and often life-saving pediatric specialty care.

We look forward to a discussion with policymakers on how we can augment California's existing health care systems for children with special health care needs. For more information, contact Linda Swan at lswan@supportforfamilies.org.

Calendar of Events

July 2007

- 20 **Screening Techniques for Children – Los Angeles** (<http://www.projectabc-la.org/home.htm>)
- 21 **1st International Costello Syndrome Research Symposium – Portland, OR** (<http://cancer.ucsf.edu/costello2007/index.php>)
- 26 **Special Start Training Program: Providing Developmentally Supportive Care at Home after the NICU – Encino** (<http://www.mills.edu/specialstart/calendar.html>)
- 27–28 **Relationship Development Intervention Program: Going to the Heart of Autism – San Diego** (<http://www.rdiconnect.com/workshops/viewAssessment.asp?wid=139>)
- 27–29 **8th International CHARGE Conference – Costa Mesa** (<http://www.charge syndrome.org/conference-2007.asp>)
- 30–Aug 1 **3rd International Conference on Patient- and Family-Centered Care – Seattle, WA** (<http://www.familycenteredcare.org/events/conference.html>)
- 30–Aug 1 **Collaborative Conference on Autism with Low Incidence Disabilities – Columbus, OH** (<http://www.ocali.org/collaborative/>)
- 31–Aug 2 **The 7th Annual National Early Childhood Inclusion Institute – Chapel Hill, NC** (<http://www.nectac.org/~meetings/InclusionMtg2007/mtghomepage.asp>)

August 2007

- 1–3 **National Prader-Willi Syndrome Association Conference – Dallas, TX** (<http://www.pwsausa.org/conference/index.htm>)
- 2–3 **MIND Institute UC Davis Summer Institute on Neurodevelopmental Disorders – Sacramento** (http://www.ucdmc.ucdavis.edu/cme/conferences/pdfs/MIND008_FINAL.pdf)
- 8–11 **USAAA 2007 Autism and Asperger International Conference – Denver, CO** (http://www.usautism.org/usaaa_conference_overview_2007.htm)
- 18–19 **“Back to School” Autism/Aspergers Conference – Pasadena** (<http://www.autism-conferences.com/>)
- 22–23 **Annual Summit on Developmental Services/Mental Health: New Solutions through Collaboration – Sacramento** (<http://www.pai-ca.org/news/summit07aug22.pdf>)
- 25–28 **17th Annual CityMatCH Maternal and Child Health Leadership Conference, “Building the Best Environments for Families and Children” – Denver, CO** (http://citymatch.org/apps/conf_agenda.php)
- 30–31 **Helping to Administer to the Needs of Diabetic Students (HAND) – Modesto** (<http://www.csno.org/docs/HANDS%20August%2030,%202007%20Registration%20Flyer.doc>)



CYSHCN Discussion Forum Report

During the 2007 Association of Maternal and Child Health Programs (AMCHP) Annual Conference, roundtable discussions on emerging issues in maternal and child health were held. One of the topical discussions focused on issues related to children and youth with special health care needs (CYSHCN). The discussion involved a number of states and a strong contingent of family representatives. Multiple states seem to be grappling with a system of services that is challenging for health professionals, service providers and families to navigate, noting that many departments work in their own domain and rarely take a holistic approach to assessing needs and devising a coordinated service plan for families. The goal of creating a seamless system of services with a no wrong door approach to service provision has been a management and logistical challenge for state Title V CSHCN programs to restructure their respective programs from direct service to infrastructure/public health models (e.g. medical home).

Parents and providers discussed the need for helpful and guiding information on available resources. MCH staff noted the need for ongoing training around the needs of CYSHCN and their families and effective ways for working with families to set and identify state priorities.

MCH staff noted the challenges they face and limited resources to increase access to coordinated, continuous and comprehensive care through a medical home which is an essential piece of the family success and quality of life equation.

Other areas discussed included: access to health care in rural areas; the lack of Medicaid providers for CYSHCN in rural and urban areas, which was also tied to low Medicaid reimbursement rates; lack of pediatric specialists; need for family and general practitioners to understand CYSHCN issues; medical debt with the large amount of out-of-pocket expenses and incomplete insurance benefit packages within public and private sectors; and, how to provide culturally effective care, especially to the undocumented populations who may be reluctant to seek care.

Strategies to Develop a Family-Centered and Integrated System of Services

- Bring families fully into all systems: provide training, child care and reimbursement so they can participate; train professionals to involve families.
- States need to take interagency agreements seriously and work as a system (could be applied at the federal level as well)

Strategies to Increase Access to Providers

- Increase training to providers and specialists, especially to family physicians, internists and

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Calendar of Events (continued)

September 2007

- 6-8 **2nd Annual Pediatric Telehealth Colloquium — San Francisco**
(<http://www.ucdmc.ucdavis.edu/children/calendar/>)
- 11 **Special Start Training Program: The Development of Self-Regulation : Birth to 3 Years Workshop — Ventura** (<http://www.mills.edu/specialstart/calendar.html>)
- 18-20 **Medi-Cal Now: Your Questions Answered — Ontario** (<http://files.medi-cal.ca.gov/pubsdoco/eo/mcnow/index.asp>)
- 27 **CRISS Workshop on Care Coordination Strategies — Oakland** (for information, contact Laurie Soman: Lsoman6708@aol.com / 510-540-8293)
- 29 **Pediatric Clinical Update — Los Gatos** (<http://www.lpch.org/pdf/cmeBrochures/cmeSanJose2007.pdf>)



October 2007

- 3-5 **21st Annual Supported Life Conference: Create Positive Change Through Shared Action — Sacramento** (<http://www.supportedlife.org/>)
- 3-5 **2007 Southwest Conference on Disability - Reaching Out and Taking Charge: Promoting Independent Living in the Community — Albuquerque, NM** (<http://cdd.unm.edu/swconf/index.htm>)
- 5-6 **Radys Children's Hospital "Evolving Concepts in the Management of Complex Congenital Heart Disease" — San Diego** (<http://www.chsd.org/documents/CME/cardiovascular100607.pdf>)
- 5-6 **The Help Group Summit 2007: Advances and Best Practices in Autism, Learning, Disabilities and ADHD — Los Angeles** (<http://www.thehelpgroup.org/conf.htm>)
- 6 **LAUSD Fifth Annual Resource Faire for Families of Children with Disabilities — Gardena** (for information, contact Teresa del Carmen Gonzalez: 213-241-6701)
- 9-11 **Autism Spectrum and Mental Health Disorders — Anaheim** (<http://store.spectrumtrainingsystemsinc.com/anco.html>)
- 11-13 **The Arc's 56th Annual National Convention — Dallas, TX** (<http://www.thearc.org/NetCommunity/Page.aspx?&pid=411&srcid=183>)
- 12-14 **CA Chapter 4, AAP Current Advances in Pediatrics — Newport Beach** (<http://www.aapca4.org/pdf/aap2007-seminars-v2.pdf>)
- 14-16 **National Academy for State Health Policy, 20th Annual State Health Policy Conference** (<http://www.nashp.org/conferences.cfm?LID=CON>)
- 22-23 **2nd Annual Transition Summit Conference: Planning for Adult Life — Los Angeles** (for information, contact Mary Hosokawa: 626-299-4643)
- 25-26 **UCSF School of Medicine, Pangea 2007 Conference on Pediatric Wellness — San Francisco** (<https://www.cme.ucsf.edu/cme/CourseDetail.aspx?coursenumber=MMJ08004>)



Med Peds who can take on the care of young adults transitioning into the adult health care system; this includes training on how to provide family-centered care and how to address needs beyond the medical realm.

- Provide more support, resources and training for rural providers as specialists are usually located hours away.

State Models

- Florida's hospice and palliative care program for children is based on an adult health model – the PAC system.
- University of Florida Medical School provides the opportunity for medical students to work with children with disabilities.

Conversation on Mental Health

During the roundtable discussion on children and youth with special health care needs, the conversation flowed into a lively discussion on access to mental health resources on behalf of patients by primary care practitioners, training needs of primary care practitioners in order to be able to provide mental health services to patients, and the lack of access to quality of mental health services. Families noted that they want information on what they can do to self-screen, advocate and communicate with one another. They want to enhance their education and awareness so they can maximize their time in the doctor's office.

The biggest issue discussed was the need for pediatricians and primary health care providers to be better trained in these issues and willing to communicate with parents about them. This is particularly critical in rural areas where specialists are harder to find. Coverage is also an issue – the additional time needed to deal with mental health issues and whether that would be reimbursed.

Access to and Quality of Mental Health Services

- In Minnesota, they are very aggressive in using Medicaid dollars for mental health, e.g. social workers in the schools – recently CMS personnel made the decision to be more conservative.
- In Florida, there is mental health access for children and parents through hospice – however, there is a lack of mental health providers for other children.
- In Massachusetts, training is needed for medical personnel – pediatricians, primary care providers – but there may still be reluctance – issues of reimbursement for depression screening.
- In addition, many rural areas have no pediatricians – training and time (extends time of patient visit) issues- may need ability to consult with psychiatrist.

(AMCHP Pulse for Partners, 5/25/07)

Calendar of Events (continued)

October 2007 (continued)

- 25–28 **Division for Early Childhood's 23rd Annual International Conference on Young Children with Special Needs & Their Families: Crossing New Borders** – Niagara Falls, Ontario, Canada (<http://www.dec-sped.org/conference/>)
- 26 **Special Start Training Program: Providing Developmentally Supportive Care at Home after the NICU** – Ventura (<http://www.mills.edu/specialstart/calendar.html>)
- 26 **13th Annual Early Start Symposium Together Is Better: Parents & Professionals in Early Start** – Stockton (<http://www.areaboard6.ca.gov/res/pdf/EarlyStart.pdf>)
- 26 **Determinants of Child Health: The Role of the Pediatrician - Community Pediatrics for the 21st Century** – San Francisco (<http://www.aap.org/peds-21/>)
- 27–30 **AAP 2007 National Conference & Exhibition** – San Francisco (<http://www.aap.org/nce/>)

November 2007

- 3–7 **American Public Health Association 135th Annual Meeting & Exposition** – Washington, DC (<http://www.apha.org/meetings>)
- 8–9 **Chronic Illness and Disability: Transition from Pediatric to Adult-based Care** – Houston, TX (http://www.baylorcme.org/pdfs/Chronic_Illness_and_Disability_Save_the_Date_revised.pdf)
- 9–11 **Children's Hospital and Research Center Oakland 37th Annual Fall Conference: Curbside Consults – Questions for the Experts – Seaside** (http://www.childrenshospitaloakland.org/upcoming_events-provider.asp)
- 15–18 **AAP CA Chapters 1,2,3,4 29th Annual Las Vegas Seminars: Pediatric Update** – Las Vegas, NV (<http://www.aap-ca.org/meetings/2007/NovemberLasVegas/2007Lvbrochure.pdf>)



Final Citizenship Guidelines for Medicaid Eligibility Documentation Expanded, Groups Exempted

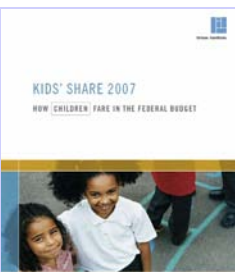
Establishing citizenship for Medicaid eligibility will be easier for states and program applicants under final regulations implementing the new law, issued by the Centers for Medicare & Medicaid Services (CMS). The Centers for Medicare & Medicaid Services (CMS) put on display at the Office of the Federal Register, the Citizenship Documentation Requirements Final Regulation. This final rule, required by provisions of the Deficit Reduction Act (DRA) and the Tax Relief and Health Care Act (TRHCA), issues the final citizenship guidelines for Medicaid eligibility.

The final regulation expands the types of documentation that can be used to establish citizenship and formally exempts certain groups from the requirements. These changes will make the establishing citizenship for Medicaid eligibility easier for both states and program applicants.

A citizenship documentation requirements toolkit will be available shortly on the CMS website. This toolkit is designed to help our partners reach and assist individuals applying for Medicaid. The kit includes, among other things, a drop-in article, fact sheet, frequently asked questions, poster, and CMS Regional Office contacts. To access the following, go to:

- Final Regulation - <http://www.cms.hhs.gov/MedicaidGenInfo/Downloads/CMS2257F.pdf>
- Citizenship Documentation Requirements Toolkit - http://www.cms.hhs.gov/MedicaidEligibility/05_ProofofCitizenship.asp
- Citizenship Documentation Requirements Press Release - http://www.cms.hhs.gov/apps/media/press_releases.asp
- Citizenship Documentation Requirements Fact Sheet: http://www.cms.hhs.gov/apps/media/fact_sheets.asp

(Centers for Medicare & Medicaid Services, 7/03/07)



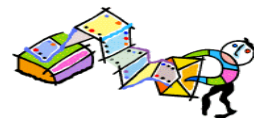
Authors Analyze Historical and Projected Trends in Federal Spending

Kids' Share 2007 examines trends in child expenditures, child expenditures within the children's budget, and the future of federal spending on children. The report updates and expands previous research published in 2000 by the Urban Institute, adding additional years and programs and projecting spending within the children's budget against other federal spending for the period 1960-2017. Children are defined as "individuals ages 18 and younger who are not yet engaged in post-secondary education," and about

Fact Sheets Summarize President's Budget Proposals for Health Insurance Coverage, Including Medicaid and SCHIP

The Kaiser Family Foundation has published three fact sheets that provide an overview of President Bush's policy plans to address health coverage issues, including Medicaid, the State Children's Health Insurance Program (SCHIP), and Affordable Choices. The fact sheets include the following:

- *President's FY 2008 Budget and Medicaid* proposes savings from Medicaid over the next 5 years through a combination of legislative and regulatory changes. The fact sheet is available at <http://www.kff.org/medicaid/upload/7634.pdf>.
- *President's FY 2008 Budget and The State Children's Health Insurance Program (SCHIP)* proposes reauthorizing SCHIP for the next 5 years by (1) adding \$4.8 billion to the current SCHIP allotment of \$25 billion over 5 years, (2) reducing the amount of time that states have to spend their allotments from 3 years to 1 year, and (3) limiting the enhanced SCHIP match to children and pregnant women with incomes at or below 200% of the federal poverty level. The fact sheet is available at <http://www.kff.org/medicaid/upload/7635.pdf>.
- *The Affordable Choices Initiative: An Overview* proposes expanding private health insurance coverage to individuals who are uninsured and to those who are difficult to insure because of high-cost medical conditions by allowing states to reprogram current spending on institutions. The fact sheet is available at <http://www.kff.org/uninsured/upload/7637.pdf>.



100 federal programs are classified within eight major budget categories including income security, nutrition, housing, tax credits and exemptions, health, social services, education, and training. The report is based on actual budget outlays and projections of spending under current law. The authors do not assess the success, efficiency, or merit of any particular type of spending. Conclusions and selected references are provided. The report is available at http://www.urban.org/UploadedPDF/411432_Kids_Share_2007.pdf. (MCH Alert, 3/23/07)

Paper Discusses Health Plan Approaches to Address Child Health Disparities

Reducing Health Disparities Among Children: Strategies and Programs reviews what is known about health disparities among children, and explores strategies for addressing these disparities. The issue paper, produced by the National Institute for Health Care Management Foundation, provides a brief overview of health disparities, including the importance of health insurance to address them, as well as its limitation in doing so. The overview is followed by a description of innovative approaches (data collection, provider education, treatment and prevention, community focused) by health plans to reduce disparities and ensure cultural competence. A framework of factors affecting health and well-being; data on the self-reported health status of children by income and parental education level, average annual physician visits among children by health status, percentage of children ever told that they had asthma, and percentage of children who are overweight; and a list of selected resources on maternal and child health disparities are included. The paper is intended to inform policymakers, health professionals, families, and others about the roots of health disparities and the current state of health disparities among children.

The paper is available at <http://www.nihcm.org/finalweb/HealthDisparitiesFinal.pdf>. (MCH Alert, 3/9/07)



Theme Journal Issues Focuses on Children's Health and Health Care

The March-April 2007 issue of *Health Affairs* is dedicated to children's health topics and, specifically, to the design of children's health care. The papers in the opening section of the thematic issue discuss why children count, how they are counted, and what is unique about children's health and well-being that requires accounting for them in new, evidence-based ways. The authors of the lead paper (Halfon, et al.) present a vision and rationale for reform of the U.S. child health system based on paradigmatic changes in the conceptualization of child health development. Many of the other papers in the volume focus on the multiple challenges that children from families with low incomes face in reaching adulthood in a healthy state. The issue examines the first decade of the SCHIP program, and concludes that by many objective standards, SCHIP has been a success, lowering uninsurance rates among children and improving their access to care. It also includes articles from leading health policy experts on a range of issues related to children's health. Lisa Dubay and colleagues examine the roles of Medicaid and SCHIP in providing coverage for children. Len Nichols writes that there is a moral case for society to provide health insurance coverage to poor children. The issue is available at <http://content.healthaffairs.org/content/vol26/issue2/>. (MCH Alert, 3/9/07, and Academy Health, 3/14/07)

National & Statewide Data: Key Child Health and Health Care Indicators

■ 2007 California County Data Book: Indicators of Children's Well-being

Wide disparities in children's well-being from county to county are presented in a new online public resource by Children Now. Recently released, the 2007 California County Data Book delivers the most comprehensive county-level data available on children's health, education and family economic status. It also presents county rankings for key indicators. To access the Data Book, go to http://publications.childrennow.org/publications/invest/cdb07/databook_2007.cfm. Please send all feedback to Corey Newhouse at cnewhouse@childrennow.org. (Children Now, 6/21/07)



■ Data Update Shows State Variations in Key Disparities Indicators

The Kaiser Family Foundation issued a new data update showing variations across states and

racial and ethnic groups for six key health and health care indicators. The data update provides a quick glance at disparities in rates of infant mortality, diabetes-related mortality and AIDS cases among whites, African Americans and Hispanics in all 50 states and the District of Columbia. It also provides similar breakdowns showing the percentage of each group in each state that is uninsured, enrolled in Medicaid, and living in poverty.

Key Health and Health Care Indicators by Race/Ethnicity is drawn from the more than 30 state-specific indicators related to race and ethnicity available on Kaiser's statehealthfacts.org (<http://www.statehealthfacts.org/compare.jsp>).

The fact sheet is available online at <http://www.kff.org/minorityhealth/7633.cfm>. For additional information, please contact Craig Palosky at 202-347-5270 or cpalosky@kff.org. (Kaiser Family Foundation, 4/19/07)



Study Provides Estimates of the Effects of Managed Care on Use of Health Care Services for Publicly Insured Children with Chronic Conditions

"Our results suggest that when CWCHC (children with chronic health conditions) enrolled in Medicaid or SCHIP are assigned to managed care plans, they experience lower use rates of commonly needed services, relative to CWCHC enrolled in FFS (fee-for-service)," state the authors of an article published in the May 2007 issue of *Pediatrics*. Although managed care holds promise for improved organization and accountability, concerns have been raised about the breadth and adequacy of provider networks, and about health plans' lack of experience delivering care to CWCHC. The article provides national estimates of the effects of different types of managed care programs on access to and use of health care services for publicly insured CWCHC. The authors examine mainstream managed care programs, both those that integrate mental health or specialty services and those that exclude or "carve-out" these services, and they also consider programs designed specifically for CWCHC.

The researchers used data from the 1997-2002 National Health Interview Survey (NHIS) to (1) identify CWCHC, (2) construct a series of child, parent, and family measures; and (3) measure access and service use outcomes. Instead of using the self-reported information on managed care enrollment, for each year of the NHIS researchers assigned information on the type of managed care implemented in the county of residence (specific to Medicaid and separate SCHIP programs) by CWCHC. Information on managed care program type was abstracted from annual Medicaid managed care enrollment reports, special surveys of state Medicaid programs and SCHIP, and SCHIP state plans. Managed care data were linked to children eligible for Medicaid or SCHIP. The researchers estimated the effects on use of services associated with four groups of mandatory managed care plans, relative to FFS, after adjustment for child, family, and area characteristics; state; and year.

The authors found that:

- The effects on use of services associated

with mandatory primary care case-management programs did not reach standard levels of significance.

- Among integrated capitated programs (without carve-outs), only unmet need for medical care reached the standard level of significance.
- Managed care plans with mental health or specialty carve-outs were associated with significant reductions in specialty visits, mental health specialty visits, vision care visits, and regular prescription drug use. The negative effects on mental health visits and prescription drug use were significantly larger for plans with carve-outs relative to plans where these services are integrated.
- Special managed care programs for CWCHC were not found to have significant effects on service use.

"The findings reported reflect the marginal changes in the probability of service use associated with each managed care model relative to FFS plans," state the authors. "However," they add, "the large differential effects associated with carve-outs suggest a need for additional study...to more clearly assess the adequacy and appropriateness of care delivered to CWCHC under managed care." (MCH Alert, 5/18/2007)

Davidoff A, Hill I, Courtot B, et al. 2007. Effects of managed care on service use and access for publicly insured children with chronic health conditions. Pediatrics 119 (5):956-964. Abstract available at <http://pediatrics.aappublications.org/cgi/content/abstract/119/5/956>.

Compendium Provides Latest Information Available on Mental Health Services

Mental Health, United States, 2004 addresses recent recommendations by the Institute of Medicine for coordinated primary and mental health and substance use care and the application of quality improvement to the mental health field. The 2004 compendium, the latest in a series published every 2 years since 1983 by the Substance Abuse and Mental Health Services Administration's Center for Mental Health Services (CMHS), is divided into five sections:

- Section 1 – introduces the quality-improvement model and its application to the mental health field.
- Section 2 – reviews measures of quality essential for any quality-improvement initiative.
- Section 3 – highlights the role of mental health care provided in primary care settings.
- Section 4 – examines population assessments to identify individuals with mental illness from community surveys and cost assessments drawn from en-

(Continued next page)

counter-payment data for consumers served in major public and private funding programs.

Section 5 – presents annual national service statistics collected through the CMHS National Mental Health Statistical Reporting Program.

The appendices provide sources and qualifications of data from the Survey of Mental Health Organizations and the 1997 Client/Patient Sample Survey, and from mental health consumer organizations and mental health practitioners and trainees. The compendium is intended for use by program administrators, policymakers, and others in helping to guide program and policy direction and identify a course toward system transformation in mental health care. The compendium is available at http://download.ncadi.samhsa.gov/ken/pdf/SMA06-4195/CMHS_MHUS_2004.pdf. (MCH Alert, 3/23/07)



Helping Families Transition to the Future: Outcome Data 2005-2006, RSA Parent Information and Training Projects

This publication summarizes the work of seven Parent Information and Training Programs funded by the U.S. Department of Education Rehabilitation Services Administration (RSA) to "provide training and information to enable individuals with disabilities, and the parents, family members, guardians, advocates, or other authorized representatives of the individuals to participate more effectively with professionals in meeting the vocational, independent living, and rehabilitation needs of individuals with disabilities (Rehabilitation Act, 1998)." The data presented here provides policymakers, administrators, and advocates with a clear picture of who is being served by RSA Parent Information and Training Programs, and the ways in which program activities influence meaningful outcomes for individuals with disabilities and their families. Data was collected from seven RSA funded Parent Information and Training Programs serving 10 states: California, Florida, Illinois, Indiana, Michigan, Minnesota, Oklahoma, Tennessee, Wisconsin, and Washington, and then compiled by the Technical Assistance on Transition and the Rehabilitation Act (TATRA) Project, also funded by RSA. It represents program outcomes for activities conducted over a 12-month period in 2005 and 2006. Available in html <http://www.pacer.org/tatra/RSA/page1.htm> and PDF formats <http://www.pacer.org/tatra/RSA/RSA.pdf>. (TATRA Center, 5/25/07)

Resources

Obesity Recommendations Implementation Guide Now Available



The National Initiative for Children's Healthcare Quality (NICHQ), together with key partners, has created an implementation guide to accompany the newly released *Obesity Recommendations*. These recommendations come from the Expert Committee on the Assessment, Prevention and Management of Child and Adolescent Overweight and Obesity, convened by the American Medical Association, Centers for Disease Control and Prevention, and Health Resources Services Administration. To learn more about the Action Network and the *Implementation Guide*, go to <http://www.nichq.org/obesityactionnetwork>. (NICHQ, 7/02/07)

New Guidebook for Caregivers of Children/Adolescents from NAMI New Hampshire

In early 2007, the National Alliance on Mental Health Illness (NAMI) New Hampshire released a guide for families and caregivers of children and adolescents with serious mental health treatment needs. This comprehensive guide covers the following topics, some of which relate to services in NH, but many of which are broadly covered and include extremely helpful information for families:

- Integrated Health Care
- Taking Care of the Caregiver
- Partnering in Your Child's Care
- About Serious Emotional Disorders & Behavioral Issues
- Navigating the Treatment System
- Safeguarding Your Child's Education
- Paying for Services
- Crisis Management Planning
- Transitioning to Adult Health Care Services

To download the guide, go to <http://naminh.org/documents/ChildGuide2007.pdf>; to order a hard copy, go to the NAMI New Hampshire web site (<http://www.naminh.org>). (NAMI, 6/29/07)

Health Care Program for Children in Foster Care (HCPCFC) On-Line Resource Guide

Children's Medical Services Branch (CMS) is pleased to announce that an on-line resource guide has been developed for the HCPCFC Program. This guide features sections such as program background information, resources, contacts, and forms to assist the public health nurse and other staff in the care of foster children in out-of-home placement. The HCPCFC Resource Guide is located on the CMS website at: <http://www.dhs.ca.gov/pcfh/cms/hcpcfc>. (Children's Medical Services Branch, 4/12/07)



Project Forum Report: *Involvement of Youth with Disabilities in State-Level Decision Making*

This In-Brief Policy Analysis is based on interviews with state education agency representatives and youth with disabilities who are involved in state-level decision making in the area of special education. How states include youth, what training and support states provide, and benefits and challenges of this work are shared from both the states' and the youth's perspectives. Policy recommendations are also given. To access the report, go to <http://projectforum.org/docs/InvolvementofYouthwithDisabilitiesinStateLevelDecisionMaking.pdf>. (TATRA Center, 6/14/07)



Research Project Evaluates 20 Years of What Works for Youth with Disabilities

The *What Works Transition Research Synthesis Project*, funded by the Office of Special Education Programs (OSEP), has published the first report in a series to be released. The project was established to review and synthesize the past two decades of research and advancements in the area of transition for youth with disabilities. By reviewing 50 previous studies, this first report examines how teaching life skills as an intervention affected the lives of 482 youth with varying levels of intellectual disabilities. To read the first report, *A Systematic Review of the Effects of Curricular Interventions on the Acquisition of Functional Life Skills by Youth with Disabilities*, go to http://www.nsttac.org/?FileName=what_works&type=1. (TATRA Center, 6/19/07)



Fact Sheet Focuses on Medicaid and SCHIP Eligibility Policies Affecting Older Adolescents

The *Public Health Insurance Cliff for Older Adolescents* reviews the mandatory and optional pathways for extending Medicaid or State Children's Health Insurance Program (SCHIP) eligibility to older adolescents (ages 19 and 20) and presents information on states that adopted each option. The 12-page fact sheet was published by Incenter Strategies, an affiliate of the Maternal and Child Health Policy Research Center. The fact sheet draws on published reports, the Centers for Medicare and Medicaid Services Web site, a review of state plan documents, and communications with state Medicaid and SCHIP agency staff. Eligibility policies under which older adolescents can be targeted specifically, as well as policies under which they can be covered as part of a larger group by virtue of their family circumstances or health status, are discussed. Two tables display 2006 data on states' Medicaid and SCHIP income-eligibility levels for adolescents (ages 12-20) as a percentage of poverty and on states' use of Medicaid options for expanding eligibility to special groups of older adolescents (ages 19 and 20). Conclusions are also provided. The fact sheet is available at <http://www.incenterstrategies.org/jan07/factsheet4.pdf>. (MCH Alert 5/4/07)

Resources (continued)

Resources on Children and Family Health Coverage

As Congress debates how to reauthorize SCHIP, the Kaiser Family Foundation's Commission on Medicaid and the Uninsured offers a round-up of state coverage trends and initiatives for children and families. Find a web-based tracking tool to examine state initiatives, a fact sheet on how SCHIP and Medicaid influence children's health, reports on technology and enrollment, and much more. To access these resources, go to <http://www.kff.org/medicaid/kcmu051607pkg.cfm>. (Connect for Kids Weekly, 5/30/2007)

NCWD/Youth *Guide* on Youth in the Foster Care System

Negotiating the Curves Toward Employment: A Guide About Youth Involved in the Foster Care System from the National Collaborative on Workforce and Disability for Youth (NCWD/Youth) encourages collaborative efforts between workforce development, child welfare, mental health, schools, and other community institutions to improve opportunities for youth in foster care so they can successfully transition into adulthood. The youth involved in the foster care system represent one of the most vulnerable populations in our society. Of the more than 500,000 youth in foster care, 30 to 40% are in special education. Building upon the NCWD's Youth Organizing Framework known as the "Guideposts for Success" this new publication helps meet the needs of youth in foster care. In addition, the *Guide* provides facts, statistics, and contextual information about youth involved in the foster care system; gives examples of states and communities that are changing policy and practices; identifies areas requiring further attention by policy makers and providers of services; and identifies resources and tools to assist cross-system collaborative efforts.

The publication can be accessed at http://www.ncwd-youth.info/resources/Publications/foster_care.html.



Authors Examine Associations Between Confidential Services and Parent-Adolescent Communication

"This study supports the hypothesis that availability of services is not a barrier to adolescent-parent communication about their health," state the authors of an article published in the June 2007 issue of the *Journal of Pediatric and Adolescent Gynecology*. Questions remain about the relationship between access to confidential services and whether adolescents communicate with their parents regarding their health care. The article describes a study to examine whether the availability of confidential services was a barrier to adolescents' communication with their parents about health issues. The researchers also evaluated whether adolescents' comfort with discussing reproductive health issues would impact future communication with parents about potentially serious and sensitive reproductive health care issues.

The study sample included 59 adolescents (ages 15-21) from an urban adolescent health clinic in Minnesota who agreed to participate and completed an anonymous survey. Females comprised 88% (N=50) of the study sample; 70% (N=35) of the adolescents were 16 and older; 23% (N=13) of the adolescents reported their race as white, 37% (N=21) as African American, and 40% (N=25) as other; 87% (N=52) of the adolescents attended school; and 43% (N=23) of the adolescents reported qualifying for free or reduced-price school lunch. The analysis examined the frequency of adolescents seeking confidential services and non-confidential services. Outcome variables included communication with parents about clinic visit and health concerns and comfort with discussing reproductive health care issues with their parents.

The authors found that:

- Fifty-eight percent of the adolescents came to the clinic for confidential services.
- Overall, 69.5% (N=41) of the adolescents told their parents they were coming to the clinic.
- Less than half (43.1%, N=25) of the adolescents reported that they would tell their parents if they were found to have a serious and sensitive reproductive health problem (sexually transmitted infection or pregnancy). Of those who would tell their parents, approximately half had come in for confidential services and half for non-confidential services.

In terms of adolescents' decisions about whether to discuss their reasons for coming to the clinic and their future communication related to serious and sensitive reproductive health care issues with their parents, there was no significant difference between adolescents who came in for confidential vs. non-confidential services.

The authors suggest that further research is needed to explore health professionals' role in helping adolescents share information about a serious and sensitive

reproductive health problem and assisting them in obtaining support from their parents. The authors add that interventions need to be in place to educate parents about communication with their adolescent and the rights of their adolescent under the minor's consent laws. (MCH Alert, 6/22/07)

Lerand SJ, Ireland M, Boutelle K. 2007. Communication with our teens: Associations between confidential service and parent-teen communication. *Journal of Pediatric and Adolescent Gynecology* 20():173-178. Abstract available at [http://www.sciencedirect.com/science?_ob=ArticleURL&_udi=B6W68-4NXH6RM-7&_user=10&_coverDate=06%2F30%2F2007&_rdoc=7&_fmt=summary&_orig=browse&_srch=doc-info\(%23toc%236592%232007%23999799996%23660502%23FLA%23display%23Volume\)&_cdi=6592&_sort=d&_docanchor=&_ct=16&_acct=C00050221&_version=1&_urlVersion=0&_userid=10&md5=a6c2471d6f4deaceef2bbb01a3c6937](http://www.sciencedirect.com/science?_ob=ArticleURL&_udi=B6W68-4NXH6RM-7&_user=10&_coverDate=06%2F30%2F2007&_rdoc=7&_fmt=summary&_orig=browse&_srch=doc-info(%23toc%236592%232007%23999799996%23660502%23FLA%23display%23Volume)&_cdi=6592&_sort=d&_docanchor=&_ct=16&_acct=C00050221&_version=1&_urlVersion=0&_userid=10&md5=a6c2471d6f4deaceef2bbb01a3c6937).



Issue Paper: Young Adults with Disabilities Aging Out of Medicaid

The Kaiser Family Foundation Issue Paper, *Aging Out of EPSDT: Issues for Young Adults with Disabilities*, examines what happens when children with disabilities age out of Medicaid. Early and Periodic Screening, Diagnostic, and Treatment (EPSDT) coverage is currently offered for low-income children with disabilities through the federal Medicaid program. When recipients of EPSDT coverage age out of eligibility at 18 or 21, youth with disabilities may find they do not meet the more stringent eligibility requirements for adult SSI recipients, or that the services available to them as adults is much more limited than what they received under EPSDT. For young adults with disabilities, these limits have important implications. Young people who lose SSI eligibility are at risk of going uninsured. In addition, young people with severe physical and mental disabilities who had previously relied on personal care services or other similar services to continue living at home or in a community-based setting may find that these services are no longer available to them. For these youth, the greatest risk in becoming an adult is the threat of institutionalization or of having basic health and daily living needs go unmet if they remain in the community. Although states have expanded the availability of home and community-based services through federal Medicaid waivers, many states have waiting lists for these services, some of which are years long. To access the paper, go to <http://www.kff.org/medicaid/upload/7491.pdf>. (TATRA Center, 5/4/2007)