



CACSHCNEWS

Children's Regional Integrated Service System (CRISS)

Since 1996 CRISS has been working to create a regional seamless system of care for CCS children in a 14-county region in Northern California. This region encompasses Alameda, Contra Costa, Marin, Napa, Sacramento, San Francisco, San Joaquin, San Mateo, Santa Clara, Santa Cruz, Solano, Sonoma, Stanislaus and Yolo counties. CRISS includes the 14 county CCS programs, nine pediatric provider organizations (including six major pediatric institutions), California's statewide family support organization, and eight local family support organizations.

What We Do

- We bring together the major CCS stakeholder groups in a cohesive regional coalition for collaboration and planning. Our mission is to promote a seamless, integrated, cost-effective and efficient regional service system that improves service delivery and coordination of care for children with special health care needs.

Major Accomplishments

- We promote family-centered care for children with special health care needs through annual conferences, information-sharing on strategies

(Continued next page)

Los Angeles County CCS Workgroup

Originally funded by a Community Integrated Service System (CISS) grant from the Maternal Child Health Bureau, the CCS Workgroup was established in 1996 and represents a diverse group of child health care interests, in particular for children with special health care needs (CSHCN) in Los Angeles County, including health care providers, health services administrators, managed care representatives, academicians, advocates, and parents of children with special health care needs. The Workgroup was brought together in re-

(Continued on page 3)

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:



- ◆ 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

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

Next Issue Date:
January 2007

for promoting family-centered care, and provision of technical assistance to support local CCS program efforts toward family centeredness, including transition planning.

- We have developed guidelines for the inter-county transfer of CCS cases to simplify the process for CCS programs and providers and eliminate delays for children and their families; for handling CCS children with pending Medi-Cal eligibility (our model was adopted by the state CCS program for the state as a whole); and for consistent, regional implementation of the recent CCS policy letter on Maintenance and Transportation reimbursement.
- We review CCS medical eligibility regulations and recommend clarifications and updates on a continual basis, thus reducing inter-county differences in interpretations that can disrupt children's care and create obstacles for large pediatric institutions serving children from multiple counties.
- We work with State Medi-Cal and EDS to identify and correct barriers to timely processing of CCS claims. CRISS efforts helped result in the elimination of EDS edits that limited CCS billing and reimbursements (e.g. frequency and location of service edits). Currently we are following implementation of Enhancement 47, apprising the state of questions and concerns and sharing information on the new authorizations and claims processes among provider groups and institutions.

Our Current Activities

- We are working to develop and implement regional and local strategies to promote medical homes for children with special health care needs.
- We will hold our annual conference on family-centered care on November 3, 2006 in Oakland. Our 2005 conference addressed consent, conservatorship, and other issues concerning CCS youth reaching age 18.
- We recently convened our first regional meeting (see page 9).
- We continue to promote a consistent regional interpretation of medical eligibility regulations in order to reduce inter-county differences in eligibility and treatment authorizations.
- We recently completed analysis of a statewide survey of local CCS programs on family-centered care activities that we conducted on behalf of state CCS.

Calendar of Events

November 2006



- 2 **California Children's Hospital Association: CCS Best Practices Conference 2006 — Oakland** (for more information, contact Betsy O'Hare: 650-497-8060, eo'hare@lpch.org)
- 2-3 **UC Davis MIND Institute: Clinical Implications of Environmental Toxicology for Children's Neurodevelopment — Sacramento** (http://www.ucdmc.ucdavis.edu/cme/conferences/pdfs/ENVTX007_11-2-06.pdf)
- 3 **Annual CRISS Conference Negotiating Multiple Transition Hurdles, One a Time! — Oakland** (for more information, contact Mara McGrath: mkmcgrath1254@aol.com)
- 3-5 **Epilepsy Foundation Greater Los Angeles: Epilepsy Brain Storm Summit IV – Los Angeles** (<http://www.epilepsy-socalif.org/index.cfm?page=content/currentevents.html>)
- 4 **Rady Children's Hospital San Diego Mini Seminar: The Science of Reading and Dyslexia — San Diego** (<http://www.chsd.org/documents/CME/neuro110406.pdf>)
- 9-12 **2006 Council for Exceptional Children Annual Academy — Garden Grove** (<http://www.calstatecec.com/conference.htm>)
- 15-18 **Coming of Age: Supporting Teens and Young Families in the 21 st Century – Anaheim** (http://www.labestbabies.org/listserv/attachments/Coming_of_Age_Conference_Brochure1.pdf)
- 16-19 **28th Annual Las Vegas Seminars (AAP California Chapters 1,2,3,4 & AAP)**
(<http://www.aap-ca.com/meetings/2006/2006%20LV%20brochure%203-31.pdf>)

December 2006

- 2 **AAP California Chapter 1: Advances in Adolescent Medical Care for the Pediatric Practitioner — San Francisco** (<http://www.aapca1.org/Meetings/December%20brochure%20as%20of%207-18-06.pdf>)
- 2 **Lucile Packard Children's Hospital Pediatric Palliative and End of Life Care — Palo Alto** (<http://www.lpch.org/CMECourses/cmePalliativeAndEndOfLifeDec2006.html>)

January 2007

- 23-26 **California Childhood Obesity Conference – Anaheim** (<http://www.labestbabies.org/listserv/attachments/CO%202007%20postcard.pdf>)

(Continued next page)

For more information on CRISS, contact:
Laurie A. Soman
Lucile Packard Children's Hospital
725 Welch Rd. MC5524,
Palo Alto, CA 94304
Phone/fax: 510-540-8293
E-mail: LSoman6708@aol.com

sponse to the implementation of Medi-Cal managed care and the legislative "carve-out" of California Children's Services (CCS) services, but soon expanded its focus to the quality of care for CSHCN in Los Angeles County across systems. The group meets on the second Tuesday of odd months from 1-3 pm at the Center for Healthy Communities, at the California Endowment in Los Angeles. The meetings are open to all interested parties.

The workgroup is currently supported by the Los Angeles Partnership for Special Needs Children (LAPSNC). The mission of LAPSNC is to improve the health and well being of children with special needs in Los Angeles County by improving the systems of care for these children, advocating for clients served by LA County CCS, assisting with the provision of high quality services, advocating for improved systems of care at the county, state and federal levels, serving as a resource for other public and private entities serving CSHCN, and assisting in educating providers and consumers regarding systems of care. Members of LAPSNC include major pediatric hospitals, health plans, LA County Department of Health Services, the local chapter of the American Academy of Pediatrics (AAP) and advocates.

While LAPSNC provides oversight and funding for the CCS Workgroup, LAPSNC activities are carried out by Workgroup members. Joint activities of LAPSNC and the CCS Workgroup have included: 1) the organization of conferences on such topics as mental health services, transition for youth with special needs, and the CCS program; 2) a survey to examine capacity issues in pediatric facilities; and 3) the development of a parent handbook for the local CCS program.



Early Results from the Healthy Kids Evaluation

Started in 2003, the Los Angeles County Healthy Kids program gives universal coverage to children (birth to 18) in families with incomes below 300 percent of the federal poverty level. The early results are promising: children in the program were more likely (92 percent of enrollees) to have an established, usual source of care than those who had just enrolled (75.5 percent); they were also more likely to have a usual source of dental care. Enrollees were slightly (7 percent) more likely to access preventive care than before enrolling in Healthy Kids. Parents involved in the program said they were more confident they could get care for kids if needed without straining their budgets. To view the brief, go to http://www.urban.org/UploadedPDF/311407_healthy_kids.pdf (Connect for Kids Weekly, 7/31/06)

Policy Statement Recommends Developmental Surveillance at Every Well-Child Visit



Identifying Infants and Young Children with Developmental Disorders in the Medical Home: An Algorithm for Developmental Surveillance and Screening provides a strategy to support health professionals in establishing a pattern and practice for addressing developmental concerns in children from birth through age 3.

The American Academy of Pediatrics' policy statement, published in the July 2006 issue of Pediatrics, presents a 10-step algorithm in both text and flowchart formats. Selected steps include eliciting and attending to parents' concerns, maintaining a developmental history, making accurate and informed observations of the child, identifying the presence of risk and protective factors, and documenting the process and findings.

Information about implementing the tool, such as choosing developmental screening tools, incorporating surveillance and screening in the medical home, and screening payment, is also provided. The policy statement concludes with a summary and 15 recommendations for the medical home, policy and advocacy, and research and development. The policy statement, intended for use by pediatric health professionals in making developmental surveillance a component of every preventive care visit, is available at <http://aappolicy.aappublications.org/cgi/content/abstract/pediatrics;118/1/405?etoc>. (MCH Alert 7/14/06)

Calendar of Events (continued)

January 2007 (continued)

- 26–27 **Reflective Supervision and Consultation: Creating the Capacity for Authenticity and Connection** — San Leandro (<http://first5solano.org/home/first5s/home/first5s/MyMedia/Training%204.pdf>)
- 29 **Reflective Supervision & Consultation: Creating the Capacity for Authenticity & Connection** — Los Angeles (for more information, contact Maureen Maki: mmaki@chla.usc.edu)

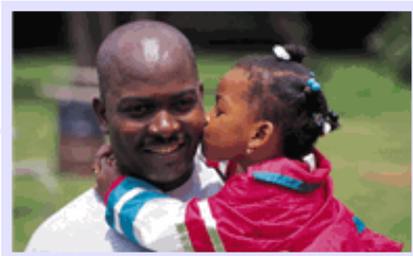
February 2007

- 15 **Coordinating Services for Children with Special Health Care Needs in the Community** — Los Angeles (for more information, contact Laura Schweers: laschweers@chla.usc.edu)
- 26–28 **Special Education Early Childhood Administrators Project (SEECAP) Lessons for Leadership Symposium** — San Jose (<http://www.sdcoe.net/student/eeps/see-cap/?loc=calendar>)

To access the inaugural issue (July 2006) of

CACSHCNEWS,

please visit <http://uscucedd.org>.



Hospital Discharge Questions for Families of Children with Special Health Care Needs

Family Voices of California (FVCA) is part of a national grassroots network of families and friends, seeking to improve the lives of children with special health care needs through information and education provided to families, professionals, policymakers, and communities at large. The FVCA Council is made up agencies from across the state representing urban, suburban and rural areas in 36 counties.

The Parent Health Liaison (PHL) network, a project of FVCA, is a statewide network of Family Resource Center staff providing PHL services in their local communities. More than 25 parent health liaisons statewide participate in monthly conference calls to track emerging issues important to families, identify information and training needs of PHLs, develop best practices, and exchange information and resources.

The development of "Hospital Discharge Questions for Families of Children with Special Health Care Needs" was a collaborative effort between the FVCA Council and the PHL network responding to the information needs of families as they prepare to care for their child in the home. The questions were designed by families of children with special needs and reflect information that they wish they had received or did receive but did not fully understand upon leaving the hospital. The "Discharge Questions" tool will also include information about services and supports offered by the local Family Resource Center (FRC) as well as contact information.

Families are encouraged to use the questions as a guide or prompt to obtain important information from providers and to ensure that they understand this information before they leave the hospital. There are a total of 41 questions divided into 5 categories (see below). There is also a medication chart to assist families in tracking their child's medications with space for listing the dosage, when to administer, side effects, impact on

their child, etc. The following is a sample of questions:

1. Medical Care:

- Will you go over my child's condition with me, and help me understand the medical terms?
- Which doctor is in charge of my child?

2. Medications:

- Will my child need special medications when we leave the hospital?

3. Equipment & Supplies:

- Will my child need special equipment when we get home?
- Who will deliver the equipment?

4. Insurance:

- My child required care and services in the hospital that we had not planned for.
- Will my insurance cover all these services?

5. Respite & Transportation:

- Will you help me find respite care?

If you have any questions or would like a copy of the "Discharge Questions" form please contact Linda Vossler-Swan at lswan@supportforfamilies.org.

Announcements

FVCA KASA Youth Advisory Council

Family Voices of California KASA (Kids As Self Advocates) is committed to changing the way that transition services are delivered to youth to provide a more comprehensive, effective and efficient system. With that goal, we are creating a 12 member Youth Advisory Council to gather information and ideas from young people with disabilities throughout California (ages 14-24) and to enable them to act as a sounding board for possible changes. We think it is important that youth have a voice in the way the system operates.

We hope to create a Council that reflects the diversity of California's youth in age, gender, disability, ethnicity and geographic location. It is our hope that these young people will reflect both their own opinions and those of their peers. The council will meet monthly by telephone conference call and 4 times a year in face to face meetings in either Sacramento or the SF Bay area. All travel expenses will be reimbursed and a stipend of \$50.00 per meeting will be paid.

We are looking for a dozen young people who want to participate in this exciting opportunity to make a change in the systems that affect them. For more information or to refer a youth, please contact Judith Lesner, Youth Coordinator at MAVENno1@aol.com.

Using Early Identification and Intervention to Reduce Health Disparities in Los Angeles County

The Los Angeles County Early Identification and Intervention Group (EII Group) aims to improve the lives of children and families through early identification and intervention of disabilities, developmental delays or other problems. Its goal is to work with its partners to assure that every child in Los Angeles County gets developmental screenings early, often and with a high-quality screening tool; and any child needing help receives it at the earliest possible moment. The EII Group does this by educating its participants, policymakers, parents, practitioners and others; and developing, identifying, advocating and implementing effective and culturally competent policies, practices and strategies.

Recipient of the
**Dale Richmond
Award**
American Academy of
Pediatrics

Begun just three years ago at an informal lunch, the EII Group has evolved into a large, diverse coalition that includes local public agencies practitioners, advocates, and academics. Through frequent emails and personal contact, it also informs and engages partners across the state and nationwide.

Successes

The successes of the EII Group have also been substantial, and include the following:

- Improving policy to create sustainable improvements
- Being a catalyst to improve local practice
- Pursuing promising innovations
- Expanding the knowledge base
- Building will and skill
- Getting the word out through articles and publications — *Recognizing the importance of the EII Group, LA County Children's Medical Services, under the leadership of Shavonda Webber-Christmas, submitted a summary of this work to the National Association of County and City Health Officials for inclusion in an upcoming publication addressing ways in which local health departments are working to reduce health disparities.*

For more information, contact:

Shavonda Webber-Christmas
Children's Medical Services
LA County Dept. of Public Health
9320 Telstar Avenue, Ste. 226
El Monte, CA 91731
Phone: 626-569-6001
E-mail: schristmas@ladhs.org

Margaret Dunkle
LA County Early Identification & Intervention Group
2195 Beverly Glen Place
Los Angeles, CA 90077
Phone: 310-441-2345
E-mail: MargaretDunkle@aol.com

Report Calls for Sustained Multi-Dimensional Efforts to Reduce Health Disparities Among Children

Improving Children's Health: Understanding Children's Health Disparities and Promising Approaches to Address Them identifies policies and practices that can advance the health of all children by reducing health disparities. Produced by the Children's Defense Fund, the report begins with an overview of health disparities and selected determinants of health outcomes. The report then documents disparities in outcomes across several major conditions affecting children, provides an analysis of indicators related to children's health, and explores community strategies that have been effective in reducing disparities in many health-related conditions. The report concludes with recommendations for broader policies and initiatives to eliminate health disparities for children, focusing on the role that prevention and expanded access to health care for all children can play in improving health outcomes. The report is available at http://www.childrensdefense.org/site/DocServer/CDF_Improving_Children_s_Health_FINAL.pdf?docID=1781. (MCH Alert, 6/26/06).



Public Financing of Home and Community Services for Children and Youth with Serious Emotional Disturbances: Selected State Strategies

Parents often struggle to find and afford appropriate care for children who are diagnosed with severe emotional disturbances – some are even forced to give up custody of children in order to get them the treatment they need. As states work to improve home- and community-based mental health services for these children, it's no surprise that funding is an issue. This report from Mathematica Policy Research looks at effective strategies, including agency partnerships and several specific Medicaid waivers. For more information, go to <http://www.mathematica-mpr.com/publications/pdfs/pubfinhome.pdf>. (Connect for Kids Weekly, 8/7/06)

CCS Numbered Letters and Information Notices

CCS Numbered Letter 10-0806 : **AUTHORIZATION OF EMERGENCY SERVICES RELATED TO TRAUMA**

- Addresses patients with trauma admitted to non-CCS approved hospital or treated in Emergency Department and follow-up services
- Addresses coordination with Medi-Cal Managed Care or Healthy Families plans

<http://www.dhs.ca.gov/pcfh/cms/onlinearchive/ccsnl.htm>

CMS Information Notice 06-05 : **THE NEWBORN HEARING SCREENING PROGRAM (NHSP) ALTERNATIVE NEONATAL INTENSIVE CARE UNIT (NICU) PROTOCOL**

Due to shortage of audiology providers, this protocol permits the re-screening of NICU infants who do not pass the initial screening rather than require a complete audiology diagnostic evaluation. Where implemented, this protocol will decrease the number of requests for diagnostic evaluations, shorten the length of time for diagnostic appointments, and therefore reduce the demand for audiology services.

<http://www.dhs.ca.gov/pcfh/cms/onlinearchive/cmsin.htm>



One-e-APP : One Stop Access to Health Care

One-e-App is a Web-based system for connecting families with a range of publicly funded health and social service programs. It is currently used in five counties (Alameda, Fresno, San Mateo, Santa Clara, and Santa Cruz) to screen and electronically route applications for programs such as Medi-Cal, Healthy Families, Healthy Kids and county indigent care. One-e-App offers counties the flexibility to choose which programs they would like to include, and each of the counties has taken a different approach to implementation. Los Angeles County and San Joaquin County are in the process of implementing One-e-App. For more information about One-e-App and The Center to Promote HealthCare Access, visit www.oneeapp.org.

Good News from the State: Child Health Bills Signed by the Governor

AB 2379 — by Assemblymember Wilma Chan (D-Oakland): This legislation extends until 2012 the existing carve-out of CCS services from most Medi-Cal managed care plans. The carve-out extension ensures that for the next six years children who are Medi-Cal managed care enrollees and have complex medical needs will continue to be treated through the California Children's Services network of specialty/subspecialty providers and special care centers.



AB 1745 — by Assemblymember Wilma Chan (D-Oakland): This legislation requires the California Department of Health Services to develop, implement and evaluate a pilot project waiver to provide a pediatric palliative care benefit under Medi-Cal, including those services that are available through the existing Medi-Cal hospice benefit. This bill will help children live longer and have a better quality of life during treatment by having the Department of Health Services seek a federal waiver to allow children receiving hospice services to also continue to receive curative treatments.

AB 2651 — by Assemblymember Dave Jones (D-Sacramento): This bill requires acute care hospitals to participate in the California Newborn Hearing Screening Program and to administer a hearing screening test to all newborns. The bill will increase the number of newborns and infants who receive hearing screenings either at birth or shortly thereafter and will identify hearing loss in infants as early as possible.



LAO Ballot Measure Analyses for Public Display

The Legislative Analyst's Office's (LAO) analyses of measures included in the November 7, 2006 special election are available at the following link: http://www.lao.ca.gov/ballot_source/Propositions.aspx. For the public display of the full voter information guide, go to the Secretary of State's website (http://www.ss.ca.gov/elections/elections_vig_publicdisplay.htm).



**November 7th
ELECTION**

Answers Being Found to Help Children and Families Living with Epilepsy

In the United States, approximately 300,000 children under the age of 18 have epilepsy and an estimated 50,000 new cases are diagnosed every year. "Children living with epilepsy must deal with the fear of having a seizure, the loss of self control during the seizure episode, and oftentimes stigma and misperceptions among their peers, neighbors, teachers and other important adults in their world," says Tony Coelho, Chair of the Epilepsy Foundation, and former U.S. Congressman. "I know how challenging living with epilepsy can be for a child or adolescent because I grew up living with epilepsy," concludes Coelho.

Many children with epilepsy do not have access to quality healthcare and may not be receiving the care and support they and their families need. Most, with the proper medication, treatment and support, can have their seizures controlled and lead near-normal lives, participating in all traditional life experiences.

Delivering on that promise is the goal of an emerging national initiative, *Project Access: Improving Care for Children with Epilepsy*. Under the initiative, eight States, including California through the USC University Center for Excellence in Developmental Disabilities at Childrens Hospital Los Angeles, have been selected to identify new and better answers to delivering needed healthcare and related services to children and families living with the condition. Funded by the Maternal and Child Health Bureau, a component of the Health Resources and Services Administration (HRSA) of the U.S. Department of Health and Human Services, these demonstration programs are delivering on a Congressional directive to demonstrate how we can improve healthcare services and access to care for all children with special health care needs, including epilepsy. The Epilepsy Foundation and the National Initiative for Children's Healthcare Quality (NICHQ) are working with HRSA to support each site's education, advocacy and service efforts.

Program elements being tested across the eight sites include providing timely access to epilepsy specialists; screening children on a regular basis for special healthcare needs; organizing and raising awareness of community services and resources to better assist families in need; and demonstrating how best to coordinate and integrate the healthcare and related services that may be required. In each site, there also is a special emphasis on making sure that children and their families are partners in the decision-making about the healthcare and social supports they require. The eight demonstration sites are California, Illinois, Mississippi, Oregon, West Virginia, Wisconsin, the District of Columbia, and New Jersey.

Partners collaborating with the California site:

- Parents Helping Parents
- Partnership HealthPlan of California

California Team — NICHQ Epilepsy Learning Collaborative



Clockwise from top left: Bill Stack¹, Neva Hirschhorn¹, Tara Dilliplaine², Kristie Freeman³, Laura Schweers⁴, Maria Tupas³, Cary Kreutzer⁴, Kathie McCall⁴

- 1 Epilepsy Foundation of Northern California
- 2 Parent Expert
- 3 Children's Hospital Orange County
- 4 USC UCEDD at Childrens Hospital Los Angeles

- Alameda County Committee on Children with Special Needs
- Rowell Family Empowerment Center of Northern California
- Southern California Regional Office, California Children's Services Medical Branch
- Children's Hospital Orange County (Epilepsy Center and Primary Care Clinics)
- UCLA Mattel Children's Hospital Epilepsy Program
- California Epilepsy Foundation Affiliates (Greater Los Angeles, Northern California, and San Diego)
- Epilepsy Alliance of Orange County

For more information about Project Access, contact Lynda Honberg, Project Director, Epilepsy Initiative; Integrated Services Branch Division of Services for Children with Special Healthcare Needs at 301-443-6314 or visit <http://mchb.hrsa.gov/>.

For more information about the California demonstration program, contact Cary Kreutzer, Project Director, at ckreutzer@chla.usc.edu / 323-671-3830.

For more information about epilepsy and the resources available to help individuals and families living with the condition, contact Neva Hirschhorn at nevah@epilepsynorcal.org / 800-632-3532.



E P I L E P S Y

Awareness Month

— NOVEMBER —

CCS High Risk Infant Follow-up Program

California Children's Services (CCS) High Risk Infant Follow-up (HRIF) Program has been in place since the 1970's. The program serves infants discharged from a CCS approved neonatal intensive care unit (NICU) in order to determine if they might develop a CCS eligible medical condition. Over the years, the program has undergone changes that have allowed more children to receive these services with the most recent changes instituted on July 1, 2006. Each CCS-approved NICU is required to either have its own HRIF program or have a written agreement with another CCS approved NICU to provide the services.

Infants are eligible for HRIF services on discharge from a CCS approved NICU if they:

- Met CCS medical eligibility criteria for NICU care
-OR-
- Had a CCS eligible medical condition while in the NICU and a birthweight less than 1500 grams or a gestational age less than 32 weeks
-OR-
- Had a CCS eligible medical condition while in the NICU with a birthweight greater than 1500 grams and a gestational age greater than 32 weeks
-AND-
- Met an additional high-risk criterion including:
cardiorespiratory depression at birth; prolonged hypoxia; acidemia; hypoglycemia or hypotension requiring pressor support; persistent apnea requiring medication at discharge; chronic lung disease; receipt of extracorporeal membrane oxygenation (ECMO); receipt of inhaled nitric oxide greater than four hours for persistent pulmonary hypertension of the newborn; documented seizures; intracranial pathology; or other problems that could produce neurologic sequelae.

Infants must have established medical eligibility as described above. Although there is no financial eligibility requirement for participation in the program, families are requested to provide insurance information as CCS is the payor of last resort. Parents or legal guardians of the baby must demonstrate that they are residents of the county in which they are applying for services.

Infants are eligible for the HRIF Program from the time of NICU discharge until 36 months of age. The basic services are usually provided at approximately four to six months of age, nine to 12 months of age, and 18 to 36 months of age, unless it is determined earlier that services are no longer needed. In some situations, additional services may be recommended.

The basic services include a comprehensive history and physical examination and a developmental assess-

ment. A family psychosocial assessment is performed a minimum of one time during this period. Ophthalmology assessments are performed by a CCS approved ophthalmologist until the infant is determined no longer to be at risk for developing retinopathy of prematurity. Hearing assessments are done for infants who were not screened prior to discharge, who did not pass the inpatient hearing screen, or did pass the newborn hearing screen but are at risk for developing a progressive or late-onset hearing loss. Home assessments, through a home health agency, may be provided for infants to evaluate the family for specific needs.

Each HRIF Program has an identified coordinator who is the primary person responsible for coordinating services with county CCS programs, other HRIF programs, clients, families, specialists, primary care providers, and others related to the HRIF services. HRIF services are provided by a multidisciplinary team that may include a pediatrician, neonatologist, or pediatric nurse practitioner, nurse specialist, physical therapist, occupational therapist, psychologist, and/or social worker. After each evaluation, a summary report is prepared by the team and sent to the local CCS office and to other providers as appropriate. In addition, a data collection form has been developed for submission to the State of California Children's Medical Services Branch. A full description of program, including program policy, may be viewed at the program's website: www.dhs.ca.gov/cms/hrif.



Report Investigates Problems and Solutions in Public Health Insurance Coverage for Children and Families

Instability of Public Health Insurance Coverage for Children and Their Families: Causes, Consequences, and Remedies examines the problem of coverage instability within public health insurance programs and looks at strategies that can make coverage more stable for children and families. The report, published by the Commonwealth Fund, draws from findings from a variety of sources, including an in-depth examination of the experiences of four states (LA, RI, VA, and WA) in averting coverage instability by adopting key policies and procedures. In particular, the report focuses on the phenomenon of "churning," which occurs when individuals lose and regain coverage within a short period of time. Intended for use by state and local agencies in maintaining or improving participation rates among eligible children and families, the report is available at http://www.cmf.org/usr_doc/Summer_instabilitypubhltinschildren_935.pdf. (MCH Alert, 6/30/06)

Improving Care Coordination for Young Children in Multiple Systems: CRISS Convenes a Regional Meeting of Agencies Serving Young Children

This past March CRISS convened a regional meeting of agencies serving children from birth to age 5 in the 14-county CRISS region in order to discuss ways to improve care coordination for children involved in multiple service systems. CRISS envisioned the meeting as an opportunity to bring together the CRISS constituencies (families, CCS, and providers) and other agencies that serve young children with special needs — county children's mental health, Regional Centers, and county office of education infant coordinators — for the purpose of identifying ways to improve care coordination and reduce systems barriers among the major service systems for these children. The target outcomes for the meeting were identification of top priorities that the group can realistically address to improve coordination.

Attendees included thirty representatives of CCS, families, provider groups, regional centers, county mental health children's services coordinators, and county Office of Education infant coordinators. Rocio De Mateo Smith, Executive Director of Developmental Disabilities Area Board V, facilitated the meeting. A parent panel, lead by Juno Duenas of Family Voices of California/ Support for Families of Children with Disabilities, and Mouna Raad of Parents Helping Parents, addressed barriers and successes in coordinating care among multiple service systems for young children. CRISS staff presented a summary of the different service systems used by many children with special health care needs and how they do or don't interface and introduced Medical Home Project materials in use in several CRISS counties. Finally, group discussion identified priority areas that attendees agreed require attention.

Top Priorities to Address:

- Implement paid, comprehensive care coordination, through funded staff and/or provider reimbursement
- Address language barriers by assisting families with no or limited English and families who don't know what or how to ask (e.g., lack of familiarity with agency jargon, programs, and eligibility requirements)

(Continued next page)

Resources

NCWD Releases New Mentoring Guide

Mentoring is recognized as one of the most important strategies for assisting youth in making a positive transition into adulthood. Despite all of the information available on mentoring, very little information exists about mentoring youth with disabilities or about career-focused mentoring of older youth. *Paving the Way to Work: A Guide to Career-Focused Mentoring for Youth with Disabilities* has been developed by the NCWD/Youth to specifically address the needs of youth with disabilities during their transition from school to work. The guide can be found at http://www.ncwd-youth.info/resources_&Publications/mentoring.html.

CRISS Promotes Medical Homes for Children with Special Needs

One of the CRISS goals for the Maternal and Child Health Bureau "Integrated Systems of Care" project is to promote medical homes throughout the CRISS region through several strategies including distribution of medical home materials. The materials currently available from CRISS include:

- Child Health Notebook, a vehicle for organizing and sharing children's health and other records available in both English and Spanish;
- Multi-Agency Spreadsheet, a quick guide to the major programs serving children with special health care needs; and
- Medical Home Binder, with comprehensive information on programs serving children with special health care needs.

We are working on customizing two other tools for each of the CRISS counties:

- Quick-reference guide to commonly used community resources for providers and agencies;
- Resource referral pad with commonly used agency names and contact information to be given to families to assist them with referrals.

The Child Health Notebook, Multi-Agency Spreadsheet and sample Medical Home Binder are available from Laurie Soman, CRISS Project Director, at 510-540-8293 or LSoman6708@aol.com. The quick-reference guide and resource referral pads will be available this fall.

KIDS COUNT 2006 Data Book

Data from the Annie E. Casey Foundation's 2006 KIDS COUNT Data Book are now available in the online database, "State Level Data Online", that allows users to generate custom graphs, maps, ranked lists, and state-by-state profiles — or — to download the entire data set as delimited text files. Pull-down menus also allow for reading online or viewing in PDF format. Go to <http://www.aecf.org/kidscount/sld/databook.jsp>.



(Continued next page)

(Continued – Improving Care Coordination)

- Improve customer service through family support organization trainings for agency staff (including addressing intake and reception)

CRISS is collecting information on paid care coordination in addition to researching methods that other states have implemented to fund care coordination. A brief report to inform potential options for California will be presented during the next regional meeting which will convene in the fall of 2006. For more information on the multi-agency regional meetings, contact Laurie Soman, CRISS Project Director, at 510-540-8293 or LSoman6708@aol.com.



Brief Explores EPSDT'S Role in Early Childhood Comprehensive Systems

Maximizing the Use of EPSDT to Improve the Health and Development of Young Children reviews research about Medicaid; the Early and Periodic Screening, Diagnosis and Treatment (EPSDT) program; and young children and the role of EPSDT in Early Childhood Comprehensive Systems (ECCS).

The brief, published by the National Center for Children in Poverty, examines the role of EPSDT in financing early childhood services such as newborn screening, early intervention, home visiting, and early childhood mental health treatment and how ECCS leaders across the country are working to ensure access to health care and a medical home for all young children. State EPSDT performance rates and inter-agency collaborative efforts to improve EPSDT performance in the context of ECCS are discussed. Tips for states and federal guidance for the EPSDT child health benefit under Medicaid are also presented. The brief is intended for use by ECCS leaders and partner stakeholders in improving the health outcomes of young children from families with low incomes. The brief is available at <http://nccp.org/media/tst06b.pdf>. (MCH Alert, 6/30/06)

Resources (continued)

Children's Health Insurance Programs: Facts and Figures

Since 2000, the number of children enrolled in California's public insurance programs has increased by nearly 43 percent, to more than 4.3 million children. Despite this progress, 800,000 children still lack coverage. A new California HealthCare Foundation publication featuring facts, figures and trends, provides an overview of California's public and private children's health insurance programs, and where they may be headed. Available online at <http://www.chcf.org/topics/view.cfm?itemID=122730>.

New AHRQ Asthma Care Resource Guide Offers Help to States

AHRQ, in partnership with The Council of State Governments, released *Asthma Care Quality Improvement: A Resource Guide for State Action* and its companion *Workbook*, both of which are designed to help state leaders identify measures of asthma care quality, assemble data on asthma care, assess areas of care most in need of improvement, learn what other states have done to improve asthma care, and develop a plan for improving the quality of care for their states. This new Resource Guide uses data from AHRQ's National Healthcare Quality Report and National Healthcare Disparities Report and Web-based State Snapshots to help inform the nation and states, respectively, about the quality of asthma care. The Guide and its companion Workbook can be found online at <http://www.ahrq.gov/qual/asthmaqual.htm>. Printed copies are available by calling the AHRQ Publications Clearinghouse at 1-800-358-9295 or by sending an e-mail to ahrqpubs@ahrq.gov. (AHRQ's Child and Adolescent Health ListServR - Volume 8, Number 19, 7/11/06)

"Covering Kids and Families" Launched

With the release of *The State of Kids' [covering kids & families](http://www.coveringkidsandfamilies.org)* Coverage, the Robert Wood Johnson Foundation kicked off its *Covering Kids and Family* annual initiative. The study finds that while the overall number of uninsured Americans is rising, the number of uninsured children has dropped since 1997, thanks to Medicaid expansions and the creation of the state Children's Health Insurance Program (SCHIP). Even as the share of kids with private insurance dropped in nearly every state during this period, at least 5 million more children benefited from public health care coverage. Yet some 8.3 million kids remain uninsured – far too many to consider it a job well done. Parents can call toll-free 1 (877) KIDS-NOW to find out if their uninsured children are eligible for Medicaid or SCHIP. For more information about this initiative, go to <http://coveringkidsandfamilies.org>. (Connect for Kids Weekly 8/14/06)

Article Examines Parental English Proficiency and Children's Health Services Access

"We found that, in California, children of parents who do not speak English very well are more likely to lack health insurance and more likely to go to other countries for health care," state the authors of an article published in the August 2006 issue of the American Journal of Public Health. Several studies have found that individuals in the general population with limited English proficiency face barriers to accessing and receiving health care. The article examines the association between parents' level of English proficiency and their child's access to health care.

Data for the study were drawn from the 2001 California Health Interview Survey, a random-digit-dialed telephone survey of adults, adolescents, and children conducted in English, Spanish, Chinese, Vietnamese, Korean, and Khmer. If a respondent selected English as the language spoken at home, the person was classified as an English speaker at home. Those not speaking English at home were asked whether they spoke English very well, fairly well, or not well. If the interview was conducted in a language other than English, respondents were asked if they spoke English very well, well, not well, or not at all. Measures of health care access included type of health insurance, usual source of care, contact with the doctor, emergency room visits, delaying or forgoing care, traveling to another country for health care or prescription drugs, and discrimination in health care. Covariates included child's age, gender, citizenship status, area of residence, and medical insurance; parent education; and family income level. Researchers examined data on the demographics of children (N=12,797) and the prevalence of selected access characteristics by the English proficiency of the responding parent. Researchers also examined the independent effects of English proficiency on health care access, while controlling for confounding variables.

The authors found that, compared with children from households in which the respondent was classified as an English speaker at home:

- Children of parents who spoke English not well or not at all were significantly more likely to lack health insurance.
- Children from households in which English was not the language spoken at home were less likely to visit the emergency room within the past 12 months and less likely to report having delayed or forgone care.
- Children from households in which English was not the language spoken at home were more likely to have gone to other countries for health care and prescription medications.
- Children from households in which the parents spoke English not well or not at all were less

likely to have parents who reported being discriminated against in health care.

"We found that, in California, children of parents who do not speak English very well are no more likely than other children to lack a usual source of care or to not have seen a doctor within the past 12 months," state the authors. They conclude that "further research on access to care among immigrant families and the role of health services received outside the United States is needed." (MCH Alert 8/18/06)

Yu S, Huang J, Schwalberg RH, et al. 2006. Parental English proficiency and children's health services access. American Journal of Public Health 96(8):1449-1455. Abstract available at <http://www.ajph.org/cgi/content/abstract/AJPH.2005.069500v1?ct>.

Article Assesses Satisfaction with Primary Health Care of Families of Children with Developmental Disabilities



"Evaluation of the satisfaction levels expressed by families imparts important information that may be used to enhance the way care is provided to families and children," write the authors of an article published in the July 2006 issue of the Journal of Pediatric Health Care. Children with special health care needs (CSHCN) have complex medical needs. Patient satisfaction is an important measure of quality of care. The purpose of the study described in this article was to evaluate the perceptions of families with a child with special health care needs regarding their primary care physicians and to determine whether differences exist for families who have children with different conditions.

The survey sample included children who were currently receiving services at the Kirsch Developmental Services Center, Golisano Children's Hospital, University of Rochester Medical Center. This program provides care to children who have physical disabilities such as spina bifida and cerebral palsy, as well as developmental disabilities such as autism and mental retardation. Surveys were mailed to 300 families. A total of 121 surveys were returned for a corrected return rate of 44%. The authors found that:

- Thirty-three percent of the sample rated primary care physicians' ability to put them in touch with other parents as fair or poor.
- More than 20% of the sample rated physicians as fair or poor on the following items: (1) understanding the impact of the child's condition on the family, (2) ability to answer questions about the child's condition, and (3) information and guidance for prevention.
- Physicians' knowledge about complementary

and alternative medicine and their qualification to manage developmental disabilities ranked worse than neutral.

- Families rated physicians highest on their ability to keep up with medical skills and knowledge of new things and about their caring more about the needs of children than about what is convenient for the physicians.
- Families with a child with autism rated physicians' ability to answer their questions regarding their child's condition worse than families with a child with physical disabilities or mental retardation. Families with a child with autism also rated physicians worse on their ability to understand how the child's condition affects the family.
- Families with a child with autism were more likely than families with a child with physical disabilities or mental retardation to disagree with the statement that most doctors are well qualified to manage medical conditions like their child's. Families with a child with autism also rated physicians worse on their knowledge of complementary and alternative medicine.

The authors conclude that "concerns identified by families may be addressed by care practitioners. Particular attention may be given to those variables, some disability-specific, that affect quality of care." (MCH Alert, 7/21/06)

Liptak GS, Orlando M, Yingling JT, et al. 2006. Satisfaction with primary health care received by families of children with developmental disabilities. *Journal of Pediatric Health Care* 20(4):245-252. Abstract available at http://www.ipedhc.org/article/PIIS0891524505004980/abstract?browse_volume=20&issue_key=TOC%40%40JOURNALS%40YJPHC%400020%

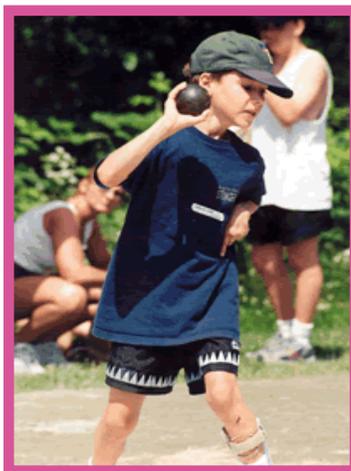


IDEA Part B Regulations Released

On August 3, 2006, the U.S. Department of Education announced the final Part B regulations (<http://www.ed.gov/policy/speced/guid/idea/idea2004.html#law>) to implement the *Individuals with Disabilities Education Improvement Act of 2004 (IDEA)*. On August 14, 2006, the official copy of the final Part B regulations of the *IDEA* was published in the *Federal Register*. Part B covers education programs for children with disabilities and preschool grants. The rules, among other things, clarify the definition of a child with a disability, add Tourette Syndrome to the list of "other health impairments" and further define highly qualified special education teachers.

UN Agreement Reached on New Convention on Disability Rights

After five years of negotiations, countries have agreed on a new convention to protect the rights of persons with disabilities. This is the first convention of this magnitude for this century, United Nations General Assembly President Jan Eliasson said after the agreement was reached. He told the negotiators that they were sending an absolutely wonderful message to the world. "You are sending the message that we want to have a life with dignity for all and that all human beings are all equal."



This marks a great day for the UN and for persons with disabilities,

said New Zealand's Ambassador Don MacKay, who chaired the negotiations through its final sessions. Its a good convention and it will make a difference for millions of people.

The successful completion of the treaty, after a day of intense negotiations and compromises, was met with thunderous applause by well over a hundred government delegations and hundreds of representatives of disability organizations who participated in the process of negotiating the 40-article treaty.

Proponents of the convention maintained that the treaty was necessary because persons with disabilities represented one of the most marginalized groups and that their rights had been routinely ignored or denied throughout much of the world. While the convention does not create new rights, it specifically prohibits discrimination against persons with disabilities in all areas of life, including civil rights, access to justice and the right to education, health services and access to transportation.



The convention was largely approved by consensus, although there was a vote on a provision concerning foreign occupation that was included in the preamble. With five countries voting against, the provision was adopted. It will be formally sent to the General Assembly for adoption at its 61st session that began in September, after which it will be open for signing and ratification by Member States. It is estimated that 10 per cent of the world's population, or about 650 million people, have disabilities. For more international news issues, see www.aapd.com/News/international/060923ncd.htm. (TATRA Center, 8/30/06)

