



# CACSHCN NEWS

## Two Studies Focus on Parents of CSHCN in the Work Place

- Family Leave Use by Parents of CSHCN
- Understanding the Needs of Workers with CSHCN

### **Need For and Use of Family Leave Among Parents of CSHCN**

Parents of children with special health care needs are especially vulnerable to work-family conflicts that family leave benefits might help resolve. In this study, published in the May issue of *Pediatrics*, researchers find that many full-time working parents of kids with special health care needs say they need more leave than they are currently offered. To access the full article, go to <http://pediatrics.aappublications.org/cgi/content/full/119/5/e1047>.

(Connect for Kids Weekly, 6/20/07)

### **Benefits For Employees With Children With Special Needs: Findings From The Collaborative Employee Benefit Study**

"Despite the relatively high prevalence of disabilities among children of working Americans, employers in our study had little awareness of the scope or potential impact of this population on their employees' workplace participation," write the authors of an article published in the July/August 2007 issue of *Health Affairs*. The prevalence of special health care needs among children of working parents is approximately 9% of a typical U.S. workforce. Parents of children with chronic health conditions experience greater financial hardship, reduced employment, poorer mental health, and increased stress compared to parents without such children. The authors explored how employers and employees understand the needs of workers with children with special health care needs. Specifically, the authors asked the following questions:

- 1) How do employers view the needs of employees caring for children with special

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CACSHCN NEWS 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



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

To receive CACSHCN NEWS, please send an email message to [ycaillas@chla.usc.edu](mailto:ycaillas@chla.usc.edu) with "CACSHCN NEWS" in the subject line.

**Next Issue Date:**  
**January 2007**

- health care needs?
- 2] How do current benefit structures help these employees?
  - 3] How do employees themselves view their needs as they strive to manage a child's health needs while meeting job demands?
  - 4] What opportunities do employers and employees see for improving and maximizing the usefulness of benefits for families of children with special health care needs?

The authors conducted a qualitative study of employers as well as parent focus groups in four U.S. urban markets: Boston, Cleveland, Miami, and Seattle. Authors interviewed 41 employers and conducted five focus groups between November 2003 and June 2004. Focus groups included 6-20 parents.

Authors' findings:

- Most companies that provide high-quality benefits do so because they think that it is the right thing to do, and it makes good business sense.
- In all but one company, issues related to children with chronic conditions were addressed case by case or when specific needs arose. Only one company had a specific program for children with special health care needs.
- Although employers expressed little enthusiasm for considering health-insurance-benefits enhancements, most identified other benefit opportunities that could aid employees with children with special health care needs: flexible spending accounts, leave policies, employee-assistance programs, and work-life programs.
- Parents indicated that they were reticent about disclosing family circumstances to their employers for fear of loss of their jobs, being bypassed for promotions or career opportunities or being perceived as "problem" employees.
- Employers repeatedly stressed the potential to increase the value of certain benefit programs without requiring major investment of additional company resources.

The authors conclude that the findings "indicate that an interesting opportunity exists for the health community to interact with employers to improve workplace conditions and supports and thereby improve family health and well-being."

(MCH Alert, 7/27/07)



Perrin JM, Fluet CF, Honberg L, et al. 2007. Benefits for employees with children with special needs: Findings from the Collaborative Employee Benefit Study. *Health Affairs* 26(4):1096-1103. Abstract available at <http://content.healthaffairs.org/cgi/content/abstract/26/4/1096?etoc>.

## Calendar of Events

### October 2007

- 26 **Special Start Training Program: Providing Developmentally Supportive Care at Home after the NICU — Camarillo** ([http://www.mills.edu/special\\_start/calendar.html](http://www.mills.edu/special_start/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/>)
- 29-31 **March of Dimes of California Second National Summit on Preconception Health and Health Care — Oakland** ([http://www.marchofdimes.com/california/4947\\_25340.asp](http://www.marchofdimes.com/california/4947_25340.asp))
- 30 **Project ABC Child-Parent Psychotherapy — Los Angeles** (for information, contact Maureen Maki: [mmaki@chla.usc.edu](mailto:mmaki@chla.usc.edu))
- 31 **Cultural Diversity Issues in Pediatric Health Care — Wilmington, DE** (<http://www.pedseducation.org/conferences/Diversity/overview.html>)



### November 2007

- 1 **Assisting Mothers to Successful Baby Led Latching — Los Angeles** (<http://www.breastfeedingtaskforla.org/seminars/110107.pdf>)
- 2 **AAIDD Region II Conference: Lost in the System? Transition from School to Adult Life – Los Angeles** (for information, contact Dawn Marie: 714-957-5046)
- 2 **CRISS Annual Conference: Hot Topics arising in the Medical Therapy Program – Oakland** (for information, contact Mara McGrath: [mkmcgrath1254@aol.com](mailto:mkmcgrath1254@aol.com))
- 2–4 **Epilepsy Brain Storm Summit — Los Angeles** (for information, call 800-564-0445)
- 3 **Spina Bifida Conference “Building Bridges Together” — Los Angeles** (for information, contact Carrie Ward: 323-361-7079)
- 3–7 **American Public Health Association 135<sup>th</sup> Annual Meeting & Exposition — Washington, DC** (<http://www.apha.org/meetings>)
- 5 **Pediatric Feeding Assessment and Intervention: Strategies for Young Children — Yorba Linda** ([http://www.idaofcal.org/Images/Pediatric\\_Feeding.pdf](http://www.idaofcal.org/Images/Pediatric_Feeding.pdf))
- 7–10 **19<sup>th</sup> Annual CHADD International Conference — Crystal City, VA** ([http://www.chadd.org/Content/CHADD/Conferences\\_Training/2007\\_Conference/default.htm](http://www.chadd.org/Content/CHADD/Conferences_Training/2007_Conference/default.htm))
- 8–9 **Chronic Illness and Disability: Transition from Pediatric to Adult-Based Care — Houston** ([http://www.baylorcme.org/pdfs/Chronic\\_Illness\\_and\\_Disability\\_Save\\_the\\_Date\\_revised.pdf](http://www.baylorcme.org/pdfs/Chronic_Illness_and_Disability_Save_the_Date_revised.pdf))



## Hablamos Juntos Develops Models for Language Access

Hablamos Juntos (Spanish for "We Speak Together") is a project funded by the Robert Wood Johnson Foundation and administered by UCSF Fresno Center for Medical Education & Research for the purpose of developing affordable models for language access. The ten demonstration sites funded under Hablamos Juntos include health plans, hospital systems, nonprofit community organizations, and educational institutions. To learn more visit: <http://www.hablamosjuntos.org>.

The report *Developing Better Non-English Materials: Understanding the Limits of Translation* shares lessons learned regarding barriers faced by health care organizations in producing useful translated text and in evaluating those products for quality. The report is available at: [http://www.hablamosjuntos.org/resource\\_guide\\_portal/pdf/Brief-NonEngl-Final.pdf](http://www.hablamosjuntos.org/resource_guide_portal/pdf/Brief-NonEngl-Final.pdf).  
(*Champions for Inclusive Communities eNewsletter*, 6/19/07)



## JAMA Theme Issue Focuses on Chronic Diseases of Children

The June 27, 2007, issue of *JAMA, The Journal of the American Medical Association*, contains original contributions, reviews, commentaries, editorials, and medical news perspectives focused on chronic diseases of children. The issue includes findings from a randomized trial of pediatric weight management to compare an intensive family-based program involving supervised exercise, nutrition education, and behavior modification with traditional semi-annual clinical weight-management counseling. Other topics addressed in this issue include health outcomes in long-term cancer survivors, diabetes in youth, place of death among children, changes in the prevalence of cerebral palsy, and defining chronic health conditions in childhood. The theme issue is available to journal subscribers at <http://jama.ama-assn.org/content/vol297/issue24/index.dtl?etoc>.  
(*MCH Alert*, 7/20/07)



## New Edition of *Child Health USA* Released

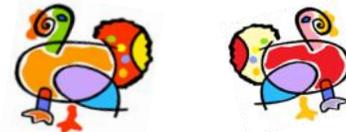
*Child Health USA 2006* reports on the health status and service needs for the target population of Title V funding: infants, children, adolescents, children with special health care needs, and women of childbearing age. The book, published by the Health Resources and Services Administration's Maternal and Child Health Bureau, comprises secondary data for more than 50 health status and health care indica-

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# Calendar of Events (continued)

## November 2007 (continued)

- 9–11 **Children's Hospital and Research Center Oakland 37th Annual Fall Conference: Curbside Consults, Questions for the Experts — Seaside** ([http://www.childrenshospitaloakland.org/documents/monterey07\\_invite.pdf](http://www.childrenshospitaloakland.org/documents/monterey07_invite.pdf))
- 10 **Diabetes Society Diabetes Symposium for Health Professionals — Santa Clara** (<http://www.thediabetessociety.org/Events/sympSC.html>)



- 10-14 **Association of University Centers on Disability (AUCD) 2007 Annual Meeting & Conference — Washington, DC** (<http://www.aucd.org/template/page.cfm?id=526>)
- 14 **38th Annual Robert O.Y. Warren, MD Memorial Seminar — Wilmington, DE** (<http://www.pedseducation.org/conferences/Roy2007/overview.html>)
- 15–18 **AAP CA Chapters 1,2,3,4 29<sup>th</sup> Annual Las Vegas Seminars: Pediatric Update — Las Vegas** (<http://www.aap-ca.org/meetings/2007/NovemberLasVegas/2007Lvbrochure.pdf>)
- 27–29 **Centers for Disease Control and Prevention Creating a Culture of Wellness: National Prevention and Health Promotion Summit — Washington, DC** (<http://www.cdc.gov/cochp/conference/index.htm>)
- 28 **Lucile Packard Children's Hospital Popular Pediatrics Clinical Topics — Kohala Coast, HI** (<http://www.lpch.org/CMECourses/cmePopularPediatricClinicalTopics2007.html>)

## December 2007

- 1 **AAP CA Chapter 1 The Pediatric Immune System, Friend or Foe?— San Francisco** (<http://www.aapca1.org/Meetings/AAP%20December%202007%20Brochure%20Final.pdf>)
- 7 **Special Start Training Program: Providing Developmentally Supportive Care at Home after the NICU — Visalia** (<http://www.mills.edu/specialstart/calendar.html>)

## January 2008

- 23-25 **March of Dimes 8<sup>th</sup> Annual Conference for Health Professionals "Preventing Prematurity, Birth Defects & Infant Mortality: Current Trends and Future Paradigms — Costa Mesa** (<http://cfhcweblog.typepad.com/titleupdates/pdfs/2007/20070801MarchOfDimes.pdf>)
- 23–26 **CA School Nurses Association 58th Annual Conference—San Diego**(<http://www.csno.org/?Page=Events>)
- 28–Feb 1 **22<sup>nd</sup> Annual San Diego International Conference on Child and Family Maltreatment — San Diego** (<http://www.chadwickcenter.org/conference.htm>)

(Continued – Child Health USA)

tors, provides both graphical and textual summaries of relevant data, and addresses long-term trends where applicable and feasible. The first section, Population Characteristics, presents statistics on factors (including poverty, education, and child care) that influence children's well-being. The second section, Health Status, contains vital statistics and health behavior information for the maternal and child health population. Health Services Financing and Utilization, the third section, includes data on health care financing and newly implemented health policies. The final sections, State Data and City Data, contain information on selected indicators at state and city levels. The book is available at [http://www.mchb.hrsa.gov/chusa\\_06/](http://www.mchb.hrsa.gov/chusa_06/).

(MCH Alert, 8/24/07)



### **Child and Youth Emergency Mental Health Care: A National Problem – Issue Brief from the National Center for Children in Poverty**

Increases in emergency use rates for mental health care by children and youth are emblematic of problems with access to community-based mental health services and supports. These visits further stretch an overextended emergency health care system. Emergency departments are poorly equipped to address the mental health needs of children, youth, and their families who seek psychiatric attention. While they encounter challenges meeting the need for pediatric and adolescent services, they are even less prepared to provide pediatric and adolescent mental health care. This issue brief reviews the state of mental health services for children and youth who visit hospital emergency departments for mental health-related reasons and provides an overview of the challenges associated with mental health-related emergency department visits. It discusses the policy implications of using emergency department services for mental health reasons for children and youth and makes recommendations for policy action. Access the full report at [http://www.nccp.org/publications/pub\\_750.html](http://www.nccp.org/publications/pub_750.html).

(NYU School of Social Work *Information for Practice*, 8/24/07)



## Calendar of Events (continued)

### February 2008

- 2 **UCSF School of Medicine, Risk and Resilience in Child Development: Perspectives From Attachment and Trauma Research in Regional, Community, and Family Settings – San Diego** (<http://www.ucsfcmc.com/2008/MPS08004.pdf>)
- 11-13 **National Birth Defects Prevention Network Annual Meeting – Washington, D.C.** ([http://www.nbdpn.org/current/annualmeeting/index07\\_savethedate.html](http://www.nbdpn.org/current/annualmeeting/index07_savethedate.html))
- 12-14 **Centers for Disease Control and Prevention 13<sup>th</sup> Annual MCH Epidemiology Conference – Atlanta** (<http://www.cdc.gov/reproductivehealth/MCHepi/2007/AboutConference.htm>)
- 19-22 **2008 Public Health Preparedness Summit – Atlanta** (<http://www.phprep.org/>)
- 22-24 **CA Chapter 3, AAP & Rady Children's Hospital San Diego, Advances in the Practice of Pediatrics – La Jolla** (<http://www.aapca3.org/events/peds2008.pdf>)
- 25-26 **2008 National Early Hearing Detection and Intervention (EHDI) Conference – New Orleans** (<http://www.infanthearing.org/meeting/ehdi2008/index.html>)
- 26-28 **Special Education Early Childhood Administrators Project (SEECAP) Symposium 2008 – Newport Beach** (<http://www.sdcoe.net/student/eeeps/seecap/?loc=symposium>)
- 27-29 **Spotlight Positive Youth Development Building Partnerships for Youth – Chevy Chase, MD** (application available at <http://cals-cf.calsnet.arizona.edu/fcs/content.cfm?content=spotlight>)



### **Agency for Healthcare Research and Quality (AHRQ) Issues Technical Review on Care Coordination for CSHCN**

*A Critical Analysis of Care Coordination Strategies for Children with Special Health Care Needs*, Technical Review Number 14 (Publication No. 07-0054), examines the issue of care coordination for children with special health care needs (CSHCN). Of particular interest is the knowledge base relating to those aspects of care coordination for CSHCN that are of greatest importance to current practice and policy challenges. Visit and download abstract at <http://www.ahrq.gov/clinic/t/cshcntp.htm>, and Technical Review at <http://www.ahrq.gov/downloads/pub/evidence/pdf/cshcn/cshcn.pdf>.





**Closing the Divide: How Medical Homes Promote Equity in Health Care**

The Commonwealth Fund 2006 Health Care Quality Survey finds that when adults have health insurance coverage and a medical home—defined as a health care setting that provides patients with timely, well-organized care, and enhanced access to providers—racial and ethnic disparities in access and quality are reduced or even eliminated. When adults have a medical home, their access to needed care, receipt of routine preventive screenings, and management of chronic conditions improve substantially. The survey found that rates of cholesterol, breast cancer, and prostate screening are higher among adults who receive patient reminders, and that when minority patients have medical homes, they are just as likely as whites to receive these reminders. The results suggest that all providers should take steps to create medical homes for patients. Community health centers and other public clinics, in particular, should be supported in their efforts to build medical homes for all patients.

[http://www.commonwealthfund.org/publications/publications\\_show.htm?doc\\_id=506814&#doc506814](http://www.commonwealthfund.org/publications/publications_show.htm?doc_id=506814&#doc506814)  
 (Commonwealth Fund, 6/27/07)



**Medical Home Featured in EP Series**



In its September 2007 issue, *Exceptional Parent Magazine* rolled out a continuing series on the American Academy of Pediatrics and its model of medical home. These medical home features will run until summer of 2008. The series is in partnership with the Pennsylvania Chapter of the American Academy of Pediatrics, Educating Practices in Community Integrated Care Medical Home Program and is being authored by various professionals involved in care for children and youth with special healthcare needs. Over the next year, this series will present the concept of the medical home in a novel

and reader-friendly way -- through a fictitious case study. *Exceptional Parent* readers will visit with Amita and Samir and their daughter, Anjali, a "make believe" family, and will learn about medical home through their experience. The September issue installment will set the stage for future issues with Anjali's premature birth and subsequent and mounting health concerns. Through the series, readers will be incrementally taught the concepts of the medical home with topics progressing as follows: overview of the medical home; medical home and care coordination; parent partners; community resources; education issues; medical homes as part of hospital systems; transition to adult-centered care: the early teen years; transition to adult-centered care: the mid- to late-teen years; and, transition to adult-centered care: high school graduation. (AMCHP Pulse for Partners, 10/12/07)



**Article Assesses Physicians' Perspectives and Practices Relevant to Serving as a Medical Home for Children with Hearing Loss**

"The majority [of responding pediatricians in Rhode Island] felt that they were the medical home for children with HL [hearing loss]. However, this was not reflected in their reported care-coordination practices, and they felt ill-informed about the paths of follow-up and needed services," write the authors of an article published in the August 2007 issue of *Pediatrics*. Although more than 90% of infants in the United States currently have their hearing screened at birth, almost half of those referred for diagnostic evaluation do not receive it. The pediatrician, as part of a well-functioning medical home, can be critical in ensuring timely diagnosis, early intervention, family support, and, ultimately, better long-term outcomes for infants identified with HL. The objectives of the study described in this article were to (1) determine whether pediatricians believe themselves to be the medical home for infants and young children with HL; (2) describe pediatricians' reported office-coordination practices, specialty provider interactions, referral patterns, and knowledge of newborn hearing screening, follow-up, and intervention; (3) evaluate pediatricians' beliefs about the psychological impact of HL on families; and (4) identify preferred educational modalities for becoming better informed in these areas.

The authors conducted an observational study between September 2001 and March 2002. Inclusion criteria for the study included Rhode Island pediatricians and family practitioners practicing primary care for in-

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phants and children from birth to age 5. The final analysis included 107 physicians.

Authors' findings:

- Among participating physicians, 59% agreed or strongly agreed that their practice was the medical home for their patients with HL, and 62.6% that they should be coordinating services.
- Fifty-six percent of participating physicians agreed that it was their role to help parents create an intervention plan, and 72.7% agreed that pediatrician guidance is needed to meet a child's educational needs.
- Only 45.1% of participating physicians agreed that they are well informed about paths of follow-up care, and only 43.3% reported that their practices are well informed about the services needed for children with HL.
- The majority of the physicians (62.6%) believed that their practices should coordinate services for their patients with HL, but only 41.4% reported that they actually did coordinate care most of the time or always.
- Among participating physicians, 55.8% believed they should help create an intervention plan, and 72.7% believed they should provide guidance in educational planning, but only 8.8% reported participating in the development of an individualized family service plan and 10.3% in the development of an individualized education program most of the time or always.
- Physicians reported that they would be likely or highly likely to use educational information about HL in children in the following formats:
  - 1] a resource guide on care in Rhode Island,
  - 2] grand rounds,
  - 3] professional journal articles.

The authors concluded that "although progress is being made in the development of effective medical homes for children with HL, the fact that physician belief ratings were consistently higher than the practice ratings suggests that motivation exists, but that additional educational efforts and strategies for enhanced care coordination are needed."

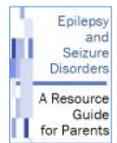
(Centers for Medicare & Medicaid Services, 7/03/07)



Dorros C, Kurtzner-White E, Ahlgreen M, et al. 2007. Medical home for children with hearing loss: Physician perspectives and practices. *Pediatrics* 120(2):288-294. Abstract available at <http://pediatrics.aappublications.org/cgi/content/abstract/120/2/288>.

## Resources

### NEW Resource Guide for Parents of Children with Epilepsy



This guide provides very basic information about epilepsy/seizure disorders and is intended to serve as a starting point for parents of a child with a new diagnosis as they begin learning about this condition. In addition to the three sections listed below, the guide also includes an appendix with forms to help track seizure and other health information:

- 1] Understanding Epilepsy/Seizure Disorder
- 2] Health Care for My Child—Access to Care/Access to Services
- 3] Advocacy and Support

Beginning mid-November 2007, you may access an electronic copy of the guide by going to [www.uscucedd.org](http://www.uscucedd.org) (click on PROJECTS, then select EPILEPSY). A hard copy can be obtained by calling the USC UCEDD at 323-361-3830.

### New Addition to *Chicken Soup for the Soul Series* Addresses Children with Special Needs

*Children with Special Needs: Stories of Love and Understanding for Those Who Care for Children with Disabilities* features powerful testaments to the love and strength of families, the dedication and promise of teachers and caregivers, and the resiliency and hope of anyone who cares for children with disabilities. To find out more, go to [www.chickensoupstories.com](http://www.chickensoupstories.com).

(*Champions for Inclusive Communities eNewsletter*, 6/19/07)

### Training in Menstrual Self-Care for Girls and Young Women with Severe Developmental Disabilities

*Janet's Got Her Period*, new from Australia's Victoria Health Foundation, addresses the problems of menstrual management for girls and young women with special needs. Developed for professionals to use with their lower-functioning students, *Janet's Got Her Period* tells the story of a young girl who learns self-care responsibility from her mother and sister. (<http://www.stanfield.com/sexed-1.html>)

### Special Needs Resource Project Provides Guide for Parents of Children with Special Needs

This website, <http://www.snrproject.com/> provides a set of links for each state to familiarize parents with local resources. It also provides links to National, Military, and Native American resources which help families and communities meet the needs of parents of children with chronic health issues, disabilities, and special health care needs.

(*Champions for Inclusive Communities eNewsletter*, 7/24/07)

### NICHCY's *Basic for Parents Series*

This series developed by National Dissemination Center for Children with Disabilities (NICHCY), written in easy-to-understand terms, looks at aspects of the special education process and provides parents with valuable information. To access electronically, go to <http://www.nichcy.org/basicpar.asp>.

**SCHIP (Healthy Families)  
Reauthorization Loses Vote –  
Congress Fails to Override Bush's Veto**

On October 18<sup>th</sup> the U.S. House of Representatives failed to override President Bush's veto of bipartisan legislation to expand the State Children's Health Insurance Program (SCHIP, in California called the Healthy Families Program) despite tremendous advocacy by organizations in our state and around the country. Thursday's vote total was 273–156, just 13 votes short of the two-thirds majority needed to override the president's veto of the bill on October 3rd. The override vote drew eight more votes than the 265–159 final passage vote on September 25<sup>th</sup>. (If you'd like to know how your Representative voted, go to the Families USA Medicaid and SCHIP Action Center at <http://www.familiesusa.org/resource-centers/medicaid-action-center>).

The defeated measure would have expanded SCHIP by \$35 billion over five years, to a total of \$60 billion for the five years. The additional funding would have been financed through an increase in the federal tax on tobacco products (e.g. a pack of cigarettes would have been taxed and extra \$0.61). In order to try to attract more votes for the override vote, the bill would have imposed some restrictions on eligibility for both children and adults, including:

- States would not have been permitted to cover children in families with incomes over 300% of FPL (with two exceptions—New York and New Jersey—that already had federal approval for the higher income level).
- The bill would have phased out the ability of states to cover childless adults or parents (previously approved by federal CMS for some states), but states would have had the option to use SCHIP funds to cover pregnant women.

The Congressional Budget Office (CBO) estimated that nearly four million children nationally would have gained coverage, and that 84% of those children would be low-income—i.e. already eligible for SCHIP or Medicaid under existing guidelines. About 70% of the children who would have enrolled would have come from families making less than 200% of FPL. In California, passage of the bill would have resulted in insurance coverage for about 765,000 currently uninsured kids—more than half the children now uninsured.

Although the Senate passed the measure last month by a veto-proof vote of 67–29, the House failure to override signifies that this legislation is dead. House Speaker Nancy Pelosi has said that Democrats immediately would begin work on another SCHIP bill to send to the president. Details on what the new bill would look like have not been released, although Speaker Pelosi has said that Democrats will not consider a different funding offset (i.e. the tobacco tax increase) and will require that a new bill cover 10 million children, up from the estimated 6.6 million currently covered. President Bush has signaled his willingness to accept some expansion of the program beyond the \$5 billion he proposed earlier this year, and, given how close bill supporters came to overriding the veto, analysts believe that the proposal may not need substantial revision. At the end

of September Congress had approved a \$5 billion extension of SCHIP authorization through Nov. 16, providing a few more weeks to resolve the standoff between legislators and the president.



**CA Health Care Reform — Dead or Alive?**

The future of health care reform in California is more complex than ever. Here's the thumbnail sketch:

- The Legislature is in Special Session, considering health care and other issues critical to the state.
- The Legislature passed AB 8, Assembly Speaker Nunez's health care reform bill, and the Governor vetoed it on October 12<sup>th</sup>.
- On October 9<sup>th</sup> Governor Schwarzenegger released his proposed health reform legislation. The language fleshes out the health care proposal he originally issued in January as a ten-page concept paper. The new language, substantially longer at 220 pages, embraces the original components of the concept paper but has not yet appeared in an actual bill. Assembly Democrats have scheduled a hearing on the proposal for October 31.

The Governor's proposal creates an individual mandate (i.e. everyone must have insurance coverage), requires employers to "pay or play," expands eligibility for public programs, and subsidizes coverage for low-income Californians. Speaker Nunez's bill required employers to "pay or play" and required those workers whose firms paid a fee instead of covering health expenses to enroll in a new purchasing program. It would have expanded eligibility for public programs and reformed the private insurance market. Meanwhile, Senator Sheila Kuehl still has her single payer health system proposal, SB 840, waiting in the wings. Financing for any of the major proposals would likely require a ballot measure, making the future of health care reform even more complicated to predict.

For details on the various proposals, see the California HealthCare Foundation health care reform website at <http://www.calhealthreform.org>.



**Governor Vetoes SB 137, Bill to Increase CCS Income Eligibility**

On October 10<sup>th</sup> Governor Schwarzenegger vetoed SB 137 (Torlakson), which would have increased the income ceiling for eligibility for the CCS program to match that of the Healthy Families Program—i.e. annual family income up to 250% of the Federal Poverty Level. Financial eligibility for CCS was reduced in 1982 from a maximum annual income of \$100,000 per year to \$40,000, regardless of the size of the family. Financial eligibility has been stuck at this

*(Continued next page)*

(Continued – Veto: SB 137)

level for the past 25 years. SB 137 would have:

- Updated CCS financial eligibility to match that of Healthy Families-- 250% of the federal poverty level, or up to \$51,625 per year for a family of 4;
- Allowed children to continue to qualify financially if their family's annual income is below \$40,000, regardless of family size, or the cost of medical care exceeds 20% of the family's income; and
- Made income calculation in the CCS program consistent with the Healthy Families and Medi-Cal programs so that families would have income disregards considered when applying for the CCS program.

The Governor's veto message cited his support for the CCS program but his belief that changes in program income eligibility should be addressed in the larger context of health care reform.

**Policy Corner**

For more information on federal or state issues, contact Laurie Soman at 510-540-8293, [LSoman6708@aol.com](mailto:LSoman6708@aol.com).

**Major Features of the 2007 California Budget**

On August 21, 2007, the Legislature passed the 2007-08 Budget Bill, along with implementing legislation. The Governor signed the budget on August 24, after using his line item veto authority to reduce General Fund appropriations by \$703 million. The budget package authorizes total General Fund spending of \$102.3 billion, essentially the same as revenues. Based on the 2007-08 budget plan's policies, however, the state would once again face operating shortfalls of more than \$5 billion in both 2008-09 and 2009-10. This is because many of the solutions enacted in the budget plan are of a one-time nature.

Available in the following formats:

HTML: [http://www.lao.ca.gov/2007/major\\_features/major\\_features\\_2007.aspx](http://www.lao.ca.gov/2007/major_features/major_features_2007.aspx)

Adobe Acrobat: [http://www.lao.ca.gov/2007/major\\_features/major\\_features\\_2007.pdf](http://www.lao.ca.gov/2007/major_features/major_features_2007.pdf)

**UCLA Leads Local Efforts in the National Children's Study**

The UCLA Center for Healthier Children, Families and Communities has been selected as one of 22 new study centers for the National Children's Study, a nationwide project designed to assess the effects of environmental and genetic factors on children's health in the United States. The study center will manage local participant recruitment and data collection for the largest study of child health ever conducted in the US.

The study is a collaborative effort between the U.S. Environmental Protection Agency and the Department of Health and Human Services (including the National Institute of Child Health and Human Development, the National Institute of Environmental Health Sciences at the National Institutes of Health, and the Centers for Disease Control and Prevention).

The National Children's Study will eventually follow a representative sample of 100,000 children from before birth to age 21, seeking information that will help prevent and treat some of the nation's most pressing health problems, including autism, birth defects, diabetes, heart disease and obesity. To better understand the impact of exposures on the developing fetus, infant and child, the study will recruit pregnant women, as well as women who are likely to become pregnant, in order to assess environmental health influence during the pre-pregnancy and prenatal period.

The University of California is well-represented in the study and will contribute much-needed expertise. In addition to UCLA, other new study centers were awarded to UC Irvine (for San Diego and San Bernardino counties, to go along with the existing Vanguard Center for Orange County) and UC Davis (for Sacramento and San Mateo counties). With the collaboration between the lead UC centers and additional sites, it is projected that more than 10,000 Californians will be enrolled in the study.

(Albin, *UCLA Newsroom*, 10/04/07)

To access full article, go to <http://www.newsroom.ucla.edu/portal/ucla/news.aspx?ncid=5368>. For more information and to view a list a complete list of centers and locations, go to <http://www.nationalchildrensstudy.gov/>.

**California Children's Services (CCS) Program Numbered Letters: June–September, 2007**

Number	Release Date	Index Category	Title
12-1007	10-01-07	Benefits	Cochlear Implant Batteries and Parts (Supplements NL: 09-0900) <a href="http://www.dhs.ca.gov/pcfh/cms/onlinearchive/pdf/ccs/numberedletters/2007/ccsn121007.pdf">http://www.dhs.ca.gov/pcfh/cms/onlinearchive/pdf/ccs/numberedletters/2007/ccsn121007.pdf</a> .
11-0807	08-30-07	Benefits	Hearing Aid Supplies and Maintenance <a href="http://www.dhs.ca.gov/pcfh/cms/onlinearchive/pdf/ccs/numberedletters/2007/ccsn1110807.pdf">http://www.dhs.ca.gov/pcfh/cms/onlinearchive/pdf/ccs/numberedletters/2007/ccsn1110807.pdf</a>
10-0707	07-26-07	Benefits	Revised Guidelines for Authorization of Oxygen, Oxygen Delivery Equipment, and Related Supplies <a href="http://www.dhs.ca.gov/pcfh/cms/onlinearchive/pdf/ccs/numberedletters/2007/ccsn100707.pdf">http://www.dhs.ca.gov/pcfh/cms/onlinearchive/pdf/ccs/numberedletters/2007/ccsn100707.pdf</a> (Note: This letter supersedes CCS Numbered Letter 01-0107.)
09-0607	06-18-07	Benefits	Authorization of Diagnostic and Treatment Services for Infants Referred by the California Newborn Screening (NBS) Program for Cystic Fibrosis and Biotinidase Deficiency <a href="http://www.dhs.ca.gov/pcfh/cms/onlinearchive/pdf/ccs/numberedletters/2007/ccsn090607/ccsn090607.htm">http://www.dhs.ca.gov/pcfh/cms/onlinearchive/pdf/ccs/numberedletters/2007/ccsn090607/ccsn090607.htm</a>

Full archive can be found at <http://www.dhs.ca.gov/pcfh/cms/onlinearchive/ccsn.htm>.

**Kaiser Family Foundation Launches Health08.org, A Hub for Information about Health Care and the Presidential Campaign** *New Website Provides Up-to-Date Polling, Analysis, Facts, News, Video, and Interviews from Kaiser and a Broad Range of Sources*



Menlo Park, CA – With health care emerging as the top domestic issue in the 2008 presidential election, the Kaiser Family Foundation today launched a new website – health08.org – that will provide analysis of health policy issues, regular public opinion surveys, and news and video coverage from the campaign trail.

Since March, Kaiser's tracking poll on health and the 2008 election has found that health care is a top domestic issue that the public wants presidential candidates to address, trailing only Iraq on the public's overall priority list. Meanwhile, 41% of adults are personally worried about health care or insurance costs, topping concerns about paying their rent or mortgage, being a victim of a terrorist attack or a violent crime, losing their job, or losing money in the stock market.

Nationally, 45 million Americans do not have any health coverage. And, health insurance premiums are up 87% over the last six years, more than four times the growth in wages, according to the Kaiser/HRET Employer Health Benefits Survey.

“For the first time since the early 1990s, there is a buzz in the air about the potential for a major debate about the future direction of our health care system, and how the issue plays in this presidential election will frame that debate,” said Kaiser President and CEO Drew E. Altman. “With health08.org, we will be there from start to finish with news and video as it happens, analysis of the issues, and tracking of where the public stands.”

The new health08.org website (<http://www.health08.org>) – which will be free of charge and not include advertising – will serve as a hub of information about health and the election, including original content produced by Kaiser and easy access to health-related resources from the campaigns, other organizations, and news outlets. Elements of the site include:

- Analysis of health policy issues, summaries of health reform proposals, and basic facts and information about the health system from Kaiser's research staff.
- Regular Kaiser tracking surveys examining the public's views on health issues and perceptions of the presidential candidates on health care, as well as links to the latest polls by other organizations.
- Syntheses of news coverage about health and the campaign, updated frequently.
- Video and podcasts from the campaign trail, including candidate speeches, and health-related highlights from forums and debates.
- Interviews with candidates and other key players in the

health reform debate.

- Dedicated pages for the candidates, with easy-to-access links to their health positions and other resources.
- A calendar of events taking place around the country and links to studies and resources from other organizations.
- A weekly email roundup of developments related to health and the election and free syndication of content available to other websites. Sign up for the email at <http://www.health08.org/email>.

Health08.org is one of a number of projects the Kaiser Family Foundation will undertake throughout the election season.

(Kaiser Family Foundation, 7/12/07)



## Data on Key Indicators of Child Well-Being Released

*America's Children: Key National Indicators of Well-Being, 2007*, summarizes a set of measures on important aspects of children's lives that federal agencies collect regularly, reliably, and rigorously. The 2007 report, representing the 10th anniversary edition published by the Federal Interagency Forum on Child and Family Statistics (FIFCFS), presents the conceptual framework, structure, and changes from previous annual reports, along with information on race and ethnicity data, indicators needed, and highlights. The main body of the report focuses on seven domains of child well-being, including (1) family and social environment, (2) economic circumstances, (3) health care, (4) physical environment and safety, (5) behavior, (6) education, and (7) health. A list of the FIFCFS agencies is provided. The appendix contains tabulated data for each measure and additional detail not discussed in the main body of the report. Descriptions of the data sources and surveys used to generate the background measures and the indicators are included. The report is available at <http://www.childstats.gov/americaschildren/index.asp>.

(MCH Alert, 7/27/07)





## **Kids Count Has Been Published by Annie E. Casey Foundation**

This annual publication by the Annie E. Casey Foundation contains data and information on the state of children and youth across the U.S. Data are included on demographics (such as race/ethnicity and population), education (such as percentage of youth who are high school dropouts), income and poverty (percentage of children in poverty, percentage of households that are unemployed), and health (such as infant mortality rate, percentage immunized). In addition, data can be downloaded and compared with states and the nation.

Selected findings:

- 28% of children in California live in crowded housing.
- Half of Californian fourth graders scored below the basic reading level in 2005.
- There were 46 teen deaths (by accident, suicide or homicide) per 100,000 for California in 2004 compared to 50 per 100,000 for the U.S.
- 7% of Californian children live in extreme poverty (in households earning less than half the poverty level- less than \$10,325 a year for a family of four).
- About one-fifth of Californian eighth graders scored 'proficient' or above in reading in 2005.
- One-third of children in immigrant families have parents who have less than a high school degree, compared to 8% of children in US-born families.

To access the report, go to <http://www.kidscount.org>.  
(Center for Community Research and Solutions eNewsletter, 7/30/07)



## **Brief Addresses Racial and Ethnic Disparities in Health Care**

*From Policy to Action: Addressing Racial and Ethnic Disparities at the Ground Level*, a new brief available from the Center for Health Care Strategies (CHCS), outlines practical strategies that states and managed care organizations are implementing to address inequalities in care. It also highlights the need for standardized collection of race, ethnicity, and language data; culturally competent approaches; and the participation and commitment of multiple stakeholders. The brief draws from CHCS' national initiatives to identify realistic solutions to reduce health care disparities and improve quality.

To download the issue brief and access other resources from CHCS, please visit: [http://www.chcs.org/publications3960/publications\\_show.htm?doc\\_id=519202](http://www.chcs.org/publications3960/publications_show.htm?doc_id=519202).  
(Champions for Inclusive Communities eNewsletter, 9/4/07)

## **Report Examines Trends in Children's Access to Health Insurance and Health Care Since SCHIP**

*Protecting America's Future: A State-by-State Look at SCHIP & Uninsured Kids* presents a comprehensive state-by-state analysis of children's and adolescents' access to health insurance and health care, including how that has changed since the State Children's Health Insurance Program (SCHIP) was introduced. The analysis was prepared for the Robert Wood Johnson Foundation by the State Health Access Data Assistance Center located at the University of Minnesota School of Public Health. Data for the analysis were drawn from the 1998, 1999, 2005, and 2006 Current Population Surveys; the Centers for Medicare and Medicaid Services Web site (2002-2006); the National Survey of Children's Health (2003); and the National Health Interview Survey (2006). The report comprises a series of six tables containing the following data:

- 1] Total number of children and adolescents ever enrolled in SCHIP in fiscal years 2002-2006
- 2] Percentage of children and adolescents from birth through age 18 without health insurance coverage by state, 1997-1998 and 2004-2005
- 3] Percentage of children and adolescents from birth through age 17 not receiving any medical care by state, 2003
- 4] Percentage of children and adolescents from birth through age 17 in the United States who visited a doctor's office within the past 12 months, 2006
- 5] Percentage of children and adolescents from birth through age 17 in the United States who received a well-child check-up within the past 12 months, 2006
- 6] Percentage of children and adolescents from birth through age 18 without health insurance coverage by race and ethnicity, 1997-1998 and 2004-2005

Information about methods and resources are provided. The report is available at <http://covertheuninsured.org/pdf/americasfuture.pdf>.  
(MCH Alert, 8/24/07)

## Journal Supplement Focuses on Use of Family Medical History in Pediatric Primary Care Practice and Public Health

The September 2007 supplement to *Pediatrics* summarizes a workgroup meeting to discuss extending the scope of the Centers for Disease Control and Prevention's (CDC's) Family History Public Health Initiative to include children and their families. The supplement, published by the American Academy of Pediatrics, contains articles that summarize the proceedings and explore four topics that emerged as leading issues from the meeting. Topics include (1) optimizing use of family history in primary care; (2) linking obstetric and pediatric clinicians through preconception health care; (3) assessing potential campaigns to prevent chronic disease, starting with family history assessment in childhood; and (4) using birth defect family histories for prevention efforts. The supplement content has been made available on CDC's Web site at [http://www.cdc.gov/ncbddd/bd/family\\_history.htm](http://www.cdc.gov/ncbddd/bd/family_history.htm). (MCH Alert, 9/14/07)



## Authors Evaluate Efforts to Improve Management of Family Psychosocial Problems at Well-Child Care Visits

"This study demonstrates the feasibility and effectiveness of addressing multiple family psychosocial problems during WCC [well child care] visits for low-income children," state the authors of an article published in the September 2007 issue of *Pediatrics*. Despite the existence of professional guidelines, few pediatricians routinely address families' circumstances and well-being. To better understand how to incorporate these guidelines into pediatric practice, the American Academy of Pediatrics Task Force on the Family in 2003 emphasized the need for additional research on the "mechanics, content, and effectiveness of family-orientated pediatrics practice." This study evaluated the feasibility and impact of implementing the WE CARE (Well-Child Care Visit, Evaluation, Community Resources, Advocacy, Referral, Education) intervention at a medical home for children from families with low incomes.

The study was a randomized, controlled trial conducted in an urban, hospital-based pediatric clinic at a large academic institution.

Participants included 45 pediatric residents and 200 parents of children (ages 2 months to 10 years) who presented for a WCC visit with an enrolled resident between April 11, 2006, and June 28, 2006. Parents in the intervention group (N=100) were given the WE CARE survey to complete before their child's encounter and were instructed to give the survey to their child's physician for review at the beginning of the visit.

Residents in the intervention group (N=24) participated in a 20-minute teaching session before study implementation and in a 10-minute booster educational session 1 month following study initiation. During the sessions, they were instructed to review the WE CARE survey with the parent during the visit and to make a referral (tear out and hand the parent an information sheet from the *WE CARE Family Resource Booklet*).

Parents in the intervention and control groups were interviewed immediately post-visit and were also interviewed via telephone 1 month after they had enrolled. Residents in both groups were asked to complete a survey at the end of the study. Medical charts were also reviewed at the end of the study.

Authors' findings:

- The mean number of family psychosocial topics discussed at the WCC visit was significantly higher for parents in the intervention group vs. the control group (2.9 vs. 1.8).
- Parents in the intervention group had fewer unmet desires to discuss family psychosocial topics, compared with parents in the control group (0.46 vs. 1.41).
- Fifty-one percent of parents in the intervention group reported receiving at least one referral from their child's provider, compared with 11.6% in the control group. Parents in the intervention group had significantly higher odds of receiving referrals for graduate degree programs, job training, food resources, and smoking-cessation classes than parents in the control group.
- At 1 month, 20.0% of the parents in the intervention group reported contacting a referred community resource, compared with 2.2% in the control group.
- Twenty-two (91.6%) of the 24 residents in the intervention group completed the post-study questionnaire. Seventy-seven percent of the residents who completed the post-study questionnaire reported that the survey did not slow down the visit; 54.5% reported that the survey added less than 2 minutes to the visit.

"We believe that the WE CARE intervention can serve as a model for addressing family psychosocial problems for medical homes that care for low-income children" conclude the authors, adding that "additional research will be needed to assess the long-term impact of family psychosocial screening interventions on parental outcomes and child health, behavioral, and developmental outcomes."

(MCH Alert, 9/7/07)

Garg A, Butz AM, Dworkin P, et al. 2007. Improving the management of family psychosocial problems at low-income children's well-child care visits: The WE CARE project. *Pediatrics* 120(3):547-588. Abstract available at <http://pediatrics.aappublications.org/cgi/content/abstract/120/3/547>.





### **Solutions in Health Care: Advantages of Telemedicine**

With healthcare costs on the rise and families struggling to keep up, communities are looking for solutions to handle healthcare needs in a more efficient and economical fashion. Recently The Children's

Partnership, a non-profit child advocacy organization, published an Issue Brief to inform leaders and the public of how telemedicine can address the health care needs of California's children.

Telemedicine is the use of Information and Communications Technology (ICT) to provide patient care from a distance. Types of ICT can range from a doctor regularly communicating with a patient via e-mail to using satellite technology and video-conferencing to conduct real-time consultations between medical specialists.

Innovative telemedicine programs are currently being used across the nation. One of them is Baby CareLink. This program was developed to enhance interactions between families, staff, and community providers to improve the health of low-birth weight babies. Through videoconferencing, families can participate in virtual visits and distance learning from home during an infant's hospitalization.

Short-term studies show that, although the initial investment in a telemedicine program can be costly, the longer term benefit pays dividends. Also, according to the report, underserved communities stand to benefit the most. ICT cuts out transportation costs for doctors and families, and links families with expert doctors who may not otherwise serve children and families in medically underserved areas.

To download a copy of the report, go to <http://www.simplesend.com/clientimages/first51a/TelemedicineIssueBrief.pdf>.

(First 5 LA's Monday Morning Report, 10/15/07)



### **Ohio Hospital Taps Telemedicine to Treat Students with Disabilities**

Akron Children's Hospital in Ohio is using telemedicine to connect to two schools for children with cognitive and physical disabilities to prevent students from having to leave school for medical examinations, the *Akron Beacon Journal* reports. The program, called Tele-Health-Kids, allows sick students at Ida Sue School in Wooster, Ohio, and Dale Roy School in Ashland, Ohio, to receive care remotely. School nurses check students using specialized devices and then send participating pediatricians digital pictures and audio via a computer.

Pediatricians from the Cleveland Clinic Family Health Center, Children's Hospital Physician Associates and Pediatric Consultants then view the data and, if necessary, conduct live examinations online using computerized video cameras in the pediatric practices and the schools.

The project has been used on a limited basis in the summer session this month at Ida Sue School and will be fully operational at both schools when regular sessions begin this fall.

The Office for the Advancement of Telehealth within the Health Resources and Services Administration awarded Akron Children's Hospital a three-year, \$750,000 grant to fund the project. Part of the federal grant also will be used to reimburse physicians \$50 per appointment, but the goal is eventually to persuade insurers to pay for the telemedicine visits, Diane Langkamp, medical director of the program, said. The hospital is contributing \$79,000 to the project.

(Powell, *Akron Beacon Journal*, 7/27/07, as cited in *iHealthBeat*, 7/27/07)



### **Article Assesses the Effects of an Early Childhood Education Program on Adult Health and Well-Being**

"This study provides evidence that established early educational interventions can positively influence the adult life course in several domains of functioning," write the authors of an article published in the August 2007 issue of *Archives of Pediatric and Adolescent Medicine*.

Early childhood interventions have demonstrated consistent positive effects on children's health and well-being. However, there is only a small amount of evidence that large-scale public programs have long-term effects into adulthood. In this article, the authors describe a follow-up study at age 24 to assess Child-Parent Center (CPC) program links with measures of educational attainment, economic status, crime, health status and behavior, and mental health. The CPC provides comprehensive services to children ages 3-9 and their families and has been administered through the Chicago public school system since 1967.

Data for the study come from the Chicago Longitudinal Study, a prospective investigation of the life course of a cohort of 1,539 children with low incomes and from minority groups (93% black, 7% Hispanic) born in 1979 or 1980 who attended early childhood programs in 25 sites between 1985 and 1986. The original sample included 989 children who attended the CPC. The comparison group consisted of 550 children who participated in alternative full-day kindergarten programs that were available to families with low incomes.

(Continued next page)

Relative to the comparison group and controlling for pre-program characteristics, individuals who participated in the CPC in preschool:

- had significantly higher rates of high-school completion and 4-year college attendance and more years of education;
- had significantly lower rates of felony arrest and incarceration and were less likely than the comparison group to be found guilty of a crime both overall and for a felony;
- were somewhat more likely to have a stable employment history or to have attended college by age 24;
- and were less likely to have one or more depressive symptoms.

The authors conclude that "the scope and magnitude of intervention effects reveal not only the benefits to participants in fundamental indicators of health and well-being but also the potential returns to society for investments in early educational programs."

(MCH Alert, 8/24/07)

Reynolds AJ, Temple JA, Ou S, et al. 2007. Effects of a school-based, early childhood intervention on adult health and well-being. Archives of Pediatric and Adolescent Medicine 161(8):730-739. Abstract available at <http://archpedi.ama-assn.org/cgi/content/full/161/8/730>.



### Postsecondary Education Resource for Youth with Cognitive Disabilities

The Postsecondary Education Research Center (PERC) project, coordinated by TransCen, Inc. has a website that provides information and resources on college options for students with intellectual disabilities. The site provides answers to frequently asked questions (FAQs) related to developing or expanding services for students with intellectual disabilities in college settings. It also provides access to a free online evaluation tool, the PERC Self-Assessment Tool, that allows users to evaluate aspects of programs or services for students with intellectual disabilities on college campuses. This self-assessment tool provides a snapshot of the quality of existing services and provides users with a concise evaluation report. It also provides users with the opportunity to create an itemized action plan that can be used to address areas in need of improvement. PERCs website can be found at <http://www.transitiontocollege.net/>.

(TATRA Project Reference Points, 9/24/07)



### 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 access the first report, *Systematic Review of the Effects of Curricular Interventions on the Acquisition of Functional Life Skills*, go to [http://www.nsttac.org/?FileName=what\\_works&type=1](http://www.nsttac.org/?FileName=what_works&type=1). As they become available, additional reports will be posted on the site.

(TATRA Project Reference Points, 6/19/07)

### Brief Highlights State Support for Local Early Childhood Systems Development



*Local Systems Development* (Short Take No. 6) highlights the efforts of 10 states and illustrates various approaches for state-to-local support for early childhood systems. The brief is the sixth in the Short Take series published by the National Center for Children in Poverty's Project Thrive, with support from the Maternal and Child Health Bureau.

The content is based on a review of state Early Childhood Comprehensive System (ECCS) plans and proposals for evidence of local systems development and on additional information collected from selected states. A table presents information on the strategies states use, alone or in combination, to support local communities. Strategy approaches include the following: direct funding to communities; policy, regulation, or guidance; and direct and indirect technical support (such as offering tools). Statewide approaches used in Arizona, Iowa, Ohio, and Vermont and targeted approaches used in Colorado, Illinois, Massachusetts, Michigan, Oklahoma, and Washington are discussed in detail. The authors conclude with key points. The brief is available at [http://www.nccp.org/publications/pdf/text\\_758.pdf](http://www.nccp.org/publications/pdf/text_758.pdf).

(MCH Alert, 9/14/07)

## NCSER Issues Fact Sheet and Report

### Secondary School Experiences of Students with Autism

The National Center for Special Education Research at the Institute of Education Sciences has released a new fact sheet on the National Longitudinal Transition Study-2 (NLTS2) entitled *Facts From NLTS2: Secondary School Experiences of Students With Autism*.

This fact sheet provides a national picture of the secondary school experiences of students with autism using data from the NLTS2. This study has a nationally representative sample of more than 11,000 students with disabilities. Approximately 1,000 youth with autism are included in the sample. The fact sheet provides information on such topics as the courses taken, instructional settings, the nature of the curriculum and instruction, teacher perceptions, and the types of accommodations and supports provided for students with autism. To access, go to <http://ies.ed.gov/ncser/pubs/>.

(TATRA Project Reference Points, 7/23/07)



### Perceptions and Expectations of Youth With Disabilities: A Special Topic Report of Findings From the National Longitudinal Transition Study-2 (NLTS2)

This report from NCSER provides a picture of the self-representations and expectations of youth with disabilities, how they differ across disability categories and demographic groups, and how they compare with youth in the general population. The National Longitudinal Transition Study-2 (NLTS2), funded by IES, was initiated in 2001 and has a nationally representative sample of more than 11,000 students with disabilities. This report presents findings drawn primarily from telephone interviews or self-administered mail surveys collected from youth when they were ages 15 through 19. The report addresses questions such as how youth with disabilities describe their feelings about themselves and their lives, their secondary school experiences, their personal relationships, and their expectations for the future. To access, go to <http://ies.ed.gov/ncser/pubs/index.asp#NLTS2perceptions>.

(TATRA Project Reference Points, 9/12/07)

## CACSHCNEWS

Previous issues available at

[http://uscucedd.org/CACSHCNEWS/  
tabid/665/Default.aspx](http://uscucedd.org/CACSHCNEWS/tabid/665/Default.aspx)

### GAO Report: Federal Disability Programs "Poorly Positioned" to Help People Go to Work

A recent report by the watchdog US Government Accountability Office (GAO) stated "social and legal changes have promoted the goal of greater inclusion of persons with disabilities in the mainstream of society, including adults at work. For example, the Americans with Disabilities Act (ADA) supports the full participation of persons with disabilities in society and fosters the expectation that persons with disabilities can work and have the right to work. However, GAO's reviews of the largest federal disability programs indicate that such programs have not evolved in line with these larger societal changes and, therefore, are poorly positioned to provide meaningful and timely support for persons with disabilities." The report further cites the looming crises in the slowdown in the nation's labor force and the low rate of return to work for individuals with disabilities receiving cash and medical benefits. The report can be found at <http://www.gao.gov/new.items/d07934sp.pdf>.

(TATRA Project Reference Points, 9/10/07)

### New Report from the US Department of Justice

The US Department of Justice Civil Rights Division has posted their recent report, *Access for All: Five Years of Progress, A Report from the Department of Justice on Enforcement of the Americans with Disabilities Act*, on their website for viewing and downloading. The report can be found at <http://www.usdoj.gov/crt/ada/5yearadarpt/fiveyearada1.htm>.

(TATRA Project Reference Points, 6/22/07)



## New Fact Sheets from NSTTAC and DCDT

Two new fact sheets developed as a collaborative effort between the Division on Career Development and Transition (DCDT) and the National Secondary Transition Technical Assistance Center (NSTTAC) are now available on the NSTTAC web site:

- *Student Involvement in the IEP* features two evidence based strategies to involve students in the IEP process.  
[http://www.nsttac.org/pdf/dcdt\\_fact\\_sheet.pdf](http://www.nsttac.org/pdf/dcdt_fact_sheet.pdf)
- *Age-Appropriate Transition Assessments* provides a working definition of "age appropriate transition assessments," examples of formal and informal types of assessments, and offers guidance to practitioners on selecting and conducting assessments.  
[http://www.nsttac.org/pdf/trans\\_fact\\_sheet.pdf](http://www.nsttac.org/pdf/trans_fact_sheet.pdf)

Note that a draft version of a longer *Age Appropriate Transition Assessment Guide* is also available ([http://www.nsttac.org/pdf/transition\\_guide/nsttac\\_tag.pdf](http://www.nsttac.org/pdf/transition_guide/nsttac_tag.pdf)).

DCDT is a division of the Council for Exceptional Children (CEC) and NSTTAC is funded through the Office of Special Education Programs, Office of Special Education.  
(TATRA Project Reference Points, 9/4/07)



## UCP Releases New Medicaid Report

United Cerebral Palsy is offering strategies and ideas on how to improve Medicaid services for people with disabilities at the local, state, and national levels. *The Plan for Inclusion* report includes a menu of policy options and tactics designed to work in tandem with their recently released report, *The Case for Inclusion*, which ranks and analyzes how states are serving Americans with intellectual and developmental disabilities under Medicaid. The full text for both reports and state-by-state data are available at <http://www.ucp.org/medicaid>.  
(TATRA Project Reference Points, 6/25/07)



## Disability Data Resources

The U.S. Department of Labor, Office of Disability Employment Policy, provides direct web access to several comprehensive sources of disability statistics. Find, for instance, FedStats, Bureau of Labor Statistics, National Center for Health Statistics, Disability Statistics Center, and others. Go to <http://www.dol.gov/odep/pubs/fact/finding.htm>.  
(TATRA Project Reference Points, 8/13/07)

## Youth Self-Advocacy Tips from FVCA KASA

### POWER UP : Tips for Self-Advocacy

*Family Voices of California KASA (Kids As Self-Advocates) Group*

Do you want to make your own decisions? Are you sick of your service providers not providing good service? Are you tired of not being heard? Are you fed up with being a follower and not a leader? If you answered "yes" to any the above, we have some tips to help you.

READ ON!

### Qualities of a Good Self-Advocate

A good self-advocate:

- ★ is someone who not only recognizes their needs but also reaches out for help.
- ★ is aware of the resources that are at their disposal and makes efforts to use them.
- ★ is responsible for their actions.
- ★ is assertive and honest.
- ★ recognizes their own strength and weaknesses.
- ★ knows who they can go to for help.
- ★ knows their rights.
- ★ knows how to work with the system.
- ★ does not take "no" for an answer because they know about the appeal process.
- ★ knows who their service providers are and has a direct way to reach them.
- ★ organizes their priorities.
- ★ knows their own limitations and how to ask for support in dealing with them.
- ★ takes every opportunity to speak and speak up.

### Tips — California KASA

- ✓ Always speak up; never be afraid to do so.
- ✓ Remember, there are no stupid questions, especially when it is about your health or overall success.
- ✓ The only goals that are out of reach are those you do not try to achieve.
- ✓ Don't wait for people to do things for you (i.e. make your own appointments).
- ✓ Collaboration is the key; confrontation is the last resort.
- ✓ Always say "thank you."

*If you wonder where our expertise comes from, we are a group of young self-advocates. We are the Family Voices of California KASA (Kids As Self-Advocates) group. You can reach us at [Mavenno1@aol.com](mailto:Mavenno1@aol.com). We encourage you to pass these tips along to anyone who would benefit from them. Feel free to reproduce this article but please send us a copy of your publication.*