



California Advocacy Network

for Children with Special Health Care Needs

Newsletter

June 12, 2014

NETWORK NEWS



It Takes a Family: Study Documents Low Family Participation in Policymaking

California's uncoordinated system of care for children with special health care needs often creates significant difficulties for families, yet family voices are generally absent from policymaking. A new report, funded by the Lucile Packard Foundation for Children's Health, documents the relatively minimal family participation in decision-making processes for organizations that influence the health and well-being of their children, and offers recommendations.

[Read the report.](#)

New Grants Aim to Boost Care Coordination and Family Participation in Policy

Helping families coordinate care for their children with special health care needs is the focus of two new grants awarded by the Lucile Packard Foundation for Children's Health. A third grant is designed to increase families' role in policymaking for state and county programs that serve these children. [Read more.](#)



Member Profile: Pilot Program Seeks to Screen, Intervene Early

Dr. Susanne Martin Herz is on the front lines of a San Mateo County demonstration project to improve early screening and treatment of children at risk for developmental disabilities. [Read more.](#)

CALIFORNIA CHILDREN'S SERVICES (CCS)

Stakeholders Identify Core Values to Maintain in CCS

On May 12, Richard Pan, MD, chair of the Assembly Health Committee, convened a small group of stakeholders at the California Health Care Foundation offices to discuss the future of the California Children's Services program. The group included representatives from families, children's hospitals, county health executives, child advocacy groups, foundations, health plans, providers, and the Department of Health Care Services. This was the first in a series of meetings to identify core values of CCS and identify opportunities for increased efficiency. The group identified core values including: regionalized care is crucial; the whole child (primary and specialty care) should be cared for; the current CCS standards must be maintained; family-centered care is essential; and shared metrics and quality indicators will be important. The need to review and update qualifying CCS conditions and to examine the various funding streams for children currently in the CCS program also was discussed. For more information, contact Dr. Lisa Chamberlain, lchamberlain@stanford.edu. For additional background, see a report from the Lucile Packard Foundation for Children's Health, [*Transitioning the California Children's Services Program to a New System of Care: Stakeholder Issues and Considerations.*](#)

Stanford Center Analyzes CCS Data

The Center for Policy, Outcomes and Prevention at Stanford University has conducted a series of studies regarding the California Children's Services program, with the goal of providing guidance to policymakers as they consider changes to the program. [See a series of fact sheets.](#)

CALIFORNIA POLICY

Dental Association Cites Poor Access to Care for Medi-Cal Patients with Special Needs

California Healthline reports that the California Dental Association is warning that Medi-Cal patients with special needs are finding it nearly impossible to get access to dental care in hospitals because of low reimbursement rates. [Read more.](#)

CARE COORDINATION

AAP Policy Statement on Care Coordination; Free Access to an Online Curriculum

The American Academy of Pediatrics has published a policy statement, [*Patient- and Family-Centered Care Coordination: A Framework for Integrating Care for Children and Youth Across Multiple Systems,*](#) as well as an accompanying article, [*Beyond the Medical Home: Coordinating Care for Children.*](#) To encourage implementation of care coordination, Boston Children's Hospital offers a free online resource, [*Pediatric Care Coordination Curriculum.*](#)

AFFORDABLE CARE ACT

[*Insured Young Cancer Patients Fare Better, Live Longer: Study*](#)

Reuters, 6/2/14

RESOURCES

Journal Encourages Children to Record Their Feelings about Serious Illness

Digging Deep, an interactive journal for young people who face health challenges, provides an opportunity for children and adolescents to create a personal book where they can record their thoughts and feelings about their experiences. The 140-page journal offers guided exercises on topics such as hospitals, doctors and treatments; anger, fear and understanding; and love and gratitude. [Learn more.](#)

Other Useful Links

EPSDT - A Guide for States: Coverage in the Medicaid Benefit for Children and Adolescents is a new publication available from the federal Department of Health and Human Services. It is intended to help health care providers and others to understand the scope of services that are covered. [Read more.](#) The June issue of *Complex Child*, an e-magazine created by parents, focuses on special education. [See the issue.](#)

WEBINARS

Autism Spectrum Disorders: An Overview in Spanish

Saturday, June 21

10 - 11 a.m.

The Autism NOW Center, a project of The Arc and the Autism Society of America, will offer a webinar entirely in Spanish, about autism spectrum disorders. [Register here.](#)

Autismo: Una Visión General en Español

Sábado, 21 de Junio

10 - 11 a.m.

El Autism Now Center y el Autism Society se han asociado para ofrecer un recurso gratuito para las familias de habla hispana. Únete a nosotros en este seminario, que será ofrecido completamente en español, para aprender más acerca de los trastornos del espectro autista. [Regístrate en este seminario.](#)

RESEARCH

Reading Called Possible for Many Children with Low IQ

A new study from Southern Methodist University finds that children with low IQs are capable of learning to read if they receive specialized instruction over a significant period. Such results could have major implications, as even minimal reading skills can lead to a more independent life, the researchers note. [Read more.](#)

Study: Mental Health Disorders Double Health Care Costs for 'Dual-Eligible' Individuals

A Commonwealth Fund study has found that among the "dual-eligible" population under age 65 -

individuals enrolled in both Medicare and Medicaid-those with mental disorders incur nearly twice as much in health care costs as those without. The authors suggest that better case management to coordinate medical, mental health, and substance abuse services could yield substantial savings. [Read more.](#)

CSHCN IN THE NEWS

[Approval of Autism Benefit in Louisiana May Influence California Budget Talks](#)

California Healthline, 6/11/14

[Caring for Those with Autism Runs \\$2M-Plus for Life](#)

USA Today, 6/9/14

[New Ways to Get Children to Take Their Medicines](#)

Wall Street Journal, 6/8/14

[Parents of Mentally Ill Adult Children Frustrated By Privacy Law](#)

Kaiser Health News, 6/5/14

[Many Minority Kids with Cancer Missed Needed Medication, Study Finds](#)

DailyRx, 6/4/14

[I Want the World to See Beauty in Being Different](#)

Huffington Post, 6/3/14

[Court Throws Out 'Mental Retardation': Column](#)

USA Today, 6/1/14

[In Emergencies, People with Disabilities Often an Afterthought](#)

Disability Scoop, 5/30/14

[For Hire: Dedicated Young Man with Down Syndrome](#)

Al Jazeera America, 5/25/14

WE'D LIKE TO HEAR FROM YOU

Let us know what's happening with your organization or family. E-mail Network Manager Janis Connallon at Janis.Connallon@lpfch.org with your news or updates. Newsletter Editor: Eileen Walsh

Network Staff Contact:

Janis Connallon, Manager

*California Advocacy Network for Children with Special Health Care Needs
Lucile Packard Foundation for Children's Health*

email: janis.connallon@lpfch.org

www.lpfch-cshcn.org

Please forward this newsletter to your colleagues and encourage them to [sign up](#) for the Advocacy Network.

To see past issues, visit the [Network Newsletter Archive](#)



The California Advocacy Network for Children with Special Health Care Needs is a collaborative organized by the Lucile Packard Foundation for Children's Health.

E-mail not displaying correctly? [Click here to view it in your browser.](#)

This email was sent by: **Lucile Packard Foundation for Children's Health**
400 Hamilton Ave, Suite 340 Palo Alto, CA, 94301, USA

[Update Profile](#)