### Children and Youth with Special Health Care Needs Network Newsletter

News, policy updates, resources, events, and advocacy opportunities

**FAMILY ENGAGEMENT** 

Families, Pediatric Teams

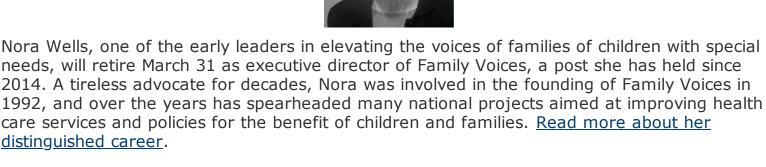
#### Family engagement in systems-level activities -- such as participation in advisory and other decision-making groups, or creation and revision of policies -- has not been studied in detail. A

Family Engagement at the Systems Level: A Framework for Action

new open-access article in the *Maternal and Child Health Journal* reviews the literature and presents a framework that describes the information and supports that help families partner with professionals and contribute to systems-level activities. The research was supported by our Foundation. Read the article. Invitation to Submit Articles to *Pediatrics* Demonstrating Collaborations Between

#### Pediatrics, the journal of the American Academy of Pediatrics, publishes a section called Family Partnerships that features articles describing successful collaboration between patients, families, and their pediatric care teams. These articles, which must be written collaboratively,

can highlight partnerships that occur in the care of individual children and/or in pediatric health systems level work. Submissions are accepted on an ongoing basis. Read more and see the author instructions. See past articles. Family Voices Executive Director Nora Wells to Retire



PUBLIC HEALTH EMERGENCY UNWINDING Webinar: Unwinding - What to Know and How to Prepare

partners with their outreach efforts. An extended question-and-answer

### **TIME** 9 to 10 a.m. Pacific Time SPONSOR Department of Health and Human Services (HHS) and the Centers for

National Health Law Program

distinguished career.

# **DETAILS** Speakers will review recently released CMS unwinding resources to help

**DATE** Wednesday, March 22, 2023

Medicare & Medicaid Services (CMS)

session with CMS experts will address issues related to Medicaid renewals and terminations, Medicaid to Marketplace transitions, Medicaid to Medicare transitions, communication and outreach strategies, and more. Register.

• Fact Sheet: COVID-19 Public Health Emergency Transition Roadmap – from the Department of Health and Human Services

The new issue of the *Pediatric and Palliative Care e-Journal* considers how and why perinatal and neonatal palliative and hospice care have spun off from the broader scope of pediatric palliative and hospice care. The authors discuss what distinguishes this type of care, and how all obstetric and newborn services can incorporate perinatal/neonatal palliative care principles.

• <u>Keeping Medi-Cal When Renewals Restart in 2023</u> – Recording of a webinar from the

Read the issue.

PEDIATRIC PALLIATIVE CARE

In Brief

# **NATIONAL POLICY**

Judy Heumann Led a Reimagining of What It Means to Be Disabled from NPR.

**Exploring Perinatal and Neonatal Palliative and Hospice Care** 

'Mother of Disability Movement' Sparked a Revolution Judy Heumann, who contracted polio when she was 18 months old, spent a lifetime as an advocate for the rights of individuals with disabilities. She was a fearless and groundbreaking leader in many realms, including passage of the Americans with Disabilities Act. Read Activist

• The ACA's Preventive Services Benefit Is in Jeopardy: What Can States Do to Preserve

• No Surprises Act Update: The Latest Litigation, Enforcement, and Implementation

# In Brief

**HEALTH EQUITY** 

In Brief

Read the report.

In Brief

**RESOURCES** 

<u>Access?</u> – from the Georgetown Center for Children and Families • The 'Family Glitch Fix' Gives Families New Options to Purchase Quality Affordable Health Coverage – from the National Health Law Program

<u>Challenges</u> – A webinar recording from Manatt

**DATE** Monday, March 27

INTELLECTUAL AND DEVELOPMENTAL DISABILITIES

- Webinar: Exploring Alternatives to Guardianship
  - TIME 12 p.m. Pacific Time **SPONSOR** Center on Youth Voice Youth Choice

**DETAILS** The first in a four-part series, Supporting Youth and Young Adults with

Intellectual and/or Developmental Disabilities with Decision-Making: What

providing decision-making support, review the facts and myths about these

determination, and emphasize strategies and action steps for parents and

Every Parent Needs to Know. Series speakers will discuss options for

options, discuss ways to maximize youth decision-making and self-

**DETALLES** Got Transition y Family Voices organizarán un seminario virtual en español,

con interpretación simultánea en inglés. Únase al seminario virtual para

# Seminario Web: Transición del Cuidado de Salud Pediátrico al de Adulto

FECHA Miércoles, 29 de marzo

HORA 1 p.m. Tiempo del Pacifico

youth. <u>Register</u>.

obtener más información sobre los recursos que las familias de habla hispana pueden usar para guiar a sus jóvenes a través de la transición a los servicios de salud para adultos. Leer más y registrarse.

<u>Care Coverage</u> - from the Center for Health Care Strategies

**CALIFORNIA REGIONAL CENTERS** 

**Addressing Inequities in Regional Center Services** 

**CALIFORNIA POLICY** 

State Offers Education to Families, Providers on Medi-Cal Benefit for Kids & Teens

Health Care Services to educate and inform families and providers in Medi-Cal about the federally required Early and Periodic Screening, Diagnostic, and Treatment (EPSDT) benefit.

A Medi-Cal for Kids & Teens Outreach & Education Toolkit is available from the Department of

A report from Disability Rights California notes that ethnic and racial disparities persist in California's regional center system. The authors propose four community-led strategies to encourage policy changes that would address structural barriers affecting individuals of color.

• <u>Covering All Kids: Strategies to Connect Children of Undocumented Status to Health</u>

### • Analysis: When the Power Goes Out, These Devices Save Lives. More Californians Need <u>Them</u> – from California Health Report

Pregnancy Prevention Program

Disability Scoop, 3/2/23

• <u>American Sign Language Storytelling Videos</u> – from the American Society for Deaf Children

<u>Developmental Disabilities</u> – from Family and Youth Services Bureau's Adolescent

• Sexual Health Resource Toolkit for Parents and Caregivers of Youth with Intellectual and

### Study Finds Psychiatry Training on Developmental Disabilities 'Insufficient' Disability Scoop, 3/13/23 Nation's Disability Services at Breaking Point, Report Finds

IN THE NEWS

- WE'D LIKE TO HEAR FROM YOU
- newsletter editor: Eileen Walsh at Eileen.Walsh@lpfch.org. Join The Network
  - To see past issues, visit the <u>Network Newsletter Archive</u>.

editor Hannah Au at Hannah.Au@lpfch.org with your news or updates. Or contact

Let us know what's happening with your organization or family. Email newsletter assistant