

Children and Youth with Special Health Care Needs

Network Newsletter

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

FAMILY ENGAGEMENT

Family Engagement at the Systems Level: A Framework for Action

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 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 Families, Pediatric Teams

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



Nora Wells, one of the early leaders in elevating the voices of families of children with special needs, will retire March 31 as executive director of Family Voices, a post she has held since 2014. A tireless advocate for decades, Nora was involved in the founding of Family Voices in 1992, and over the years has spearheaded many national projects aimed at improving health care services and policies for the benefit of children and families. [Read more about her distinguished career.](#)

PUBLIC HEALTH EMERGENCY UNWINDING

Webinar: Unwinding - What to Know and How to Prepare

DATE	Wednesday, March 22, 2023
TIME	9 to 10 a.m. Pacific Time
SPONSOR	Department of Health and Human Services (HHS) and the Centers for Medicare & Medicaid Services (CMS)
DETAILS	Speakers will review recently released CMS unwinding resources to help partners with their outreach efforts. An extended question-and-answer 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.

In Brief

- [Keeping Medi-Cal When Renewals Restart in 2023](#) – Recording of a webinar from the National Health Law Program
- [Fact Sheet: COVID-19 Public Health Emergency Transition Roadmap](#) – from the Department of Health and Human Services

PEDIATRIC PALLIATIVE CARE

Exploring Perinatal and Neonatal Palliative and Hospice Care

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. [Read the issue.](#)

NATIONAL POLICY

'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 Judy Heumann Led a Reimagining of What It Means to Be Disabled](#) from NPR.

In Brief

- [The ACA's Preventive Services Benefit Is in Jeopardy: What Can States Do to Preserve Access?](#) – 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
- [No Surprises Act Update: The Latest Litigation, Enforcement, and Implementation Challenges](#) – A webinar recording from Manatt

INTELLECTUAL AND DEVELOPMENTAL DISABILITIES

Webinar: Exploring Alternatives to Guardianship

DATE	Monday, March 27
TIME	12 p.m. Pacific Time
SPONSOR	Center on Youth Voice Youth Choice
DETAILS	The first in a four-part series, <i>Supporting Youth and Young Adults with Intellectual and/or Developmental Disabilities with Decision-Making: What Every Parent Needs to Know</i> . Series speakers will discuss options for providing decision-making support, review the facts and myths about these options, discuss ways to maximize youth decision-making and self-determination, and emphasize strategies and action steps for parents and youth. Register.

HEALTH EQUITY

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

FECHA	Miércoles, 29 de marzo
HORA	1 p.m. Tiempo del Pacífico
DETALLES	Got Transition y Family Voices organizarán un seminario virtual en español, con interpretación simultánea en inglés. Únase al seminario virtual para 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.

In Brief

- [Covering All Kids: Strategies to Connect Children of Undocumented Status to Health Care Coverage](#) - from the Center for Health Care Strategies

CALIFORNIA REGIONAL CENTERS

Addressing Inequities in Regional Center Services

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. [Read the report.](#)

CALIFORNIA POLICY

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

A [Medi-Cal for Kids & Teens Outreach & Education Toolkit](#) is available from the Department of 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.

In Brief

- [Analysis: When the Power Goes Out, These Devices Save Lives. More Californians Need Them](#) – from California Health Report

RESOURCES

- [Sexual Health Resource Toolkit for Parents and Caregivers of Youth with Intellectual and Developmental Disabilities](#) – from Family and Youth Services Bureau's Adolescent Pregnancy Prevention Program
- [American Sign Language Storytelling Videos](#) – from the American Society for Deaf Children

IN THE NEWS

- [Study Finds Psychiatry Training on Developmental Disabilities 'Insufficient'](#) *Disability Scoop, 3/13/23*
- [Nation's Disability Services at Breaking Point, Report Finds](#) *Disability Scoop, 3/2/23*

WE'D LIKE TO HEAR FROM YOU

Let us know what's happening with your organization or family. Email newsletter assistant editor Hannah Au at Hannah.Au@pfch.org with your news or updates. Or contact newsletter editor: Eileen Walsh at Eileen.Walsh@pfch.org.

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