

California Advocacy Network for Children with Special Health Care Needs

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

Editor's Note – The Newsletter will not publish on November 26, Thanksgiving Day. Our next issue is scheduled for December 3. Our best wishes for a healthful and happy holiday.

Family Engagement

Moving Beyond the Family Engagement Check Box

Many child-serving organizations recognize the value of involving families in their work, but struggle with how to engage family members. A new report, *Moving Beyond the Family Engagement Check Box: An Innovative Partnership to Promote Authentic Family Engagement in Systems Change*, describes an initiative developed by Family Voices and the Center for the Study of Social Policy. This case study presents a framework for implementing family engagement, offers insights into best practices for ensuring meaningful partnerships, and highlights the importance of providing adequate funding for family participation. [Read more.](#)

Social Determinants of Health

Combining Medical and Social Complexity Data to Assess Children's Health Status, Improve Care Coordination

Researchers in Oregon, with support from our Foundation, have developed a novel methodology that merges data on medical complexity and social complexity to create a new health complexity measure at both the population and individual level. In an open-access article in *BMJ Innovations* the authors note that their findings demonstrate that a large number of Medicaid/CHIP-insured children could benefit from targeted care coordination and differential resource allocation that aligns with their health complexity. [Read more.](#)

Viewpoint

A Parent Speaks: When a Child's Quality of Life Outweighs the Next Test or Procedure

Meghan Halley, a researcher at the Stanford Center for Biomedical Ethics, discusses how she navigates the uncertainties of making medical decisions for her 5-year-old son who has an undiagnosed genetic disorder. [Read her Q&A](#) and listen to a podcast.

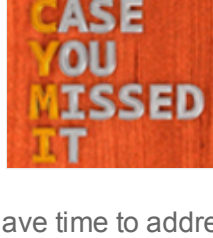
Children with Medical Complexity

Webinar: Community Ecosystem Learning Collaborative

Date Thursday, November 19
Time 11 a.m. to 12 p.m. Pacific Time
Sponsor National Center for Complex Health and Social Needs
Details Center staff will discuss the [Community Ecosystem Learning Collaborative](#). This 15-month learning collaborative, which begins in April 2021, will give teams from across the country the opportunity to develop complex care ecosystems in their communities. During this webinar, staff will review the learning collaborative's goals, the request for proposals, the application, and key dates. Not pediatric specific, but of interest. [Read more.](#)

Archived Webinar

Hospital Discharge Planning



Read responses to questions that panelists did not have time to address during the webinar [Improving Discharge Care for Children with Special Health Care Needs through a Nurse-led Learning Collaborative](#).

COVID-19 Information

Two-part COVID-19 Webinar Series:

LENS Care: Leading Equity Now in Systems of Care

Date Tuesday, December 1
Time 1 to 2 p.m. Pacific Time
Sponsor National Institute for Children's Health Quality
Details Speakers will offer an in-depth look at how bias limits quality care for those who need it most during this pandemic, and share resources and ideas focused on achieving health equity and combatting health disparities rooted in the structures of care systems. [Register.](#)

Pediatric Telehealth Strategies During and Post (?) the COVID-19 Pandemic

Date Thursday, December 3
Time 1 to 2 p.m. Pacific Time
Sponsor National Institute for Children's Health Quality
Details Health and social service providers will learn how to best connect with children and their caregivers during a virtual visit to help ensure that families receive the health care they need during and after this pandemic. [Register.](#)

Please find additional resources and information on our [COVID-19 web page](#).

Telehealth

Family Voices Creates Telehealth Checklist

Families of CSHCN across the country have had to learn how to navigate telehealth platforms and have discussions with their providers in new ways. Family Voices has created a two-part tool, a checklist and worksheet, to help families manage telehealth, before, during and after visits. [Read more.](#)

CSHCN and Equity

- [Black and Latinx Children with Disabilities in California Face Layered Inequities in Health and Social Care](#) – A November 9 article from the California Health Report includes information from a Public Counsel [report](#) funded by our Foundation that examined Regional Center inequities.

Resources

How Definitions of Special Needs Affect Care

Federal and state program approaches to defining children and youth with special health care needs (CYSHCN) can influence how these agencies determine eligibility for health care services and supports, evaluate the impact of services, and measure outcomes. A new issue brief from the Catalyst Center and the National Academy for State Health Policy describes how states define CYSHCN within Medicaid and Title V CYSHCN programs, and explores the implications of these definitions. Read [The Role of State Medicaid and Title V Program Definitions of Children and Youth with Special Health Care Needs in the Provision of Services and Supports](#).

In Brief

- [Exceptional Parent Magazine](#) November Issue – [Annual Financial Issue](#)
- [Complex Child](#) – [November Issue](#)

National Policy

Due Soon: Comments on Federal Plan for Improving Systems for CYSHCN

The federal Maternal and Child Health Bureau is encouraging public comments and suggestions to inform its *Blueprint for Change: Guiding Principles for Advancing the System of Services for Children and Youth with Special Health Care Needs and Families*. Comments must be submitted to CYSHCN@hrsa.gov by **November 30**. [Read about the plan.](#)

In Brief

- [Trump's 'Public Charge' Immigration Rule Is Vacated by Federal Judge](#) – New York Times, 11/2/2020

Webinar

Post-Election Analysis and Discussion

Date Friday, November 13
Time 1 to 2 p.m. Pacific Time
Sponsor Association of University Centers on Disabilities (AUCD)
Details Speakers from the AUCD's Policy Team will discuss the sponsor results of the November 3 elections and consider what they could mean for the disability community. [Register.](#)

Special Education

- [Civil Rights Data Collection: The Use of Restraint and Seclusion on Children with Disabilities in K-12 Schools](#) (PDF) – A report from the US Department of Education

Did You Know?

2019 Data Available from National Survey of Children's Health

The National Survey of Children's Health has released data from 2019. The survey provides information on the physical, emotional, and behavioral health and well-being of U.S. children ages 0 through 17, their families, and their communities. Data on children with special health care needs are included. [See the data.](#)

In the News

- [As Pandemic Persists, Parents of Students in Special Ed Face 'No-Win Situation'](#)
Disability Scoop, 11/4/20

We'd like to hear from you

Let us know what's happening with your organization or family. Email newsletter editor Eileen Walsh at Eileen.Walsh@lpcfh.org with your news or updates.

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