

California Advocacy Network for Children with Special Health Care Needs

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

Transition to Adult Care

Transition Summit to Focus on Patient Advocacy

The Child Neurology Foundation is sponsoring a summit to help young adults and their families gain the knowledge, tools, and confidence to make the transition to adult care and to advocate for their needs. The summit will include live talks and pre-recorded videos released between June 15 and June 24. Each event will highlight a different topic related to the transition process. Although the focus is on neurological conditions, many of the topics have broad applicability to all CYSHCN. [Read about the events and register.](#)

Advance Planning: Key to Successful Transition for Young Adults

Helping young adults with complex medical needs make a smooth transition from pediatric to adult care is the topic of a newsletter from the Pediatric Palliative Care Coalition. The newsletter includes advice on how to prepare in advance for transition, along with a list of resources. [Read more.](#)

In Brief

- Got Transition and the American Academy of Pediatrics have developed a payment tip sheet. Go to [GotTransition.org](#) and search for *2021 Coding and Payment Tip Sheet for Transition from Pediatric to Adult Health Care*.

Home and Community Health Care

Webinar: Strengthening the Direct Care Workforce – Scaling Up and Sustaining Strategies That Work

Date Thursday, June 3
Time 9 to 10:30 a.m. Pacific Time
Sponsor Mathematica's Center for Studying Disability Policy
Details COVID-19 has had devastating effects on the already-challenged workers who provide home- and community- based care for people with disabilities. Experts will discuss evidence-based policies and practices for strengthening the direct care workforce, and will highlight state and local initiatives that have scaled up evidence-based recruitment, retention, training, and career advancement strategies. Speakers also will discuss the national and state policies that are needed to expand and sustain these efforts. [Read more and register.](#)

Webinar: Innovating Long-Term Care Models to Promote Living Longer, Healthier Lives with Dignity

Date Wednesday, June 9
Time 10 to 11 a.m. Pacific Time
Sponsor Manatt Health
Details A panel of industry leaders will examine the effects of COVID-19 on populations using long-term care, particularly on racial and ethnic minority populations. The session will explore opportunities that the pandemic created to rethink the system and chart new policies. [Register.](#)

Medical Complexity

Not Too Late to Apply to Host a Regional Complex Care Convening

The National Center for Complex Health and Social Needs has extended the deadline for proposals from organizations to hold a regional convening in their community to encourage creation of coordinated systems of care for individuals with complex health and social needs. [Read more and apply](#) by **June 9**.

Family Engagement

Family Voices Leadership Conference Sessions to Highlight Family Engagement, Equity

Two Foundation grantees will present their work at the virtual 2021 Family Voices Leadership Conference in mid-June. CYSHCN researchers will discuss *Involving Youth, Families, and Patients as Research Partners: A Comprehensive Guide to Successful Partnerships*. Family Voices will present on *Using the Family Engagement in Systems Toolkit as Evidence-based or Informed Strategy Measures for Assessing Family Engagement in Title V Programs*. The conference, which is sponsored in part by our Foundation, also will feature five workshops in a track on Achieving Health Equity. [Read more and register in English or Español.](#)

Telehealth

Reviewing Telemedicine and Home-Based Pediatric Palliative Care

Using telehealth to provide home-based palliative care for children with serious illness is a promising strategy for increasing access to care, but more robust research is needed, according to findings from a literature review conducted by researchers at Children's Hospital Los Angeles and the USC Keck School of Medicine, with support from our Foundation. [Read the abstract](#) from their journal article.

States Expand Medicaid Reimbursement of School-Based Telehealth Services

During COVID-19 many schools adapted by using telehealth, and some states implemented policies that allow Medicaid to reimburse for school-based telehealth services. An issue brief from the National Academy for State Health Policy discusses the types of policies that were implemented and key considerations for states during and beyond the pandemic. [Read the brief.](#)

COVID-19 Information

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

Webinar: Students with Special Needs – Combating Learning Loss During the Pandemic

Date Thursday, June 3
Time 4 to 5 p.m. Pacific Time
Sponsor Exceptional Parent Magazine
Details Many students with special needs have been especially hurt by learning loss due to inconsistent delivery of services during the pandemic. Speakers will offer parents practical tips for securing appropriate and effective interventions. [Register.](#)

Health Equity

- [Survey: Physician Bias Toward People with Disability and Implications for Treatment](#) – from the Better Care Playbook

Mental and Behavioral Health

- [Five Ways Pediatrics Can Support Social Emotional Development](#) – from the National Institute for Children's Health Quality
- [California's Medicaid Breakthrough: An Opportunity to Advance Children's Social and Emotional Health](#) – from the Georgetown Center for Children and Families

Resource

Including People with Disabilities in Emergency Preparedness

Mobilizing disability organizations and their local networks to foster connections with emergency and public health professionals to ensure inclusion of people with disabilities is the aim of *Prepared4ALL: Whole Community Inclusive Emergency Planning*. Prepared4ALL is an initiative of the Association of University Centers on Disabilities Technical Training Center. [Read more.](#)

Events/Eventos

Congreso Familiar Virtual 2021

[Congreso Familiar](#) es una conferencia dedicada a promover la educación y el liderazgo en familias latinas que tienen hijos o familiares con discapacidades. Únase los próximos sábados, empesando el 5 de junio a las 10 a.m. hora del Pacífico, para aprender sobre varias temas. Los presentadores hablaran sobre calificaciones para un IEP y el Departamento de Rehabilitación. [Ver el horario y registrarse.](#)

[Congreso Familiar](#) is a Spanish-language conference dedicated to promoting education and leadership in Latino families who have children or relatives with disabilities. On upcoming Saturdays, starting June 5 at 10 a.m. Pacific Time, presenters will discuss qualifications for an IEP and the Department of Rehabilitation. [See the schedule and register.](#)

Special Education

- [US Department of Education Sets Expectations for Special Education as Schools Reopen](#) – from Disability Scoop

Fellowship Opportunity

Webinar: Apply for a Casey Children and Family Fellowship

Nominations and applications are being accepted by the Annie E. Casey Foundation for an intensive executive leadership program designed to give child- and family-serving professionals the confidence and competence to lead major system reforms and community change initiatives that get equitable results. The Casey Foundation will host a webinar about the [fellowship](#) and the selection process on **June 10** at 11 a.m. Pacific Time. [Register.](#)

In the News

- [How America Failed Students with Disabilities During the Pandemic](#)
Washington Post, 5/20/21
- [Teen's Documentary about Life with Disabilities to Screen Worldwide](#)
Disability Scoop, 5/18/21

We'd like to hear from you

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

[Join the 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. Through grantmaking, advocacy, and communications, the Foundation promotes a system of care that improves the lives of children with special health care needs and their families.

