

## California Advocacy Network

for Children with Special Health Care Needs

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

### Network News

#### New Grants: Implementing Care Coordination Standards, Assessing Impact of COVID-19 Policy Changes on CSHCN

Four grants recently awarded by our Foundation address the adoption of care coordination standards, the effects on CSHCN of federal, state and provider COVID-19-related policy changes, family engagement in California policymaking, and the results of California's Title V needs assessments over time. [Read more about the grants.](#)

### Transition to Adult Care

#### Options for Improving Transition for Youth

The vast majority of youth with and without special health care needs do not receive the necessary services to transition from pediatric to adult care. Without adequate support during this transition, they face an increased risk of adverse outcomes. In a new paper, produced with support from our Foundation, the National Alliance to Advance Adolescent Health highlights a series of implementation, payment, and research options that could accelerate adoption of recommended transition processes. [Read more.](#)

### CSHCN and Equity

#### Data Analysis Documents Disparities for Children with Special Health Care Needs

A 2020 issue brief from Child Trends examines the most recently available data on children and youth with special health care needs and their families. Findings indicate that, compared to their peers without special health care needs, CSHCN are more likely to experience circumstances that pose challenges to their well-being in economic, academic, and social-emotional domains, in addition to health. Racial and ethnic disparities in access to opportunities and supports exacerbate inequities that CSHCN and their families experience, the study reports. [Read the issue brief.](#)

#### For Mothers of Black Children with Disabilities, Living with Twice the Fear

In a *Forbes* column, Black parents describe their concerns about how their children's disabilities make them more vulnerable when they are out in public, and how some disability-related behaviors might affect their child's interactions with police. [Read more.](#)

### Children with Medical Complexity

#### Hospital's Care Coordination Team Reduces Stress on Families

To assist in care coordination for families of children with the highest levels of medical need, Lucile Packard Children's Hospital Stanford operates the Coordinating and Optimizing Resources Effectively (CORE) program. This "virtual clinic" offers a range of services for parents who are trying to navigate the complexities of the health care system and manage care across multiple subspecialties and community services. Team members help parents find ways to stay on top of overwhelming logistics and facilitate communication between a family and their subspecialists, and among the subspecialists themselves. [Read more.](#)

### COVID-19 Information

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

- [Coping with Disrupted Routines During COVID-19](#), a video from the [Child Neurology Foundation](#), features a parent of a child with special needs and a manager of an autism learning program.
- The [US Department of Education](#) has issued guidance for [dispute resolution](#) in special education during the pandemic.
- The [California Department of Developmental Services](#) has updated its [COVID-19 webpage](#) as of June 24, with many items presented in multiple languages.
- [Health Equity Principles for State and Local Leaders in Responding to Reopening and Recovering from COVID-19](#) is the subject of an issue brief from the [Robert Wood Johnson Foundation](#).
- Webinar: [Supporting People with Serious Illness During the Pandemic: The Growing Need for Palliative Care](#) – Tuesday, June 30, 10 – 11 a.m. Pacific Time, sponsored by the [National Academy for State Health Policy](#). Not pediatric specific.

### California Children's Services

#### CCS Advisory Group to Meet

**Date** Wednesday, July 8  
**Time** 11 a.m. Pacific Time. [Register](#). Please check the website closer to the meeting date to confirm the time.  
**Dial-In** 1 (415) 655-0001; Passcode: 1456495142  
**Details** Details are provided on the Advisory Group [website](#).

#### New Director for Department of Health Care Services

Will Lightbourne has taken the helm of the Department of Health Care Services as of June 16, replacing Brad Gilbert, who served since January after coming out of retirement. The Department oversees California Children's Services and Medi-Cal, both of which serve children with special health care needs. [Read about the new director.](#)

### Family Engagement

#### Caregivers of Children with Serious Illness Sought for Study

The National Alliance for Caregiving is developing a guidebook for caretakers of children with serious illness. The researchers are seeking past and current caregivers to participate in a focus group discussion in July to share experiences that will inform the creation and development of the guidebook. [Read more](#) (PDF).

### Pediatric Palliative Care

#### Virtual Town Hall: Grief and Memorialization During COVID-19

**Date** Tuesday, June 30  
**Time** 12 p.m. Pacific Time  
**Sponsors** Pediatric Palliative Care Webinar Series and the Social Work Hospice and Palliative Care Network  
**Details** A panel of pediatric palliative care social workers and researchers will discuss research, clinical observations, and methods for supporting families and care teams in light of the grief related to both COVID-19 and the racial inequities that recently have received increased public attention. [Read more and register.](#)

### National Policy

- [Advocates Seek Senate Action on HEROES Act, the House-passed COVID-19 Relief Bill that Helps People with Disabilities](#) – The Arc, 5/19/20
- [Hospitals Told to Allow Visitors for Individuals with Disabilities](#) – Disability Scoop, 6/10/20

### California Policy

#### Major Budget Cuts Possibly Avoided as Deal Reached

Californians may be spared some of the steep budget cuts that the Governor had proposed, including reductions in funding for services that support individuals with special needs and their families. Details of the budget, which depends on assistance from the federal government, are not yet available. [Read more.](#)

### Special Education

- [School Groups Want Flexibility on Special Ed Spending Due to COVID-19](#)
- [Parents, Educators Split Over Resuming In-Person Special Education](#)

### Resource

- [Exceptional Parent Magazine](#) June Issue – [Summer Fun](#)

### Did You Know?

- [The Case for Inclusion 2020](#) is a comprehensive assessment of how well programs in all 50 states and the District of Columbia are serving people with intellectual and developmental disabilities.

### In the News

- ['I Only Like Mom School': Why My Autistic Son Thrived During the Pandemic School Closures](#)  
*Washington Post*, 6/22/20

#### 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@lpfch.org](mailto:Eileen.Walsh@lpfch.org) with your news or updates.

