

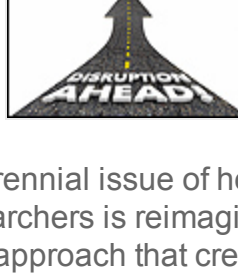
California Advocacy Network

for Children with Special Health Care Needs

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

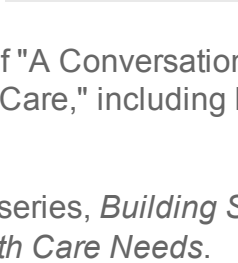
Children with Medical Complexity

Disruption Ahead! A Human-Centered Design Approach to Care Coordination



Taking a fresh look at the perennial issue of how to provide effective care coordination, a team of researchers is reimagining the process using human-centered design, an approach that creates systems based on users' expressed needs. The goal is to integrate medical, educational, financial, and other services so that the needs of children, families, providers, and payers can be met more effectively. The researchers suggest that disruption of the current system may be necessary to implement this approach, and they note the potential roadblocks to change. [Read the report.](#)

Recap of Conversation on Payment Models

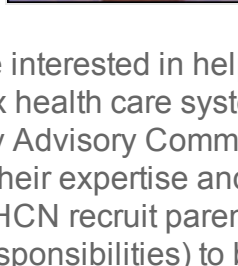


The [slides and a recording](#) of "A Conversation on the Effect of Payment Models in Children's Health Care," including links to related information, are available.

See [all conversations](#) in the series, *Building Systems that Work for Children with Complex Health Care Needs*.

Family Engagement

Top Tips for Engaging Families in Advisory Roles



Many parents of CSHCN are interested in helping to improve the quality and efficiency of the complex health care systems in which they and their children are involved. Family Advisory Committees (FACs) are one venue in which families can share their expertise and perspectives. But how do organizations that serve CSHCN recruit parents (already busy beyond the realm of normal parenting responsibilities) to become a committee member, and how can they keep them engaged? Teresa Jurado, an experienced advisory committee chair, [offers her tips.](#)

Care Coordination

Webinar: Medicaid Managed Long-term Services and Supports Programs for CYSHCN

Date Tuesday, December 4
Time 12 p.m. to 1 p.m. Pacific Time
Sponsor National Academy for State Health Policy (NASHP)
Details States increasingly are providing services to Medicaid beneficiaries with complex health care needs through managed care delivery systems. Some states also are starting to include behavioral health and long-term services and supports (LTSS) in Medicaid managed care. This webinar will provide an overview of a recent NASHP analysis of how state Medicaid LTSS programs serve CYSHCN, and the potential of these programs to improve care and quality of life. [Register.](#)

Network News

Last Call: The deadline for submitting a letter of inquiry for grant funding from the Lucile Packard Foundation for Children's Health for the upcoming docket is **December 5**. [See the application process.](#)

California Children's Services

New Members for CCS Advisory Group

Three individuals have joined the CCS Advisory Group, which provides counsel to the Department of Health Care Services on CCS operations, including the ongoing transition of some CCS clients to Medi-Cal managed care. [Read more.](#)

In Brief

- [Centers for Medicare and Medicaid Services \(CMS\) Releases Proposed Medicaid Managed Care Regulations](#) – from Health Management Associates. Summarizes key provisions of proposed regulations to update several sections of the Medicaid and Children's Health Insurance Program (CHIP) managed care rules.

Transition to Adult Care

New Transition Coding and Reimbursement Tip Sheet

Got Transition and the American Academy of Pediatrics have released a 2018 Transition Coding and Reimbursement Tip Sheet to support the delivery of recommended transition services in pediatric and adult primary and specialty care settings. [See the tip sheet.](#)

In Brief

- [Transition of Care](#) – An extensive list of resources for providers and families. Compiled by the Child Neurology Foundation but applicable to many children and youth with special health care needs.

Health Care Financing

Documenting Inequities in Insurance Coverage for CSHCN

As part of a series on health care financing, the Catalyst Center has created a one-page infographic illustrating important elements of inequities in coverage and financing of care for CSHCN. This infographic notes several subgroups of children who are less likely to be adequately insured and face a greater risk for adverse health effects as a result. [See the infographic and related resources.](#)

Quality Standards/System Improvement

In Brief

- [Creating Better Systems of Care for Adults with Disabilities: Lessons for Policy and Practice](#) – from The Commonwealth Fund. Focused on adults, but relevant to CSHCN. The report highlights health plans and clinics that have created custom models for people with different types of disabilities: physical, intellectual and developmental, and those related to serious mental illnesses.

National Policy

Webinar: The Public Charge Rule – What It Is and How It Will Affect Children and Families

Date Wednesday, December 5
Time 12 p.m. to 1 p.m. Pacific Time
Sponsor Family Voices of California
Details Children Now will give an overview of the proposed Public Charge Rule, which may affect benefits for children from immigrant families, including children with potentially life-threatening conditions and special needs. Learn about the proposed change and its potential impact on children. Comments on the proposed rule are due by **December 10**. [Read more and register.](#)

Also See:

- [Public Charge Rule Would Have Significant, Negative Impact on Immigrants' Health Care and the Safety-Net Delivery System](#) – from The Commonwealth Fund
- [Public Charge Resource Sheet](#) (PDF) – from Community Health Councils

Bills to Watch

[Health Homes for Chronically Ill Kids Spark Lame-Duck Battle](#) (HR 3325) – The Advancing Care for Exceptional (ACE) Kids Act, a bill that is widely supported by children's hospitals, is running into some opposition. The bill would allow a state Medicaid program or child health plan to provide coordinated care through enhanced pediatric health homes for children who have complex medical conditions, even allowing enrollment across state lines.

California Policy

Town Hall Listening Session: Assembly Select Committee on Intellectual and Developmental Disabilities

Date Wednesday, December 5
Time 5:30 p.m. to 7:30 p.m. Pacific Time
Location Riverside County Board of Supervisors Chambers
4080 Lemon Street, Riverside
Details One in a [series of listening events](#) around the state. An opportunity to speak directly to the Legislature about experiences with Regional Centers or related topics. [Read more](#) (PDF).

Webinar

Deep in the Weeds: Medical Marijuana and Pediatric Palliative Care

Date Thursday, December 6
Time 12 p.m. to 1 p.m. Pacific Time
Sponsor Coalition for Compassionate Care of California, in collaboration with the Pennsylvania Pediatric Palliative Care Coalition and Greater Illinois Pediatric Palliative Care Coalition
Details Will include discussion of the history of medical marijuana and the current medical marijuana laws in the United States, as well as current evidence and recommendations for medical marijuana use in pediatric palliative care. [Learn more and register.](#)

Resources

- [Sensory-Friendly Santa](#) – To assist families of children with special needs, a visit with Santa in a subdued and calm environment is available at various locations across the country. [Check your state.](#)
- *Exceptional Parent Magazine* November issue – [Financial Planning](#)

Employment Opportunity

Family Engagement Manager Sought

Family Voices of California is accepting applications for a Family Engagement Manager to conduct statewide outreach, education, training, and activation of families around health policy issues. Located in San Francisco or Sacramento, this is a full-time position with a benefits package. [Learn more and apply.](#)

In the News

- [Improv Therapy Helps Pediatric Patients Laugh](#)
Children's Hospital Association, 11/19/18
- [With Brain Implants, Scientists Hope to Translate Paralyzed Patients' Thoughts into Speech](#)
STAT, 11/15/18

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 with your news or updates.

