



California Children with Special Health Care Needs and Their Families

Resources from the Lucile Packard Foundation for Children's Health

In California, more than one million children have a special health care need, which is a chronic physical, developmental, behavioral or emotional condition that requires more than routine health and related services. The Lucile Packard Foundation for Children's Health works in three focus areas, systems standards and quality, care coordination and family engagement, to improve the system of care for children with special health care needs and their families. Below is a list of select resources by focus area. You can learn more about our work at lpfch.org/cshcn.

System Standards and Quality

- Standards for Systems of Care for Children and Youth with Special Health Care Needs (Version 2) [\[Link\]](#)
- The Health of Latino Children and Families in California [\[Link\]](#)
- What Children with Medical Complexity, Their Families, and Healthcare Providers Deserve from an Ideal Healthcare System [\[Link\]](#)
- Putting a Spotlight on Children with Health Complexity: Overview of a Novel and Applied Methodology to Identify Children with Health Complexity In Order to Inform Investments and Improvements [\[Link\]](#)

Care Coordination

- Pediatric Integrated Care Survey [\[Link\]](#)
- Achieving a Shared Plan of Care [\[Link\]](#)
- Aligning Services with Needs: Characterizing the Pyramid of Complexity Tiering for Children with Chronic and Complex Conditions [\[Link\]](#)
- The 'Hidden Health Care System' in California Schools and Children with Special Health Care Needs [\[Link\]](#)
- Threading the Labyrinth: Why Children in California with Special Health Care Needs Endure Delays in Securing the Medical Equipment and Supplies They Need [\[Link\]](#)
- Access to Mental Health Services for Children with Special Health Care Needs: Analysis and Recommendations [\[Link\]](#)



Family Engagement

- In Their Own Words: Improving the Care Experience of Families with Children with Special Health Care Needs [\[Link\]](#)
- Engaging Families in Improving the Health Care System for Children with Special Health Care Needs [\[Link\]](#)
- Family Engagement in State Title V Maternal and Child Health (MCH) and Children with Special Health Care Needs (CYSHCN) Programs [\[Link\]](#)
- A Framework for Assessing Family Engagement in Systems Change [\[Link\]](#)
- Project Leadership: Effecting Change, One Parent at a Time [\[Link\]](#)
- How California Children's Services Programs in the 21 Whole-Child Model Counties Engage with Families [\[Link\]](#)
- It Takes A Family: An Analysis of Family Participation in Policymaking for Public Programs Serving Children with Special Health Care Needs in California [\[Link\]](#)

For additional questions or inquiries, please contact the Lucile Packard Foundation for Children's Health via email: info@lpfch.org.

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