



Working Together to Improve California's System of Care for Children with Special Health Care Needs

An Invitation to Join a New Statewide Collaborative

November 16, 2010

Dear Colleague:

California is home to 1.4 million Children with Special Health Care Needs. Yet our state ranks *last in the nation* on a minimum quality of care index that assesses adequacy of insurance, provision of basic preventive care, and meeting minimal criteria for care that is ongoing, comprehensive, coordinated, and family-centered.

This striking finding comes from a just-released study, [Children with Special Health Care Needs: A Profile of Key Issues in California](#), commissioned by the [Lucile Packard Foundation for Children's Health](#) and prepared by the Child and Adolescent Health Measurement Initiative (CAHMI).

The researchers also found that California ranks at or near the bottom nationally on numerous other measures, including transition to adult health care, stress among parents, and receipt of needed mental health services.

Such troubling findings will come as no surprise to California families who are caring for a child with special needs, or to the thousands of individuals throughout the state who work with, and on behalf of, these children and their families. The roadblocks that prevent development of a high-quality system of care are longstanding, complex, and difficult to overcome.

At the Lucile Packard Foundation for Children's Health, we believe that these findings signal that the time has come to join forces in a new way to bring about broad and lasting change. Two years ago, the Foundation's board of directors approved a [new focus area](#) on improving health outcomes for Children with Special Health Care Needs. Since that time, the Foundation has held several convenings with a wide range of knowledgeable individuals to develop a model for a higher quality care system. Now, we are launching the California Collaborative for Children with Special Health Care Needs to create a shared agenda and to advocate for changes that bring the system closer to this model.

A key goal of this ongoing, statewide Collaborative will be to look beyond specific organizational issues and speak with one voice to decision-makers about the need for a more effective and efficient system for *all* children with special needs. The Collaborative will not replicate the many valuable efforts under way throughout the state, but will offer a unique opportunity for a cross-system partnership that can assemble the critical mass necessary to bring about significant change.

Collaborative members will include patients, families and caregivers, providers, insurers, disease-specific advocacy organizations, educators, researchers, and public and private agencies. Members will share information and will address issues that matter to all of these constituencies, such as:

- Ensuring adequacy of insurance
- Easing access to medical specialists, and educating primary care providers about special health care needs
- Improving care coordination
- Making support for families an integral part of public policies related to special needs
- Addressing ethnic and income disparities in care
- Smoothing the transition to adult health care

Our Foundation is committed to working with others on a long-term basis to bring these issues to public attention and to achieve results. We are investing staff time and resources to ensure that this Collaborative becomes a successful reality. We hope you will [sign up](#) now to receive information about the Collaborative as it develops.

Sincerely,

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