
Executive Summary

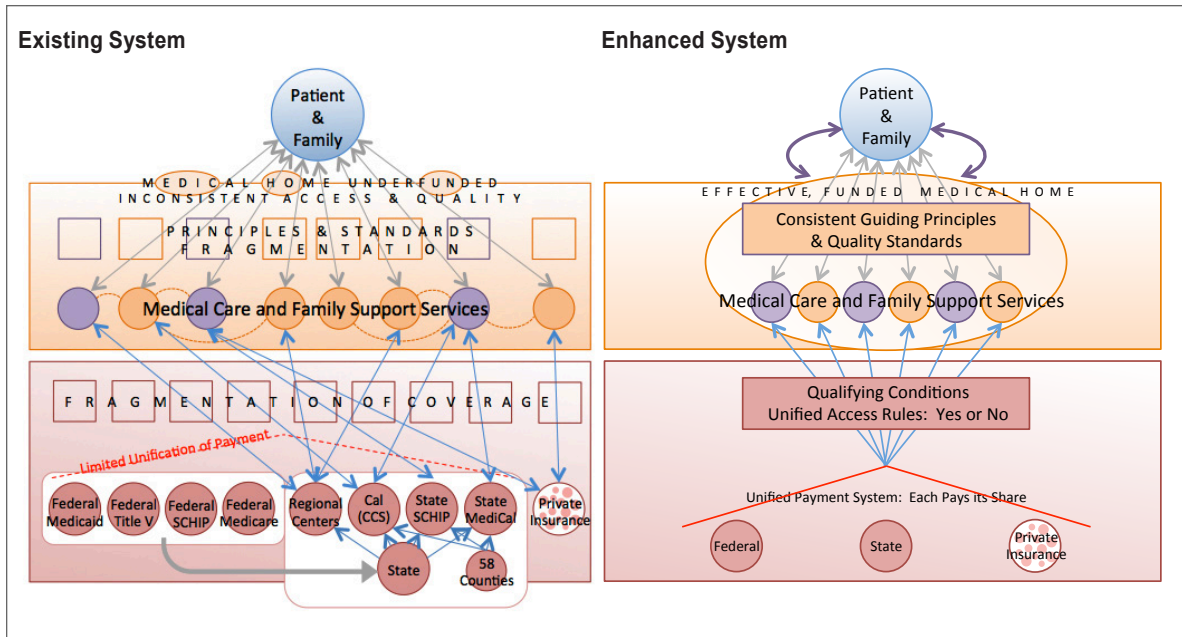
Tremendous advances in pediatric health care over the past several decades have created a challenge for those who care for children. While growing numbers of children survive previously fatal illnesses, many of them now live permanently with complex chronic conditions. Unfortunately, our health care system has not evolved along with this historic shift in childhood epidemiology, and our delivery system continues to be organized primarily around the needs of children with acute illnesses.

When children with chronic conditions are acutely ill, they generally receive high-quality, well-coordinated medical care. Once the acute stage has passed, however, families typically find that ongoing care for the child involves uncoordinated and costly services and programs. Lack of communication among providers, limited access to pediatric subspecialists, inconsistent eligibility criteria for service, multiple sources of provider reimbursement and lack of quality standards all contribute to less than optimal care. The result often is adverse health outcomes for children, tremendous strain on families, and increased costs both for families and for the health care system.

To address these issues, the Lucile Packard Foundation for Children's Health since 2009 has been investing in strategies to improve the system of health care for California's children, with a particular emphasis on children with special health care needs (CSHCN).

The Foundation sponsored two [facilitated convenings](#) to achieve consensus on the strengths and weaknesses of the California's current system for CSHCN. Convening participants included parents, care providers, youth with special needs, public officials, academic researchers, educators and health plan administrators. (See Appendix for convening details and lists of participants.)

Using industrial design techniques, participants in these convenings created a model of the current system of care, documenting its complexity and highlighting the number and breadth of participants in the system and the multitude of their interactions. Convening participants then assessed areas of fragmentation and the significant variability in the extent of coverage and quality of care that children receive. The result was a model of the system as it now operates, compared to an "enhanced" model that would encourage better health outcomes for children with special health care needs and a better quality of life for these children and their families:



The enhanced model identifies five key points for beginning system change:

1. Fragmented coverage by public programs should be unified by the adoption of **simplified and uniform eligibility criteria**.
2. A **uniform benefits package** should be adopted for all children with special health care needs regardless of their source of coverage.
3. Fragmented payment from multiple state programs and private insurance should be replaced with a **unified system of payment**.
4. Inconsistent standards for system performance and quality standards for care providers should be replaced by **consistently applied, evidence-based guiding principles and quality standards**.
5. The absence of both accountability and coordination should be addressed by the **adoption of the family-centered medical home concept**, to be implemented systematically and uniformly throughout the state.

Moving toward an enhanced system will require the concerted, long-term efforts of all of those who interact with the system — families, policymakers, care providers, insurers and many others.