

Issue Brief

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An Enhanced Model of Health Care for Children with Special Health Care Needs in California

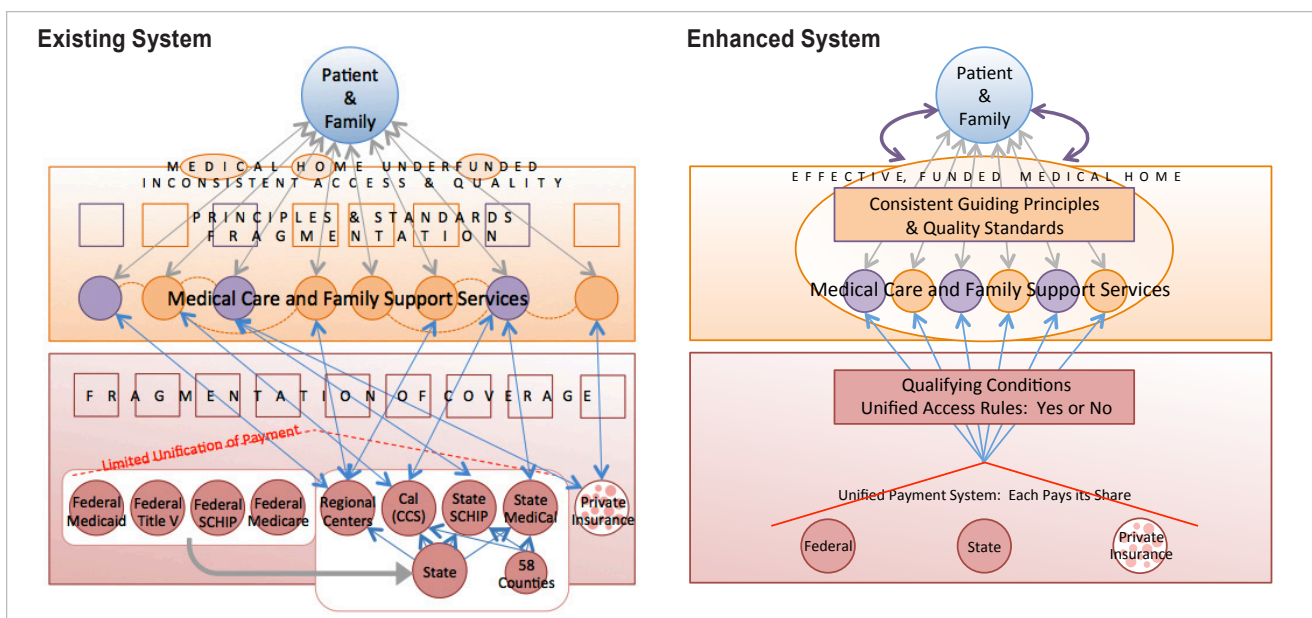
The pattern of children's illness has changed dramatically in recent decades. Thanks to medical advances, growing numbers of children now live with complex, chronic conditions that previously would have been fatal. Unfortunately, our health care system has not evolved along with this historic shift in childhood epidemiology, and care continues to be organized around acute illnesses.

When children with chronic conditions are acutely ill, they generally receive good-quality medical care. Once the acute stage has passed, however, families frequently find that ongoing care for the child involves a range of uncoordinated 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 suboptimal health care for children, unnecessary stress and 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 state's current system for CSHCN. Convening participants, both local and national, included parents, care providers, youth with special needs, public officials, academic researchers, educators and insurance plan administrators.

Using industrial design strategies, participants in the convenings described the current system of care. They documented the number and breadth of participants in the system and the complexity of their interactions. They then assessed areas of fragmentation and the significant variability in the extent of coverage and quality of care 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:



Given the multiplicity of payers and service providers, the lack of care coordination, shortage of pediatric subspecialists, low reimbursement rates from public programs and absence of consistent quality standards, California's system of care clearly is in need of reform. A [report](#) published in 2012, *Children with Special Health Care Needs in California: A Profile of Key Issues*, documents the many ways in which the state lags far behind other states in providing a high quality system.

Acknowledging these many challenges, it still is possible to conceive of an enhanced, better performing system of care, but achieving it will require substantial changes in programs and policy. Specifically:

Unified Financing and Uniform Benefits —

The first and most substantial change under the enhanced model is unification of payment. This does not mean a *single payer system*. Rather it would mean creation of an entity, perhaps a claims clearinghouse, to which all claims would be submitted and through which they would be paid, regardless of the insurer responsible for that care. Ideally, the benefits package would be standardized for all children with special health care needs, and providers would be paid uniformly. Public and private payers would need to coordinate their work to create a unified payment system.

Standardized Eligibility Determination —

It has long been acknowledged that public programs create complexity and confusion because each has its own eligibility criteria. Although it may not be possible, in the short term, to standardize eligibility criteria, creating opportunities to operate programs in a more uniform manner is a reasonable goal. The definition of qualifying conditions would also be consistent throughout the state.

One approach to standardization is unification through the creation of a statewide care management system. An administrative agency created under this model, perhaps a form of an accountable care organization, would have responsibility for a sufficient volume of children with rare and complex conditions to learn how to manage these conditions effectively. The definition of qualifying conditions would be consistent statewide. Eligibility would be based on complexity of needed care rather than diagnosis. The system would include all children with special needs regardless of their

primary source of insurance coverage; it would incorporate care according to care guidelines and continuing quality improvement; and it would provide for high quality care coordination.

Adequate Provider Reimbursement — Low payment levels for providers in public programs is a persistent issue with a simple but politically difficult solution — raise levels of provider reimbursement sufficiently to assure access. Payment rates are closely tied to state and county budgets. Payment rates affect the willingness of health care providers to accept patients/clients and can influence the content and quality of care. Therefore, raising provider rates is critical to reforming health care systems to better care for children with special health care needs.

Care Principles and Quality Metrics — The enhanced model requires systems and providers to be accountable for specified levels of performance, i.e., quality and efficiency, regardless of where care is being provided. To the extent possible, care should be informed by evidence. In addition, system monitoring should be comprehensive and transparent, but should not be used punitively; rather, it should be part of a process of continuous improvement of system operation and of the care of the children and families being served.

Medical Home — A medical home is a central aspect of a system for children with special health care needs. Although that concept is still evolving, sufficient work has been done to delineate the essential elements of a medical home so that it is possible to evaluate the extent to which practices have the structural capacity to meet the needs of children and families. In addition, care coordination, which is consistently identified by families as a critical service, is an essential element of medical homes. Care coordination needs to be defined, supported by a community or statewide infrastructure, and routinely provided as a covered benefit.

Family-Centered Care — Family-centered care has been a defining characteristic of medical homes since the introduction of the concept by the American Academy of Pediatrics. A family-centered care system begins with the acknowledgement that the family is the constant in a child's life, and that the best outcomes are achieved when families and professionals work together

respectfully in the best interest of the child. This kind of partnership requires frequent, open communication and information sharing that is the basis of mutual decision-making. Family-centered care also supports families, not only in the decision-making process, but also by striving to enhance the capacity of families to meet the needs of their children, other family members, and other families in their community.

Accountable Care — Overarching all of the above components of an enhanced model of a system of care for children with special health care needs must be determination and acceptance of accountability. Policymakers and system managers are accountable for removing barriers to efficient, high quality care, for creating realistic budgets, and for creating alignments between payment and the performance they desire. The performance metrics they adopt in conjunction with providers and families must be important, feasible, timely and transparent. Health care providers are responsible for the efficiency and quality of care they provide, and for patients' care experiences. Families and patients are responsible for communicating information to their child's providers, for actively participating in decision-making, and for being the primary care giver, care coordinator, source of social and emotional support and advocate for their child.

The Lucile Packard Foundation for Children's Health will continue to invest in promoting and facilitating these changes through its grant making programs, advocacy efforts and communications activities. Though sweeping change will not take place all at once, careful planning and determined effort can result in improved clinical outcomes for children with special needs, and enhanced quality of life for these children and their families.

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