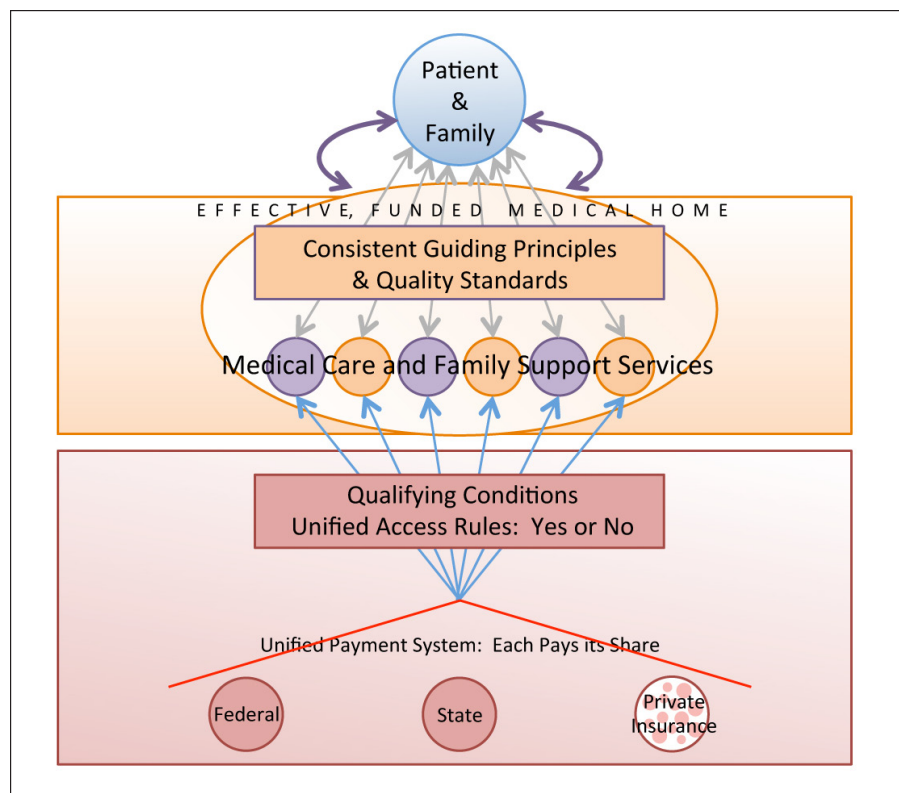


Report

Strengthening the System

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



Foreword

Dear Colleague,

If you could create an ideal system of care for children with special health care needs and their families, what would it look like?

To address this question, the Lucile Packard Foundation for Children's Health convened dozens of experts and asked them to take a step back from their roles in the existing health care delivery system and imagine a reconfigured system that would produce optimal health outcome for children and families.

Using industrial design techniques, participants in these convenings identified weaknesses in the current system and proposed alternatives. They then constructed a model of an enhanced system, which is described in this report. The model, developed jointly by families, care providers, insurers, researchers and policymakers, has largely informed our Foundation's investments and strategies to improve the system of care.

We hope you will join with us and hundreds of others in advocating for an improved system by [signing up](#) for the California Advocacy Network for Children with Special Health Care Needs.

David Alexander, MD
President and CEO
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ABOUT THE FOUNDATION: The Lucile Packard Foundation for Children's Health works in alignment with Lucile Packard Children's Hospital and the child health programs of Stanford University. The mission of the Foundation is to elevate the priority of children's health, and to increase the quality and accessibility of children's health care through leadership and direct

Executive Summary

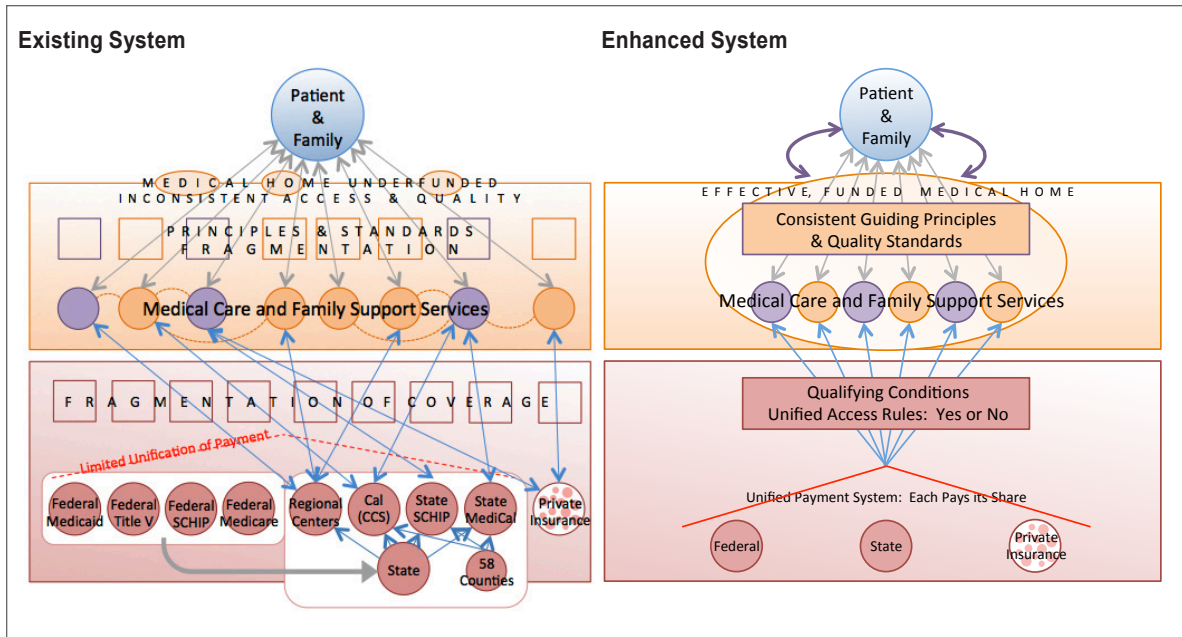
Tremendous advances in pediatric health care over the past several decades have created a challenge for those who care for children. While growing numbers of children survive previously fatal illnesses, many of them now live permanently with complex chronic conditions. Unfortunately, our health care 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.

Introduction

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The Existing System

In California, children with special health care needs and their families currently must interact with multiple systems whose policies and operations vary widely. The public systems serving these children tend to be administered or regulated by separate government agencies at the state and county levels. These agencies receive funding from different sources according to various rules. They also apply different eligibility criteria, use different data collection and information systems, and provide related but uncoordinated and thus fragmented and sometimes duplicated services. Added to these are private insurance programs and other privately provided services. Such a hodge-podge of systems inevitably yields inequalities in services, accessibility, quality and cost.

Figure 1 shows four of the major elements of the system, with the patient and family at the center:

- The patients and their family members.
- The payers who fund the system, often through intermediary agents, i.e., insurance companies.
- The health care professionals who provide the clinical care.
- The family support organizations that provide additional care and services.

Figure 1: Some Major Participants in the System

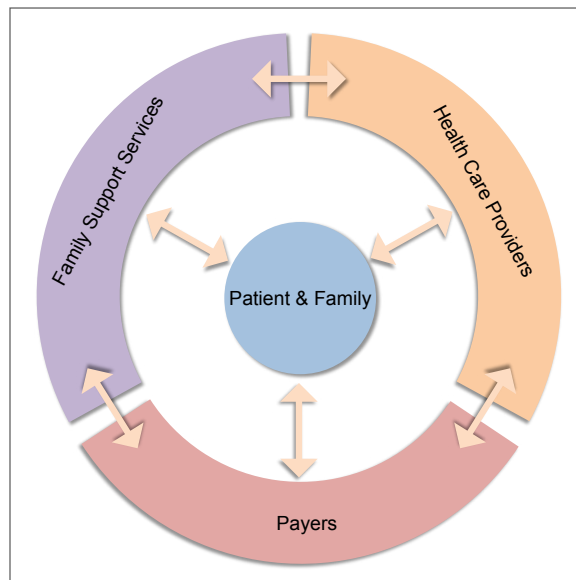


Figure 2: Interactions Among System Participants



Figure 2, while not exhaustive, highlights the types of complex interactions with which families must cope on a regular basis. The bottom of Figure 2 lists some of the many public agencies that pay for services for children with special needs, and also notes the role of private payers.

Another way to view the current system places the payers at the bottom, the service providers in the middle, and the patient and family at the top (Figure 3). This model shows the complexity of the payer and service provider aspects of the system.

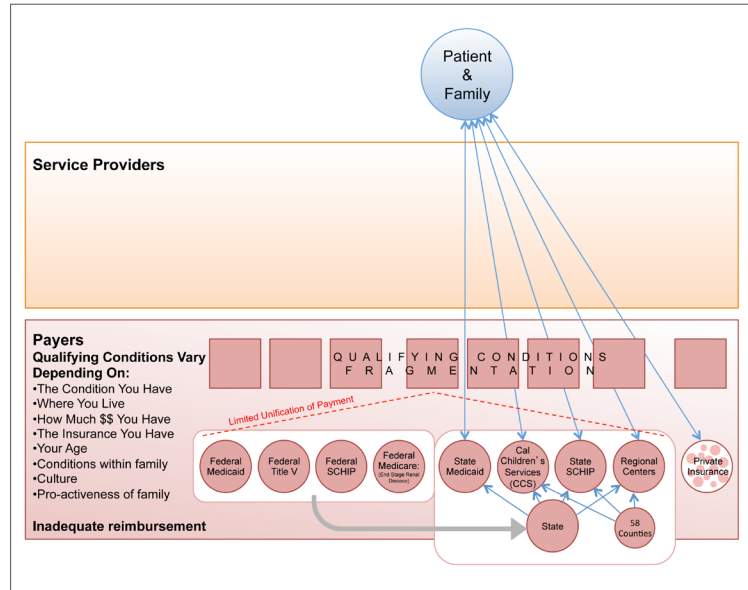
Payment Sources

Federal Funding

As Figure 3 illustrates, the federal government provides four major sources of funding for children with special health care needs.

- 1) **Medicaid** — The federal government contributes to Medicaid (Medi-Cal in California), which is not an insurance plan but a financing method for state-run insurance plans. Federal funding is provided according to a formula that matches state funds. The matching rate or ratio of federal to state dollars varies, but in California the ratio is 1:1, i.e., 50% federal to 50% state funds.

Figure 3: Model of Existing Systems for Financing and Payment of Care



Fragmented Payment System: Each pays according to different guidelines. Eligible conditions overlap among some payers.

Federal Medicaid regulations set minimum eligibility standards based on household income for participation in state programs. Eligibility also includes documentation of citizenship, though legal immigrants who have been in the United States for at least five years are eligible, and states have the option to offer coverage to lawfully residing immigrant children using state funds. Medicaid regulations also establish important standards for the benefits that state programs must offer, including guaranteeing access to a comprehensive package of services for children known as the Early Periodic Screening, Diagnosis and Treatment (EPSDT) program. The EPSDT program guarantees “medically necessary care” for children enrolled in state Medicaid programs. In general, when states offer more generous eligibility or benefits and thus expend more state dollars, the federal contribution increases to maintain the predetermined matching rate.

- 2) **Title V Maternal and Child Health Block Grant** — Each state is eligible to receive federal grant funding from the Maternal and Child Health Bureau (MCHB) intended to ensure the health of mothers, women, children and youth, including children and youth with special health care needs, and their families. State maternal and child health programs may serve as the payer of last resort for direct services not covered by any other program. As with Medicaid, states are expected to match federal dollars. States must match every \$4 of Federal Title V money with at least \$3 of state or local money. States are required to spend at least 30 percent of their funding on primary and preventive services for children and also are required to spend at least 30 percent on children with special health care needs. Title V does not include a citizenship determination in order to receive services.

- 3) **Children’s Health Insurance Program (CHIP)** — This federal program provides matching funding to help states provide health care coverage, including medical, dental and mental coverage, to children whose family income is too high for Medicaid but less than three times the federal poverty level. The federal government share of CHIP funding generally is higher than it is for Medicaid funding. In California, the federal contribution is equivalent to 65 percent of expended dollars. CHIP eligibility is limited to citizens and legal immigrants. Current federal funding is authorized until October 1, 2015.
- 4) **Medicare** — Medicare is a financing and health insurance program operated by the federal government and has no state component. It contributes in a limited way toward the care of children with special health care needs, in that it pays for end-stage renal disease for patients of all ages. Medicare does not include an income eligibility determination and instead is based on age or disability.

California Funding

The state also plays a pivotal role in obtaining and expending federal health care dollars, as well as contributing substantially to the pool of available resources.

In California, children may receive services from several programs at the same time. Figure 3 shows the major state programs on which families of children with special health care needs depend. These programs operate independently and are run by separate state departments and agencies. The inherent fragmentation of responsibility and resources is a major shortcoming of California’s ability to care for children with special needs.

- 1) **Medi-Cal** — In California, the Medicaid program is known as Medi-Cal. Children who are citizens or legal immigrants and whose families meet annual income restrictions are eligible to receive health care financed by Medi-Cal. Income eligibility varies with the age of the child. Infants ages 0-1 whose family income is less than 200 percent of the federal poverty level (FPL) are eligible; the income eligibility limit for children ages 1-5 is 133 percent of the (FPL) and for children 6-19 it is 100 percent of the FPL. In 2010, more than 3.2 million children (about 40 percent of the state’s child population) were enrolled in Medi-Cal.

Medi-Cal payments to physicians in California are among the lowest in the nation, which reduces the incentive for physicians to care for children covered by Medi-Cal or to care for them comprehensively. This limits patient access to care. Payments to hospitals are similarly low. Providers typically rely on higher payments from private sector insurers to offset these low Medi-Cal reimbursements.

- 2) **California Children’s Services** — Many states have established separate programs, often supported by Title V funding, to support an administrative and services infrastructure to supplement care of children with special health care needs, most of whom are covered by Medicaid programs.

California is relatively unusual in having a separate program, California Children’s Services (CCS), which is supported primarily with state and county funds, and pays for children’s health care for certain chronic conditions. While the list of conditions that CCS covers is long, it is also arbitrary, meaning that some serious conditions are not covered, and others are covered that may not truly constitute a special need.

Like Medi-Cal, CCS is operated by the California Department of Health Care Services. Children whose family income is \$40,000 or less are eligible for CCS, as are families whose out-of-pocket cost of caring for the child's condition exceeds 20 percent of the family's income. Since CCS pays only for care related to a covered condition, other health care needs of these children, such as preventive care, is paid for by another source, such as Medi-Cal.

CCS programs also play a role as direct service providers to children with qualifying conditions who need occupational and physical therapy. Programs operate medical therapy programs (MTP) for children who have handicapping conditions, generally due to neurological or musculoskeletal disorders. The medical therapy programs also provide medical case management through use of an interdisciplinary team meeting.

California Children's Services (CCS)

- Largest single payer for specialty care for children in California
- Coverage provided for specific conditions only
- Whole child not covered
- Covers only poor children
- 180,000 children currently enrolled
- \$2 billion annual cost
- Variability in administration by county
- Sets baseline standards for care for children in California

CCS limits payment to a panel of credentialed health care providers, generally pediatric subspecialists. The program also pays these providers at a higher fee-for-service rate than does Medi-Cal, a policy that has facilitated access to care for children with special health care needs. Currently the state spends almost \$2 billion annually on CCS, and serves about 180,000 children. Like Medi-Cal, the CCS program is a decentralized program, operated by individual counties, each of which contributes local funds to support its operation. Because the distribution of children with special health care needs varies among counties, and county revenue also varies, the relative support given to CCS programs differs among the counties.

- 3) **Healthy Families** — California's version of the Children's Health Insurance Program (CHIP) is called Healthy Families, and serves children whose family income is too high for them to qualify for Medi-Cal. The state began to phase out the program in January 2013, and it plans to move 875,000 children to Medi-Cal coverage.
- 4) **Regional Centers** — California's Department of Developmental Services operates another service frequently used by children with special health care needs: the Regional Centers. The 21 Regional Centers are independent non-profit, state-funded organizations that were set up to provide case management and coordination for children with developmental disabilities, generally children with epilepsy, cerebral palsy, autism, or mental retardation. Infants and toddlers (age 0 to 36 months) who are at risk of having developmental disabilities or who have a developmental delay also may qualify for services. The centers provide diagnostic services, and help families plan, access, coordinate and monitor services that are needed because of a developmental disability.
- 5) **Health Benefit Exchange** — Under provisions of the Affordable Care Act, California has established a Health Benefit Exchange known as Covered California. Beginning in January 2014, some children with special health care needs who meet eligibility requirements may be enrolled in plans under the Exchange. These requirements have not yet been established.

Private Sector Funding

Private health insurance covers the costs of health care for the majority of California children with special health care needs. With the passage of the Affordable Care Act, these children are no longer subject to lifetime caps or exclusions for pre-existing conditions. However, coverage limitations, deductible costs and co-payments require substantial payments by families. The rate of private coverage for these children may change with the establishment of the Health Benefit Exchange, and, potentially, with decreasing rates of family coverage by employers.

These many federal, state and county payers, along with the private insurance system, combine to create an inefficient and sometimes ineffective system of care.

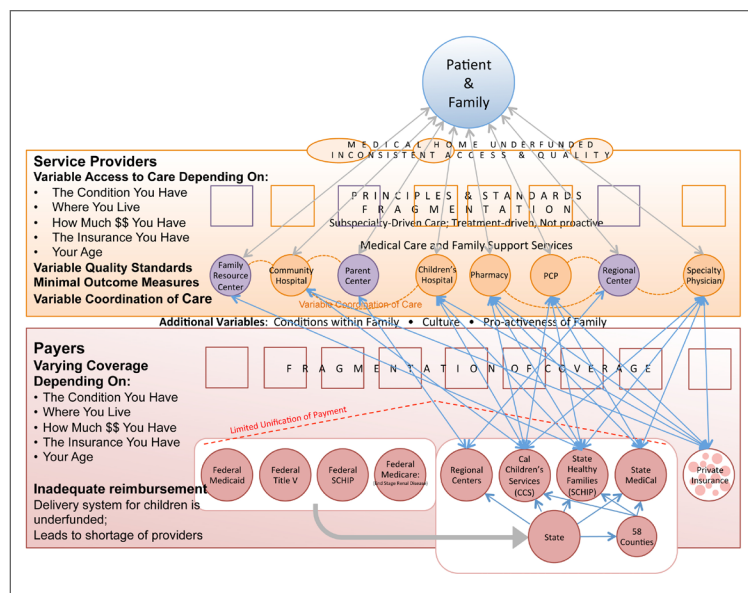
Service Providers

Along with the complex payment options, the multiple providers who serve children and families add to the fragmentation in the current care system, resulting in a model of a system that looks like Figure 4. While not fully representative of the system, this model reflects the major components. The pink-shaded box is intended to illustrate the financing and insurance component, and the orange-shaded box represents key health care providers and some family support services. The blue lines model reimbursement for services being provided by state and private payers to medical care and family support providers, who also have direct relationships with the children and their families, as suggested by the gray lines.

Additional factors also influence a child's and family's health and health care, including educational status, health literacy, language, and racial/ethnic group.

A further complication is that few of these care providers have adopted explicit, measurable standards of care for children with special health care needs. Most do not monitor the quality of care being provided and the outcomes attained in order to guide ongoing efforts to assure and improve quality and efficiency.

Figure 4: Model of Existing System for Children with Special Health Care Needs in California



Challenges for California

Further evidence of the consequences of the complexity of California's system can be found in data drawn from the 2009-10 version of National Survey of Children with Special Health Care Needs. This parental survey reflects the views of families of children with a broad range of conditions, served by both the public and private systems. Key findings from a report analyzing the survey, *California Children with Special Health Care Needs: A Profile of Key Issues*, include:

- California ranks 50th in the nation in the percentage of children with special health care needs whose parents report having problems getting needed referrals for specialty care.
- Although most California children with special health care needs are insured, just 59 percent of those who are insured report consistent and adequate health insurance coverage to meet their health needs.
- Nearly half of California children with special health care needs do not receive effective coordination of their medical treatments. The state ranks 46th in the nation on this measure.
- Families of children with special health care needs in California are more likely than families in all other states to report cutting back on or stopping work due to their child's condition.

Additionally, in the course of the Foundation's convenings to develop an enhanced model of care, participants identified key problem areas in the existing system:

Problems Noted in the Existing System of Care for Children with Special Health Care Needs

<p>Treatment</p> <ul style="list-style-type: none"> ■ Treatment is frequently disease specific and not holistic ■ Families are not sufficiently part of the treatment process ■ Lack of care coordination ■ Poor communication among various providers ■ Lack of trained treatment work force ■ Lack of research ■ Lack of IT systems to coordinate care ■ The overall approach to the design of the system does not meet the needs of children ■ Treatment is inconsistent across the state ■ Mental health is not treated ■ Transition to adult life is not well managed ■ Adult services do not exist <p>Management</p> <ul style="list-style-type: none"> ■ Lack of outcome measures ■ Lack of accountability ■ Lack of leadership ■ No capacity in the system to innovate or improve the system 	<p>Fragmentation</p> <ul style="list-style-type: none"> ■ Lack of coordination between institutions / organizations ■ There is no common framework to address the needs ■ Lack of health literacy ■ There are multiple systems without adequate coordination or integration ■ Access to information is generally poor and inconsistent ■ Multiple agencies perform the same functions, while other functions are not performed at all <p>Funding</p> <ul style="list-style-type: none"> ■ Care coordination and the medical home model is not funded ■ Structural budget problems prevent stability ■ Allocation of funds according to a scarcity model ■ Siloed financial sources prevent collaboration ■ Lack of funding is destroying provider networks ■ Different rules for public and private payers ■ Medical debt destroys family financial security
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Toward an Enhanced System of Care

Given the multiplicity of payers and services providers, the lack of care coordination, shortage of specialists, low reimbursement and absence of consistent quality standards, California's system of care clearly is in need of revision.

The federal Maternal and Child Health Bureau has established six core outcomes that should characterize systems of care for children with special health care needs:

- Families should be partners in decision making at all levels and be satisfied with the services they receive;
- Children and youth should receive coordinated ongoing comprehensive care within a medical home;
- Families should have adequate private and/or public insurance to pay for the services they need;
- Children should be screened early and continuously for special health care needs;
- Community-based services should be organized so families can use them easily;
- Youth with special health care needs should receive the services necessary to make transitions to all aspects of adult life, including adult health care, work, and independence

The Bureau's core outcomes are necessarily broad. Convening participants also enumerated additional desirable characteristics. The majority of these address system attributes that are likely to increase the effectiveness of the system and the care provided; other characteristics address access to care and responsiveness to the needs of families, providers and society.

Goals and Principles for an Ideal System of Care for Children with Special Health Care Needs

Access

- All children have access to high quality care
- All children have access to comprehensive care
- All needs are identified early
- Children receive proper care at appropriate time by appropriate provider for their health care needs

Responsiveness

- The system is responsive to the needs of children and families
- Care is cost effective for families and society
- The system and all its elements are held accountable to individuals and society

Effectiveness

- Family at the center
- Evidence-based treatment
- Treatment is provided for the whole child
- Care provided is culturally and linguistically competent
- Care is coordinated among all providers, including PCPs and specialists in a medical home
- Effective information provided to families
- Adequate and consistent reimbursement
- Effective communication among all participants, including families
- The system has well-defined process and outcome metrics for evaluation and improvement
- Children transition successfully to adult life

Medical Home

A key idea in creating an effective system is the concept of a medical home. The term was first introduced by the American Academy of Pediatrics (AAP) in 1967 as a central repository for a child's medical records; it was noted that this was of special importance to CSHCN.

The concept took on its current, broader meaning in the late 1970s and became a formal goal of pediatric care in a definition published in a policy statement by the AAP in 1992. This statement identified seven components of a medical home, i.e., accessible, continuous, comprehensive, family-centered, coordinated, compassionate and culturally effective.

Subsequently, research has shown that when children have a medical home they are somewhat less likely to experience unmet needs for health care. However, defining a medical home and assessing its quality remains an area of active investigation. Despite the lack of clear consensus on its definition and a paucity of evidence of its impact on children's health, there is a strong belief that medical home should be a central component of a redesigned system of care for CSHCN.

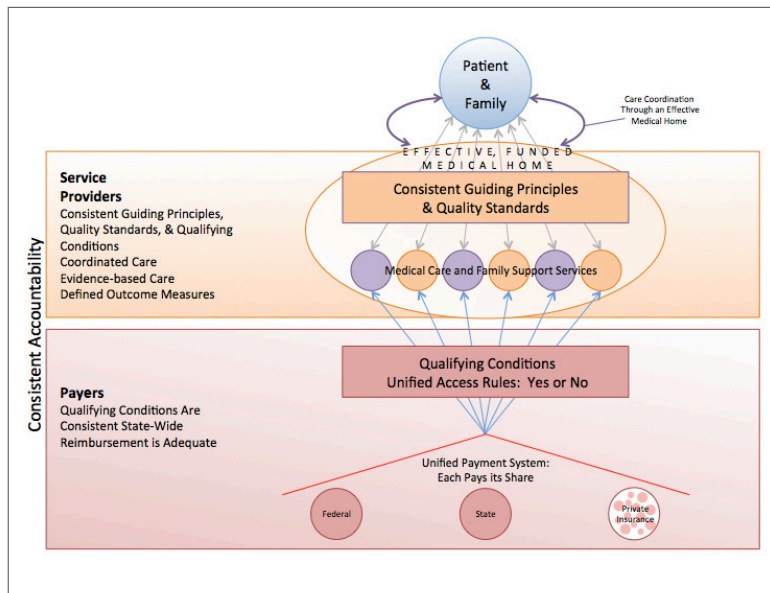
However, the experience of families of children with special health care needs, as reported anecdotally and [documented in ethnographic research](#), is that frequently it is the child's specialty care provider rather than their primary care provider who is seen as the medical home. Many specialty care providers echo this perception. Given that, for children with special needs the concept of the medical home may be quite different than for healthy children. While the medical home model now encompasses consideration of all of the service needs of families of children with special health care needs, not only those provided in the context of a primary child health care practice, it does not address the context in which individual services are provided, including:

- financing of health care,
- eligibility for coverage and service programs, and
- content and limitations of covered benefits

Elements of an Enhanced Model

Acknowledging the many challenges limiting the ability of existing health systems to fully meet the needs of children with special health care needs and their families, it still is possible to conceive of an enhanced, high performing system of care.

Figure 5: Model of an Enhanced System for Children with Special Health Care Needs in California



An enhanced model would simplify financing, eligibility, service organization, provider reimbursement, quality metrics, family involvement and accountability. It would require substantial changes in programs and policy to create real-world change. Specifically, it would require:

Unified Financing — The first major change under the enhanced model is unification of the source of payment. This does not mean a *single* payment system, but a *unified source* of payment to simplify the financial and administrative process for all payers and providers. Public and private payers would need to coordinate their work to create a unified payment system.

Standardized Eligibility Determination and Uniform Benefits — 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, within states it is a reasonable goal to operate programs in a more uniform manner. The definition of qualifying conditions would also be consistent throughout the state.

One approach to standardization is unification. An administrative agency created under this model would have responsibility for a sufficient volume of children with rare and complex conditions to learn how to manage these conditions effectively. It would include all children with special needs under its management, and it would manage effectively through consistent guiding principles and quality systems, and an effectively funded system of care coordination. The definition of qualifying conditions also would be consistent throughout the state, as would benefits under every type of coverage. Eligibility would be based on complexity of needed care rather than diagnosis.

Adequate Provider Reimbursement — Low payment levels for providers in public programs is a persistent issue with no simple solution. Payment rates are closely tied to government health 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 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 CSCHN. 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 a key element of medical homes and the one receiving the greatest support and scrutiny.

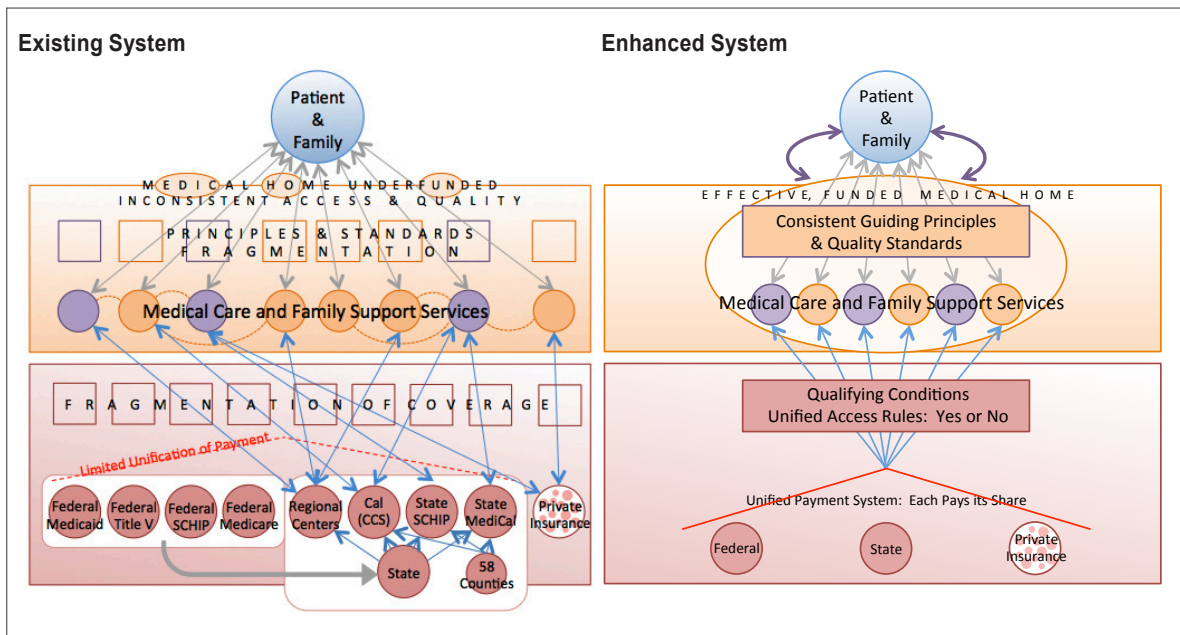
Family-Centered Care — Family-centered care has been a defining characteristic of medical homes since the introduction of the concept, and is one whose value has repeatedly been documented. A family-centered care system begins with the acknowledgement that the family is the constant in a child's life, 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.

Conclusions

It is apparent that the system of care for children with special health care needs can and should be improved. Moving from the current complex, fragmented care system in California toward an enhanced and more idealized model will be a long and challenging journey. Figure 6 contrasts a model of the existing system with the one envisioned by the participants who were convened by the Foundation.

Figure 6: Moving Toward an Enhanced System for CSHCN



These changes will not be easy to accomplish, but the voices of all the participants in the convenings clearly expressed the need to make these transitions. The Lucile Packard Foundation for Children's Health will continue to invest in promoting and facilitating these changes through its grantmaking programs, advocacy efforts and communications resources. Improvements will happen on an incremental basis, as sweeping change will not take place all at once. Careful planning and determined effort can bring about significant change that will result in improved clinical outcomes for children with special needs, and an enhanced quality of life for these children and their families.

See related [publication](#): *Six Models for Understanding How Families Experience the System of Care for Children with Special Health Care Needs: An Ethnographic Approach*

Appendix

Convenings to Developing an Ideal System of Care for Children with Special Health Care Needs Full Results and Participant Lists

Session 1 — September 9–10, 2009

<http://www.innovationlabs.com/lpfch/1/x-participants.html>

Session 2 — October 13, 2009

<http://www.innovationlabs.com/lpfch/2/x-participants.html>