

Report

The Missing Piece:

Medical Homes for California's Children with Medical Complexity



Prepared By

Jeffrey G. Lobas, M.D., Ed.D., M.P.A.

ABOUT THE AUTHOR: Jeffrey G. Lobas, M.D., Ed.D., M.P.A., has had a diverse career in health care administration, clinical practice and academia. Most recently he was chief executive officer at Children's Hospital of Orange Health Alliance in Orange, California. He also has been chief medical officer at Southern Illinois University School of Medicine and Cardon Children's Medical Center at Banner Health in Arizona. He served as director of Child Health Specialty Clinics (Iowa's Program for Children with Special Health Care Needs) at the University of Iowa.



400 Hamilton Avenue, Suite 340, Palo Alto, CA 94301 (650) 497-8365
www.lpfch.org

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Executive Summary

Description of Project

Children with Medical Complexity (CMC), a subgroup of children with chronic health problems, make up a small but especially vulnerable population in California. These children are characterized by their dependence on multiple pediatric subspecialists and often on medical technology; they are medically fragile and are particularly dependent on care coordination to maintain stable health. Although few in number they account for a disproportionate share of health care costs for children. This project set out to understand how CMC are currently receiving health care, what ideal health care for them might look like, and what the barriers to obtaining optimal care might be.

Eleven primary care programs, most associated with children's hospitals, have established programs for this population, and these programs are the focus of this report. Chief medical officers and program directors from each facility were interviewed about the organization and operation of their clinics that care for CMC. Data were collected and a report was generated that became the focus of an in-person meeting and several telephone meetings among program leaders. The information collected and the dialogues that ensued were the source for this analysis.

Findings

The study identified eight key focus areas as critical, high-leverage program components that must be addressed if existing services are to be improved and extended. These were Models of Care; System Design and Regionalization; State and Federal Policy; Workforce Development; Research; Data and Quality; Financial Models; and Mental Health.

Summary

Each of the 11 centers is attempting to incorporate the principles of the Patient Centered Medical Home into their care of CMC, but their approaches and capabilities vary greatly. Some centers have adopted team-based care, electronic medical records, care coordination and outreach services, while others consist of a small number of dedicated physicians with little ancillary support. Some clinics serve as the medical home for CMC, while others also support local, community primary care providers who are assuming some ongoing responsibility for CMC. Because of their distribution within the state, these centers are regional in scope, though they are not formally organized in that way. Providers in the centers are uniformly committed to providing high quality care, yet they tend to be working with little institutional support, inadequate reimbursement, and in isolation from each other and from their colleagues caring for CMC in other states. Many more children could benefit from receiving coordinated, complex care but services are not available to meet the need.

Conclusion and Recommendations

Specialized primary care clinics, operating as team-based medical homes, are a feasible and valuable component of a comprehensive system of care for children with complex care needs. They are likely to be cost-saving to the health care system overall, and undoubtedly provide higher quality care and greater patient/family satisfaction. However, the potential contribution of these clinics is not well appreciated by payers and sometimes not by the institutions with which they are affiliated. Children's medical centers, especially those desiring to be part of an organized delivery system for children with chronic health care problems, should be developing and supporting complex care clinics, and advocating for changes in health care reimbursement and financing that would help support the operation of these clinics. A collaborative, regional approach to team-based primary care for CMC would be a major achievement and a major contribution to the health and well-being of these highly vulnerable children.

Children's medical centers, especially those desiring to be part of an organized delivery system, should be developing and supporting complex care clinics.

Introduction

Within the population of children with chronic health problems is a subset of children, estimated to comprise between 1 and 3 percent of the total, who account for up to 33% of the resources utilized. These are Children with Medical Complexity (CMC), who tend to depend on multiple pediatric subspecialists for their care, are often technology dependent, are medically fragile and are particularly dependent on care coordination to maintain stable health. There is accumulating evidence that providing these children with high quality, coordinated, team-based care in a medical home contributes to their achieving optimal health outcomes.

As the population of CMC grows, barriers to their care become more apparent and consequential.

As the population of CMC grows, barriers to their care become more apparent and consequential. These include the failure to identify them as a special subpopulation; lack of a regular source of comprehensive care; lack of adequate reimbursement of the provider time required to meet their needs; absence of care plans that include preventive and health-promoting care; and the lack of programs to help these children transition from pediatric to adult primary and specialty care as they reach adulthood.

Caring for CMC in California

California's approach to serving children with special health care needs (CSHCN), including CMC, needs to be improved in both the public and private sectors. The most common word used to describe current service systems is "fragmented." Compared with their counterparts in other states, California's children with special health care needs are receiving care that is less coordinated, less family-centered, and fails to meet a number of key quality indicators set forth by the Federal Maternal and Child Health Bureau. Clearly, at least for these children, the current system of care is not working as it should.

This project addresses the ambulatory care of CMC, from a primary care perspective. Leaders from 11 California specialized pediatric health care facilities that have assumed some significant responsibility for caring for CMC were identified and engaged. These key informants were interviewed about how their clinics, which are generally associated with children's hospitals, care for CMC. Clinic data and policies were collected. Recommendations to improve care were developed, and a meeting of representatives from 10 of the 11 programs was held to review a preliminary report and discuss future activities.

Eleven centers throughout the state were identified as having assumed some significant responsibility for caring for CMC.

- Lucile Packard Children's Hospital Stanford
- Mattel Children's Hospital UCLA
- LA Children's Hospital (Children's Hospital of Los Angeles)
- Rady's Children's Hospital
- Children's Hospital of Orange County
- UC Davis Children's Hospital
- Children's Hospital of Central California
- Miller Children's Hospital
- Children's Hospital & Research Center Oakland
- UCSF Benioff Children's Hospital
- Loma Linda University Children's Hospital

Of the 11 centers participating in this project, three have invested in a specific “complex care clinic” to deliver care to this population. An additional facility has chosen to limit its practice to the care of technology-dependent children. The other seven facilities use their general pediatric clinic, often a resident-faculty continuity clinic, to manage children with chronic and complex conditions. A child with a higher level of complexity may have an extended appointment, but the approach to the patient does not differ from the usual care model.

The three programs with a complex care clinic have developed care models specifically for CMC. The other centers (8) have not developed care models to address complex needs. The panel of children included in these clinics varies from a total population of approximately 250 to more than 1,600.

Eligibility for these clinic programs is not well defined. Only one clinic utilizes a risk assessment tool to determine eligibility. All programs include NICU/PICU graduates and technology-dependent children. Four centers base eligibility on the California Children's Services program eligibility criteria.

Due to limited capacity, most of the clinics do have exclusion criteria. Generally, children with single organ system conditions are excluded, as are children with autism spectrum disorder or severe behavioral disorders, though in two clinics some psychiatric and behavioral health services were available.

Preferred Future and Challenges to Realization

Appreciative Inquiry (AI) was utilized as a methodology in this project to identify “ideal” service capacities that clinic leaders thought would enhance the care they provide. (Table 1) Subsequently they were asked to identify the barriers that needed to be overcome in order to achieve this ideal. (Table 2)

Table 1: New Capacities that Would Be Helpful to Clinics

Dream/Idea	Description/Explanation	Frequency of Mentions
Sufficient Resources	Financial models that support care management, prevention, and comprehensive care	9
Care Coordination	Staffing and support for this essential service	7
Patient Centered Medical Home Model	Development of PCMH as the standard of care	5
Dedicated Clinic/Program	Focused strategy applied	5
Population Management	Development of registries and proactive approaches	3
Improved Data Collection	See below	3
Home Visiting	Essential component that needs to be included in coordinated services	3
Improved Communication	Use of technology to enhance	3
Hospital Administration Awareness	Leadership support	2
Technology	Telehealth/home monitoring added to PCMH	1
Self-Management	Standardized approaches for Pt. participation	1
Parent Advisory Council	Consumer input included	1
Written Plan/Contract	Formal standardized plan to guide care	1
Parent Family Capacity	Training programs developed for parents	1
Attitude of Specialists	Mutual understanding/respect	1

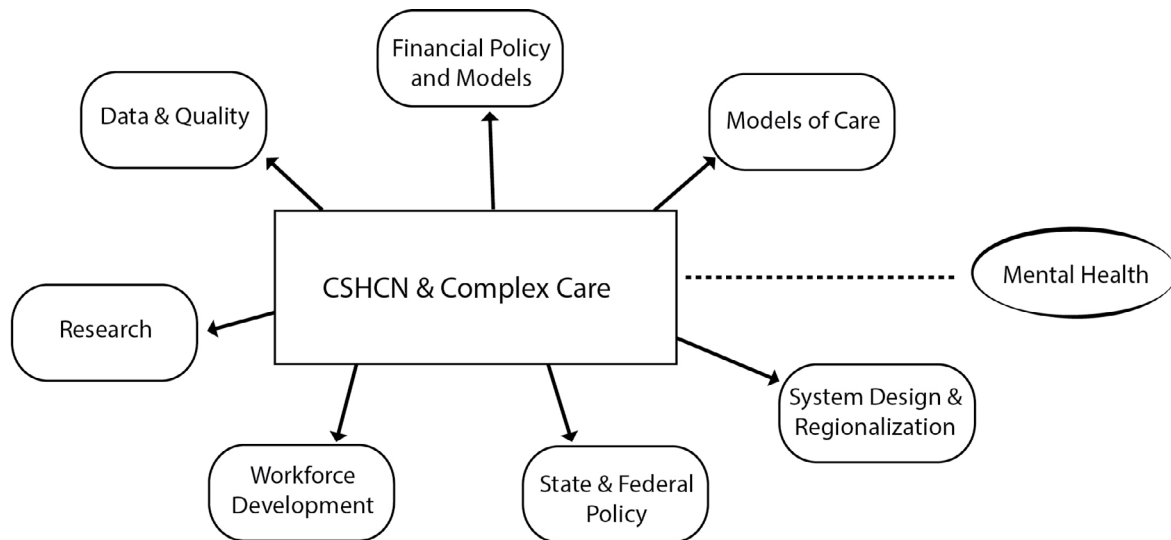
Table 2: Issues and Barriers within Current Models of Care

Barrier and Challenge	Description/Explanation	Number
Financial models	Fee-for-Service and Relative Value Units system seen as inappropriate	11
System development	No overarching strategy	9
Care models	Patient-centered medical home/care coordination lacking	9
Data and quality	Relevant real time data needed	6
Mental health	Major issue/lack of providers	6
Workforce	Lack of providers and training	6
Attitude and culture	Creates negative bias	5
Home care	Needs to be part of the system	4
No show rate	12% to 16% rate is unacceptable	3
Social isolation	Has significant negative impact	2
Transition planning	In most cases it does not exist	2
Legislative term limits	Lack of knowledge and advocacy	1

Components of a High Performance System for Children with Medical Complexity

It was apparent that system change will be required in order to provide efficient and effective care for CMC. Figure 1 depicts the major areas to be addressed.

Figure 1: Models of Care: A Medical Home for Children with Medical Complexity



The preferred model of care for CMC identified by the clinic leaders was the patient-centered medical home (PCMH). Whether referred to by name or not, the standard components of the medical home were identified as important to the care of CMC:

- Comprehensive, Continuous Services
- Primary Care Team
- Care Coordination/Case Management
- Structured Process/Standardized Care/Evidence-Based Standards
- Population Health/IT/Informatics
- 24/7 Coverage
- Family/Patient-Centered Care
- Quality Improvement Program

The clinic leaders discussed the contribution of each of these components.

Comprehensive Services

Comprehensive care, including a strong emphasis on preventive care, was highly valued but often not provided. The lack of integrated and coordinated care among the child's various providers, including the primary, subspecialty and home care providers, was a common and serious problem.

Primary Care Team

Team-based care was a common ideal, though the composition of the care teams at the 11 facilities varied greatly. The program at Lucile Packard Children's Hospital Stanford suggested a possible way in which to reconcile this diversity. That clinic utilizes a conceptual framework of two teams, a Core Team and a Dynamic Team. The Core Team is the consistent primary care provider responsible for coordinating care delivery. Its members include a pediatrician, nurse practitioner, care coordinator, registered or licensed practical nurse, medical assistant, social worker and population management nurse. The Dynamic Team composition varies depending on the needs of the child, but may include medical subspecialists, surgical subspecialist, therapists, mental health professionals and community advocates. These teams collaborate in the care of the child.

Care Coordination/Case Management

The attendees uniformly shared the opinion, belief, and experience that care coordination is one of the most essential components of a medical home for CMC. A definition that seemed to ring true with this group is that care coordination is "sustained and active follow-up." All leaders said they do not have the appropriate care coordination resources. In addition they agreed that there is no standard approach to care coordination and the methodology is highly dependent on the specific coordinator. Caseloads in the clinics vary from 70 to 500 children; minimum standards for services, training, skills, and credentials are not being used.

Structured Process/Standardized Care/Evidence-based Medicine

In general, there is little standardization of the medical care of CMC in these clinics, though clinic leaders recognize that variation in care can result in less than optimal results, and that standardization is desirable. Most providers, however, noted the difficulty of developing care standards for children with rare or unusual conditions. Where science does not offer guidance, expert opinion and agreed-upon approaches should be utilized. It would be desirable for the complex care clinics themselves to collaborate to develop these approaches.

Despite the difficulty, three facilities have developed standard protocols and some decision support methods for a few diagnostic categories. One facility has developed a tiered, systemic approach that categorizes patients by the intensity of the care they need or by the number of organ systems involved. This tiered approach incorporates standard methodologies for approaching the management of the condition, including guidelines for goal setting, follow-up, quality metrics, and use of evidence-based treatment, care coordination and communication. In addition these three programs have instituted a standard process that is utilized to assess children, develop a care plan and monitor care. This process brings together many of the essential components of a medical home.

Population Health, IT, and Informatics

All of the clinics use an electronic health record (EHR) and find it a useful tool for the management of individual patients. They expressed hope that ultimately it will give them the ability to build registries and manage populations. One of the most useful aspects of the EHR to the complex care clinic staff is the ready access it provides to see specialists' notes and to communicate with them. In situations where the specialist is not in the local EHR system, efforts have been made to include them through a portal. Pediatric complex care modules, registries, and decision support ability are not currently available.

24/7 Coverage

One of the foundational elements of the medical home is the timely availability of providers to support families with CMC. All of the programs in the state are trying to provide this. Attending physicians cover phone calls and provide extended clinic hours in some settings; in others the existing call centers utilizing resident physicians provide this service.

Family/Patient-Centered Care

One important role that the medical home plays is to educate, engage, and empower patients and families so they are better able to use services and to provide self-management services at home. The program directors indicated that in general a strategy aimed at accomplishing this will lead to better quality of care and improved health of the child. The extent to which each is achieving this goal is not clear.

Quality Improvement Program

Participants said that a medical home for CMC must operate so that the quality of care is continuously assessed and improved. Clear metrics and goals must be incorporated into care plans and regularly assessed. For both providers and families, as well as for the program overall, quality assessment and improvement will assure that the best care is being delivered.

Additional Components of a High Performance System for CMC

As Figure 1 above illustrates, system change must go well beyond the adoption of the medical home.

Financial Policy and Models

Most of the program leaders said that current levels of reimbursement and the limited availability of other resources challenged their ability to appropriately manage the care of this complex population of children. The form of reimbursement was also identified as an important consideration, and fee-for service (FFS) payment was generally seen as an inappropriate method of payment for service for chronically ill patients. Three of the facilities have been designated as Federally Qualified Health Centers (FQHC), which provides them “cost based” FFS reimbursement. Even this enhanced reimbursement is not adequate to cover the cost of care for the management of this population of children.

The current payment system is based on relative value units (RVU) that create an incentive to increase visits rather than efficiently manage a child’s health care. (RVUs are a method for calculating the volume of work expended by a physician in treating patients.) Clinic leaders agreed that for their patients a system that rewards prevention and care management, thereby decreasing visits and hospitalizations, would be a more rational approach. The system as it exists does not provide the resources necessary to build and sustain a medical home. One leader stated, “this is a huge problem and it will exist as long as the RVU system is in place.” However, per member per month capitated payments that are not risk-adjusted also are not adequate to cover needed services.

System Design and Regionalization

The demographics of CSHCN and CMC in California and the epidemiology of their conditions argue for some type of regionalization of the services on which they depend. Such regional redesign, though, must focus well beyond hospitals and consider all aspects of the “system of care” on which these children and families depend, encompassing an array of services and supports available at all levels—community, county, region and state. Complex care clinics could serve as a focal element of a coordinated, regionalized system.

Data and Quality

Though not readily available, accurate, timely relevant data to assess and guide the care of individuals and populations is essential for complex care clinics, and comparability across clinics is desirable. Key data elements identified by the clinic leaders included:

- Medical home index
- Assessment tools for care planning
- Cost and expense data
- Total cost of care
- Utilization, including therapy and home care
- Quality of Life/Health Index
- Patient and provider satisfaction

- Individual patient data—physiologic and medically related
- Admissions
- Length of stay
- ED/Urgent care
- HEDIS and health plan standards
- Home care measures
- Agreed-upon quality measures for conditions and programs

State and Federal Policy

Clinic leaders understood that public policies and programs shape their care models and services. Among the many policy-related influences that were identified, those that merited priority for change included:

- CCS reorganization
- CCS and insurance policies that fragment the care of CSHCN
- Financial redesign to promote comprehensive, coordinated care
- Medical home certification and standards
- Mental health policy to allow primary care to bill for behavioral health care
- Incentives for network development
- Training in the care of CSHCN for all primary care providers

Research

All participants agreed that any system design and improvements must include a research component. Innovation and improvement require thoughtful and methodical approaches. As new care models and protocols are introduced it will be important to monitor and evaluate those changes.

Workforce Development

Leaders are concerned that few providers, whether they are newly trained or have extensive practice experience, seem to be interested in a career caring for CMC. As those with experience and their peers leave practice and their numbers dwindle, there may be too few pediatricians available and willing to serve these children. Efforts to improve training in the care of CMC, recruit providers of all types, and build and support interdisciplinary teams are desperately needed.

Mental Health Services

As one program leader stated, “The 900-pound gorilla in the room is mental health.” Unknown but seemingly large portions of CMC need behavioral or mental health services. Yet these services are not integrated with the rest of the medical care systems, and mental health services for children and adolescents in the state are severely under-resourced and difficult to access. The shortcomings of the public mental health system and the availability of adequate and appropriate services is a major concern for all of the complex care programs.

Additional Themes

Several other themes were identified but were not explored in depth. These included the need for improved communication at all levels—patient to doctor and primary care to specialist. Concern was expressed that administrators and policymakers do not adequately understand the challenges and barriers to delivering care to this population. It was also noted that families and patients need to be involved in setting directions for the programs. The majority of those interviewed said that services for CSHCN and CMC should be organized and structured as separate entities and not as add-ons to general primary care clinics. They said that a separate entity would result in a more focused and strategic approach to the care of the patient, improved advocacy, and, ultimately, improved quality.

Summary

Current Status

Complex Care Clinics have great potential, and in some places are approaching that potential, to provide a medical home for children with complex medical conditions who otherwise would suffer from the profound fragmentation that characterizes the health care system. The picture that emerges from studying the 11 Complex Care Clinics in the State of California is one of a small number of very committed providers struggling to do the best possible job given limited resources and support. These clinic leaders feel isolated from one another, and the important work they are doing often is not acknowledged by their own institutions. They provide a unique array of services to a highly complex population of patients, but do so in an environment with many barriers and challenges.

A variety of factors—political, financial, professional and geographic—have created this situation. Leaders involved in this project said that collaborative and cooperative efforts among the centers are likely to strengthen their ability to succeed in their mission. They realize that for their clinics to succeed they will have to engage in much difficult work, planning, advocacy and research. Beyond that which is within their control, addressing the existing fragmentation of care for children with chronic and complex health problems will require leadership, vision and the political will to redesign the larger health care system so that it is able to serve CMC in California.

Financial Benefit

The financial argument for investing in improved care systems for CMC is clear. Although these children represent a small number, the total cost for the state is significant. Each center presently sees between 400 and 1,600 children with medical complexity. This is only a small portion of the total number of children who have such conditions. The pilot programs that were proposed several years ago in California provided some initial data regarding costs. These preliminary data indicated a monthly PMPM of between \$1,500 and \$4,000 depending on the diagnosis. This was likely only a portion of the total expense, as some data were not accessible. A conservative estimate of \$30,000 per year as an expense and an average panel of 1,000 children at a given center would come to a total cost of \$30,000,000 at a center. It is not difficult to believe that there is some low-hanging fruit in terms of the ability to create savings related to care. Standardized approaches, coordinated care plans, and care maps would certainly result in some benefits. Even a small 3% savings would amount to nearly \$1M at each center. In reality this is only the tip of the iceberg, as these centers currently have the capacity to see only a very small percentage of the children who need comprehensive care.

Potential savings exist in the provision of more preventive care and adoption of population health management. Currently, the larger health care system provides incentives for high volume, episodic care rather than planned management of a condition and the promotion of optimal health outcomes. Population management has not been well established for children with special health care needs in the state, and standardization of clinic models, credentials, services, and care maps has not been widely adopted. These are approaches that could yield substantial quality improvement and cost savings.

The Complex Care Clinics staff could serve as leaders and their clinics as a foundational element for the development of a true system of care for CMC. The 11 children's hospitals all have committed providers who, despite appreciable barriers, have been willing to step up to the plate and serve these children. Of these 11 centers, three have invested substantial resources, found grant funding, and built maturing programs that emulate a medical home model. The other eight aspire to create this, but have not had the institutional support or resources to truly create a model that is optimal. Additional centers could be created so that effective, rational regionalization of this specialized care could be achieved statewide.

Conclusions and Recommendations

Children with medical complexity make up a small, vulnerable and costly subgroup among children with special health care needs, and their numbers are growing. Parents of these children, as well as their providers, are frustrated with the status quo. Responding to these patterns and to the fragmentation and discontinuity of the usual approach to the care of CMC, some medical centers in California and nationally have begun to develop complex care clinics.

Preliminary evidence suggests that team-based, coordinated care using a medical home model can demonstrably improve the experiences of these children and their families. Appropriately designed and implemented, complex care clinics can provide better care, improve prevention, and promote health while reducing utilization and health care costs.

Children with chronic health problems, especially those with medical complexity, need comprehensive, standardized, high-quality care that is delivered by adequately resourced, highly skilled teams of providers. New financial models must be developed, and increased adoption and creative use of technology must occur. In California, children's hospitals partnering with community health care providers, other community service providers and parents are in an ideal position to make this happen. Figure 2 schematically describes a model system of care for CMC and CSHCN. It operationally integrates many of the components and operations upon which CMC and their families depend.

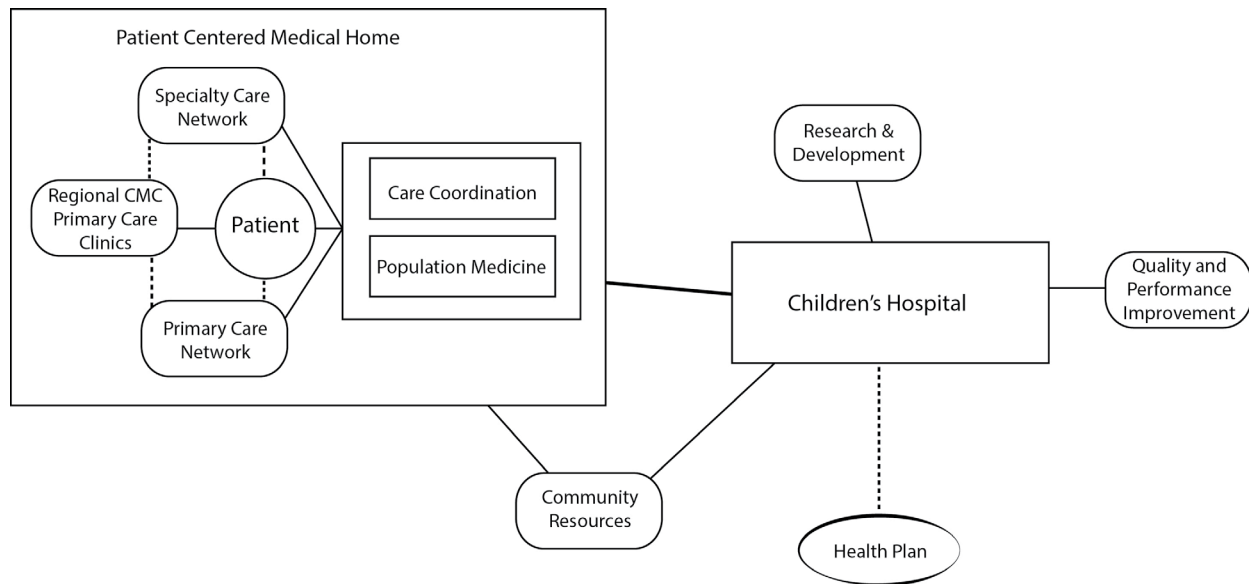


Figure 2: Major Components of a Care System for Children with Medical Complexity

In this model, children's hospitals would serve as the organizing body for the development of a system of care for children with special health care needs and medical complexity in their region. They would organize networks of primary care and specialty physicians, promote adoption of the patient-centered medical home across the system, partner with community child and family service providers, implement quality assessment and improvement activities, and evaluate the processes and outcomes of the organized delivery system.

Moving Forward

A system that can effectively and efficiently serve CMC will be able to meet the needs of all children. At the present time most primary care providers and managed care organizations do not possess the skills, infrastructure, and knowledge to provide optimal care for CMC. The complexity of these children's needs requires a commitment of time and resources that are difficult to provide in the current environment. The clinical and social challenges presented by CMC, the substantial and growing costs of their care, and the perverse incentives of current reimbursement policies all argue for systemic changes within the health care system. A strategy that encompasses changes at multiple levels, local/regional and statewide, likely would be most successful in the transformation that is necessary to deliver affordable, high-quality care.

The low prevalence and geographic dispersion of CMC present many significant challenges in any efforts to create a system capable of meeting their needs. Practices with the capacity to serve as medical homes for children with chronic and complex health problems should be identified or developed and receive special designation and commensurate reimbursement rates from the CCS program and other payers. Standardized processes for determining eligibility of children for care in these clinics would have to be adopted, and quality standards developed.

The existing complex care clinics in the State need to be strengthened and operated collaboratively. Partnerships among health plans and with the 11 children's hospitals could support the regionalization of complex care clinics and help assure the availability of scarce, high-quality services. Such an integrated, systems approach could connect the entire state through shared goals, technology, quality metrics, innovations and expertise. Support for these developments should come from those entities that already have a vested interest in the care of CMC, including the California Children's Services and Medi-Cal programs, Pediatric Subspecialty Coalition, and the California Children's Hospital Association. There is no doubt this will be challenging work but there is no doubt that the result will be worth the effort.

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