



Introduction

Creating an effective system of care for children and youth with special health care needs (CYSHCN) is one of the most challenging and pressing roles for state health leaders. In the United States, 9.4 million children, or almost 13%, have special health care needs. These children have or are at increased risk for chronic conditions, and many require extensive health services. Moreover, CYSHCN require access to treatment and special services that take into account their overall growth and development. These services may include pediatric specialty and tertiary care, family support services, including respite care, special education and related habilitative and rehabilitative services. A major challenge for families of CYSHCN is accessing an often-fragmented system of care. In many cases, specialty services are not coordinated with primary care or other community-based services, and coverage for services is not comprehensive. Furthermore, the current economic downturn is placing unprecedented stress on state budgets across the nation, threatening programs that support the needs of CYSHCN and further exacerbating the gaps in services.

While each state's ability to meet the needs of CYSHCN is affected by numerous factors, such as its size, health care structure, economic strength and political climate, California faces particularly tough challenges in creating a system of care. The sheer size of California as the nation's most populous state, its economic and cultural diversity, as well as the par-

ticularly acute budget crisis, pose added pressures to ensuring optimal health and well-being for CYSHCN in the state. Public health in California, including some services for CYSHCN, is administered by 61 local health jurisdictions (which includes 58 counties and three incorporated cities.) Complicating efforts to reform systems of care, California often receives the same funding as other smaller and less populous states for federal discretionary grant funded projects, potentially diluting the ability of the funding to effect statewide change.

Because of the uncertain environment caused by the national health reform debate and major cuts to California's health programs, it is challenging to determine which models could be most successful in California at the present time. Even with major health reform, California CYSHCN and their families may still face difficulties of underinsurance, coordination of care, access to a medical home, and transition. California, and all states, will continue to need leadership and guidance from families in developing family-centered care and culturally competent models. Therefore, identifying effective and sustainable programs for CYSHCN is especially timely.

The goal of this report is to provide a range of models of care for CYSHCN that the Lucile Packard Foundation for Children's Health can review and discuss as a starting point for mapping out a strategy to support transformation of the system of care. These

models were collected primarily from states with similar socio-demographic, geographic, and structural characteristics as California. Key criteria for model selection were programs that demonstrated innovation, some type of evaluation and/or results, as well as a sustainable funding stream.

MATERNAL AND CHILD HEALTH AT THE FEDERAL AND STATE LEVEL

In an effort to encourage states to focus their efforts on improving the system of care for CYSHCN, the Health Resources and Services Administration's (HRSA) Maternal and Child Health Bureau (MCHB) adopted six critical systems outcomes presented in the Healthy People 2010 National Health Objectives and the President's New Freedom Initiatives. These national outcomes for CYSHCN focus on families as partners, medical homes, financing, coordinated services, screening, and transition (<http://mchb.hrsa.gov/CSHCN05/MCO/intro.htm>) and serve as a framework for state CYSHCN programs. California has identified coordination of services, access to providers, and medical home as its top priorities for CYSHCN, according to the former Chief of the Children's Medical Services Branch.

When examining the system of care for children and youth with special health care needs, state CYSHCN programs are a key resource and often a first point of contact for policymakers. Within each state, the Maternal and Child Health (MCH) and CYSHCN program (known as the Title V program) is charged with providing "family-centered, community-based, coordinated care." Authorized by Title V of the Social Security Act, the Maternal and Child Health Services Block Grant supports the infrastructure for maternal and child health services in every state and territory. Consisting of the state MCH and CYSHCN programs, Title V supports efforts within both the public and private sectors to shape and monitor health-related services for women, children and youth. Although several state programs may provide services for CYSHCN, Title V programs often have the greatest expertise in reaching the CYSHCN populations, the strongest connection to networks of pediatric specialists, and the best data on the service

needs of CYSHCN and their families. Because of the leadership and the resources of state Title V programs, this report relies heavily but not exclusively on the input of State Title V leaders.

METHODS

The Association of Maternal and Child Health Programs (AMCHP) used a multipronged approach to collect the models presented in this paper. AMCHP conducted a literature review of relevant research on CYSHCN programs, held key informant interviews with more than thirty national experts in the field of CYSHCN, health care financing and state health policy, and convened a group of state Title V leaders from select states to gather significant input. This group of seven state Title V leaders was selected because they lead CYSHCN programs in states most similar to California and are recognized leaders in the field. In addition, AMCHP fielded a query to all state Title V programs for suggestions of promising practices in order to gather information from all state programs. This query yielded a response from an additional eight states. Experts were consulted via conference calls and follow-up emails to gather guidance and suggestions in identifying effective and innovative models for both an overall system of care for CYSHCN and MCHB's six core outcomes. A complete list of experts consulted is included at the end of the report. The models were broken down into the following nine specific areas:

- Overall system of care
- Medical home
- Care coordination
- Cultural competency
- Family-centered care
- Transition
- Palliative, hospice and respite care
- Financing
- Health Information Technology

Because AMCHP understood that a companion paper to this one focusing on the system of care in California was also being produced, AMCHP deliber-

ately did not include examples from the state of California, although certainly, across the state there are promising models of care in many of the above areas. Descriptions of promising models are based on expert conversations, written and online reports, and state Title V Block Grant narratives available on the Title V Information System (<https://perpdata.hrsa.gov/mchb/tvisreports>).

In preparation for the expert calls, AMCHP consulted with staff from the California Title V CYSHCN program as well as other experts familiar with the health system in California to get a better sense of the strengths and weaknesses of the California system as it now exists. Recognizing that California's population literally dwarfs all other states (the closest comparable is Texas at about half the population), AMCHP tried to focus on high population states, but also recognized that some smaller states have effective and innovative models to share. In addition, AMCHP viewed more closely states with some similar characteristics as California, such as diverse populations, western locations, the organization of state health services, and a strong county-based health system. We explored, in some cases, examples from small states (which could even be comparable in size to a California county) because of the strength of the model and the belief that it could be replicated in California, perhaps with initial pilots at the county level.

MODEL SELECTION PROCESS

When choosing which states and/or models to highlight, AMCHP based decisions on the frequency with which a particular state was mentioned by experts and for what area (e.g., financing, medical home, strength of collaboration). It is important to note that while many promising models and programs feature the involvement of the Title V program this was not a prerequisite for inclusion. In each category, AMCHP tried to present a range of approaches, focusing on the uniqueness, sustainability, and evaluative aspects of the models. Please note that because of the large amount of information collected, we are only able to present the highlights of these models. However, all the experts consulted enthusiastically

agreed to participate and to provide further assistance upon request should more information be needed.

CLASSIFICATION OF MODELS

AMCHP defines "best practices" as a continuum of practices, programs and policies that range from *emerging* to *promising* to those that have been extensively evaluated and proven effective ("best practices"). AMCHP outlines three categories of best practice. Those categories and the related criteria are listed below.

An emerging practice:

- incorporates the philosophy, values, characteristics, and indicators of other positive/effective public health interventions
- is based on guidelines, protocols, standards, or preferred practice patterns that have been proven to lead to effective public health outcomes
- incorporates a process of continual quality improvement that has an evaluation plan in place to measure program outcomes, but does not yet have evaluation data available to demonstrate the effectiveness of positive outcomes.

A promising practice (in addition to the criteria above):

- has strong quantitative and qualitative evaluation data showing positive outcomes, but does not yet have enough research or replication to support generalizable positive public health outcomes.

A best practice (in addition to the criteria above):

- has been reviewed and substantiated by experts in the public health field according to predetermined standards of empirical research
- is replicable, and produces desirable results in a variety of settings
- clearly links positive effects to the program/practice being evaluated and not to other external factors.

The models presented in this paper were categorized using these criteria. All models were considered either emerging or promising (there were no programs meeting all of the best practice criteria). The section, Models of Care, provides a snapshot of three

states' overall system of care, and thus is not amenable to categorization by this classification scheme.

For ease of reading, models were also classified as public, public/private and private. These classifications refer to either the nature of the collaborative, the sources of funding, as well as leadership and administration. In virtually all the cases, there is some level of collaboration between public (governmental) and private organizations (e.g., local health plans, state chapters of the AAP, American Academy of Family Practice (AAFP), etc.). Public/private partnerships, however, refer to a heightened level of involvement from the private sector.

WILL IT WORK IN CALIFORNIA?

With the continuing economic turmoil in the country and ongoing efforts in states to cut programs, AMCHP can not guarantee that the structure of the programs and models as described in this report will remain the same in the future. Moreover, the extreme budget cuts in California to key programs for CYSHCN, including the Children's Health Insurance Program (CHIP), may pose additional challenges for innovation at the current time and further exacerbate challenges for CYSHCN. While AMCHP can not say for certain that any one of these programs will be successful in California, AMCHP is confident that these models do deserve careful consideration by leaders interested in transforming the system of care for CYSHCN in California.