



Executive Summary

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 percent, have special health care needs. 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 supporting the needs of CYSHCN and further exacerbating 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 particularly acute budget crisis pose added pressures to ensuring optimal health and well-being for CYSHCN in the state.

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, CYSHCN and their families may still face difficulties of underinsurance, coordination of care, access to a medical home, and transition.

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 transform 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.

METHODS

The Association of Maternal and Child Health Programs (AMCHP) used a multi-pronged approach to collect the models presented in this paper. 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 Maternal and Child Health Bureau's (MCHB) six core outcomes. The models of care were then 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

WILL IT WORK IN CALIFORNIA?

Each model contains a brief concluding analysis that attempts to answer the question, “Will it work in California?” While AMCHP cannot 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.

MODELS OF CARE

Each topic area contains at least three models of care with information about structure, financing, and evaluation of the program, as well as any analysis of whether it will work in California. The Models of Care highlighted in the Executive Summary only include basic information and are a snapshot of what follows in the paper. For more information about financing, evaluation, and “will it work in California” for each of these models, please refer to the full report.

1) Overall System of Care

FLORIDA: *Creating an Integrated Network of Care for CYSHCN*

Florida has developed a uniquely strong system of care for its CYSHCN. Of special interest is the Children’s Medical Services Network (CMSN), originally created in 1996 and administered by CMS (Children’s Medical Services, the Title V CYSHCN program), which now serves as a managed care choice for Medicaid and CHIP beneficiaries who must choose a managed care option. Families of Medicaid eligible children who meet the clinical screening criteria may choose CMSN as their provider.

Each CMSN enrollee is eligible to receive care coordination. The care coordinator is a critical link in the development of a true medical home for the child and family. CMS has designed the Child Assessment and Plan (CAP), a web-based application, to document comprehensive care coordination services to all CMSN enrollees. CMS area office staff utilizes CAP to record patient assessments, care plans, and notes.

National experts attribute the strength of the Children’s Medical Services program to its ability to anticipate the needs of the population in the realities of a managed care system. In addition, CMS has benefited from the longstanding support of the Florida Chapter of the American Academy of Pediatrics (AAP), which helped support the original development of the CMS program and has continually advocated for CYSHCN and the need to develop a service system that meets the unique and specific needs of this population.

2) Medical Home

PENNSYLVANIA: *A Medical Home in Every County*

Pennsylvania’s Medical Home Initiative, EPIC-IC (Educating Practices in Community Integrated Care) is the largest CYSHCN Medical Home Program nationally, based on both the number of participating medical home practices and the number of children identified in the project’s patient registry. The project has been cited for the breadth of involvement across the state, the strength of its data collection system, including the development of patient registries, and its payment system.

The EPIC-IC medical home project is based on the Educating Physicians In their Communities (EPIC) model. Since its inception in 2002, the EPIC-IC Pennsylvania Medical Home Initiative has provided Medical Home training to over 100 practice sites, 53 of which continue ongoing quality improvement activity. EPIC-IC provides mini-grants for care coordination to practices based on certain criteria. In addition, some (not all) payors provide reimbursement for such items as care plan development and oversight, telephone calls and patient conferences.

3) Care Coordination

ILLINOIS: Linking Care Coordinators to Medical Homes

Illinois, a high density state like California, has a well-developed medical home effort and has made significant progress in integrating its medical home project and care coordination services. The Division of Specialized Care for Children (DSCC) in Illinois provides care coordination to families with children who meet program medical eligibility requirements through 13 regional offices that cover the state. Through the state's Medical Home efforts (described in the Medical Home Section), DSCC has encouraged primary care physicians to designate an individual in their office as a care coordinator. Those practices that have participated in a medical home quality improvement team (QIT) have had additional connection to DSCC care coordinators in their communities because the DSCC care coordinator has participated in the QIT. Primary care physicians are encouraged to contact DSCC care coordinators to get information about community resources.

4) Cultural Competency

UTAH: Removing Language Barriers in Medical Homes

The South Main Clinic, one of seven clinics participating in the Utah Medical Home Project, participated in the Medical Home Project with a goal of increasing access to care. The clinic primarily serves Spanish-speaking families with CYSHCN. The clinic collaborated with Utah State University to conduct focus groups to gather information, and, as a result, identified a number of issues such as language barriers and isolation.

Focus group findings led to a number of new strategies, including 1) having the Spanish-speaking clinic coordinator and the parent advocate triage calls to the clinic to determine when to contact the doctor for after-hours care; 2) using flagged patient charts to ensure that children with complex medical conditions received enhanced attention and extended appointment times; and 3) using volunteers, promotores/as and parent advocates to help link families to resources.

5) Family-Centered Care

MICHIGAN: Making Family-Centered Care an Executive Level Function

Children's Hospital of Michigan in Detroit is often cited as an effective model of care because of its strong partnership between families and providers. One critical step that has helped Children's Hospital was hiring a parent of a special needs child (and long-time advocate for kids at the hospital) as Director of Family Centered Care in 2005. Having a parent as an administrator/advocate is especially helpful for patients and their families. While the Director says that "Patient and family-centered care has been going on at the Children's Hospital of Michigan for years," the hiring of a parent has formalized the efforts, including the development of a Family-Centered Care Advisory Council.

6) Transition

MISSOURI: Building Capacity in Schools

The Missouri Transition Outcomes Project (TOP) program is an example of improving transition services by building capacity within schools to address the transition needs among their student population by collecting and using baseline data to direct next steps. The Missouri TOP, which began in 2007, operates through the Division of Special Education and aims to increase the knowledge and understanding on the part of school administrators, educators, parents and students of the transition services requirements for the Individuals with Disabilities Education Act (IDEA). After this training, school staff is then able to pull the records for all the students with disabilities and analyze these data to determine whether gaps in transition services exist. TOP staff members follow-up with the school districts 1-2 years later to evaluate the impact of the program in terms of addressing identified gaps in service.

7) Palliative and Respite Care

FLORIDA: *Partners in Care*

In July 2005, Florida's Partners in Care (PIC) program for children with life-limiting illnesses was created. This was a result of the approval of the first Federal Medicaid waiver granted to provide this comprehensive service delivery system designed to enhance the quality of life for this vulnerable population. PIC is the first publicly financed health program for children in the nation to utilize a pediatric palliative care model that integrates palliative with curative or life-prolonging therapies. PIC is based on the Children's Hospice International Program for All-Inclusive Care for Children and their Families national model of pediatric palliative care, which strives to provide a "continuum of care for children and families from the time that a child is diagnosed with a life-threatening condition, with hope for a cure, through the bereavement process, if cure is not attained."

8) Financing

MICHIGAN: *Special Needs Fund*

Michigan's Title V CYSHCN program operates a Special Needs Fund in which families can apply for funds to handle catastrophic conditions in which out-of-pocket expenditures exceed a certain percentage of income. The Special Needs Fund was originally established in 1944 by a bequest to the state from a Dow Chemical Stock. The fund operates solely off the interest from the stock. The fund helps families pay for large expenses such as ramps into homes as well as a parent participation program.

9) Health Information Technology

COLORADO: *Integrated Child Health Registries*

Colorado is working to develop integrated registries and databases. A Centers for Disease Control and Prevention (CDC), Early Hearing Detection and Intervention (EHDI) grant awarded the Children

with Special Health Care Needs Unit funding to integrate newborn hearing screening, newborn metabolic screening and the Colorado Responds to Children with Special Needs (CRCSN) birth defects registry data. The IT system began in 2000 and will eliminate duplicate records for more efficient follow-up, reducing duplicate contacts for families. The project has also developed database software for numerous agencies. Future integration of screening results and birth defects with primary health care offices through the state's Immunization Registry is planned.

KEY RECOMMENDATIONS

While experts had a number of specific recommendations, particularly in the area of medical homes for CYSHCN, a key overall recommendation repeatedly shared was the need for the Foundation to plan and conduct its initiative in a coordinated manner that can benefit the entire state. Respondents recognized the challenge of California's size and population but felt strongly that even if an initiative was originally piloted in a county or at the regional level, it had to be a piece of a coordinated effort to improve care across the state.

In addition, experts encouraged the Foundation to consider the unmet mental health needs of the children as a whole and CYSHCN, in particular, when designing new initiatives. Investing in strong and coordinated partnerships with Title V, pediatricians, family physicians, and family organizations to help plan and grow programs, and help provide the political capital to sustain promising programs is also essential. As the Foundation expands its work in CYSHCN, it will be critical to engage families in the planning and implementation of this work. Lastly, experts pointed out that California has some promising models that can be expanded, and that this effort should also build on them.