

Models of Care for Children and Youth with Special Health Care Needs



Promising Models for Transforming California's System of Care



Prepared by the Association of
Maternal and Child Health Programs

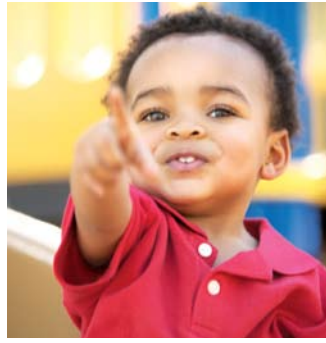


For The Lucile Packard Foundation
for Children's Health

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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*

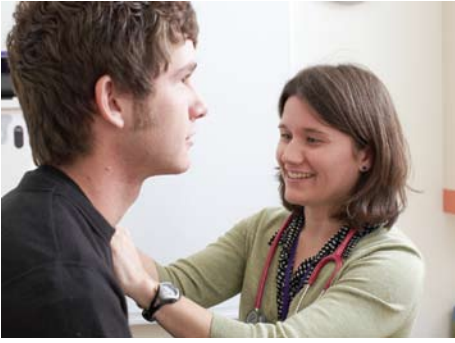
Colorado is working to develop integrated registries and databases. A Centers for Disease Control and Prevention (CDC), Early Hearing Detection and Intervention (EHDI) grant awarded the Children

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.



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.



Models of Care

OVERALL SYSTEM OF CARE FOR CHILDREN AND YOUTH WITH SPECIAL HEALTH CARE NEEDS

Every state has a unique structure for its system of care for CYSHCN based on a variety of factors such as historical commitment to children with disabilities, the availability of specialty care throughout the state, relationships with key constituencies, as well as financial and demographic issues. No state has an ideal health care system to meet the needs of children and their families uniformly well in all six core outcomes for CYSHCN. Nevertheless, certain states appear to have systems and approaches in place that allow for more consistent and long-term collaboration as well as more diversified funding that allows for the continued development of innovative programs.

When looking at systems of care for CYSHCN, it is important to view the population broadly, using the Maternal and Child Health Bureau's definition of CYSHCN: "those who have or are at increased risk for a chronic physical, development, behavioral, or emotional condition and who also require health and related services of a type or amount beyond that required by children generally." While it can be difficult for program directors to look beyond the population directly served by their programs, it is essential if one hopes to truly transform the system of care. Often overlooked in discussions of CYSHCN are children with behavioral mental health issues such as ADHD and schizophrenia. In addition, rising numbers of

children diagnosed with autism spectrum disorders are placing further strain on the system of care.

The following three models of care are highlighted because of their size, the diversity of their population, and/or the strength of their system of care for CYSHCN—beyond the Title V program. While the following four state models are characterized by strong involvement from the State Title V CYSHCN program, other organizations (e.g., foundations, nonprofits, state agencies) dedicated to CYSHCN can also provide essential leadership in transforming a system of care and leading similar initiatives. The descriptions are intended to give a sense of the strengths of that particular state system which may be of interest to California and how they have addressed particular challenges; however, they are not intended to be fully comprehensive.

Dr. Charles Homer of National Initiative for Children's Healthcare Quality (NICHQ) has developed a quality index to look at Title V CYSHCN programs—which is applicable to the larger CYSHCN system of care. The index comprises six areas: 1) Overall leadership; 2) Partnerships across public and private sectors (which includes families); 3) Quality improvement; 4) Use of available resources; 5) Coordination of service delivery; and 6) Data infrastructure. The models presented in this section may not address all six areas equally well; key strengths of all four systems are family involvement, partnerships, and creative and diversified funding. Currently each of these states is

experiencing major budget shortfalls that may impact their overall system of care for CYSHCN although perhaps not to the extent of California's budget cuts. (Source: Homer, Charles: Title V/CYSHCN Program: Index, National Institute for Child Health Quality)

Note: Because this section describes the overall system of care and not a particular program, there are no best practice classifications listed.

NEW YORK: BUILDING FAMILY-CENTERED CARE FROM THE COUNTY LEVEL UP

Public

System of Care: New York's system of care for CYSHCN benefits from a rich Medicaid and CHIP benefits package, a strong belief in family-centered care, and a strong and effective collaboration between the Title V CYSHCN program, Medicaid/CHIP, Early Intervention and other programs supporting CYSHCN. In addition to Medicaid and Child Health Plus (New York's CHIP), the state offers Family Health Plus for adults with children and single adults who meet the income criteria.

Collaboration and Financing: Because the Title V, Medicaid, and CHIP programs are in the same department, they have been able to communicate easily, with the Title V program sharing information from the local county level about how programs work, and improving benefits packages to better serve CYSHCN (e.g., providing vision screening and benefits). Currently, Medicaid is working on developing an enhanced reimbursement for primary care providers, hopefully using the Medical Home model for children. Due to the continued involvement and encouragement of Title V, it is planned that children will be included in the statewide Medical Home model. While the Title V CYSHCN program does not provide or fund care coordination, it is working to improve care coordination provided by managed care programs.

County Relationships: Relationships with counties are extremely important in New York. Staff in the CYSHCN program working at the county level is closest to the families served, and as a result they best understand what families are facing and can provide

the best intelligence to staff at the state level. Currently, the Title V CYSHCN program is considering changing its role in serving CYSHCN at the county level. Right now, each of the 57 counties administers a program to purchase health care benefits for certain CYSHCN who are either underinsured or uninsured. However, each county determines eligibility and benefit levels, leading to inequity across counties. The Title V CYSHCN program would like to develop a systems coordinator role at the county level to link families to benefits, and to strengthen family-centered care and access to medical homes. Ideally, such a transformation would lead to Title V being able to: 1) assess the health status of CYSHCN at the county and state level; 2) assess the system of care at the county level; and 3) help families access and deal with health insurance programs.

Recent Initiatives: New York has benefited from a Child Health Improvement Partnership (originated at the University of Vermont, <https://www.med.uvm.edu/VCHIP/TB2+BL+CL.asp?SiteAreaID=721>), which has allowed staff in the health department to work with the District Office for the American Academy of Pediatrics (like California, New York has multiple chapters of AAP), Family Voices, and the American Academy of Family Physicians to strengthen partnerships, ensure family-centered care, and improve health care. New York State has been working on a project to improve developmental surveillance and screening within health practices throughout the state and ensure family-centered care.

Will it Work in California: Like New York, California has a strong (although much larger) county system, and, like New York, faces issues of inequity across counties. However, California might benefit from a Child Health Improvement Partnership led in partnership with the District AAP to help design programs that better meet the needs of families, children, and providers.

Source: New York profile based on the following print sources in addition to expert conversations: State of New York Title V Block Grant Application Narrative, FY 2009. Retrieved August 13, 2009, <https://perfdata.hrsa.gov/mchb/tvisreports/>.

WASHINGTON STATE: A STRONG COLLABORATIVE PROCESS TO BUILD AND SUSTAIN PROGRAMS

Public

With 39 counties and 36 local health jurisdictions, Washington State does not match California in size or population density. However, its location as a western state, the increasing diversity of its population, particularly in urban areas such as Seattle, and the collaborative processes it has developed across state and local agencies and programs to ensure a system of continuous quality improvement make it worthy of review.

System of Care: The system of care for CYSHCN in Washington State is coordinated primarily through the Title V CYSHCN program located in the Office of Maternal and Child Health. The CYSHCN program is not a direct payor for services to children with special health care needs but relies on a partnership with the state Medicaid Program to cover the medical needs for financially eligible children. In addition, care coordinators, funded by Title V MCH Block Grant funds, are located in every local health department to help CYSHCN and their families link to local services.

Financing: Led by the Governor, Washington recently expanded its CHIP program to cover children up to 300% of poverty level with a comprehensive benefits package for all children including those with special health care needs. Children on Medicaid in Washington often have far better coverage than those in middle income families on private insurance. The Governor's efforts to expand coverage are helping more families have access to richer allowable benefits.

The Title V CYSHCN Program has worked closely with Medicaid partners over the years to assure that allowable Medicaid billing codes and procedures have a pediatric focus when needed. For example, children have greater access to nutrition services and supplements than adults; children with hearing impairments need more flexibility due to growth in the allowable number of hearing aids and ear molds; and allowances for some types of durable medical equipment are different from those for adults.

CYSHCN section staff, in partnership with the Health Recovery and Services Administration (HRSA)

and local health jurisdictions, work with Medicaid managed care plans to meet requirements of the Centers for Medicare and Medicaid Services (CMS) 1915B waiver requiring HRSA to identify, track, and provide enhanced care coordination for children in managed care who are also served by Title V, and to allow families to request an exemption from managed care if needed. Seventy percent of children on Medicaid in Washington are currently in managed care; HRSA is working to shift 50,000 more children to managed care by 2011. Health plan representatives have become a part of the quarterly CYSHCN Communication Network meetings.

Collaboration: DOH works with HRSA and the state Health Care Authority to develop performance measures for providers, health plans, and other partners involved in health care delivery, especially publicly funded health coverage for children. The Washington Department of Health has worked with the Washington Chapter of the AAP to support medical home collaboratives across the state to focus on children with special health care needs. A current DOH effort has expanded to include a collaboration with Washington Academy of Family Physicians in developing Patient Centered Medical Homes for adults and children.

In developing new programs and approaches to such topics as expanding medical homes and developing systems of care for autism, Washington State follows a tried and true formula of involving families in program development, collaborating across programs, and developing memoranda of agreement. A recent summit of providers across the state involved in diagnosing children on the autism spectrum is laying the foundation for the potential development of regional diagnostic centers across the state. Family members, autism support organizations, developmental pediatricians, psychologists, school administrators, early intervention programs, private therapists, and hospital administrators all participated with public health to collaborate on solutions to the challenges surrounding screening, early diagnosis, and referral for treatment of children with autism.

New Initiatives: Through funds received through the federal Maternal and Child Health Bureau for

autism and epilepsy awareness, Washington State is able to pilot new approaches for these specific conditions, which could be expanded to the whole system of care for CYSHCN. The epilepsy grant is allowing the CYSHCN program to work more closely with providers in rural areas and with more diverse families who do not speak English. The grant is also helping the state strengthen the privately funded Epilepsy Foundation Northwest for collaboration with publicly funded activities and local agencies, like local health departments and parent support organizations. The hope is that these new partnerships will be sustained beyond the federal grants.

Will it Work in California: California could learn from Washington State's formula for including families and other stakeholders in the decision-making process and for developing memoranda of agreement between agencies to ensure ongoing relationships.

Source: Washington profile based on the following print sources in addition to expert conversations: State of Washington Title V Block Grant Application Narrative, FY 2009. Retrieved August 9, 2009 <https://perfddata.hrsa.gov/mchb/tvisreports/>.

FLORIDA: CREATING AN INTEGRATED NETWORK OF CARE FOR CYSHCN

Public

Florida is the fourth largest state in the country. Like California, Florida is challenged by the sheer size of the state, the growing numbers of families in need of health services, and the large number of immigrants; nevertheless, it has managed to develop a uniquely strong system of care for its CYSHCN. Strengths of the health care system for CYSHCN in Florida include its large system of providers and centers of excellence in universities across the state, a strong state commitment to funding for children's health, and the ongoing support and strong political influence of the state chapter of the AAP.

System of Care: The Title V CYSHCN program in Florida, known as Children's Medical Services (CMS) provides children with special health care needs, from birth to age 21, a family-centered, comprehensive, and coordinated statewide managed

system of care that links community-based health care with multidisciplinary, regional, and tertiary pediatric care. CMS defines CYSHCN as "those who have a chronic physical, development, behavioral, or emotional condition and who also require health and related services of a type or amount beyond that required by children generally." The CMS system of care includes a network of services that range from prevention and early intervention programs to primary and specialty care programs, including long-term care for medically complex children. CMS enrollees may receive medical and support services through 22 CMS area offices staffed by private physicians, in local private physician offices or other health care organizations, through regional programs, hospitals, referral centers and statewide specialty programs.

Financing: The Children's Medical Services Network (CMSN), originally created in 1996 and administered by CMS, 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. Services are reimbursed directly by Medicaid on a fee-for-service basis. The Florida legislature directed CMS to maximize federal Title XIX and XXI (Medicaid and CHIP) funds for its salaried staff. The CMS Program obtained federal approval to draw down Title XIX funds as a result of administrative claiming. In addition to the two CMSN insurance products (funded by Title XIX and Title XXI, depending on the child's income level), CMSN also provides the original Safety Net services for CYSHCN who are not eligible for either of the other funding sources.

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. The integration of MCHB's six critical systems outcomes into the CMS Program Goals, Performance Measures and CAP further enhances the care coordination activities

by ensuring the provision of ongoing, coordinated, culturally competent, comprehensive care, within the context of a medical home. For example, beginning at age 12, all teens and young adults with special health care needs who are enrolled in the CMS Network and their families will receive the services needed to make transitions to all aspects of adult life, including adult health care, work, and independence. (See section on Care Coordination for more information.)

The CMS system as a whole is supported through a variety of funding streams beyond Title V MCH Block Funds, including Tobacco Settlement Trust Funds, General Revenue, Title XXI and Title XIX. While Medicaid operates on a fee-for-service basis under CMS' arrangements with Medicaid, CMS actually receives a risk-adjusted premium to operate the Title XXI component. CMS also receives Temporary Assistance for Needy Families (TANF) funds for the early intervention program and hospital fees for the newborn screening program. General Revenue and Tobacco Settlement funds provide the greatest portion of CMS funding.

Evaluation: The CMSN pieces of Medicaid and Title XXI are part of an annual evaluation using Consumer Assessment of Health Plans Study (CAHPS) and Healthcare Effectiveness Data and Information Set (HEDIS) measures.

Other Initiatives: The Department of Children and Families' Behavioral Health Network works in conjunction with CMS to address the behavioral health needs for children age 5 to 19 who are between 101% and 200% of the Federal Poverty Level. Diagnoses covered include mood, psychiatric, or anxiety disorders; severe emotional disturbance; and substance dependence. Children who are eligible for Medicaid receive behavioral health services through Medicaid.

Florida's Medical Foster Care (MFC) Program is a coordinated effort between the Florida Medicaid Program within the Agency for Health Care Administration, CMS and the Child Welfare and Community Based Care Program within the Department of Children and Families. The program provides family-based care for medically complex children in foster care who cannot safely receive care in their own

homes. This program is a cost-effective alternative to hospitalization, long-term, in-home, private duty nursing, or skilled nursing facility placement. The program currently serves approximately 650 children per year. CMS also trains a subset of foster parents to provide certain medical care for foster children with special health needs which has resulted in a higher rate of adoption and reunification of children with families. This program has been evaluated by the University of Florida.

Collaboration: 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 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. In addition, CMS leaders point to strong relationships from academic medical centers who are training future CYSHCN providers, as well as from Children's Hospitals.

Will it Work in California: California should explore the development of an integrated managed care network for CYSHCN that could ease enrollment and better coordinate services across primary and specialty care. A first step in this process could be the establishment of a policy unit (ideally public-private) that could begin to examine purchasing specifications, agreements between programs and providers, and other limitations and opportunities to structuring such a system of care.

Source: Florida Profile based on the following print sources in addition to expert conversations: 1) Hill, I. , Westphal, Lutzky, A., Schwalberg, R., Are We Responding to Their Needs? States' Early Experiences Serving Children with Special Health Care Needs Under SCHIP. (Washington, DC: Urban Institute. May 2001) Retrieved August 6, 2009, <http://www.urban.org/url.cfm?ID=310286> , 2) State of Florida Title V Block Grant Application Narrative, FY 2009. Retrieved August 6, 2009. <https://perfddata.hrsa.gov/mchb/tvisreports/>.



The Importance of Integrated Services

A system of services is a family-centered network of community-based services that is designed to promote the health and well being of CYSHCN and their families. Ideally, community-based service systems are organized so families can use them easily. Care coordination, access to a medical home, family-centered and culturally competent services are considered key elements of coordinated services for families of CYSHCN. However, many families of CYSHCN face frustration accessing services. Eligibility requirements, policies, procedures, and multiple locations of services can leave families feeling overwhelmed. There are often gaps in services due to agencies that provide limited services or duplication in services from multiple coordinators and service plans. Families may also need to travel great distances to obtain specialized services.

The examples in the following sections, from medical home, care coordination, family-centered care, to cultural competency, as well as the common application forms found in the health information technology section, all address some piece of a coordinated system of care—although no state or community addresses all issues equally well. The following models of care often use strategies recommended by Champions for Inclusive Communities for developing coordinated services: including the use and development of interagency councils, partnerships with coalitions, supporting the development of family leadership and family-directed programs, and promoting linkages at the local and state level. For local level examples, please refer to the Star Communities on the Champions website: www.Championsinc.org.

The Importance of Integrated Services

Medical Home

All states, including California, have some type of initiative in place to promote the Core Outcome established by MCHB of ensuring that “children and youth with special health care needs receive coordinated ongoing comprehensive care within a medical home.” Leaders in medical home efforts believe that two pieces are essential to the success and sustainability of the medical home: policy and payment. Clear policies should support the location of medical homes in the primary care setting and help facilitate practice transformation. Practices need to invest in the involvement of families in decision-making, trusting the care coordinator, and learning how to work as a team and to link with the larger community. Financial incentives are necessary to help practices undergo such a transformation, and enhanced reimbursements, mini-grants, and other financial supports are essential. For this report, AMCHP is using the American Academy of Pediatrics’ (AAP) definition of medical home: “A medical home is defined as primary care that is accessible, continuous, comprehensive, family-centered, coordinated, compassionate, and culturally effective.

States have had varying degrees of success, with some leaders concerned that a recent push for medical homes in the adult health care community (and accompanying National Committee for Quality Assurance (NCQA) standards) may eclipse the momentum for medical homes in the child community. In addition, while evaluations for the success of a pediatric medical home may be more complex than those for an adult medical home, they are still necessary.

Four states—Illinois, Pennsylvania, Colorado, and North Carolina—have been consistently cited as strong and unique examples of how the medical home process can work. While each model features different strengths, including the extent to which the needs of CYSHCN are addressed, all include a strong state level Medical Home advisory group, involving the AAP as well as other provider groups, and strong buy-in of state agencies.

ILLINOIS: USING FACILITATORS TO PROMOTE MEDICAL HOME QUALITY IMPROVEMENT IN PRIMARY CARE PRACTICES

Public/Private Emerging Practice

The Illinois Medical Home Project (IMHP) is administered by the Illinois Chapter of the American Academy of Pediatrics (ICAAP) in collaboration with the Illinois Title V CYSHCN program (known as the Division of Specialized Care for Children). The goal of the Illinois project is to use medically trained facilitators to provide a structure for implementing quality improvement in pediatric and family physician primary care practices to promote community-based and family-centered medical homes. The Illinois project is highly regarded because of its strong evaluation piece and its success in gaining private grant funding to sustain the program.

System of Care: The Division of Specialized Care for Children (DSCC) and the Illinois AAP chapter help practices by providing access to quality improvement (QI) processes involving partnerships with parents, linkages to community resources, and

modest mini-grants. Nine practices are currently participating. Facilitators are generally professionals such as nurses, social workers and speech pathologists who are care coordinators for families served by DSCC and have received extensive training in the concepts of the medical home model and in facilitation. Once facilitators are assigned to a practice, their first assignment is to help the practice do a medical home assessment using the Medical Home Index and a modified form on the Medical Home Family Index designed by Dr. Carl Cooley at the Center for Medical Home Improvement (http://www.medicalhomeimprovement.org/pdf/PediatricMedicalHomeFamilyIndexandSurvey_2005.pdf). Some practices hired a care coordinator, while others delegated care coordination responsibilities to practice staff.

Financing: Practices also receive modest (originally \$5000 annually) mini-grants to use for such items as providing stipends for family members to attend meetings, purchasing necessary computer equipment to support the project, purchasing USB drives for families to store care plans, or for compensating parents to design a resource guide for the practice. These mini-grants are considered a modest but essential piece of the program. They have been particularly helpful in recruiting medical home practices to establish a Quality Improvement team. The mini-grant amounts have been reduced in the current phase of the program because practices were not using the full \$5000. In addition, participating practices could choose to participate in the larger state Medicaid Primary Care Case Management Program (which primarily focuses on the assignment of a primary care provider as a medical home) and receive monthly case management fees based on number of patients on their roster (per member/per month). PCPs may also receive performance bonuses for achieving certain levels of compliance with specific practice standards.

The IMHP was originally supported through a \$1,000,000 nearly five-year grant to ICAAP from the federal Maternal and Child Health Bureau and is now sustained by a grant from the Michael Reese Health

Trust (an Illinois Foundation). The second phase of the original grant was designed to determine the effect of the medical home training sessions, resources, tools and curriculum provided to all practices, as well as what effect facilitators have on the process and outcomes when implementing a medical home plan.

Evaluation: Throughout Phase II of the grant, nine practices participated in the Illinois Medical Home Project. The grant was evaluated by the University of Illinois at Chicago School of Public Health's Center for the Advancement of Distance Education (CADE). The evaluation used tools such as the Center for Medical Home Improvements' (CHMI) Medical Home Index and found improvements in delivery of care, access to community services, satisfaction with care received, and changes in provider and family competencies. For more information, visit the project website at www.illinoisap.org/medicalhome.htm.

Will it Work in California: This project may be of interest and replicable in California because it is sustained by private grant funding. A key issue would be the costs of training the facilitators, which was an in-kind expense for ICAAP and DSCC.

Sources in addition to expert interviews: 1) Kaye, N., Takach, M. Building Medical Homes in State Medicaid and CHIIP Programs. National Academy for State Health Policy. Copyright 2009 (www.nashp.org) 2) State of Illinois Title V Block Grant Application Narrative, FY 2009. Retrieved August 7, 2009. <https://perfddata.hrsa.gov/mchb/tvisreports/>.

PENNSYLVANIA: A MEDICAL HOME IN EVERY COUNTY

Public/Private Emerging Practice

Pennsylvania's Medical Home Initiative, Educating Practices in Community Integrated Care (EPIC-IC) is a medical home development project, and 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 project is a collaborative effort of the Pennsylvania Department of Health–Division of Special Health Care Programs (Title V), family community organizations, and the PA Chapter of the AAP.

System of Care: The EPIC-IC medical home project is based on the Educating Physicians In their Communities (EPIC) model. EPIC-IC is a statewide provider of education/quality improvement programs, using office-based change as the key to improving the care provided to CYSHCN. The mission of EPIC-IC is to enhance the quality of life for CYSHCN through recognition and support of families as the central caregivers for their child, effective community-based coordination, communication, and improved primary health care. The EPIC-IC project facilitates the provision of medical homes to CYSHCN throughout the Commonwealth of Pennsylvania.

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. Currently, there are 31 practice sites that are in recruitment. Thus, the PA Medical Home Initiative currently works with 84 practice sites. These practices represent 37 counties in all six regions of Pennsylvania, including urban, suburban, and rural areas and multiple ethnic/racial groups. Among the practice sites are Federally Qualified Health Centers, Rural Health Centers, and three major children’s hospital systems. The size of the participating practices varies from 1,500-30,000 patients. EPIC-IC has a goal of having a Medical Home practice in each of the 67 counties in the state to foster dissemination and sustainability of medical homes for CYSHCN.

In order to participate in the program, practices work with EPIC-IC to meet many care coordination criteria. The criteria include the following: 1) Identification of practice team members; 2) Recruitment of Parent Partners to work with the practice team; 3) Development of a process for creating a comprehensive and continuously updated patient registry of CYSHCN; 4) Submission of a brief monthly report; 5)

Collaboration with local, community-based organizations; 6) Participation in EPIC-IC monthly conference calls; and 7) Attendance at EPIC IC conferences.

Financing: EPIC-IC is funded by the Pennsylvania (PA) Department of Health (Title V) and the federal Maternal Child Health Bureau. 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.

Evaluation: Similar to other quality improvement projects, EPIC-IC uses many tools to measure and monitor strengths, weaknesses, outcomes, and successes of the project. A number of measurement instruments have been developed for the project, with validated tools used to monitor the progress of the Medical Home Initiative with the practices that have received training.

Will it Work in California: Pennsylvania’s Medical Home system encompasses the type of systematic overhaul of pediatric care for which experts advocate. Such an initiative in California would require the strong partnership of AAP Chapters, buy-in from health plans, and a solid investment in the infrastructure (e.g., CYSHCN patient registries) needed to build such a system.

Sources in addition to expert interviews: 1) Pennsylvania Medical Home website: www.pamedicalhome.org, 2) State of Pennsylvania Title V Block Grant Application Narrative, FY 2009. Retrieved August 7, 2009. <https://perfdata.hrsa.gov/mchb/tvisreports/>.

NORTH CAROLINA: ENHANCED PRIMARY CARE CASE MANAGEMENT SYSTEM

Public/Private

Promising Practice

North Carolina has been recognized nationally as a leader for its comprehensive Medical Home project. Although it is not specifically targeted to CYSHCN, experts repeatedly mentioned the program as worthy of review because it has been in place for so long and

so thoroughly evaluated. In addition, in recent years a number of efforts have been made to address the needs of CYSHCN. Also, North Carolina, similar to California, has a strong county health system.

System of Care: North Carolina's coordinated care/medical home effort began in 1998 as a one-county pilot called Community Care, based on an earlier Primary Care Case Management (PCCM) program for Medicaid that began in 1991. The program was taken statewide in 2005 as Community Care of North Carolina (CCNC) through the creation of 14 local/regional networks across the state. Each network includes primary care providers, safety net and specialty care providers in collaboration with the local health departments, departments of social services and hospital(s). (Source: Governing, Medical Home). Primary care providers direct the care that CCNC enrollees receive.

Financing: North Carolina pays two fees per member per month for each enrolled individual—one to the primary care provider and one to the network to which the provider belongs. The networks use this payment to pay for medical home supports that a single practice might not be able to afford. For example, networks have hired: 1) a part-time or full-time medical director to oversee quality, meet with practices and serve on the State Clinical Directors Committee; 2) a pharmacist for medication management; 3) a clinical coordinator/director to oversee network operations; and 4) care managers to assist practices with such services as case management and coordination across delivery settings, as well as support in implementing practice improvements recommended by CCNC.

Evaluation: An outside analysis by Mercer Consulting showed that North Carolina Community Care operations in State Fiscal Year 2004 saved \$244 million in overall healthcare costs for the state while improving overall health outcomes for select illnesses. Subsequent analyses in 2005 and 2006 found similar results. In 2007, the North Carolina state legislature mandated CCNC coverage for all of the state's aged, blind and disabled recipients in addition to all recipients of the State Children's Health Insurance Program.

Special Initiatives for CYSHCN: While North Carolina's general program is not specifically directed to CYSHCN, over the last four years CCNC has used grant funding from two North Carolina foundations to partner with pediatric subspecialists in six major North Carolina medical centers to improve coordination of care of CYSHCN both within each medical center and between the medical center and each patient's medical home. CCNC continues to evaluate the cost and quality outcomes of its programs and is planning new initiatives for adults and children in integrated behavioral health delivery.

In addition, the North Carolina Medical Home Initiative for CYSHCN has collaborated with a variety of networks in the CCNC to meet the medical home needs of these children. For example, in one regional network, Partnership for Health Management, four practices within the Partnership for Health Management have incorporated the medical home index and family survey tools, pre-visit contacts, CYSHCN registries, and complexity ratings in their practices. In a separate network, Chapel Hill Pediatrics (CHP) received a commendation from MCHB in the "Promising Approaches" document of the Federal Expert Workgroup on Pediatric Subspecialty Capacity for its inclusion of the pre-visit contact. Data from Blue Cross/Blue Shield of NC indicated emergency room utilization for CYSHCN was significantly lower in this practice than in other area practices.

The Managed Care Solutions Committee (originally sponsored by the NC Pediatrics Society, now known as the Pediatric Council) has sponsored statewide trainings for health care providers on billing for medical home related services for CYSHCN. Cost-savings data, attributed to the utilization of the medical home approach, have been collected by the 14 provider networks within Community Care of NC, the first medical home demonstration project, and from ongoing data collection as part of the second medical home demonstration project, which targets numerous Community Care of NC practices. Data have demonstrated favorable results thus far regarding the reduction of Emergency Department (ED) usage and hospitalizations among CYSHCN. The NCPS

has created a Quality Improvement Committee over the last year, which will explore ways to promote the use of the NCQA Patient Centered Medical Home process to advance the medical home concept among pediatricians and others who care for children and youth in North Carolina.

Will it Work in California: While the CCNC program is not specifically directed to CYSHCN, it is building the capacity to address the needs of CYSHCN, and is part of a larger system with well-established evaluation methods and cost-savings data. The evidence of cost-savings, in particular, could be very compelling in tight economic times. The CCNC could be piloted in counties or across the state in California, although it is important to note that the NC system is not a managed care network.

Sources in addition to expert interviews: 1) Kaye, N., Takach, M. Building Medical Homes in State Medicaid and CHIIP Programs. National Academy for State Health Policy. Copyright 2009 (www.nashp.org) 2) Community Care of North Carolina (www.communitycareNC.com) 3) Buntin, John. "Health Care Comes Home," March 1, 2009 *Governing Magazine*. Retrieved August 12, 2009. (www.Governing.com/node/633) 4) State of North Carolina Title V Block Grant Application Narrative, FY 2009. Retrieved August 12, 2009, <https://perfddata.hrsa.gov/mchb/tvisreports/>.

COLORADO: MEDICAL HOME FOR ALL CHILDREN, POLICY CHANGES AND BROAD-BASED SUPPORT

Public/Private Emerging Practice

Colorado is a western state with a strong county health department system. While its population is a fraction of California's, Colorado's approach to building a medical home system by focusing on medical home teams for all children, supporting collaborative partners, the policy changes which enable change, and the diversity of funding merit review.

System of Care: The Colorado approach to the Medical Home concept states that "Colorado is going beyond traditional definitions of a medical home by

identifying it as a team approach to health care. Colorado is also building a Medical Home System, which is the infrastructure to support a Medical Home Team for all families." The Colorado Medical Home Initiative is housed in the Title V agency and is directed by a parent leader who also serves as the family leadership director for the state.

The Colorado Medical Home Initiative began in 2001 in response to the Title V/Maternal and Child Health (MCH) national outcome measure, *all children will receive comprehensive coordinated care within a Medical Home*. The Colorado Medical Home Initiative looks to serve as a neutral facilitator in identifying barriers while promoting solutions in developing a quality-based system of health care for children. The Colorado Medical Home Initiative is currently working to promote the medical home team approach and implement the medical home system in four local communities in Colorado. These communities are supported with technical assistance and resources as they develop community Medical Home Improvement Teams committed to implementing the medical home team approach through systems development.

The Medical Home Initiative in Colorado is supported by state legislation. Senate Bill 07-130, signed by Governor Ritter in 2007, designates the Department of Health Care Policy and Financing (HCPF) to take the lead in assuring an increase in the number of children who have access to a Medical Home team, specifically those children eligible for Medicaid and SCHP in Colorado. Colorado's Medicaid agency, the Department of Health Care Policy and Financing (HCPF) is responsible for collaborating with the Colorado Medical Home Initiative to implement the requirements of the bill, creating an effective braiding of direct care services and systems-building efforts.

Financing: In terms of financing, Colorado's Department of Health Care Policy and Financing is piloting a program to pay an enhanced fee to primary care providers who meet particular medical home standards during all Early Periodic Screening, Diagnosis and Treatment (EPSDT) visits. The enhancement is calculated to be about the equivalent of \$3 per member per month for a year (\$36).

Collaboration: Colorado's Medical Home Initiative concept enjoys the support and endorsement of many state organizations, including the state chapters of the AAP and AAFP, Kaiser Permanente, The Children's Hospital Denver, and several family organizations including Family Voices. Colorado's Medical Home Standards for children, a deliverable of the medical home legislation, were developed in 2008 by the Colorado Medical Home Initiative's evaluation task force made up of family leaders, mental, oral and physical health providers, NCQA, local chapters of the AAP and AAFP, researchers and state agency staff.

Family Registry Data: The Colorado Medical Home Initiative is also developing a centralized database of all emerging family/youth leaders to capture specific areas of expertise and core competencies. Developed with a strong evaluation component, the database will be able to track the progression of family leaders. In addition, the information will have a query function that will serve to match family leaders with specific opportunities.

Evaluation: The Colorado Medical Home Initiative works hard to integrate all medical home efforts within the state. In particular, impressive outcomes have been demonstrated through the partnership of the Colorado Medical Home Initiative with the Colorado Children's Healthcare Access Program (CCHAP).

The Colorado Children's Healthcare Access Program is a non-profit organization devoted to ensuring that children enrolled in Medicaid and the SCHIP program have access to comprehensive healthcare through private primary care providers in order to build a medical home team approach. In addition, CCHAP supports providers through a process of self-assessment using the Colorado Medical Home Standards in conjunction with the Medical Home Index. Through this thorough self-assessment process, providers are able to identify areas of need/strengths related to their process to provide a medical home approach. CCHAP then works with the Colorado Department of Health Care Policy and Financing to determine if the provider is eligible to receive an increase in their reimbursement rate.

Will it Work in California: California may want to look at Colorado's strategy of ensuring for *all* children as a mechanism for broad-based support of the concept. In addition, Colorado's reimbursement process and family registry may also be of interest as discrete approaches. At the same time, it is important to note that Colorado's size, population and diversity (as well as economic status) is smaller and more homogeneous than California.

Sources in addition to expert interviews: 1) Kaye, N., Takach, M. Building Medical Homes in State Medicaid and CHIIP Programs. National Academy for State Health Policy. Copyright 2009 (www.nashp.org) 2) State of Colorado Title V Block Grant Application Narrative, FY 2009. Retrieved August 12, 2009. <https://perfdata.hrsa.gov/mchb/tvisreports/> 3) Colorado Children's Healthcare Access Program (www.cchap.org).

The Importance of Integrated Services

Care Coordination

Care coordination is an integral piece of comprehensive, quality care provided within the medical home model for CYSHCN. Care coordination focuses on the broad range of services that are needed by a child with a complex medical condition. It is a process that helps ensure that the child with special health care needs and his or her family find the services they need, are linked with appropriate providers, and have help getting care when care and services are either not available in the community or do not seem to be working for the child and family with the overall goal of achieving optimal health. Recently, pediatric care coordination was defined as “a patient and family-centered, assessment-driven, team-based activity designed to meet the needs of children and youth while enhancing the caregiving capabilities of families. It addresses interrelated medical, social, developmental, behavioral, educational and financial needs to achieve optimal health and wellness outcomes” (Antonelli, R. et al. Making Care Coordination A Critical Component of the Pediatric Health System: A Multidisciplinary Framework. The Commonwealth Fund, May 2009).

States support a variety of care coordination activities, ranging from office-based care coordination, to home visiting programs, to agency-based programs. These programs are largely evaluated through family satisfaction surveys and assessments. The state programs highlighted in this section present a range of models that differ in terms of type of services provided, location of service, funding source and type of personnel used to deliver care coordination.

OREGON: CaCOON PROGRAM

Public

Emerging Practice

The Oregon Center for Children and Youth with Special Health Needs (OCCYSHN), the state Title V Program, operates the care coordination home visiting program, CaCoon. CaCoon provides funding, training and consultation to public health nurses in all 36 counties in Oregon to provide care coordination to CYSHCN from birth through age 20. Similar to California, Oregon is a West Coast state with a diverse population and, like California, the CYSHCN program is outside of the Department of Public Health, in this case in a university setting.

System of Care: In Oregon, each county has a designated CaCoon Coordinator. All of the CaCoon Coordinators are registered nurses. The CaCoon programs also support promotoras in four counties that have a high proportion of Latino families. These promotoras are community health workers who collaborate with the CaCoon Coordinator to teach families such skills as how to make an appointment, fill a prescription, or arrange transportation to an appointment. The majority of services provided are home visits, although public health nurses often may make several follow-up phone calls to support the coordination of care.

Children from 0-20 years are eligible for CaCoon services; though the majority of children seen are from birth to three years. This occurs for many reasons, including limited capacity in health departments, and the Targeted Case Management (Medic-

aid) funding that is available for children in the 0-3 year old group.

Key partners in the CaCoon program are the local public health departments. OCCSYSHN also works closely with the Oregon Office of Family Health and the Oregon County Health Leaders group, known as MCH-CLHO, that focuses on Maternal and Health issues as a vehicle for getting feedback and leadership level input into the program.

The program serves a diverse population in Oregon. Children are referred into the program regardless of ethnicity and/or language. Local health departments contract with local agencies to provide interpretation for home visits, or they use health department providers as interpreters. As noted above, CaCoon supports promotoras in four counties that have a high proportion of Spanish-speaking families.

Financing: CaCoon is funded through the Title V CYSHCN program as a sub-contract to each of the local public health departments in Oregon. Counties receive about \$900,000 each, though the amount is based on a formula that includes variables such as: rurality, live births, and salary levels for the area. This has been sustainable through continued funding of the Title V MCH CYSHCN program, which is an inter-agency agreement from the Department of Human Services where the larger MCH program resides.

Evaluation: The program is evaluated using several methods. Two OCCYSHN Nurse Consultants provide at least one site visit per year to each county to review program standards, discuss additional training needs, and to consult with the nurses on individual children. A chart review tool was recently developed. In addition, Oregon started using a database called ORCHIDS (Oregon Child Health Information Data System) about a year and a half ago that allows public health nurses to document their encounters. This database was developed by the Oregon Office of Family Health in collaboration with the OCCYSHN program. ORCHIDS collects demographic data as well as some limited outcome data on issues addressed by care coordinators such as nutrition, child development, parent, injury, and family knowledge of their child's

condition. The program is just beginning to analyze data from the first full year of data collection.

CaCoon is developing a desktop data system that will have the ORCHIDS data so that CaCoon consultants can easily examine data from each county on a quarterly basis. In addition, the ORCHIDS database will allow for analysis of certain segments of the population of children served by CaCoon. The program is also beginning to analyze services provided to adolescents who were seen by CaCoon nurses.

Will it Work in California: This program may be of special interest to California because it is based in all counties across the state, utilizes promotoras to reach the Latino population, and has some level of evaluation and sustainability.

Sources in addition to expert interviews: <http://www.ohsu.edu/cdrc/oscsn/community/nursing1.php>. Retrieved August 26, 2009.

ILLINOIS: LINKING CARE COORDINATORS TO MEDICAL HOMES

Public/Private

Promising Practice

Illinois, a high density state like California, has a well-developed medical home effort and is fairly advanced in terms of medical home/system integration and care coordination.

System of Care: 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. Care coordination is provided through two-person teams, a professional (nurse, medical social worker, speech/language pathologist/audiologist) and a paraprofessional with social service experience. Each team has a caseload of families across the range of eligible medical conditions.

Contact with families occurs in many ways, including home visits, meeting at medical appointments, phone, and mail/email. Additionally, each regional office has satellite sites in other communities where they can meet families and network with

referral sources and other community resources. The state plans to transition to an electronic case management information system (probably an electronic record) so that care coordinators can be more mobile and not tied to an office building. This would potentially facilitate connections in the communities with families and resources.

Through the state's Medical Home efforts (described in the Medical Home Section above at page 15), 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.

Care coordination services are available at no cost to any family whose child has an eligible medical condition. This includes helping families and care providers develop a plan of care, coordinating services, linking families with other resources and programs, parent-to-parent support, information provision, helping families advocate for their child and making the best use of insurance and other payment sources. DSCC invests a lot of training in the care coordinators in the beginning to ensure the provision of high quality service coordination.

Evaluation: The program is evaluated in several ways, including a family survey conducted every five years as part of the Title V Block Grant needs assessment, which includes questions about care coordination, and through a short returnable postcard sent to families that have been part of the program for one year and those that have been in the program three years. Data from 2007 show very high satisfaction from families: 96% of families who responded indicated they were satisfied with the services they were receiving from DSCC; 99% indicated they were treated well by staff; 97% indicated their calls were returned in a timely manner; 95% indicated that DSCC assisted them in finding resources for their

child; 98% indicated that staff listen to them; and 98% indicated they got answers to their questions.

Additionally, through the Home and Community-based Services waiver program, the training and technical assistance unit contacts a sample of families with children in that program to determine satisfaction with services, including care coordination. The managers also use record reviews and other management strategies for performance appraisal annually as well as asking families about the care coordination they are receiving when they have contact.

Will it Work in California: The program is provided through regional offices across the state, a structure that may work in California and has a high level of family satisfaction.

Sources in addition to expert interviews: http://internet.dsc.uic.edu/dscroot/core_prog.asp. Retrieved August 26, 2009.

FLORIDA: COMPREHENSIVE CARE COORDINATION FOR CYSHCN

Public

Promising Practice

Florida's well-established Children's Medical Services (CMS) (described in detail above on page 12) has both nurses and social workers who perform care coordination activities. Care coordination activities are provided in 22 CMS area offices around the state. In addition, as part of CMS' statewide medical home initiative, there are physician practices that have CMS nurses out-posted in the physicians' office. In this medical home concept, the nurse works with the physician to identify all the children with special needs in the physician's practice, and care coordination services are provided to all these children regardless of CMS eligibility.

System of Care: Children's Medical Services assigns a nurse care coordinator to each child enrolled in the program. Nurse care coordinators work with families, the child's physicians and other providers, and other agencies (such as schools and social services programs) to ensure that children receive

needed care that is non-duplicative and comprehensive. If psychosocial issues are identified during the initial assessment, the child is also assigned a social worker care coordinator. CMS has care coordinators who have case loads of children with mixed diagnoses, as well as care coordinators whose case loads are composed of children with specific diagnosis, such as diabetes. Care coordinators may be state employees or are employees of contracted agencies.

Standards and Guidelines: In addition, CMS manages the statewide early intervention program that contracts for service coordinators who may be nurses, early interventionists, social workers, or other licensed professionals. The service coordinators follow the federal IDEA regulations governing family support planning, service authorization, etc. Children’s Medical Services has a comprehensive plan to educate new employees about CMS care coordination guidelines. Currently CMS is working with two Florida universities to update the current CMS care coordination guidelines and develop disease management guidelines, an acuity determination matrix, and training methodologies for these initiatives.

CMS has outlined in the Children’s Medical Services Care Coordination Guidelines criteria for medical and psychosocial assessments, care plan development, the implementation of the care plans, and the role of the care coordinator with the child’s assigned primary care physician. Each child enrolled in CMS receives a comprehensive medical and psychosocial assessment; a care plan is then developed based on those assessments. These care plans are provided to each child’s primary care physician. If indicated by the assessment a CMS social service referral is completed. The social worker referral form is completed by the nurse care coordinator when it has been determined that the client has needs that would best be addressed by a social worker. All assessments, care plans, care coordination tasks and activities are documented in the CMS electronic care coordination record.

Financing: This is a publically financed program through CMS.

Evaluation: Specific care coordination performance measures are incorporated in each care coordinator’s performance evaluation and the employee is evaluated on the performance measures annually by their care supervisor. CMS contracts with the Institute for Child Health Policy to conduct annual family satisfaction surveys that include an evaluation of care coordination services.

Will it Work in California: Like California, Florida is a large and diverse state. Florida has a strong CYSHCN program, of particular interest to the California Title V CYSHCN program staff. The clear guidelines and standards of care as well as the annual evaluation may be helpful in attempting to replicate this program.

Source: Expert interviews.

RHODE ISLAND: A CARE COORDINATION MODEL FOR PARENT PEERS

*Public/Private
Promising Practice*

Although housed in the smallest state in the nation, Rhode Island’s Pediatric Practice Enhancement Project is a model for all states and has been replicated. The Pediatric Practice Enhancement Project (PPEP) utilizes parents of CYSHCN within a medical practice to assist in system navigation, referral for specialty services and access to community-based resources. The PPEP was implemented in 2004 in eight pediatric primary care practices, including private practices, community health centers and hospitals. The PPEP was expanded to add three specialty sites to create an integrated service delivery system for CYSHCN in 2005. During the period 2006-2008, nine additional sites, including primary care practices, specialty practices, and urban health centers provided partial funding to participate in the project.

System of Care: The key innovation of the project is the parent peer model and its ability to affect the lives of individual families, healthcare delivery providers and an integrated system of care. The parent peer model is quite different from professional case management. The PPEP model has similarities

to the “patient navigator” role for chronic conditions and to the community health worker role in low-income/immigrant groups, in that parent consultants provide a peer/consumer approach to managing services and supports.

From its inception, the PPEP has been a partnership that included the Rhode Island Department of Health, Department of Human Services, Rhode Island American Academy of Pediatrics (RI AAP), Neighborhood Health Plan of RI (NHPRI) (the state’s largest Medicaid Managed Care Insurer), Family Voices and the Rhode Island Parent Information Network.

Financing: The PPEP was initially funded primarily by the Rhode Island Department of Health through a three-year grant from the New Freedom Initiative, which ran from May 2006 to April 2009. Other funding sources included the Title V Block Grant, State Medicaid Agency, and a grant from NHPRI, and participating sites. At the completion of the grant funding cycle, all participating sites have agreed to continue to fund the project to varying degrees to suit their individual site needs. True sustainability of the model requires RI health plans to differentially recognize and fund enhanced medical home practices without credentialing and other constraints that exclude the PPEP. The Rhode Island Department of Health has had the most success working with NHPRI to implement utilization reviews and cost analysis that have resulted in positive outcomes in support of the project. The PPEP has a program manager, data manager, and 24 parent partners who were hired, trained and supervised through the Rhode Island Department of Health’s subcontractor, the Rhode Island Parent Information Network. The PPEP annual operating budget is approximately \$835,000, consisting primarily of the salaries of the parent partners.

Evaluation: The Department of Health has studied and documented the effects of parent partners on policy, service delivery, and consumer education, including cost savings due to a decrease in overall health care costs. In addition, the PPEP has been measured at the individual, practice and systems level. At the individual level, the PPEP was responsible for many improvements in public programs,

health plan benefits, and provider practices. The most important achievement was that CYSHCN received more effective, complete and appropriate referrals, evaluations and interventions. Through addressing family’s concerns in education, behavioral health, specialty services, health insurance, parenting, childcare, basic needs and equipment, the PPEP has resolved 75% of the problems identified. During September 2006, the Department of Health worked with NHPRI to evaluate PPEP outcome data from the participating PPEP practices.

NHPRI conducted a utilization review to compare the healthcare costs for 70 CYSHCN a year before and a year after incorporating the PPEP. The utilization analysis showed a decrease in overall health care costs, specifically a decrease in institutional level care and an increase in community-based services. In early 2009, a cost-benefit comparative analysis was conducted to evaluate healthcare utilization and costs between PPEP and non-PPEP CYSHCN. Outcome data resulting from program enrollment showed that for PPEP participants: (1) the average number of health care encounters per CYSHCN was 21% higher, (2) the average inpatient utilization was 38% lower, and (3) the annual healthcare costs were 15% lower.

Will it Work in California: The program has a strong evaluation component, is a public-private partnership and has sustainable funding. It could be replicated initially as a county-based pilot with plans to go statewide.

Sources in addition to expert interviews: <http://www.health.ri.gov/family/specialneeds/ppep.php>. Retrieved August 24, 2009 and submission to AM-CHP’s Best Practices program.

OHIO: HOSPITAL-BASED CARE COORDINATION

Public

Emerging Practice

The Ohio Department of Health’s care coordination program, operated through the Bureau for Children with Medical Handicaps (BCMh), the state CYSHCN program, uses hospital-based team service

care coordination offered at tertiary care centers within the six metro areas of Ohio.

BCMh offers service coordination in the following areas: medical home, technology dependent conditions and palliative care. Service coordination is provided for the following conditions: myelodysplasia, craniofacial, hemophilia and clotting disorders, cystic fibrosis, oncology, and cerebral palsy. Additional requirements to be eligible for service coordination include age (birth to 21) and residency (resident of the State of Ohio). Services authorized by BCMh include the service coordinator and the BCMh public health nurse.

Hospital-Based Team Service coordination is a team approach with the service coordinator, client and family, and the BCMh public health nurse. The service coordinator is able to assist the client and family to navigate the child's care within the health care systems (which is often complex and involves multiple providers) which also includes assisting with enrollment of BCMh diagnostic and treatment programs. BCMh public health nurses also assist the clients and families in rural areas. A team-based service coordinator from the specialty team will work with the child and family when the child visits the team. The team service coordinator will communicate with the public health nurse (PHN) in the child's local community. These service coordinators will work together with the family to follow the child's progress and help the child receive necessary team and community services.

The service coordinator completes a comprehensive service plan in conjunction with the client/family and the public health nurse. This plan is able to be used as a tool to identify and prioritize needs, identification of available resources to meet needs, identification of barriers, identification of reasonable, attainable, and measurable goals (short and long-term). The plan can be utilized as a compact medical record to assist in hospital admission databases if admitted.

Funding: Service coordinators are able to bill for comprehensive service planning up to two times

a year when the plans are submitted. Public health nurses can bill for their service in 15 minute units.

Evaluation: The program uses six outcome standards to measure effectiveness and uses a bi-annual family survey to measure family satisfaction.

Will it Work in California: This program utilizes children's hospitals and other tertiary care centers in large metropolitan areas to deliver services across the state.

Source: Expert interviews.

NEW HAMPSHIRE PARTNERS IN HEALTH PROGRAM: PROVIDING FAMILY SUPPORT SERVICES

*Public/Private
Emerging Practice*

In New Hampshire, like California, CYSHCN operates outside of the public health agency. While New Hampshire is unlike California in terms of size and diversity of the population, this program has a unique funding source and focus, is a public-private partnership and has been sustainable.

System of Care: The Partners in Health Program complements the New Hampshire Department of Health and Human Services medical care coordination program by providing supports for families of CYSHCN for services not typically covered through care coordination and other state-funded programs. Partners in Health works to help families advocate, access resources, navigate systems and build capacity to manage their child's chronic health condition. The program primarily supports services that are traditionally difficult to fund but that are necessary for the overall health and well-being of the family, such as respite care, support for auto repairs so that a family can go to medical appointments, and even recreation support for siblings of CYSHCN.

There are 13 contracted community-based sites across the state, covering the whole state. Family support coordinators at each site work with families to find and access services and resources, arrange for special needs during hospitalization and after

discharge, help with school planning, and provide recreational and respite opportunities. Many of the family support coordinators are parents of CYSHCN. Each site has a Family Council that plans interventions and programs.

To be eligible for the program children must have a chronic medical condition that impacts daily life and is certified by a medical provider. The program does not cover children who have a developmental disability as the primary diagnosis because there are other programs that provide care coordination and case management services for that population.

Financing: The program is administered by the Children with Special Health Care Needs program of the New Hampshire Department of Health and Human Services, which is located in the Division of Community-based Care Services, and thus organizationally sits outside of the Title V Program. A unique feature of this program is that it is funded through the Social Services Block Grant with other funds from Medicaid targeted case management.

The Partners in Health program has been operating for approximately 15 years. It began through a pilot program funded through the Robert Wood Johnson Foundation through a grant to the Hood Center at Dartmouth University. The program was very well received and expanded quickly. As the grant funding was ending the program approached the state to assist with sustainability. The state was able to leverage the Social Services Block Grant, which has proven to be a flexible source of funding, and use Medicaid case management billing to support the program. The program was administered by the Hood Center but recently moved into the health department because it can administer the program at a significant cost savings. The program is contracted out to 13 community-based sites across the state. The budget for the program includes approximately \$750,000 from the Social Services Block Grant and approximately \$509,000 in Medicaid billing, which includes the state match.

Evaluation: Partners in Health has an annual family satisfaction survey that has had consistently

high results. Families overwhelmingly report finding value in the services provided and report that they would refer other families to the program.

Will it Work in California: The CYSHCN program is located organizationally outside of the Title V program in the Division of Community-based Direct Services along with mental health and developmental disabilities. The program is a partnership between an academic site, the health department and communities. The program has been sustainable using the Social Services Block Grant and Medicaid targeted case management.

Sources in addition to expert interviews: <http://nhpih.dartmouth.edu>. Retrieved August 24, 2009.

(Note: This program also has relevance for the Respite Care section.)

Additional Care Coordination Sources

Antonelli, R., McAllister, J., Popp, J. Making Care Coordination a Critical Component of the Pediatric Health System: A Multidisciplinary Framework Commonwealth Fund Report. Vol 10;21 May 2009.

Pediatrics 2005;116: 1238-1244; Care Coordination in the Medical Home: Integrating Health and Related Systems of Care for Children With Special Health Care Needs.

Kay Johnson and Jill Rosenthal. Improving care Coordination, Case Management, and Linkages to Services for Young Children: Opportunities for States. Commonwealth Fund. April 22, 2009, Volume 107.

The Importance of Integrated Services

Cultural Competency

The need for families with CYSHCN to have services coordinated and delivered in a culturally competent manner is essential for their understanding and comfort with the system of care, as well as their understanding of their child's health condition. Cultural competence means to have a defined set of values and principles, and demonstrated behaviors, attitudes, policies and structure that will enable organizations and systems to work effectively cross-culturally. As states across the country, in particular California, provide services to increasingly diverse populations, the ability to meet the needs of so many different cultures and ethnicities is extremely challenging.

The three models highlighted below each target the Latino population, though they use different strategies that are relevant to California. Utah uses a parent advocate from the Latino community, Tennessee targets fathers, and Wisconsin uses multiple activities to reach out to undocumented children.

UTAH: LEARNING FROM FAMILIES TO REMOVE LANGUAGE BARRIERS

*Public/Private
Emerging Practice*

System of Care: The South Main Clinic, one of seven clinics participating in the Utah Medical Home Project, primarily serves Spanish-speaking families with CYSHCN, many of whom are undocumented. A primary goal of the clinic's Medical Home project is to increase access to care. The Parent Advocate on the Medical Home Team, a Latina mother of a child with disabilities, has been instrumental in establish-

ing trusting relationships with families and sharing information with the team about barriers and issues raised by families. In addition, 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.

Evaluation: 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. In addition, because of the Parent Advocate's success in meeting the needs of Spanish-speaking families, the employee position is now a permanent position at the clinic. In the community, the clinic has earned a reputation for being an accessible and responsive health care resource for Spanish-speaking families.

Project leaders attribute much of this project's success to the collaboration between the Utah Department of Health, Utah State University–Department of Pediatrics, and Utah Family Voices.

Will it Work in California: This program could be a community-based model in culturally diverse areas. The model will be influenced by focus group discussions to help identify specific cultural barriers, and relies on building ties between parent advocates for disabilities (e.g., Family Voices) and the local Latino community.

TENNESSEE: REACHING THE FATHERS

Public/Private

Emerging Practice

System of Care: Tennessee's State Title V Program, Children's Special Services (CSS) developed a program, Hispanic Friends, to provide medical coverage for undocumented children through Tennessee's expanded Medicaid program, TennCare. CSS care coordinators joined with other CSS employees of Latino origin to collaborate with local Latino community organizations to provide access to families and also to leverage resources, especially in rural areas. Through the Hispanic Friends program, CSS has been able to provide medical coverage to children with kidney disease, cancer and heart problems. At a systems level, CSS increased efforts to recruit and hire bilingual staff, and has developed a growing awareness of the need to hire diverse staff who are representative of the community.

Evaluation: When conducting home visits, care coordinators encountered a key barrier to enrolling children in the Hispanic Friends program: they had not connected with the fathers, who held the decision-maker position in the families. To address this issue, the CSS care coordinators joined with other CSS employees of Latino origin to build ties with Latino community organizations. The community organizations are able to leverage resources and serve as cultural brokers or liaisons to increase awareness and knowledge of services offered by the Hispanic Friends program and assist in identifying families with CYSHCN. In this way, the care coordinators were able to establish connections with the fathers, to inform them of services and supports available through the program.

Will it Work in California: Given California's large Latino population, California may want to consider a similar strategy that builds ties with community based organizations and connects care coordinators with fathers.

WISCONSIN: FATHERS AS CULTURAL BROKERS

Public

Emerging Practice

System of Care: Wisconsin Department of Health and Family Services, Title V CYSHCN Program funds five regional CYSHCN centers. Because a survey conducted by the Regional Centers documented that Latino families underutilized services, the Southeastern Center launched an initiative to build partnerships with Latino families and providers funded by Title V. Center staff hired a Latino father to lead community outreach and to serve as a cultural broker through one-on-one services to help families navigate the health care system.

Evaluation: Center staff increased the number of materials available for Latino families and convened community meetings to identify strategies to improve family access to health information and services. For interpreter services, the center staff partnered with a local college to arrange for students to provide interpreter services and developed a training curriculum to help standardize the quality of the interpreter services.

Center staff also partnered with families and the community to conduct a conference to increase providers' knowledge and cultural awareness of Latino population groups. Additional partnerships were formed with the public schools and other Milwaukee community agencies to host a Latino forum addressing special education issues, access to health care services, including transition, and related community resources.

The Center collaborated with leaders in the Latino community as well and partnered with community agencies, including churches, to ensure family participation and partnership in all aspects of developing and implementing program activities.

Will it Work in California: This model builds on the traditional role of the father in the Latino community by using a father to lead outreach and reach

families and give legitimacy to the services and systems. Like the other two models, even though these models have worked with Latino populations, they could potentially be replicated in California with other ethnic communities.

Source for all three profiles in addition to expert interviews: Goode, T. D., Jones, W., Dunne, C., & Bronheim, S. (2007). *And the journey continues...Achieving cultural and linguistic competence in systems serving children and youth with special health care needs and their families*. Washington, DC: National Center for Cultural Competence, Georgetown University Center for Child and Human Development. Retrieved August 11, 2009. <http://www.gucchdgeorgetown.net/NCCC/journey/>

The Importance of Integrated Services

Family-Centered Care and Family Involvement

At the practice level, family-centered care is an approach to the planning, delivery, and evaluation of health care that is grounded in mutually beneficial partnerships among health care providers, patients, and families. It redefines the relationships in health care.

Family-centered practitioners recognize the vital role that families play in ensuring the health and well-being of infants, children, adolescents, and family members of all ages. They acknowledge that emotional, social, and developmental support are integral components of health care, and they promote the health and well-being of individuals and families and restore dignity and control to them. Family-centered care is an approach to health care that shapes policies, programs, facility design, and staff day-to-day interactions. It can lead to better health outcomes and wiser allocation of resources, and greater patient and family satisfaction.

At a policy level, developing family-centered care is one aspect of a larger approach to family involvement. When programs talk about family involvement for CYSHCN, they are not referring to families involved in the care of their own children, but rather, a range of activities that involve families in the planning, development and evaluation of programs and policies. Family involvement can mean the hiring of staff to serve as a family involvement coordinator or parent representative at the state or local level, contracting with a parent group such as Family Voices to

advise on family issues, or including families as members of advisory groups and boards. Each state configures its family involvement differently, although most share a common view of the importance and value of family input and leadership. The following four models show approaches to family-centered care and family involvement examples at the hospital, medical home, family resource, and state level.

MICHIGAN: MAKING FAMILY-CENTERED CARE AN EXECUTIVE LEVEL FUNCTION

Private Emerging Practice

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. The Hospital staff and administration recognize the vital role that families play in ensuring the health and well-being of infants, children, and adolescents. To effectively and accurately identify, diagnose and treat the health care needs of children and adolescents who rely on Children's Hospital for state-of-the-art health care services, families are collaborative partners in every aspect of the care delivery system.

System of Care: The hospital supports families by respecting their decisions; offering comfort as they cope with the child's illness; meeting the social, developmental, spiritual and emotional needs of the child; and fostering family members' confidence in their ability to care for their child. Family-centered

care emphasizes that caregivers must be flexible so they can meet the needs and preferences of all families. The professional staff provides medical information to families and values the personal information families provide about their children. This information exchange builds trust and contributes to the partnership between families and caregivers.

Financing: This program is supported by the Children’s Hospital of Michigan.

Evaluation: 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.

In addition, several other changes have occurred to increase family-centered care, such as changing the visitation policy so that family members other than parents can stay with a sick child; creating a family center with educational materials; establishing a relaxation room that offers a quiet, peaceful place to nap, read and rest; creating a Family Information Guide with words of advice from other families at Children’s Hospital; and allowing access to a concierge for families to run errands. In addition, the hospital is working on enhancing electronic medical records so families only have to provide a child’s medical history one time. Recently, a Youth Advisory Council was created of 11-20 year old current and former patients who meet monthly to evaluate food service, select artwork for the hospital and provide general feedback about their care.

Will it Work in California: Children’s Hospitals should look to the experience of Michigan in hiring a parent (and parent advocate) as Director of Family-Centered Care, an executive level position, to formalize family-centered care, as well as adopting policies to support families during hospital stays.

Source in addition to expert interviews: Children’s Hospital of Michigan: http://www.childrensdmc.org/upload/docs/About%20Chil%20Sp09_Final.pdf.

MINNESOTA: FAMILY CENTERED CARE IN THE MEDICAL HOME

*Public
Emerging Practice*

The state of Minnesota has made family-centered care an integral component of its Medical Home efforts. In 2002 the Minnesota Title V Children with Special Health Needs section at the Minnesota Department of Health received an MCHB Medical Home grant to begin the Minnesota Medical Home Learning Collaborative. In 2005, it received additional grant funding to continue this work. Minnesota Medical Home Learning Collaborative is a nationally recognized leader in the movement. The collaborative ended June 30, 2009 when the grant ended.

System of Care: Twenty-one teams worked to spread the medical home concept throughout the state. Each team was formed from a primary care practice within its own community. Teams consisted of at least two parents who have children with special health care needs, a primary care physician, and a person chosen by the primary care physician, who could serve in the role of care coordinator, such as an RN, LPN, or nurse practitioner. The teams met twice a month. Participating practices were compensated \$400 per month, and the parent members received stipends for their work.

Three times a year, all the teams gathered for a learning session. Family-centered care and parent/professional collaboration skills were taught to new teams. Veteran parents helped to train new parent members.

Financing: This initiative was funded through an MCHB Medical Home grant.

Evaluation: All of the participating primary care practices have made significant changes to their practices and clinics that have been tailored by and to the specific needs of the people in each clinic setting. Examples of positive changes include:

- The identification within the clinic of children with special needs, and the development of a registry
- The development and implementation of care plans
- Chronic care management improvements, such as longer appointments, special appointment times, and special access to physicians or care coordinators
- Improvements in the physical space within the clinic, such as having a wheelchair scale and pictoboards
- Coordination to meet the needs of the family in the community
- Promotion of family networking opportunities.

As a result of the Medical Home collaborative, the state scaled up its concept called “health care home” for all Medicaid enrollees, state employees, and fully insured plan subscribers. “Health Care Homes” will be certified by the Commissioner of Health beginning in Fall 2009.

Minnesota’s program had a state-level leadership team consisting of 12 to 15 members, including physicians, state government employees, academicians, and two parent leaders, which met monthly. This leadership team collected data and worked on outcome surveys, which included information from patients and families that were used to help measure improvements in outcomes.

Will it Work in California: Minnesota’s success depended on a strong commitment from the state to involve families, by providing mentorship to new parents and stipends to parent members of the team.

Source in addition to expert interviews:
<http://www.familycenteredcare.org/tools/downloads.html>

COLORADO: FROM FAMILY INVOLVEMENT TO FAMILY LEADERSHIP

Public Emerging Practice

Colorado’s Title V CSHCN program has employed parent consultants for twenty years. Originally, the consultants worked with families to access resources and support groups, but as Colorado’s CSHCN pro-

gram moved away from providing direct services, parent consultants evolved into conduits to the community. Parent consultants now serve as equal partners with Title V staff, with key roles in program and policy planning.

System of Care: Colorado currently employs one person full-time as family staff (known as a family consultant) at the state level, and fourteen family staff (some full/some part-time) at the local level. In addition, the state contracts with other family leadership staff on part-time basis to work on family leadership training and cultural brokering projects. Local parent consultants are located in health departments throughout the state. State family staff are official employees of the state on a salaried basis.

Collaboration: Local family staff help recruit families to participate on local committees and discussion groups. Parent groups such as Family Voices and Family to Family Health Information Centers also help identify families. In addition, the state supports several non-profit organizations that specialize in cultural brokering for Spanish-speaking families, Asian-Pacific and African American families. Among the major activities of Colorado are the following:

- **Family Leadership Registry:** (See Colorado Medical Home description)
- **Parent Leadership Training Institute (PLTI):** Colorado has recently contracted with the state of Connecticut to provide a Parent Leadership Training Institute, an evidence based curriculum that has been implemented in Connecticut for almost twenty years. The trainer model will help families acquire a core set of competencies in civic involvement to better equip them for policy leadership. By the end of 2009, Colorado hopes to graduate almost 80 family leaders as a result of offering this curriculum in local communities across the state.

Financing: Each local office where family staff is located has a \$2500 line item from Title V for family activities. Decisions as to how to use the money are made locally, but funds are often directed to help family staff attend regional and national conferences and trainings.

Will it Work in California: Colorado has a unique focus on creating family leaders by building leadership at the community and state level, and developing a family registry and Parent Training Institute. These activities depend on extensive partnership and support from multiple levels.

Source in addition to expert interviews: “State Profiles in Family Involvement,” Association of Maternal and Child Health Programs, 2009. In process.

HAWAII: FAMILY TO FAMILY WORKING DIRECTLY WITH MEDICAID

Public

Emerging Practice

Hawaii’s Hilopa Family to Family Health Information Center is working with Medicaid to promote family-centered care in Medicaid Managed care. Similar to California, Hawaii’s fiscal crisis may lead to an increase in the Medicaid eligible population. This program also uses a family peer model to advocate on behalf of families directly with managed care plans. Access to insurance, and insurance coverage, are critical parts of family-centered care, and this program creates partnerships to help assure access to family-centered care.

System of Care: Hilopa’s Family to Family Health Information Center is designated as the state Medicaid Managed Care (QExA) Ombudsman by the state Medicaid agency to implement an independent access point into the system to address concerns and issues. The program works to bring individuals from fee for service Medicaid into managed care. Hilopa’s Family to Family Information Center engages directly with the medical directors and administrators for each health plan on behalf of CYSHCN regarding plan performance. The program serves individuals in Medicaid who are either aged, blind or disabled and has served approximately 40,000 people to date. The numbers are increasing every month due to the economic downturn.

This program operates with a family perspective at the forefront, working in collaboration with families, medical providers and medical plans to

achieve family centered care. The broad partnership with the state Medicaid agency, Medicaid Managed Care Health Plans, Hawaii state legislature, consumer advocacy organizations, provider organizations, including the state chapter of the AAP, the Children’s Community Council, and the Developmental Disabilities Council has been helpful in implementing family-centered care.

Financing: This program is financed through Medicaid.

Evaluation: The model has the ability to deliver accurate information and resolve concerns in a timely manner with the direct access to Medical plans and their directors. The evaluation is done through a phone interview.

Will it Work in California: California communities (and/or the state) could consider using a Family to Family Health Information Center to take the lead in working to assure managed care plans are family-centered. This approach simply expands the roles of an already existing parent resource (with proven and trained staff). Similar to California, Hawaii has a very diverse population and may be experiencing an increase in Medicaid population as the economy worsens.

Source in addition to expert interviews: Joint Meeting of the Family to Family Health Information Center Grantees and State Implementation of Systems of Services for CYSHCN Grantees 2009. http://www.familyvoices.org/pub/general/Activities_05-01-2009.pdf. Retrieved August 14, 2009.

The Importance of Integrated Services

Transition

Among youth with special health care needs, transitioning into adulthood in terms of both health care and career planning/secondary education has added complexities. Therefore, it is vital for this population to have services in place that are appropriate and easy to navigate in order to ensure a successful transition into independent adult living. The most common recommendations among transition experts are that transition should start early (at the minimum age of 13) and should involve the youth, their pediatrician and a primary care doctor, so that everyone is included in the discussion of the expectations and goals for this process. The four models discussed below incorporate many of these recommendations into their programmatic approach to transition and may serve as promising examples.

FLORIDA: YOUTH AND YOUNG ADULT TRANSITION—CHILDREN’S MEDICAL SERVICES

Public

Emerging Practice

Florida, a state with a large and diverse population, is a leading model in terms of services for their CYSHCN population, with a long history on transition as well as positive evaluation data. Currently, Florida’s Children’s Medical Service (CMS) is working to establish a State Office of Health Care Transition to provide technical assistance and support for the development of local coalitions, implementation of education and training activities for both consumers and providers, and advocacy for improved health care financing strategies and policies. One of the goals of CMS transitions program is to help youth and young

adults with special health care needs learn self-determination and develop strategies for a successful transition into adulthood.

System of Care: Each of the 22 CMS area offices in Florida has designated a care coordinator (either a nurse or social worker—some offices have teams) as a point of contact for communications about youth and young adult transition. The care coordinator identifies national, state, and community resources for the successful transition of youth and young adults with special health care needs to all aspects of adult life, including health, work, and integration within their community.

Financing: These activities are funded and sustained through Medicaid.

Evaluation: Preliminary evaluation data show that the percent of youth 12 and older, who have received transition education increased to 51.5% in 2008 compared to 40.7% in 2007. Additionally, the percentage of youth aged 16 and older, whose regular source of primary medical care facilitates the transition from pediatric to adult providers increased to 44.4% in 2008 compared to 33.7% in 2007. Finally, according to a survey given to CMS families, 72% of CMS families reported that their primary care provider discussed transition and adult health care with them; a significant improvement from previous years. The CMS transition information and workbooks, both English and Spanish, are available at <http://www.cms-kids.com>.

Will it Work in California: California could explore this type of transition piece through a larger care coordination demonstration program or through CCS (California Children’s Services) case management.

Source in addition to expert interviews: AMCHP's collection of best practices as well as information taken from <http://www.cms-kids.com/cmsnetwork/transition.html>. Retrieved July 24, 2009.

OREGON: YOUTH TRANSITION PROGRAM (YTP)

Public

Promising Practice

System of Care: Oregon's Youth Transition Program is repeatedly mentioned by experts as a model of care with a strong evaluation, diverse funding sources and the potential for replicability. The program was created from a partnership between the state's Vocational Rehabilitation Services, local school districts and the University of Oregon. The purpose of the program is to prepare youth with disabilities for employment or career related post secondary education or training. Vocational rehabilitation counselors meet with students to discuss career planning, job training or other resources that are available. The YTP provides services to youth that begin during the last two years of high school and continue into the early transition years after leaving high school. More than 50% of youth served by this program come from low income families. This program, which began in seven schools in 1990, is currently operating throughout Oregon in approximately 103 high schools. During the 2007/09 biennium, YTP was funded in 38 local sites, serving 1,556 youth. YTP currently operates in 45% of Oregon high schools.

Financing: The YTP is funded through a combination of state and local education funds as well as money from Oregon's Vocational Rehabilitation Service. Additional funding has been provided through a new collaboration with the Oregon Masonic Charitable Trust.

Evaluation: An evaluation for the years 2007-2009 found that 77% of the students who exited the program were engaged in either work, secondary training or some combination of work and training. This percentage remained the same when these students were contacted after one year.

Will it Work in California: The clear structure and strong evaluation of this program, in addition to its current private funding, could potentially be successfully replicated in California.

Source in addition to interviews with experts: Information taken from <http://www.ytporegon.org/node/6> on July 31, 2009.

MISSOURI TOP PROGRAM: BUILDING TRANSITION SERVICES IN SCHOOLS

Public

Promising Practice

The Missouri Transition Outcomes Project (TOP) is an example of improving transition services by building capacity within schools to address the transition needs among the 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). By law, states (i.e., school districts) are required to comply with the transition services requirements of IDEA (indicator 13) to receive funding. Indicator 13 ensures that children with disabilities have Individualized Educational Plans (IEPs), which outline educational goals for the student. IEPs are an important part of the transition process.

System of Care: Many states and local school districts have difficulty complying with indicator 13 due in part to a lack of understanding of the language and a lack of knowledge about how to address both the mandate and intent of the legislation. Also, there is often a disconnect between collecting transition related data (in the form of IEPs) and using that data to create action plans for youth with disabilities. Missouri has employed TOP contractors for the past two years to train staff at 60 schools. The two-day training includes a presentation on the IDEA legislation regarding indicator 13 using more comprehensible language. Staff members are also trained on collecting IEP data from their student population and enter-

ing these data into a central computerized database.

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. If gaps exist, the staff can further use this information as baseline data from which to set future performance targets. 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.

Financing: TOP is typically funded and sustained through a combination of state funds, funds from the Vocational Rehabilitation Services and the U.S. Department of Education. In Missouri, TOP contractors are funded through federal money received by the Division of Special Education. TOP has been replicated in over 20 other states.

Evaluation: After the first year of implementation, preliminary evaluation data from many school districts has shown significant improvements in the way that IEP data are collected and used. These results are still being analyzed. Missouri plans to increase its TOP training to a total of 150 schools.

Will it Work in California: This program has been replicated in 27 other states and has some evaluation data to demonstrate its effectiveness. However, Missouri's success in the TOP program can also be attributed to a well-established infrastructure to support transition.

Source: For more information about the Transition Outcomes Project, visit the following websites: <http://www.rfcnetwork.org/content/view/205/47/> and <http://www.cuttingedj.net/resources.html>.

DISTRICT OF COLUMBIA: ENGAGING PHYSICIANS IN TRANSITION

Public Emerging Practice

The District of Columbia may be very different from California in terms of size and infrastructure, but its approach to transition by trying to improve the system of care by engaging physicians most affected by medical transition may still be of interest to California.

One of the most problematic issues surrounding medical transition for this population is that they are often under the care of a pediatrician past the age of 18, and when there is a desire to transition to more appropriate adult care, there may be a shortage of primary care doctors to provide services for CYSHCN for a number of reasons (e.g., the complexity of the cases combined with lack of insurance).

System of Care: The National Alliance to Advance Adolescent Health will work in collaboration with local medical universities, health centers, Family Voices-DC, and national partners at Healthy and Ready to Work and the Center for Medical Home Improvement to conduct a two year Action Learning Collaboration (ALC) focusing on engaging physicians around the topic of transition.

The main activities of this project involve surveying and convening a meeting with pediatricians and primary care doctors to solicit ideas and potential policies to address the difficult aspects of transitioning a young adult with special health care needs into adult care. The purpose of this project is to address transition by impacting the systems in which care is provided. In this case, the district is being used as a "system" due to its relatively compact and well defined population. The ALC is currently in its initial stages of development, but will collect evaluation and outcomes data as activities progress.

Financing: The National Alliance to Advance Adolescent Health, located in Washington, DC, recently received funding from the DC Department of Health to address the issue of transition among CYSHCN.

Will it Work in California: If California wanted to do a similar project, it might want to use one insurer, such as Kaiser Permanente as its "system" and conduct surveys and meetings with those physicians and try to impact the quality of medical transition among their CYSHCN clients.

Source: The information about Washington DC's transition activities was obtained during expert interviews with Margaret McManus, MHS and Patience White, MD, MA.

The Importance of Integrated Services

Palliative and Respite Care

Although many states report that CYSHCN and their families have a high demand and need for palliative and respite care, these services are often underfunded. According to experts, effective palliative and respite care should be tailored to the needs of the participants. The services should also be culturally competent since they will be used by a diverse community. The models below demonstrate effective approaches to palliative and respite care.

FLORIDA: PARTNERS IN CARE

Public

Emerging Practice

Florida has a diverse population that is similar to California, and leaders of California's Title V CYSHCN program have shown particular interest in its palliative care model.

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. Prior to the establishment of the PIC program, children with life-limiting illnesses received hospice care under a Medicare model, which precluded curative treatment. Because the lifespan of a child with a life-limiting illness is difficult to predict and the specific factors associated with childhood illnesses may require treatment up to the time of death, the Medicare model of hospice care is inappropriate for a pediatric population.

System of Care: This program is targeted to children/adolescents who are 0-21 years of age and enrolled in the CMS (Children's Medical Services) network under Medicaid or CHIP (KidCare). Each participant must be certified annually by their primary care physician to have a life-threatening condition.

The overall objectives of this program include:

- Enabling children with potentially life-limiting conditions and their families to access a support system that is continuous, compassionate, comprehensive, culturally sensitive and family centered from the point of diagnosis, with hope for a cure, through the provision of end-of-life care if needed
- Identifying and removing barriers that prohibit access to pediatric palliative care that is a compassionate, comprehensive, coordinated blend of services that support both curative and comfort care while preserving the quality of life for children with potentially life-limiting conditions
- Supporting families and caregivers of children with potentially life-limiting conditions as they work to manage their lives given the circumstances brought about by the child's illness

Financing: 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.”

Evaluation: PIC, which is funded and sustained by Medicaid, currently serves more than 300 children and is in the process of expanding to new sites. Some of the services provided by PIC are pain and symptom management, respite care and hospice nursing care. An evaluation of the PIC program is under way.

Will it Work in California: Florida’s experience implementing a pediatric palliative care program may be of special interest to California since it has recently received federal approval to implement a similar type of program. California’s program will start enrolling children in Fall 2009 (<http://www.childrenshospice.org/>).

Source: http://ahca.myflorida.com/Medicaid/quality_management/mrp/contracts/med052/annual_report_2007-08.PDF. Retrieved August 13, 2009.

OREGON: RESPITE CARE FOR THE LIFESPAN

Public Promising Practice

Oregon’s Lifespan Respite Care Program has been mentioned as a model by numerous experts and in 1991 was identified as one of the five best practice models among 33 programs surveyed (Family Caregiver Alliance, October 1999).

System of Care: Created by legislation passed in 1997, the Oregon program directs the Department of Human Services (DHS) to assist local communities in building respite access networks for family and primary caregivers—regardless of age, income, race, ethnicity, special need or situation. DHS, through the Oregon Lifespan Respite Care Program, contracts with private non-profit, for-profit or public agencies in communities throughout the state. Each of these agencies acts as a single local source of information, referral and access to local respite care services. Respite care is one of the most identified services requested by primary caregivers.

Financing: This program is funded and sustained primarily by Medicaid.

Evaluation: In 2007, the Legislature approved funding for DHS to renew a strong commitment to ensure that Community Lifespan Respite Care Program partners are able to coordinate respite care to family caregivers. During 2007-2008, 4,000 people accessed respite services. Currently, 22 networks in Oregon provide the following services in all 36 counties:

- Recruitment and training of respite care providers
- Coordinating necessary respite-related services based on each caregiver’s and family’s needs
- Information and referral to respite-related services
- Linking families with potential respite care payment resources

Will it Work in California: The respite care program in Oregon gives local communities control over the services they provide, thus it may be of interest to California, given its diverse communities and county-based systems. Also, this program is an example of a public-private partnership.

Source in addition to expert interviews:
http://www.oregon.gov/DHS/respite/about_us.shtml. Retrieved July 31, 2009.

WASHINGTON: FAMILY-CENTERED AND CULTURALLY COMPETENT PEDIATRIC PALLIATIVE CARE

Private Emerging Practice

The Seattle Hospital for Children offers palliative care for children and teens with potentially life-limiting or complex conditions through its Pediatric Advanced Care Team (PACT) program.

System of Care: This program, which began in 1997, includes a nurse, doctor, social worker and chaplain, who work closely with patients and families to craft a palliative care plan that meets their needs. The team also consults with the child’s primary care physicians so that they are involved in the process. Another component of PACT is ensuring that families are aware of resources and information they need.

Understanding and respecting patients’ cultural diversity is an important part of PACT. Team mem-

bers work closely with staff from the Children’s Center for Diversity and Health Equity to better understand patient families from different backgrounds and cultures. Additionally, PACT staff has been trained by the Initiative on Pediatric Palliative Care (IPPC), which encourages staff members to practice cultural humility.

Financing: There is no fee for PACT patients since PACT services are supported by a combination of hospital administrative funds and funds allocated from a private endowment dedicated specifically to palliative care. Program staff is currently working on developing an appropriate quality metric to serve as an evaluation tool for its services. This metric will take into account the unique and challenging situation these patients and their families face.

Will it Work in California: This program is an example of how a hospital system approaches palliative care for its patients. It includes aspects of family involvement and cultural competency as the foundation for patient care. It may be of interest to the foundation because of its close relationship with children’s hospitals in California.

Source in addition to expert interviews: http://www.seattlechildrens.org/our_services/palliative_care_consultation/. Retrieved August 12, 2009.

The Importance of Integrated Services

Financing of Care

Financing of care is one of the most challenging but important aspects of meeting the needs of CYSHCN. As a recent report from the Catalyst Center noted, “Families need a range of financing solutions to finally break the link between their children’s special health care needs and financial hardship. They need comprehensive health insurance, family supports and a broad investment in public health.” States are challenged by the pull of needing to develop a solid benefit package that will meet the needs of CYSHCN versus what is actually affordable. Yet, if families have access to adequate health insurance and financial supports, it is more likely that they will not be drowning in debt, family stress will be lower, and they will be participating in economic life.

While no state has or even claims to have an ideal financing system of care for this population, certain states have taken more proactive and in some case creative approaches to reduce the financial burden on these families either through Medicaid Buy-In programs, broad child health insurance programs, and other more directed financial supports. The models presented here demonstrate both system-wide health insurance approaches as well as more modest approaches that still make a difference in the lives of families with children with special health care needs. (For discussion of financing in Florida and other states, please refer to Overall System of Care).

Note: Each of the financing strategies below are deemed “emerging” practices since they represent relatively new mechanisms for financing and have insufficient data to demonstrate an impact on the CYSHCN population and their families.

ILLINOIS: COMPREHENSIVE HEALTH INSURANCE FOR ALL KIDS

Public/Private

System of Care: In 2000, Illinois launched its KidCare (CHIP) program for children in families with income up to 185% FPL. In 2006, Illinois became the first state in the nation to provide affordable, comprehensive health insurance for every child through its All Kids Program. Of the 250,000 children in Illinois without health insurance, more than half come from working and middle class families who earn too much to qualify for state programs like KidCare, but not enough to afford private health insurance. Through All Kids, comprehensive health insurance is available to every uninsured child, at rates their parents can afford. Parents pay monthly premiums for the coverage, but rates for middle-income families are significantly lower than they are on the private market. For instance, a family of four that earns between \$42,000 and \$63,000 a year pays a \$40 monthly premium per child, and a \$10 co-pay per physician visit. The program income limit goes as high as a Premium level 8 which allows income of \$14,701 or more a month for a family of four.

Evaluation: The All Kids program (KidCare has since been folded into the larger program) has helped reduce the number of families with CYSHCN without health insurance. In 2000, about 16% of enrolled CYSHCN were without any health insurance. With the inception of KidCare, the Illinois Title V CYSHCN program required every uninsured family to apply to KidCare in order to continue receiving financial assistance. The number of uninsured families has since

been reduced to about 5%. There are no particular or specific provisions in either KidCare or All Kids related to CYSHCN, but for much of their care, the program provides comprehensive healthcare coverage. As All Kids came into play around 2006, Illinois anticipated that with the same procedure of requiring families to apply for All Kids to continue receiving financial assistance from the CYSHCN Program, the number of uninsured children could be nearly 0%. This has helped the Illinois CYSHCN Program to save money and provide more financial assistance for families with health insurance where the health insurance does not cover or does not fully cover the cost (i.e., acts as a gap-filler for insurance). Illinois recently enacted legislation for a Medicaid Buy-In program as part of the Family Opportunity Act (FOA) but implementation has been delayed due to budget matters. FOA is part of the federal Deficit Reduction Act of 2005. Among the options it offers states are the ability to create a buy-in program to expand Medicaid coverage to children who meet SSI disability criteria and whose family incomes are too high to be eligible under current regulations but yet fall below 300% of the Federal Poverty Level (FPL). Medicaid buy-in programs allow some individuals or families who do not meet these income requirements, but meet other eligibility criteria, to purchase Medicaid coverage. They can “buy in” to Medicaid either as their only source of health care coverage, or as a supplement to private insurance.

Source in addition to expert interviews: All Kids website: www.allkidscovered.com; Frequently Asked Questions about the Family Opportunity Act’s Medicaid Buy-In Option. Catalyst Center. February 1, 2007. Accessed October 4, 2009. www.hdwg.org/resources.

MASSACHUSETTS COMMONHEALTH: MEDICAID BUY-IN

Public

System of Care: CommonHealth is a Medicaid buy-in program for CYSHCN (and adults with disabilities) who meet SSI clinical criteria but whose families are over-income for Medicaid. Family income is disregarded, and families pay a premium based on a sliding fee scale for either full or wrap-around

Medicaid coverage. There are no income limits on the program but the top premium amount is now \$600 per year. As a report celebrating the inception of CommonHealth more than 20 years ago notes, “Families of children with disabilities benefit from the CommonHealth program: they can work, stay married and not have to fear being forced to relinquish custody of their children with special health care needs in order to access Medicaid for them.”¹

Evaluation: Since Massachusetts implemented CommonHealth more than 20 years ago, Congress passed FOA in 2005. In addition to Massachusetts, Pennsylvania and Vermont also had some type of Medicaid buy-in program for CYSHCN prior to the FOA. To date, the following states have passed legislation to allow Medicaid buy-in through FOA: North Dakota, Louisiana, Illinois, Iowa, and Texas. However, implementation of the program in Illinois and Iowa has been delayed, apparently due to state budget issues. The Medicaid buy-in option represents a promising approach for states but is highly dependent on the quality of the Medicaid package families are buying into.

Will it Work in California: Budget problems may preclude California from pursuing this option as it has delayed implementation in other state such as Illinois. In addition, California will have to determine if its Medicaid benefits package meets the needs of CYSHCN. And, of course, such a program requires approval by the state legislature.

Sources in addition to expert interviews: Comeau, Margaret. Catalyst Center Presentation, September 25, 2008, “The Massachusetts CommonHealth Medicaid Buy-in Program at 20: A Retrospective and Celebration,” retrieved August 15, 2009. http://www.communitycatalyst.org/doc_store/publications/commonhealth_20_year_retrospective_aand_celebration_brief.pdf, Catalyst Center’s “Breaking the Link

¹ Comeau, Margaret. Catalyst Center Presentation, September 25, 2008, “The Massachusetts CommonHealth Medicaid Buy-in Program at 20: A Retrospective and Celebration,” retrieved August 15, 2009. http://www.communitycatalyst.org/doc_store/publications/commonhealth_20_year_retrospective_aand_celebration_brief.pdf

Between Special Health Care Needs and Financial Hardship,” February 2009 (www.Catalystctr.org).

SPECIAL NEEDS RELIEF FUNDS: NEW JERSEY, MASSACHUSETTS, MICHIGAN

Public/Private

Both New Jersey and Massachusetts offer Catastrophic Illness in Children Relief Fund funds for families in which families can apply for funds to handle catastrophic conditions in which out-of-pocket expenditures exceed a certain percentage of income. In Massachusetts, an expense qualifies as catastrophic if it represents at least 10% of family income. In this way, families have some assistance with the large purchases related to caring for CYSHCN (e.g., van conversion, home remodeling) that can pose such a burden on families. The funds are self-sustaining because they are funded by a \$1 per employee tax on employers who contribute to the state Unemployment Compensation Fund.

Michigan operates a similar type of fund called the Special Needs Fund, the oldest of the three, originally established in 1944 by a bequest to the state of 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.

Additional approaches to reducing the financial burden on families not outlined in this section include such programs as specialized day care, benefits counseling, consumer directed benefits, care coordination and consumer-directed benefits/flexible spending accounts.

Will it Work in California: A regional pilot for this type of fund in combination with other programs such as benefits counseling and/or care coordination could be part of an overall approach to reduce the financial burden on families. A key issue would be finding a source to sustain the fund.

Sources in addition to expert interviews: Catalyst Center’s “Breaking the Link Between Special Health Care Needs and Financial Hardship,” February 2009 (www.Catalystctr.org).

The Importance of Integrated Services

Health Information Technology

The term Health Information Technology (HIT) can be interpreted narrowly and broadly. Narrowly interpreted, the term refers to electronic medical records (EMR) at the patient and practice level, as well as integrated child health data sets at the systems level. More broadly, it refers to the use of innovative technology to improve systems (e.g., common application) and provide care (e.g., telehealth).

For medical homes, HIT, through patient registries, offers enormous potential to track CYSHCN and build stronger and more effective linkages between primary and specialty care (see Pennsylvania Medical Home model). At this point, however, only a small percentage of practices have adopted this technology, in some cases because of the relatively small size of their practices and also because of the lack of good pediatric models that can capture the type of information (e.g., growth charts) necessary to track child health. Ideally, the EMR will be able to interface with public health through integrated child health information systems. A number of states have developed linked child health data systems such as immunizations and newborn hearing screening that pediatric providers can access through a web-based system.

At the broad end of the spectrum, Utah presents an example of a common application and Florida offers telehealth specifically for CYSHCN. The examples provided in this section provide a sense of the possibilities of HIT, although in all cases, leaders say more investment is necessary to reach more families and better meet the needs of CYSHCN.

UTAH: INTEGRATED CHILD DATA SETS

Public

Emerging Practice

System of Care: Child Health Advanced Records Management, CHARM, is part of the Utah Department of Health's (UDOH) data integration effort. It links child health information from several programs that currently include: Vital Records (birth and death certificates), USIIS (Utah's Immunization Registry), Newborn Hearing Screening and Baby Watch/Early Intervention. Future developments will include the Newborn Screening (heelstick) program and the Birth Defects Network. CHARM provides access to information that is stored in specific program databases to track and monitor child health status, such as screening results, immunization status, referrals, assessment, treatment, and outcomes for children and their families.

CHARM acts as an electronic broker (middleware). It does not replace existing UDOH databases. The participating programs are fitted with their own front-end "agent" that plugs in to the CHARM infrastructure. CHARM is taking a modular approach to integrating systems, beginning with a core of programs and leveraging funding and incremental successes to achieve a long-term vision for a statewide integrated system.

Evaluation: The management approach of CHARM has resulted in a tightly integrated plan with a high degree of accountability. Due to its complex

nature, CHARM was organized into three phases: Needs Assessment, Planning and Implementation.

Will it Work in California: California may want to consider the planning approach used in the CHARM data integration system, should it embark on an integrated data planning initiative. It is important to note that it may require significant and blended funds to undertake such a project.

Source in addition to expert interviews: <http://charm.health.utah.gov>. Retrieved August 6, 2009.

COLORADO: INTEGRATED CHILD HEALTH REGISTRIES

Public

Emerging Practice

System of Care: Colorado is working to develop integrated registries and data bases. 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. CRCSN is Colorado's birth defects monitoring and prevention program. CRCSN maintains a database with information about young children with birth defects, developmental disabilities, and risks for developmental delay. CRCSN and the Health Care Program for Children with Special Needs (HCP) share data so that local HCP offices can provide health care coordination and /or link children and families who have been identified with birth defects and related disabilities with early intervention services. Information is transmitted securely and electronically to an HCP public health office in every county of the state.

Evaluation: The IT system began in 2000 and will eliminate duplication of records for more efficient follow-up, reducing duplicate contacts for families. The project has also developed database software for numerous agencies. In addition to HCP, software has been developed for the metabolic clinics at Children's Hospital, and the Traumatic Brain Injury program. In 2010 the system will be web-based and the EHDI program will be fully automated, allowing hospi-

tal coordinators and audiology providers to update screenings and diagnosis information. Early interventionists currently can log into the system and provide early intervention information. Future integrating of screening results and birth defects with primary health care offices through the state's Immunization Registry is planned.

Will it Work in California: The program in Colorado is noted for its consistent software across agencies. Using such a model could be applicable to California and other states as well.

Source in addition to expert interviews: State of Colorado Title V Block Grant Application Narrative, FY 2009. <https://perfddata.hrsa.gov/mchb/tvisreports/>. Retrieved August 12, 2009.

UTAH: UTAH CLICKS—A COMMON APPLICATION

Public

Emerging Practice

System of Care: Based on the Universal Application System (UAS) technology, Utah Clicks is a web-based interagency application process designed to help families apply for multiple programs. Families can complete paperwork online in a non-duplicative manner and submit their applications electronically to participating programs, such as Medicaid, WIC, CHIP, Head Start and others. The objective of this program is to create a streamlined process for families and children with special health care needs to apply for multiple services and programs. This program is targeted to Utah families who need to access multiple services.

Parents, state and local program staff for multiple agencies, and evaluators were involved throughout the grant cycle. State programs that are included as part of the Utah Clicks program are: Medicaid, CY-SHCN, WIC, Baby Your Baby, Early Intervention, Division of Services for Persons with Disabilities, Part B Preschool, Mental Health, and Head Start. Although not all of these partners' paperwork/application is currently available via Utah Clicks, their collaboration has been vital for the success and promotion of Utah Clicks.

Financing: This program was originally funded by a Maternal and Child Health Bureau grant. Additionally, participating programs in Utah (e.g., Medicaid, WIC, etc.) contribute a portion of the annual funds needed to maintain Utah Clicks.

Evaluation: Utah Clicks was launched in Utah in May 2005 and is currently available to all families statewide. A survey connected with Utah Clicks indicates that only 2% of consumers using Utah Clicks actually go into agency offices to use the system. With only word-of-mouth publicity during the initial five-month period, approximately 600 applications were submitted via Utah Clicks. In October 2005, two newspaper articles introduced Utah Clicks to the public, thus providing slightly higher visibility. During the second five-month period, 4600 applications were submitted via Utah Clicks, a 780% increase in usage. These results suggest that there is a high demand for this service. Additionally:

- 97% of UAS users who completed the online survey would recommend the UAS to other families.
- 40% of the electronic submissions are sent before/after business hours, indicating that 24/7 availability is of value to consumers.
- More than 50% of those surveyed use the program on their home computers and less than 5% use computers at agency offices to access service.

Will it Work in California: While cost savings information is not yet available, such a statewide common application program could potentially save money by reducing on-site visits. In addition, it could provide a mechanism to identify CYSCHN earlier and more efficiently.

Source in addition to expert interviews: Utah Clicks website: www.utahclicks.org. Retrieved August 11, 2009.

FLORIDA: A TELEHEALTH MODEL

Public

Emerging Practice

System of Care: Florida's Children's Medical Services (CMS) program operates a number of tele-

health programs to support child protection teams, pediatric endocrinology, and genetics.

- **Child Protection:** In the area of Child Protection, the CMS Telehealthogram works with the Child Protection Teams (CPTs) to provide medical examinations of alleged child victims who are located in remote areas. A U.S. Department of Agriculture, Rural Utilities Services grant was awarded to CMS in 2004 to enhance capabilities at the current seven telemedicine sites and added two new remote sites in middle/north Florida. A grant was secured to support expansion of telemedicine services into three locations in the Florida Keys region. CPT is now available at 14 services sites. In FY 2006-2007 the CPTs handled 27,470 cases involving child victims and their families and provided 37,008 team assessments, 1,684 staffing, and 797 court testimonies.
- **Endocrinology:** The Children's Medical Services Network (the special health care plan for CYSCHN) works with the Special Technologies Unit to maintain the CMS contracted program with the University of Florida's (UF) pediatric endocrinology staff that provides telehealth services for CMS enrollees with diabetes and other endocrinology diagnoses served by the Daytona Beach CMS area office. The use of two-way interactive video technology has proven to be an effective way of ensuring the availability of expert medical services to outlying rural areas.
- **Genetics:** A genetics telemedicine project enables a pediatrician and a University of Florida geneticist to communicate via two-way interactive video technology. This project has reduced the wait for a genetic screening consultation from one year to less than two months. A similar telemedicine project has been implemented at the University of Miami where the genetics team uses video conferencing to provide consultation for the Ft. Pierce and West Palm Beach CMS area offices.

Evaluation: Other CMS telehealth and telemedicine initiatives include: a partnership with the Institute for Child Health Policy, University of Florida, to refer CYSCHN who are seen at three of the state's community health centers to a CMS office for enrollment; nutritional, neurological, and orthopedic consults for CMS enrollees in Ft. Pierce, West Palm

Beach, and Ft. Lauderdale; craniofacial team meetings; various educational presentations between CMS area offices; and numerous administrative and consultative meetings with CMS staff. Some CMS offices are beginning to work with the University of Miami (UM) to develop teledermatology clinics as well.

Will it Work in California: Florida's far-reaching telehealth program provides of model of collaboration between the state, academia and the hospital system that children's hospitals and universities in California may want to consider.

Source in addition to expert interviews: State of Florida Title V Block Grant Application Narrative, FY 2009. <https://perfddata.hrsa.gov/mchb/tvisreports/>. Retrieved August 12, 2009.

NEW YORK: PUBLIC-PRIVATE TELEMEDICINE PARTNERSHIP

Public/Private Promising Practice

System of Care: Health-e-Access is a telemedicine program located in Rochester, NY, in which childcare sites and schools can obtain off-site health-care from physicians through the use of computer technology. The Health-e-Access Telemedicine Model is guided by the concept of the medical home. The approach to sustainability is based on a model of organizational architecture that recognizes three key drivers: incentives, decision rights, and performance evaluation. Guidelines for care within the Health-e-Access Telemedicine Model detail expectations for certified telehealth assistants at child sites and for telemedicine clinicians in primary care practices.

The primary partners that were involved in the collaboration were health insurance organizations, community- and medical center-based primary care medical practices, child sites in both urban and suburban settings (childcare programs, elementary schools, day programs for developmentally disabled) and telemedicine systems from TeleAtrics, Inc.

Financing: Approximately \$4,000,000 has gone into the development and evaluation of Health-e-Access. Funding was received from federal agencies,

NY State, national and local foundations and from individual donors. The program was initiated in May 2001. Health-e-Access is an ongoing program and is currently sustained from reimbursement for telemedicine visits by all local payers, including Medicaid Managed Care.

Evaluation: Over 7,000 telemedicine visits were conducted through March 2009. The telemedicine program includes more than 30 primary care clinicians who have conducted visits. Approximately 96% of telemedicine visits are completed without the need for travel or any additional in-person visits. The evaluation demonstrated that 95% of parents would choose a child care program with telemedicine over one without it, and parents estimate that a telemedicine visit saves them 4.5 hours on average compared to an in-person visit.

The evaluation of this program also addressed the impact of telemedicine on: absence of children due to illness, parents' absence from work, utilization of traditional health services (e.g., emergency department) and overall cost of care. The results of the evaluation include the following:

- There was a 63% reduction in absence due to illness among children attending inner city childcare, which was attributable to telemedicine.
- There was a 22% reduction in emergency department utilization, which was attributable to telemedicine.
- Given that reimbursement rates for emergency department visits are much greater than for telemedicine visits (reimbursed at the same rate as office visits), the Health-e-Access telemedicine model results in substantial cost savings.

More information about this program is available at www.teleatrics.com. A success story can be found at www.teleatrics.com/media/.

Will it Work in California: California may be interested in the cost savings data and evaluation piece of the Health-e-Access program.

Source: Information taken from materials from AMCHP's Best Practices Program.



Recommendations and Considerations

This section summarizes recommendations and considerations shared by the array of experts consulted for this report. While experts had a number of specific recommendations, particularly in the area of medical homes for CYSHCN, a key overall recommendation repeatedly heard was the need for the Lucile Packard Foundation for Children’s Health to plan and conduct its initiative in a coordinated manner that can benefit the entire state. Experts recognized the challenge of California’s size and diverse population, but felt strongly that even if an initiative were originally a pilot in a county or at the regional level, it had to be part of a coordinated effort to improve care across the state. Experts noted that at the federal grant level, California has been somewhat disadvantaged in discretionary grant funding because it receives the same amount of dollars as smaller states—enough to perhaps focus on one county, but not to effect statewide change. A larger and more population-appropriate statewide investment in some target areas could make a real difference.

In addition, experts emphasized the importance of 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.

The following provides some specific recommendations and considerations for the Foundation based on each topic covered.

SYSTEMS OF CARE

- Start with a focus on one issue (e.g., transition or health information technology) that is agreed upon by key stakeholders. As a next step, bring teams of state experts from model states/programs to California to participate in an action learning laboratory to provide a give and take between California leaders and other states.
- Consider the unmet mental health needs of the children as a whole and CYSCHN, in particular, when designing new initiatives.

MEDICAL HOME

- Invest funds in practice transformation by building the teams and the competencies necessary to provide appropriate medical homes. Ideally, this could be in partnership with Medicaid to provide funds for enhanced reimbursement.
- Provide funding to build and strengthen the capacity of state AAP chapters to promote medical home as practice. Some level of financial support, however modest, is important to pediatricians and other health care providers.

- Support the establishment of medical home efforts in primary care practices, not specialty care clinics. CYSHCN programs must build linkages to primary care, beyond specialty care. Look at providing incentives for sizeable networks that include primary care and medical homes in the network and provide an opportunity to model and evaluate programs.
- Medical home initiatives must connect with the larger community and system of services and not focus only on individual medical practices.
- When designing the evaluation of medical homes, it is important to look at evaluating costs in terms of savings in emergency room visits, savings in ratio of primary care/specialty care, and clinical outcomes such as reduced hospitalization. In addition, examine functional outcomes, such as school absences, family levels of satisfaction, work absences, and family stress.

CARE COORDINATION

- Invest in models that most meet the needs of families in California, whether practice, agency or home-based.
- Explore support for a central database or health record that contains all pertinent medical information as well as care coordination services as part of an overall quality improvement effort.
- Support a program or pilot that uses parent peers or care coordinators who are culturally and linguistically competent for the population being served in a particular practice or county.
- Support initial financial support for practices to have care coordinators on staff if a practice-based model is pursued.

FAMILY-CENTERED CARE

- Include family leaders in the planning and implementation process for Foundation activities for CYSHCN and include family involvement as a requirement for Foundation funding.
- Invest in family leaders at all levels, including executive level positions.
- Ensure that efforts invest in building family relationships. True family involvement requires time spent on key relationships, a financial com-

mitment and a level of support for family leader's growth.

- Continue to share with colleagues the value of family involvement, which is especially important in tough budget times. Family involvement is synonymous with consumer input which is a critical need as programs for CYSHCN across the country work to retain their operating budgets.

CULTURAL COMPETENCY

- Explore the use of cultural brokers to strengthen ties to targeted groups.
- Ensure that all Foundation efforts for CYSHCN include elements that provide for culturally competent care.
- Conduct or support focus groups with target populations throughout the state in order to provide more family-specific and culturally relevant information about the system of care of CYSHCN in the state.

TRANSITION

- Increasing public-private partnerships to make transition not only effective in terms of outcomes, but cost-effective as well.
- Focus on access to health insurance for CYSHCN, including helping youth maintain the insurance that they already have and increasing the maximum age at which CYSHCN can remain on their parental insurance to 25 years or higher. These efforts can help support sustainability of transition programs.
- Recognize that transition programs may cost money on the front end, but will generate money on the back end as CYSHCN are better transitioned to the work environment and thus able to become tax payers. Additionally, if a youth can live more independently, their caregivers may be able to return to work thereby generating more tax revenue.

RESPIRE AND PALLIATIVE CARE

- Invest in a strong infrastructure to support respite care services that takes into account diverse needs within the communities served, and focuses on

improvements in coordination of services related to both palliative and respite care.

- Leverage collaborations through public-private partnership to provide respite services.
- Support programs that address families' many needs that are not traditionally covered through other funding sources, such as respite care and recreational support that help support overall family health and well-being.

FINANCING

- Pursue a combination of approaches to financing and operate some type of pilot. A variety of support services, from trust funds to care coordination to benefits counseling, may help alleviate the financial burden on families.
- Explore the state Medicaid benefits package and determine if it currently meets the needs of CY-SHCN, and whether it could offer an enhanced benefit package or a bundle of services for those with chronic illnesses and disabilities.
- Create a Medicaid Buy-In Program through the Family Opportunity Act that may represent an overall worthwhile and cost-effective intervention if the Medicaid package is relatively robust.

HEALTH INFORMATION TECHNOLOGY

- Invest in a statewide CYSHCN registry. Current registry models are adult-focused and there is currently no strong pediatric models for EMRs or registries. Developing CYSHCN registries can help providers better follow their patient load. This could be in combination with the development of a stronger Electronic Medical Record model.
- Ensure that investments in health information technology software for coordinating the care of CYSHCN are transferable across states.



Expert Consultants and Bibliography by Topic Area

OVERALL SYSTEM OF CARE FOR CYSHCN

Experts Consulted

Holly Grason, Women's and Children's Health Policy Center, Johns Hopkins University

Charles Homer, National Initiative for Children's Healthcare Quality

Lynda Honberg, Maternal and Child Health Bureau

John Hurley, Minnesota Department of Health

Chris Kus, New York State Department of Health

Cassie Lauver, Maternal and Child Health Bureau

Maria Nardella, Washington State Department of Health

Chuck Onufer, Division of Specialized Care for Children, University of Illinois (Retired)

Phyllis Sloyer, Florida Department of Health

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INTEGRATED SERVICES

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Richard Roberts, Champions for Inclusive Communities

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MEDICAL HOME

Experts Consulted

Gerri Clark, Division of Specialized Care for Children, University of Illinois

Michelle Esquivel, American Academy of Pediatrics

Eileen Forlenza, CSHCN, Colorado Department of Public Health and Environment

Charles Humble, North Carolina AccessCare

Marie Mann, Maternal and Child Health Bureau

Danielle Matula, North Carolina Department of Human Resources

Chuck Onufer, Division of Specialized Care for Children, University of Illinois (Retired)

Fan Tait, American Academy of Pediatrics

Mary Takach, National Academy for State Health Policy

Renee Turchi, St. Christopher's Hospital for Children

Kathy Watters, Colorado Department of Public Health and Environment

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National Center of Medical Home Initiatives for Children with Special Needs: www.medicalhomeinfo.org

Center for Medical Home Improvement: <http://www.medicalhomeimprovement.org>

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CARE COORDINATION

Experts Consulted

Jim Bryant, Ohio Department of Health

Gerri Clark, Division of Specialized Care for Children, University of Illinois

Elizabeth Collins, New Hampshire Department of Health and Human Services

Deborah Garneau, Rhode Island Department of Health

Marilyn Hartzell, Oregon Center for Children and Youth with Special Health Care Needs

Lynda Honberg, Maternal and Child Health Bureau

Phyllis Sloyer, Florida Department of Health

Jennifer Warfel, Ohio Department of Health

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Experts Consulted

Sophie Arao-Nguyen, Family Voices

Juno Duenas, Family Voices, California

Wendy Jones, National Center for Cultural Competence

Websites and Written Resources

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Experts Consulted

Betsy Anderson, Family Voices

Sophie Arao-Nguyen, Family Voices

Bev Crider, Children's Hospital Michigan

Eileen Forlenza, Colorado Title V CYSHCN Program

Bev Johnson, Institute for Family Centered Care

Leolinda Parlin, Hilopa's Family to Family Health Information Center, Hawaii

Nora Wells, Family Voices

Websites and Written Resources

Family Centered Care Self Assessment Tools: http://www.familyvoices.org/pub/projects/fcca_FamilyTool.pdf
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TRANSITION

Experts Consulted

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Margaret McManus, National Alliance to Advance Adolescent Health

Patience White, George Washington University School of Medicine and Health Sciences.

Jeri Dickinson, Oregon Youth Transition Program

Ed O'Leary, Transition Outcome Projects

Barbara Gilpin, Missouri Department of Elementary and Secondary Education

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PALLIATIVE AND RESPITE CARE

Experts Consulted

Ross Hays, Seattle Children's Hospital
Jill Kagan, National Respite Coalition
May Martin, Oregon Lifespan Respite Program

Websites and Written Resources

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FINANCING

Experts Consulted

Gerri Clark, Division of Specialized Services for Children, Illinois
Margaret Comeau, Catalyst Center
Cathy Hess, National Academy for State Health Policy
Lynda Honberg, Maternal and Child Health Bureau
Henry Ireys, Mathematic Policy Research
Kathy Stiffler, CYSHCN, Michigan
Mary Takach, National Academy for State Health Policy

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HEALTH INFORMATION TECHNOLOGY

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Carl Cooley, Center for Medical Home Improvement
Michelle Esquivel, American Academy of Pediatrics
Marie Mann, Maternal and Child Health Bureau
Jeanne McCallister, Center for Medical Home Improvement
Fan Tait, American Academy of Pediatrics