



# 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/>.