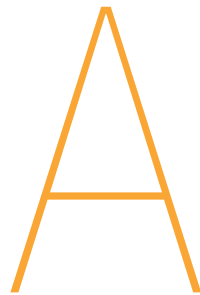


SUMMARY AND RECOMMENDATIONS



As with the discussion of system gaps above, the following recommendations were culled from earlier papers addressing service delivery organization for CYSHCN. The recommendations cited from those earlier papers represent the analysis and experience of many stakeholders whose lives and work focus on vulnerable children and their families. As the authors note in the above section on gaps in the service system, the reports cited earlier in this paper demonstrate that there has been substantial work already in California to analyze gaps and barriers and recommend strategies to address those problems and create a true system of care for CYSHCN. In fact, to a great degree the recommendations from the different reports are in agreement.

The authors present the following recommendations as the latest in a long series of attempts to move California toward a comprehensive system of care for its children and youth with special health care needs and their families. In keeping with national directives for the care of CYSHCN, the recommendations are framed in the context of the MCHB Core Performance Measures.

Each core performance measure includes a recommendation that the state set clear criteria for state achievement of that measure and that state progress be measured and reported publicly. This recommendation is made in order to ensure that the state has clear and measurable goals for the achievement of each measure and that its performance is evaluated and reported.

Families of children and youth with special health care needs partner in decision-making at all levels and are satisfied with the services they receive.

1. Families and youth should be represented at all levels of planning and implementation of the service system, including a formalized structure at the state level to model parent/professional collaboration. This could be accomplished via an ongoing state-level workgroup with representation from family groups, agencies, providers, and others involved in care for CYSHCN that is charged with improving quality, family-centeredness, and coordination of care.
2. There should be a formal evaluation process, including ongoing interviews and surveys, to assess family and youth satisfaction with the services they receive. At minimum, state programs essential to this population of children

and youth should participate, such as regional centers, CCS, special education, and mental health, with periodic public reporting of results.

3. There should be clear state standards for family-centered care in all systems serving CYSHCN. For example, standards for local public programs, special care centers, and other services for CYSHCN should address the provision of family centered care.
4. There should be mechanisms for providing ongoing information, education and support for leadership development among families and youth to improve their capacity to represent their interests and participate fully in decision-making at the state and local levels.
5. Parent health liaison services should be made available for all CYSHCN receiving services from public programs at the local level to assist families in navigating the different systems children require; PHLs also can assist local programs in assessing the degree to which families are satisfied with the services received. Ideally, implementation of PHL services would be provided by funded contracts with family resource centers in order to build on a system that already exists and build on families' knowledge of and experience with the services for CYSHCN. Such contracts also would contribute to leadership development and capacity-building with families and youth.
6. The state should ensure that California sets clear criteria for achievement of this core measure and that the state's performance and progress are measured periodically and reported publicly.

Children and youth with special health care needs receive coordinated, ongoing, comprehensive care within a medical home.

1. The state should define and operationalize the concept of a "medical home" for CYSHCN, ensuring that mechanisms are in place to assist in linking families to a medical home. All publicly funded programs should ensure that CYSHCN have an identified medical home and if not, should assist families in identifying an appropriate one. As a first step, the state should ensure that all children have an identified primary health care provider, the designated health care provider who will hold responsibility for coordinating health care for the child. This provider may be a pediatric subspecialist or other provider rather than a primary care physician, depending on the needs of the child.
2. An infrastructure to support training and education of providers to assist them in serving as medical homes for CYSHCN should be developed. Preliminary work on the state CCS Medical Home Initiative could assist planners in this task; in addition, there are several interesting models in other states that can provide guidance (e.g., Illinois, Washington, and Texas).
3. Mechanisms should be established for Medi-Cal billing and other reimbursements for care coordination within the medical home. Preliminary work was done on potential Medi-Cal billing options in the state CCS Medical Home Initiative; other states also offer possible options for structuring and financing of care coordination reimbursement.

4. The state must address the crisis in the pediatric provider network by taking steps to increase the numbers of primary, specialty care, and other providers serving CYSHCN. Appropriate reimbursement is critical to maintaining the adequacy of the provider network. Reducing CCS and Medi-Cal claims problems with EDS and reducing administrative burdens in the Medi-Cal system in general also would support provider participation in CCS and Medi-Cal.
5. Regionalized services such as hospitals and other providers serving CYSHCN from multiple counties should ensure that children's care is coordinated with the medical home in order to address the needs of the child regardless of the county of residence.
6. Families must be recognized as the true medical home for many CYSHCN and their participation in formal medical home approaches and structures should be supported at both the state and local levels.
7. The state should ensure that California sets clear criteria for achievement of this core measure and that the state's performance and progress are measured periodically and reported publicly.

Families of CYSHCN have adequate private and/or public insurance to pay for the services they need.

1. California should set as an overarching goal the assurance of comprehensive insurance coverage for all CYSHCN, regardless of income, and should consider strategies to achieve this goal, including implementation of the Family Opportunity Act (federal legislation that permits states to create a Medicaid buy-in option for individuals who have SSI-eligible disabilities and have incomes below 300% of FPL, but whose income is above regular Medicaid income eligibility) as a potential source of insurance for families of CYSHCN who currently are not Medi-Cal-eligible; review of existing Medicaid waivers and consideration of opportunities for expansion to include Medi-Cal determination of eligibility for additional CYSHCN and elimination of a waiting list for access to home- and community-based waivers; and elimination of exclusions based on preexisting conditions.
2. The state should clarify payment policy among its various agencies so that there is a payer of first resort, rather than families and providers having to sort out payment among multiple "payers of last resort." "Pay and chase" and other strategies could be explored to solve the payment dilemma.
3. The EPSDT benefit package and federal medical necessity definition should be established as the medical standard for care for all children in the state. As discussed earlier in this paper, EPSDT and the medical necessity definition together constitute the gold standard for care of children, particularly for CYSHCN.
4. CCS state quality standards should be established as the standard for all pediatric care in the state. These standards set the bar for pediatric subspe-

cialty care for CCS certification and in the process create standards of excellence for pediatric services for all children. Implementation of this recommendation would require amendment of the state Insurance Code to require private health maintenance organizations (HMO) and preferred provider organizations (PPO) to meet CCS pediatric standards of care.

5. The state should establish the CCS program as the whole-child program of comprehensive care for CYSHCN and should consider adjustment of CCS program financial eligibility to restore the income limit to \$100,000; deem children enrolled in Healthy Kids programs as financially eligible for CCS; and link CCS financial eligibility to the federal poverty level (FPL) with calibration by family size.
6. The state should strengthen Healthy Kids programs by setting statewide standards for benefits and financial eligibility criteria.
7. The inadequacy of private insurance in addressing CYSHCN should be addressed through such steps as elimination of annual and lifetime caps on insurance coverage and establishment of the right of young adults to age 28 to buy into their parents' insurance at group rates.
8. The state should ensure that it sets clear criteria for achievement of this core measure and that the state's performance and progress are measured periodically and reported publicly.

Children are screened early and continuously for special health care needs.

1. As recommended by a number of reports, the state should establish use of a standardized screening tool or tools for identification of children with health, developmental, behavioral, and mental health concerns. Clear and workable funding and billing mechanisms should be established for administration of the screening tool(s).
2. There should be state performance standards for early and continuous screenings (e.g., CHDP Health Assessment Guidelines) implemented in both public and private health plans. The standards should include the use of accepted health, developmental, and mental health screening tools.
3. The state should implement an outreach and education plan for health providers that will promote early and continuous screening and surveillance, identification of CYSHCN, partnering with families, and understanding of appropriate resources for follow-up.
4. The state should align the CHDP periodicity schedule with the current American Academy of Pediatrics (AAP) schedule and ensure that children can obtain both periodic and inter-periodic visits as needed. The state could consider developing a risk-adjusted screening periodicity schedule for CYSHCN with a number of visits beyond the current American Academy of Pediatrics (AAP) periodicity schedule.

5. The state should ensure that California sets clear criteria for achievement of this core measure and that the state's performance and progress are measured periodically and reported publicly.

Community-based services for children and youth with special health care needs are organized so families can use them easily.

1. There should be a statewide interdepartmental coordinating body created, with entities such as the departments of health, mental health, social services, developmental services, education, and others as needed; families; advocates; and representatives of county departments, in order to address how the multiple services for CYSHCN can be better organized and coordinated for easier use by families. This recommendation is a common theme in many statewide reports addressing organization of care for CYSHCN and is essential to think through and address strategies recommended under other core performance measures.
2. The state should ensure consistency across regions and counties in the interpretation and implementation of state law, regulations and procedures regarding program and benefits eligibility for children's programs, including regional centers, CCS, and mental health.
3. Policies on sharing of information among public and private agencies under the Health Insurance Portability and Accountability Act (HIPAA) and other federal and state laws should be clarified. All agencies serving CYSHCN should be required to share information to the extent permitted by confidentiality law in order to ensure identification, access to care, coordination of services, and quality improvement. This recommendation has consistently been identified as critical in existing state reports on CYSHCN.
4. The state should develop and implement strategies and funding mechanisms that will support activities to improve coordination of services such as:
 - Local agency "roundtables" to coordinate access to services;
 - "Single point of entry" (SPOE) mechanisms for easy access to all children's programs;
 - Special care center-sponsored multidisciplinary team meetings with community-based services and families;
 - Neonatal intensive care unit (NICU) discharge planning meetings with all agencies;
 - Universal parental consent form to improve referral to and sharing of information among agencies;
 - CCS public health nurse (PHN) positions (modeled after foster care PHNs to coordinate between CCS and schools);
 - Increased support component within CCS through CCS social workers and/or parent health liaison (PHL) services;
 - Models for a "system navigator" and/or ombudsperson to assist parents to access service across systems.

5. All families should have a hard copy and/or electronic health record for their children and tools to assist them in tracking their medical care, including child health notebooks that can be used across service systems. Several models of hard-copy child health notebooks already in use in the state among CYSHCN could be distributed to families; in addition, several models of family-friendly electronic medical records currently are being tested for wider use.
6. The state should ensure that California sets clear criteria for achievement of this core measure and that the state's performance and progress are measured periodically and reported publicly.

Kathy, who just turned 18, has developmental disabilities and special medical needs. Her parents were just provided with some basic information on conservatorship, special needs trusts, adult day programs, supported living, and other transitional programs. Her parents are frantic and feel pressed for time. They wish one of the professionals in their daughter's life had exposed them to these issues when she was 16 instead of now, when she is 18.

Youth with special health care needs (YSHCN) receive the services necessary to make transitions to all aspects of adult life, including adult health care, work, and independence.

1. An infrastructure to support the implementation of standardized transition plans and coordinate transition among the multiple systems serving YSHCN should be created. Creation of the infrastructure and implementation process could be taken on by the statewide interdepartmental body recommended above.
2. The state should commit to ensuring that YSHCN do not transition out of public or private insurance into the ranks of the uninsured. To that end, the state should consider strategies to assure that youth retain current coverage or achieve new comprehensive coverage through means such as increasing the number of conditions covered by the Genetically Handicapped Persons Program and/or extending CCS coverage beyond age 21 for specific conditions; modifying financial eligibility for Medi-Cal for YSHCN over age 21 to expand their access; and establishing a right to benefits for YSHCN under parental coverage to a specific age such as 24. (See also strategies to address private insurance issues discussed earlier.)
3. The state, in concert with pediatric experts and adult-oriented medical groups, should consider ways to support and strengthen the capacity of adult-oriented providers to serve youth and young adults with special health care needs, including adults with pediatric-oriented conditions that are more commonly being seen now among adults.
4. Provider rates and other incentives should be instituted to fortify the provider network for YSHCN, e.g., by applying the increased CCS specialty rate to Genetically Handicapped Persons Program (GHPP) specialists and to other non-physician CCS providers such as durable medical equipment (DME) vendors.
5. California must set clear criteria for achievement of this core measure and the state's performance and progress measured periodically and reported publicly.