

EXECUTIVE SUMMARY



The authors believe that proposals that further achievement of the MCHB Core Performance Measures and meet core principles for health care delivery to CYSHCN stand the best chance of building a true system of care for vulnerable children and youth.

The future of children with special health care needs and their families is at a crossroads as a result of a number of pressing factors: ever-increasing numbers of children with special health care needs due to lifesaving interventions and early identification; the push toward full inclusion and optimal independence for individuals with disabilities and chronic conditions; the increasing cost of health care; the public debate to reduce health care costs and lower taxes; the decreasing availability of specialty care providers; the lack of access to comprehensive care coordination; and recent service cuts for vulnerable populations.

Children and youth with special health care needs (CYSHCN) are caught in the throes of this perfect storm; their well being is at risk. The Lucile Packard Foundation for Children’s Health has requested a paper that provides an overview of the current system of care for children with special needs and their families in California as the state contemplates changes in how these services are organized and delivered.

This report begins with an overview of the health and related systems designed to serve children with special health care needs, including publicly and privately funded services, as well as those specific to certain populations. Detailed information about each service system is located in the appendices at the end of the report, and referenced in the text. The next section consists of an analysis of the strengths and gaps within the current service system, and their impact on families. The report ends with a summary and recommendations for addressing some of the primary concerns in the current system of care.

WHO ARE CHILDREN WITH SPECIAL HEALTH CARE NEEDS AND THEIR FAMILIES?

Children and youth with special health care needs are defined by the Maternal and Child Health Bureau (MCHB) of the Health Resources and Services Administration, U.S. Department of Health and Human Services (US DHHS), as:

“...those who have or are at increased risk for a chronic physical, developmental, behavioral, or emotional condition and who also require health and related services of a type or amount beyond that required by children generally.”

This definition was deliberately designed to be broad and inclusive, to reflect the characteristics held in common by children with a wide range of

diagnoses. However, publicly funded agencies do not base eligibility for services and programs on this broad federal MCHB definition, and instead tend to base their program eligibility on very specific conditions and diagnoses. In many instances, a single child with multiple special needs receives services and case management from a host of public programs for a complex medical condition, a developmental disability, a specific mental illness, and for special educational needs, while at the same time receiving basic health care via public and/or private health insurance.

According to the 2005-06 National Survey of Children with Special Health Care Needs (NS-CSHCN), 13.9% of U.S. children have special health care needs, and 21.8% of households include at least one child with a special health care need. According to the NS-CSHCN, children with special health care needs comprise between 9.9%-14.5% of children in California (US DHHS, 2008; CAHMI), or approximately 964,167 children.

Special populations within the broader group of CYSHCN face greater difficulties accessing health, developmental, behavioral, and educational services. These special populations include children in poverty; children whose parents do not speak English; children in foster care and other out-of-home care; and adolescents, including emancipated and homeless youth.

MCHB CORE PERFORMANCE MEASURES

In 1998, the federal Maternal and Child Health Bureau established a goal for state Title V programs for children with special health care needs to provide and promote family-centered, community-based, coordinated care for CYSHCN and to facilitate the development of community-based systems of services for these children and their families (MCHB, 2008). MCHB identified six core outcomes to promote this system of care mandated for all children with special health care needs under Title V, Healthy People 2010:

- 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.
- Children and youth with special health care needs receive coordinated, ongoing, comprehensive care within a medical home.
- Families of CYSHCN have adequate private and/or public insurance to pay for the services they need.
- Children are screened early and continuously for special health care needs.
- Community-based services for children and youth with special health care needs are organized so families can use them easily.
- Youth with special health care needs receive the services necessary to make transitions to all aspects of adult life, including adult health care, work, and independence.

Cultural competence is not a performance measure, but MCHB has included it as a guiding principle, which goes across all performance measures

(Goode, T.D., et al, 2007). This guiding principle and the six outcomes are designed to give the states and MCHB a way to measure progress on achieving the goal of family-centered care. The authors use the core measures as a framework for identifying strengths, gaps, challenges, and recommendations.

CALIFORNIA'S "SYSTEM OF CARE"

Terms like "system of care" are often used to refer to the panoply of services available to CYSHCN in California. In fact there is no "single system" but rather a complex "series of systems" that exist independently of each other, occasionally overlapping and sometimes conflicting. These coexisting, overlapping, and contradictory systems and funding mechanisms result in an extraordinarily complex maze of services, dueling eligibility criteria, and financing approaches that can confuse even the savviest advocate and result in delayed or denied services for children and major financial outlays for families. Ultimately, the success of CYSHCN in accessing services in the "system of care" is dependent on families' ability to negotiate this maze.

At the time of this writing, as a result of the state's desperate financial situation, everything connected with these "systems" is fluid, and there could be major changes in the coming year. We also recognize the potential impact of federal health care reform, which could result in significant redesign of the health system nationally, with repercussions for public and private health care coverage in our state.

PROGRAMS FOR CHILDREN

Publicly funded services for CYSHCN in California can be characterized in two ways: (1) basic health service programs, and (2) specialized service programs.

The report goes into depth on basic health service programs, including federal Medicaid; Early Periodic Screening, Diagnosis, and Treatment (EPSDT); federal Medicaid waivers; California's Medi-Cal; health services for immigrants under Medicaid; state Children's Health Insurance Program (CHIP) and Healthy Families; Medicare; TRICARE; Indian Health Service; Federally Qualified/Migrant and Rural Health Centers (FQHC); Supplemental Security Income (SSI); Social Security Disability Insurance (SSDI); Child Health and Disability Prevention (CHDP); and Access for Infants and Mothers (AIM).

The report also goes into depth on specialized service programs, including California Children's Services (CCS); the Genetically Handicapped Persons Program (GHPP); Regional Centers for Persons with Developmental Disabilities; special education; In-Home Supportive Services (IHSS); the state High Risk Insurance Pool; and mental health services.

Privately funded services for CYSHCN in California include private health insurance and foundations/support organizations and are discussed in detail in the full report.

OVERVIEW OF SERVICES FOR FAMILY SUPPORT

Whether families are in the hospital, at a doctor’s office, or at a community-based agency, they face a confusing maze of services and systems. As their children grow older and become more independent, the youth themselves need to understand the systems that serve them. Although many systems have case managers, families and youth often take the primary responsibility for coordinating their care across systems. In order to do this, families and youth need ongoing information, education, and support. They need to learn the intricacies of the different systems, and how to become partners in making decisions about their own care.

California has a variety of cost-effective, community-based resources that work together to assist families in navigating these complex systems and regulations. These services help families obtain adequate and appropriate care for children and youth with special health care needs. These community-based resources are rooted in a parent-to-parent and empowerment-focused philosophy and include Family Resource Centers (FRC); California Association of Family Empowerment Centers (CAFEC); Family Voices of California (FVCA); Parent Training and Information Centers (PTI) and Community Parent Resource Centers (CPRC); and United Advocates for Children and Families (UACF).

IS THERE A SYSTEM OF CARE FOR CYSHCN? ANALYSIS OF THE SYSTEMS, THEIR STRENGTHS AND CHALLENGES

Services for CYSHCN are provided in a variety of inpatient, outpatient, and community settings, depending on a number of factors including funding source, where the child lives, services needed, the child’s medical condition, and available specialists. These settings include children’s hospitals, CCS special care centers, community hospitals and clinics, pediatric subacute facilities, and home health care. Developmental and mental health services are provided by regional centers and county mental health programs; special education services are provided by individual or county school districts. Every report addressing access to care for CYSHCN in our state has commented on the need for California to address its silos of health, developmental, and mental health programs and to create mechanisms for the delivery of true coordinated, collaborative care.

PRIOR EFFORTS ADDRESSING CYSHCN

A number of reports aimed at assessing or improving California’s system of care for children with special health care needs are highlighted and discussed in this report. The paper builds on and incorporates these findings in its analysis of system gaps and recommendations.

STRENGTHS, CHALLENGES, AND GAPS IN THE SERVICE SYSTEM

California has many important components in place that foster implementation of a system of care for CYSHCN, including:

- A strong network of family organizations and a statewide chapter of Family Voices that bring the perspective of families to the design and operation of a family-centered system of care for CYSHCN.
- A dedicated pediatric provider network of physicians and other health care providers and tertiary and quaternary pediatric hospitals that are the envy of many states.
- Committed advocates for children and youth, including advocates specifically focused on improving access and care for CYSHCN.
- Publicly funded programs such as Medi-Cal that typically exceed the minimum required by federal law, bringing vitally needed services to low-income CYSHCN.
- A number of specialized programs designed specifically for special populations of children such as CCS and regional centers/Early Start.
- Public and private foundations whose interests are focused on CYSHCN.

At the same time, the national and global economic downturn, coupled with the state's own political and budgetary problems, presents major challenges at the macro level to achievement and maintenance of any system of care. These challenges, which affect funding and political support for programs that serve CYSHCN, include the following:

- The impact of the global economic meltdown has had catastrophic effects on California, including double-digit unemployment (11.6% in August, 2009) and a substantial drop in revenue to the state.
- California has a huge economy (8th largest in the world) that typically is slower to move into a recession but also slower to recover from one.
- California has severe structural budget imbalances, e.g., 55% of state revenue comes from personal income tax, as opposed to most other states that typically have a one third division among income tax, property tax, and sales tax. This imbalance leaves the state very vulnerable to a drop in income tax receipts such as the state is experiencing now.
- The economic situation is compounded by huge state budget deficits over the past few years that have resulted in major reductions in overall state spending, amounting to a drop in state spending of almost 20% in the last two years.
- The power of the governor and legislature to address structural imbalances is limited by California's status as the only state to require a super majority for both passage of the budget and any increase in state taxes.

As a result of these factors, California finds itself in the worst fiscal crisis in at least 20 years, with concomitant impact on funding for the services that make up the existing system of care for CYSHCN.

Even before the current fiscal situation and its potential impact, California had major gaps in its service system that leave vulnerable children and families at risk. Major service gaps that we have identified are grouped according to the six federal MCHB Core Performance Measures. The service gaps are organized

by measure because these are national goals our state is expected to meet. These measures define the service system that families and maternal and child health professionals agree must be in place for vulnerable children. Most of the gaps identified below have been culled from existing reports and surveys concerning access to care for California's CYSHCN that have been produced by major stakeholder processes over the years and reflect the thinking of many professionals and family members.

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 in California do not have structured and institutionalized opportunities to partner in decision-making at all levels.
2. There are no clear, published standards for family-centered care.
3. There is no formal evaluation or tracking system.
4. Infrastructure does not exist to ensure that families or youth have ongoing access to information, education, and support for leadership.

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

1. California does not have an operational definition of "medical home" for CYSHCN and it does not have clear numbers on how many medical homes really exist or a way to ensure that all CYSHCN have one.
2. There is no infrastructure to support ongoing training of and information for providers who want to implement medical homes.
3. There is no mechanism for Medi-Cal billing or other financial enhancement for care coordination in the medical home context.
4. California has an increasingly fragile provider network and continues to lose pediatric subspecialists to other states.
5. There also are long wait times for other providers serving CYSHCN, e.g., mental health professionals, particularly child/adolescent psychiatrists and physical and occupational therapists.
6. Health, developmental, and mental health services are more likely to be located in urban areas than in rural areas.

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

1. Many families and youth with special health care needs do not have insurance or are underinsured.
2. Children may lose eligibility for public or private health insurance throughout the year.
3. Many families may qualify for insurance but because of a lack of information, they do not access it.

4. High out-of-pocket expenses are a barrier to children receiving the comprehensive services they need.
5. “Adequate” insurance can be a nebulous concept, since coverage that may appear adequate at first can lose its effectiveness depending on the changing health needs and program policies related to payment.

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

1. California does not have a standardized screening tool for identifying special health care needs.
2. Providers are not always knowledgeable about resources for follow-up when screening identifies problems.
3. Appropriate resources for follow-up once screening has taken place often are limited

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

1. There is no state inter-departmental coordinating body to work toward better organization of the multiple service systems for CYSHCN.
2. There is a lack of consistency of interpretation of state regulations/laws from county-to-county and across the multiple systems serving CYSHCN.
3. While many entities purportedly provide care coordination, there is a lack of communication among the multiple agencies serving the same child.
4. Most families report that they serve as their children’s care coordinators.

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. There is no coordinated transition process for youth who are aging out of child-focused programs.
2. There are too few adult-oriented health care and other providers for youth as they age out of pediatric-oriented care.
3. Many youth lose insurance as they age out of eligibility for public insurance or insurance coverage through their parents’ employers.

SUMMARY AND RECOMMENDATIONS

The following recommendations build on findings in previous reports addressing service delivery organization for CYSHCN. The recommendations from earlier findings represent the analysis and experience of many stakeholders whose lives and work focus on vulnerable children and their families.

In keeping with national directives for the care of children with special health care needs, our recommendations are framed in the context of the MCHB Core Performance Measures.

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 in a formalized structure at the state level to model parent/professional collaboration.
2. There should be a formal evaluation process, including ongoing interviews and surveys, to assess family and youth satisfaction with the services they receive.
3. There should be clear state standards for family-centered care in all systems serving CYSHCN.
4. There should be mechanisms for providing ongoing information, education and support for leadership development among families and youth.
5. Parent health liaison services should be made available for all CYSHCN receiving services from public programs at the local level.
6. The state should set clear criteria for achievement of this core measure and ensure that its 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.
2. An infrastructure to support training and education of providers to assist them in serving as medical homes for CYSHCN should be developed.
3. Mechanisms should be established for Medi-Cal billing and other reimbursements for care coordination in the medical home context.
4. The state must address the crisis in the pediatric provider network by taking steps to increase the numbers of primary and specialty care providers serving CYSHCN; appropriate reimbursement is critical.
5. Regionalized services 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 their CYSHCN, and their participation in formal medical home approaches or structures should be supported at both the state and local levels.
7. The state should set clear criteria for achievement of this core measure and ensure that its 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.
2. The state should clarify payment policies among its various agencies so that there is a payer of first resort,
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.
4. CCS quality standards should be established as the standard for all pediatric care in the state.
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 parents' insurance at group rates.
8. The state should set clear criteria for achievement of this core measure and ensure that its 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.
2. There should be state performance standards for early and continuous screenings (e.g., CHDP Health Assessment Guidelines) for use in both public and private health plans, including HMOs and PPOs.
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, 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.
5. The state should set clear criteria for achievement of this core measure and ensure that its 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. The state should create a statewide interdepartmental coordinating body 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.
2. The state should ensure consistency across regions and counties in the interpretation and implementation of state law, regulations, and procedures.
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 and 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.
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 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.
6. The state should set clear criteria for achievement of this core measure and ensure that its performance and progress are measured periodically and reported publicly.

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.

2. The state should commit to ensuring that YSHCN do not transition out of public or private insurance into the ranks of the uninsured and consider strategies such as increasing the number of conditions covered by the GHPP 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.
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.
4. Provider rates and other incentives should be instituted to fortify the provider network for YSHCN.
5. California must set clear criteria for achievement of this core measure and ensure that its performance and progress are measured periodically and reported publicly.

LOOKING FORWARD: CALIFORNIA AT A CROSSROADS

As noted throughout this report, California's budget situation has resulted in major cuts to a number of programs that serve children and youth, including those with special health care needs. While the situation is fluid and not all details are known, certain budget impacts are clear for health and developmental programs that are fundamental to the care of CYSHCN.

In this climate of severe budget reductions, program rollbacks, and state proposals for major overhaul of long-standing programs, it is especially critical that there are clear standards for the treatment of children and youth with special health care needs, against which proposals for change can be measured. For this reason, the authors strongly recommend two steps:

1. **The state must commit to achieve the federal MCHB Core Performance Measures**, which lay out nationally accepted goals for the care of CYSHCN and the system that serves them. The state should set clear operational criteria for achievement of each measure, and state progress should be evaluated and reported publicly on a regular basis.
2. **The state must commit to basic principles of care for CYSHCN in any major change of the health care system that serves them.** These principles, which have been accepted by several groups of providers and families in California, include the following:
 - Families/youth must have access to ongoing information, education, and support in order to be an informed and effective partner in the care of their children/themselves.
 - All health care delivery to children, particularly children and youth with special health care needs, should be based on and flow from their medical and related needs.
 - Children should have access to medically, developmentally, and behaviorally appropriate care regardless of their geographic region. County-based

systems of care that limit access to pediatric and/or other appropriate providers are not acceptable for CYSHCN. Children should retain access to regionalized pediatric health care systems such as CCS-approved neonatal, pediatric intensive care, and other pediatric care.

- CYSHCN should have clearly identified medical homes including primary care providers, access to pediatric subspecialists, and care coordination. Families should be recognized and supported as central to the organization and coordination of their children's care, and should have the ability to exercise choice in selecting providers that meet pediatric credentialing standards.
- Provider networks should include all pediatric sub-specialties, pediatric hospitals, child-appropriate durable medical equipment (DME) and other supply vendors, and other pediatric-appropriate services. Providers should meet clearly established standards for credentialing that reflect pediatric training and experience.
- The benefits package for children should be broad and representative of children's needs, including appropriate medical, dental, developmental, behavioral, and rehabilitative services; pharmaceuticals; DME and medical supplies; and ancillary services. Care coordination should be a recognized component of service delivery to CYSHCN. The federal EPSDT benefit and medical necessity definition should serve as the model for care of children and youth.
- Financing of health care delivery to CYSHCN should recognize their special needs, and children's access to health care should not be hindered by inadequate reimbursement to providers. Fee-for-service systems should reimburse at rates that reflect actual costs of care, and reimbursement should include the capacity to cover pediatric services beyond typical medical care (e.g., office visits), such as care coordination. Capitated systems should have rates that are risk-adjusted to reflect actual costs of care, and include additional services such as care coordination. Capitated systems should not include risk to providers (thus removing financial disincentives to provision of necessary care) and should avoid full risk to plans through strategies such as reinsurance or risk-sharing with the state (such as the current CCS carve-out).

Drawing on these past experiences, the authors believe that proposals that further achievement of the MCHB Core Performance Measures and meet core principles for health care delivery to CYSHCN stand the best chance of building a true system of quality care for vulnerable children and youth. California is indeed at a crossroads, with difficult decisions ahead, and with the most vulnerable populations at risk. It is clear that in order to address the strategies and recommendations outlined in this report, we must also garner the political will to make this systemic change.