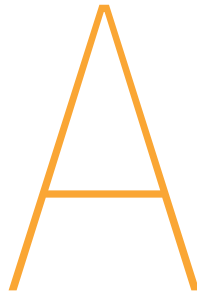


PRIOR EFFORTS ADDRESSING CYSHCN



number of efforts aimed at assessing or improving California's system of care for children with special health care needs have been carried out in recent years. These efforts have served both as incremental steps toward improvement of the system, as well as highlighting challenges that continue. Below is a summary of those efforts.

Your Voice Counts, Family Voices of California

In 1998, Family Voices of California was actively involved with Family Voices National and Abt and Associates, Inc. in a survey of 954 parents of children with special health care needs in California. This survey identified parent concerns and the obstacles they face in obtaining health care services for their children. The main research questions were related to understanding these families' experiences with the health care system, including access to care, utilization, coordination of care, parental satisfaction, and the impact on families of having a child with special health care needs. The entire report is available in Appendix 7.

Most of the children whose parents participated in the study had multiple conditions and disabilities that were moderate to severe. The most common condition was cerebral palsy, and 14% of the children were technology dependent. Findings from the study were as follows:

- **Health insurance coverage:** Most were enrolled in Medi-Cal and CCS and 82% were in managed care, with 10% without health care coverage at some point during the previous 12 months.
- **Utilization of providers and hospitals:** Almost all children had seen a primary care provider and a specialist at least once and 28% had seen a specialist six or more times in the last 12 months. Half had been hospitalized at least once, 10% had been hospitalized three or more times, half had been treated in an emergency department (ED) and 15% had been treated in an ED three or more times. As expected, utilization was higher among those with more severe levels of disability or more unstable health care needs.
- **Need for specialty services and problems with access in the prior 12 months:** Over 80% needed a specialist, two-thirds needed therapies, and half needed durable medical equipment. Forty percent of parents reported

having difficulty getting mental health services, 39% had difficulty getting home health services, and 35% had difficulty getting therapy services for their child. Children with health care needs that change often were twice as likely to have difficulty obtaining medication, and those with behavior problems were more likely to have difficulty accessing mental health services.

- **Coordination of benefits and care.** Parents reported they were unaware of any formal coordination of benefits between their insurers, including CCS; only half identified a case manager for their child, typically from regional center (35%) or CCS (28%); and case management services varied greatly. Many parents reported that they find information themselves or from other parents.
- **Satisfaction with primary health plan.** Two-thirds were satisfied with their child's plan in terms of capacity and overall benefits package, but less were happy with the family centeredness of the plan. Parents were more likely to be dissatisfied with their plan if their child was more severely disabled and less stable. Satisfaction was low among parents whose children were in private managed care compared to Medi-Cal managed care plans, and lower among those in Medi-Cal managed care compared to fee-for-service Medi-Cal.
- **Satisfaction with the physician care.** Most parents were highly satisfied with their child's physician, but less so in terms of availability and coordination of care. Parents of those in Medi-Cal managed care were less satisfied with provider communication with other providers and agencies compared to those in fee-for-service Medi-Cal; those in commercial managed care were least satisfied.
- **Family impact.** Having a child with special needs has a significant impact on families, affecting finances, jobs, and time spent providing care at home. Approximately half of parents reported spending over \$1,000 out of pocket for services for their children while 10% reported spending \$5,000 or more. Nearly two-thirds of parents reported either reducing work hours or stopping work due to their children's health care needs. Over half of mothers reported spending time providing health care (e.g., physical therapy, dressing changes, etc.) for their children at home, with 20% reporting spending at least 20 hours a week providing health care services.

The report recommends a comprehensive benefits package whether the child is in the Medi-Cal program or commercially insured, flexibility in health care plans, in particular related to choice of providers, care coordination, clear information from the health plan about plan benefits, improved access to mental health, home health, and durable medical equipment providers, and more information and help in order to ensure that the health care system works for their children. While there have been no specific initiatives to address the identified issues, the information has been used to inform other processes.

California's Ailing System of Caring for Children With Special Health Care Needs (Peter Hansel and Cori Reifman, California Senate Office of Research, May, 2000)

In June, 1998, the Senate Office of Research (SOR) was asked by the then-chair of the Senate Health and Human Services Committee to study the California Children's Services (CCS) program to determine the extent to which the program was providing timely access to services for children eligible for the program. SOR interviewed numerous organizations and individuals involved with the CCS program, including medical providers, state and county program administrators, and family representatives. In total, SOR interviewed or received comments from over 50 stakeholder representatives and policy experts. This report often is mentioned in state-level discussions of potential strategies to strengthen the CCS program, but no specific commitment to implementing its recommendations has been made by the state. See Appendix 8 for the Executive Summary of the report.

Despite the success of the CCS program in helping children with special health care needs gain access to medical treatment and therapy necessary to restore and improve their functioning and long-term prognosis, SOR concluded that a number of problems limited the ability of the program to provide timely and seamless services to eligible children. In some cases, this produced very lengthy delays in children receiving services. These problems included:

Ten year old Sue is hearing impaired and needs to see an audiologist. The first available appointment is in three months for this pediatric specialist.

- **The adequacy of provider participation:** The report found that low reimbursement rates for CCS and Medi-Cal services caused many physicians and other providers to cease seeing CCS/Medi-Cal patients or limit the number they treated. As a result, waiting times of three to six months or longer for services were not uncommon, depending on the subspecialty. Lengthy delays in claims reimbursement and claims editing procedures only served to further reduce the effective rate of payment to providers. The report outlined options to increase rates, speed up payment, and better track provider participation in the CCS and Medi-Cal programs.
- **Inadequate case management staffing:** According to material reviewed by SOR, staffing standards at the time permitted staff-to-client ratios in excess of 500-to-1 in larger counties and in excess of 1,000-to-1 in the state regional offices serving smaller counties, far too high to permit timely eligibility determinations, treatment authorizations, and claims payment in many counties. Providers and families reported having to wait months for treatment approval in some cases, while the child's condition went untreated. The report recommended that CCS staffing standards be updated and made more consistent with those used in other programs serving children and adolescents.
- **Need for better state oversight and enforcement of program standards:** Lack of resources for state oversight of the CCS program and delays in implementation of a state-county linked management-information system resulted in a lack of compliance in many counties with basic program standards, including timeliness standards. The report outlined a number of options for addressing this, including increasing the frequency of county and

provider site reviews and expediting implementation to all California counties of CMS Net, the state database and management information system for the CCS program. There has been continued improvement in this area with the nearly complete statewide implementation of CMS Net.

- **Inadequate attention to family-centered care as a program goal:** The report found that lack of focus on family-centered approaches to care resulted in the CCS program being frequently confusing for families, making it difficult for them to participate. The report identified a number of options for addressing these problems, including increased training for CCS staff and providers, greater efforts to make CCS documents and materials more understandable, establishment of a family ombudsperson and 800 telephone number, and clarification of standards regarding access to medical transportation services. A network of parent health liaisons developed, in part, as a result of these findings.
- **Inconsistent county application of program standards.** The report found that county funding pressures may have led to an inconsistent application of program standards. This resulted in children with similar conditions receiving publicly financed health services in some counties and not in others or receiving different types of care. Differences in application of standards also resulted in different financial obligations for similarly situated families. The report outlined options that include providing greater CCS staff training on program standards, conducting more frequent county site reviews, making it easier for families to access CCS services while their Medi-Cal applications are pending, and returning the county share-of-cost for CCS to the 25% level that existed prior to the 1991 program realignment.

The Children's Regional Integrated Service System (CRISS) project, a collaborative of family support organizations, pediatric provider organizations, and hospitals, and county CCS programs in 25 Northern California counties, was cited in the report as an example of a successful strategy for reducing inter-county variability. For example, CRISS has reduced inter-county differences in medical eligibility determination and benefits in its region, and developed guidelines for inter-county case transfers for CCS-enrolled children who move among CRISS member counties. The inter-county transfer guidelines, which preserve children's access to authorized services during family moves to other counties, were subsequently established as statewide CCS policy.

- **Fragmented service delivery as a result of managed care carve-out.** Because CCS services are provided separately from other services children receive when they are enrolled in Medi-Cal managed care plans (referred to as being "carved out" of the plan contracts), delays and disruptions in continuity of care frequently resulted. The report detailed options in this area, including implementing a "medical home" concept for CCS-eligible children, in which responsibility for primary care and care coordination would be assigned to a primary care provider or specialist, depending on the nature of the condition. In addition, DHS could be required to contract for a study of medical outcomes, family satisfaction, and health status of CCS-eligible children enrolled in managed care plans.

- **Outdated income eligibility standards.** Over 27 years ago, in 1982, the financial ceiling for eligibility for the CCS program was reduced from \$100,000 in annual gross household income to \$40,000. Over time, the effect of this change has been to reduce the number of children eligible for the program, as well as those who remain eligible for the program once in it. At least 22,000 and perhaps as many as 130,000 additional children would be eligible for the program if the income standard was returned to \$100,000. The report put forward options to increase or index the financial eligibility limit to a standard that more realistically reflected the financial burdens CCS conditions could impose on families.
- **Need to develop more flexible medical eligibility standards.** A number of stakeholder representatives expressed a desire to see medical eligibility for the CCS program eventually based on general criteria, including a child's functional status, level of condition, or need for services, rather than on defined medical conditions, which they believed acted to exclude some children who could benefit from the services provided by the program. The report suggested requiring DHS to study the feasibility of developing alternative medical eligibility criteria.

Medi-Cal Managed Care Division, Task Force on Children with Special Health Care Needs (Linda Rudolph, MD, and Sharon Rothman King, MSW, 2003)

In February, 2002, the Medi-Cal Managed Care Division (MMCD) of the California Department of Health Care Services convened a task force on Children with Special Health Care Needs to provide input on improving the quality of care for CYSHCN enrolled in Medi-Cal managed care plans and implementing the federal requirements of the Balanced Budget Act of 1997. (The Act was federal legislation that required states to meet specific requirements for individuals with special health care needs enrolled in Medicaid managed care plans; these requirements included plan identification and assessment of these individuals, attention to their access to specialists, and measurement of the quality of care they receive from plans.)

MMCD's longer term goals were to ensure that: (1) children with special health care needs who are enrolled in Medi-Cal managed care plans have adequate access to high quality, coordinated services which meet the needs of the children and their families; (2) MMCD implements quality measures to facilitate monitoring and improvement of care for CYSHCN; and (3) MMCD, contracted plans, and other agencies build a culture of collaboration to foster quality care for CYSHCN. The task force comprised a wide variety of stakeholders from many groups serving children with special health care needs including representatives from state and local agencies (e.g., health, mental health, regional centers); managed health care plans; advocates; and pediatricians and children's hospitals.

For over a year, the task force met monthly to examine the definition and identification of children with special health care needs, access to specialists and special services, care coordination, confidentiality, quality measures and

monitoring, and quality improvement. In addition, the task force examined the coordination of care for specific population groups receiving services from Medi-Cal managed care and other service systems, including children with developmental disabilities, children in foster care, children who need mental health and special education services, children with drug and alcohol problems, and children who are clients of CCS. A full copy of the report can be found in Appendix 9.

A number of recommendations were made by the task force, and are grouped by key areas. Overarching recommendations include the following:

- Mandate all agencies serving CYSHCN to develop a matrix that clarifies agency roles and responsibilities with respect to identification, screening, referrals, assessment, treatment, and care coordination.
- Require that all agencies serving CYSHCN and plans at the state and local levels meet regularly and share information (as allowed by confidentiality laws) to ensure identification, access to care, coordination of services, and quality improvement.
- Clarify the way in which federal and state laws allow sharing of information among providers of care for CYSHCN for purposes of improving care coordination and quality of care.
- Convene an ongoing workgroup with representation from parents, agencies, providers, and plans to specify and review the implementation of the task force recommendations.
- Require inclusion of families at the agency, plan, and provider levels.
- Address diverse cultural and linguistic needs of CYSHCN and their families.

Identification

Identification is a necessary first step to ensure the quality of care for CYSHCN; without awareness that a child has special needs, providers and plans cannot take steps to assess how well those needs are being addressed, or to arrange for or provide needed services. Task force recommendations on identification of children with special health care needs include the following:

- Develop and implement a process to supplement and verify identification based on administrative data, through use of a parent-reported CYSHCN screener.
- Use state-held eligibility and administrative (encounter and claims payment) data to pre-identify some CYSHCN to health plans.

Coordination

Many children require services from multiple providers in separate care delivery systems. Coordination of care among providers and systems is perhaps the most critical element in ensuring that CYSHCN have access to the quality care they need. Care coordination also increases family satisfaction and helps prevent costly medical errors and duplication of services. Task force recommendations on identification of, and coordination of care for, children with special health care needs include the following:

- Educate agencies and providers about legal information sharing, consistent with federal and state laws.
- Develop a standardized informed consent for information sharing.
- Implement and promote a standardized parent/caretaker held tool (i.e., a “health passport” or parent notebook) to facilitate information sharing and encourage the use of a written care plan with input from the family and all of a child’s providers.
- Clarify policies and increase consistency of policy administration and processes across counties for program eligibility determination, referrals, information sharing, authorization, and payment.
- Require that plans ensure the designation of CYSHCN care coordinators who are available to participate in the coordination of care so that the needs of all CYSHCN are appropriately met.
- Support and encourage development of “medical homes” for all CYSHCN.

Quality of Care

Measuring the quality of care is fundamental to health care accountability and improvement. Two core dimensions of quality should be assessed: (1) the health care needs of consumers, and (2) components of quality such as effectiveness, safety, and timeliness. Selecting quality measures requires decisions about what and whom to measure, and what indicators to use. Task force recommendations related to quality of care include the following:

- Implement a core CYSHCN measure set, including the Consumer Assessment of Healthcare Providers and Systems (CAHPS) CYSHCN survey and other CYSHCN-relevant Healthcare Effectiveness Data and Information Set (HEDIS) measures, to annually assess access, care coordination, and parent and child experience of care in Medi-Cal managed care plans.
- Report on quality measures in ways that maximize value for plans, providers, and state agencies.
- Implement a cross-agency program to train and support providers on CYSHCN screening, primary care treatment, and referral for mental health, developmental, and substance abuse problems.
- Implement payment strategies to ensure fair, timely, and appropriate reimbursement of plans and providers for time and resources required for quality care and care coordination for CYSHCN, based on the prevalence and burden of service needs of their population (e.g., streamline payment, increase reimbursement, risk adjustment, reimbursement for assessments).
- Offer financial and other incentives to plans and providers for quality improvement.
- Initiate collaborative quality improvement efforts to improve the care of CYSHCN.

Virtually none of the recommendations of the MMCD have been implemented on a systematic, statewide basis, although there are local efforts aimed

at some of the recommendations. For instance, interagency groups meet locally to discuss efforts aimed at improving care for CYSHCN, including the CRISS group in the north, a CCS Workgroup in the south, and a group in San Diego County.

Prior to devastating budget cuts, many of the county CCS programs included families as advisors either by employing family support staff or contracting with local family resource centers. Both the CCS Workgroup and the CRISS group include family representatives, and Family Voices of California is actively involved in advocating on behalf of CYSHCN. These activities are not well integrated into agency operations. Legislation exists to address cultural and linguistic needs of CYSHCN and their families. This is likely the only recommendation that appears to be implemented statewide through Medi-Cal requirements for linguistic services by Medi-Cal managed care plans.

CYSHCN are not routinely identified by health plans, although some, such as HealthNet, do make an effort to identify these children and coordinate care based on this identification. Family Voices of California, many family resource centers, CCS special care centers, the CRISS group, and the CCS Workgroup promote and facilitate the use of parent notebooks to promote information sharing and encourage the use of a written care plan, but this effort represents a small number of children with special needs. One of the primary goals of the CRISS group, as a multi-county organization, is to clarify policies and increase consistency of policy administration and processes across counties for program eligibility determination, referrals, information sharing, authorization, and payment. Finally, state CMS had begun an initiative to support and encourage development of “medical homes” for all CYSHCN, but this has been curtailed due to budget cuts.

California Medical Home Project

In 2001, the California HealthCare Foundation funded the California Medical Home Project, aimed at spreading the medical home model by increasing the quantity and quality of medical homes, as well as the number of children who have a medical home, particularly those served by the CCS program. The project used three strategies to address policy, community, and practice level barriers, including a statewide coalition to address state policy and administrative barriers, seven local coalitions, each receiving 18 months of funding to plan and implement improvements, and a program office to provide technical assistance to the local coalitions and convene them periodically to exchange knowledge. The local coalitions and their lead agencies included:

- Alameda County: Alameda County Committee on Children with Special Needs
- Contra Costa County: Contra Costa County Health Services
- Los Angeles County: Los Angeles Partnership for Special Needs Children
- Santa Clara County: Parents Helping Parents, Inc.
- San Benito County: San Benito Public Health Services

My son’s medical care has been orchestrated by a special needs pediatrician who coordinates his health needs: immunizations, check-ups, therapies, orthopedic surgeon, ophthalmologist, neurologist, and podiatrist, to name just a few.

- Shasta County: Far Northern Regional Center
- Solano, Napa, and Yolo counties: Partnership Health Plan of CA

Each coalition was charged with developing strategies and carrying out activities to address the project aim, based on local needs and resources. Activities included parent and provider trainings, outreach activities, recruitment of providers, and development and implementation of practice improvement tools and strategies.

An evaluation of the project was conducted by the UCLA Center for Healthier Children, Families, and Communities. A copy of the final evaluation can be found in Appendix 10. The evaluation identified the following:

- **Improvements in care**, including identifying primary care providers in the two rural counties, helping families to organize medical records for improved communication with providers, especially in underserved areas, increasing the number of children with an identified medical home, practice level change, improved relationships with community-based providers, and increased expertise regarding the medical home model.
- **Successful strategies**, including using a structured approach to physician education and practice change, providing practical tools and coaching to physicians, using physician time wisely, providing ongoing support to physicians from an expert team, targeting practices willing to make change, having action oriented agendas for coalition meetings, focusing on practical steps, and focusing on the consumer perspective.
- **Barriers and environmental factors**, including an unstable financial environment limiting implementation of some strategies and attention to the project goals by some agency stakeholders, and limited impact on state-level planning due to barriers such as difficulty obtaining and sharing information about clients, difficulties in engaging key agencies, and lack of progress on systemic issues such as physician reimbursement and risk adjustment.
- **Opportunities for sustainability and replicability**, including professional development among physicians, improving policies and procedures of organizations and agencies, such as identification of CYSHCN by health plans and providers, sustaining planning efforts to continue improvements, and expansion of project activities into other geographic regions.

To date, some activities have been carried out to continue to move the medical home efforts for CYSHCN forward, although as with other efforts, some have been halted or limited due to budget constraints. In 2008, Children’s Medical Services (CMS) began a Medical Home Initiative to include identification of medical homes for children in the CCS program, linking individual children to a medical home, providing resources to county CCS programs and to providers regarding medical home activities, and early discussion regarding funding of care coordination efforts carried out within medical homes. This initiative was developed with the assistance of the Los Angeles CCS Workgroup/ Los Angeles Partnership for Special Needs Children (LAPSNC), Family Voices of California, and the Children’s Regional Integrated Service System (CRISS) and

drew on these organizations' experiences with organizing medical homes for CYSHCN. Unfortunately, this process was stalled in the fall of 2008 due to California's budget crisis.

Nationally, as well as within California, there is increasing interest about the medical home model as part of health reform. Much of the work done in the California Medical Home Project and by CMS can be used to inform and operationalize efforts in this area.

Title V Children with Special Health Care Needs (CSHCN) Needs Assessment Report: California Children's Services (CCS) Program Systems Issues and Priority Action Objectives (Family Health Outcomes Project, May 23, 2005)

As per federal statute, California's Title V CSHCN program, California Children's Services, must complete an assessment of the health problems and needs of its target population every five years; the last assessment was completed in 2005. The Children's Medical Services Branch, the administrator of the CCS program, recognized that a critical aspect of the assessment process was to encourage and facilitate participation by stakeholders throughout the state to assist in identifying health systems' problems/needs, prioritizing among the identified issues, developing strategies to intervene in prioritized issue areas, and evaluating the effectiveness of intervention strategies. Accordingly, CMS established a CCS Needs Assessment Stakeholders Group and contracted with the Family Health Outcomes Project (FHOP) to: (1) identify and analyze data for the purpose of targeting the most important and potentially effective areas in which CCS could improve services for CCS-eligible children, and (2) facilitate the stakeholder process for providing input into problem/issue identification and determining the action priorities that would be addressed during FY 2005-10.

Based on this requirement, it was decided that the workgroup would identify three priority needs to be addressed in the five-year plan and for which action strategies and performance measures would be included. As part of the broader planning process and the identification of the three priority CYSHCN action areas, CMS conducted an assessment of the needs and systems issues related to delivering services to children and families eligible for the CCS program. A complete copy of this report can be found in Appendix 11.

Fifteen major systems issues were identified through examination of the data, stakeholder interviews/questionnaires, breakout workgroups, and by CCS staff. Two overarching principles were identified: (1) CCS will address disparities in impact and outcomes by gender, age, geographic location, and race/ethnicity issues when developing strategies and tracking priority objective outcomes, and (2) the CCS program will ensure that children participating in CCS have access to and receive services from appropriately trained pediatric providers and develop and apply standards of care intended to lower morbidity and mortality rates among eligible children.

The resulting priority objectives were ranked as follows:

1. Expand the number of qualified providers participating in the CCS program, e.g., medical specialists, audiologists, occupational and physical therapists, and nutritionists.
2. Coordinate to develop and implement a system of timely referral between mental health, developmental services, social services, special education services, and CCS.
3. Increase the number of family-centered medical homes for CYSHCN and the number/percentage of CCS children who have a designated medical home.
4. Increase access of CCS children to preventive health care services (e.g., primary care providers, well child care, immunizations, screening) as recommended by the American Academy of Pediatrics (AAP).
5. Increase family access to educational information and information about accessing CCS services, including availability of and access to services offered by health plans.
6. Increase access to services for CCS youth, 17-21 years of age.
7. Decrease the time between referral to CCS and receipt of CCS services.

As with many of the other efforts identified, there has been progress in some, but not all, of the objectives, often limited by severe budgetary constraints. Per the 2007 Specialty Care Coalition survey cited in the Gaps section (see page 73), the number of qualified providers continues to drop as inflation and costs rise and reimbursement remains flat or decreases. While individual nurse case managers and social workers in various service systems (CCS, regional centers, schools, health plans, special care centers) coordinate care and provide referrals to related services, there is no systematic effort to assure that this occurs for all children with special health care needs, nor are there standards in place for care coordination.

While efforts to increase the number of medical homes for CYSHCN have begun, as described above, greater attention needs to be paid to this, and funding for provider training and compensation will be required to achieve this objective statewide. Although there were efforts to address parent information and education through delivery of parent health liaison services, those services have been cut dramatically. Family access to information and support varies, and responsibility often rests with the family to seek this out. CMS has developed information for county CCS programs and providers related to transition services for youth; some individual counties—for instance, Los Angeles County—have initiated their own transition efforts. A lack of adult providers willing to care for these youth and lack of clear standards regarding transition services continue to hinder achievement of this objective.

(Note: State Children's Medical Services recently began convening stakeholders for a new Title V Needs Assessment process for the new five-year period beginning in 2010.)

Children’s Medical Services Branch (California Department of Health Services California Statewide Strategic Plan for Children with Special Health Care Needs 2006–2010)

In August 2005, the State Children’s Medical Services (CMS) Branch of the California Department of Health Care Services convened a nine-month strategic planning process on behalf of children with special health care needs. The planning effort was funded by the federal Champions for Progress, a Maternal and Child Health Bureau (MCHB) initiative to support state efforts to develop a statewide strategic plan to meet the needs of CYSHCN. California’s state plan was intended to assist the state in reaching the national MCHB core performance measures for CYSHCN. This plan focused on those children eligible for the state CCS program, while recognizing the importance of improving communication and coordination among systems serving all CYSHCN and their families.

The state strategic plan for CYSHCN was part of a three-pronged effort by the CMS Branch to achieve a statewide system of care for these children:

1. State CMS Branch Needs Assessment

The Champions planning process was built on a needs assessment for CYSHCN conducted in 2005 by the Family Health Outcomes Project (FHOP) at UCSF for the CMS Branch as part of the state’s Title V Block Grant application. The needs assessment employed a broadly representative stakeholder group to identify the top priority issues for the Branch.

2. Champions for Progress State Strategic Plan

The Champions project convened the stakeholders group from the needs assessment project in order to develop the strategic plan. The stakeholder group adopted the following vision statement, developed by an earlier Task Force on Children with Special Health Care Needs.

Vision for Children with Special Health Care Needs: All children with special health care needs will be identified and will have access to quality health care that is:

- Family-centered and supportive
- Community-based
- Coordinated and seamless
- Effective, appropriate, and efficient
- Culturally and linguistically effective

(Task Force on Children with Special Health Care Needs, August, 2003)

The Champions stakeholder group considered strategies that would assist the state to achieve the six MCHB core performance measures and to meet the priorities identified by the state in its needs assessment process. The core performance measures served as the goals for the plan, with specific and measurable objectives and action steps, and assignments of responsibility for implementing the objectives.

Each stakeholder was charged with assisting in developing strategies for action, circulating draft documents within member organizations for feedback and support, and reaching consensus within the group on a final plan. The Champions planning process was convened by Dr. Marian Dalsey, then chief of the Children’s Medical Services Branch; facilitated by Carolyn Verheyen of Moore Iacofano Goltsman; and staffed by Juno Duenas, Family Voices of California; Kathryn Smith, Los Angeles Partnership for Special Needs Children; and Laurie A. Soman, Children’s Regional Integrated Service System (CRISS) Project.

See Appendix 12 for the Strategic Plan.

3. Federal MCHB Grant: “Implementing Integrated Systems of Care for CSHCN”

This federally funded project, conducted by Juno Duenas of Family Voices of California, Kathryn Smith, and Laurie A. Soman under the auspices of the USC University Center of Excellence in Developmental Disabilities at Children’s Hospital Los Angeles, in collaboration with Children’s Medical Services, promoted implementation of the state plan strategies both statewide and regionally. The Champions stakeholder group served as the advisory group to the MCHB grant and met on a quarterly basis to review and comment on implementation progress through June, 2008.

The MCHB, in awarding the Integrated Systems Grant, intended that the money be used to begin the process of addressing the core measures, with the state Title V program assuming responsibility for resourcing the continuation of the efforts. Initial efforts began to address the medical home and transition core measures, but due to severe budgetary constraints, efforts have not continued. The state is currently engaged in discussions aimed at developing a waiver to incorporate medical homes into the CCS program and this will require renewed attention to the concept, including education, and the development of implementation and training strategies.

Progress was made on a number of steps during the grant period that subsequently were sidetracked by state budget reductions (e.g., planning for a state CCS Medical Home Initiative; plans for a major statewide transition planning process through county CCS programs; and plans to establish a state inter-departmental group on CYSHCN). Other activities, such as the promotion of family-centered care by Family Voices, meetings of a statewide youth advisory council established under the grant, and the activities of established local coalitions such as the Los Angeles CCS Workgroup and CRISS, and emerging coalitions in Riverside-San Bernardino and San Diego continue today.