

**APPENDIX 9: MEDI-CAL MANAGED CARE DIVISION**  
**TASK FORCE ON CHILDREN WITH SPECIAL HEALTH CARE NEEDS:**  
**SUMMARY**

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**MEDI-CAL MANAGED CARE DIVISION**  
**TASK FORCE ON CHILDREN WITH SPECIAL**  
**HEALTH CARE NEEDS**

**SUMMARY**

**Children with special health care needs are 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.**

**U.S. Maternal and Child Health Bureau**

**August, 2003**

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We thank Debra Read and Christina Bethell of The Foundation for Accountability (FACCT) for their expert consultation and technical assistance, and also thank the many Task Force participants who provided comments on earlier versions of the report. The Task Force was partially supported by a grant from the California Health Care Foundation.

We are especially grateful to all of those who graciously gave of their time and expertise to participate in the Medi-Cal managed Care Task Force on Children with Special Health Care Needs.

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## **EXECUTIVE SUMMARY**

Children with special health care needs (CSHCN) are children with an array of different physical, developmental, or emotional conditions, with a broad spectrum of needs. It is estimated that about one quarter of children in Medi-Cal have special needs. These children are some of the most vulnerable in our society. The Federal government incorporated specific requirements pertinent to individuals with special health care needs enrolled in the Medicaid managed care program, in its implementation of the Balanced Budget Act of 1997. The Medi-Cal Managed Care Division convened a Task Force on Children with Special Health Care Needs to provide input to the Division on improving the quality of care for CSHCN enrolled in Medi-Cal managed care plans and implementing the new federal requirements.

The Task Force, comprised of representatives of State agencies serving CSHCN, providers, managed care plans, and consumer and family advocates, met eleven times over the course of more than a year. Discussions included definition and identification of CSHCN, care coordination, confidentiality, and quality measurement and improvement. Participants in the Task Force did not agree on basic issues such as whether children with special health care needs should be enrolled in managed care plans at all, or whether the relationship between managed care and other agencies is workable as currently structured. But all agreed that there is much room for improvement in the quality of care for CSHCN, and that a committed and concerted effort toward improvement should be made within the current context of Medi-Cal managed care.

This report summarizes the Task Force discussions and its recommendations for improvement. While the Task Force focused on children with special needs, many of the discussions and recommendations are highly relevant to all Medi-Cal Managed Care enrollees with chronic illness or special needs.

### **Overarching Issues**

Task Force discussions returned repeatedly to several over-arching issues that must be addressed if the care of CSHCN is to be improved. CSHCN receive care from multiple systems of care, each of which is complex. Families, providers, Plans, and agencies themselves are often confused about the roles and responsibilities of the various parties. There are frequently differences in policies and processes among county-based agencies and Plans, which exacerbate this confusion. There are many examples of excellent collaboration, but too many agencies maintain a silo mentality. Building and maintaining avenues for good communication, in the context of clearly defined roles, is key to the creation of a culture of collaboration.

The critical role of parents in caring for CSHCN, and in designing programs and systems that work for CSHCN, is often overlooked. Inclusion of families at all levels is an important mechanism to assure that service delivery systems and care are patient-

centered. The cultural and linguistic diversity of CSHCN and their families must be consistently addressed.

Several challenges must be overcome to implement the Task Force recommendations on these issues. Not all agencies are currently required to coordinate with each other. It is unclear which agency should take the lead to convene an on-going inter-agency and stakeholder work group or initiate a process to clarify roles. Also, many agencies are operating with a “scarcity mindset”, although building a culture of collaboration may be more important than ever in an era of limited resources.

### ***Task Force Overarching Recommendations***

- ***Mandate all agencies serving CSHCN to develop a matrix which clarifies agency roles and responsibilities with respect to identification, screening, referrals, assessment, treatment, and care coordination.***
- ***Require that all agencies serving CSHCN 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 CSHCN for purposes of improving care coordination and quality of care.***
- ***Convene an on-going 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 CSHCN and their families.***

### **Identification**

Identification is a necessary first step to ensure the quality of care for CSHCN; without an awareness that a child has special needs, providers and Plans cannot take steps to assess how well those needs are being addressed, nor to arrange for or provide needed services. Early identification allows early intervention; because childrens’ conditions and needs change over time, identification should ideally occur at multiple points of contact.

There are several different approaches to the identification of CSHCN, each with its pros and cons. Administrative encounter and claims payment data are often unable to identify many CSHCN, especially those with developmental disabilities and mental health problems. Many experts now recommend the use of a consequences-based survey screening tool; the parent-reported CSHCN screener has been validated and is in widespread use.

Administration of the screener requires considerable resources. The use of state-held administrative data to pre-identify some CSHCN could help reduce the burden of survey administration. Implementation issues include determination of exact specifications for administrative identification, and assignment of the responsibility to administer the screener at various possible points of contact (e.g. at the time of eligibility determination, Plan enrollment, Initial Health Assessment, or during well child visits).

### ***Task Force Recommendations on Identification***

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

### **Care 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 CSHCN have access to the quality care they need. Care coordination also increases family satisfaction, and helps prevent costly medical errors and duplication of services.

Care coordination is a proactive, family-centered, collaborative, outcomes-focused process of teamwork with families and providers designed to: assess child and family needs; facilitate timely access to needed services and resources; promote bridges between families and health, education, and social services; provide referrals, information and education for families and across systems; and maximize effective and efficient use of available resources.

Families need a “yes”-driven system in which each family has access to an individual who can provide needed care coordination, and communication and coordination across providers and agencies allow streamlined access to needed services. But the challenges to care coordination are legion. Care for CSHCN in California is extremely fragmented and complex, involving many agencies, inadequate reimbursement for the time and resources required, confusing and variable policies and processes, and diverse cultural and linguistic needs. Some families have many assigned case managers, but none coordinating across agencies. Delays in access may occur as “payors of last resort” sort out which agency is responsible for care. Concern and confusion about state and federal confidentiality laws inhibit sharing of information, even when it is legally allowed.

### ***Task Force Recommendations on Care Coordination***

- ***Educate agencies and providers about legal information sharing, consistent with federal and state law.***
- ***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 CSHCN care coordinators who are available to participate in the coordination of care so that the needs of all CSHCN are appropriately met.***
- ***Support and encourage development of “medical homes” for all CSHCN.***

### **Quality Measurement and Quality Improvement**

Measuring the quality of care is fundamental to health care accountability and improvement. Two core dimensions of quality should be assessed: the health care needs of consumers, and components of quality such as effectiveness, safety, and timeliness. Selecting quality measures requires decisions about what and who to measure, and what indicators to use. Quality measurement uses many sources of data, each with strengths and weaknesses; the CAHPS CSHCN module is in increasingly widespread use to assess the family and patient experience with care.

Challenges in the measurement of quality of care for CSHCN include the small numbers of children with any one condition, and lack of evidence-based guidelines for many conditions. The fragmented delivery system also makes it especially difficult to assess the quality of care, because it is more difficult to ascertain which services have been received. Also, when many providers and agencies all share responsibility for the quality

of care, it is important that each be held accountable only for the care for which they are responsible.

Quality improvement requires systematic efforts to enhance efficiency and consistency, eliminate defects, and achieve higher levels of performance. Improvement requires attention at all levels – the patient/family, the provider, the health care organization and system, and the policy environment. Key challenges for providers and Plans in implementing quality improvement programs include lack of time, money, and resources, non-recognition of the need for improvement, and the lack of incentives (financial and non-financial) for improvement. The fragmented nature of service delivery for CSHCN may also complicate the implementation of quality improvement and incentives for quality. Collaborative projects provide support for organizations engaged in quality improvement efforts.

***Task Force Recommendations on  
Quality Measurement and Quality Improvement***

- ***Implement a core CSHCN measure set, including the CAHPS CSHCN survey and other CSHCN-relevant 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 CSHCN 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 CSHCN, 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 CSHCN.***

Improving the quality of care for CSHCN will require leadership, commitment, and resources. But the payoff is potentially great – in increased family, child, and provider satisfaction, in more effective and efficient use of limited resources, and in improved health, education, and social outcomes for children with special health care needs.

## **INTRODUCTION**

Children with special health care needs (CSHCN) are children with an array of different physical, developmental, or emotional conditions that, if not properly managed, may affect their ability to function, with a broad spectrum of needs. These children are some of the most vulnerable in our society. Not only are they in need of the routine care afforded all children, but also they and their families must learn to negotiate many complex systems to assemble services and health care that meet their changing needs on a daily basis. Providing comprehensive, coordinated, family-centered care to children with special needs can be very challenging, particularly when systems of care are fragmented as in California.

In 1994 the U.S. Maternal and Child Health Bureau (MCHB) established a work group to recommend a definition of children with special health care needs. The definition adopted represents a consequence-based definition that captures children with any chronic condition requiring more health care than the average user. The definition considers the existence of a condition and its expected duration, in addition to how much health care the child is expected to need.<sup>i</sup> The California Task Force agreed to use the Federal definition, while recognizing that the “at-risk” component may be difficult to operationalize. Using this definition, it is estimated that 13 - 18% of all children in this country have special health care needs<sup>ii</sup>; about one-quarter of the Medicaid child population has special health care needs.<sup>iii</sup>

### ***Definition***

*Children with special health care needs are 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.*

*U.S. Maternal and Child Health*

Children with special health care needs merit special attention because their needs are both different than other children and different than adults with special needs. Children with special health care needs utilize substantially more service dollars and a larger variety of services than other children. They may need multiple visits to a primary care physician, and access to pediatric subspecialists and any or all of the following services: mental health care, habilitative services, special education, durable medical equipment, emergency services, hospital care, durable medical equipment, speech therapy, prescription medications, substance abuse treatment, child welfare services, legal services, or many others.

Children’s needs change as they grow, and the nature of their condition changes as well. Children are dependent upon adults for their care and their health is influenced by their family’s health and socioeconomic status. Children with special health care needs experience many rare conditions of low incidence as opposed to adults, more of whom experience more common conditions.<sup>iv</sup>

Managed care could potentially benefit children and their families by improving access and coordination of services. However, there have been concerns that managed care could also create incentives to limit utilization or access to specialists, and that safeguards are needed to ensure that CSHCN enrolled in managed care plans receive needed services.<sup>v</sup> Therefore, the Federal government incorporated specific requirements pertinent to individuals with special health care needs enrolled in the Medicaid managed care program, in its implementation of the Balanced Budget Act of 1997. The final rules for Medicaid Managed Care include requirements for identification, assessment, access to specialists, and measurement of quality of care for enrollees with special health care needs.<sup>vi</sup>

In February, 2002 the Medi-Cal Managed Care Division (MMCD) of the California Department of Health Services convened a Task Force on Children With Special Health Care Needs to discuss approaches to improving the quality of care for children with special health care needs who are enrolled in Medi-Cal managed care. Through the Task Force deliberations, MMCD sought public input that could inform MMCD’s implementation of the new Federal requirements, and its development of an all-plan policy letter on children with special health care needs.

***Task Force Vision***

*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.*

MMCD’s longer term goals are 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 CSHCN; and
- (3) MMCD, contracted plans, and other agencies build a culture of collaboration to foster quality care for CSHCN.

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 California Children’s Services.

The Task Force discussions were often highly spirited and contentious. Task Force members maintain very different perspectives on the basic question of whether managed care is a viable approach to improving care for CSHCN. Some participants believe the current carve-out structure should be terminated and the role of managed care expanded; others think that CSHCN should never be mandatorily enrolled in managed care. Some participants wanted to focus only on the responsibilities of managed care plans, while others urged more focus on the issues related to inter-agency and plan-agency coordination.

However, every Task Force member genuinely cares about children with special health care needs. The focus of the Task Force was to find areas of common ground for improving their care ***within the context of the current Medi-Cal managed care structure***. This document summarizes the discussions of the Task Force, and identifies specific recommendations around which the group was able to reach agreement.

***MMCD Task Force on CSHCN Topics***

- *Overview of CSHCN*
- *Definition and Identification of CSHCN*
- *Access to Specialists and Special Services*
- *Care Coordination for CSHCN*
- *Confidentiality Concerns*
- *Care Coordination for Children with Mental Health Care Needs*
- *Care Coordination for Children with Developmental Disabilities*
- *Care Coordination for Children with Drug and Alcohol Problems*
- *Care Coordination for Children in the California Children’s Services Program*
- *Care Coordination for Children in Foster Care*
- *Coordination with Schools*
- *Measuring Quality of Care for CSHCN*
- *Quality Improvement for CSHCN*
- *Balanced Budget Act Medicaid Managed Care Final Rules*

## IDENTIFICATION

The Federal government requires that individuals with special health care needs in Medicaid managed care are identified by or for managed care organizations. Identification is necessary in order to ensure that CSHCN receive adequate assessment of their needs, appropriate access and referrals to care, and care coordination. Without identification, the quality of care for CSHCN cannot be measured and monitored, and managed care plans (Plans) cannot implement quality improvement efforts. Risk adjustment of payments to reflect CSHCN enrollment and increased utilization of services also requires identification.<sup>vii</sup>

The earlier that CSHCN are identified, the sooner their needs can be appropriately addressed. Early identification allows early intervention, with improved medical and functional outcomes. Because CSHCN have changing needs over time, and because children may develop special needs at any time, it is important that identification efforts be continuous. Children with special health care needs may be screened at multiple points of contact with the family: at eligibility, at plan enrollment, and periodically at the primary care physician level.

The use of standardized methods to identify CSHCN provides consistency in estimating the population of CSHCN, and in measuring quality across Plans. However, there is no perfect tool for identification; any one approach to identifying CSHCN will be imperfect and each has its strengths and weaknesses. Some children may still fall through the cracks, while some children who do not have special needs may spark unnecessary or redundant further assessment and attention. The goal is to use a simple, quick, feasible method that finds most of the children who have special needs, and does not identify large numbers of children who do not have such needs. Identification of large numbers of children could dilute attention to the children most in need. There are many approaches to the identification of CSHCN, using either administrative (e.g. claims or encounter) or survey data.

### *Approaches to Identification*

- *Categorical (aid code) : requires eligibility in specific programs (e.g. SSI, Title V)*
- *Diagnostic: requires specific diagnoses in patient record or condition checklist*
- *Services: based on utilization of service, e.g. hospitalization, therapies, drug use*
- *Cost: based on total cost of medical services*
- *Consequences-based: based on health consequences and need for services*

### ***Advantages and Disadvantages of Identification Methods***

#### ***Administrative Data***

- (+) *Readily available*
- (+) *Relatively inexpensive*
- (-) *Misses uncoded educational, behavioral, developmental disorders*
- (-) *Misses CSHCN using services outside benefit structure*
- (-) *Misses children in transition (e.g. foster children)*

#### ***Survey Data***

- (+) *Captures experience of family and child*
- (+) *More accurate and timely*
- (-) *Resource intensive*
- (-) *Relatively expensive*
- (-) *Difficult to reach enrollees for good*

Many experts now favor a parent-reported consequences-based approach.<sup>viii</sup> This approach is amenable to uniform data collection through parent survey. It increases the probability of identifying children without recorded diagnoses in patient records, or whose diagnosis is not recalled by parents; at the same time, it reduces the likelihood of identifying children who have a condition, but who have no or few functional or service use needs consequences. Unfortunately, one-question screens have been demonstrated to be ineffective for the identification of CSHCN, both identifying children without special needs, and missing children with special needs.

Several survey tools have been validated, including the CSHCN Screener<sup>ix</sup>, and the original and shorter revised version of the Questionnaire for Identifying Children with Chronic Conditions (QuICCC and QuICC-R). The CSHCN Screen is currently being used in the National Survey of Children with Special Health Care Needs, the National Medical Expenditure Panel Survey (MEPS), and has been incorporated as an optional module in the Consumer Assessment of Health Plans Survey.<sup>x</sup>

### ***Children with Special Health Care Needs Screener***

*The CSHCN Screener, developed by the Child and Adolescent Health Measurement Initiative coordinated by FACCT, was designed to reflect the MCHB definition of children with special health care needs.*

*The Screener first ascertains whether a child experiences any of five health consequences:*

- 1) Use or need of prescription medication*
- 2) Above average use or need of medical, mental health, or educational services*
- 3) Functional limitations compared with others of same age*
- 4) Use or need of specialized therapies (e.g. OT, PT, speech)*
- 5) Treatment or counseling for emotional or developmental problems.*

*To qualify as having special health needs, a child must meet these three conditions:*

- a) the child currently experiences one of the above consequences.*
- b) the consequence is due to a medical or health condition*
- c) the duration or expected duration of the condition is 12 months or longer.*

Using a combination of administrative and survey approaches to identification addresses some of the flaws in each separate approach. In the Medi-Cal population, survey responses have been low, in part due to frequently inaccurate contact information. Supplementing surveys with administrative data (aid code, diagnosis, services) may allow identification of some children for whom additional outreach or coordination efforts are warranted.

***Task Force Recommendations on Identification***

- ***Use state-held administrative data to pre-identify some CSHCN to health plans. (encounter and claims payment).***
- ***Develop and implement a process to supplement and verify identification based on administrative data, through use of the parent-reported CSHCN screener.***
- ***Convene a Work Group to define specifications for the use of encounter and claims data, including diagnosis, aid code, and paid services from other agencies, and to consider data confidentiality issues.***

**ACCESS TO CARE**

Access to care can be a major challenge for children with special health care needs. Of particular concern are the problems that families report in accessing pediatric subspecialty care, and in access to a “medical home”. About 22% of parents of CSHCN in Medi-Cal report that they can not see the providers their child needs. While nearly all children eventually get the specialty care they need, about 1/3 of CSHCN in Medi-Cal - twice as many as in private insurance) - report problems getting referrals to specialists. And, many CSHCN parents report that they do not have a personal doctor (24%), don’t have enough time with their child’s provider (33%), and don’t receive information they need about caring for their child (15%).<sup>xi</sup> In one published study, all private patients but only 2% of Medi-Cal patients were offered pediatric orthopedic appointments within one week.<sup>xii</sup>

These problems persist despite Medi-Cal managed care requirements to assign every enrollee to a primary care provider, to maintain adequate networks of specialists, and to allow direct access to specialists for children with chronic illness through standing referrals, use of specialists as primary care providers, or other mechanisms. In fact, for most CSHCN in most Medi-Cal Plans, specialist care and specialty services are “carved out” (excluded) from the Plan’s responsibilities. Thus, most CSHCN specialty care is

delivered through programs such as California Children’s Services (CCS), or the local mental health agencies.

There are complex reasons for access problems. There do appear to be absolute shortages of pediatric sub-specialists in California.<sup>xiii</sup> Anecdotally, these shortages are most notable in the areas of mental health, developmental pediatrics, orthopedics, dermatology, and neurology. More important, however, is that many physicians are unwilling to participate in Medi-Cal. A recent survey of California physicians found that only 25% of specialists have Medi-Cal managed care patients in their practice, and that less than ½ of all physicians are accepting any new Medi-Cal patients. Medi-Cal patients are perceived by physicians as having complex medical and psychosocial problems that require extra time.<sup>xiv</sup> For pediatricians, major reasons for limiting participation in Medicaid are low reimbursement (68% of California pediatricians), paperwork concerns, and unpredictable payments.<sup>xv</sup> Some specialists also perceive that time-pressured primary care providers may “over-refer” children, creating additional backlogs for specialist care. Medi-Cal managed care plans have attempted to alleviate access problems through higher specialist reimbursements or subsidization of specialty clinics, with some success.

The complexity of California’s child health system is another major factor which impedes access to care for CSHCN enrolled in Medi-Cal managed care plans. Multiple public care delivery systems maintain responsibility for the delivery of particular segments of services to which children are entitled. Each has its own eligibility rules, referral procedures, provider networks, reimbursement structures, and case management processes. This complexity has led to what Task Force Participant Juno Duenas describes as “a system driven by ‘no’”. It leads to significant delays in access to needed services and in provider reimbursement. In some cases children “slip through the cracks” and forego needed services altogether. This issue is addressed in further detail in the next section.

#### ***Task Force Recommendations on Improving Access***

- ***Provide resources and train providers on referral processes and appropriateness***
- ***Provide additional training for some primary care pediatricians in key areas (e.g. mental health, developmental issues, orthopedics), and on referral processes and available services.***
- ***Reimburse providers for care coordination***
- ***Streamline reimbursement by addressing administrative inefficiencies, and improve reimbursement levels for providers and plans***
- ***Conduct QI activities to improve referrals and access.***

## CARE COORDINATION

Children with special health care needs may require services over time from a broad range of providers and agencies, including medical, mental health, social, developmental, and educational services and supports. Only through the integration of these services can children be assured a high quality program of care for the child and family.<sup>xvi</sup> Experts believe that care coordination can realize substantial benefits, including less stress and more satisfaction for families and providers, higher school attendance, improved self-sufficiency, improved clinical outcomes, and cost savings realized from fewer and shorter hospital stays.<sup>xvii</sup>

California's Medi-Cal provides a rich benefit package to enrolled children, including full Early Periodic Screening, Diagnosis, and Treatment (EPSDT) supplemental services. The Medi-Cal benefit is thus intended to provide access to regular primary care and timely access to specialist providers and special services. However, California's health system for children is extraordinarily complex and fragmented. Often, the maintenance of separate and distinct funding streams is not aligned with the needs of children.

Navigating through multiple different systems can be extremely challenging for both families and providers. Coordination of care among these systems is perhaps the most critical element in ensuring that CSHCN have access to the quality care they need, and it requires the commitment and cooperation of all of the agencies and individuals involved in caring for CSHCN.

### ***California Agencies Serving CSHCN***

- *Medi-Cal – Plans and FFS*
- *County Mental Health Agencies*
- *Regional Centers*
- *California Children's Services*
- *CHDP*
- *Local Education Agencies*
- *Special Education Local Programs*
- *Social Services – Foster Care*
- *Alcohol and Drug Programs*
- *Juvenile Justice*
- *GHPP (Genetically Handicapped)*

Care coordination is a proactive, family-centered, collaborative, outcomes-focused process of teamwork with families and providers designed to assess child and family needs; facilitate timely access to needed services and resources; promote bridges between families and health, education, and social services; provide referrals, information and education for families and across systems; and maximize effective and efficient use of available resources.<sup>xviii</sup>

Care coordination and traditional case management are not the same. Case management is based on a traditional medical model, focused on medical costs and services within an organization. Care coordination uses a social services model, and focuses on facilitating access to services through patient advocacy, problem-solving, family involvement, and collaboration across providers and organizations to meet the ever-changing needs of children and their families.<sup>xix</sup> The goals of care coordination are to improve and sustain

family and child quality of life; assure access to optimal care; and improve the system of care.<sup>xx</sup>

### ***Key Elements in Family-Centered Care Coordination for CSHCN***

- *Locus: family focused with on-going family involvement and cultural sensitivity*
- *Assessment: written care plan identifies needs, clarifies roles and responsibilities of all care providers to meet needs*
- *Access to health, developmental, and behavioral services: to variety of providers in different systems, with means to ensure timeliness and payment; access to care coordinator 24/7*
- *Access to non-health services: address home, social, educational needs; transportation, respite care, etc.*
- *Assures linkages: to community services and among agencies; sensitivity to confidentiality;*
- *Facilitates access to benefits: find and refer; advocate for receipt of benefits*
- *Monitors satisfaction and quality*

*(Matrix from Susan Epstein, MSW, of New England Serve, with integration of Task Force priorities)*

Families, providers, plans, and agencies all have important roles in care coordination. Families are, in fact, at the center of care coordination. They assess a child's status on a daily basis, determine the need to seek care, provide information to care providers, and directly experience the impacts of care on a child. Ensuring family participation in the child's care is thus a critical component of care coordination, and good care coordination empowers families to better fulfill their role, through respect, support, provision of information and training, cultural sensitivity, and involvement in systems design.<sup>xxi</sup>

### ***Medical Home***

*“A Medical Home is the provision of care that is accessible, family-centered, continuous, comprehensive, coordinated, compassionate, and culturally competent. Providing a medical home means addressing the medical and non-medical needs of the child and family.”*

The American Academy of Pediatrics encourages primary care physicians to provide a “medical home” for all CSHCN. Providing a medical home means creating a partnership with the child's family to develop a long-range health care plan for the child which address the medical and non-medical needs of the child and family.<sup>xxii</sup>

Comprehensive assessment and development of a written care plan are important components of good care coordination. Once identified as being a child with special

needs, careful and regular assessment is required to determine the full scope of needs, and to monitor whether the care plan as implemented is addressing needs and fostering improvement in a child's health and well-being. The initial assessment should also identify services currently being received, to facilitate coordination among all care providers.

While care coordination is an essential element of health care for children with special needs, providers are often constrained in their ability to provide it. Good care coordination requires time, resources, information, skills, and support. Providers generally receive no additional reimbursement for care coordination, and often have no training in this area.

Medi-Cal managed care plans and other agencies (CCS, RC) are already required to case manage and coordinate care for CSHCN. Plans are specifically required to enter into Memoranda of Understanding with their local public health department's California Children's Services (CCS) and Child Health and Disability Prevention (CHDP) programs, and with the local County Mental Health agency. However, operational challenges in implementing the MOUs remain; plans and primary care providers are often unaware that children are receiving services from other agencies, or the nature of those services. Lack of communication and coordination still cause some families to confront delays or impediments in accessing care, and to inefficient care delivery. Families complain that they are "punted" from one agency to another, while each agency waits to see if another will assume responsibility for the child. Ironically, some families have many case managers from different agencies, but none who really fulfill the families' care coordination needs because of role limitations and turf issues.

#### ***Challenges to Improved Care Coordination***

- *Complexity of system and programs*
- *Organizational culture of silos, lack of trust*
- *Inadequate (or no) reimbursement for care coordination*
- *Provider lack of time and staff*
- *Lack of information about resources*
- *Concerns about confidentiality*
- *Shortages of specialists*
- *Variation in local and Plan processes*
- *Delays in determining payment responsibility*
- *Diversity of cultural – linguistic needs*

There are significant challenges in improving care coordination for CSHCN enrolled in Medi-Cal managed care plans. Foremost amongst these is the complexity of California's child health system. Multiple programs, each with complex eligibility and operational requirements, operate in their own silos, with legal, financial, and organizational constraints on their ability to weave a whole system of care for CSHCN. In some cases,

several case managers (e.g. from Plans, CCS, Regional Centers, foster care public health nursing), may all attempt to coordinate care at once. Variations in processes (e.g. for determining eligibility or handling referrals) among locally-controlled agencies and among Plans lend to further confusion. Also, because several agencies are “payors of last resort”, multiple written denials may be required before responsibility for payment can be determined, leading to delays in accessing services.

The sections below provide an overview of the key agencies with responsibilities for providing health care services to children with special health care needs, and a brief summary of some of the special issues confronting sub-groups of CSHCN.

### **CARE COORDINATION FOR CHILDREN WITH MENTAL HEALTH NEEDS**

It is estimated that more than a million California children experience emotional, behavioral, or mental health problems each year.<sup>xxiii</sup> With a few exceptions, mental health services in Medi-Cal are “carved out” of Plan contracts under the Specialty Mental Health Services Consolidation program. Plans are responsible for provision of “primary care mental health services”.

Specialty mental health services are provided by locally controlled county mental health agencies on a fee-for-service basis. Children with serious emotional disturbances (SED) receive care through a comprehensive mental health services system – Children’s System of Care – which was designed to facilitate collaboration among all systems providing care for children with SED. Some mental health services may also be provided through special education, juvenile justice, child welfare, or CCS.

The Department of Mental Health determines eligibility for specialty mental health services on the basis of stringent “medical necessity” criteria. The child must have a qualifying diagnosis, significant impairment as a result of the mental disorder, and the expectation that the proposed intervention will be helpful.<sup>xxiv</sup>

Every child should regularly receive screening for emotional or behavioral problems; if a mental health disorder is suspected, the child should be evaluated and treated, if necessary, by a mental health professional. Many children who need mental health services may not receive them because their needs are not identified; the use of standardized tools considerably increases identification rates.<sup>xxv</sup> Some providers are not familiar with universal screening recommendations; others are reluctant to identify mental health needs, because of difficulties in accessing consultations and services.

### ***Challenges in Mental Health Coordination***

- *Shortage of child mental health providers*
- *Poor access to mental health consultation and services*
- *Lack of universal screening to identify children with mental health needs*
- *Confusion about agency/Plan responsibilities*
- *Confidentiality concerns*
- *Stringent mental health eligibility criteria*

There is significant confusion on the part of providers, Plans, and even county agencies regarding access to and responsibility for mental health evaluations, and for care of children with mental and behavioral health problems who are not eligible for carved out specialty mental health services.

However, there is general agreement that there is a severe shortage of child mental health professionals in the state; this shortage is exacerbated in Medi-Cal, in part due to low reimbursement rates. Because of the shortage, there are long waiting lists to access mental health evaluation and treatment services in many areas. Children who need mental health services but are ineligible for county services under consolidation may find access especially difficult.

There is a special sensitivity, and specific regulations, about the confidentiality of mental health services, due to concerns about the still-present stigma of mental illness. However, it is also particularly important that there be coordination of physical and mental health care. Providers must be aware of all of the medications a patient is prescribed in order to prevent adverse drug interactions. Mental health problems may also impact patient compliance. Better mechanisms for appropriate exchange of information between mental and physical health providers must be implemented.

### ***Task Force Recommendations on Mental Health***

- ***Clarify agency and plan responsibilities for mental health services.***
- ***Educate providers about use of screening tools, mental health referrals, and available resources.***
- ***Increase training for PCPs on child mental health.***
- ***Improve information sharing (among physical/mental health); clarify that sharing of mental health information for care coordination and quality improvement is allowed..***
- ***Increase provider reimbursement.***
- ***Decrease variation in local policies/procedures.***

## **CARE COORDINATION FOR CHILDREN WITH DEVELOPMENTAL DISABILITIES**

The Federal Individuals with Disabilities Education Act (IDEA) and the California Early Intervention Services Act and Lanterman Act mandate provision of a broad array of services and supports, including assessment and case management, for children with or at risk for developmental disabilities. Early Start provides services for children ages zero to three with or at risk of developmental disabilities (DD), and their families.<sup>xxvi</sup> The State Department of Developmental Services contracts with a network of twenty-one independent, not-for-profit, locally controlled Regional Centers for services provided to about 170,000 persons with developmental disabilities.

Medi-Cal Managed Care Plans are required to coordinate closely with Regional Centers in providing screening, assessment, development of treatment and service plans, and case management services.<sup>xxvii</sup> Regional Centers do their own assessments and provide case management; determinations of eligibility may lead to lifetime services.

As in mental health, confidentiality concerns often hinder information sharing or identification of patients receiving Regional Center services. The Welfare & Institutions Code specifies that Regional Centers are the payors of last resort. Poor coordination may result in duplication of services. Lack of clarity regarding payment responsibility, inadequate primary care screening for developmental delay, and shortages of developmental pediatricians may lead to delays in services, particularly for developmental assessments, neuropsychological testing, and therapies.

### ***Challenges in Coordination with Regional Centers***

- *Shortage of developmental pediatricians*
- *Lack of universal screening to identify children with developmental delay*
- *Confusion about agency/Plan responsibilities for assessments, services, and payments*
- *Cumbersome process for determination of payment*

### ***Task Force Recommendations on Developmental Disabilities***

- ***Improve information sharing among Regional Centers and Plans; clarify that sharing of information for care coordination and quality improvement is allowed..***
- ***Clarify and streamline payment determinations.***
- ***Decrease variation in local policies/procedures.***
- ***Train providers on use of developmental screening tools.***
- ***Cross-train Regional Center and Plan staff on role/responsibilities of each.***

## **CARE COORDINATION FOR CHILDREN WITH ALCOHOL AND DRUG PROBLEMS**

Early identification and treatment of substance abusing youths results in better outcomes. The 1998 Adolescent Alcohol and Drug Treatment and Recovery Program Act provided \$5 million annually to about half of California counties to support substance abuse treatment for youth. However, there remains a severe shortage of youth drug treatment facilities; while between 252,000 and 315,000 California adolescents need some level of drug or alcohol treatment respectively, only 21,000 received publicly funded treatment in 2001. No residential drug treatment programs are currently available for youth in the Drug Medi-Cal program.<sup>xxviii</sup>

Mental health systems may also provide drug treatment, including through the federally funded EPSDT program. However, many providers erroneously believe that these services can only be provided to children with a dual diagnosis of mental illness, exacerbating the difficulties in accessing substance abuse treatment for youth. Finally, providers lack training in screening for substance abuse problems, and may be reluctant to screen if resources for referral are inadequate.

### ***Task Force Recommendations on Alcohol and Drug Problems***

- ***Educate providers about screening and referrals for substance abuse.***
- ***Clarify availability of substance abuse treatment through mental health services and other sources.***
- ***Provide information about substance abuse services to Plans and providers.***
- ***Increase availability of substance abuse services for children.***

## **CARE COORDINATION WITH CALIFORNIA CHILDREN’S SERVICES**

The California Children’s Services Program (CCS), supported by Federal Title V Maternal and Child Health Program funds, assures that children with certain physically handicapping conditions receive necessary and appropriate health care to treat their eligible conditions at the appropriate time and place. The CCS program provides diagnosis, treatment, and medical therapy services for children with certain acute and chronic diseases, many of which are rarely observed in the usual pediatric practice. CCS empanels health care providers who have expertise in caring for pediatric conditions and approves facilities with a higher level of pediatric staffing for the provision of those services. Specific conditions are followed in Special Care Centers with multidisciplinary staffing and supervision. About 80,000 children receiving CCS services are enrolled in Medi-Cal managed care.

For most Medi-Cal managed care plans, CCS services are “carved out”; children with CCS conditions receive their primary and preventive care through the Plan, and care for

the CCS condition through the local CCS program. The carve-out is intended to assure care by sub-specialists and teams experienced in the care of rare or complex conditions, allow continuity of providers irrespective of payment source, and remove any fiscal incentives for limitation of services.

Plans are required to implement MOUs with local CCS programs, develop procedures to identify, refer, and track enrollees, and coordinate care with CCS. CCS provides listings of approved facilities and paneled providers, and plans are expected to identify CCS paneled providers within their organizations to maintain continuity of care.<sup>xxix</sup>

#### ***Challenges in Coordination with CCS***

- *Shortages of pediatric specialists*
- *Low provider reimbursements*
- *Unclear roles in diagnostic work-up*
- *Lack of PCP training about CCS*
- *Variability in plan and CCS processes*
- *CCS staff shortages*
- *Emergency coverage confusion*
- *Inadequate transition out of CCS*
- *Uneven communication between CCS and primary care provider*

Differences among plans and local CCS programs, and lack of provider education about Medi-Cal and CCS policies, create confusion for providers which can result in referral, eligibility, authorization, payment, and service delays. State billing and payment procedures add to provider frustration. State approved rates for sub-specialists may be lower than plan rates, in spite of an additional modification to state rates when the services are approved by the CCS program. Urgent or emergent care by non-paneled providers or facilities becomes problematic because of timely referral or payment issues. For a variety of reasons, primary care providers may be unaware of a child's participation in CCS.

#### ***Task Force Recommendations on Coordination with California Children's Services***

- ***Increase provider education on CCS referral and authorization policies and requirements.***
- ***Increase provider reimbursements and simplify CCS paneling process***
- ***Institutionalize multiple mechanisms for CCS/Plan communication and info-sharing.***
- ***Clarify coverage for emergency services and transition services***
- ***Clarify provider/plan/CCS roles in diagnosis, case management, and care coordination.***
- ***Develop mechanisms to ensure PCP awareness of patients' CCS services.***
- ***Decrease variation in local policies/procedures regarding eligibility, authorization, payment.***
- ***Streamline claims payment process and consider mechanisms to take provider out of middle of funding disputes.***

## CARE COORDINATION FOR CHILDREN IN FOSTER CARE

There are over 96,000 children in foster care in California, with about 35,000 new cases each year. These are children who have been removed from their homes due to substantiated abuse or neglect. Children in foster care have a higher prevalence of physical, developmental, dental, substance abuse, and behavioral health problems than any other group of children. 60-80% of children in foster care require ongoing medical treatment and have mental health problems.<sup>xxx</sup>

Children in the foster care or adoption assistance programs can voluntarily enroll in Medi-Cal managed care plans, but are exempt from mandatory enrollment, except in those counties with County Organized Health Systems. The California Departments of Social Services (CDSS) and Health Services (DHS) have recently implemented several programs which have significantly improved health care for children in foster care. The Health Care Program for Children in Foster Care employs 211 Public Health Nurses in addition to nurses employed by county child welfare agencies – who work collaboratively with social services and probation staff to coordinate the delivery of health services to children in foster care. The CDSS Child Welfare Services Case Management System (CWS/CMS) is a database which stores information on each child in the child welfare program throughout the 58 counties in California.

### *Health Care Challenges for Children in Foster Care*

- *High prevalence of health and mental health problems*
- *Multiple systems involved (health, child welfare, juvenile justice, mental health)*
- *Many transitions in living and health arrangements*
- *Eligibility system doesn't address transitions quickly*
- *Coordination and continuity (of care and medications) among counties difficult when children move*

However, due to the transient nature of this population, major challenges persist in providing comprehensive coordinated health care and continuity of care in the Medi-Cal managed care model. Placement out of the county of origin often results in delays and access problems for children in foster care; anecdotally, this may be especially difficult for children in County Organized Health Systems counties. Access and coordination of care continue to be problematic at times of transition, which children in foster care experience with frequency. Coordination among different Plans, CCS offices, and county mental health offices is especially difficult with between-county moves, including barriers to continuing access to psychiatric medications. Transition at the time of emancipation requires special attention. A Health and Education Passport (HEP), part of the CSW/CMS, facilitates sharing of information as the child and foster parent interacts with multiple systems, such as social services, probation, juvenile justice, education and public health.<sup>xxxi</sup> While the HEP provides a mechanism for improved continuity of care, it requires considerable resources to keep updated.

***Task Force Recommendations on Care Coordination for Children in Foster Care***

- ***Implement eligibility system changes to address delays associated with changes in residency, including more rapid processing of expedited disenrollment with out of county placement.***
- ***Designate plan foster care liaison to coordinate with Foster Care Public Health Nurses.***
- ***Expand public health nursing programs in child welfare agencies.***

**CARE COORDINATION WITH SCHOOLS**

School health services include screening (vision, hearing, scoliosis, TB) and assessment, nursing services, and specialized physical health care services for children with medical needs. Schools also provide mental health and special education services, including development of Individual Education Plans. Schools are particularly well situated for early detection of some problems, such as developmental delays, substance abuse, hearing, speech, and vision problems, and behavioral or emotional problems. However, much of the health care provided in schools is provided by unlicensed assistive personnel with limited training. Only about ½ of schools statewide have on-site staff with health training; still fewer schools have school-based clinics, most of which are located in high schools.

Coordination with schools can be challenging due to limited resources and the wide array of services provided. Plans may need to coordinate with a large number of school districts and special education programs, each of which has its own forms, policies, and procedures.

There are a variety of opportunities for Medi-Cal managed care plans to coordinate with local education agencies and schools. Plans can contract with school districts to reimburse for EPSDT and other preventive and primary care services. School districts can use medical consultants to facilitate coordination of care among schools and providers, and can include informed consent forms in school registration packets.

***Task Force Recommendations for Coordination with Schools***

- ***Develop tools for information exchange among schools, plans, and providers, and encourage plan-school communication .***
- ***Encourage plans to contract with school based clinics.***

A compelling conceptual framework for care coordination for CSHCN has been developed by The National Initiative for Child Health Quality (NICHQ<sup>®</sup>) and the Center for Medical Home Improvement. The Care Model for Child Health in a Medical Home integrates Dr. Ed Wagner's Chronic Care Model with the concept of the Medical Home.<sup>xxxii</sup> (see Table One)

In this model, community resources partner with the health care system to create community systems of support for CSHCN and their families. The health system adopts effective performance improvement models, fosters family participation, and provides incentives and supports for primary care providers in their care of CSHCN. CHSCN and families play an active and central role in managing care needs. The delivery system provides streamlined access to preventive and special services, and offers a CSHCN care coordinator for continuous, culturally-sensitive, comprehensive care coordination. Information is shared, with sensitivity to confidentiality and parental consent, among care providers. Providers are supported and encouraged in their use of evidence-based care. Clinical information systems are available to maintain a registry of CSHCN, monitor the quality of care, and provide feedback to family and providers for quality improvement efforts.

### **CONFIDENTIALITY**

Comprehensive care coordination requires sharing of information among the multiple agencies and health care professionals that are providing services for a child. Appropriate sharing of information: allows streamlined coordination of benefits, prevents duplication of services, protects against medical errors and adverse drug interactions, relieves families of the responsibility of repeatedly providing full medical histories, facilitates the provision of a medical home, and hastens provider reimbursement.

Yet patients and families are legitimately concerned that people who do not need medical information will access it, or that the information will be used in ways that are deleterious to a child's well-being (e.g. labeling a child in school, mental health stigma). Balancing the need for sharing information with concerns about confidentiality emerged as a major theme in Task Force discussions of care coordination for CSHCN.

A confusing multiplicity of Federal and State laws govern the exchange of confidential health and medical information, including: the Confidentiality of Medical Information Act, the Lanterman-Petris-Short Act (public mental health system), the Lanterman Developmental Disabilities Services Act (Regional Center clients), federal Confidentiality of Alcohol and Drug Abuse Patient Records provisions, federal regulations on mental health information, California Education Code sections on school and school counseling records, provisions related to juvenile court records, and special protections for adolescent sensitive services.<sup>xxxiii</sup>

These laws have been implemented in order to protect medical privacy, and to maintain a healthcare environment in which patients feel free to share sensitive information with

their providers without fear that it will be used in ways they do not want. Informed consent is always the best framework for sharing information. Many patients and families do not clearly understand how information will be used, whom it will be shared with, or why information exchange may benefit a child.

Currently, federal and state laws protecting confidentiality do allow for the sharing of information for the purpose of facilitating and coordinating the provision of care and administering State-funded benefits. Increased education of patients/families, providers, and agency staff about confidentiality and the use of standardized consent forms could facilitate information exchange. Implementation of a standardized CSHCN “health passport” or “parent notebook” would also help. But legislative clarification is also needed, to more explicitly allow for information sharing among providers and agencies caring for the same individual, consistent with HIPAA requirements.

***Task Force Recommendations on Information Exchange for Improved Care Coordination***

- ***Clarify that State laws allow sharing of information among providers of care for CSHCN for purposes of improving care coordination and quality of care.***
- ***Develop a standardized informed consent.***
- ***Implement a parent-held standardized tool for information sharing: a “health passport” or parent notebook***
- ***Educate patients and families about the reasons and mechanisms for sharing information.***
- ***Educate providers and agencies about the importance of information sharing as allowed under state and federal laws.***

Nurturing a culture of collaboration among all who provide care for CSHCN must be a top priority if the barriers to coordinated high quality care are to be eased and California is to move toward the Care Model for Child Health in a Medical Home. While the Task Force heard many inspiring stories about agencies that are genuinely working together to improve care, there remains a pervasive distrust that hinders true collaboration. Mutual respect may be the foundation for improved trust, recognizing each of the many agencies that care for CSHCN brings its own special expertise to the table. Developing an appreciation for each other’s expertise requires continued education and communication. Although laws cannot force people to trust or respect one another, requiring the development of inter-organizational structures within which communication can flower may be an important step in improving care coordination. At the State level, a thoughtful effort to carefully clarify the roles and responsibilities of each agency in each area of confusion or overlap (e.g. screening, consultation, care coordination) is much needed. The critical role of families in providing care for CSHCN must be recognized and integrated into each of the systems of care that provide CHSCN services, and in the care coordination model.

### *Summary of Task Force Recommendations on Coordination of Care*

- *Clarify agency roles and responsibilities with respect to identification, screening, referrals, assessment, treatment, and care coordination.*
- *Require that all agencies serving CSHCN 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 policies and increase consistency of policy administration and processes across counties for program eligibility determination, referrals, information sharing, authorization, and payment.*
- *Improve State agency mechanisms for sharing data, and Plan-agency data sharing, within confidentiality laws.*
- *Clarify that State laws allow sharing of information among providers of care and services for CHSCN for purposes of improving care coordination and the quality of care.*
- *Develop a standardized consent form.*
- *Implement and promote a standardized parent/caretaker held tool (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.*
- *Develop reimbursement mechanisms that do not delay payment and that don’t put families in the middle.*
- *Educate parents and providers about the importance of sharing information with all providers.*
- *Provide information and training on care coordination to families, providers, plans, and agencies.*
- *Require that plans designate CSHCN care coordinators who are available to participate in the coordination of care so that the needs of all CSHCN are appropriately met.*
- *Require inclusion and partnering with families in all aspects of the child’s health care plan at the agency, Plan, and provider levels.*
- *Implement a cross-agency program to train and support providers on CSHCN screening, primary care treatment, and referral for mental health, developmental, and substance abuse problems.*
- *Implement payment strategies (e.g. pay for care coordination activities, risk adjustment) which allow fair reimbursement for time and resources devoted to care coordination for CSHCN.*
- *Develop pilot projects for integrated care coordination, e.g., lead care coordinator who can work across systems of care, or blended funding streams for CSHCN.*

**MEASURING THE QUALITY OF CARE for CSHCN**

The Institute of Medicine defines quality as “*the degree to which health services for individuals and populations increase the likelihood of desired health outcomes and are consistent with current professional knowledge.*”<sup>xxxiv</sup> Numerous studies have documented serious quality issues in U.S. health care, including: underuse, overuse, and misuse; variable and unpredictable performance; poor compliance with best practices; poor chronic disease care; medical errors; and severe inequities in access.<sup>xxxv</sup>

Measuring the quality of care is fundamental to health care accountability and improvement. Quality information helps consumers make informed choices, allows purchasers and taxpayers to evaluate whether the huge resources invested in health care are well-spent, helps policymakers monitor health system performance, and both encourages and helps providers and Plans improve the quality of care.

The health care needs of CSHCN differ from those of other children. CSHCN generally have increased exposure to the health care system; 80% of health care costs for children are for CSHCN. Yet little is known about the quality of care for CSHCN.<sup>xxxvi</sup> Measuring the quality of health care for CSHCN is especially challenging because there are often small numbers of children with any one condition, and there may not be evidence-based guidelines available. Operationalizing important concepts – such as “medical home” and continuity of care is also difficult. The fragmented delivery system, in which CSHCN may receive care in multiple systems, also makes it especially difficult to assess the quality of care, because it is more difficult to ascertain which services have been received. Also, when many providers and agencies are involved in care, each must be held accountable only for that care for which they are responsible.

<b><i>Dimensions of Quality</i></b>	
<u><i>Components of Quality</i></u>	<u><i>Needs of Consumers</i></u>
<i>Safety</i>	<i>Staying Healthy</i>
<i>Effectiveness</i>	<i>Getting Better</i>
<i>Patient Centeredness</i>	<i>Living with Illness</i>
<i>Timeliness</i>	<i>Coping with End of Life</i>
<i>Equity</i>	
<i>Efficiency</i>	

Selecting quality measures requires decisions about what and who to measure, and what indicators to use. Ideally, measures are meaningful to users, measure things that are worth measuring, and are feasible, valid and reliable, and able to discriminate among different levels of performance. The National Health Care Quality Report Framework for quality measurement defines two dimensions of quality: quality components, and health care needs of consumers.<sup>xxxvii</sup>

Quality measurement uses many sources of data, each with strengths and weaknesses. Administrative (claims/encounter) data is relatively easy to obtain, but may be

incomplete or inaccurate. Medical records review provides a lot of detail, but is time consuming and expensive; for CSHCN, it is hard to track down multiple records from different providers and systems of care. Patient or family surveys are uniquely able to provide information on the patient perspective, and on function and outcomes; however, surveys are also expensive, and getting adequate response rates is difficult.

There are many individual aspects of quality which would be important to measure for CSHCN, including but not limited to: access to specialists, durable medical equipment, drugs; occurrence of screening for special needs, developmental disabilities, mental health; family involvement and satisfaction; access to a medical home and family support services; availability of a written care plan; provision of routine preventive services and well child care; adherence to evidence-based guidelines (e.g. asthma, diabetes); general and school-related functioning; services utilization; cultural/linguistic services and effectiveness; and satisfaction of caregivers with coordination of care.

The Child and Adolescent Health Measurement Initiative (CAHMI) developed a supplemental module for the Consumer Assessment of Health Plans Survey (CAHPS<sup>®</sup>), a standardized, validated tool which has been incorporated by the National Committee for Quality Assurance into its Health Plan Employer Data and Information Set (HEDIS<sup>®</sup>). HEDIS<sup>®</sup> is a set of quality measures used in accreditation of managed care plans, and by many purchasers, including Medi-Cal, to assess plan quality.<sup>xxxviii</sup>

The CAHPS survey is administered to families by mail and/or by phone. Nine children with special needs measures can be constructed from data collected using the CSHCN module.<sup>xxxix</sup> Additionally, the Child CAHPS with the CSHCN module can also be used to construct a measure of Medical Home, to assess the extent to which CSHCN have accessible, family-centered, comprehensive, coordinated, compassionate, and culturally effective care.<sup>xl</sup>

***CAHPS<sup>®</sup> Child Health Survey with CSHCN Module***

- *Doctors Who Communicate*
- *Getting Care Quickly*
- *Getting Needed Care*
- *Courteous and Helpful Office Staff*
- *Customer Service and Information*
- *Access to Specialized Services*
- *Access to Prescription Drugs*
- *Family Centered Care*
- *Coordination of Care*

***Task Force Recommendations on Measuring Quality of Care***

- ***Implement a core CSHCN measure set, including the CAHPS CSHCN survey and other CSHCN-relevant 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.***

## **QUALITY IMPROVEMENT**

Quality improvement is a systematic program to better the level of system performance through enhancing efficiency and consistency, eliminating defects, and achieving new levels of performance. The specific aims of health care are to be safe, effective, efficient, timely, family centered, and equitable. Improving the quality of health care requires attention at all levels – the patient/family, the provider, the health care organization and system, and the policy environment. Sometimes even very simple changes (e.g. in office systems) can have big impacts on quality. Quality improvement also requires awareness of the need for improvement, leadership and organizational commitment to improvement, ideas for improvement, and support for change. Key challenges for providers and Plans in implementing quality improvement programs include lack of time, money, and resources, non-recognition of the need for improvement, and the lack of incentives (financial and non-financial) for improvement.

One example of an idea for improvement is the model for child health care presented earlier. The Plan-Do-Study-Act Cycle for learning and improvement is a model for quality improvement that has been demonstrated to be effective in improving child health care and care for CSHCN.<sup>xli</sup>

### ***Task Force Recommendations on Quality Improvement for CSHCN***

- ***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 CSHCN, based on the prevalence and burden of service needs of their population (e.g. streamline payment, increase reimbursement, risk adjustment, pay for assessments and coordination).***
- ***Offer incentives (financial and non-financial) to plans and providers for quality improvement.***
- ***Provide resources for QI through adequate reimbursement for CSHCN care.***
- ***Implement Quality Improvement collaboratives to improve the care of CSHCN***

## **BALANCED BUDGET ACT - MEDICAID MANAGED CARE FINAL RULES**

The final Medicaid Managed Care Rules implementing the Balanced Budget Act of 1997 were published on June 14, 2002, replacing previously published rules and an earlier State Medicaid Director Letter on CSHCN. The final rules permit a greater degree of state flexibility in many areas. The rules require that State Medicaid agencies: define individuals with special needs, assess the quality of care for those individuals, identify enrollees with special needs, provide for coordination and continuity of care and direct access to specialists, and set actuarially sound capitation rates.<sup>xliii</sup>

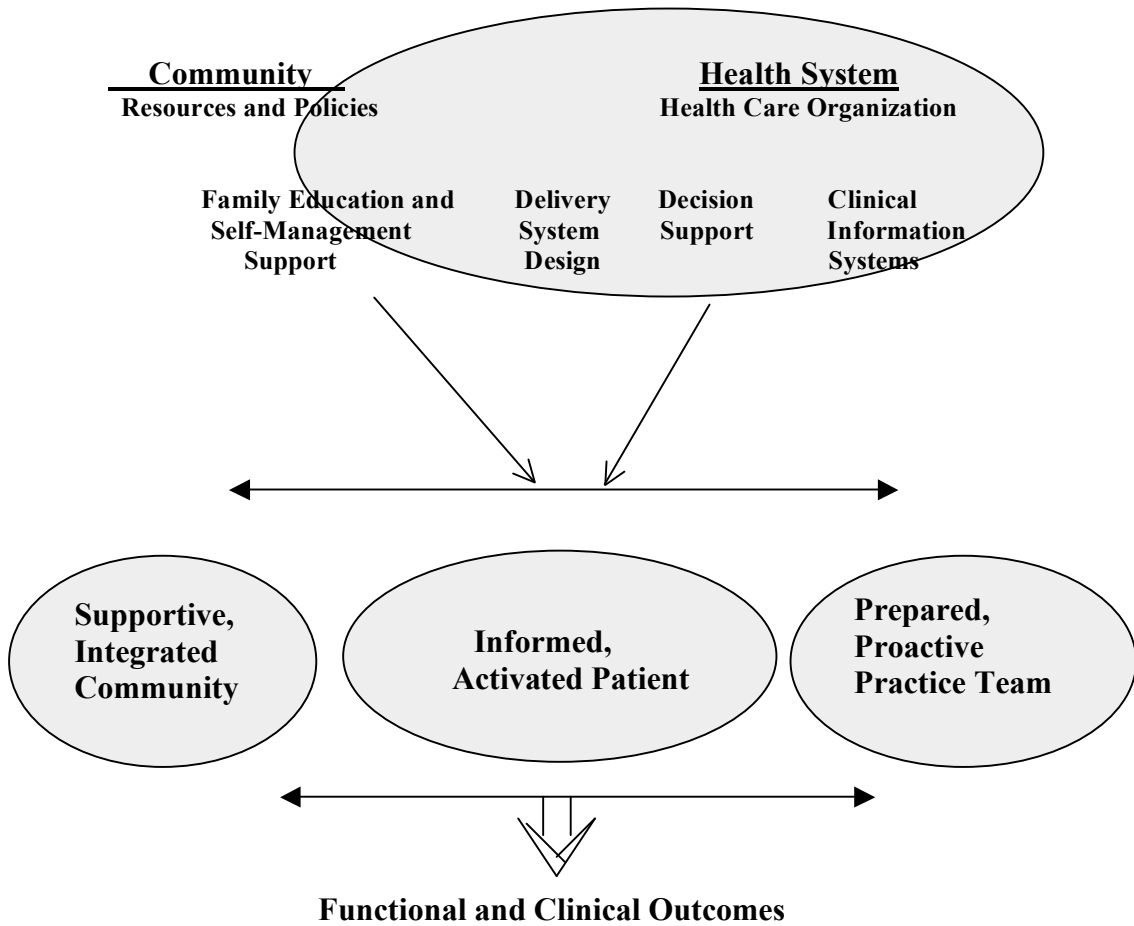
## **CONCLUSION**

CSHCN are one of the most vulnerable groups in our society. Providing them with the comprehensive, coordinated, family-centered care they need is a high priority. The Medi-Cal Managed Care Task Force on Children with Special Health Care Needs, comprised of representatives from managed care plans, providers, families, advocacy organizations, and agencies that provide services for CSHCN, met over the past year to discuss challenges and opportunities for improving the care of CSHCN.

Despite philosophical differences in individual perspectives about current and proposed child health care service systems, the Task Force agreed on a variety of key steps that must be taken to improve care for CSHCN within the context of the current structure of Medi-Cal Managed Care. It is incumbent on the Medi-Cal Managed Care Division, Plans, other State agencies, and provider and advocacy organizations to continue working together to implement these recommendations.

Table One

**Care Model for Child Health in a Medical Home**



CMHI/NICHO®

## NOTES

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<sup>i</sup> McPherson M, Arango P, Fox H, et.al. A new definition of children with special health care needs. *Pediatrics*. 1998;102(1):137-140.

<sup>ii</sup> Newacheck P, Stickland B, Shonkoff J, et.al. An Epidemiologic Profile of Children with Special Health Care needs. *Pediatrics*. 1998;102(1):117-121.

<sup>iii</sup> This number derived using the CSHCN Screener, Identifying CSHCN in Managed Care Plans, Maternal and Child Health Bureau Expert Work Group, April 2001

<sup>iv</sup> Committee on Children with Disabilities, American Academy of Pediatrics; Managed Care and Children With Special Health Care Needs: A Subject Review. *Pediatrics*; 1998;102(3):657-660., September 1998.

<sup>v</sup> Committee op.cit.

<sup>vi</sup> 45 CFR 438.208

<sup>vii</sup> MCHB Expert Work Group Meeting. Identifying Children with Special Health Care Needs in Managed Care Plans. USDHHS/HRSA Maternal and Child Health Bureau. April 5, 2001.

<sup>viii</sup> MCHB Expert Work Group, op.cit.

<sup>ix</sup> The Foundation for Accountability (FACCT): Using the Screener.

<http://www.facct.org/facct/site/CSHCN/screener/home> (site accessed 5/7/03)

<sup>x</sup> The Children with Special HealthCare Needs Screener.© FACCT

[http://www.facct.org/facct/doclibFiles/documentFile\\_446.pdf](http://www.facct.org/facct/doclibFiles/documentFile_446.pdf) (site accessed 5/3/03)

<sup>xi</sup> Inkelas, M. Access to Health Care for California's Children with Special Health Care Needs – Chartbook. UCLA Center for Healthier Children, Families, and Communities. DRAFT. March, 2003.

<sup>xii</sup> Skaggs, et.al. Access to Orthopedic Care. *Pediatrics*. 2001;107:1405-1508. 2001

<sup>xiii</sup> Hansel P, Reifman C. California's Ailing System of Caring for Children with Special Health Care Needs. Senate Office of Research. Sacramento. 2000.

<sup>xiv</sup> Bindman A, Huen W, Vranizan K. Physician Participation in Medi-Cal, 1996-1998. Center for California Health Workforce Studies. (site accessed 5/3/03)

<http://www.medi-cal.org/documents/PhysicianParticipationMediCal1996to1998.pdf>

<sup>xv</sup> Pediatrician Participation in Medicaid/SCHIP: Survey of Fellows of the American Academy of Pediatrics, 2000. American Academy of Pediatrics.

<http://www.aap.org/statelegislation/med-schip/pcp/US.pdf> (site accessed 5/3/03)

<sup>xvi</sup> National Policy Center for Children with Special Health Care Needs, Achieving Service Integration for Children with Special Health Care Needs, July 1999

<sup>xvii</sup> Carl Cooley, Presentation to the Task Force, June 2002

<sup>xviii</sup> Center for Medical Home Improvement.

<http://www.medicalhomeimprovement.org/assets/pdf/MHIK-IV-C.pdf> (site accessed 5/3/03)

<sup>xix</sup> Margo Rosenbach and Cheryl Young, Care Coordination in Medicaid Managed Care Presentation, 6/2002

<sup>xx</sup> Association of Maternal and Child Health Programs, Care Coordination for Children with Special Health Care Needs and their Families in the New Millennium, August 2000

<sup>xxi</sup> Smith K, Wainstock L, Thompson L. ACCESS-MCH: Care Coordination Outcomes for Children with Special Health Care Needs. US/DHHS, MCHB. July 1, 1998.

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- <sup>xxii</sup> Palfrey J, Haynie M. Managed Care and Children with Special Health Care Needs: Creating a Medical Home. American Academy of Pediatrics Medical Home Program for Children with Special health Care Needs. 2001.  
<http://www.aap.org/advocacy/mmcflhom.htm>. (site accessed 7/24/01)
- <sup>xxiii</sup> Young Hearts and Minds: Making a Commitment to Children's Mental Health. Little Hoover Commission. Report #161, July 2001.  
<http://www.lhc.ca.gov/lhcdir/report161.html> (site accessed 5/3/03)
- <sup>xxiv</sup> Young Hearts and Minds, op.cit.
- <sup>xxv</sup> Semansky R, Koyanagi C, Vandivort-Warren R. Behavioral Health Screening Policies in Medicaid Programs Nationwide. *Psychiatric Services* 2003 54: 736-739.
- <sup>xxvi</sup> Department of Developmental Services. Services Provided by Regional centers.  
<http://www.dds.cahwnet.gov> (site accessed 9/10/02)
- <sup>xxvii</sup> Medi-Cal Managed Care Policy Letters No. 97-02 and 97-03
- <sup>xxviii</sup> Donna Hopkins, California Department of Alcohol and Drug Programs, presentation 9/1702.
- <sup>xxix</sup> Medi-Cal Managed Care Division letters Nos. 96-10 and 96-18
- <sup>xxx</sup> Code Blue: Health services for Children in Foster Care. Institute for Research on Women and Families. CSU, Sacramento. 1998.
- <sup>xxxi</sup> Department of Health Services. Health Care Program for Children in Foster Care.  
<http://www.dhs.cahwnet.gov/pcf/cms/hcpcf/overview.htm> (site accessed 4/10/03).
- <sup>xxxii</sup> National Initiative for Children's Healthcare Quality Annual Forum, February 2003. Adapted from Institute for Healthcare Improvement's Breakthrough Series Collaborative: Improving Care for People with Chronic Conditions, Dr. Ed Wagner, Group Health Cooperative of Puget Sound.
- <sup>xxxiii</sup> Preis J. A Manual for the Exchange of Information in a California Integrated Children's Services Program. California Institute for Mental Health. Sacramento. September, 1999.
- <sup>xxxiv</sup> Institute of Medicine. Medicare: A Strategy for Quality Assurance. 1990. National Academy of Sciences.
- <sup>xxxv</sup> Institute of Medicine. Crossing the Quality Chasm. 2001. National Academy of Sciences.
- <sup>xxxvi</sup> Child and Adolescent Health Measurement Initiative. Living with Illness.  
<http://www.facct.org/cahmiweb/chronic/lwihome.htm> (site accessed 7/24/2001).
- <sup>xxxvii</sup> Institute of Medicine. Envisioning the National Health Care Quality Report. 2001. National Academy of Sciences.
- <sup>xxxviii</sup> Child Health Toolbox. Measuring Services for Children with Special Health Care Needs.  
<http://www.ahcpr.gov/chttoolbx/cshcn.htm> (site accessed 5/3/03)
- <sup>xxxix</sup> op.cit. Child Health Toolbox.
- <sup>xl</sup> Debra Read. The Foundation for Accountability (FACCT). MMCD Task Force on CSHCN Presentation, December 9, 2002.
- <sup>xli</sup> Dr. Charles Homer. National Initiative for Children's Health Quality (NICHQ<sup>®</sup>). MMCD Task Force on CSHCN Task Force. Presentation. February 24, 2003.
- <sup>xlii</sup> 42 Code of Federal Regulations 438.204 et.seq.

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## FEDERAL LEGISLATION AND REGULATORY CITATIONS

### CHILDREN WITH SPECIAL HEALTH CARE NEEDS

#### Social Security Act

1915(c)(8) The State agency administering the plan under this Title may, whenever appropriate, enter into cooperative arrangements with the State agency responsible for administering the program for children with special health care needs under Title V in order to assure improved access to coordinated services to meet the needs of such children.

#### 42 Code of Federal Regulations

438.204 Elements of State quality strategies

At a minimum, State strategies must include the following:

...

(b) Procedures that--

(1) Assess the quality and appropriateness of care and services furnished to all Medicaid enrollees under the MCO and PIHP contracts, and to individuals with special health care needs.

438.208 Coordination and continuity of care.

(a) Basic requirement--(1) General rule. Except as specified in paragraphs (a)(2) and (a)(3) of this section, the State must ensure through its contracts, that each MCO, PIHP, and PAHP complies with the requirements of this section.

...

(b) Primary care and coordination of health care services for all MCO, PIHP, and PAHP enrollees. Each MCO, PIHP, and PAHP must implement procedures to deliver primary care to and coordinate health care service for all MCO, PIHP, and PAHP enrollees. These procedures must meet State requirements and must do the following:

(1) Ensure that each enrollee has an ongoing source of primary care appropriate to his or her needs and a person or entity formally designated as primarily responsible for coordinating the health care services furnished to the enrollee.

(2) Coordinate the services the MCO, PIHP, or PAHP furnishes to the enrollee with the services the enrollee receives from any other MCO, PIHP, or PAHP.

(3) Share with other MCOs, PIHPs, and PAHPs serving the enrollee with special health care needs the results of its identification and assessment of that enrollee's needs to prevent duplication of those activities.

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(4) Ensure that in the process of coordinating care, each enrollee's privacy is protected in accordance with the privacy requirements in 45 CFR parts 160 and 164 subparts A and E, to the extent that they are applicable.

(c) Additional services for enrollees with special health care needs.

(1) Identification. The State must implement mechanisms to identify persons with special health care needs to MCOs, PIHPs and PAHPs, as those persons are defined by the State. These identification mechanisms--

(i) Must be specified in the State's quality improvement strategy in Sec. 438.202; and

(ii) May use State staff, the State's enrollment broker, or the State's MCOs, PIHPs and PAHPs.

(2) Assessment. Each MCO, PIHP, and PAHP must implement mechanisms to assess each Medicaid enrollee identified by the State (through the mechanism specified in paragraph (c)(1) of this section) and identified to the MCO, PIHP, and PAHP by the State as having special health care needs in order to identify any ongoing special conditions of the enrollee that require a course of treatment or regular care monitoring. The assessment mechanisms must use appropriate health care professionals.

(3) Treatment plans. If the State requires MCOs, PIHPs, and PAHPs to produce a treatment plan for enrollees with special health care needs who are determined through assessment to need a course of treatment or regular care monitoring, the treatment plan must be--

(i) Developed by the enrollee's primary care provider with enrollee participation, and in consultation with any specialists caring for the enrollee;

(ii) Approved by the MCO, PIHP, or PAHP in a timely manner, if this approval is required by the MCO, PIHP, or PAHP; and

(iii) In accord with any applicable State quality assurance and utilization review standards.

(4) Direct access to specialists. For enrollees with special health care needs determined through an assessment by appropriate health care professionals (consistent with Sec. 438.208(c)(2)) to need a course of treatment or regular care monitoring, each MCO, PIHP, and PAHP must have a mechanism in place to allow enrollees to directly access a specialist (for example, through a standing referral or an approved number of visits) as appropriate for the enrollee's condition and identified needs.

438.240 Quality assessment and performance improvement program

...

(b) Basic elements of MCO and PIHP quality assessment and performance improvement programs. At a minimum, the State must require

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that each MCO and PIHP comply with the following requirements:

(1) Conduct performance improvement projects as described in paragraph (d) of this section. These projects must be designed to achieve, through ongoing measurements and intervention, significant improvement, sustained over time, in clinical care and nonclinical care areas that are expected to have a favorable effect on health outcomes and enrollee satisfaction.

(2) Submit performance measurement data as described in paragraph (c) of this section.

(3) Have in effect mechanisms to detect both underutilization and overutilization of services.

(4) Have in effect mechanisms to assess the quality and appropriateness of care furnished to enrollees with special health care needs.