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August 12, 2009

Melissa Rowan, Senior Consultant
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Dear Ms. Rowan:

On behalf of the California Children’s Services (CCS) medical directors and consultants throughout the state of California, we would like to summarize our thoughts about the prospects of redesigning the CCS program. Further details, attached in response to the specific questions posed by Health Management Associates, should be viewed within the following framework.

The CCS program has been providing expert diagnostic and treatment services, medical case management, and direct physical and occupational therapy services to children with special healthcare needs (CSHCNs) for nearly 80 years. Loosely defined, the special population of CCS-eligible children and adolescents has chronic, complex, life-threatening and/or disabling medical conditions. The state of California has singled out this special population for unique treatment, because of the highly specialized multi-disciplinary pediatric medical services which are required to meet the needs of these children. Although children with mental health and/or developmental needs as their primary presenting problems should rightly also be considered children with special health care needs, the state of California has created separate programs to address the needs of these populations.

Because of the highly specialized pediatric services that are required to serve CCS children and because of the relative rarity of medical conditions which render children eligible for the program, the teams of sub-specialists serving these children are affiliated with tertiary or children's hospitals and Special Care Centers in order to ensure high quality and efficiency of care delivery. To maximize the potential for favorable clinical outcomes, and to ensure the wisest expenditure of limited healthcare dollars, it is essential to identify CCS-eligible children as quickly as possible, to link them to the appropriate regionalized services where the best subspecialty care may be provided, and to coordinate the provision of those services in an efficient way.

Bearing these factors in mind, the existing CCS program has strong and successful elements that we believe need to be retained and strengthened as a CCS redesign process moves forward. These successful elements include:

1. standard setting for CCS medical providers, especially hospitals and Special Care Centers but also including individual paneled specialists;
2. professional case management by staff credentialed and experienced in the provision of coordinated pediatric specialty services for CSHCNs;

3. commitment by the state, the counties, the CCS providers and family groups to ensuring ready access to the most appropriate clinical services available for the treatment of eligible conditions, with a primary emphasis on high-quality medical care, in order to achieve the best possible outcomes for the children;
4. demonstrated ability to envision, pilot, and implement innovative services uniquely suited to this patient population, such as the development of pediatric intensive care units and the upcoming pediatric palliative care pilot project;
5. provision of the best and most comprehensive medical therapy services in the state for children with eligible neuromuscular conditions and deformities, via the CCS Medical Therapy Program; and
6. commitment to equal access for eligible children to all of the services available in the program, regardless of the payer source or the community within which the child resides.

Given the complexity of the program, the high stakes for children's health in California, the importance of retaining these critical successful elements that we have described, and the challenges inherent in addressing the problems with the program that we will describe below, *we believe it is critically important that the CCS redesign process be carefully considered and not be rushed*.

The major problems facing the CCS program currently, as we see them, include:

1. fragmentation of care for certain CCS-eligible children, especially those with more complex medical conditions, which results from the current system dividing the responsibility for managing and funding care between primary care systems (including managed care plans) and the CCS system;
2. lack of administrative agility to address payment for the unique and complex pediatric services, durable medical equipment, home health, and other specialized needs of CCS-eligible children, which appears to be caused by inflexibly tying reimbursement rates to Medi-Cal rates and by contracting with a fiscal intermediary that is not nimble enough to respond effectively to the specialized needs of these children or their medical providers; and
3. perception of inconsistencies county-to-county and region-to-region in eligibility determinations and benefits authorizations.

Respectively, these three challenges to the program could be addressed as follows:

1. Fragmentation of care could be limited by eliminating those conditions currently eligible for CCS services which are time-limited and not complex and therefore do not require intensive medical case management services, while simultaneously implementing a system in which CCS provides comprehensive medical case management services to meet the needs of the whole child (including primary care), when the child's condition is expected to be long-term and/or multi-systemic, and complex multidisciplinary care is therefore likely to be needed to achieve the best possible outcome.
2. The payment challenges described could be addressed by creating the flexibility to pay higher rates, when necessary in order to attract and retain qualified providers, and more importantly, by creating a smaller, dedicated fiscal intermediary accountable for serving the needs of CSHCNs and their providers.

3. Inconsistencies in eligibility determinations and benefits authorizations between counties or regions may be more apparent than real, based on the experience and review of some CCS medical directors. However, this perception of inconsistency could be addressed by reinvigorating policy development at the state level and systematically involving county professionals in this process, while simultaneously creating regional collaborative groups responsible for limiting inter-county variability. These collaborative groups might be advisedly modeled on the Children's Regional Integrated Services System (CRISS) in Northern California.

Finally, it should be noted that the state of California has created administrative systems that result in additional fragmentation of care that are above and beyond the scope of CCS redesign. Specifically CSHCNs are often served not only by their medical providers but also by the Regional Center system, the mental health system, and school-based services. A truly comprehensive case management program would seek to integrate those systems into the administrative and medical case management structure.

We look forward to working collaboratively in any effort to improve the systems coordinating all the services that children in the fragile CCS population need and deserve.

Respectfully submitted,

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On behalf of the California Department of Health Care Services (DHCS), Health Management Associates (HMA) is conducting a series of stakeholder interviews to elicit your opinion regarding options available to address many of the systemic issues that have been identified as problems with the CCS program.

Feedback gathered from our discussions with stakeholders will be used to identify options for change and the pros and cons for the options for the State's consideration. In addition to this interview today, you will also have the opportunity to submit information in writing if you do not feel we have adequately covered your comments in this limited amount of time or if you are unable to participate in the interview as scheduled.

"Assumptions"

- Changes to the program will seek to be budget neutral or will identify barriers to providing services at current costs.
- To the extent possible, enhancements to the program will be funded from redirection of funds or from cost savings (or both).
- Changes and enhancements must ensure access to high-quality services delivered in a manner that has been demonstrated to be effective in meeting desired outcomes.

The following information is designed to guide a discussion of the options related to how children enrolled in the CCS program receive services, the type of arrangement used to provide services and the type of arrangement used to administer the program.

Carve Out Options

Many of the CCS children in California currently receive Medi-Cal services through health plans, in areas of the state where there is Medi-Cal managed care, while the treatment of CCS related conditions is carved out of the health plan's responsibility. In FY 2009-10, Medi-Cal will spend nearly $1,700,000,000 on services to Medi-Cal beneficiaries that are authorized by the CCS program. About $680 million is for payments for children enrolled in Medi-Cal managed care plans. The same arrangement occurs for Healthy Families subscribers with CCS eligible conditions, with CCS/Healthy Families expenditures of over $144 million on these services for the same time period.

Some children enrolled into the CCS program have an episodic and time limited, single "system" condition such as a compound fracture. Other children have conditions that are likely to continue into the future and/or that are multi- systemic (such as hemophilia or cancer). Under the carve out, all CCS conditions are treated the same without regard to the nature of the condition. Questions have arisen as to whether the carve out for treatment of a single condition or set of conditions from the primary coverage system can lead to problems coordinating care. Further, questions have been raised as to whether it is in the best interest of the child to carve out treatment of the CCS condition while the managed care plan provides primary care for children who require longer-term specialized services.

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- **Option 1:** The CCS program could continue to use a carve out as currently exists for children who have a time limited condition but a different and comprehensive health plan or network could be used for other children who require longer-term specialized services. For children with long-term and/or multi-systemic conditions, the child would be carved out into a comprehensive health care arrangement, which would be a "specialty" health plan or network. (We will discuss the options for comprehensive arrangements later).

- **Option 2:** The CCS program could carve out all CCS children and enroll them into a comprehensive arrangement, (which would be a "specialty" health plan or network).

- **Option 3:** The CCS program could end the carve out for children who have a time limited condition and make the health plan responsible for treatment of these conditions. The child's eligibility for CCS would not change, but the way they receive special services for CCS children would change. (For children with long-term and/or multi-systemic conditions, the child would be carved out into a comprehensive health care arrangement.)

- **Option 4:** The CCS program could end the CCS carve out for all CCS children and make the managed care plan responsible for all treatment (including treatment of CCS conditions). Again, eligibility for CCS would not be changed – rather the way CCS children receive special services would change.

1. Which one of the options 1 through 4 should be used for the CCS program?

    a. Is there a particular reason or reasons you prefer one option over another option?

Yes, see below

    b. What are these reasons?

We would like to present our vision for the future of the CCS program. We propose eliminating those CCS-eligible conditions that are short-term, or which involve single organ systems, and do not benefit from medical case management services; these conditions could be managed by the health plans and/or Medi-Cal. The remaining CCS-eligible conditions should be divided into two tiers, based upon the benefit gained from case management services. In one tier, CCS would limit its involvement to disease-specific case management, utilizing paneled physicians and Special Care Centers, as in the current system. In the second tier, CCS' role would be expanded to provide truly comprehensive medical case management services for children with long-term or multi-systemic conditions who derive the most benefit from case management. In current parlance, for children in this second tier, we would "carve out" the whole child as CCS eligible, not just the illness.

We believe that CCS is best suited to deliver comprehensive case management services, but regardless of the entity chosen, case management should be delivered by pediatric health professionals in a government-run entity with a public health focus, emphasizing access and quality of care provided by pediatric subspecialists in a multidisciplinary setting.

Following is an explanation of the rationale for our proposal, which might be viewed as a modified version of Option 3.

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In our opinion the CCS case management program derives its value primarily from the following elements: Skilled nursing and physician case management personnel, independent of the treating providers, assess the needs of the eligible child and work to ensure that the child has timely access to the best available medical providers knowledgeable about that child's condition. The CCS professional staff also works to ensure (1) that all services needed for managing the condition are provided in a coordinated and cost effective way, (2) that providers of these services are paid, and (3) that these services meet the standards for quality of care established by the program. Case management services of this type are most beneficial to children whose special health care needs are chronic, complex and/or disabling, and which require multi-disciplinary or highly specialized medical services in order to achieve a favorable outcome. Timely access to the right providers, coordination of services, and avoidance of duplicative or unnecessary services also serve to contain the cost of diagnostic and treatment services.

Some medical conditions currently included as eligible for the CCS program are not chronic, complex and/or disabling, and do not require multidisciplinary or highly specialized services. For these reasons, these conditions do not require CCS case management services. Examples of such conditions would include fractures of the femur or other fractures requiring open reduction and internal fixation, repair of tympanic membrane perforation, and repair of undescended testicles. Such conditions could be eliminated from the CCS program without having an adverse effect on the population served.

Other conditions currently eligible for the CCS program might be divided into two categories, or tiers: first, a tier of conditions which are time-limited or which affect only a single organ system, but which nonetheless benefit from CCS case management services; and second, a tier of conditions which are more chronic and complex, that are expected to last for a long duration and/or which affect multiple organ systems, and for which coordinated, multidisciplinary care will be needed over a long period of time. For this second tier of conditions, more comprehensive CCS case management services would be beneficial.

Our recommendation would be for the first tier of time-limited or single organ system conditions to continue utilizing the CCS carve-out as it currently exists. Examples of such conditions would include isolated hearing loss or cataracts. For the second tier of longer-term or multi-systemic conditions, we recommend carving out the entire child into a comprehensive health care arrangement including comprehensive medical case management services. The CCS medical consultants for many years have suggested that the CCS program "carve out" the entire child for this second tier population and provide all services. Examples of conditions that would benefit from this more comprehensive case management arrangement might include malignant neoplasms, complex congenital heart disease, diabetes, AIDS, and disabling neuromuscular conditions.

Of the other options presented, we cannot recommend Option 1, Option 2 or Option 4.

Option 1, in fact, suggests an arrangement rather opposite to our proposal, in which CCS would provide case management only to children with time-limited, less complex conditions. This option does not make good use of the experience of CCS health professionals or the current design of the CCS program, so we cannot recommend it.

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Option 2 does not make sense because it would require the CCS program to provide case management for all aspects of a child's care, even if the eligible condition is quite limited in scope. This would likely over utilize skilled medical and nursing professional staff and would therefore not be cost effective.

Option 4 likewise does not make sense, because it would turn over the case management of children even with the most complex diseases to existing managed care plans. This seems like a particularly BAD idea since it would likely mean no specialized case management services or other enhanced services for CCS children. Managed care plans generally have demonstrated that they do not have the specialized expertise required to manage the care of children with chronic, complex, life-threatening and/or disabling medical disorders. These plans often do not appreciate the significant differences in evaluation and management of children vs. adults with similar conditions, they generally do not have experience or knowledge in managing serious diseases that are unique to children, and they do not generally have provider networks that are regionalized and comprehensive enough to ensure that children with these conditions have access to the best quality of care available. For these reasons, we believe that carving the care of CCS children into the managed care plans would jeopardize the well-being of these children, delaying their access to the most knowledgeable providers, and putting them at increased risk for adverse outcomes that would ultimately be costly to the system both in human suffering and in dollars.

What are the options for comprehensive changes to the CCS program?

The table entitled "Programs for Children with Special Health Care Needs: Comparison of Selected State Models" provides examples of states that have made comprehensive changes to their program comparable to the CCS program.

States vary considerably in how they administer and provide services to children with special health care needs. Some states are now contracting out administration of their programs. Some states are enrolling children with special health care needs into comprehensive health plans or networks. The state examples are not intended to be models that would be adopted "as-is" for California but rather to provide some examples of several different approaches to administering and delivering services that California might want to consider when considering a California-specific design. Examples of these arrangements include:

- *The development of a specialty plan for children with special health care needs.* Florida Children's Medical Services (CMS) operates both a primary care case management (PCCM) program, with a provider network and medical home model, and a specialty managed care plan. CMS is not a licensed HMO but is instead operating as Provider Service Network or PSN. A PSN is a type of managed care arrangement authorized in Florida Statute that is comprised of a comprehensive network of providers that includes inpatient, outpatient, physician and other services. CMS is housed within the Department of Health, which is the Title V agency. CMS is also now procuring the services of a Third Party Administrator (TPA) to administer their health plan and provider network. Other specialty plans include a HMO for foster children in Texas and a not-for-profit community based organization for persons with HIV/AIDS in California.

- *The enrollment of children with special health care needs into the broader Medicaid managed care plan.* Rhode Island RIte Care is an example of this approach. The children's program can retain initial assessment and eligibility responsibilities and may also perform quality oversight under this type of arrangement.

- Contracting with an Administrative Services Organization (ASO) (sometimes also referred to as a (TPA) to administer most or some of the program. Arizona is using the ASO model. Florida CMS is currently procuring the services of a TPA.

In states that use a comprehensive health plan or network, the health plan/network is the single delivery system through which the child receives all of their health care services and which could include behavioral health services and even long-term care institutional and community-based services. A comprehensive health plan/network for children with special health care needs must include inpatient hospital services because that is where the bulk of expenditures are.

A comprehensive health plan/network is paid on a capitated basis (a per member per month payment) and may be fully at-risk, partially at-risk or have no risk (cost settle at the end of the year). Those that serve high-cost members require a capitation payment that is sufficient to ensure risk is not unreasonable (if the plan is at-risk). The risk-based rates can be developed in a way that serves as an incentive for certain desired outcomes that might include:

- Reduced inpatient care in favor of outpatient care;
- Improved care coordination;
- Use of disease management practices;
- Use of a comprehensive medical home model; and/or
- Implementation of electronic medical records, e-prescribing and other technologies demonstrated effective in improving outcomes and reducing costs.

The comprehensive health plan/network may perform an array of administrative functions now performed by the agency operating the children's program, most commonly service authorization, care coordination, claims payment, service utilization reporting (encounter data) and quality reporting. Part of the responsibility of a comprehensive health plan is to ensure an adequate network (numbers and types of providers, qualifications of providers) and adequate access (distance, travel times, wait times, case load). The agency operating the children's program typically retains eligibility determination, quality management oversight, and data analysis responsibilities. A comprehensive health plan/network can also be required to provide 24/7 nurse call line access, urgent care capabilities, and family supports.

A state can also use a combined approach enrolling children with special health care needs into a comprehensive health plan or network and contracting with an ASO/TPA (as Florida is now preparing to do).

These are just some of the features possible when designing a comprehensive health plan or network.

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2. Should California implement comprehensive changes to the CCS program?

   a. Are there any of the models described above that you clearly oppose and why?

      ☐ Enrollment of children into a comprehensive specialty health plan or network

      ☒ Enrollment of children into “regular” managed care plan

We oppose this option. Our experience with current provider networks in some of the many Medi-Cal managed care plans is that children experience a lack of access to pediatric specialists and subspecialists. CCS children with complex chronic conditions require very specialized, intensive, pediatric focused case management services to have the best possible outcome. They will not receive this in a “regular” managed care plan which virtually assures more ED visits, unnecessary and duplicative prescriptions and additional inpatient days.

      ☒ Administer some or most of the CCS program using a contract for an ASO

We believe this would create inherent conflicts of interest (see answer to 2b below).

   b. Are there any of these models you prefer over others and why?

The Medicaid Primary Care Case Management (PCCM) program described as part of Florida’s Children’s Medical Services plan is an attractive idea because of the use of co-located nurse care coordinators in the offices of PCPs. This model has potential, in that the nurse care coordinators would be truly community-based and would be expected to integrate primary care case management with sub-specialty care case management. However, implementing such an arrangement, within a program as broad as the current CCS program, would require a significant investment of resources. We do not believe that this would be budget neutral for the state of California and expect that Florida’s program must be much more limited in its scope than the current CCS program.

The Arizona plan, which appears to be designed to integrate case management for primary and sub-specialty care in a comprehensive way, also has attractive elements and this model appears at least to serve a similar population of children as the current CCS program. However, the model appears to build in significant conflicts of interest by expecting the physicians’ IPA to handle all of the eligibility determinations, enrollments, claims processing, and appeals. In our opinion, these functions need to be retained by an independent organization with a Public Health focus, whose charge is to secure access to the very best quality services available to meet the child’s needs, regardless of where those services might be located and who might benefit from payment for these services.

We do not believe that the Rhode Island plan presented, which enrolls children with special health care needs (CSHCNs) into the broader Medicaid managed care plan, could be realistically - or safely - applied in the state of California, because of the objections we have already articulated, and also because the state of California has already established separate systems for managing behavioral/ mental health conditions and developmental disabilities.

Whereas the Colorado plan purports to manage CSHCNs by enhancing the medical home, this program excludes many of the conditions that are specifically included and which derive the most benefit from CCS as it currently exists in the state of California. While we fully support the idea of enhancing and promoting medical homes for children throughout the state, we would like to see that model achieve considerable success in the general pediatric population in California before we could advise enrolling CSHCNs exclusively into such a model.

Finally, the Texas model presented addresses a much more limited population, where social needs are complex but medical needs may not necessarily be so. For these reasons we do not feel that it is really applicable in the context of CCS redesign.

c. Are there any services that should be carved out of a comprehensive health plan?

No, by definition a comprehensive health plan should include all services that are medically necessary. ”Carving out” and case managing the “whole child” rather than just the CCS eligible condition and thus only part of their care could improve overall care, avoid duplication and avoid misunderstandings. With comprehensive, specialized case management this could result in more streamlined care and thus cost containment.

d. If you do not think California should make comprehensive changes to the CCS program like the options described previously, do you believe there is a better option to improve the CCS program and what would that option be? (Skip to 4)

We are all in favor of working to improve the CCS program, but we are not convinced that the basic structure of the CCS program is broken. By and large CCS does a very good job of complex pediatric case management at the level of the County Public Health Department. CCS has been doing this for decades, and while the structure clearly could be improved, we don’t see why this structure should be dismantled. A few changes could solve most of the concerns and problems raised about CCS – specific recommendations are detailed in our cover letter.

If there were strong policy leadership at the State level, many of the inconsistencies between counties could be easily resolved. If there were a clear mechanism for submitting questions regarding interpretation of regulations and policies and obtaining answers that then set policy Statewide, consistency in decision-making could easily be maintained. Perhaps regional or even statewide collaborative bodies, as described in our cover letter (similar to CRISS), could submit such questions to the State, and if a timely response were mandated, then county-to-county variation should be resolved.

3. If you think any of the comprehensive health plan or network options should be developed for the CCS program (a specialty plan/network or enrollment into a “regular” managed care plan), which of the following financing arrangements should be used?

☐ A full-risk arrangement (responsible for all expenditures even if above the rate paid per child per month)

NO - this will result in ill-advised attempts at cost-cutting to the detriment of children’s health and perhaps survival.

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☐ A partial risk or shared risk arrangement between the comprehensive health plan (expenditures above the rate per child per month are shared by the health plan/network and the state)

☒ A no-risk arrangement (expenditures above the rate per child per month become the responsibility of the state)

We are confident that a "no-risk" arrangement is the most ideal for this patient population, because the treatment for their conditions can be very expensive and unpredictable, especially as new medical technologies become available. We wish to ensure that we do not create a system that creates fiscal disincentives for providers to offer children access to the best available treatments for their medical conditions. We do not think that enrollment of CSHCNs into a full-risk or capitated arrangement is either medically or fiscally advisable.

☐ Unsure

4. Which of the following statements do you agree with? (You may choose more than one response.)

☒ Changes to the CCS program should be implemented statewide

Improvements to the program should ultimately be implemented statewide, although piloting new approaches in one or several regions initially will likely ultimately result in better decisions about the best policy direction for the program.

☒ Changes to the CCS program should be implemented in different areas the state in different ways, depending on the area (urban versus rural, nature of existing health care structure, etc.)

The considerations of what is needed in case management to get kids into specialty care, get their medications and supplies, get satisfactory primary care and get back to follow-up vary considerably by region. For example, in many rural northern California counties there are either no pediatricians at all or no pediatrician who accepts children with Medi-Cal in the entire county. Often the only available primary care is in a busy community clinic staffed mostly by physician assistants. Consequently, these children may need much more intensive case management and care coordination than children seen in private pediatricians' offices. In rural areas, the distance to specialty care, transportation barriers, lack of DME vendors, lack of physical, occupational or speech therapy services and sometimes lack of pharmacy services require considerable problem solving.

For these and other reasons, a redesigned CCS program may need to build in some regional variations in both structure and function, even while standardizing policies statewide in order to retain the overall goal of ensuring timely access to the best available multidisciplinary care for the child's condition.

One simple example where state leadership could manage regional variations would be to establish standard policy and rates for maintenance and transportation, which would vary in a codified fashion depending on regional variations in gas and lodging prices.

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☐ Changes to the CCS program should be implemented **in different ways** depending on the "program" (funding stream) a child is eligible for: CCS-only, Medi-Cal, Healthy Families.

☒ Changes to the CCS program should be implemented **in the same manner** no matter which "program" a child is eligible for: CCS-only, Medi-Cal, Healthy Families.

We strongly believe that changes to the CCS program should be implemented in the same manner no matter which "program" (i.e., payer source) a child is eligible for: CCS only, Medi-Cal, or Healthy Families. This is very important in order to retain the program's function as a safety net for CSHCNs and to ensure fairness to the children of California and their families. Children change coverage plans frequently and we need to protect them from getting lost in the system every time their coverage changes. Maintaining and improving rather than dismantling the safety net for children with special health care needs is essential. If we don't do this there will be more ER visits, more inpatient stays and likely some deaths. To implement separate programs based on payer source for CSHCN will only fragment the program and create more inconsistencies and confusion with worse and likely more expensive care.

☒ Other, please specify

A local/regional demonstration project which enrolls children with special health care needs into a comprehensive health care arrangement should be funded and implemented.

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5. Review the table below and identify which function you believe should be performed by a comprehensive health plan or network, which by the CCS program and which by a contracted ASO.

a. If you do not think a comprehensive health plan/network should be implemented, but believe an ASO might be an option to help run the program, identify which functions should be performed by the CCS program and which by a contracted ASO.

Function	CCS Program	Comprehensive health plan or network	Contracted ASO
Eligibility Determination	X		
Program Enrollment	X		
Authorization of Services	X		
Member Services, including outreach and education	X		
Provider network development and maintenance including provider certification, provider training and provider recruitment	X		
Case management/care coordination	X		
Medical management including review of appropriate level of care and appropriate place of service	X		
Quality improvement and program oversight	X		
Claims processing	X		
Other			

We are not recommending the adoption of an ASO model, or a comprehensive health plan or network independent of the CCS program, because there is no similar entity that has currently demonstrated competence to handle the necessary functions for this population of children.

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The following questions address specific topics that are not dependent on implementation of a comprehensive health plan or network (but that could become part of the design for this program if implemented).

6. Programs for high need populations often use specialized case management/care coordination techniques to address specific needs. Do you have a preferred design for a specialized case management/care coordination model?

Case management for children with chronic and complex medical conditions should remain in the County Health Departments and be accomplished primarily by pediatric nurses or those with similar background. Most primary care providers (PCPs) do not have the time, space or staff to perform this function. Many PCPs are not pediatricians and they and their staff do not have the specialized knowledge to coordinate these children's care nor the time to problem solve equipment, pharmacy and specialist access problems. Special Care Centers can assist with care coordination but cannot effectively resolve the challenges of local care in the child's community and transportation – challenges which arise both in urban centers and in small rural communities sometimes hundreds of miles away. County Health Departments have been performing this function well for decades and should continue to do so. They have relationships with local providers and vendors and are aware of local resources. They can assist children to get to their initial specialist evaluation and get back to follow-up specialist visits in a way that the centers cannot.

In our answer to Question 1 above, we articulate a model that creates two tiers of CCS-eligible conditions, one for time-limited, single-system conditions in which CCS would provide case management only for that condition, and a second tier for long-term and/or multi-system conditions for which CCS would provide comprehensive case management covering all aspects of the child's care. We believe this model would serve the children well and would ensure the most appropriate utilization of professional case management resources. Experienced CCS case management professionals at the county level would be uniquely suited to assist the state in developing such a model.

States vary in the scope of services provided to children with special health care needs. Prior analyses of the CCS program have identified concern that additional services (including preventive care services) should be included in the program, or additional services provided for transitional age youth. In addition, concerns have been raised regarding high inpatient service use.

7. Are there services not currently included in the California's Title V Children with Special Health Care Needs (CSHCN) program that should be added?

Again, we recommend that CCS expand case management to cover the whole child for a subset of the population served, as articulated in the answers to Question 1 and Question 6. Comprehensive case management/care coordination services by pediatric-trained nurses is essential to quality care, good outcomes and in the end the least possible cost.

To the extent possible, medical homes should be established for all eligible children and standards should be set to certify medical homes as qualified to serve this population of

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children. Even as this is done, we believe these medical homes will continue to require the support of experienced case managers.

Transition services are currently being provided in a number of counties with varying degrees of success. We should build on these essential services and support their availability throughout the state.

As detailed in our cover letter, a more flexible payment structure and more nimble fiscal intermediary are absolutely essential to ensuring the availability and viability of the specialized providers serving these children.

8. Are there services not currently included in the Medi-Cal or Healthy Families programs that should be added for CCS clients and their families?

Travel assistance to out of area specialist appointments to assist with access to care should be funded via Medi-Cal and Healthy Families, not by the counties.

9. Do you believe inpatient service use is excessive?

    a. If so, what do you believe is driving excessive inpatient care?

By and large, inpatient use by CCS patients with chronic conditions treated at tertiary care centers is NOT currently excessive. Children who are critically ill are much more likely to survive and survive longer than they used to with improved treatment, which may appear to lengthen inpatient stay. Excessively early discharge before a child is stable results in re-admission and worse. Earlier and better inpatient discharge planning, particularly as regards complex, expensive DME requiring family training, might shorten a few inpatient stays. Lack of access to complex DME such as ventilators, and staffing shortages for home-based nursing and respiratory therapy services, sometimes results in ventilator dependent patients with respiratory failure staying in the hospital.

Finding creative ways for CCS to support the discharge planning process – such as hospital-based CCS liaison teams recommended by the CCS Executive Committee – might be expected to improve inpatient utilization rates.

    b. If so, what alternatives to inpatient care do you suggest?

Considerable effort and resources should be invested in the development of home health programs that can safely support technology-dependent and other difficult-to-manage children in community based settings. Reimbursement rates for home nursing services, for example, are inadequate to attract sufficient resources for this purpose in many California communities, even when families are otherwise able and willing to care for these children at home. We have had unnecessary deaths in our communities that can be directly linked to the absence of available resources to support these children at home, and some physicians are feeling pressured to discharge their patients into unsafe environments. We can and should do better than this.

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10. Are there CCS program services now being provided that should be eliminated or restricted? Why is this?

Authorizations for treatment of acute, short-term, single-system or non-complex conditions could be provided by the child's usual health plan without specialized case management. Often these do not require intensive case management and take staff time away from more essential functions. (See further detail in answer to Question 1)

However, this might result in denial of care or excessive medical bills for some "CCS-only" (9K) children.

11. Are there CCS eligible medical conditions that should be eliminated?

Conditions which could be eliminated are those medical conditions which are time-limited, not chronic, complex and/or disabling, and do not require multidisciplinary or highly specialized services. This would include, for example, conditions for which a single surgical procedure would be expected to resolve the condition, minor trauma, and acute infectious or inflammatory processes for which serious sequelae are not anticipated.

The Medical Directors of the CCS Executive Committee have already formed a subcommittee to address CCS program efficiencies, and would be happy to develop a list of conditions that should be eliminated, as well as to assist in designing the two-tiered structure for the remaining conditions which we have proposed.

While Title V programs around the nation are implementing "medical homes", the infrastructure to support these models varies, as does the design. Colorado has developed a medical home model for all children in commercial and public health care programs and developed an infrastructure to support the program including enhanced payments through Medicaid. Washington is among the states considered to have an advanced medical home model specifically for children with special health care needs. http://www.medicalhome.org/

12. Should California focus greater efforts on the medical home model for CCS?

Absolutely. Every child needs a medical home, and this need is even greater for CSHCNs. However, it is unreasonable to expect many of the "medical homes" in this state, including community clinics, rural health centers and busy provider offices to provide effective case management for children with chronic complex pediatric illnesses. This is especially true when we already have a system doing this effectively in most places.

13. How should this model be structured? Should it be focused on all children with special health care needs or any child in the state, regardless of payor source?

Any such medical home model should cover all children in the state, regardless of payer source, and should extend to all children with or without special health care needs. The state of California could build on the successes of the Child Health and Disability Prevention Program (CHDP) to create such a model, at least for all low to middle income children without adequate commercial insurance. Considerable additional funding would be required to make this dream a reality.

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14. What supports are needed to accelerate development or improve the medical home model?

For a medical home model (where the medical home really case manages care) to work for CSHCN children, there must be adequate access to pediatricians and pediatricians must receive considerable training and financial incentives to be able to hire pediatric nurses and social workers to coordinate the care of these children. They would need to see that children have access to appropriate pediatric specialists at tertiary centers, actually get to specialist care, and problem solve equipment, supply, appointment and medication issues with vendors and families. Most PCP offices in California are extremely ill-equipped to take on such a challenge. It would make a lot more sense to adequately support and strengthen the existing system.

The CCS program currently has 20+ Special Care Centers, located at tertiary hospitals throughout the state. These centers are focused on the care of certain diseases and consist of multispecialty, multidisciplinary teams of health care professions that direct, guide and coordinate the inpatient and outpatient care of a large number of CCS clients with chronic medical conditions. Examples of these centers include cardiac, hematology/oncology, hemophilia, renal, cystic fibrosis and spina bifida.

Some states have instituted disease management (DM) programs (care management and other management programs) for persons with high cost conditions using contracted vendors. DM or care management programs relevant to children target conditions such as asthma, diabetes, ESRD, hemophilia, HIV/AIDs, and sickle cell disease. For example, California has 2 DM programs and 2 chronic care management programs for adult Medi-Cal beneficiaries. Florida is developing pediatric DM programs for implementation by CMS care coordinators.

15. Do you believe a structured disease management program would be more beneficial to children and families in CCS than the current system of Special Care Centers?

Any such program would necessarily be disease-specific. It would need to be piloted in California and its efficacy carefully analyzed before we could make such a recommendation.

Each Special Care Center specializes in managing not one disease, but an entire category of diseases. The Special Care Centers are one of the unique successes of the CCS program and must not be undervalued. Any experienced pediatrician in the state can vouch for this reality. While structured disease management programs might enhance the success of the Special Care Centers in managing selected diagnoses, we do not believe that such programs could replace the existing Special Care Center system and do a better job managing the very complex children with multi-system chronic illnesses that form the core population that CCS serves.

16. Do you have a preference for how a DM program for CCS children could be delivered? As a contracted program? Through a managed care plan? By CCS? Other?

It may be worth pointing out that the CCS Medical Therapy Program (MTP) is a unique “structured disease management program” currently run quite successfully by the counties. The MTP co-exists with and supports the SCC model.

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Similarly, the pediatric palliative care pilot project, to be implemented by the CCS program in several counties later this year, is an innovative service specifically aimed at meeting the needs of CSHCNs in a manner that supports the existing SCC system.

It would make sense to ask the Special Care Centers (SCCs) to identify other diseases or conditions for which a disease management program might be needed. The SCCs should participate, and perhaps take the leading role, in designing any such program. Since both the SCCs and the CCS case management staff already work collaboratively with each other and with the affected children and their families, it would make the most sense for such a program to be delivered cooperatively by CCS case management and SCC staff.

Bear in mind that the design and implementation of a disease management program should be based upon a needs assessment, and should be successfully piloted with demonstrated efficacy before resources are expended to introduce the program widely throughout the state.

17. What disease entities/states could be included?

Again, viewing the introduction of a disease management program as an effort to enhance the functions of the existing Special Care Center structure, it makes the most sense for the SCCs themselves to identify diseases which could be targeted for improved outcomes via a disease management program. Diseases targeted should probably be relatively chronic conditions for which standard clinical recommendations can be made, and for which improved patient education and perhaps peer support might be expected to improve ultimate outcome. Diabetes mellitus is a good example of such a condition.

We believe that CSHCNs in California would benefit if the existing Special Care Center system were strengthened and expanded. Special Care Centers should continue to cover the kinds of illnesses they do now (complex congenital heart disease, cancer, hemophilias, hemoglobinopathies, chronic lung disease, spinal cord injury, etc). Creatively enhancing the connection and collaboration between the SCCs and the primary care providers for these children would result in better outcomes, improved utilization, and better client satisfaction. Oversight of SCCs, including sharing best practices to ensure adherence to protocols that enhance clinical outcome, is an important role to retain and enhance in both the State and County CCS programs.

We would also like to see an adequate number of Physical Med and Rehab (PM&R) or Neuromuscular centers to care for children with muscular dystrophy, spinal cord injuries, and chronic musculoskeletal disorders. Many of these children have fragmented care since there is very little to offer these children in certain parts of the state. We would also like to see development of Epilepsy/Neurology Special Care Centers for children with severe epilepsy and complicated neurosurgical problems who are not served by a multi-disciplinary team at this time.

States and counties have developed formal family-based support programs or included family members in the CCS program, often in outreach or linkage functions. Florida is using “grandmother health partners” to perform outreach to children who may be eligible for the Title V program (and for Medicaid or CHIP). Rhode Island has implemented the Pediatric Practice Enhancement Project (PPEP), where parent support personnel placed in PCPs offices that serve a large percentage of children with special health care needs. Massachusetts operates

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Family TIES, parent to parent program. Orange County agencies and donors support the Family Support Network for children with special health care needs and the CCS Family Centered Care Program.

18. What family-based initiatives should CCS pursue?

CCS should be a partner in but not the organizer of family support programs. Having said this, families and family support organizations should an integral partner in any effort to redesign or reconfigure the delivery of CCS services.

19. Should CCS operate or spearhead a statewide family support program?

See # 18.

Are there opportunities for cost savings within the CCS program? Some states have found that expensive inpatient services might be reduced through increased access to intensive case management, comprehensive medical homes and possibly through service substitution. Furthermore, states have demonstrated savings by implementing comprehensive, risk-based health plans for children with special health care needs.

20. What opportunities for savings exist in the CCS program or across the health care delivery system for CCS?

If CCS could case manage the whole child, especially those children with long-term and/or multi-system disease (the “second tier” described in our answer to Question 1) this would streamline the system and reduce duplication of efforts.

Improved inpatient discharge planning including timely access to appropriate DME at discharge from inpatient stay (e.g. access to ventilators, correct evaluation and fitting of custom wheelchairs) should contribute to savings. These goals could be advanced by establishing CCS hospital liaison teams at the tertiary hospitals and children’s hospitals, and by establishing a smaller and more nimble fiscal intermediary to improve claims processing to community providers making their participation in the program more attractive (see our cover letter and our answer to Question 7).

Monitoring of Emergency Department visits by CCS-eligible children, where possible, might be expected to improve case management and care coordination and thus reduce expenditures.

CCS also should not be expected to consider authorizing services deemed “not medically necessary”, “out of area”, “out of network”, etc. by any private insurance or managed care plan, until that plan’s appeals process has been exhausted. Currently, CCS considers and authorizes many services which should rightly be covered by these plans (including organ transplants), because the plans’ appeals processes are slow and delay access to essential medical services. The CCS program takes seriously its responsibility to ensure timely access and quality outcomes for children. Private insurance and managed care plans should be required to handle these appeals timely before the CCS program considers assuming responsibility for these services.

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21. Are there opportunities for inpatient savings?

Better inpatient discharge planning and timely access to necessary DME as discussed above.

22. What should occur to encourage more outpatient treatment?

Please see the answers to Questions 9.a. and 9.b.