

Children's Regional Integrated Service System

American Academy of Pediatrics, CA Dist.
California Children's Hospital Association
CARE Parent Network
CCS Programs: Alameda, Butte, Colusa, Contra Costa, El Dorado, Glenn, Humboldt, Marin, Mendocino, Napa, Placer, Sacramento, San Francisco, San Joaquin, San Mateo, Santa Clara, Santa Cruz, Shasta, Solano, Sonoma, Stanislaus, Sutter, Tehama, Yolo and Yuba
Children's Hospital and Research Center at Oakland
Children's Specialty Care Coalition
Colusa County FRC
Community Gatepath Family Resource Network of Alameda County
Family Resource Network of San Joaquin County
Family Voices of California
Lucile Packard Children's Hospital
Matrix Parent Network and Resource Center
Parents Helping Parents
Peaks and Valleys
Rowell Family Empowerment of No CA
Safe Passage FRC
Santa Clara Valley Health and Hospital System
Support for Families of Children with Disabilities
Sutter County Parent Network
Sutter Medical Center
UC Davis Medical Ctr.
UCSF Children's Hospital
WarmLine FRC
Yuba County FRN

November 12, 2009

David Maxwell-Jolly, PhD, Director
California Department of Health Care Services
1501 Capitol Avenue
Sacramento, CA 95814

RE: Section 1115 Medicaid Waiver Concept Paper

Dear Dr. Maxwell-Jolly:

We are writing on behalf of the Children's Regional Integrated Service System (CRISS) to convey our comments regarding the recently released Section 1115 Medicaid Waiver Concept Paper. CRISS is a collaborative of family support organizations, pediatric hospitals and provider groups, and county CCS programs in a 25-county region in Northern California. We previously have submitted comments to you regarding the CCS Stakeholder Guide. As we stated in those comments, for more than a decade CRISS has worked to support effective, efficient, and family-centered systems of care for children with special health care needs, identifying systems barriers as well as potential solutions, often using the CRISS region as a laboratory to test those possible solutions.

We would like to convey our thanks to Luis Rico, who very kindly alerted our Project Director, Laurie Soman, to the impending release of the draft concept paper and assured her that CRISS would be represented on the CCS stakeholder group that will be convened to work on CCS redesign for the waiver. We look forward to working with you and other stakeholders to consider ways to improve the design, quality and outcomes of the CCS program for the children and families it serves.

We have looked at the draft Waiver Concept Paper from the standpoint of what works and doesn't work for children with complex medical conditions and have the following comments and recommendations.

Concept Paper Issues and Waiver Goals

We would like to comment on the paper's discussion of the issues and goals to be addressed and want to stress that we agree completely with the Department's stated goals for the waiver process (p. 4). These are endpoints that all of us can support. With regard to the "Issue" section that opens the paper, we have some concerns.

This section laments the lack of coordinated systems of care for the state's vulnerable populations, including people in the Seniors/Persons with Disabilities Medi-Cal aid codes; dual eligibles (Medicare-Medi-Cal); children and adults with serious mental illness; and children with special health care

needs. We agree that coordinated systems are the desired approach for vulnerable groups of both adults and children, but we are concerned at the paper's failure to distinguish the state of adult-oriented care from the world of children's health care, which in many respects is very different. For example, many families dread their children's transition out of the CCS program because young adults often graduate out of child-focused, case managed, quality-assured, and increasingly family-centered systems into traditional Medi-Cal managed care plans that do not fit their needs. **We believe that it is critical to define appropriate health care and integrated systems for children and youth separately from traditional adult-oriented care.** This issue has come up repeatedly throughout the last decade as California has consolidated its reliance on traditional managed care plans as the route to achieving cost savings in Medi-Cal. One recent example is the 2005 initiative led by the Center for Health Care Strategies and the California HealthCare Foundation to develop managed care plan performance measures for people with disabilities ("Performance Standards for Health Plans Serving People with Disabilities and Chronic Conditions"). There certainly are shared concerns in the adult and pediatric communities regarding care of their special health care needs; however, the differences in the health care delivery systems often are profound, and the final product of that project could not be applied to children and youth without causing significant problems in their access to quality care. In other words, what may be a step forward in access and quality for adults with disabilities or serious medical conditions may in fact create new and daunting obstacles to access and quality for children and youth. In fact, rather than trying to apply adult models to children, it may be that the systems providing optimum care for children and youth with complex medical conditions-- such as the regionalized pediatric delivery model-- would benefit adults with complex medical conditions as well.

Waiver Initiatives to Promote Organized Delivery Systems of Care

Organized Delivery Systems and the CCS Program (page 7)

We would like to reiterate our support for the core elements of the CCS program that we believe have been very successful in ensuring that children with special health care needs (CSHCN) reach the pediatric sub-specialty care they need. At the same time, we acknowledge the confusion that can be caused by the split between CCS and traditional managed care plans for care of eligible children. In our earlier comments on the CCS Stakeholder Guide we recommended that the state consider carving out the whole child, rather than the CCS condition. As we stated, "(g)iven that by definition this population of children has complicated medical conditions, it is vital that the single system in this case be one that is driven by care of special health care needs, rather than by access to primary care, as in traditional managed care." In our experience, it is a mistake to equate enrollment in a traditional managed care plan with the receipt of organized, coordinated, integrated care, as the paper appears to do (page 3). We are unaware of any Medi-Cal managed care plan that has implemented an integrated system of care for children with special health care needs. The CCS program, which is a specialty care managed care plan for children, meets many of the elements of an organized delivery system of care as outlined in the draft paper (page 5) and in ABx4 6, including a mandatory medical home, coordinated (specialty) care, and better connections to specialty providers. In addition, the CCS provider network is statewide, ensuring that children and youth reach the specialty care that is right for them, regardless of their location; California's regionalized pediatric specialty care system, built on the statewide standards of the CCS program, is a major strength of the state and CCS. Traditional Medi-Cal managed care plans, on the other hand, typically are county-based or limited to a small group of counties, often ones without a strong pediatric specialty care network.

At the same time, the CCS program certainly can be improved, particularly in the areas of care coordination, disease management, and better alignment of incentives. CCS could be made more efficient and effective through such approaches as:

- implementation of a whole child carve-out;
- better definition and operationalization of the medical home concept (e.g. specific criteria that must be met by primary and specialty care providers who wish to serve as medical homes to CCS-enrolled children and exploration of a chronic care model for children with special health care needs¹);
- implementation of concrete strategies and fiscal incentives to improve coordination among primary care providers and the often multiple specialists used by these children;
- consideration of expansion of Special Care Centers to additional diagnoses that would benefit from a coordinated, multi-disciplinary team approach;
- more comprehensive program data collection and analysis; and
- expanded quality improvement initiatives, including initiatives addressing family-centered care and family support.

We believe that design and implementation of improvements in the CCS program such as those above should be guided by core principles for health care delivery to CSHCN that are supported by the literature and experience. We cited our core principles in our comments on the CCS stakeholder discussion guide and believe that these principles should be clearly stated in the Medicaid Waiver Concept paper. **Therefore, we recommend that the following specific language be incorporated in the concept paper in the paragraph on page 7 that addresses care for CSHCN:**

“Efforts to design and implement changes in the CCS Program, the state’s current system of care for CSHCN, will meet established principles for the care of children with complex, potentially disabling and/or life-threatening conditions:

- *All health care delivery to children, particularly children with special health care needs, will be based on and flow from their medical and related needs. The medical necessity definition will be based on the federal EPSDT standard: Children shall receive all diagnostic or treatment services to correct or ameliorate defects and physical and mental illness and conditions; services must be covered if they correct, compensate for, or improve a condition, or prevent a condition from worsening, even if the condition cannot be prevented or cured; and services shall include all those listed in federal Medicaid statute, whether or not they are covered under California’s state plan. The determination that a service is medically necessary will lie primarily with the child’s treating physician or other health care provider.*
- *Children will have access to medically and developmentally appropriate care regardless of their geographic region; county-based systems of care that limit access to pediatric or other appropriate providers are not acceptable for CSHCN. Children will retain access to regionalized pediatric health care systems for CCS-approved neonatal, pediatric intensive care, and other pediatric specialty care.*
- *CSHCN will have clearly defined and identified medical homes including primary care providers, pediatric sub-specialists and care coordination appropriate to their medical conditions. Families*

¹ See, for example, Austin, Wagner, Hindmarsh, and Davis. Elements of Effective Chronic Care: A Model for Optimizing Outcomes for the Chronically Ill. *Epilepsy and Behavior*. 2000 Aug; 1(4): S15-S20.

will have the ability to exercise choice in selecting providers, contingent on providers' meeting pediatric credentialing standards.

- *Provider networks will include all pediatric sub-specialties, pediatric hospitals and clinics, child-appropriate DME and other supply vendors, and other pediatric-appropriate services. Providers will meet clearly established state CCS standards for credentialing that reflect pediatric training and experience.*
- *The benefit package for children will be broad and representative of children's needs, including appropriate medical, dental, developmental, behavioral, and rehabilitative services; pharmaceuticals; DME and medical supplies; and ancillary services. Care coordination will be a recognized component of service delivery to CSHCN.*
- *Any managed care plan seeking to enroll CSHCN will be designed specifically for this population, and expansion of managed care enrollment of CSHCN will not take place until specific evidence is available regarding the impact of managed care on these children in terms of quality and access.*
- *Financing of health care delivery to CSHCN will recognize their special needs:*
 - *Children's access to health care will be supported by appropriate reimbursement to providers, including reimbursement of fee-for-service systems at rates that reflect actual costs of care and appropriate levels of care, both outpatient and inpatient. Fee-for-service reimbursement will include the capacity to cover pediatric services beyond typical medical care such as care coordination.*
 - *Capitated systems will incorporate capitation rates that are risk-adjusted to reflect actual costs of care and will include additional services such as care coordination. Capitated systems will not be structured on risk to providers (thus removing financial disincentives to provision of necessary care) and will avoid full risk to plans by employing strategies such as reinsurance or risk-sharing with the state (such as the current CCS carve-out).*

Any proposals for significant redesign of the CCS program will be tested in regional pilots with external evaluation and public reporting of results."

CRISS has an extensive history of considering strategies to strengthen CCS, including strategies to streamline the authorization and claims processes. **We are eager to work with the Department, the Children's Medical Services Branch, and the CCS stakeholder group cited in the draft paper in order to develop and test promising strategies, and we volunteer the CRISS region as a possible laboratory for pilot projects.**

Mandatory Managed Care Enrollment of Children with Disabilities (page 6)

We would like to register our concerns about the proposal in the draft paper on page 6 for mandatory managed care enrollment of the estimated 50,000 children receiving Medi-Cal through disability-linked aid codes. Currently these children can remain fee-for-service (except in those counties with county-organized health systems) but have the option to enroll on a voluntary basis in managed care plans. In our view this approach makes the most sense for these children. As with children in CCS, many of these enrollees require access to specialized pediatric care that may not be available in the networks of traditional Medi-Cal plans or even in the child's county of residence but that can be found in our state's regionalized pediatric specialty care system. The families of

these children and youth need the freedom to construct and access the appropriate pediatric provider network that will work for them, regardless of their county of residence. If the local managed care plan can deliver this network, then families have the option to enroll their children in the plan, as in the current system. **CRISS does not support the proposal for mandatory managed care enrollment of these children, as we believe it may interfere with their access to appropriate pediatric care.** The option to choose an “alternative model” of organized health care delivery may not work for children and youth either, if that system of care is developed on the adult model and not specifically designed for the pediatric population. As noted above, an adult-oriented “one size fits all” approach does not work for children and youth and particularly for CSHCN.

Conclusion

In conclusion, we strongly support the idea of a representative stakeholder group to develop the desired model for the new Medicaid waiver and urge you to ensure that families and consumers are part of the stakeholder process. In addition, we look forward to working with the Department on the stakeholder group specific to improving the system of care for children with special health care needs in the CCS program.

Please feel free to contact our CRISS project director, Laurie Soman, if you have any questions about our comments, and thank you for this opportunity to participate in the waiver development process.

Sincerely,

CRISS Steering Committee

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cc: CRISS Council
Laurie A. Soman, Project Director
Toby Douglas, Deputy Director, Department of Health Care Services
Luis Rico, Interim Chief, Children's Medical Services