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August 13, 2009

David Maxwell-Jolly, PhD, Director, California Department of Health Care Services
Melissa Rowan, Senior Consultant, Health Management Associates

RE: Family Voices of California Written Comments on CCS Stakeholder Process

Dear Dr. Maxwell-Jolly and Ms. Rowan:

Family Voices of California, a collaborative of Family Resource and Empowerment Centers across the state of California, has prepared the attached written comments to inform the CCS stakeholder process. In particular, FVCA is hereby responding in writing to: (1) two documents circulated from the department ("Meeting Medi-Cal's Long-Term Demands" and "Restructuring the Medi-Cal Program for Better Care Coordination and Long-Term Cost Containment"); (2) Presentations delivered on Monday, July 20th by David Maxwell Jolly (Department of Health Care Services), Valerie Lewis (California Healthcare Foundation) and Melissa Rowan (Health Management Associates); and (3) the "July 29th CCS Stakeholder Discussion Guide", "Understanding CCS Through the Data" July 20th PowerPoint Slides.

We are very concerned that the process underway of restructuring/overhauling a system of health care for children with special health care needs in California is not taking into account the impact any changes will have on the children and families who rely on these services for their survival. For these complex systems to work, history has shown that there needs to be a strong consumer input from families, youth and children. We sincerely hope the Department of Health Care Services, Health Management Associates, and California Healthcare Foundation will demonstrate their commitment to meeting the Maternal Child Health core measure, "**Families of CSHCN will partner in decision-making at all levels,**" and will hear and be responsive to its consumers—by seeking and incorporating the input of children and youth with special health care needs and their families into this restructuring process.

Thank you for this opportunity to include our input in the state's CCS stakeholder process. We look forward to working with you on this project to improve health care for children and youth with special health care needs in California.

Sincerely,



Family Voices of California
Signed by Tara C. Robinson, Manager
trobinson@familyvoicesofca.org

Cc: Marian Dalsey, Harvey Fry, Valerie Lewis, Stan Rosenstein, Lisa Maiuro, Ann Zerr, Nikki Moulton, Toby Douglas, Chris Perrone

The Family Perspective: Impacts of CCS Restructuring Process on Families of Children and Youth with Special Health Care Needs

Introduction

For complex service systems to be family-centered and effective, history has shown that there needs to be strong consumer input from families, youth and children. While systems reform has its benefits, dismantling the current system without incorporating the voices of its constituents will result in suffering among children and youth with special health care needs. Medi-Cal and CCS has typically been the payor of last resort; **families may be in danger of becoming both the *first and last* payor. And we cannot afford it.** More than half of all bankruptcies in the United States are the result of medical debt or lost employment due to illness.¹ With layoffs across California, a drastic reduction in services owing to the deficit, families of children with special health care needs are facing dire economic times:

- **35.5% of children with special health care needs in California have inadequate insurance**
- **1 in 6 families of CSHCN in California pay \$1,000 or more out of pocket in medical expenses per year for the child**
- **23.7% of families with CSHCN in California have to cut back on work or stop working all together²**

We urge you to include families of children with special health care needs into this restructuring process—beyond a small group of informants—or you risk failing some of the most vulnerable children in California.

¹ Himmelstein D, Thorne D, Warren E, Woolhandler S (2009). Medical bankruptcy in the United States, 2007: Results of a national study. *American Journal of Medicine*. In Press.

² Child and Adolescent Health Measurement Initiative. 2005/2006 National Survey of Children with Special Health Care needs. Data Resource Center for Child and Adolescent Health Website. Retrieved 05/12/2009 from cshcndata.org.

Responses:

- **Systems serving children with life threatening and complex conditions must strive to avoid prioritizing money over the quality of life of a child.** Children and youth with special health care needs require complex, comprehensive, coordinated, and costly health care. By virtue of their complex medical needs, programs that serve them cannot be expected to cost the same as those serving children without special health care needs. Focusing solely on cost-cutting measures ignores the reality that these systems provide essential services for vulnerable children.
- **Government and society have made a commitment to community-based care over institutional care. Families urge you to keep your commitment to support them in caring for children at home and not in an institution.**
- **When you make changes in a system affecting families, you need input from constituents. In order to have a deep understanding of the needs of families of children with special health care needs, you need to listen to them.** The last survey devoted to this, *Your Voice Counts*, was conducted in 1998³. Following are some highlights:
 - *Of children needing therapies, 35% reported problems, such as: **not getting the therapy they needed, not having coverage, and difficulty getting referrals.***
 - *Many children who need other specialty providers did not have adequate access to them, particularly to quality mental health providers, experienced therapists and skilled home health providers.*
 - *Children with unstable and/or severe health and behavioral needs were not receiving adequate services from health plans, public programs, and community agencies.*
 - *The more managed the plan, the less satisfaction reported by families. Restrictions on coverage and limitation on provider choice appeared to be the leading reasons for dissatisfaction with the child's health plan.*
 - *Children with special health care needs require flexibility in health care plans such as: choice of doctors and specialists, streamlined procedures for accessing specialty care, expanded coverage, and care coordination/case management.*

³ A full copy of this report is available online: <http://www.familyvoicesofca.org/PDFs/Abt%20Full%20Report.pdf>

- ***Children are often left unserved while agencies and programs negotiate among themselves for payment responsibility.*** Families face a fragmented maze of services from health plans, school systems, state agencies and other programs such as regional centers, CCS and DMH. It is often left to families to figure out who will provide and pay for therapies such as physical, occupational, speech, and mental health.
 - ***Ten years ago, almost half of the parents reported spending between \$500 and \$3,000 out of their own pocket for the special health care needs of their child. One-tenth said they spent \$3,000 or more.***
 - ***Many families provide significant amounts of complicated healthcare for their children at home, which impacts a parent's job, family finances and time.***
 - ***For children whose primary health coverage benefits are limited, secondary health care coverage, like CCS, was essential.***
- **Any health care administration needs to establish and ensure high standards of service for children with special health care needs.** CCS as a system has improved the quality of services for children and youth with special health care needs through its standards of care. For example, CCS has set standards of care utilized by other systems and provides some case management services (e.g. to assist children to leave the hospital setting or utilize specialty care).
 - **Any health care administration needs to ensure appropriate funding for its providers.** California is facing serious problems with an inability to recruit and retain pediatric providers owing to the low rate of medical reimbursement. This has seriously impacted children's ability to access appropriate specialty care providers.
 - **CCS provides OT and PT expertise to children within the special education system.** Without feeding and positioning expertise, children's health, well-being and ability to function would be compromised. This must not be lost.

Recommendations

1. **Families of children and youth with special health care needs (CYSHCN) will partner in decision-making at all levels and will be satisfied with the services they receive.**
 - a) An up-to-date assessment must be conducted with constituents around the needs of children with special health care needs and their families.

- b) Families of children with special health care needs must be supported to participate in any conversations about restructuring a system that serves their children. Incorporating constituents will ultimately strengthen the value of the waiver application to the federal government.
 - c) An infrastructure must exist and be supported in order to ensure that families have the information and education they need to participate as key partners in decisions around managing the health care needs of their children.
 - d) Doctors and families need to be able to make health care decisions for a child. Reflected in *Your Voice Counts*, families who have complex medical needs struggled more with managed care plans than with fee-for-service plans. We believe this is due to a focus on managing costs by shifting care-related decisions away from doctors to insurance companies. By allowing this to happen, children's lives are at risk and undue stress placed on families.
- 2. All CYSHCN will receive regular ongoing comprehensive care within a medical home.** California needs to operationalize the medical home concept by establishing a statewide infrastructure. This infrastructure will provide medical home standards, adequate (and expanded) funding for provider coordination, and ongoing medical home training. The infrastructure will also incorporate a tracking system to ensure every child has a medical home.
- 3. All families of CYSHCN will have appropriate and continuous private and/or public insurance to pay for the services they need.** Families need to have insurance that will provide increased access to the appropriate services and supports needed to care for their children at home, limiting gaps in care and financial burden on families. The comprehensive Medi-Cal benefit package could serve as a model for all children needing specialized health care services, whether publicly or privately funded.
- a) Children and youth with special health care needs must not go one day without health care coverage. A 2005 survey indicated that over 76,700 CSHCN in California were uninsured at some point in the year.⁴ About 1/3 of these children had no insurance at all during the year and 2/3 experienced gaps in coverage.
 - b) Policies, coverage and treatment standards will cover costs regarding the special health care needs of a child. Families face tremendous out-of-pocket costs that include items such as: DME maintenance, drug costs, and therapies.
- 4. There will be a system that ensures early and regular screening and intervention for all CYSHCN that includes recognized tools for screening.** Early and intensive intervention has a profound impact on the quality of life for children who are at-risk and their families and the cost savings are dramatic. For example, providing sealants

⁴ National Survey of Children with Special Health Care Needs (2005). Retrieved August 6, 2009 from www.cshcndata.org.

for children's teeth is much more cost effective than treating cavities or resultant health complications.

5. Community-based service systems will be organized in ways that families of CYSHCN can use them easily.

- a) Institute a Task Force on Children with Special Health Care Needs that is made up of: families, youth, advocates and agency representatives (state and local) to create and monitor a system that ensures family-centered, culturally-competent, community-based services.
- b) Institute coordinating bodies that ensure comprehensive service delivery at the local level (e.g. Local Interagency Coordinating Area (LICA)).
- c) Build on current models that improve the system, including:
 - Family Resource Centers, which provide family-oriented and parent-to-parent support services for children with disabilities
 - Parent Health Liaisons, implemented through health care agencies contracting with Family Resource Centers
 - The Children's Regional Integrated Service System (CRISS), a collaborative of family support organizations, pediatric hospitals and provider groups, and county CCS programs in a 25-county region in Northern California.

6. All youth with special health care needs will receive the services necessary to make appropriate transitions into all aspects of adult life, including adult health care, work, and independence. An infrastructure will be developed to ensure that families have access to appropriate and trained adult providers for transitioning youth.

Conclusion

Incorporating best practices will ultimately yield the most efficient use of dollars. There have been many initiatives started in California regarding children with special health care needs with excellent strategies and recommendations.

The State must avoid prioritizing money over the quality of life of a child with special health care needs. Children and youth with special health care needs require complex, comprehensive, coordinated, and costly health care. By virtue of their complex medical needs, programs that serve them cannot be expected to cost the same as those serving children without special health care needs. By focusing solely on cost-cutting measures, you ignore the fact that these systems provide essential services for vulnerable children.

(Continued on next page)

The following organizations have signed on in support of this document:

California Association for the Education of Young Children

Family Resource Centers Network of California

Family Voices National

Friends of Children with Special Needs

Genetic Alliance

Maternal and Child Health Access

National Health Law Program

The ARC of California

The State Council on Developmental Disabilities, Area Board 5

Trisomy 18 Foundation