

**SECTION 1115 COMPREHENSIVE DEMONSTRATION PROJECT WAIVER
CALIFORNIA CHILDREN'S SERVICES (CCS) TECHNICAL WORKGROUP
Meeting #1 – Tuesday, February 9, 2010
10:00am – 2:30pm
Sacramento Convention Center, Room 203**

The meeting convened at 10 AM.

Attendance

Technical Workgroup members attending: Erin Aaberg Givans, Children's Specialty Care Coalition; Bob Achermann, CA Association of Medical Product Suppliers; David Alexander, Lucile Packard Foundation for Children's Health; Yvette Baptiste, Family Resource Center; John Barry, Shasta County; Gregory Buchert, CalOptima; Albert Carlson, SEIU; Ronald Chapman, Solano County; Ricky Choi, Asian Health Services; Mary Davis, Orange County; Juno Duenas, Family Voices; Wesley Ford, Los Angeles County; Marilyn Holle, Disability Rights California; Greg Janos, Sutter Medical Center; Tom Klitzner, UCLA Medical Center; Sherreta Lane, California Children's Hospital Association; Janice Milligan, Health Net of California; Diana Obrinsky, Alameda County; Chris Perrone, California Healthcare Foundation; Tara Robinson, Family Voices; Debbie Ruge, Los Angeles County; Laurie Soman, Children's Regional Integrated Service System.

Others attending: David Maxwell-Jolly, Director, Department of Health Care Services (DHCS); Gregory Franklin, Director of Medi-Cal Operations and Project Director, 1115 Demonstration Waiver Project, DHCS; Luis Rico, DHCS; Marian Dalsey, Medical Consultant, Children's Medical Services Branch, DHCS; Monique Parrish, LifeCourse Strategies; and Catherine Teare, Pacific Health Consulting Group.

Public in Attendance: 20 individuals attended in person, and 62 people called in on the listen-only telephone line.

Welcome and Introductions

Monique Parrish, LifeCourse Strategies provided an overview of the agenda.

David Maxwell-Jolly, Director, Department of Health Care Services (DHCS) and Chair, Stakeholder Advisory Committee introduced the workgroup charter. The workgroup's goal is to advise the Department on what the proposed 1115 Waiver could include that would improve California's care for children with special health care needs (CSHCN). Broadly, the waiver effort is designed to provide better outcomes using health care dollars more efficiently. Currently, care for CSHCN is divided among a variety of different organizations - a division of labor that is inefficient on its face. David Maxwell-Jolly cited general agreement that the State can do more to unify the care of the whole child. He said, however, that the workgroup and waiver are *not* about the following: 1) Changing the system across the whole state by finding a single "right answer" or big idea with respect to the program. The State may need different solutions for different children, different conditions, or different parts of the state; or 2) Spending additional money. As indicated, the charge for this workgroup and for the waiver process as a whole, is to find better use for the money we are already spending, thus freeing up additional funds. Reiterating the workgroup goal, David Maxwell-

Jolly encouraged members to identify some concrete models worth testing to provide more effective and timely care in the CCS system, and, through these models, making a credible case to the federal government that California is interested in long-term reform with regard to the care and treatment of CSHCN.

David Maxwell-Jolly thanked the Lucile Packard Foundation for Children's Health for support of the workgroup, and in particular David Alexander for his involvement and expertise. He recognized DHCS staff for their work on the CCS workgroup process and thanked members of the workgroup for their dedication and expertise.

Monique Parrish, LifeCourse Strategies provided detail on the logistics of the workgroup meetings:

- Five meetings will be held in total: the remaining four on March 16, March 30, April 12, and May 18.
- Meeting summaries will be posted on the waiver website, CCS Technical Workgroup page (<http://www.dhcs.ca.gov/provgovpart/Pages/TechnicalWorkgroupCCS.aspx>) within a week of each meeting.
- Short lunch break at 12:45.
- Members are expected to participate actively.

David Alexander, Lucile Packard Foundation for Children's Health (LPFCH) gave an overview of the Foundation's work. He highlighted LPFCH's new funding initiative dedicated to building better systems of care for CSHCN in California. While CCS is not the central focus of the initiative, because it is a major payor for children's health care it is a major topic of discussion. So far, LPFCH's initiative has developed several resources exploring effective organized systems of care for CSHCNs, including a white paper on best practices in other states, and a paper on the state of the delivery system in California (both available on the LPFCH website at www.lpfch.org). The foundation has also been examining the development of an idealized delivery system of care for CSHCN and has held two convenings to date to address this issue, with the primary goal of identifying incremental changes that are in line with such a system.

The third of these convenings will focus on CCS. All workgroup members are invited to participate (note: the LPFCH meeting has no formal relationship to the waiver process). The meeting is by invitation only but will be publicly available by phone. There may be an opportunity for other invitees to attend – if interested, contact Eileen Walsh (Eileen.Walsh@lpfch.org, 650-736-2881). Travel expenses for workgroup members can be covered. The format will include small groups discussing and developing recommendations regarding an improved organized system of care model. The meeting will be held on March 1st from 10-5, at the Crowne Plaza Hotel at San Francisco Airport.

Erin Aaberg Givans asked for clarification about the overall process of the 1115 waiver, and the extent of the focus on hospital finance versus special populations. David Maxwell-Jolly responded that there have been a number of waiver engagements over the years, focusing first on Los Angeles (LA) hospitals, second on expansion of parent eligibility for the Healthy Families Program (HFP), and most recently (2005) on a follow-on to the LA waiver with broader hospital finance restructuring (as well as other issues in all three cases). When contemplating this renewal, the initial idea the State considered was to take the hospital

waiver and grow it for inflation. Later, the State elected to explore opportunities to provide substantial reforms to Medi-Cal that would realize cost-savings that could justify an even greater federal investment in the California's Medi-Cal program. DHCS staff identified the following areas of potential inefficiencies/opportunities for reform: Seniors and Persons with Disabilities (SPD) in organized systems of care, CCS, and Behavioral Health (BHI). The incentive behind the reforms is to put forward a waiver that makes the case that, through reforms the State can mitigate Medicaid costs and with the savings reinvest in programs such as indigent care. The reforms would also provide additional federal money with which to make other program funding matches.

Wesley Ford, Los Angeles County, thanked David Maxwell-Jolly for addressing fiscal issues. He noted that the CCS workgroup charter does not address fiscal neutrality, and wondered if it needed amendment.

CCS Program Overview

Marian Dalsey, MD, MPH, Medical Consultant, Children's Medical Services Branch presented overview information on the CCS program: history, eligibility, provider standards, state/county responsibilities, funding, caseload, expenditures and the Medical Therapy program. The presentation is available at <http://www.dhcs.ca.gov/provgovpart/Documents/CCS%20Program%20Overview.020910.pdf>, and supporting materials are available on the CCS Workgroup web page.

A few key data points from the presentation:

- Total program expenditures more than doubled in the last decade.
- Administrative expenses approximately doubled in the same period, from \$73M in 2000-01 to \$153M in 2008-09.
- Caseload in that period grew at a much slower rate, from approximately 157,000 in 2001-2001 to 162,000 in 2007. January 2010 caseload was 178,530, of whom 76% were Medi-Cal enrollees, 14% had Healthy Families, and 10% had other or no insurance.
- The CCS Medical Therapy Program (MTP) provides Occupational Therapy (OT) and Physical Therapy (PT) services to approximately 26,000 children and is funded at approximately \$115M annually. Under state law, CCS/MTP is responsible for the delivery of "related services" in an Individualized Education Plan (IEP). Services are provided by county employees at no cost to the family under the terms of the IEP.

Diana Obrinsky, Alameda County, said that the financing information presented lacked context and by itself didn't show whether increases or decreases in spending are appropriate or inappropriate.

Mary Davis, Orange County, noted that counties are now capped for their administrative budgets, and are currently approximately \$49 million over their Maintenance of Effort (MOE) level as a group. She suggested the workgroup group look at state financing and right-sizing the counties in the process. *Laurie Soman, Children's Regional Integrated Service System* pointed out that CCS is a heavily managed health care delivery system with the additional complication that the management is limited to the CCS-eligible condition. She noted that increasingly the CCS program structure puts the counties at risk, particularly with

capped allocation at the local level. Marian Dalsey responded: the realignment statute from 1990-91 changed the requirement of how much funding counties put into CCS and created a MOE requirement based on what counties were spending at the time – a little over \$50 million. Counties currently spend approximately \$100M. There is a question whether the MOE level was properly a cap, or a floor. *John Barry* mentioned that the independent/dependent county status with regard to the CCS program is not always clear, with dependent counties having taken on some of the functions of regional offices, i.e., Shasta doesn't open CCS cases, but does do all the authorizations.

Marilyn Holle asked how Title V MOE requirements for the State are addressed in CCS. Marian Dalsey replied that DHCS has overmatched MOE greatly for many years, and that Medi-Cal expenditures are counted against the MOE.

Erin Aaberg Givans asked for detail on the federal match for county staff. For Medi-Cal it's a 75% match for skilled staff, and for HFP it's a 65% federal match for any staff. Marian Dalsey explained that the reimbursement structure makes it a very complex situation for CCS staff. They have to use time studies and allot hours for the various children being served by the program, and then show, for Medi-Cal beneficiaries, whether their activities really required a skilled medical professional (75% match) or could have been done by someone else (50% match).

Diana Obrinsky clarified that, in the charts of expenditures, blood factor is counted separately from pharmaceuticals. She also asked where diabetes would appear on the list of expenditures; Marian Dalsey explained that diabetes is a relatively low-cost condition within CCS, accounting for approximately \$10 million in total.

In response to a question from *Bob Achermann, CAMPS*, regarding the increase in expenditures for HFP enrollees, Marian Dalsey mentioned a study undertaken to examine this cost increase for the period 2001-2005, but noted it did not come to a conclusion about the reasons (available at <http://www.dhcs.ca.gov/provgovpart/Documents/CCS%20Revised%20Final%20Report%20-%20Final%2010-19-07.pdf>). *Marilyn Holle* suggested that the problem could stem from problems in the HFP application process that fails to identify children who should actually qualify for SSI and thus for Medi-Cal. She stated it might be more cost-effective for children to stay in HFP, and in some cases families might stay in HFP in order to stay out of Medi-Cal managed care and to have greater choice of providers. This could account for the increased costs seen for HFP CCS kids.

Laurie Soman asked whether pent-up demand in HFP could account for increased costs. Marian Dalsey said that the fact that the number in HFP does not continue to grow every year argues against this, but said that the current data is not able to answer the question for sure. CMS data also cannot capture children going on and off HFP.

David Alexander pointed out that pediatric care has changed significantly in the last generation, with many more children living with chronic conditions that might not have survived in earlier times. Today, 1000-gram babies go home and become children with expensive illnesses. He asked DHCS whether, in looking at costs, they were considering overall program costs, or costs per enrollee. David Maxwell-Jolly replied that the *waiver's goal* is to mitigate long-term increases in costs. He further stated that assuming the State is

not going to expand eligibility criteria, the focus is on the rate of growth for those children the State is now covering. (It is possible that costs could increase from the enrollment of eligible children who have not yet been reached, but that is not a concern of this process.) He noted that with respect to efforts with the federal government, the waiver can be framed in terms of the cost per individual, adding that although this won't necessarily help California from an overall budgetary perspective, for the purposes of the workgroup, it's a good starting point.

Greg Buchert, CalOptima agreed that looking at the cost per individual is important, but cautioned against looking only at CCS costs. A child could be on Medi-Cal, with payers including CCS, Medi-Cal Managed Care, Medi-Cal Fee-for-Service (FFS), Medi-Cal managed mental health, LEA, Denti-Cal, Regional Center, County Public Health, and the Child Health and Disability Prevention Program (CHDP), and we should keep an eye on the *total* cost to the state. *Juno Duenas, Family Voices* added out-of-pocket costs to parents to that list.

Tom Klitzner, UCLA said that it may be important in designing systems of care to look at the cost per child, since the medical home is different for high-cost kids than for others. A high-cost child may need an entirely different system of care than a child with the same diagnosis, but with much less acuity.

There was significant discussion of the Medical Therapy Program (MTP), and what DHCS may be thinking about doing with it. *David Maxwell-Jolly* said that MTP is something of an outlier, given that county employees provide services directly and that MT beneficiaries aren't necessarily financially eligible for the larger CCS program. *Diana Obrinsky and John Barry* stated their view that most children receiving CCS MT services *are* financially eligible for CCS; *Marian Dalsey* said that the program does not know the answer. *Juno Duenas* said that the CCS MT program is extremely helpful for parents in negotiating with schools and other providers, and represents one of the few sources of aid that is community-based and not hospital-based. *Tom Klitzner* said that Medical Therapies Units (MTUs) are a rich source of CCS providers, and are important to the larger program in this way as well. *David Maxwell-Jolly* suggested that coming up with ideas for CCS overall, and then seeing how MT fits, may be the most productive approach. The MTP is on the agenda for the third meeting of the workgroup.

Greg Buchert asked how long it currently takes for DHCS to approve a facility as a CCS provider. *Luis Rico* responded that while there's no exact answer to that question, it is taking *too* long – many months at this point, due to loss of staff.

Janice Milligan asked if there was any share of cost in CCS. *Marian Dalsey* responded that enrollment fees and assessment fees for families not in Medi-Cal or HFP bring in some funds, but not much. *Diana Obrinsky* said that fee collection costs as much in staff time as it brings in, and is probably a wash, if not a cost to the program. *Janice Milligan* asked about CCS coordination with Regional Centers. *Marian Dalsey* said that the most active collaborations are with special education and that there is little active engagement with mental health.

Workgroup member summarized the following questions for DHCS:

- How many children receiving CCS services also have IEPs?
- What is the authorization time for children entering CCS?
- How many CCS children are in dependent v. independent counties?
- Clarify the impact of the Governor's 2010-11 budget proposals on CCS

Options for Organizing Delivery of Care: What Are They and How Do They Work?

Alice Lind, RN, MPH, Senior Clinical Officer, Center for Health Care Strategies presented information on evolving state purchasing strategies for people with disabilities and chronic illness in Medicaid, based on a survey of Medicaid officials in 12 states. Her presentation is available at

<http://www.dhcs.ca.gov/provgovpart/Documents/Lind%20Feb%209%20Final.pdf>.

Alice Lind can be reached at alind@chcs.org.

Key points from the presentation:

- Growing momentum to move beyond FFS to more coordinated approaches
- Increasing interest in alternative financing mechanisms
- Emerging efforts to develop/test appropriate performance measurement and monitoring strategies.

Medical Home

The workgroup discussed the *Joint Principles for a Patient-Centered Medical Home* released in 2007 by the American Academy of Family Physicians (AAFP), the American Academy of Pediatrics (AAP), the American College of Physicians (ACP) and the American Osteopathic Association (AOA) and used by CHCS for this presentation. (Available at http://www.acponline.org/advocacy/where_we_stand/medical_home/approve_ip.pdf?hp). Several members noted that this definition loses some key language that came from the CSHCN context, dropping reference to family-centered care and focusing on a *personal physician*. *Tom Klitzner* pointed out that the joint definition also fails to mention cultural competency, which is critical for California's CCS population. *Yvette Baptiste* said that from the parents' perspective, the medical home is the family home, and that should be recognized as the center of the child's care. *Juno Duenas* pointed out that Kaiser Family Foundation definition lacks "family-centered care," and further pointed out that since care for CSHCN doesn't end when a person turns 18 or 21, family-centered care should be discussed in the other workgroup (SPD, BHI) as well.

Mary Davis asked whether medical homes that Medicaid agencies were seeking were stand-alone homes or worked under an umbrella. She mentioned that Orange County CCS answers thousands of calls each month, and that no individual physician could do this. Alice Lind offered that different states have handled this differently.

Wesley Ford, LA County asked how states had adapted the medical home definition to the CCS population. Alice Lind said that most states have broad definitions that allow almost any physician to serve as a medical home, as long as he or she meets the requirements of providing well-child care, assessments, and referrals. Thus, for a child with congestive heart disease, the medical home might be the pediatric cardiologist. *David Alexander* said that

there are not enough pediatric sub-specialists to take on the responsibilities of whole child management/medical home. At the same time, though, primary care pediatricians are not trained to be the medical home for kids with chronic illness and disability.

Alice Lind cited several references regarding medical homes and enhanced medical homes:

- Homer, Charles, et al. A Review of the Evidence for the Medical Home for Children with Special Health Care Needs. *Pediatrics* 2008; 122; e922-e937
- *Evaluating Managed Care Plans for Children with Special Health Needs: A Purchaser's Tool*

Models that Support Medical Home

1. State-Operated Enhanced Primary Care Case Management (EPCCM) – Oklahoma

45 nurses are employed by the state Medicaid agency to support and strengthen the existing primary care provider network through activities including care management, quality improvement, provider training, etc. The program does include CSHCN – there is a high-risk care management program that includes children receiving in-home private duty nursing. Oklahoma used to pay a partial capitation to providers, but now pays FFS with a pay-for-performance (P4P) bonus.

Questions from the workgroup:

- How many CSHCN are enrolled in Medicaid in OK and in the high-risk CM program?
- How is the P4P program set up?
- Are there issues unique to CSHCN in P4P? How is this system currently applied to this high-need and diverse group (in OK or elsewhere), and how could it be applied?
- Is this program related to Oklahoma's visiting nurse program?

An additional reference is a study of the program by Mathematica, available at http://www.chcs.org/publications3960/publications_show.htm?doc_id=835881.

2. Single Private Vendor ASO (Admin Services Organization) – Illinois

Illinois hired a single contractor to provide a wide range of services: provider services, beneficiary enrollment, education, billing, etc. Under IL's contract, the ASO provides support for beneficiaries and providers including care management for children with asthma and with high ED use, but not including CSHCN. In some areas, there is a subcontract for care coordination for high risk populations (*David Alexander* said that there is definitely a model of enhanced medical home for CSHCN in IL; see the report on models of care in other states at <http://lpfch.org/nationalmodels/>).

A potential benefit of an ASO for the state is that it is quick to implement and can be contracted at risk. A potential liability is that services are not specifically designed for the local environment. Another difficulty with this model is that the contract requires extensive management.

Questions from the workgroup:

- Why did they exclude CSHCN?
- Are adults with special needs included, and how do they do?
- Is Cook County treated differently than other areas of the state?

An additional resource is the white paper on CSHCN produced by LPFCH, and available at <http://lpfch.org/nationalmodels/>.

3. Local Public/Private Partnership Accountable Care Organization (ACO) – North Carolina

North Carolina's *Community Care* program is a hybrid consisting of a local healthcare organization and a related set of providers that can be held accountable for cost and care. The model has gained momentum over the last few years, and has drawn the interest of the federal government and policy researchers. North Carolina took federal PCCM money, split it, gave half to providers (on average \$3 -5 per member per month (PMPM)), and gave the other half to multi-county local entities (about 15 in the state) who were charged with bringing providers together, managing Quality Improvement (QI) efforts, sharing Case Management (CM) and Health Information Technology (HIT) resources, etc. The model now incorporates SPD, and the state is considering adding dual-eligibles. Community Care has achieved dramatic cost savings and efficiencies, but not in the first few years. One of their key successes is how long they were able to hold off questions of cost savings. Community Care includes CSHCN as a voluntary population.

Questions from workgroup:

- What is the take-up rate among CSHCN?
- How are PCCM fees stratified? Do providers get more for CSHCN?
- What are the requirements for providers who take on CSHCN?
- Who is in the provider network (in this model or in any of the others)? For example, Oklahoma only has *one* children's hospital, so it's already pretty well integrated of necessity.
- How much does California currently spend per CCS child per month on coordination activities? What do those entail, and what is paid at the provider level? (Marian Dalsey said this would be hard to answer – Medi-Cal doesn't pay county staff for care coordination, and in Special Care Centers billing for coordination doesn't actually account for all the time that care center staff actually spend on these activities.)

4. Specialty MCO – DC Health Services for Children with Special Needs

Washington DC's Specialty Managed Care Organization is a care management network coordinating health, social, and education services for the pediatric SSI-eligible population. Includes traditional Medicaid benefits plus individualized care management; 24-hour access to care coordination; outreach services; respite care; medically necessary home modifications; and mental, behavioral, and developmental wraparound services. It is a not-for-profit that started as a demonstration project under an 1115 waiver in 1995.

5. Alternative Models:

- Pennsylvania EPCCM:
 - State staff provides care management/coordination for complex special needs children enrolled in PCCM program.
- Seattle Children's Hospital
 - Complex care management for children at high risk of hospitalization
 - CCM program provides additional resources to the PCP (medical home): shared care plan; case management; transition planning; expert consultation; CCM Clinic

Following a brief lunch break, the Workgroup reconvened and participated in a discussion of the following question: What are the essential elements of the CCS program that need to be maintained in a new model of care delivery?

A threshold question was whether the discussion should focus only on the CCS Medi-Cal population, or the entire program. *Greg Buchert, CalOptima*, said that since the goal is a Medi-Cal waiver, Medi-Cal needs to take precedence, but noted that the workgroup members would not want to leave other children out and lose the ability to leverage services for these children based on the size of the overall population. He further noted it may not be cost-effective to fragment by payer type. *Laurie Soman* agreed, saying that in any case children don't stay in one insurance program their whole lives, so any fix has to work for all of those who fit the medical criteria. One good thing about CCS is that once a child is eligible, they generally can stay in the program until they age out.

Workgroup members identified a number of key strengths of the program. These are listed here, with discussion following:

- Provider network
 - Statewide network, organized regionally
 - Quality standards: institutional and provider level, which drive quality improvement statewide
 - University affiliations of providers
 - Care team approach
 - Special Care Centers
- Medical outcomes
- Administration
 - Local/regional structure and accountability
 - CCS staff's knowledge of CSHCN issues
 - Case management expertise
- Medical Therapy program, especially community-based structure
- Parental involvement
- Program designed specifically for CSHCN
- Human capital created through the years

Laurie Soman echoed the benefits of the provider network, which she noted is really a statewide network, organized regionally. This means that patients are not constrained by their county or region of residence, and are steered to wherever in the state they can get

the care they need. *Marilyn Holle* said that university affiliations ensure that CCS services are good, versus just good enough.

Several members addressed the benefits of CCS's provider standards. *Diana Obrinsky* pointed out that CCS has standards that apply to hospitals and other institutions, and additional standards that apply to individual providers. *David Alexander* said that the CCS standards are probably the best thing that the state has going to drive quality of care for *all* kids, not just those in CCS. (Provider standards will be made available on the DHCS Waiver Renewal website in the CCS Technical Workgroup section.)

Greg Buchert said that regional accountability is strength of the program. The ability to call someone locally, to know the CCS providers and administrators, is much easier and more effective than trying to work with a stranger in Sacramento.

Wesley Ford cited CCS's strong case management expertise. *John Barry* said that in rural counties, that local/regional case management is essential in finding resources that are not close by.

Albert Carlson SEIU: Need good public oversight and accountability in whatever system is designed – transparent quality standards, advocacy mechanisms.

Juno Duenas spoke to the need to keep the MT program, and preserve the community-based aspect of program. *Yvette Baptiste* echoed this, and said that having choice and flexibility is also essential. CCS works one-to-one and provides individualized care – she reported that families fear that managed care would lose the focus on the individual needs of the child, and CCS avoids that. *Tara Robinson* said that in a recent focus group of CCS families, all were scared that the program might go away and leave them with Medi-Cal alone. What is valuable to families is their ability to access the assistance of CCS administrators, who actually understand their children's medical conditions.

Laurie Soman said that one of the most attractive things about CCS, despite flaws, is that it was designed for CSHCN – not for kids in the middle of the curve. It has both a pediatric focus, and a focus on children and youth with special needs.

Greg Janos added that over the years, CCS has created a huge amount of human capital in its networks that should not be wasted. *Tom Klitzner* pointed to the program's excellent medical outcomes.

Janice Milligan said that managed care and CCS have not only learned to coexist, but also collaborate and promote outcomes and access. Since CCS is a carve-out in 2-plan models counties, plans have had to learn what CCS is, how it works, and how to get children into the program. In some cases, Medi-Cal managed care has worked to promote the quality standards of CCS. In LA, for example, when Medi-Cal Managed Care (MCMC) started there were 21 NICUs that *weren't* CCS-paneled – plans have put resources into those facilities in order to get them to meet CCS standards. For HealthNet, CCS identifies provider shortages that are bigger than any one plan. HealthNet would not have been a player at the table, was it not that the state required Managed Care Organizations (MCOs) to have agreements with CCS.

Workgroup members also identified shortcomings in the program. A number of these related to funding shortfalls that have led CCS either to cut back on staffing and services, or prevented the program from keeping up with current practice and new developments in chronic disease treatment. *Erin Aaberg Givans* said that the state program needs strengthening in order to oversee maintenance and the improvements that are needed to keep the program current with new technologies. *Marilyn Holle* said she was unhappy that there have been no additions of other Special Care Centers and clinics, for instance for the dystrophies and genetic diseases. CCS needs additional support from the DHCS in order to keep up with current needs and to fund more specialized clinics.

Juno Duenas said that the loss of funding for the Parent Health Liaison Network that operates in some counties has been a significant problem. *Laurie Soman* cited previously strong initiatives around family-centered care, such as transition programs for adolescents that have slowed or stopped as a result of budget cuts.

Diana Obrinsky pointed out that Medi-Cal standards for equipment and supply needs are adult-based, which makes it hard to find certain equipment for children, such as ventilators for home use.

Workgroup members returned to the question of defining the workgroup's task. *Luis Rico* and *Greg Franklin* agreed that they wanted to discuss both what is succeeding in the program and where there are problems and things that need to be fixed. *Tom Klitzner* referred to the Health Management Associates (HMA) report (available at <http://www.dhcs.ca.gov/provgovpart/Documents/CCS%20FINAL%20DRAFT%20REPORT%2009%2016%202009%20final.pdf>), saying that the report identifies many of the same issues raised in the workgroup. The primary problem for the state is the rapid growth of program costs. For CCS providers, another problem is cost shifting – some centers employ staff just to chase down which payer is responsible for which days of care. *Greg Buchert* agreed, saying that there should be savings to be had through simplification – multiple case managers (health plan, CCS, Regional Center, schools) cost additional money. Pharmacies have to split every bill. There is surprisingly little communication among the various payers – CalOptima can't see prescriptions that CCS providers have put a kid on, for example. The various programs do try to cost-shift to each other.

Tom Klitzner said that his specialty clinic was able to reduce Emergency Department (ED) visits by almost 1 per child per year *and* increase specialist outpatient visits at the same time, by using a medical home model at the primary care clinic with linguistically-appropriate counseling. Length of stay was also reduced. *Ron Chapman* said that CCS overall is effective, but not efficient, and that he hopes for more efficiencies in order to be able to maintain local support for the program. Currently, the fact that counties are paying double their MOE level puts the program at some political risk, as county supervisors may have to choose between law enforcement and CCS. Any efficiency would therefore be welcome at the county level.

Juno Duenas asked exactly what services the state couldn't afford, pointing out that there are more children surviving who need ongoing care, and the costs are going up – care should not be rationed. *Diana Obrinsky* said that this point should be explicit in the conversation: the number of kids and the cost of care are both up, driving the overall cost of CCS up, and while the cost of administration is a problem, it's a miniscule percentage of the

total. It is just barely possible that there won't be a lot we can do, because improvements in cost of care sometimes cost more. *Wesley Ford* agreed, and *Laurie Soman* said that the program is already heavily managed, and that the 7% going to administration is already too little.

In response to a comment about single-payer, David Maxwell-Jolly suggested that the single payer legislation on the table in CA only addresses the population with higher incomes, and is silent on the creating greater efficiencies in programs that serve low income persons level. He said, though, that in the case of CCS, California should perhaps be more "single-payerish:" while there may not be enormous savings from simplification, improvements to CCS (and other programs) would put California in a better position to ask Washington for more and better Medi-Cal funding.

Erin Aaberg Givans said that more data is needed on costs:

- How do CCS costs compare to those in other states?
- What is the per patient per year cost in CA and elsewhere?
- What is the administrative cost in CA and elsewhere?

Marian Dalsey said that CMS is working with Paul Wise at Stanford to extract and analyze data, including Medi-Cal FFS and MCMC data to get an all-around picture of what's been spent on CCS kids. This will be forthcoming.

Debbie Ruge agreed that more information is needed, and that we can't assume that there are savings to be had everywhere. In Los Angeles, the CCS medical director looked at inpatient days for leukemia in an effort to reduce them and found that LA was already 4 days under the national average.

Chris Perrone pointed out that CSHCN does not appear to have the benefit of the metrics that are available in care for adults with disabilities or seniors, and wondered if the baseline data is sufficient. *David Alexander* confirmed that this area lacks quality metrics, though CHIPRA has made – for the first time – a federal investment in metrics for kids. Results may be useful for the next round of the waiver. *Tom Klitzner* pointed out that the problem is partially a lack of attention to metrics, but largely a function of the low incidence of any given condition in children: in pediatric cardiology, there is heart disease in .5 – 1% of births, only 10% of those end up in CCS, and there could be 50 illnesses that cause the condition. He also pointed to the fact that a large proportion (about 40%) of the total cost of CCS was for NICU stays, and NICU is completely outside the CCS system of care discussed today. A growing proportion of NICU costs are due to "late-term prematurity" resulting from elective or semi-elective C-sections before 39 weeks and consequent lung disease.

David Alexander said that everyone needs to advocate for valuing children's health care more highly. A pediatrician gets paid far less than what Medicare pays. We can work to change that, and we should. However, given current priorities, how do we make *this* system work, while we work at same time to raise priority of children's health? The idealized model envisioned by LPFCH is not single-payer, but is single-system – a portion of the premium from anyone in the health plan goes to an organization that manages care for these kids.

Laurie Soman identified several possible areas to look for efficiencies in treatment: 1) A whole child carve-out, so two entities aren't arguing over which body part they're responsible for; 2) Tom's Klitzner's medical home model; and, 3) The DC model mentioned by Alice Lind, which allows flexibility to use funds differently, and is not as tied to procedure code/audits model. David Maxwell-Jolly reiterated that DHCS is not looking for global changes, but rather discrete models that are realistic and have promise. One model may not work, one may be reduce length of stay and be family-centric and culturally sensitive.

Next Meeting and Feedback on Today's Meeting

Workgroup members were reminded of the March 1 LPFCH convening at the Crowne Plaza Hotel, San Francisco Airport.

The next CCS Technical Workgroup meeting #2 will be held on March 16, 2010 from 10:00am – 2:30pm.

Monique Parrish asked that feedback on agendas for upcoming meetings be sent to mparrish@lifecourse-strategies.com, and said she would be contacting workgroup members to set up brief phone interviews over the next few weeks.

The meeting was adjourned at 2:30 PM.