

CCS Title V Needs Assessment – Key Informant Interviews

Data Summary

Program Strengths

1. Reports on the CCS program prepared by Health Management Associates and from the California Health Care Foundation, as well as comments from CCS Needs Assessment Stakeholder group, indicate that there are many positive attributes of the CCS program. We have grouped into 3 areas, including:

ACCESS

- the regionalization of the programs increases access to quality specialty care
- providing CCS children with access to the same centers of excellence that privately insured children have
- good coverage for medical equipment when compare to other states
- access to newborn genetic or hearing screening and automatic referrals
- providing children with comprehensive services for their CCS conditions
- Maintaining access to services by keeping reimbursement outside of managed care

LOCAL PROGRAMS/PROVIDERS

- local nurse case managers
- partnerships with county programs and providers; openness to parent inputs
- partnerships between schools, regional centers and CCS Programs with the Medical Therapy Program
- setting standards of care for providers and hospitals

FAMILIES/CONTINUITY

- Support for family advisory groups in CCS Programs

Do you generally agree that these are program strengths?

Large majority agreed

Are there any other particular strengths of the program that we should know about?

- specialty care centers team approach
- MTP multidisciplinary team, whole child approach
- CCS provides equipment and resources, less restricted than Medi-Cal
- MTU program, staff
- set standards, supports provider networks
- importance of regionalization and local governance/oversight
- Openness to parent input because of CRISS and in LA
- best care, team approach -- if you can access it
- special care centers, program standards, advocacy
- regionalization increases access for larger but not rural communities
- multidisciplinary approach
- care is better for CCS because of specialty care centers
- local case management ensures recognition of local issues and resources
- CCS standards have improved care for all children
- standards ensure all children have access to same services and most managed care could not do that
- best and most comprehensive MTP
- able to implement innovative service strategies, need money
- not modeled on adult care
- creative problem solving; get loads what they need

Program challenges/other issues/suggestions mentioned:

- family advisory groups vary, especially in rural areas
- long authorization process for equipment
- lack of service coordination because of county staff cuts
- suggests a separate managed care system for CCS and all CSHCN
- not enough local nurse case managers
- few counties have time for parent input
- bad relations with MTP in larger counties
- state staff cuts limit standard setting
- fewer staff for family advisory groups
- lack of standards for nurse case managers,
- issues with costs of follow up and treatment newborn screening and referral
- fewer local nurse case managers
- child focused sub-specialists need to be concentrated in tertiary hospitals and outpatient centers
- reimbursement should be in managed care; for medical home, need care in one place; good relation with local HMO
- access to services and quality will drop if under managed care
- partnerships an issue in LA with so many providers; State needs family centered care position
- can strengthen family advisory groups
- What are the benefits and drawbacks of a regional system of oversight versus state oversight?

2. **Many of our stakeholders have stated that CCS's role as a certifier and in setting standards is one of the strengths of the CCS program. Do you agree with assessment?**

Most agree that it is a strength and many suggested ways to improve

(If "Yes") How can the CCS program maintain its role setting standards?

- Need more certified providers and centers to meet standards
- Closer monitoring of special care centers; need someone at the State who understands standard setting; involve county medical directors and consultants
- Not enough state staff, which results in delays - suggests provisional certification
- Less oversight of standards at lower level; burden put on regional centers to provide oversight but not realistic because no resources and already tension between higher and lower levels of care

(If "No") How could the CCS program improve its role setting standards?

- Not enough State staff for facility oversight and checking standards, not enough staff for site visits; need more regional or state staff
- With less staff loss of institutional memory
- Improve relationship between CHDP and CCS
- More quality control standards
- Maintain up to date standards
- Need technical advisory committee
- Lack of leadership at State – need strong State staff
- Need more systematic review process at State
- clarify treatment, for best care across the state; issue of waiting for new standards to be written and not upholding quality

3. **How do the CCS standards function and what do they accomplish?**

- ensure qualified programs and providers; ensure quality of care; need to consider quality over cost effectiveness
- ensure quality care and providers = better outcomes
- specialists should drive care

- assure quality; also consistency across program; issue if not enough providers or facilities (Central Valley)
- do not function well; need to be revised and consistently implemented
- high quality care
- can change infrastructure to improve quality of care
- save lives
- assures appropriate care in appropriate setting at appropriate time; problem if services are not available; if not approved, CCS won't pay

Access to Care

4. **CCS has been having increasingly more trouble recruiting medical specialists to care for California's growing CCS population. From your perspective, what are the major barriers to medical providers participating in CCS program?**

- Low Medi-Cal rates; no increase for DME or PT/OT
- Provider enrollment; less state staff - bureaucratic problem not a provider problem
- Medi-Cal children require more time and effort
- Claims not paid in timely manner; local billing staff have high turnover
- Provider perception of CCS, do not want to be CCS paneled; can only afford a certain number of CCS kids
- Delays, inconsistent authorizations, low reimbursement
- application errors
- If you move, have to apply again
- Paper work and low rates
- Provider database not accurate or updated
- Kaiser good at enrolling docs
- EDS difficult to deal with
- Competition between programs for providers in CA hurts but at least keeps providers in state
- Small providers have limited capacity; local programs used to process claims
- Increase Medi-Cal patients, income goes down; not enough incentives for pediatric specialists
- Delays getting paid, biggest impact for smaller practices
- Lack of state staff results in enrollment delays
- hard to recruit specialists;
- CCS has authority to change treatment authorization process but staff have not; need to revamp process
- state staff resistant to change
- pediatricians over-refer for primary care issues
- system problems; managed care encourages volume
- rates are too low; cost of living is high; cost of business is high
- DME rates too low - system does not recognize extra complexity, time, and money
- provider fear of balance billing
- high demand, low supply and low rates, results in losing specialists

(follow-ups: Is having to get a Medi-Cal Number a big problem?

(if "Yes") Why is this a problem?

- Misperception about taking Medi-Cal patients, especially for subspecialists
- Medi-Cal number is not retrospective; doctor misperception about taking Medi-Cal patients
- Medi-Cal dispute charges; a problem because fee for service without appropriate implementation system; managed care not better for CCS

- There was wide agreement that there are delays in enrolling providers in CCS and lack of state staff is seen as a big part of the problem
- some fraud issues for new DME providers; more scrutiny, delay for new providers
- do systems analysis to find delay issues
- fast track applications for new providers
- increase priority for applications from pediatric subspecialists
- increase staff at DHCS

5. What could be done to help overcome ... (specify each of the barriers interviewee identified)?

Low Rates:

- increase state staff for enrollment
- increase rate, adjust for inflation
- raise the rate; rate based on cost of equipment and servicing it
- get tax payers to see increasing salaries as a priority
- match reimbursement to complexity

Delays in Payments and authorization:

- pay claims faster; training for billing employees
- do equipment with discharge planning
- CCS do more letters; Counties follow letters better; get code recognized right away
- consistency, awareness, and information
- better rates; allow PCP to continue treatment (for DME and scripts)
- more staff
- revamp EDS
- ongoing training for providers on billing; local liaisons for billing

Providers not wanting to participate with CCS or get Medi-Cal number

- educate providers about CCS
- show the benefits of working for CCS
- could create an exception or waiver for getting Medi-Cal number
- improve certification and Medi-Cal number efficiency; more state staff; incentives for primary care, put them on case management team;
- support local training and recruitment

6. Administrative inefficiencies often act as barriers to recruiting and maintaining providers in the CCS Network. Are there challenges in getting authorizations or payment for specialty services through the CCS program?

(If “Yes”) What kinds of challenges? What could be done to improve this situation?

Challenges: Many respondents felt that dealing with EDS was a big challenge and suggested making changes at EDS

- trouble getting authorization, varies by county depending on staffing, independent vs. dependent counties
- some providers do not have a number to access the authorization system
- consistency a problem for authorization between counties; if authorized in one county, should be in the next if child moves; long-term needs should have long term authorization
- CMSNet versus non-CMSNet counties – hard for providers to know all the procedures in different counties;

- fractionation of care between the plans and CCS;
- lack of knowledge about who to bill; more direction from state and regional offices;
- not enough CCS staff, delays in payment and authorization
- challenge for payments - authorization should be a promise to pay not an authorization to bill; CCS not a priority to EDS
- some counties have difficulty getting authorization; some delays because no one provider to authorize because of eroding provider network;
- result is no provider and no services; inefficient and unresponsive reimbursement system; can make direct links to poor patient outcomes
- less county staff, hospitals waiting longer for authorization; issue with getting priori authorization and hospitals seeing inconsistencies across counties; Dependent counties run out of money

(If “Yes”) What are the effects of inefficiencies on families?

- results in delayed care and frustration
- families cannot get low cost interventions, have to go to ER, or get more expensive treatment
- families have poor access, have to travel, long appointment waits

How to Improve:

- change state and county roles, state centrally manage authorization and payment
- can have case managers and financial people work together
- have a centralized managed care system for CCS to coordinate care and payments
- can streamline through redesign; families get confused and overwhelmed
- get kids out of plans and into fee for service medi-cal;
- coordinate care instead of payment;
- put whole child in; less inefficiencies at centers
- Data from state could identify where counties are struggling with authorizations
- have a carve in and give plans more money; sort out claims at end of year
- need coordinated CCS teams that communicate; electronic records; private insurance should cover some; need staff for recruitment; consistency of standards;
- need state policy setting and leadership

7. In many areas of California, CCS families rely on local primary care physicians (pediatricians and family practitioners) for routine medical care when their specialty care is provided in children’s hospitals or other special regional hospitals far from their homes. We’ve heard that some families and many specialists hold the view these primary care providers aren’t qualified to care for children with special health care needs. It has also been noted that training programs for primary care physicians don’t include skills needs for caring for this population. What are your thoughts on this subject? And do you think that training these primary care providers should be a focus of State CCS in the future?

Many respondents felt that PCPs don’t currently have the knowledge or training to care for CSHCN, but many felt that with training, there is a role for the PCP – especially for PCPs in rural communities. Some thought PCPs could do case management and provide a medical home, while others thought that is better done by subspecialists

- PCPs don't have the knowledge; state and counties work with medical schools; have MTU conferences, conferences for pediatricians and orthopedist and pay them to attend; increase internship opportunities
- State cannot make PCPs comply, what is the incentive for PCPs?
- PCPs don't have the skills, are not interested; CCS should do training, especially for rural pediatricians

- some pediatricians should have extra training and a desire to treat, and be part of team care
- PCP needs help on knowing how to coordinate care; CCS could set standards, maybe work with CHDP who has been successful
- pediatrician need to be encouraged to practice at the top of their license
- PCP not best for leading case management
- PCP should work with CCS center care
- PCPs should be part of case management and get reimbursed
- CCS should work with training programs
- PCP should be part of care team, can provide a medical home, need financial incentives
- connect PCP and subspecialist
- check with Paul Wise; PCP should identify kids and get them to subspecialists
- Internists are more qualified and with training could provide

8. **We've heard that most trained providers who care for adults don't have the training to care for those that have aged out of the CCS program. Do you agree with this assessment?**

The vast majority of respondents agreed with this assessment, and sighted the following reasons for this problem:

- staff cuts, fewer nurses have larger caseloads, no time
- no model for adult care like the child care model
- limited number of providers
- good in regional centers; others have to look for Medi-Cal providers but there are not enough
- more kids surviving; many transitioned kids do not get any care or go to ER
- limited incentives
- families have no access to social worker
- lack of adult providers and community resources
- many types of transitions; budget cuts eliminated transition planning activities, county staff don't have time
- more kids surviving; part not having expertise, part not knowing how to bill
- a cultural problem; difficult for non-CSHCN; family and provider reluctance to transition; in pediatrics, system is responsible, in adult care, patient is responsible;
- loss of insurance an issue
- adult doctors do not have case managers or social works to assist
- if chronic complex medical conditions; most adult providers are not experienced
- many adult practices do not take Medi-Cal
- doctors feel obligated to keep seeing patients, resulting in a loss to providers and hospitals

What could be done to increase the number of providers for transitioning kids?

- go through professional organizations to offer training to adult providers on how to care kids that age out
- need reimbursement; not built into program
- address with residency trainings, train adult oriented specialists
- increase age for using pediatrician;
- increase reimbursement rates to attract adult subspecialists
- address with financial incentive to providers; change CCS to 19 and under
- create collaborative coalitions between pediatric and adult providers
- importance of local medical providers; transition needs to have a more systematized system, for example paneled adult providers
- issue is lack of organized network of providers and staff to assist; what is working with kids should be tried on adults

- providers need to be interested in the population

(Probe: Is this because of not knowing how to bill or complete claims?)

- also a billing issue; providers don't know how to complete claims

9. Are there problems accessing services or gaps in coverage as a result of a client moving from one payer to another?

(If "Yes") What could be done to address these gaps?

- more bureaucratic work, but not result of not getting care
- issue of gap with Healthy Families and not being retroactive; need single payer system or universal coverage
- issue with disconnect in the system, EDS does not have the numbers or code; need communication with EDS when something becomes a benefit
- hard for providers to coordinate and figure out benefits and who is responsible
- For DME, hard to know who gets billed first; less money and taking more time, building DME takes time
- Issue of pre-existing condition and youth aging out of parent's insurance
- Need portability; no exclusions for pre-existing
- Nightmare to have multiple payers; easier to be just CCS and a bad incentive
- For transitioning kids - issue of communication and lack of providers
- Need education for families on responsibilities and paperwork
- Often not clear who will pay; need central payment for all bills regardless of payer
- Change should be seamless; use common application
- CCS needs to communicate with families and provide paperwork support
- design of CCS tries to prevent this; issue is also in HMO, HMO must deny a benefit for CCS to cover
- State CCS could work with MRMIB
- some counties have good Medi-Cal standards for provider reports on effect of medical therapy; HMO says it is medically unnecessary
- CCS only covers the condition; county variation in authorization
- CCS should be about child not condition - whole child should be covered state covered

Access to Durable Medical Equipment (DME)

10. A survey done in 14 counties in 2007 found that CCS clients have trouble accessing durable medical equipment. Are you still hearing about CCS clients having this problem?

- Small ticket items can be hard to get because vendors can't make \$\$
- claims hard to process - EDS issue
- Reimbursement rates too low
- Problems with hospital discharge planning and time to get authorizations - especially on Friday afternoons.
- Authorization process too complex - takes too long
- Legislature can't expand the benefit package and then not provide funding. "Legislature piles on more and more things but more funding is not given to make it a reality"
- When DME providers leave, hard to find new providers for patients.
- Few companies that do disposable medical supplies because reimbursements so low
- Margin low and maintenance not covered. Won't fix equipment unless it is destroyed - reverse incentive. Lots of cost shifting
- DME providers need to have special staff (i.e. respiratory technicians and other to fit equipment) - very expensive.

- Harder to make financially feasible when DME providers have to go to patient's home – not paid for travel
- Seen Apria take a wheel chair away because won't work with CCS because of payments and claims taking too long or not going through.
- Some counties hard to contact about authorizations - no voice mail. Some counties take months to authorize because so backlogged.
- Kids on vents real problem with accessing home health.
- Limited vendors in some regions
- State cut list of equipment so less is covered.
- When kids leave hospital, they don't have access to appropriate CCS staff so there are delays.
- Pediatric DME is very complex and very different from adult; Medi-Cal does not take this into account
- Huge problem - especially respirators, wheel chairs
- Vendors don't deal with CCS and Medi-Cal because of rate and patients end up back in the hospital

Potential solutions?

- programs have capacity locally to cut a check and get reimbursement after the fact; different system than EDS
- More consistent and efficient authorization process
- better reimbursement and recognition of provider costs for certain types of equipment
- Medi-Cal DME codes need to be looked at, adjustments need to be made for costly equipment, so vendors can meet their costs; develop specialized codes for pediatric DME
- Need centralized authorization and payment for DME for all CHSHN regardless of insurance
- Authorizations could be expedited.
- Suggestion of loaner program until proper equipment identified. Early discharge planning for respirator equipment.
- maybe home visiting requirement could be not so stringent
- Some of the DME providers that are serving children with a managed care program because capitated - can learn from managed care?
- Speed up authorizations and payments to DME providers - maybe do at hospital level rather than have CCS make authorization

Case management/Care Coordination:

Both counties and some tertiary medical center providers have told us that they provide case management for CCS clients.

11. From your perspective, who is providing medical case management for CCS clients?

- Decreasing staff at county level will negatively impact case management - reduction in social workers
- Both counties and children's hospitals are viewed as doing case management - although perceptions of what they do vary
- Variability in the level of case management provided by counties
- Suggestion to change state regs. to allow unlicensed folks to provide some case management - would need to change legislation to let this happen. Others opposed to having unlicensed people and want better support for PHN, RN and SW
- County case management primarily involves approving authorizations
- Medical case management primarily happening at tertiary centers for kids who get cared for at these centers

Who is providing social support and related case management for CCS clients?

- Many unclear regarding who provides social support
- social support needs not being met

12. What are the elements of case management within local CCS programs?

- Some counties appear to play a significant role in case management and coordinating services, and there appears to be significant variation in case management by county. Some respondents think the only thing the counties are doing is providing authorization while others believed that counties are doing much more.
- They do everything - look at reports, authorize, talk to parents, talk to providers, coordinate between parents and providers; part of job to help parents become more independent and advocate for their child
- Example: Peds clinic, physician, therapist, nurse case manager, and social worker – all would look at the whole kid, and try to address all needs and broker the services and follow up on the services the child needs – not just related to CCS medical eligible condition. Able to point and direct and make contacts, to broker the services the child needs. The parents receive the direct line to the nurse case managers, to the financial case manager, and can call with any concerns; and call about everything, and then we direct them and try to help even if not part of CCS condition, and relationships are established, and parents become comfortable making contact.
- CCS case manager is like the maestro; since kids visit multiple special care centers, they may not be aware the child has been visiting multiple parts of the same hospital. Can have the different sections, we conduct all these different skills, who are excellent at what they do, to get the sweet music, need a maestro
- Often coordinating the care, trying to get all of the entities hooked into the family, and helping them understand why they need to go to that appointment. Working hand in hand with those that we authorize to see what is happening on their end. For transitioning youth, making sure they know what is available to them. Also assistance for getting to appointments, travel and lodging
- Trying to identify kids that are eligible and might benefit – actively case finding. Then they analyze the child's medical situation and determine whether child is eligible, and if so, for what services. And then they review the medical reports, they piece together a package of services that the CCS program can authorize, and they link the child to the very best and most comprehensive medical resource that is available to us within the CCS program to treat that child. In a diagnostic case, they are knocking down barriers and streamlining access to most highly qualified team to clarify diagnosis and make treatment plan. For eligible child, looking at all elements of care from care team and making sure child has ready access to all elements and they are coordinated.
- bring clients in to see MD and review case every 6 months and determine level of equipment and OT, PT services, but not overall case management
- They act as refers and do the authorization, maintaining the network but can't think of case management that happens locally. Might make sure enrolled in regional center or hooked up to MTU, but for his/her patients not seeing lots of care coordination or case management of any type
- For all the non specialty care center patients, local programs are the medical case managers, eligibility, authorization, determination of benefits , most appropriate care, sources of care and monitoring care all medical decisions by physician protocols.
- Determine eligibility, make and assure completion of specialty referrals, coordinate process of getting DME. Face to face mtg once a year the rest by phone.
- Appropriate care by appropriate provider at appropriate time – some counties better than others at doing this.

(If talking to parents) What case management has your child received from CCS?

- Eligibility determination, medical need for services, care coordination, knowledge of the condition - organized around medical issues. Have not felt the medical home

13. What could the CSS program do to improve case management and make it more effective?

- Problems with staffing because of funding - need more staffing to improve
- Counties get reimbursed more for providing case management so more cost effective to have counties do, but should get them to put case managers in the hospitals.
- Need to increase consistency across counties
- Medical home model could be used - have lesser skilled people provide case management
- Problems with staffing because of funding - need more staffing to improve
- Counties get reimbursed more for providing case management so more cost effective to have counties do, but should get them to put case managers in the hospitals.
- Need to increase consistency across counties
- Medical home model could be used - have lesser skilled people provide case management
- Unifying case management by carving in whole child to one agency; children are very complex, and chronic, and care and billing and authorization are fragmented
- Restoring client case management ratio to better than it is (1:600)
- "the program needs funding to improve anything"
- Need funding for CMs and SWs at county level and recognition at county level that parents need independent, language appropriate in-home support and also social support
- Standardize case management protocols available to all counties
- Improve rates
- Arguments between health plans and CCS over who is going to cover what. Need strong leadership at the state to clarify policies and negotiate with partner agencies to draw lines.
- Advocated for a 2-tiered approach. We have a set of regulations that tell us who is eligible. Within that body of regulations, some diagnoses do not require medical case management. Ex. An uncomplicated fracture of the femur. Other examples, CP and leukemia – a truly comprehensive case management structure would serve the child and the family better. And another tier – for these patients who benefit case management but don't need to comprehensive case management, ex. Newborn with a cataract. CCS can ensure they get to someone with the right qualifications, and they get the correct post-op services. But after, that kid doesn't need us anymore.

14. What could be done to improve case management and make it more effective in other settings?

- Special care centers required to do case management but not sure enough state staff to provide oversight to make sure they are doing it
- Increase reimbursement rates for case management
- If each family had a person who knew resources in communities and could help families work their way through the system – like a medical social worker
- Primary care docs needs to be involved locally because kids far from centers and these docs need to have the medical home skills, resources, and volume
- Most counties think they provide good case management

Would providing medical case management through the tertiary medical centers/special care centers be more efficient and effective?

- Providing medical case management through the tertiary medical centers/special care centers makes perfect sense
- tertiary providers, much better at connecting to community agencies and resources, and can get a better quality of life
- Tertiary centers – are great, but, if you had every kid eligible being case managed through tertiary centers, would have to hire more staff. Also, problem for kids who live far away from the centers

- Don't know what would make the tertiary medical center or special care center more efficient or effective
- Doesn't think tertiary care hospitals should do case management. People working within a tertiary care hospital are bound to that institution, and have a built-in conflict of interest.

15. Have you observed or experienced variability in the amount and quality of case management in different counties?

- There is variability in case management between counties
- One county will approve and accept a medical explanation for one service but another county won't approve the same service with the same explanation. Creates more work for the counties and the hospital.
- Less variability would be better
- Variation much more in eligibility and authorizations than case management

(If "Yes"), do you have an idea about why there are county to county differences?

- Variability a function of size, resources and geographic location and personalities
- State leadership needs to clarify requirements and expectations
- Riverside and San Bernardino meet regularly with health plans to coordinate care and assure consistency
- Participant heard that some counties work very hard to deny services and not open cases if they can get away with it – not sure if true
- county budgets do effect the availability of nurses and therapists, and in some counties, will causes case load to be much higher
- State should look at county differences and share strategies where things are working well
- Variability because of how the state program is set up – Central valley has dependent and independent counties, and then 3 levels of dependent counties.
- Medical consultant piece varies considerably from county to county - some thought that they have different interpretations of the guidelines
- State leadership needs to clarify requirements and expectations
- Certain philosophies of different areas and who is running the particular office. Some very hard nosed, and almost a program of exclusion, not inclusion.
- In Fresno, cannot call and speak with someone or even leave a message.
- Some counties are great and connect the kids and follow-up - Ventura for example
- Requires leadership at the state level to clarify expectations and require consistency
- Some big counties eliminating CM staff due to local revenue constraints

16. From your perspective, how does the carving out of a child's CCS medical condition impact the continuity of and coordination of care and services for the child?

- Ping-ponging – it is difficult to coordinate their primary preventative services and specialty services. "Everyone is trying to keep them moving so they don't end up holding the ball and having to pay."
- CCS only kids are at greatest risk but happens with MediCal and HF also if local program doesn't assure regular communication with health plans and providers.
- Confusion for family
- Can delay care and impede services. Often times children have received care - it is matter of figuring out who is going to pay for it.
- Makes it harder to coordinate care
- Leads to fracturing of care

- Regional centers and CCS – costs are pushed out on each other, and don't know how to stop that

Are there any strategies you can suggest for improving the continuity of and coordination of care and services where there is a carved out system?

- Support carve out but need coordination of care and team approach
- Nice if counties had legal authority to case manage for the whole child whenever kid is declared eligible for CCS
- Need carve out until redesign completed. State needs to provide leadership and support for communication between CCS and Medi-Cal there are county models id admin issues at central level. Need to integrate CCS and Medi-Cal
- ultimately we need a comprehensive case managed plan, at least for the most complicated children
- Managed care medi-cal should approve payment for non-CSS services before sending it to CCS to save time and allow the local CCS program to do more.
- Take kids out of managed care plans and make all fee for service
- If kids all fee for service – then one entity could do the coordination
- Carve out has been important for improving quality of care and access for CSHCN. The “carve up” does come with problems. Carve out as-is is far preferable than going to carved in to managed care
- PC docs trained and part of specialty care team so that they automatically get info on care provided by specialty care providers and participate in ongoing related care and decisions. Funding and regs that assure coordination
- Create medical homes to coordinate all care
- Have CCS address the whole child
- To improve - More awareness of provider type and role in providing care, broaden tent and bring more people in; contracting with DME providers to use certain standards of care, give program more comfort in who they are working with; timeliness; have accredited providers, have a level playing field for providers and adequate reimbursement; greater respect for what they are submitting if they know the providers better and agreed via contract to meet certain obligations
- Have to make it easier for providers to work it – Need education from the get go.
- Strategies: Keep a carve out, keep track of what is being done and then settle at the end of the year. For certain conditions that have to have center based care – keep those conditions carved out to CCS. Or, Have NICUs all carved out. Or, flip around, and carve NICU in, and increase capitation rate for each member

CCS Administration

17. Do you think that there is a lack of consistency in the application of CCS rules and regulations across counties?

- Suggested explanations for perceived variation: comparing apple to oranges, counties have differing amounts financial resources and some pay for things not required to pay for
- No - just minor differences
- People believe this is true, but the degree to which it is true is less than it is perceived
- In any large organization, there will be some differences in interpretation. Some is urban legend, some is true
- Inconsistency comes not only from how rules and regs are applied, but with county match and funding formula, those rules within county changes as the end of the fiscal year comes and they run out of money. Regional center serving 5 counties has to learn 5 set of rules and then the funding

stream in each county. Some regional centers have given up on CCS and don't count on for anything – in certain parts of the state.

- No data to show; medical directors talk and have an idea about consistencies
- Yes, one county will definitely will pay for cholecystectomy and another will not
- Yes - if you are in certain counties, you know it won't be covered and we don't even ask.
- Yes there is a lot of inconsistency, especially with DME and amount of PT and OT at MTUs
- Yes – eligibility especially

(If “Yes”) What impact, if any, does this have on access to CCS services?

- Care for non-urgent services can be delay
- Not anything the counties are doing. But have had differences for years, and kids have been getting great services for year.
- Trying to get child what they need more often than trying to deny

18. Do you think that there should be any changes in the medical eligibility guidelines for CCS? If so, what changes should be made?

- Could design or encourage the design of a system to id CCS children instead of CCS conditions. If certain % of care is provided by CCS or has a combination of conditions, then take all the services and manage the whole child instead of bifurcating kid between CCS and non-CCS conditions
- Require all families to apply for both Medi-Cal and HF. Should start at hospital after CCS condition identified - seamless eligibility process
- Issue with comprehensive case management: cover diagnostic services if a condition is suspected; or have gene but not condition; baby can be open for a whole year; these could be eliminated in the name of cost effective case management, CCS should have diagnostic services or just case manage CCS conditions.
- Delete reversible and short-term conditions
- Delete simple, single organ system that don't benefit from having and RN case manager - eliminate after careful consideration
- Medical directors have put something together on this - delete non-chronic, simple chronic, eliminate malocclusion, orthodontia not related to another condition
- Could change age from 21 to 18
- Plans should handle low acuity conditions; preemies with no CCS condition should stay in health plans - but need to maintain credentialing for the providers that care for these kinds. OR, have NICUs compete on quality and give better rates to those with good quality

Do you think that there should be any changes in the financial eligibility guidelines for CCS? If so, what changes should be made?

- \$40,000 is absurd in the Bay Area, you are in deep poverty. 2.5 times the poverty level seems more realistic
- For higher income levels could be co-pays up to 200% of poverty. Take CCS out of realignment and state should take it back
- Yes should be eligible up to 250% of FPL

Funding

- 19. We acknowledge that due to the recession counties are experiencing a tremendous drop in revenue, from both federal and state allocations, as well as local property taxes. With this decline in revenue coupled with an increase in demand, some counties are questioning their ability to continue to fund 50% of CCS-only diagnostic and treatment services at the current level, which is**

now at about twice the amount of the Maintenance of Effort level from 1991 Realignment Legislation. What are your thoughts on this issue and how it might be addressed?

- Explore new realignment - some re-allocation of the liability and responsibility of these kids. Maybe state takes over all of the medical management of these kids. Families will continue to need services that the state doesn't provide so take medical care and regionalize or put under state jurisdiction and leave the rest of the responsibility the county
 - Realignment formulas don't take into account changes in population. This has resulted in some counties like SF getting more per capita but rapidly growing counties like riverside getting less. Needs legislative action. CA decided to require a 17% match for HF for diagnosis and treatment and administrative. This was a state decision and could be rescinded
 - Concerns that if a child is Medi-Cal eligible, then refer to Medi-Cal (but they don't have to go); instead they should be made to go instead of making the county bear the burden of CCS only
 - MOE should be raised to where it is actually needed - then wouldn't have local boards of supervisors questioning why we are spending so much money (and more than required to spend)
 - need to right-size funding for program through collaborative effort
 - the counties are not sure of the state continuing to cover their 50%. They may have to pick up more if the state does continue to match it
 - [How to address?]: Eliminate diagnostic services – open cases when a CCS condition is already identified
 - IF county co-funding – getting squeezed from every corner. Getting kids out of more expensive places for care and getting them home is more cost effective
 - managed care plans are getting better at identifying CCS eligibility, resulting in an increase number of CCS kids. Make it a carve in, they still get the care they need and managed care plans would get higher reimbursement.
 - Take out of realignment
 - New legislations to increase state share. Care is now rationed by what counties can afford to pay for and how many kids get in and what they get
 - Have heard that some counties are question the MOE because they are exceeding it
 - State should buy counties as suggested in the HMA report
20. **Are Medi-Cal reimbursement rates (the rates that used to reimburse for CCS authorized services) for clinical care, diagnostic tests and durable medical equipment appropriately structured to support optimal care?**
- Need consistent costs for a particular service regardless of setting
 - Allocations at odds with state staffing guideline - state requires staffing but then can't pay for it; Counties end up paying more - inordinate burden on counties; county has unfunded mandates
 - Rates way to low - results in very few medi-cal providers

(Probe – For example, do the rates encourage more use of inpatient instead of outpatient care?)

- Heard about this, and doctors say other specialties do this but not their own, but have never seen any data that illustrates this. Hospitals say they won't do this and are doing care in outpatient setting at a loss to the hospital.
- Doesn't think use of more inpatient care is a problem - medical directors address this and CCS won't pay for what is more than medically necessary
- Seems like higher usage of inpatient - but speculating, not from data.
- Some patients are hospitalized that don't need to be. Not incentives to set up 23 hour care center

Are there unintended and possibly negative consequences as to the way the reimbursement rates are structured? (If yes) Please describe such unintended consequences.

- Higher rates needed for some services and DME. Race to the bottom. If you can't find need DME or services in the community, then can't be discharged and stay longer
- Some cases kids stayed in hospital because could not get equipment to maintain child at home
- Provider networks are eroding. Cannot attract providers (of all kinds) into state and cannot retain them once they are here. Cost of living too high and reimbursements too low. Private insurance industry thinks they can get away with paying low rates too. Difficult to get in-home nursing services. Can cite 3 examples of kids dying at home, and lack of or inadequate in-home nursing significant contributing factor. Health care infrastructure in CA has been eroded and continues to erode.

21. We are told that the MTUs have increasing number of children eligible for services but capped funding from the state. Do you have any ideas on how to address this issue?

- The County role in providing MTU services for all children with an IEP that prescribes them causes big financial problems for counties. Families not required to try and get other coverage like private insurance, so counties are running out of money for MTU staff. Then school refers family to vendor and CCS has to pay
- Some kids don't get services because of increased cost for MTU care and capped realignment funding
- Should be case load driven - not capped
- need an efficiency review of MTP to decrease costs
- No financial criteria for qualifying for the MTU. Have MTU be able to bill private insurance.
- Higher caps on funding or more funding available
- not enough providers mean long waits; kids get consultation instead of direct services
- Admin decisions by DHS to cap funding. This was not a legislative decision so could be changed. Counties could challenge it and demand change
- Big problem with not enough PT OT county staff due to cuts. Schools are mandated to use vendors if no county staff but reimbursement rates very low and vendors often will not participate
- LA - no increase in numbers and slight decline. More children not the issue - cost is the issue and capped funding from the state is not enough
- Not enough money and many kids so have to prioritize. School Districts end up becoming the payor of last resort

Satisfaction with services

22. How could services be more family centered?

- Families would be better served if had to interface with fewer jurisdictions
- Reestablish parent health liaisons
- Need medical home and funding for MDs to have time to work more intensively with families
- Establish medical home - but reimburse appropriately for time involved and having social workers involved. Hard with to do with some populations.
- Medical home model is the right one; have someone coordinating care with a team of providers; people treated with transparency; access after hours and on weekends for consultation
- Whole child care with medical home and incentives for CM that is broader than medical case management
- Special care centers are family centered because they are all sitting down together, and also some MTU
- CCS is just one aspect of the needs; more social work aspect for parents; better mechanisms to collaborate with regional centers, schools, DME, families, etc. It's a village. Need to communicate what is available.

- Enhance access to medical social workers within CCS and standardize their training. It is not a requirement to have one. The role is not always clear - so we are depending on the ingenuity and tenacity of the individual social worker. Could improve the family centered nature of the program.
- Involve them in ongoing planning as stakeholders including the redesign effort
- Have family work groups, and actively solicit feedback and incorporate their recommendations
- Having family advisory panel at state level on how to better integrate services
- Counties could implement more family advisory groups
- Stronger alliances with family support organizations
- Identify groups of families with similar challenges so they can help each other. Need a systematized way to link families.
- Establish clear links to adult services – and that would require state leadership
- Personal: stop calling people mom, taking time to know someone's first name. Doctors can give options in an approachable language; information given is often inaccessible; family friendly language, and give advantages and disadvantages
- Mental health issues often overlooked; we are not meeting emotion or social needs right now. Needs to be an increased focus on meeting these needs
- Major disparities between AIM and CCS for eligibility criteria, both run by state.
- Trying to standardize the maintenance and transportation benefit could really help. Limits families in rural/poor areas from participating the ways they want.
- Expedite appointments. Have medical providers come to the kids in some instances - need to see school environment and meet staff and be more collaborative. Need more education for parents to understand conditions, treatment options, and resources available

(Possible Probes): Are there ways to help doctors make parents feel like partners in the child's care decisions?

- Doctors may not be able to communicate well with families; need to have dialogues overtime about the purpose of CCS program, and rationale and significance of having parents involved

In what ways could services be better organized to meet the emotional, social and developmental needs of children?

- Clarifying where families can get assistance. State could provide more assistance in how to get services form DD, SS and Mental health. Even a resource guide and with types of programs, interactions eligibility
- All 'CSHCN in one system that cares for whole child with whatever mix of conditions
- Streamlining the system, reducing fragmentation of care. MTP is where CCS really interfaces with clients

How could the CCS program better integrate the strengths and priorities of CCS families into all aspects of the service system?

- call/contact the families and have a dialogue; ongoing monitoring to discuss resources availability; communication with the families, and identifying how their priorities have been met
- Survey parents to get an idea of how well we are doing
- Need Education, information, and training for families
- having the parents educated up front about what CCS is when they sign up, rather than when the child is in crisis
- Bottom line: build empowerment, to help parents; because with an uneducated/dependent family, you are not helping them by doing things for them
- Need to involve parents in the decision making process, educate them about options

Other Issues

23. We've discussed a lot issues regarding the CCS program. Are there any particular challenges that the program is facing that we haven't discussed?

(If "Yes") Please tell me a bit about more about these challenges and if you have any suggested solutions that should be implemented.

- identity as CCS now limited, communication is limited, need to talk about what is the goal of CCS, not just the details
- CCS moved over in the DCHS and there is pressure to remove the public health focus of the program. The leadership at the state at CMS is gone (maybe because of this none-public health focus). There is no vigor in the policy development section. And this has got to be fixed and must be fixed fast. Otherwise the program will spiral down
- Stress need for local coordination, the CRISS model, can make a difference in the system, but relatively inexpensive and has made a big impact in the Bay Area – coordination and family involvement have come through that program; also improved efficiency and effectiveness
- Program needs to look at facilitating data collection and research – this has been lacking. Real need to be sure that we are providing the most effective treatment
- To help with continuity, focus more staff on policy development. Work with county reps to come up with policies that work for counties and regions and then disseminate in a user-friendly way so that we do have more consistency
- Constantly negotiating where CCS is responsible and where school is. Still negotiating whose role it is to do what.
- Lack of leadership. Medical directorship at state level vacated precipitously and hasn't gotten in strong leadership at the top. Need strong medical director and staff in Sac.
- Haven't talked about disparity between Medi-Cal and Healthy Families -for CCS to cover in emergency admission, health plans have 24 hours to notify CCS, and they have to have clinical criteria to accept referral. If the referral is Medi-Cal, it is accepted, no timeliness issue (because of a lawsuit again state from a provider). But if Healthy Families member, and facility admits on Friday and on Monday you do not notify, CCS would not pick up days Fri, Sat, Sun, Mon. Only way to get that changed would be to change legislation. Other situation - Healthy Family member can be responsible for payment, but the Medi-Cal are not. MRMIB wrote a letter than said we cannot have families going to collections, so it is up to plans – for until CCS patient is authorized, Health Plan is responsible. The letter promoted bad behavior on the part of the health plans. When we try to defer to CCS, it is too late
- For redesign, need so much more info to come up with data-based changes
- Duplication between OC and PT that is provided by schools and by CCS. MediCal reimburses OTP services provided by education and also those provided by CCS. MediCAL should stop reimbursing education for OTPT services for MTP eligible kids
- Lows salaries limit ability to attract talent

24. Are there any particular challenges that CCS clients and families are facing that the CCS program isn't currently addressing but should address?

- Economic stress is really affecting this population of families. And some need to leave one county for services in another county
- Families need equipment and supplies on time
- Some families are under stresses from a variety of directions, cuts in multiple service providers; many families feel rug is being pulled out; to balance life of these kids and keeping them healthy and going, relied on a delicate web; need to think of families in the center of all these things, not just in isolation in their relation to CCS
- Families are caught in the middle. Education is really, really important

- Need for Spanish speaking support groups and services. Need for more accessing in-home support and social support in general