

Key Informant Interview Summary – CCS Needs Assessment 2018-2020

Table of Contents

Strengths of CCS2

CCS Standards.....3

Application of CCS Rules and Regulations applied across counties:4

Financial Eligibility Criteria:4

Medical Eligibility Criteria.....5

Medi-Cal Reimbursement Rates for CCS Authorized Services6

Data7

CCS’s role as an approver of facilities:.....8

CCS Special Care Center designations recommendations:.....8

Access to care for CCS clients and CYSHCN9

Greatest barriers to accessing care for CCS clients and/or non-CCS CYSHCN: 11

The quality of specialty medical care provided to CCS clients and CYSHCN: 12

The quality of preventative care, acute care, and/or primary care provided by CCS providers to CCS clients and their families and non-CCS CYSHCN: 13

Health disparities observed in access to quality care, and subsequent outcomes based on race, ethnicity, creed, health literacy, geography or insurance type:..... 14

Challenges in recruiting and maintaining healthcare providers for CCS Children: 15

Access to medically necessary durable medical equipment (DME), medical supplies, and other services for CCS clients: 16

Case Management/Care Coordination in County CCS Programs:..... 17

Medical Home 19

Family Centered Care 20

Emotional, Social, and Developmental Needs 22

Transitioning Adolescents 23

CCS Partnerships..... 25

Medi-Cal Managed Care (MCMC)/Whole Child Model (WCM) 26

Biggest Unmet Needs for CCS Clients + Focus for the next 5 years: 28

Biggest Unmet Needs for CYSHCN that are not served by CCS:..... 29

Greatest Successes of CCS:..... 30

Feedback on how CCS and Non-CCS CYSHCN and their families are managing within the current structure: 30

Last additional experiences, thoughts, comments, suggestions regarding CCS: 30

Strengths of CCS

Summarized through key informant statements and quotes:

- **Strength: the availability and proficiency of specialists:**
 - “That there are providers that are paneled and that provides some assurance on quality. Result of CCS program – the Special Care Centers. I like that there are two parts of the system to ensure quality”
 - “The expectation that CYSCHN, especially very unique needs get service from a provider with expertise in that condition, also centers of excellence throughout the state, and having those overseen.”
 - “All of the diagnostic programs, metabolic screenings, etc. Standards and special care centers”
 - “Just the fact that it exists as a focused program for kids with SHCN, provides access to pediatric sub-specialists for low income kids, this provides a foundation for pediatric care sub-specialists for all kids.”

- **Strength: A state-run program versus private insurance or out of state programs for CYSCHN:**
 - “All people with [redacted] disorders have access to broader and better wraparound coverage than people with private insurance”
 - “A lot of our healthiest kids are the ones that have been through CCS”
 - “A primary strength is that it sets the standards statewide whether in CCS or not – everyone [in California] can benefit from it. “

- **Strengths: Care Coordination/Case Management:**
 - “Family centered case management and care coordination works well for the most part”
 - “Attempts at care coordination – even if it does not always work.”
 - “Case management is a strength, having a pivot point to help guide family through dynamic and complicated process.”
 - “Case management through the county-based system is essential to meeting the needs of kids, in [specialization center]—[providers] being able to communicate with multiple providers and have long lasting relationships with our families.”
 - “Availability of coordination of care; point of contact with MD who can bill CCS.”

- **Strengths: Family engagement/centeredness and patient-centeredness/access to care:**
 - “Helps parents get a lot of needs met in one place.”
 - “Access to care – kids have complex needs. Get kids care and access to the most cutting edge care.”

- “Allows patients to get resources might not otherwise have. For [specialized center] that means centralized care for them that is critical. Allows them to provide social work, care coordination, and additional services. Won’t be able to get these things without CCS.”
- “CCS engages families and parent voice shapes the program, and that stands out.”
- “Fact that it pays above Medicaid rates = increased access.”
- **Strengths: Systemic and administrative:**
 - “The administration of CCS is fiscally disinterested in terms of access to specialty care.”
 - “Access extended to non-CCS kids as well”
 - “Strong institutional knowledge.”
 - “Great oversight.”
 - “The quality of care that CCS requires by way of panels”
 - “The program is set up to serve kids with SHCN and structured to add special supports. We have to meet support needs as well as direct medical needs. One of the biggest strengths”

CCS Standards

Comments on the existing standards in place:

- Standards are: **outdated and in need of updates that may benefit from provider input**
 - Several key informants said some permutation of this statement: “CCS standards are old and need updating.”
 - “There need to be physicians in DHCS who look at what the standards are and how we are going to uphold those standards.”
 - “State is updating all of them. This needed to happen. At a crossroads. Many are old, and the new ones are good and appropriate. Involving [specialist providers] to update standards.”
- Standards are: **hard to understand and/or inconsistent**
 - “Ours are open to interpretation, so consistency across the state is not present.”
 - “Very complicated. We are partially independent, but it is hard to figure out how to place case as a CCS eligible condition and how eligibility works.”
 - “Might not be consistently or uniformly enforced, not much effort into enforcement of them.”
 - “Standards don't feel applicable to health plan (provider only), guidance is too varied, numbered letters are hard to parse out and apply to programs, and there should be a WCM for each standard.”
- Standards are: **valued and comprehensive—it is appreciated that providers have to be up to standards**
 - “Provider standards are stringent but don’t keep them away, just make sure the providers are up to par. Lots of thought has gone into them. They keep adult providers from caring for these kids – because that would dilute the quality of the care.”

- “Important to have provider and care standards and have that as way to ensure that all kids get same standard of care”

Application of CCS Rules and Regulations applied across counties:

- CCS Rules and Regulations are: **highly variable across counties**, all key informants mentioned this. Here are some of the more specific ways that the rules and guidelines vary and how that is represented across the state:
 - “We do get calls from vendors saying that such and such a county cover this, I also hear this from families. This makes families frustrated, and fragments care.”
 - “Each county is completely different in terms of what and when they improve...The interpretation of guidelines and what is needed and not needed is open for interpretation which is both good and bad because it can lead to the loss of standardization.”
 - “I’m a little concerned that funding resources may affect whether or not counties are acting similarly. More wealthy counties, particularly those who have added money, may be more generous.”
 - “Variability relies on medical directors, sometimes they lean towards different diagnoses that are more or less complex.” This key informant meant that medical directors choose their preferred diagnoses to focus attention and eligibility on, rather than following a particular rule or regulation.

Financial Eligibility Criteria:

*Comments on **financial eligibility criteria** for CCS (\$40K/year/family OR medical costs = over 20% of family’s yearly income):*

- Financial eligibility criteria **must have been considerate of the state’s financial capacity and therefore is fair and/or makes sense:**
 - “It overlaps with Medi-Cal eligibility overall, and helps when people fall off CCS for money reasons.”
 - “I’m assuming that if there are still funds, that it must be appropriate.”
 - “20% is fair”
- Financial eligibility criteria is widely outdated and **does not adequately meet or consider the needs of low-income families in California with CYSHCN:**
 - “It is pathetic – it is an insult and so unrealistic, especially with inflation. It shocks me really. Especially hard in high cost counties.”
 - “I wish that all kids had the same access as those that are financially eligible.”
 - “I did CCS 30 years ago in another county and then moved away. 40K is still the same amount as back then. Hasn’t kept pace with inflation.”
 - “Some families have to “spend down” to get on the program. One family member may quit their job to bring the family income down. This was extremely common before ACA, because the disease is catastrophically expensive (pre-existing conditions).”

- Financial eligibility criteria could benefit from **re-evaluation and a new perspective**:
 - “I don’t feel qualified to know if the number or where to draw the line on income should be answered by those that need the care, not providers”
 - “They need to focus on coordination for those with private insurance or other insurance AND CCS and how much denial [patients that are denied based on financial eligibility but would otherwise need CCS services] falls on CCS and public programs are asked to pick up services that the plans probably should cover.”

Medical Eligibility Criteria

Please note that we have bolded some statements regarding the **standards being too focused on specific diagnoses and conditions within the interviewee quotes because they came up often*:*

- Medical eligibility criteria is **very complicated**:
 - “It can be complicated when adjudicating and figuring out what is eligible. Why is it that some cardiac conditions are covered and others aren’t? Creates confusion and frustration for providers.”
- Medical eligibility criteria **does not cover all of the diagnoses that it should or is too focused on conditions or diagnoses (with a large emphasis on Autism Spectrum Disorders being left out)**:
 - “It needs to be broader. There has been talk about adding conditions but I don’t see it happening soon. [For example] CP is such a broad condition. Some kids with CP are found not to be eligible. Some have complexities but don’t quite fit into a category. Some kids are undiagnosed – can be complex and fragile and have no diagnosis so don’t qualify. So narrow. It is hard for families to understand reasoning behind decisions for eligibility. It pits families against each other. **Focus on diagnosis** instead of functioning.”
 - “The focus on medical and limit on behavioral conditions is very limiting to the program. Autism and developmental disorders should be included. Doesn’t include all high need children.”
- Medical eligibility criteria is **in need of suggested improvements**:
 - “I would not make it **diagnosis driven** but instead based care coordination and case management needs, essentially taking care of whole child. When you go by a diagnosis only, you are not coordinating all things that the child needs.”
 - “The system is not set up to work for kids who become adults. Need to look at diagnoses and medical condition and build out the system for them – maybe going beyond 21 years of age. No good plan of them when they age out.”
 - “**Too focused on conditions**. When symptoms are similar to another condition, then person should also get the same level of care instead of focusing on diagnosis.”
- Medical eligibility **works for some populations**:
 - “Our population is pretty thoroughly covered through CCS.”

- “Seems reasonable, includes most chronic or catastrophic conditions”

Medi-Cal Reimbursement Rates for CCS Authorized Services

And if they support optimal care:

- MC rates for CCS **need to be higher:**
 - “Historically **quite low**, and low for types of services that are most effective – good care coordinators and multi-disciplinary teams pay for things that will keep the kids out of the hospitals.”
- MC rates for CCS are **problematic for vendors, especially for Durable Medical Equipment (DME) vendors—sometimes resulting in untimely care or additionally burdened patients and families:**
 - “I can’t really speak to clinical care and diagnostic tests, but in terms of DME there are many things that can’t be provided because vendors are **not receiving high enough reimburse rates** and would be losing money. Even though they are supposed to be CCS benefits, they are not because Medi-Cal does not reimburse enough. We can sometimes furnish a denial in order for the regional center to pick it up. Many families can’t afford [DME] on their own.”
 - “**Definitely too low**. Providers won’t participate – especially vendors for DME. Need to be changed. It can put a burden on those who do accept Medi-Cal, very few providers that end up accepting all of the patients. Also there are problems with timely reimbursements – would then have to slow things down. Very complicated for families. This also creates a large paper burden for families.”
- MC rates for CCS **do not always match the treatments for certain conditions:**
 - “**Definitely low**, but the categories for reimbursement don’t necessarily meet the conditions super well. Comprehensive visits at [specialty] centers (federally funded [CCS condition redacted] treatment centers), take several hours and they meet so many different members of their care team (physician, social worker, and therapist), and then are reimbursed at the same rate as a basic hospital visit. They are missing some of the categories that some patients need at specialty centers. There needs to be better reimbursement for comprehensive care models such as this, a billing item or billing category for comprehensive, multi-care giver visit.”
- MC rates for CCS are **further complicated or will be further complicated by the Whole Child Model (WCM):**
 - “As we going into WCM and we move away from service groupings and they need to ask for every single thing independent, are they going to get rejected? Do we need to make everything eligible so providers can get reimbursed? Will that happen? We will no longer be case managing and how often will we be able to address co-morbidity?”
 - “Complication of WCM. It is a future hit for hospitals. Interacting between MC, CCS, and MMC – has significant financial downsides for children’s hospitals because of way that the formula works in WCM. Hospitals that see a lot of CCS will lose money in WCM counties. Provider fee model has a

built in lag so there will be a few years before impact will happen. Provider fee pot is paid to the size of Medicaid program so some effects will be offset by growth in Medicaid.”

Data

Meaningful data sources or data collection methods relevant to CCS clients and/or CYSHCN:

- Some data collection methods can be linked directly to key informants so there is only one direct quote in this sub-section in order to protect the anonymity of our key informants. Instead, we will list some of the common themes in **meaningful data and data collection for CCS clients and CYSHCN:**
 - Utilization data (including CCS authorizations) is rare, but very valued—especially for CCS, but also for CYSHCN, and special conditions.
 - CCS and the state itself does not help with data efforts including collection and analysis of data already collected.
 - Some major EHRs like EPIC provide opportunities to collect data, but many say this is a missed opportunity because it can’t be aggregated in meaningful ways for CCS/CYSHCN. Also use of EHR is inconsistent across the state anyhow.
 - It is difficult to get data from large, established state and national data sources, especially for smaller regions and counties.
 - The state and federal government provide no financial support to collect this data, even though there is a notable cost associated with data collection.
 - CCS children will get “washed out by volume” of Medi-Cal children if data isn’t collected carefully and specifically.
 - One key informant summed up what a lot of others said: **“A lot of counties are trying hard to establish outcome measures to demonstrate that our program is worth tax dollars and relevant to the families that we serve. It would be nice if we were able to collaborate with different universities or organizations...I don’t think we have the staffing, but I think we have a lot of data to provide someone that would want to do research, but we need more staff.”**

- Data that **should be collected that would be meaningful concerning CCS children and/or CYSHCN:**
 - Data that focuses on specific diagnoses and conditions in order to have **“evidence informed practice.”**
 - “Need county by county data. California is large and variable.”
 - “Interested in parent survey and parent experience. That is what has been missing from this. Parent assessment of all aspects of quality, including transportation. More public info about what the program is doing to address identified needs.”
 - “Efficacy of case management and efficacy of care coordination. Build data set of interventions with disease and then outcomes using nursing metrics and efficacy on screening programs”
 - “Would be good to get data from comparable programs and see if there are systemic issues that need to be address”
 - “Timing from when you request a vendor service to when they receive it – DME. Would be good to track that.”
 - “Something on transition planning – huge issue for families – who is responsible, we need a way to measure”
 - “Are CCS patients getting better quality of care? I would love to have this looked into.”

- “Are we able to meet the needs of all of the diagnoses that we serve?”
- “Behavioral health needs and who they are seeing in community.”

CCS’s role as an approver of facilities:

- CCS’s role as an approver of facilities is **important and valuable**:
 - “It is fantastic that CCS has a role. They know the standards.”
 - “They’ve done a good job approving and making sure they meet the criteria. Hospitals have to have a certain standard and that means that all non-CCS kids benefit.”
 -
- CCS’s role as an approver of facilities is **unclear and may be inconsistent across the state**:
 - “Not sure. Pretty inconsistent over the years.”
 - “I am not familiar, except that they probably don’t do it very often, and need to increase staff with expertise to really look at what is going on. And I don’t know what we do about the remote areas of the state and families that have to travel.”
- CCS’s role as an approver of facilities **sometimes results in delays and complications for hospitals**:
 - “Hospitals experience long delays for getting approval for new centers, a year or more. There is pressure from some quarters to weaken standards so more providers can come in. I’m concerned about this, but delays are the biggest problems. We don’t want Medi-Cal plans approving [and then hospitals being] conflicted and trying to find cheaper place for kids to go.”

CCS Special Care Center designations recommendations:

- Some suggestions for **CCS Special Care Center Designations**:
 - “Can we **combine any of the special care centers**? It would be like making a medical home. There is room for further regionalization of highly specialized care. Some smaller centers providing care but shouldn’t be – but do because of funding.
 - “Some folks there have a desire for **colorectal [special care centers]**.”
 - “[Redacted] wants a **program related to transgender issues**.”
 - “There are one or two for **Rhett’s syndrome** – but parents have had to advocate for this. Kids with Rhett’s have been in and out of qualifying for CCS – would benefit from security in eligibility of continuity of care.”
 - “I do think it is kind of challenging being in [redacted California city], our kids with muscular dystrophy have to go all the way to [redacted California city ~90 miles away] and I wonder if the **standards are too strict and that facilities find it difficult to become specialty care centers?**”
 - “If they go through each category of disease and find if there is **sufficient numbers statewide, should be a special care center**.”
 - “Only one mentioned earlier, **asthma**, such a common problem... Asthma kids never seem to qualify unless on verge of serious lung problems.”

Access to care for CCS clients and CYSHCN

Challenges encountered or witnessed by key informants:

- **Good quality medical homes and primary care:**
 - “Challenges with access to good quality medical homes or primary care.”
 - “The data says most of these kids don’t have a medical home.”

- **Getting access to dental care:**
 - “Dental is a problem for both populations. Especially when specialty care or anesthesia is needed. Not accessing dental care enough. Long wait lists.”

- **Timely or costly DME or DME at all:**
 - “Heard about complaints regarding access to support services and DME. For some new drugs, high cost ones – delays in department approval and challenges”
 - “Mostly been around timeliness, ... if waiting a long time for DME and medical supplies, this needs to change after things have been ordered.”

- **Timely authorizations for care:**
 - “Recent backlog in authorizations and renewals.”

- **Getting children enrolled in CCS and keeping them enrolled, especially when moving across counties:**
 - “The complexity of the application and the application process, especially if there is not staff available for follow-up on the applications, fine details sometimes missed and that becomes a barrier because it is not communicated.”
 - “Sometimes challenges getting them enrolled but once in, it is a great system. Going from one county to another can be a bit of a barrier.”

- **Difficult for transition-aged youth to get access to care or transition services:**
 - “Especially hard with transition youth – hard to access care. Need to have some sort of continuation of care”

- **Non-CCS children miss out on quality care and care coordination:**
 - “I know that our [redacted hospital name] nearby tries to get a lot of children [CCS] eligible. For our children, because we provide comprehensive case management, I don’t know of any other programs

that would provide this for children that aren't insured, I'm not sure how that works, that might be a challenge for children not [CCS] eligible and uninsured."

- **Financial eligibility criteria for CCS and cost of care for non-CCS:**
 - "Given how expensive it is to live in CA, the adjusted gross income seems a little low for the cost of care for our population"
 - "The extremely high cost of care for someone not insured/on private insurance. These families meet their deductible every single year, families have to pay deductibles every year and then end up unable to pay. If they know they aren't going to be able to pay the entire maximum deductible January 1st then they will skip out, which means they sometimes need to skip out on medications and they become temporarily non-compliant and end up in the ER for care."

- **Access to care based on where clients live and distance to care:**
 - "Distance is a huge factor. Especially provider capacity, there are not enough providers."
 - "Also hard for families that are geographically isolated."

- **Time spent getting care:**
 - "[Some of the] biggest challenges [are] distance, time, and number of times have to go. Coordinating all of the appointments on to one day would be great. Some programs exist, but children have to have significant issues. Shortages of staff too, but that also leads to long wait times."

- **Challenges presented by the WCM—including language barriers and losing access to specialty care centers:**
 - "In WCM – access to program info is mostly in English, even the line to call if you need info in another language is in English. That is hard for non-English speakers to access info. Language access can be improved."
 - "Access to specialty centers related to the WCM, some patients may lose access to their specialty care centers"

- **Not enough pediatric sub-specialists:**
 - "Might be a lack of pediatric specialist so there may be issues with booking timely appointments. Too few pediatric subspecialist means challenges in recruiting too."

- **Access to behavioral and mental health care:**
 - "Challenges with access to mental health services."

- “Once you have a kid with a unique condition and has an additional problems, it is hard to find behavioral health services that meets their needs.”
- **Logistical and technical issues:**
 - “Technological issues, like when we authorize a child to go see the physician, within CMS it is hard to figure out what the right number is for a physician. Physicians can be entered as many times as possible, there should be a central way of inputting their phone number. Can mean that a family would get the wrong number and not get access to care.”
- **Issues with Family-Centered care:**
 - “Family centered care is a high priority, but there is room for improvement.”
 - “[Challenges have been] mostly around family-centered and equitable care.”

Greatest barriers to accessing care for CCS clients and/or non-CCS CYSHCN:

- A great barrier to accessing care is **geography and transportation:**
 - “Transportation is a barrier. Traveling long distance and more often than they need to. They should be able to get all appointment on same day.”
 - “Geography is a big challenge.”
 - “Worry a lot about rural kids who have to go distances and travel far from home without proper or bare bones living situations to get care.”
- A great barrier to accessing care is **poor care coordination**
 - “Failure to coordinate services is a barrier. The inefficient way of coordinating and managing care is a barrier.”
- A great barrier to accessing care is **lack of appropriate language and cultural competency:**
 - “Language and cultural competency and how different families understand and respond to early signs that something is wrong. Some are being identified too late in life.”
 - “Ethnic diversity, the system is not culturally congruent. They need cultural humility [by] coming to space of understanding that you can’t be an expert in somebody else’s experience. You can only hear them.”
- A great barrier to accessing care is a **lack of vendors and providers that will take Medi-Cal:**
 - “Not being able to get vendors to provide supplies or timely access to behavioral health depending on who will and won’t take Medi-Cal. For the broader group [non-CCS CYSHCN], same kind of challenge, if they don’t qualify for CCS and just have Medi-Cal, it is very limited about what can be provided to them. Access issues because of Medi-Cal reimbursement. This is the group that falls

through the cracks but none of their issues qualify them for CCS. But county programs and Regional Centers can't do it all."

- "Lack of capacity – for some metabolic disorders, more kids that need to be served than can get in the system."
- "Having enough CCS paneled providers. Delays because not enough appointment slots. To some degree a reflection of reimbursement"

- A great barrier to accessing care is **family engagement/family-centeredness**:

- "Barrier, they don't give families enough info and assistance to navigate on their own"
- "Families don't always have the capacity to get what they need, need help navigating. Need more providers with expertise."
- "Families understanding payer of last resort and how the program functions. Many families' members don't even realize how care is being paid for. Lack of education about the systems and how they work together – what is state, what is county, what is MCMC, what does fee for services mean? Parents are intimidated by the system, but they need to be a partner."

- At least one key informant expressed that they hadn't encountered barriers.

The quality of specialty medical care provided to CCS clients and CYSHCN:

- The quality of specialty medical care is **excellent for CCS**:

- "Good at acute hospital setting issues, but less acute, preventative side of things, the coordination of care drops off. It is hard to get providers on the same page about coordination."
- "If we get the kids to the right provider that is CCS Paneled, it is excellent. For non-CCS, the run-off benefit."
- "If they get to a CCS facility, the quality is excellent. In more remote areas, might be harder to get to a CCS facility. Have to believe that most of the children's hospitals have the same kinds of waits for services."

- The quality of specialty medical care is **lacking in quality assurance**:

- "We don't know, that is part of the problem. Don't have quality measures, care is individualized and no quality standards."
- "Questions could be asked that aren't disease specific but get at quality. State has been reluctant to really ask about them because answers need to come from clients by in large. State hasn't done secret shopper surveys, with variation by insurance status, and specialty type needed. State should be asking questions."

- The quality of specialty medical care is **great and valuable to parents**:

- “Our nurses do a fantastic job of really helping families access providers and I haven’t heard if it is difficult outside of [redacted special care designation].”
 - “SCCs are phenomenal. I get to read all of the notes and I’m amazed at things they think of and the abilities they have. I love the fact that providers have good communication and care coordinators and know parameters.”
 - “Love SCC. Haven’t met a parent that doesn’t like them when care working well.”
- The quality of specialty medical care is **lacking for non-CCS CYSHCN**:
 - “Outside of CCS most only have access one time a year and many major insurers only allow one annual visit to the specialist. That is the biggest barrier that most private insurers don’t provide access to specialists and don’t have their own.”

The quality of preventative care, acute care, and/or primary care provided by CCS providers to CCS clients and their families and non-CCS CYSHCN:

- The quality of preventative care, acute care, and/or primary care provided by CCS providers is **inconsistent (especially for non-CCS CYSHCN)**:
 - “Highly dependent and variable, some [providers] are very comfortable with complex needs of their patient population, and some not. PCPs outside of CCS don’t have the skills to take on complex kids.”
- The quality of preventative care, acute care, and/or primary care provided by CCS providers is **sometimes under-utilized, especially the preventative care piece**:
 - “The tricky part is how they use primary care services. When you talk to pediatricians, they say access really varies based on practices. For acute and primary care, reasonable network but more about families using it and there is a tendency to go to emergency department or specialist only when they have problems. Preventive piece is more of a problem, we need a combination of mind shift and having resources to reach out to patients.”
- The quality of preventative care, acute care, and/or primary care provided by CCS providers is **not good at transition care or caring for aged out CYSHCN**:
 - “With CCS being up to 21, challenge is that may be 21 but not really 21 and peds don’t want to keep kids in that age range. Very limited PCPs that will take kids as they get older.”
- The quality of preventative care, acute care, and/or primary care provided by CCS providers **needs improvement because it is difficult to maintain primary care providers**:

- “Problem with primary care is that it is hard to find MDs who feel comfortable with taking care of these kids. [Primary care] can fall to special care center or to general peds at special care center, but not all have SCC have general peds.”
- The quality of preventative care, acute care, and/or primary care provided by CCS providers **needs to be improved, specifically the preventative/primary care practices and non-CCS CYSHCN:**
 - “Not enough preventive care or enough discussion between providers to ensure that the child gets to the level of care that they need. Parents say they go back to PCP several times before being sent to the specialist. Their PCP didn’t know enough about the condition and that caused delays. Not a good system of referral and enough understanding among general peds leads to delays in kids seeing specialists. For non-CCS, PCPs don’t know a referral source or how to deal with particular issues. Might happen a lot for kids in foster care.”

Health disparities observed in access to quality care, and subsequent outcomes based on race, ethnicity, creed, health literacy, geography or insurance type:

- **Large disparities based on social, economic, and educational background of family:**
 - “Real disparity in the success of the program depending on the social and economic status of the family they are from. There is a wide variety within in CCS. Ability to navigate the system to some degree relates to privilege and education level, which extends to getting kids screened early, doesn't happen if children don't have a 'strong advocate'.”
- **All groups within CYSHCN experience disparities in mental and behavioral health, and oral health care access and utilization:**
 - “Huge disparities in mental health and oral health, geographic and financial, can be urban and rural but some urban areas are not served well either.”
 - “Oral health, really struggled to find people to treat these kids. Hard to find dentist, as soon as they find out they have sickle cell or hemophilia, very few that want to treat them.”
 - “In CCS they have to go to the dentist they are assigned and most dentists don’t know how to say that they don’t know how to provide specialty dental services. Families don’t know where to go and we don’t know where to refer them. In my opinion I feel like the mental health care is out there, I think it is more an issue of people admitting they have a mental health need in order to access the health care services.”
- **Geographic and cultural disparities:**
 - Also have geographic disparities, harder from some to come to services and communicate, cultural or geographic areas that probably don’t have the same outcomes.”

- **Disparities in access for Black and African American families:**
 - “Thought that there was a disparate access for African Americans, quality of care is different.”
- **Disparities in access based on income and poverty status:**
 - “Hard for homeless population.”
 - “If in middle group of hard working families with not much money, may have worse access than very poor or more well off.”
- **Disparities based on insurance provider (*only mentioned in context of dental and mental health care*):**
 - “Heard that Medi-Cal patient better off than commercial insured for mental health services.”
 - “With insurance, with Medi-Cal, hard to access oral health.”

Challenges in recruiting and maintaining healthcare providers for CCS

Children:

- **Geography—it is both difficult to get providers in remote areas and to keep providers in areas that are expensive to live in (due to lower reimbursement rates):**
 - “Not a one answer question. Where I live it isn’t a problem, but in inland and northern California, it is hard to get the same quality of providers, and patients need to travel farther to get quality. Same for non-CCS. Medi-Cal becomes very difficult, they [providers] lose money if they see ‘Medi-Cal,’ if CCS didn’t exist, patients would be in real trouble.”
 - “Facility dependent. Has to do with how much the facility pays. Taking care of these kids isn’t easy.”
 - “Hard to recruit and maintain providers. Distance from more urban areas. Have to want to live in a rural area. High provider loan rate is hard for providers to repay.”
- Related to the above quotes, **Lower salaries:**
 - “Low salaries make it difficult to retain. We don’t have specific experiences with interns, but hearing from others it is an awesome place to work—usually they end up staying.”
- **Medi-Cal plans aren’t communicating with providers (especially with Whole Child Model):**
 - “Some of the Medi-Cal providers in WCM plans telling families that if they want a provider in the plan, the family should ask them. Shouldn’t be the families’ responsibility. Originally, plans were supposed to reach out to providers to see if they would join the network.”
- **Rare disorders = small patient populations, which are not enough for large, thriving practices:**
 - “Most MDs don’t specialize because there aren’t enough patients to sustain that many people going into the specialty unless they go to a [redacted CCS disorder] specialty center.”
- **Lack of diversity among provider pool:**

- “In this country, there is a lot of lip service to diversity but not a lot of actual doing of diversity. Language, race and culture of providers, sexual orientation. **Providers don’t reflect the community.** Makes it harder for parents to connect with the provider and trust the provider. I want to see a diverse workforce. What I see is people hiring folks that look like them. Reality is that in the health profession, most of the people who make these decision are white.”
- **Not enough sub-specialists:**
 - “There seems to be shortage of some pediatric sub-specialists, this has to do with pipeline issues and what people choose based on life style, training requirements...”
 - “Not enough sub-specialist to go around. If there is a way to have MD extenders work with subspecialists.”

Access to medically necessary durable medical equipment (DME), medical supplies, and other services for CCS clients:

- **It is inconsistent and dependent on a lot of different factors:**
 - “Unfortunately, it depends, and now will depend on managed care in addition to CCS and regional centers. For costly equipment and personalized equipment, there are issues with vendors. They are not being paid well, and there are not many pediatric vendors. For supplies, more of a bureaucratic problem in getting authorization that stands in the way of making it more efficient.”
- **Not well, because vendors have a hard time reimbursing through CCS, which results in delays and a lack of vendors willing to work with CCS:**
 - “Very frustration thing. Vendors are ready and willing, but payment comes late for vendors and they can be frustrated by that. Delays in getting equipment”
- **Not well for families with other insurance in addition to CCS, results in complications:**
 - “This is a real issue... [Then provided a specific example:] Because parent has insurance and CCS, CCS refused to pay for DME even though insurance denied the request. CCS felt that insurance shouldn’t have denied DME. Which led to parents wanting to drop their private insurance. If insurance denies because they decide it isn’t medically necessary as opposed to and insured, covered item, it leads to a stalemate and the CCS child loses out.”
- **Not well in general, for CCS and non-CCS CYSHCN:**
 - “Access is bad overall for CCS and non-CCS kids. In Fee-For-Service for sure. With Medi-Cal Managed Care, I have heard that it might be a bit better, but low rates.”
- **Really well for some counties and specialties:**

- “This is something that [county name redacted] does pretty well, conversing with Partnership Health Plan to understand. I think we are going to be OK going forward. DME numbered letter is being modified as we speak, trying to incorporate academic/scholarly research about why things need to be covered.”
- “[Redacted specialty center] we do a fantastic job of making sure the needs are met with the exception of the [redacted diagnosis] population that we can’t help.”

Case Management/Care Coordination in County CCS Programs:

- **Major barriers: varies in quality and clarity on a county by county basis:**
 - “Varies enormously. **Huge case load differences across counties.** Some places it is probably done well and some done minimally. No standardized way to stratify CCS clients.”
 - “If ‘case management’ falls under the umbrella of ‘care coordination’, then we are doing case management for eligible conditions.”
 - “Mostly observational, patients coming from dependent to a large county with more services and resources.”
 - “I would have at one time said that we do a great job, but we don’t. Within our county we’ve never been proactive in case management, **it is almost crisis driven** which does not meet the definition of case management.”
 - “In my experience, I think we do a fantastic job of providing comprehensive case management for our clients.”
- **Major barriers: large and unmanageable caseloads, and the introduction to WCM (losing CMs):**
 - “We currently have **one nurse case manager for 900 cases**, they do their best they can. We have two Social workers. They work very hard but hard to get to everyone. It is hard to do case management the way they want to. We had a case manager leave and it is hard to replace them because of Whole Child Model and job ending. State gives limited money for case management. I have heard that Partnership has 80 cases per case manager. **Decreasing the case load would be good.**”
 - “The definition of case manager and what they do (the activities listed) are not aligned. They are the catalyst and the advocate, they are only supposed to have a few dozen cases, but CCS staff has hundreds of cases, as a result some get managed really well and others don’t. **The term case management doesn’t make sense when the case load is so large.**”
- **Both a barrier and a success of case management and care coordination: family engagement and participation:**
 - “Parents do and are helped by others. There are good outcomes because of a strong parent at the head of the table. But, should parents have to do that? Some parents wouldn’t give up leadership no matter how competent other people at the table are. But, this could help to lift the burden on families.”

- “It varies. If you have a strong, decisive leadership from parents and other professionals around the table, you can have well-coordinated care, but there are other things that can get in the way, for example, [parents will have] problems getting DME.”
 - When asked who coordinates care for CCS clients: **“I would be surprised if the answer was anything other than the parents. There isn’t a single care coordinator that I’ve ever seen for our children.”**
- Suggestions for improvement are **communicating and working with community partners**:
 - “Get to know community partners and partner. Don’t be a closed system.”
 - “Too big a job for CCS to do with current capacity and coordination. What [redacted hospital] recommended to [redacted county name] CCS was build relationships with their community partners, counties don’t typically do that, it is a very isolated and closed system. They started to get results when they started helping [redacted specialty center] get to know the community partners. If they don’t know who is in the community, they can’t tell the family.”
 - “Part of the problem is that it involves lots of different agencies and hard to make it convenient for families. Incentives just aren’t there to be an active partner. To make it work, everyone needs to feel invested in getting best outcomes but no incentives other than meeting system needs. We need to prioritize family needs. How do we set better incentives for the right outcomes?”
- Suggestions for improvement are **clarity around roles in case management and coordination**:
 - “Sorting out who should be doing what. For CCS kids, CCS should take the lead in sorting it out.”
- Suggestions for improvement are to **increase knowledgeable staff to conduct case management and/or care coordination**:
 - “We need more and better trained, delegate tasks that don’t requiring nursing expertise”
 - “More case managers, making the Primary Care Physician the pivotal point. The PCP could see the client in a different way.”
- Suggestion for improvement is **additional state funding to bolster case management and care coordination staff and efforts**:
 - “Reducing caseloads. More training in case management funded by state.”
 - “Getting there, but resources are allocated disproportionately.”
- Suggestion for improvement is to **do care coordination and case management with the specialists**:
 - “Looking at different model and actually doing care navigation and integration with specialist. We have done some of this in the past when in the program and working with hospital. It needs to be more holistic. We wanted the provider to take care of whole child, and not the health plan.”

- Also important to note, **some key informants thought that Whole Child Model will or already is improving these services:**
 - “What they are trying to do with pilot [of whole child model]. Focus, redirection and resources.”
 - “If we were not in our pilot [for WCM], care coordination in anemic and not happening.”

Medical Home

Summary of comments on **Medical Home** for CCS and non-CCS CYSHCN:

**Note: key informants were read the AAP definition of Medical Home prior to this section of questions.*

- **Not many children, CCS or non-CCS have a Medical Home:**
 - “Very few of the kids really have this. No driving medical home plan for these families.”
 - “Not many. All have a Primary Care Physician, and in Medi-Cal Managed Care. They all have one in theory, but how functional in terms of the AAP definition, not very, not meeting.”
 - “As defined, NONE, I don’t think our primary care providers are set up to do this.”
- If they knew of a **Medical Home or worked with one, it was incomplete in some way:**
 - “For those in [redacted county name], coordinate the diagnosis for them, but that’s not the definition of the full vision, but they are doing this.”
 - “We ran a study, did a survey based on the AAP definition [of Medical Home], and figured out that only 44% of CCS clients met criteria for a basic medical home.”
 - “With this definition, very few, maybe 20% and I’m being generous. We have pieces, we might have access to medical care, but might not be able to access early childhood education because of some health issue, or because the family doesn’t feel comfortable. Then who supports family around that issue?”
- Sometimes, **FQHCs (Federally Qualified Health Centers) are considered Medical Homes for CCS clients:**
 - “I only know about CCS, all of our clients do because they are in the FQHC or RHC. For non-CCS, I don’t know.”
- **Other hospitals mentioned that work as Medical Homes:**
 - “Children’s hospitals and UC hospital – CCS designated centers. Both primary and specialty care all in the same environment. One stop shop for the families. Every center has the capability but doesn’t want to put in the resources. Funding from state and CCS to major centers (children’s hospitals). Centers should do this. In Southern CA, way more centers than there should be because everyone wants a piece of the pie.”
 - “Kaiser is a medical home. Working with kids who have Kaiser, challenge is when family wants a second opinion or want to see doc outside of Kaiser for sophisticated procedure, can’t. But that was a while ago and might have improved.”

Family-Centered Care

Summary of comments on how well CCS addresses family capacity and needs, how family-centered CCS care is, and what improvements could be made:

- **CCS is not very ‘family-centered’ but it also doesn’t seem to consider that a requirement:**
 - “I have heard that it is not as family centered as it should be. Providers are getting better but the CCS program hasn’t had an explicit expectation for it. **Not a systemic expectation.**”
 - “Philosophically, it depends on the organization and their view.”
 - “I think that CCS gets frustrated with trying to explain things to families and then they decide that the family just can’t understand.”

- **Family-centeredness varies from county to county:**
 - “It is a work in progress. Larger and better funded counties have made better strides. Parents are interviewed when they get in the program, and they have a family assessment.”
 - “It varies based on providers, and may also vary based on level of education of the family. Lots of room for improvement.”

- **Family-centeredness is considered a top priority and many key informants work on it:**
 - “We are really working hard towards that, and using a tool called the Canadian Occupational Performance Measure that is geared towards family centered care, to determine what are the most important needs of the family rather than just what the therapist thinks is most important.”
 - “We make it very family centered. We want everyone to have input. I get permission to reach out to other family members who provide care and include them as well.”

- **When care is family-centered and/or addresses the needs of families and family capacity, everyone benefits:**
 - “Oftentimes decisions are already made for the child without the family being part of the team. Families don’t always receive timely, accurate information. Families need to be at the center of the whole care team. Right now it is not that family centered. Parents know their children the best but they are not recognized for that and valued, and then lots of things get lost in translation. No effort to meet in the middle and see where other is coming from.”
 - “We try to identify what resources a family has when we decide to provide home programs, if a family cannot come in based on a lack of resources, we meet them in their home. We can help them to achieve better independence this way, so they don’t have to come in every two weeks, which can be a hardship. They are better at meeting goals with daily home programs.”
 - “We have to take this into consideration when setting up treatment plans and discharging kids. If families doesn’t have resources at home, then the child can’t be discharged and this results in higher costs.”

- **There are resources available within CCS to address gaps in family capacity:**
 - “...it is so involved and the care is comprehensive enough to meet the needs of families. There are usually resources available to help families who face barriers to accessing the care. “

- “We try to take on the burden of having to navigate the system. Once they are in CCS, it is not an issue”
- **There are gaps and issues in how CCS addresses family capacity, mainly that it is a missed opportunity in continuity of care:**
 - “...if a kid is going to see a surgeon and planning a big surgery we need to send along a therapist to make sure that the family is able to manage the outcomes of surgery. Or the outcomes of any other procedure. [We try to] tell the physician to be considerate of what the family needs and can provide after [big medical procedures]. Even also waiting for dad to get off of work to have a meeting, that stuff isn’t considered at all.”
- **Capacity and family-centeredness is sometimes broken down by complexity of need within CCS and for CYSHCN:**
 - “Family capacity is determined by a social worker evaluation. If they have lots of needs, the social worker and nurse care manager try to meet. It is variable.”
 - “Always considering that. We look at what is available to them and what level of resiliency they have. Some know how to navigate and other families need more help.”
- **Suggestions to change (if they would change) care coordination, case management, and continuity of care for both CCS and non-CCS CYSHCN to make it more family centered:**
 - **“Medical homes, regionalization of care to center of excellence.** Look at the data and use to improve outcomes.”
 - “Needs to be **legislative advocacy at a really high level and family centeredness.** Until systems are integrated and talking to each other – has to happen at top level, like making shared plan of care required by law.”
 - **“Training for staff** might help. Coming up with **good behavioral questions** to ask families to get a good assessment of what is going on. We have so many clients that can’t do it. **When thinking of the child, think of whole families because it affects them too. When families are in the know, it is easier and better for the child.**”
 - “Getting **more involvement of families in advisory council.** Also need to engage families differently to be more family centered – engaging a family”
 - “...do care planning, make sure every CCS client has a **real care plan.** What are family’s goals and priorities and what role do they want to play. If they **required care plans,** that would at least get the information. Needs to **be standardized and comprehensive care planning.** For both CCS and non, this would educate families to expect family centered care”
- **CCS supports the involvement of families in program and policy development, but with some limitations and variation across counties (there is no standard or consistent example):**
 - “There are some counties that I heard will have family groups to hear needs of families, I don’t know how much that goes into program and policy development. I attended a Family Voices meeting last

year and they were very into getting families involved in policy. We don't here in [redacted county name] and don't know what counties might be doing that."

- **CCS does NOT support the involvement of families in program and policy development:**
 - "Not very. It depends on the source of care. I would give it a low grade and would give a low grade to DHCS and state CCS staff. Until legislation was passed that required advisory groups, it wouldn't happen. In county CCS, family centeredness varies and lots of room for it [to improve]."

- In order to **engage families in a meaningful way in program and policy discussions**, CCS should:
 - **Forge trusting relationships with parent communities and community liaisons:**
 - "Supporting a parent liaison to speak for the other parents. Look in the communities where the parents are located and go to them."
 - **Compensate families for their input and engagement at the county level (and create guidelines on doing so):**
 - "Having paid positions would really help. A guideline from the state about how to involve families at the local level...having paid parent position at state and local level."
 - **Create standards and/or guidelines for how to facilitate family participation at the local level:**
 - "I don't know myself as a [specialist] and a county employee, I don't know how much I can even participate in policy, it is unclear to me so I don't know how I would get families to participate if we don't know ourselves."
 - **Meet families where they are at:**
 - "Making it more accessible. We need more regional meetings or to let them be on the phone or skype – having them participate in that way because of distance and transportation [would help]."

- **CCS sometimes facilitates parent to parent support (mostly via special care centers), some other organizations do too:**
 - "There are in certain clinics and specialists [within CCS]. Pretty common to be offered."
 - "I know don't know, can't even think of one time. We try to hook them up with **Family Voices (FV)**. Probably low. In [redacted county], there aren't parent mentors that I know of, just the **FRC** and **FV**, which do have parent mentors."
 - "Our infant program does, but that is part of the **county office of Education** so it doesn't really fit. But a parent mentor is the first to go and start the process."
 - "**Packard** does. They have a very formal parent mentoring program and they have asked for support to teach it to other children's hospitals."

Emotional, Social, and Developmental Needs

Summary of comments on how well **emotional, social, and developmental needs of both CCS and non-CCS CYSHCN are being met:**

- **The emotional, social, and developmental needs of CYSHCN are NOT being met by CCS or otherwise (especially because of the emphasis on medical diagnoses):**
 - “This is a real area of opportunity for improvement because there is not currently a consistent way that these needs are being met.”
 - “Given that we don’t have comprehensive care coordination, mental health or developmental screening...not doing well.”
 - “Definite gap in services. Focus has been on medical diagnosis – big blind spot.”

- **Some specialty care centers or specialists are working on the emotional, social, and developmental needs of CYSHCN and their families:**
 - “I think our therapists are doing a fantastic job, so much of it is the whole family and I think our therapists really try and see where the parents are at and what are their well-being and social needs. We do a good job of asking. And the education we provide helps with developmental needs.”

- **Sometimes these needs are met, but only after the situation becomes an emergency:**
 - “Have to be suicidal or psychotic to really get resources. There are limited resources and visits and families don’t have ability to pay [specifically talking about non-CCS CYSHCN].”

Transitioning Adolescents

Summary of comments on how well families and adolescents are prepared for transition both in and out of CCS:

- Transition is **always complicated**—it is **consistently hard to find adult providers for individuals with special health care needs**, but *sometimes* specialty centers or specialty programs create a ‘safety net’ for transition, but they take years to establish and are only for very small portions of the special health care needs population, and *sometimes* these programs are doing it under CCS direction, but that isn’t common or consistent:
 - “In specialty centers, we have a process to transition to adult specialty care but not so much with primary care. We have a good process and start early and document well...I’m not sure what CCS does with those transitioning. In pilot [WCM pilot], they should be working on both primary and specialty care get transition services.”
 - “Very difficult. There have been some efforts, but it is a systems issues and people have to be on the same page. If CCS is trying to get hospitals to play with them around transition and the hospital doesn’t want to do it, it is a big loss to kids. Not a requirement. Lots of work for CCS to do to change the system.” **(Please Note: it is, in fact, a requirement for County CCS Programs.)**
 - “So many working on it but not sure it gets done. There are three challenges: first, make sure kid is adequately engaged in providing their own self-care. Two, adequate adult providers to take care of

kids – especially ones that take Medi-Cal, and three – couldn't we all have a shared consolidated plan? Each entity could take a part e.g. health plan, SSC, etc.”

- “I am unaware of any. But a good idea.”

- **The majority of CYSHCN and adults with SHCN experience gaps when they age out of CCS, and it seems to be similar for non-CCS populations as well:**

- “Yes, gaps in every disease state. Not enough providers. If they had a **common transition database** that all could work with and the various agencies that work with child.”
- **“There is no system for kids aging out.”**
- “On the private insurance side, there is such a lack of understanding about how this works, especially with SHCN, they are not prepared for what it takes to navigate and make this transition.”

- **Suggestions to improve transition services for CCS clients:**

- **Keep patients into adulthood, forget about age requirements:**
 - “In my practice, **I treat the condition not the ages**. Patients don't want to leave and we never ask them to. The majority of them over are 18, and I do take Medi-cal.”
- **Have dedicated staff whose only job is transition:**
 - “[Redacted county] has someone dedicated to this.”
- **Create a training for all staff and providers within CCS or guidelines, and standards/guidelines within CCS:**
 - “There needs to be a curriculum for training staff and providers. Needs to start early, it always sneaks up on people.”
 - “Needs to be a definition of what are appropriate and best practice activities for transition. Statewide policies and guidelines.”
- **Teach families and teenagers how to advocate for themselves before transition age hits, because nobody else is there to help with transition:**
 - “Building advocacy skills for child and family...But they are teenagers so there are challenges with self-care. Not a lot of follow-up to make sure that they are getting adult services and getting access – no accountability.”
- **Each county having a directory of providers that are comfortable with adult SHCN:**
 - “Nice if each county could have a resources manual or list of PCPs comfortable taking care of aging out CYSCHN. For example, GYN is hard since most providers don't feel comfortable seeing [special needs individuals for that]. **Building out network of adults providers.**”
 - “...There isn't a warm hand off. It would be excellent if they all knew who each other was.”
- **Get Medi-Cal to pay more for transition services:**
 - “Not sure how to address the issue of finding adult providers – real dilemma. CCS could do training programs or **get Medicaid to provide enhanced payment**. Planning and educating would be easier. Also, other human services are paid for by the state think about transitioning.”

CCS Partnerships

How well does CCS partner with state and local entities, and recommendations for partnership:

- **State partnership and communication between CCS and Medi-Cal Managed Care (MCMC) has improved, but still has a long way to go:**
 - “When we started the project, CCS and MCMC weren’t talking at all and I think that has improved a lot, MCMC has been more communicative, there is still much to be done with CCS.”
- **Local partnerships with CCS are positive and effective:**
 - “Actually, locally there is good partnering. MTUs is a shining example – they know more than county CCS. In a lot of areas, it depends on how the groups work together and there are lots of efforts to get them to work together.”
- **Local partnerships are varied, especially health plans and local CCS, and even more especially after Whole Child Model (WCM) is implemented:**
 - “It is extremely variable. Seeing this in WCM too (for example the relationships with health plans). I do think that CCS programs overall do well partnering with specialty care centers where they send their kids.”
- **Local partnerships with schools and school districts are fraught (especially with MTP)—this is related to the State not communicating with the State department of education** (note: CDE = California Department of Education):
 - “I am a part of the MTP advisory committee that includes several chief and supervising therapists statewide. We talk a lot about school relationships, most counties feel like there isn’t a great relationship because CCS and the schools have an interagency agreement, not all county CCS programs are getting those funds and those needs met at this time because CCS staff were told not to go into the schools and instruct and that has the schools (due to legal issues) thinking ‘why are you here then and why are we paying you?’ which strains the relationship.”
 - “There is an ugly disconnect between CDE and DHCS and how both programs are being managed. It is **something that the state is really trying to ignore at the state level and they really need to sit down and talk to each other**. We work with the schools and that could be really great for these kids to receive care. It is getting worse and needs to get better.”
- **State partnerships and communications needs to be improved:**
 - “The State does a terrible job. **Counties do better**. Almost nothing is going on at the State across these agencies.”
- Suggestions of who should partner with CCS are:
 - “**AAP** would be great, they partner with Medi-Cal, but it needs to be more formal. **Regional centers, and the school district** would also be beneficial.”

- “Works with **MCAH** and so should state.”
- “Partner with the entities listed above. Some sort of **interagency coordination**” (the listed above were: **Early Start** and **CA Interagency Coordinating Council**)
- “Including the **community chapters**”
- “Education and regional centers”

Medi-Cal Managed Care (MCMC)/Whole Child Model (WCM)

Summary of comments on observations and/or anticipation of the changes that come or will come with WCM/MCMC and how they affect local and state CCS:

- **Pilot programs, and those about to pilot are struggling with the transition and the clarity around how WCM will function at the local level:**
 - “My anticipation is that it will improve care overall and not fragment care and not confuse families, which is a win for families. Interesting process. Lots of demands on counties and very time intensive with lots of meetings and MOUs and policies and procedures. Trying to figure out what the State wants with CCS and Medi-Cal locally. They need one person answering questions. We’ve been meeting monthly, and trying to make it a good process. Trying to mitigate misinterpretation of things.”
- **The case management transition from county CCS to MCMC Health Plans is NOT going smoothly:**
 - “...people are really worried about case management transition from county to MCMC and concerned MCMC won’t have experience, knowledge, relationships. Evaluation of how transition going might not be accurate, what is being considered is written grievances [as complaints/evaluation] and that is a barrier for families to do. Difference in philosophy with what CCS did for families and what MMC will do. **MCMC will put burden of proof of necessity of care on families and when county CCS did –tried to help families get care. Insurance companies generally try to limit care.**”
- **WCM is variable from county to county and has left a lot of people confused about the role of CCS moving forward:**
 - “**We have just divided the state into two systems of care** (WCM and classic CCS), and families are going to be in and out of MCMC and families won’t be able to access. There are a lot of people working to improve classic CCS. We have worked a lot with [redacted health plan name], but I think it is stupid and what I am hearing from my colleagues, it isn’t working in a lot of places.”
 - “The State has been walking a tight rope in terms of contracting with Medi-Cal Managed Care and what the role of CCS will be. It has taken a different shape in different counties and left a lot to be worked out by MCMC and not a lot of direction from the state.”
- **It will be hard to determine if it is working well because there was no initial evaluation of WCM:**

- “Too early to say much, but one big frustration is the lack of baseline data and being able to make good comparisons.”
 - “Hard question to answer, we struggle with how to evaluate what we are doing. We were supposed to have an evaluator for our program, but it never happened. How do we prove that it is working? Hard to know how to measure success. It makes it very difficult to compare your performance to other entities.”
- **Clear and consistent communication is needed with MCMC Health Plans—but that doesn’t seem to be happening:**
 - “I assumed that there would be more challenges with accessing specialty care, but I’m not sure that is happening. In [redacted county name], the Health Plan is being more restrictive in networks while all the other plans have been taking the position of open network so they are not trying to be narrow, and will except lots of providers in network. Continuity of care – if the network is open – then accepting the providers [providers that normally provide CCS care to CYSHCN]. We need to set up meetings with each of the Health Plans and they need to be agreeable.”
- **MCMC Health Plans need to build their knowledge if they are going to appropriately serve CYSHCN:**
 - “**Care coordination** is interesting – ostensible reason for WCM – but MCMC needs to invest in care coordination and **be explicit about expectations.**”
 - “...my only concern would be do the MCMC plans have enough knowledge of all of the services that CSHCN need? And are they getting sent to the right providers. For example: at the MTP if we are not aware of certain specialty care providers, how is MCMC aware of them?”
 - “**On transition** – no, not working on it. Met with some of the health plans and they didn’t even know what it was.”
- **Medical Therapy Programs (MTPs) are unsure of their role:**
 - “There has been talk that MTP will go away, but I don’t believe that is going to happen based on some of the pilot counties. Most MCMC plans seem to be working *with* county MTP. One of the most difficult things is knowing when something has actually been paid for via MCMC as far as DME. We do authorization, but unless the vendor tells us they didn’t get paid, we assume they got paid. It would be great if we would be able to look up when Medi-Cal furnished the vendor.”
- **CCS patients are losing out on vendors and hospitals that are used to working with them and other CYSHCN because Health Plans (via MCMC) either don’t want to contract with them or can’t contract with them:**
 - “...Pharmacies not accustomed to these kinds of patients, don’t always meet those standards.”
 - “Patients may have to go across networks. Who in the network will be influenced by cost? I think it will effect patient care.”

- **Transportation is/will be a huge issue under WCM:**
 - “Concern about transportation, because it’s not clear who is responsible for that. CCS used to pay, and it’s not clear if plans have the funds [anymore]. Have asked for help from families on thinking about transition issues, but I’ve seen no data on how it is going. All anecdotal.

- **Local CCS is negatively impacted by WCM:**
 - “...it included a lot of new changes and created some tensions”
 - “...they let go or didn’t replace a lot of case managers, so they are severely short on case managers and they aren’t sure what they are going to do.”

- Key informant’s **greatest needs** in regards to implementation of WCM:
 - “**Care coordination and virtual medical home** – I’m concerned about time to test and number of kids but excited to demonstrate and impact. [Also needed:] **Provider based orientation** – we work with families every day, which is more efficient and can **reduce fragmentation, shared EMR, and access risk assessment and risk score** – gets in psychosocial and family – 360.”
 - “[I am] Hoping the new governor is not interested in WCM and will not force the issue. Big mess to clean.”
 - “Make sure **plans understand how to take care of these kids.**”
 - “Oversight in a more analytical way.”
 - “From the initial pilot, I’d say: **more patient-focused education** on how it works because there is a lot of confusion (example: in regards to pharmacies that families have been assigned, a letter that was sent did not have clear info), **clear and comprehensive education for patients and families on what the switch is and means, and how to navigate the system.**”
 - “**I want patient care to not be impacted and for them to get the testing and care that they can get now.** Parts of the pie are going to the network and plans. Unless more money than is going into CCS now, less money will be available for patient care. **If it is not working well, they need to be willing to scrap what they are doing and go back to the previous.** Should be viewed as pilot.”

Biggest Unmet Needs for CCS Clients + Focus for the next 5 years:

- “**Mental health, school-based services** (taught in a natural environment and given the tools to thrive), disparity of parents that can navigate the system and parents that are left behind.”
- “Unmet need is **complete, comprehensive patient education about transition, and WCM/MCMC** and what will happen and how to navigate it.”
- “Biggest area of concern for next 5 years: **keeping access to special care centers that is comprehensive**”
- “I’d love to see us attempting to **take data collection seriously.** And the claims data focus of WCM doesn’t tell me anything about outcomes”
- “**1. Supporting CCS kids in rural areas** – making sure that they get them the services they need. Is the department **embracing technology to help?** **2. Transition** – better supporting kids and families and holding health plans accountable as kids age into the system. **3. How do we make sure that families are getting the support they need to keep their kids home** (DME and home health in particular).”

- **“Timely Access.** We know that each of the children’s hospitals has ample services, but getting in can be really challenging. Genetics, neurology. There should be an expectation about how long it should take to get an appointment (for example, how many days).”
- **“Families and kids can have the services and supports that they need to be able to have good health both emotionally and physically and that we focus on working across systems to support families and ask families whether their needs are being met more frequently and that we have a plan to respond to identified issues.”**
- **“Making the eligibility process more streamlined.** Making certain codes eligible would make it easier and get care quicker, rather than having to make the child eligible.”
- **“Consistency statewide for MTPs** because our families move out of county so frequently, it would be nice if there was more consistency so families wouldn’t feel like their needs were being shifted or unmet. We are trying to get a learning management system like blackboard to store data and have trainings, all the regs would be posted in one place and easy to find—especially for numbered letters so we can know if numbered letters have been superseded. So if we had it all in one place primarily for MTP that would be helpful. Our proposition is that we would be able to provide training to all therapists in the state because it would be in the learning management system. There would be a question forum and everyone could have access to them and be doing things consistently.”
- **“Probably expansion beyond the medical and focusing on coordination of care with child and family as focus** and what resources are needed and links to school and home and cultural environments and recognizing that even if the medical condition is not severe, the impact can be severe if all these other things are taken into account. **Virtual medical home could help**...Focus on health instead of illness. How do we make this kid and this family function at the highest level? **Increasing self-management and education.** For those with chronic condition, many not understanding discharge instruction –some of their flare ups they see - e.g. asthma – can cause ED use. Medical Home and better management could lead to cost reductions.”
- **“Whole child [model] – family centered care. Meaning that every client needs a care plan and care coordinator and a team and some way to assure that the family is an equal partner in processes of health care for their child and family gets support they need to do what they need to do to support child’s care.”**
- **“Working well, don’t change it! Medical homes** would be good. Providers should get together and work on improving quality and lowering costs. CCS could provide money to providers to do this.”

Biggest Unmet Needs for CYSHCN that are not served by CCS:

- **“The need for respite for families,** even when they get IHHS and respite I don’t know if they use it for that. I can’t begin to imagine what the parents of our kids with special health care needs go through. **The health and well-being of the parents and are they getting respite.”**
- **“More providers for access issues.** Pay providers for what they are doing. Pay them for the time they need to spend for children with special health care needs. **Pay the vendors better,** 10% more than what product costs.”
- **“Emphasize emotional needs, especially for young adults. Transition should include identification of those needs.** If we can ensure that they have a good transition plan and tell them what the resources and supports are to help them get a leg up.”

- “For youth, transition services. For younger kids, access to good care coordination and timely specialty visits”
- “Behavioral health. CSHCN have higher incidences of behavioral health needs but **we don’t do a good job of diagnosing or treating these conditions.**”

Greatest Successes of CCS:

- “Assuring access to subspecialists.”
- “Work that is done in MTUs. Most **family focused, family friendly** services that she has seen”
- “The way the **program sets standards**, including **regionalized system of care and robust services** for kids.”
- “The fact **that it exists** and really calls out and provides, and has an **expectation of specialty care** is its biggest success.”

Feedback on how CCS and Non-CCS CYSHCN and their families are managing within the current structure:

- “Some families are doing well, but it is very **dependent on a parent’s ability to manage across so many systems**. Either they have that innate strength or...I don’t think **we are doing much to help**. There are individuals helping all of the time, but not systems. **I think the system gets in the way more than it helps.**”
- “It is tough to have a kid with a chronic condition. **Need more universal referral for parent to parent services.**”
- “Families getting lots of different letters about WCM and getting confused. **Having to educate the families about this [WCM].**”

Last additional experiences, thoughts, comments, suggestions regarding CCS:

- “It is going to be **important to “modernize” CCS program as a whole**, around **medical eligibility, stronger state leadership, more consistency around guidance**, it is a great program that still could use improvements. Standard of care across the board, **ad hoc care coordination is not sufficient and does not meet the needs of the child in question**. We would also love to capture data on current state of CYSHCN. **Data-driven decision making is a good direction to go in so we aren’t navigating in the dark.**”
- “Much **more explicit standardized performance expectations of the CCS system** and measure of those expectation and measures and **accountability for failure** to meet them. And we need a **more open and responsive state agency that collaborates with families and other state agencies.**”
- “At **state CCS, lack of capacity**. Many have left. **Lack of attention and leadership being paid to CCS program**. The Department sees the program as a drag on a **mission to move everyone to managed care**. There isn’t a commitment to CCS, which is a longer-term philosophical problem. **No champion within the Department for CCS anymore**. There are some well-meaning people there working hard under difficult circumstances but the **program suffers from being neglected** – so many other programs and priorities.”
- “It is a **great program, very unique** and we really like it. **Nervous about what is going to happen**. Afraid that costs are going to limit care need by this.”