

**TITLE V CCS NEEDS ASSESSMENT:  
COUNTY CCS ADMINISTRATORS &  
WHOLE CHILD MODEL HEALTH  
PLANS FOCUS GROUP SUMMARY  
REPORT**

UCSF Family Health Outcomes Project, August 2019

## PRESENTATION OBJECTIVES

- Describe the work being done for the Title V CCS NA
- Summarize County CCS Administrators Focus groups through multiple topic areas
- Summarize WCM Health Plan focus group through multiple topic areas

# TITLE V CCS NEEDS ASSESSMENT

- DHCS contracted FHOP to conduct a 5-years Needs Assessment
  - Title V Block Grant
  - Components of the Needs Assessment: Key Informant Interviews; Focus Groups with Families, Providers, CCS Administrators, and Health Plans; Survey of Providers, Administrators, and Families; analyses of administrative data; review of other relevant data and research
- Today's presentation will cover two components:
  - Focus groups of County CCS Administrators (2) – one group with CCS Administrators in Whole Child Model Counties, one with CCS Administrators for traditional CCS counties
  - Whole Child Model (WCM), Medi-Cal Managed Care (MCM) Health Plans (1)

CCS COUNTY ADMINISTRATORS  
FOCUS GROUPS SUMMARY

# BARRIERS TO CARE FOR CYSHCN & THEIR FAMILIES

- Access to CCS services
- Especially to specialty clinics & services for CYSHCN in remote areas
- Cultural & language differences

“We have a transient population, it is difficult to tell where they are going or currently at to ensure timely access to care.”

“[In] some counties it is difficult to get access for CCS patients to state-approved specialty clinics. Some patients have long distances to go to get care they need.”

“Language and culture continue to be a barrier. We have a lot of Spanish-speaking monolingual clients in our county. Not just because we can't communicate, but there is a lot of cultural fear or temperament that creates a barrier. They won't answer calls, won't open mail. And these people don't have legal immigration status. This is getting worse, especially with [this] population.”

# BARRIERS TO CARE FOR CYSHCN & THEIR FAMILIES

- Communication & Clarity from CCS
- Transportation services

“In theory families are supposed to be allowed to use their own vehicles and get reimbursed—but in practice families are having a lot of difficulties in getting reimbursed. It has to do with strange policies via CCS that reimbursement has to go to the client or through the client and that doesn't make sense because sometimes they are three years old.”

“I agree, people don't know. We do a lot of outreach. Set up regulations so we can have kids coming in young, but that doesn't happen. We often don't get people early, we have to wait until the kid is not sitting upright and is older. Getting earlier referrals from outreach is key, speaking mostly about MTUs.”

# COMMUNICATION BARRIERS

Barriers presented as a result of the Whole Child Model implementation:

“Confusion. A lot of the community believes that CCS is going away due to confusion about Whole Child Model. Within the school system, they say ‘why would we provide you with notes, CCS is going away?’ Also identifying patients and getting them connected with the right care and the right specialist at the same time—that isn’t our role anymore, more concerns with this going away.”

“We have run into issues where the Health Plan is even introducing themselves as CCS, which is an even bigger issue. They are not doing case management or care coordination the way that we did.”

# WHOLE CHILD MODEL: BARRIERS TO CARE FOR CYSHCN & FAMILIES

- Access to paneled providers

“Our Health Plan also subcontracts transportation, pharmacy, and radiology, and there is a lot of fragmentation because the family needs to call these different companies in order to access the services. We hear from families that they need to make multiple phone calls—whereas in the past we could make sure that they get what they need. Not all families are equipped to do this.”

“Health Plans are supposed to follow our numbered letters and our guidelines and panel specialists, the problem is that they will only be choosing whoever is in their Health Plan network already that can handle it and take care of the continuity of care. Favoring in-network, not necessarily paneled providers.”

- Secondary diagnoses issues leading to delays in care

- Carrying over of services can create gaps in care

“Secondary diagnosis is annually reviewed so children are going to go several months before getting care.”

## WHOLE CHILD MODEL: BARRIERS FOR PROVIDERS OF CARE

- DME authorizations are more difficult
- HPs getting up to speed

“Just understanding the ins and outs of CCS, the difference between diagnosis and treatment, there are these specifics of CCS that they don’t understand.”

“The providers that knew it before, knew about authorization. In Medi-Cal Managed Care it is actually fragmented and they want a separate authorization—providers feel like they have to ask for everything. When we do authorizations, these authorizations tend to encompass that diagnosis—so it is a broader authorization off of a specific diagnosis. Now, with Whole Child Model they are adding additional steps and complications.”

- Difficult to navigate new provider network

“With our really specialized kids, it’s hard enough to get them a provider. If you tell them that they have this added burden of managing them in this way, they won’t want to treat these kids.”

## WHOLE CHILD MODEL: CASE MANAGEMENT CHANGES

- County CCS Admins feel that traditional case management has been lost:

“In reading 586\*—it seems like there was an expectation that nurse case managers from CCS would start working with the Health Plans. We were rapidly disabused of that expectation. They took a couple of our staff, but they were not at all interested in CCS experiences. They’re not doing case management, so they didn’t really care about how CCS did case management.”

“There is nobody doing oversight, we’ve actually been told when we ask case management questions, we are told ‘well, that’s not your business.’ Clients don’t know who to call at the Health Plan—they have to tell their story to four different people in four different departments.”

\*SB 586 is the bill associated w/ WCM

# COUNTY CCS ADMIN RELATIONSHIPS WITH HEALTH PLANS

## ❖ Regular communication is key

“There are certainly problems, but when the CCS program and Medi-Cal Managed Care work closely together on the issues they are much more effective at solving problems. If they are aligned in their message, they can completely change the landscape of care in a community.”

“Responsive and quick to help with problem solving. The capacity to serve children in Whole Child Model is going to be gradual and take a lot of time.”

“On the admin side—the relationship with our plans is positive. There are regular meetings, they often hear that they are good and communication is good. We work on better way of doing things.”

“We do have quarterly meetings with Medi-Cal Managed Care reps. Hot topics include duplicated services—identified who to contact, other big thing is helping clients transition to adult providers for both healthcare and DME—they didn’t realize there were bumps there—but we’re getting that info to the table.”

## EVALUATION OF WHOLE CHILD MODEL

“When we started Whole Child Model as a pilot, they weren’t even evaluating us. Do I think that we did good? I think maybe we prevented harm, we saved money, but as far as outcomes for our kids **I have no idea how they are doing.** I hope now that there is evaluation, that maybe we will help. I don’t know who is doing evaluation—I see the Health Plans numbers of admits, but that is it. But **there was no baseline,** the Health Plans are good at their stats and their HEDIS measures but **there is no measure of how CCS kids are doing.**”

# CASE MANAGEMENT

- As previously mentioned, changes due to WCM:

“Most of them have not hired anyone new for CCS, it is just in general an add-on. Health Plans end up with around ten thousand patients to manage. With that kind of a structure, I don’t know how that works. But with no dedicated CCS staff, I’m pessimistic about them being able to do what we have done. But our piece is gone, they don’t have the staffing to do what we do because their ratio is ridiculous. There is no ability for case managers through Health Plans to form any relationship with the CCS kids or families. Sometimes will just add it to a pediatric nurse or a non-clinical case manager who doesn’t know much and doesn’t have clinical expertise for CCS diagnoses.”

- Staffing issues for CM in general:

“In our county it is six nurses for ninety thousand cases, how do you accurately manage that many cases? You can’t really do anything when you only have fourteen days to do everything. They can’t carry the weight of the combined caseloads. They will never get to the right level. You can’t take six people, divide it by ninety thousand and expect them to accurately case manage them.”

“Generally speaking we have a good set-up. Not novel, but it works. Impacted by staffing shortages and vacancies as they occur. Big acuity model being worked on in our county—that will impact case management.”

# PROVIDER COMMUNICATION

Provider communication is important & coordinating them to communicate is difficult:

“I would say that within each hospital system there is always room for improvement on communication. EMR has helped, but has not solved all problems with communications because it can sometimes be filled with inaccurate information because there is lots of cutting and pasting that happens. We’ve struggled because reports are incomplete or inaccurate or hybrid reports and can’t figure out what is current and what is not. Hopefully we can have them understand how to make EMR reports more accurate. I don’t know how to do that other than one on one meetings with physicians. Other issue is inter-system communication. Huge problem with Kaiser if we need them to send a kid to a university hospital—there is no way for them to communicate with each other. Definitely could be improved, don’t know other than training and outreach how to fix that.”

# CARE COORDINATION/SHARED PLAN OF CARE

- County CCS Admins all thought that Shared Plan of Care (SPoC) is how CCS was meant to run:

“Sounds like the old CCS.”

“We’re not doing anything like that because that sounds like traditional CCS case management. It depends on who is the ‘owner’ of the plan.”

- Some also felt that SPoC needed to be assigned to a responsible party:

“One concern is that the entity that is doing the SPoC would need to be fiscally disinterested in the plan. And that is why I would feel a lot more comfortable with that role residing in the public health department.”

“We’re trying to do that and even managed care has to have a plan in place for each of its members, but the ongoing issue is who holds that responsibility and who has ownership of following up on the status of things. Because it is good to have a plan, but it doesn’t go anywhere because there is no accountability. We give annual high risk assessment plans, but nobody has to ‘own’ it, they just contribute. Until we deal with the issue of ownership, then nothing will happen.”

# MEDICAL HOME

“I think the plan is trying to make that happen. It’s not happening. You can’t have it without all of the buy in. They need to know what is expected of them. Nobody is informing them of that, there is a lack of education of the appropriate people...”

Admins know many are trying, but not always successful

Some have their own protocols

Medical Home (MH) capacity varies by geography

EMR & EHR are not always built to accommodate the concept of MH

“I think the answer varies with the geographic region you are talking about. We are a very pediatrician-rich community because of the hospitals that we have—have fed pediatricians into the community that have stayed. We are pretty lucky in that the pediatricians in our community are pretty good at providing care coordination, because our kids are low-income and the pay isn’t very good, and the private MDs can’t take too many kids with Medical Cal so FQHCs cover the gaps because they are not scared of the low reimbursement rate.”

# CCS MEDICAL ELIGIBILITY

- Many CCS County Admins feel it is too restrictive and doesn't include other disorders & diagnoses that should qualify for CCS:

“We are able to use them, we are working to improve interpretation of medical eligibility. For example, there is a whole classification of disorders known as auto-inflammatory disorders that isn't even addressed. There are certain medical conditions that are very complex, but don't qualify. One example is gender dysphoria—most people think of this as psychological, but the medical aspect of it is very complex, another is anorexia nervosa. There are particular areas where the regulations need to be updated, which is difficult because they are in law, but it needs to be done.”

“Too many times when I have had to call families and say ‘your child really deserves therapy, but they don't qualify.’ It is really hard, but you know that they would benefit. They haven't updated the regs since I've been around and I really think that they need to look at that. I think it is a great program, but there are kids that really fall through the cracks that could benefit from the program and it isn't fair to not let them in.”

# FINANCIAL ELIGIBILITY

- CCS County Admins believe that \$ eligibility is too low and should not determine if a child receives care

“That it is low. I talk to families that may not qualify because they are \$100 or \$200 over and then I’m looking what their out of pocket is going to be and it is right under 20%...the cost of living is so high and the \$40K is so low.”

“I agree that \$40K is ridiculous. So many families are losing their care. \$50K is still a huge hardship if you have a child with a special health care need.

To me, the monetary figure is arbitrary and it should only have to do with medical need that should be the basis for CCS only.”

# DURABLE MEDICAL EQUIPMENT (DME)

“Some of the rates are good and some are bad, can’t get a vendor to pay for certain things unless we pair them all together. For example, a helmet is hard to get from a vendor unless the child is getting a wheelchair, and a walker, then they’ll throw the helmet in—they don’t want to do all that paperwork for just a helmet.”

- Inconsistent availability of vendors
- Problematic practices w/ authorizations
- Sometimes vendors prioritize private insurance payers
- Authorization rates delay DME

“Also have had a problem in the past with ventilators and respiratory equipment. People have issues discharging kids because they don’t have a ventilator. Has been a big problem that has to do with the rates and vendors willing to work with the program.”

# DURABLE MEDICAL EQUIPMENT (DME)

*WCM specific DME comments...*

- MTP/MTU role under WCM unclear & causes delays
- Multiple mentions of issues w/ Continuous Glucose Monitoring DME, indicative of other issues with HP's using DME familiar to them and not the child

“...Sometimes the DME has been provided more quickly because MTP was involved and the Health Plan doesn't know, there may be times when they get the equipment more quickly but less appropriately because they don't work with the MTPs.”

“Diabetics have had a problem because we approve continuous glucose monitoring, and we authorized a certain thing, and Health Plans have a different one, and the families have to get that reauthorized.”

“This happens a lot where a child has a product they've been using for years and they are familiar with it, and the Health Plans will say 'no you have to use ours now' and this results in complications in authorization and then there are delays.”

# TRANSITION TO ADULT CARE

- Adult providers resistant to take on CYSHCN

“The other issue that we faced is that PCPs in the community were afraid to take on complex kids as adults.”

- Unsure of how it will be affected by WCM, but some HPs have plans in place

“Our plan has a three-year follow-up period. So at a minimum they have to check in once a year.”

- Special care centers sometimes have their own transition plans

# FAMILY CAPACITY

Family capacity is already stressed, County CCS admins feel WCM changes create further issues with...

- Confusing process for grievance filing
- Family engagement/communication
- Transportation reimbursement issues

“Transportation issues, sending (through uber or lyft) jeeps with dogs in them, sports cars for fragile infants, just sending the wrong kind of transport. Our Health Plan does not want to reimburse families either—they do sometimes if a family member drives them but they don’t advertise that. Also, we sometimes have nobody that will transport children or families because they are out of county and funding for out of county transport is a huge issue. They will not go, especially if they haven’t been paid since last time. Creates delays in care because they have to wait for transport to centers out of county. Initially the vendor was really unprepared for the volume. Not being able to take siblings and there is no day care, big issues with that.”

# MENTAL AND BEHAVIORAL HEALTH

- WCM Health Plans have more mental & behavioral health providers; need more that specialize in CYSHCN:

“Our plan contracts out with a group to provide mental health—I don’t know if we did prior to Whole Child Model, we had a social worker available at all times to meet with families and she could help assess and assist. Our Health Plan does have social workers too; however, I don’t know that they are trained at the right level for these families and their needs. They can call and get assistance with domestic violence, but I don’t know that they have a skill set for mental health.”

# MENTAL & BEHAVIORAL HEALTH CONTINUED

- CCS County Admins on mental & behavioral health care within CCS generally:

“I have always thought that the family is sacrificed in the program, when they put CCS together—they should have built in for there to be someone to handle the grief that a family feels when they have a disabled child. Someone that can handle and help these families through a grief process. I don't think we have a very good system in place for mental health—there are some programs to refer but they depend on the family's insurance, but there is always a huge waitlist in getting kids into any kind of behavioral program. We're not equipped to help families through this, that's not our training. I see this as a real need.”

“...The grief and the trauma of multiple medical procedures, it can't be overstated how stressful that is for the kids and the families and siblings. The numbered letter on mental health services is way outdated and even though it says that CCS is here to provide the mental health services and pay for them—we just aren't able to. The provider community in the mental health community is not by and large prepared to deal with special health care needs, especially non-verbal or deaf. Buildings are not wheelchair accessible. Difficulty teasing out the mental and cognitive issues for children with intellectual disability. Services are not very well tailored to the needs of chronically ill children. There should be a psychotherapist at every special care centers to provide group therapy to diagnosed populations.”

# PRIORITIES FOR THE NEXT 5 YEARS

“Paying for more nurse case managers, and nurse case managers that don’t have extremely high caseloads.”

- Increase Nurse Case Manager workforce & capacity
- Better & consistent communication between HPs & County CCS
  - Better communication from DHCS
- Provide specialty care to CYSHCN regardless of CCS status

“Have specialized groups within and outside of CCS.”

# PRIORITIES FOR THE NEXT 5 YEARS

WCM related needs:

**“CCS needs consistency in quality of care**, we were incentivized to give the very best care possible and now the incentive is financial, and I am worried that is going to trickle down into all of these issues. Or is what is happening. You just feel like you don't know what is really happening to these patients that we used to know really well.”

**“Mental and behavioral health of the child—it** is lacking and has never been well addressed.”

“There are some things that I am worried about as more things that we are experts in are handed off to Medi-Cal Managed Care plans. **I hope the state is able to develop county to county and Whole Child Model to non-Whole Child Model CCS transfers—at the minimum know what has been authorized**, what meds they are taking, and who they have seen, Medi-Cal Managed Care plans have the ability to pull this down—we want a minimum standard that they get this and I don't think anybody should have to wait five years for this”

**“Increasing the financial and medical eligibility.** Also seconding the above about communication from the state.”

“New governor's budget, there may be money **for evaluation of Whole Child Model and that should be done.** Tried in the past and because it cost too much they scrapped it. “It was either the cost or maybe they just didn't want that data” whatever the cost, they are not really motivated to have useful data.”

“The state got it exactly wrong, we are all in favor of Whole Child Model, we just wanted CCS to be the holders of it.”

WHOLE CHILD MODEL HEALTH  
PLANS FOCUS GROUP SUMMARY

# BARRIERS TO CARE

The biggest barriers to Whole Child Model (WCM) implementation & maintenance of CCS goals...

## Higher costs that effect partnerships:

“We hired a lot of county staff that I had worked with so we felt like we started on a great level because we took knowledgeable CCS Staff. But the biggest thing that we had to deal with are the rising expenses, we did cost comparative analysis—our in-patient rates have gone up about 35%. UCSF has refused to contract with us and Lucille Packard refused as well—they want to do 90% charges, which puts strains on us financially.

## Eligibility issues that result in delays in care:

“We are one of the few that has “dependent” counties and that makes it hard, we meet monthly with all of the counties together and the difference between dependent and independent we always have to stop and think about how to determine how eligibility or how things work. Delays for enrollment and eligibility as a result. Many of these counties may have only had a small amount dedicated to small counties FTE, so taking from county staff was tough. Timeliness and accuracy of information for approval for enrollment. We’ve had to come up with safety nets like how long will they have to wait to be eligible in our system based on what the state is saying in their system. We tend to disagree with the state on eligibility or we think that they are [eligible], and the state doesn’t, and they think they are and we don’t. Access is always a huge issue for us, particularly our CCS kids because we don’t have a lot of pediatric specialists in our remote counties, which creates a lot of transportation issues.”

# BARRIERS TO CARE

The biggest barriers to Whole Child Model (WCM) implementation & maintenance of CCS goals...

- **Lack of access to CMS Net/Other EHR**

“Not having access to the systems that we would have wanted to when we went live, I.E. CMS net. We have it now. It is being spread across the counties.”

- **Lack of baseline data/evaluation of WCM**

“One of the challenges is the evaluation of the implementation; the providers all have different relationships with the patients and different relationships with each other. Parent’s expectations are driven by the county previously or their relationships with providers and organizations. Which level of satisfaction is the standard? Had we had that to begin with, we would have known what to do. In [redacted] county there was no CCS staffing, they were really struggling. We would have all known what we were aiming for.”

# MOVING FROM CCS MEDI-CAL TO MEDICAL MANAGED CARE (MCMC)

- **Transition has been hard on all parties involved:**

“Our teams have always worked very closely with the counties, we had CCS liaisons, we had MOUs with the programs. We had a really good partnership. It is the expectation of how it’s going to go—with different counties, it is really hard. There was a grieving period during that transition because the county had to let go and they were losing something. The level of investment that they need to maintain the kids that have remained is higher than the state anticipated.”

- **Hiring of county staff has been difficult (but has worked out in some cases!):**

“We did with one county, but it didn’t last very long. But what we and CCS didn’t realize is that the approach is so different, we all just thought that they could just come over and do the same work, but it was really a different job and I don’t know how well that the county prepared those staff for it, but they weren’t and they left.”

## MOVING FROM CCS MEDI-CAL TO MEDICAL MANAGED CARE (MCMC)

Lastly, DHCS lacked communication or facilitation of communication that might have helped the transition to be easier:

“We were aligned at the policy level with the county, and the county had open positions for CCS, and then that made it less challenging. The counties had conversations with DHCS separately, at least in our case, we would immediately talk about those conference calls. They did that instead of having the two parties get together. DHCS talked with the counties under a code of silence and then with the Health Plans under a code of silence. We have a great relationship with our counties, we work really well together, I think there is an idea in Sacramento that we don't, so they keep us separate—but that isn't true.”

# CASE MANAGEMENT

- Case management has not translated exactly as it was w/ County CCS
  - Resulted in massive caseloads (1 case manager for 500 kids)
- HPs feel that their new way of doing things leads to fewer gaps in case management:

“In theory what everyone here is saying is that case managers had large caseloads in the hundreds and they were only working with about 30 of them that were very complex. And they feel like now under this new model they are able to get access and to reach the other hundreds...”

- HPs making efforts to ensure families get to have someone to call:

“One of the things that we heard from the counties is that they wanted to get to know the people they were calling. So we made sure that there would be at least three people per county that could take that on.”

# CASE MANAGEMENT

- HPs feel that **increasing social workers & utilizing ‘risk tiering’** can support case management practices:

“We used a risk scoring system, but we took the approach of everyone has to have the option to interface with someone. Granted it has been really difficult to get that going. We have very clear guidelines and expectations, but we have staff that is doing things in a meandering way. I think it is useful to think about whether you want care coordination, service coordination, or case management. If these people are going to self-assess and see what is going on, we can see what they need and evaluate if they can get things done. Right now all we can do is get that risk assessment done slowly and painfully. Case managers were involved in all aspects of their patient’s care, and when we moved them from that to our model, it was hard for them to let go of this and [they] feel like their work is less meaningful.”

# MEDICAL HOME

- HPs have the capacity to provide Medical Homes (some even have them already)

“Medical Home is a philosophy of Medi-Cal Managed Care, most that transitioned were linked to a Medical Home through their PCP and that was maintained. We promote that model of making sure that it is going to the PCP. PCPs are not paneled, but all of the specialists are paneled.”

“In terms of having a Medical Home, we feel better about people having ‘one stop shopping.’ We had patients in CCS that didn’t know that they had appeal rights. Now they know, and I don’t think we’ve had any grievances filed. We help them predominately to navigate the system.”

- Primary care MDs from HPs are still learning how to work w/ CYSHCN

“Not every PCP is as comfortable with a complex kid—sometimes specialists like Lucile Packard are used to that, they have PCPs that are used to it there.”

## TAR VS. SAR

- Health plans find that utilizing Treatment Authorization Requests (TARs) more than Service Authorization Requests (SARs) means more specificity in care:

“Because a SAR is very broad, the CCS nurses could just initiate a SAR, but with the health plans a TAR is more specific—we adjudicate but we don’t drive the care and so there has to be a PCP that has to initiate that care and they end up more involved as a result. Nurses can’t do it anymore under Whole Child Model.

We’re looking at medical appropriateness by doing it this way, versus having a SAR authorize them for a year. A SAR would allow almost anything, a lot of those things within the SAR don’t require a TAR—so you have to put it into perspective because an MRI requires a TAR, but the things around it don’t (i.e. blood draw, medical apt). This way now we have a total knowledge around things, what we read was there were really tedious and detailed codes via SARs.”

# MEDICAL & FINANCIAL ELIGIBILITY

HPs feel that medical eligibility is arbitrary & would benefit from including mental & behavioral health issues...

“I find it to be very arbitrary; also there is no inclusion of behavioral and mental issues. They could really benefit. The problem is that it differs across counties such as asthma, but then they end up in ERs in counties where they don't qualify...”

...They also believe that financial eligibility is inadequate:

“...You can also have someone fall off of financial eligibility and that doesn't mean that they don't still need it. So there is an inequity building because they have less funding support outside of CCS eligibility. I would love to have a pediatric team that doesn't operate within this arbitrary line; I don't think it benefits the children.”

## HEALTH PLANS ON ELIGIBILITY IN GENERAL...

HPs see WCM as a way to get around restrictions put in place by eligibility criteria...

“We have to think about it from the patient or family perspective, if a kid is having a negative experience, we want our team to be able to get involved regardless of eligibility. This is what the Whole Child Model allows us to act on. My son had very acute and time related issues and was on CCS and it was terrible, and so I called the [the Health Plan] and they helped. And I would want to still be on [Health Plan] if I were still in need. I kept wondering ‘I work in this industry, how can other families that don’t have this knowledge navigate this?’”

...They have also identified some specialized areas where it is particularly problematic

“If I could be an advocate for any particular issue, it would be the NICU, we are literally afraid to touch it—there is a policy that is functioning well enough, but anything can change and cause a lot of confusion. Our CCS team receives all of the NICU requests to cover the expense or authorization request. The NICU complexity is all tied up in Medical eligibility and that changes, and trying to keep up with that on a day to day basis is difficult and these are some of the most expensive cases and they shift over time. There is no way to tell what the baby’s insurance will be after the first two months on the mom’s [insurance].”

# DURABLE MEDICAL EQUIPMENT (DME)

“The coordination with the MTPs has been a change and what we were able to do is to give them access to our provider portal and that helped because then they were able to have insight into where they were in the process. They were wanting us to follow-up, because those were some of the conversations that they used to have, and now the MTP knows that they need to be coordinating follow-up with the vendors themselves, which they were in the past using CCS staff to do.”

- HPs have mostly positive relationships w/ vendors
- Role of MTP/MTU continues to be uncertain, HPs troubleshooting issue
- HPs have diff experiences & ideas about DME delay, but all agree that specialized DME causes delays

“We had a DME person come and set expectations on what a normal delay would be based on the nature of something needing to be custom built. We are trying to monitor for system delay versus building delay.”

“We agree there are delays on highly specialized DME.”

# TRANSPORTATION

Funding/administration of transportation benefit is/was disorganized...

“Counties have capped funding and it was all over the map for how they were administering that benefit. We are working on it because it was complicated, and we had a recent situation when we had to fly parents out and I asked about what happened in the past and they were not applying it in accordance with the letter. Some counties used to pay for both parents, but they are only supposed to pay for one.”

...As a result, changes during the implementation of WCM are causing confusion

“You get a lot of backlash for how they are used to handling transportation. The CCS program historically was more adaptable to county specific needs, and when you transition that to the expectation that the health plans are going to follow the numbered letters to the letter of the law it feels like there is a disruption of the benefit. But in reality that rule always had to be followed and we have to figure out how to make it a cohesive program. It was well intentioned because they were trying to do what was best for the families. We’re [often] stuck in the position to pay people from other counties to drive in remote counties. We do gas reimbursement when possible, but we have to be creative.”

# MENTAL & BEHAVIORAL HEALTH

- HPs have similar issues & struggles as providers/county CCS; sometimes utilize county partnership

“We partner with county behavioral health, usually. And once someone gets into treatment we are less worried, but getting them into treatment for mental and behavioral health is harder, and I’m sure that varies plan by plan.”

- HPs feel these issues extend beyond the CYSHCN populations

“I would say that across all populations the lack of mental health providers is a huge issue in general. We’re trying to support our clinics and hire in more behavioral health into the clinical setting. The networks are adequate, and all of the areas are underserved.”

“Our challenges with behavioral health and mental health are not unique to children and youth with special health care needs and their families.”

## SUGGESTIONS/EXAMPLES TO IMPROVE MENTAL & BEHAVIORAL HEALTHCARE

“I do think that the **proactive assessment should include identifying that need and linkage to MH and BH for mom and child.** I don't think that intentional linking existed before. I think that identifying the need for those services is a positive thing.”

At [Health Plan], we really pushed **telehealth**, and the number one specialty that we are providing through telehealth is behavioral health, and we have contracted with Beacon to do it. In the [city] office, we have a behavioral health team from Beacon sitting 20 feet from our care coordination team.”

# FAMILY PARTICIPATION & ENGAGEMENT

HPs encourage family participation through **family advisory committees, stakeholder meetings, and community forums:**

“Family advisory committees, we also had stakeholder meetings in the beginning. Until it actually comes down to the time, we didn’t get a lot of participation. We asked our county CCS partners for families to be on our advisory committees and **we gave them incentives.** We also partnered with Family Voices. Some of these families and kids were only seen once a year, **we had to send some of our staff to the clinics so they could know our face and voice, which is what they asked for.”**

“We hosted community forums starting in 2015 and going forward. Worked with CRISS and Family Voices. We sponsored families to go to the Family Voices conferences. Once we got the advisory up and running, we are meeting monthly and letting the committee drive that. They have coalesced and formed and they are more engaged now. We do it by phone and we aren’t formally doing it as a Brown Act advisory board because you can’t do it by phone, so we aren’t calling it an ‘advisory group’ it is called a ‘committee.’ We made that shift two or three months ago. We also have televideo. **Some of it is earning people’s trust and making sure that they know that their participation can make a difference.”**

LAST COMMENTS REGARDING  
SUGGESTIONS FOR PRIORITIES FOR THE  
NEXT 5 YEARS

“Improve the info coming back and forth, the **communication** between who is and isn't CCS.”

“The **system needs to recognize the social determinants of health** and provide funding to address those in addition to the funding to address the health need.”

*Please note: these slides are filled with suggestions, these are just the last comments made as the focus group came to a close*

QUESTIONS?