

## CCS Administrators Focus Group Summary CCS Title V Needs Assessment 2018-2020

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### Barriers to Care for CYSHCN & Their Families

Barriers witnessed by County CCS Administrators:

County CCS Administrators stated that **the barriers to care are:**

- **Access to CCS services, including Specialty Clinics for CYSHCN depending on where they live:**
  - “Some counties—difficult to get access for CCS patients to state-approved specialty clinics. Some patients have long distances to go to get care they need.”

- “We have a transient population, it is difficult to tell where they are going or currently at to ensure timely access to care.”
- **Cultural and language differences:**
  - “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 the latinx population.”
- **CCS communication and clarity with CYSHCN and their families:**
  - “Program may not be terribly well known in the community, especially by hopefully future clients. Pediatricians were often reluctant to refer because they would have patients taken away, they felt we would send them to Stanford instead.”
  - “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.”
  - “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.” *Note: Both CCS Administrator groups had a mix of Whole Child Model and non-WCM counties represented.*
- **There are issues with 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.”

## Whole Child Model

County administrators commented on the changes from the transition of CCS from County CCS to Medi-Cal Managed Care Health Plans:

### Barriers to care of CYSHCN:

- **Not having the paneled providers that were available to the CYSHCN previously:**
  - “There’s not the requirement from the state that Whole Child Model children see panel providers, that is gone and that is a major concern.”
  - “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.**
- **Services once provided by County CCS are not adequately being carried over, which can have negative outcomes for CYSHCN:**

- “I heard from a medical director from a large clinic that all of CCS has switched over to [Health Plan] and now there is no CCS. **That is a big problem, them thinking that there is no CCS anymore.**”
- “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.”
- “Here we are nine years later where they told us that Whole Child Model was going to help reduce the fragmented care, and now it is EVEN more fragmented than it was before.”
- **Lack of clarity during transition from County to WCM Health Plans on multiple aspects of a child’s care:**
  - “We are a new Whole Chile Model county, we just phased in—the barrier would be confusion from providers on who is responsible for what. Where do they send the referral, to the Health Plan or the county? Do we review it at the county-level? We are needing clarity on who is responsible for what. Health Plans are under the impression that they are responsible for determining eligibility for [special care program], we thought we would be responsible for that—if we are, in fact, not—that creates an appropriate referral issue.”
  - **“It’s the new clients that I am worried about**—they don’t know that they are eligible for something and they don’t know any better. But in general, if I were knew to CCS and I wanted to get a DME, **I might be eligible and CCS would know this, but since CCS is out of the picture, Medi-Cal Managed Care doesn’t know enough to review the numbered letter to make sure it computes—and that’s where going forward I’m concerned.** Even for glucose monitoring, there was a big issue if we weren’t involved. Our MTU patients know what they need. The new ones, since we don’t touch them after eligibility—we can’t help them get DME... **This results in pts being 3-4 years behind where they should be.**”
- **Providers are not getting secondary diagnoses and that is resulting in delays in care and lower quality of care:**
  - “Secondary diagnosis is annually reviewed so children are going to several months before getting care.”
  - “Also one they are deficient in—we are not seeing referrals for secondary diagnosis. That is a big loophole because if we don’t add the second diagnosis then there is no requirement to have a paneled MD or specialist for enhanced services.”

#### Barriers for providers of care:

- **Providers have to work much harder to get authorizations for DME or services:**
  - “It has been good, but it has been very difficult because the response from the plan is only if you become loud and noisy and demanding in order to get them to respond. We had that experience with DME and the MOU for medical reports.”
  - “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.”
- **There is a lot to learn about CCS and Health Plans are not necessarily always 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.”

- **It is generally difficult to get providers for CYSHCN, WCM has made it more so since there are new providers in 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.”
  - “Biggest glitch in dealing with Medi-Cal Managed Care is the formulary for medication is sometimes different than what the child was prescribed. Not honoring “SARS” because pharmacy doesn’t take [Health Plan] insurance.”

#### WCM Transition Effect on Case Management, and Medical Therapy/Physical Therapy:

- **Most County CCS Admins feel that much has been lost in the transition in terms of Case Management:**
  - “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.”
  - “If I am aware of a situation, I can get a handle—but unfortunately we aren’t even aloud to know. **We wouldn’t know if the patients were dead or alive.** I’m concerned that they are using non-paneled providers. They [Health Plans] are supposed to be following CCS guidelines, that was made clear from the very beginning.”
  - “For us, we used to do intensive Case Management, where the plan wants to refer that back to the “medical home,” and now you are relying on the medical home to be reviewing those reports and saying ‘I know that this child has A B and C and I need to act on this.’ We were seeing that the patient was being referred to the county and the EMR has no connection to the health plan.”
  - “**With us a whole child would have been a whole child. With them, it is a transaction.** If you’re not a plan member anymore, you’re history. You are someone else’s whole child, not my whole child. The case management was unacceptable.”
    - There is more in case management in the case management section that follows.
- **Medical Therapy Units (MTUs or MTPs) are also losing a lot of their agency to work with CCS kids:**
  - “Only clients that are aware are in the MTU program because they did not get their authorizations and that was a major impact.”
  - “We were also told that this would not affect MTP, but it affected MTP on so many levels. We get a lot of feedback from these patients. They are having trouble getting DME now. I’m worried about the non-MTP kids that we don’t see. There are a lot of kids that don’t know what they are eligible for. The medical home, you can’t really plant all of that responsibility back to them.”
  - “Supervising therapists are still trying to communicate with providers through the Medical Therapy Conference—even though it is problematic in MTP, I can only imagine how much worse it is outside of MTP. We hear from a lot of providers that they are struggling to get authorizations because they don’t know who to go to. They are calling us to find out because they are blocked.”

### Positive Statements about WCM and Health Plans:

- “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.**
- “We have limited experience with [Health Plan] and very little communication—but because they are statewide they have figured out statewide issues quickly (for example the waiver). They do share the same mission with us but don’t share specialized knowledge, they lean heavily on us to understand case management—we lean on them for understanding adult service models. Have to do more work, but at least we have great people at the table.”

### The relationships between County CCS and Medi-Cal Managed Care Health Plans can be positive, especially with regular meetings and communication:

- “DME part—for the most part we have very good communication with Medi-Cal Managed Care. Sometimes a little bit of a problem because they want us to pay for all DME, but some is their responsibility because it deals with CCS diagnosis. Good communication for the most part, which depends on regular meetings.”
- “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.”
- “Benefits—they’ve been super responsive on pharmacy issues.”
- “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.”
- “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. It’s a struggle to get transport in place through the health plan. When we are having planning meetings with [Health Plan] we will work together to come to an agreement and get feedback from families in the weeks following that things aren’t happening the way that we agreed they would and I think it is taking time to communicate these things to staff in the Health Plan.

### Statements About the Evaluation of WCM:

- “**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

- **Many County Administrators feel that Case Management has declined since the Whole Child Model, in some counties because Health Plans are not willing to listen or accommodate this service:**
  - “Our plans [Health Plans] tell us that they weren’t ready for it, we’ve also had to be loud about things and then they fire back and say ‘well we don’t have that infrastructure.’ And I don’t remember our nurses going over there to help them. Even though they were supposed to work with nurse case managers. They are not reciprocal in hearing what we have to say. We have to be really forceful to get them to listen to them.”
  - “Families have ‘groups’ and not case managers within the Health Plans. Some of them have only been doing it for a few months and they aren’t considered responsible for that, they are basically just sending them to the PCP.”
- **They also are finding that the Health Plans lack the personnel and/or infrastructure to provide Case Management in the same way that County CCS has:**
  - “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.”
  - “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.**”
- **Case management can suffer from staffing issues regardless if it is County CCS or Health Plan based:**
  - “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.”
  - “Improving staff needs—supporting staff needs. We need more social workers, currently only have one. Hopefully where we could improve.”
- **For some counties, they feel that Case Management has been a really positive aspect of CCS:**
  - “It varies a lot from county to county, mainly because there are different levels of support of staffing, some are more robust counties. **In the counties where I have worked, if the administrator has a clear vision of how to create a multi-disciplinary case management team, it goes way better.** Sometimes used in very creative ways, for example, we have a DME coordinator. It depends a lot on the ‘creative thinking’ that is happening on the county level. If we have the team and we don’t have excessively large caseloads, I think we are pretty good at CM. **If we had better tools to measure our success, that would be good.** So far, the program hasn’t really done that.”

- **Some administrators had suggestions for how to better support the practice of Case Management:**
  - “...There was a tool developed in county to measure complexity—justify amount of time and energy expended for complex needs. Works well for us and makes sense. One challenge is that sometimes we view our Case Manager role as limited to those services that we could actually authorize directly, but oftentimes we could identify needs that CCS doesn’t deliver and partner with organizations that can and create that link.”
  - “We are currently trying to expand our transition program. Trying to develop a stronger parent advisory group. Trying to expand CCS out to the community by sending notice to families, texting and messaging system for all new clients for welcome orientation—will also send them a welcome packet with information One of the biggest things is that people don’t know who CCS is. Case management helps and supports this.”
  - “We have implemented social service system for Case Management—basically creating a ‘pod’ around the child—taking a group of staff that will follow the child through documentation to medical case management. Having a few staff members wearing multiple hats.”

## Provider Communication

- **Communication between providers is very important and pivotal, but it is hard to get providers in one place:**
  - “We are somewhat rural so a lot of communication between PCPs and SCCs is vital and they have a long standing relationship. If patients are directed to different PCPs and SCCs in the middle of a long-standing relationship with another, there is going to be a huge problem. If the pediatricians here really understood that this may happen, they would be extremely upset. The last time that we had a meeting to inform them, nobody showed up and I think they would be really concerned if they knew. I think this will affect the quality.”
  - “I think we need much better communication—really great if the kid is in clinic—not in clinic communication is spotty. We’ve had issues where pulmonology is concerned about scoliosis but not talking to the ortho doc and the kid is scheduled for surgery and the pulmo doc isn’t signing off on it. There are other examples where we don’t know how to intervene. Communication needs to be improved. Ideas for improvement: what we have sometimes done is have “clinic physicians.” Sometimes works. You would think that email would help, but it’s not a real consistent way to communicate. Just trying to make sure we know exactly what the child needs to have the best outcome. It is a problem in my opinion.”
  - “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

- **Some CCS County Administrators had heard of Shared Plan of Care, for others, it was new—their responses were variable on who’s responsibility it would be and how feasible it could be:**
  - “Sounds like the old CCS.” One focus group participant stated after hearing the definition.
  - “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.”
  - “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.”
- **They did have concerns about the model:**
  - “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.”
  - “Ownership of plans, I’m sorry, there has to be money that follows.”

## Medical Home

- **CCS County Administrators did feel that many providers and Health Plans are trying to implement medical home models and practices, but that they are not always successful:**
  - “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. No, it’s not happening.”
  - “We’ve come up with a list of criteria for CCS medical homes that they [MDs] should meet, absolutely required, and then just desired criteria—when we showed this to the MDs in the community they said they couldn’t meet AAP criteria because the bar was too high, but they could meet our criteria. I think we are going to have PCPs that are very interested in getting authorization because we can with our criteria and definition. [County name] developed a tool to evaluate medical home, validated the tool and administered it—the only problem is that it is entirely de-identified—but it does described the quality of medical home services that kids in [county] are receiving.”
- **Some of the County CCS programs have their own protocols for trying to ensure that CYSHCN have medical homes:**
  - “We had a person in our program who was running reports, so all of our kids in MTU have a medical home and we have a monthly report that reminds us “does this kid have a medical home?” So we are always reminding them. We only had one family that did not want a medical home. But because we have this report, we work really hard on getting them a medical home. Our goal is for the definition above, but sometimes is it just having a PCP—it depends on the care—of course our goal is to meet AAP definition—but to some extent we just want to make sure they have somebody. We take what we can get and we are happy that we can at least get the kids signed up for something.”
- **Medical home capacity varies based on where CYSHCN and their families live:**
  - “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 Medi-Cal so FQHCs cover the gaps because they are not scared of the low reimbursement rate."

- **There are a lot of technical issues with implementing medical homes:**
  - "One of our big problems is cleaning up the medical home database and E47. The problem is that, and IT people at the state know this, the medical home field can be completed by anyone that has access to E47, and every time someone is added—that variation of that person's name is added multiple times there can be unlimited entries—the state is just beginning to work on this problem. Trying to clean that up. There is no mechanism of making sure that a different county doesn't enter the same MDs name in a totally different way—it doesn't allow us to map where our kids are going."

### Capacity/Resource Needs to Implement Medical Home

- **"Care coordinators and case managers.** Have been told that there isn't **funding** for that."
- "If the physician does take it on, **you need licensed people because these are complex kids. Needs more funding.** MDs say they cannot afford to high more staff."
- "That's why the MOU required that **CCS staff go in and case manage**, and the state's intention was that Health Plans would do that care coordination and case management, **but that's not happening.**"
  - "Our plan has told us that it is not them it is the PCPs that do case management, but they didn't tell them that..."

## Medical & Financial Eligibility Criteria

### Administrator comments on medical eligibility criteria for CCS:

- **Inconsistent needs for paneled providers:**
  - "There is one change, the medical eligibility used to be based on that the child would see a paneled provider and that doesn't exist anymore and that does have an impact. We are trying to push back, but when asking the question directly of the state on state calls they have said 'it's none of your business whether it is a paneled provider or not.' We have so little left, that we are trying to hold the line while we can."
- **Too restrictive to disorders 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."
  - "I agree with the above on medical eligibility. 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."

#### Administrator comments on financial eligibility criteria for CCS:

- **Financial eligibility criteria is far too low:**
  - "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."
  - "If CCS would advocate for \$300K then we (CCS) would be back in business!"
  - "YES YES YES—\$40K is ridiculous, it hasn't been looked at in many years. Needs to be increased."
  - "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."
- **Financial eligibility should not be a factor in whether or not a child receives care from CCS:**
  - 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)

- **The availability of vendors is inconsistent:**
  - "What doesn't?" When asked what has an effect on the availability of vendors.
- **Some vendors have problematic practices with authorization, and sometimes prefer Medi-Cal to CCS:**
  - "We had vendors that would delay authorizing equipment to kids until after they aged out because Medi-Cal Managed Care would provide a better rate. I would say that the DME reimbursement is negotiable with Medi-Cal Managed Care and that made DME providers more hostile towards CCS and more favorable to Medi-Cal."
- **DME vendors sometimes delay authorizations because they give priority to private insurance payers:**
  - "Also the timeliness of it, if DME has privately insured people, then they get to them first. They tend to take longer to get DME to Medi-Cal and Medi-Cal Managed Care families."
- **Vendors sometimes delay authorizations because they want to group like items together, regardless of whether or not it is good for the child:**
  - "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."
- **Authorization rates sometimes also cause delays in getting 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.**"

#### DME Issues Specific to WCM:

- **Health Plans are still working out the issues with DME (and the role of MTP/MTU is unclear):**
  - "There were issues and delays at first when the Health Plans were trying to get their documentation together in terms of DME—now we can look into their portal to see if

something has been ordered. **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.**"

- "For us at least, they totally defer to the MTU therapists for DME. There's a reason why, some of this you don't want to authorize in just five days because you need to measure things. This happens also with formula because pharmacies have short turn-around time, but we have restrictions based on numbered letters that need to be looked at more carefully. Complicated administrative denials."
- **Uniquely, county Administrators did mention multiple times that there have been issues with Continuous Glucose Monitoring (CGM) DME:**
  - "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."
  - "Has been a slow-down DME in the communication and the processing. Initially shocked that they weren't going to follow through with standard of care for diabetes."
- **The issues with CGM are also indicative of other issues with DME where Health Plans have different products in plan that are not always appropriate to the CYSHCN who has been using something:**
  - "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

### Transition with WCM:

- **Most are unsure of how this will progress, there are not too many CYSHCN that have transitioned since implementation of WCM:**
  - "It's too short a time to tell if it's changed."
  - "I don't know what the Health Plans are requiring for transition training. We have a webinar this afternoon on that, but don't know so far. We've been working on this in CCS for years. But I know that our Medi-Cal plan is just now starting to develop a protocol. Here in the past, it has often been difficult, but it has been my role in the past to make calls to adult providers—and often that doesn't work, patients would have to travel outside of our county very far."
- **In some cases the Health Plans have great plans in place for transition:**
  - "Our plan has a three-year follow-up period. So at a minimum they have to check in once a year. In the past, our biggest challenge was those that were aging out of Medi-Cal."

### Transition in General:

- **Adult providers are resistant to take on individuals with complex medical diagnoses:**
  - "The other issue that we faced is that PCPs in the community were afraid to take on complex kids as adults."
  - "Some specialists don't mind keeping special health care needs patients after 21, but oftentimes we started that convo way beforehand and we were active in finding them an adult care PCP. I'm not sure what that would look like in managed care. No warm hand off anymore, but don't know."

- **Specialty care centers sometimes have excellent plans in place for transition care, however CYSHCN have such complex issues during transition that they might not be the solution:**
  - “We have a transition specialist that is great and if we did not have FQHCs that take low-income special health care needs patients, we would be in trouble. Sub-specialty has problems, no contracts to continue from private hospitals unless Medi-Cal Managed Care plan can justify single-case agreement. It is a huge problem. There are many areas where we have challenges—different special care centers have different levels of success in transition. There aren’t always sub-specialists that are more ready and willing to manage Medi-Cal patients than a pediatrician is. We have patients with really poor outcomes in that transition age. Many low-income kids with concurrent mental illnesses really fall through the cracks and the special care centers have a great deal of difficulty managing an 18 year old that is homeless and being trafficked, the psychosocial challenges of these cases exceed the capacity of the special care center—it’s not that they are not doing a good job—it is just another level of services that the community isn’t doing a good job of providing. Don’t have a good solution, but needs one.”

#### Suggestion to Improve Transition Care:

- “I think that MDs have to give patients some options. **What the plans [Health Plans] need to do is help them to find insurance rather than an MD.** I don’t remember docs dropping kids, our MTU docs were adult providers. The thing is that we have to get someone to pay for that care.”

### Addressing Family Capacity

- **Family capacity is already stressed, but further stressed by WCM changes:**
  - **Specifically pertaining to transportation (but transportation is consistently a hardship within CCS):** “The family has to advocate for themselves in the model and they are given an 800 number to call. There’s that issue and there is also the **transportation**—oftentimes not considering family needs and they’ll send a 4-person car to a 6-family medical appointment. Or they won’t send wheelchair accommodating vehicles. **And I don’t think they’ve really educated families what to ask for and so they don’t because they were used to the nurse Case Managers doing everything. Also limited English.**”
  - “Families don’t usually want to take the next step of issuing a grievance, and the family doesn’t want to or can’t take that on themselves. Limited capacity too, they just want to get their kid care. **Health Plans have been saying, “they’ll figure it out.”**”
  - “I’m very fearful that Health Plans don’t continue to schedule meetings—they’ll schedule them only for a few months. We aren’t going to be able to get through this transition for at least a couple of years. I’m afraid that we are going to lose the communication that we already have. **They don’t know that they need to care about family capacity.**”
  - “**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 & Behavioral Health

- **Health Plans under WCM have opened up CCS patients to their network of mental and behavioral health providers (which is sometimes larger than that of county mental health programs), but the expertise needed for this population is not always present:**
  - “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.”
- **The mental and behavioral health needs of the family members of CYSHCN are not part of CCS or WCM, and they are barely there for CYSHCN as it is:**
  - “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.**”
  - “Same for our county. We build relationships with parents, and so do our office support staff, but the best thing we can do is listen and give them resources we are aware of, but they have to pursue it on their own. We only really have general resources.”
  - “I agree with all of the above. 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.**”

## Family Participation in CCS

- **Family participation is important and valued, and there is a lot in MTP/MTU:**
  - “It’s sort of natural and encouraged in MTP, because we do require families to be present.”
  - “We have always had a parent liaison, and that has been very beneficial, because they have important input. They helped us to develop pharmacy formulary, they’ve tested out products from DME vendors for things like diapers. They’ve actually changed vendors and preferred products due to family input. We made sure there was a mix of MTU and Admin because it is

easier to get MTU parents involved, we wanted to be sure to say, ‘all CCS children would benefit.’ Contracted with legal aid for pro-bono for conservatorships process. They helped us get higher rates for PDN [private duty nursing, respite] providers. That has all been beneficial, so once Health Plans get that going and really listen, that will be good.”

## Priorities for the Next Five Years

- **Increase Nurse Case Manager workforce and capacity:**
  - “Paying for more nurse case managers, and nurse case managers that don’t have extremely high caseloads.”
  - “If nurse case managers could take only small amounts of kids, really high need and complex care.”
- **“Better and consistent communication between Health Plans and county CCS.”**
  - “Communication about what is happening week-to-week and month-to-month, year-to-year is not enough. Would like to be able to see medical notes.”
- **Provide specialty care to CSYCHN regardless of if they are in CCS:** “Have specialized groups within and outside of CCS.”
- **Better communication from the state:** “The state should be more solicitous of what is going on and more responsive to the concerns that we raise. There are some things that really have to come from the state and they are so slow to even start the action. Month after month we are bringing up the same issues and they are treating them like it’s the first they’ve heard of them.”
- **“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.”**
- **Whole Child Model specific concerns & requests for the next five years:**
  - **“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”**
  - **“Due diligence to make sure that Health Plans are following the standards. Also, paneled providers, there is a reason for that. A lot of their providers would probably have an easy time getting paneled, but pushing it on them to do, the Health Plans should help in that—that would help in continuity in all CCS programs. It’s very obvious that the state does not want to be in the CCS business. The state has made it obvious that they want to hand this off to Medi-Cal Managed Care plans—and I want to be sure that this continuity of care is equal to everybody”**
  - **“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."**
  
- **"Mental and behavioral health of the child—it is lacking and has never been well addressed."**
  - "Second that priority."
  - "I also total agree and third that priority. Also wanted to add that, instead of cutting funds because there are issues with funding, they should get us together to talk about it rather than making changes without consulting us."
  
- **"Increasing the financial and medical eligibility.** Also seconding the above about communication from the state."
  
- **"Echo mental and behavioral health and financial eligibility increase."**