

Appendix 16 - Family Focus Group Summary

Summary of Family Focus Groups – Title V CCS Needs Assessment 2018 – 2020

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Familiarity with CCS

We asked families how familiar they were with CCS, what it does, and what it covers. Here are some of their responses:

Familiarity with CCS varies, **some families were unaware of CCS altogether, some knew about it, but still found it unfamiliar, and others were very familiar due to all of the time that they worked with CCS on their child’s care:**

- “What is CCS?”
- “Pretty familiar, have had to deal with it since our son began.” *Son is currently 15.*
- “Sometimes I feel like I do know and sometimes I don’t. They have covered a lot.”
- “It has been a while so I don’t know what they are doing now.”
- “I felt like I knew, for the most part, what it covered and most of her [my daughter’s] needs were met. But also was my responsibility in asking those questions.”

Families have **felt the changes to CCS from Whole Child Model** (we did focus groups with both WCM and non-WCM counties):

- “I feel like until they made the changes, I had a little more knowledge what was covered. Now there are things that still exist, but I’m not aware of them. Though things have changed. I feel like ‘this time’ I don’t know everything.”
- “It was very good about that [telling us what conditions were eligible], but it isn’t anymore. The whole child model—people are struggling because they are CCS eligible, but not allowed to use CCS fee-for-service. Half of them haven’t even read it at [redacted name of health plan] and cannot interpret it. Pretty much didn’t tell us anything until it happened. It is difficult now because we are really CCS clients, but we can’t use it. [Health plan] is still figuring out how to fit it into their system.”
 - More on WCM transition to this health plan: Others here were not invited to the orientation from the health plan on managing the care of their children. They have been reached for assessment to find out what “risk” they were. Some received a brief letter, one parent called to make sure the case manager was the same and they told her not to worry.
- ...in response to other parent’s comments about losing case manager with the health plan: “because what they don’t tell you is that the county or health plan might not keep the case manager”
- “They knew that my daughter was admitted to ICU and not once did they say “look, what I can do for you.” I didn’t reach out because to me, if there are changes; it is their responsibility to inform parents of the changes.”
- “[Health plan], god help them, they don’t even know what CCS is.” *Note: this is likely untrue, but is reflective of a parent’s perspective on transition to whole child model, and the knowledge that health plans are still lacking.*

Non-Medical Services (Transportation, etc.)

- **One person used the transportation service and it worked smoothly for them, they had to call 5-7 days before your appointment. A quote in response:**
 - “That is wonderful, **but I had an emergency and I couldn’t sit there and wait for transport.**”
- **Transportation services are changing under Whole Child Model for the worse:**
 - “In the past, I was able to meet with my case manager and reach her, and turn in receipts and then get reimbursed for travel. Now you have to call eight times, might not reach them at all.”
 - “[Health plan] will not reimburse parents for mileage; they have to take [the health plan’s] uber or angel van that isn’t set up for our specific child. Sometimes we have a van or a car and [health plan] won’t pay for that—you have to submit a grievance....”
 - **“I’d rather be in debt then entrust my daughter’s life to some random uber driver through [health plan].”**

The **lack of consistency around non-medical services leads to many different complications for families:**

- “Also, if you have to stay in a hotel you don’t eat or get transportation? You have to eat all of the meals in the hospital. **Financially it has been complicated.** Our out of pocket expenses are increasing.” *Note: whole child model county.*

How well are your child's needs being met?

The following details the responses of CYSHCN and their families:

Many families feel that CCS has been supportive and helpful since their child was diagnosed (with the addendum that most feel that Whole Child Model and health plans have changed this):

Comments from families in Whole Child Model, Medi-Cal Managed Care health plan counties:

- “It was wonderful, before the change. I liked CCS. They did the AFOs, they did the tubes, the diapers, they did PT, they were awesome. They were always there.”
- “In the beginning, when you have a child with a life-changing, lifelong diagnosis, there are so many agencies coming at you. In CCS, my daughter had the same case manager the entire time, maybe two in all of her years, she had CCS until she turned 21. If I had a question, I could call Patty [case manager], if I had a “share of income letter,” that scared me, I could call Patty. Supplies were covered very constantly. They even helped with transition.” Note: this person’s child aged out of CCS prior to WCM.
- “All the people you dealt with had such great expertise.”
- “They’ve met all of her needs. The diapers too, they give you an extra money for two different types of diapers. As of right now, [health plan] is not covering it right now because of my grades. They were putting \$30 onto my mom’s EBT. I asked and they didn’t do anything, but sometimes I don’t feel like asking again and again.” *Note: we believe that this participant received misinformation because this particular health plan would never restrict access based on someone’s grades. The parent in this case was a teenager.*

In particular, they feel that health plans do not familiarize themselves at all with individual cases and that is problematic for the care of medically complex children:

- “I complained to [health plan] and I asked them why they were doing this, they aren’t becoming more familiar with my daughter—CCS used to be like my family away from family because I didn’t have to justify with them. They knew my child’s history; if they had questions, they’d call me or get back to me.”
- “One of the problems that [health plan] is having is that they hired people that don’t know what CCS does and they don’t provide direct care. If this is the same care, why do we have to work so much harder for it? The [health plan’s] complaint department only keeps complaints for 24 hours.”
- **“The difference between CCS and [health plan] is, that CCS errs on the side of the child and [health plan] is cost-saving.”**

Sometimes CCS (both with and without the WCM changes) isn’t really modeled to make the most sense or in consideration of things outside of the child’s medical condition for CYSHCN and their families:

- “My son had a neurologist in [city over 100 miles from where we live], and he knew my son and his issues really well—but in order to see this same specialist, he has to go to his PCP for authorization first.”
- “CCS has been a big help...Only thing that is hard for me is that they don’t have after hours for therapy (OT), he has been missing school and getting depressed because he isn’t doing well in school.”
- “After hours therapy would have been helpful so that A) kids don’t get pulled out of school, and B) parents are able to be there to learn what they need to duplicate at home.”

- Several other parents expressed that their children were being pulled out of class, and sometimes they didn't have any idea of what CCS was doing in these sessions. *Note: it is unclear of whether or not this is an issue with CCS or the school district.*
- Other parents also mentioned children missing school for OT/PT, and being held back and missing classes for medical appointments.
- “It is very hard to make appointments or schedule regular appointments. The employees are switched a lot. It doesn't make sense why I can't have a regular appointment (ex. Regular apt at 8 on Tuesdays).”
- “They don't cover vitamins and it gets very costly outside of CCS.”

Comments from families that are **not** in Whole Child Model counties:

- “Just started OT and PT through CCS, on campus where she goes to preschool. Have two 30 minute sessions each week—it has actually been going really well so far. There has been an issue with covering visits with specialists, but I feel good about that being covered.”
- “CCS has been a big help, major surgery at [local children's hospital] recently that went really well. The OTs and PTs are great and very knowledgeable about the MDs at [local children's hospital]. No complaints about them. Only thing that is hard for me is that they don't have after hours for therapy (OT), he has been missing school and getting depressed because he isn't doing well in school.”

One common theme in our family focus groups: **families worried that CCS services would be taken away if they found out families were utilizing private insurance services:**

- “CCS would not allow us to do private therapy as well as CCS—we found out that she would be kicked out of CCS if they found out that we were accessing private insurance too. Why couldn't we take her to get extra therapy without keeping it ‘hush-hush’?”

Administrative and Enrollment Issues & Delays in Care:

Families have experienced difficulties with applying for CCS and reimbursements for their child's care, which often results in delays in care:

- “Difficulty applying for CCS, and getting reimbursed from time of diagnosis. **Steps to apply were not clear and resulted in a delay in getting services for my CCS child.**” Other parents had a hard time applying, it's not clear online. They keep asking for “supporting documents” or missing paperwork.

Some families were dropped from CCS with little to no explanation (and in one case, as the result of citizenship status):

- “Removed from CCS, and said that they removed my child because all conditions were being covered by Medi-Cal.
 - Another participant (who did not speak English) stated that they were removed, but they never explained why. The translator said: “She [the parent] does not speak English, and then **she found out that they removed CCS because she was undocumented and her family and children with conditions were undocumented**—she would like to get it back because she is seeking immigration status.”
 - “A lot of cases have been closed by CCS without a lot of explanation and it looks and feels like they are closing cases so that other insurers can pay for the services. Medi-Cal is

supposed to pick it up, but in all of these cases mentioned, Medi-Cal does not pick it up, they then leave our kids with nothing.”

Other families **experienced losing CCS, or CCS services for somewhat unclear reasons, or possibly due to the fact that certain conditions are no longer linked to the CCS condition:**

- “Medi-Cal has removed my child from CCS for their asthma, they had covered them when they were little, but then dropped them. The coordinator at the regional center hasn’t been helpful in finding out how to get back on CCS. **I have had to go to Tijuana to purchase asthma medication because it has been too expensive here.**”
- “My child was moved to Obamacare, then deleted because there were duplicates of him in the system. I do not know where to go to get access to CCS.”
- “Parents are not informed when the eligibility criteria changed, additionally they do not have this information in Spanish for Spanish speaking parent’s to learn of changes.”

CCS authorizations for CYSHCN sometimes result in delays in care. Private insurance also seems to cause complications when it interacts with CCS:

- “Immediate authorization was given in the NICU, but transitioning out of the hospital became difficult. **Because we had private insurance it became difficult, especially because of the complexity, CCS children have to wait six months out.** This isn’t efficient because it should be based on the child’s medical needs...We ended up having more surgeries because it was not proactive care that happened right away, we had to wait months for medical equipment and appointments.”
- “For my child, they stopped occupational therapy completely for her because they think that she has reached as far as possible, and she won’t improve more. But I feel like my daughter has potential and could improve more with PT. Because there are PTs in the school, CCS thinks that the children are getting better by them and then they take away other therapy for the child. For three years they gave her less and less—would only give therapy after intensive surgery”

Medications & Medical Supplies

Families have had issues with getting access to supplies that are not Durable Medical Equipment (DME) with whole child model health plans. There is miscommunication or lack of communication between CCS and health plans and vendors:

- “I never had a problem with the diapers before, they would come all of the time and on time and then we started to notice that they weren’t showing up. When June came, I called to find out and they said that she needed to get a prescription from the vendor. When I called the vendor they said that due to the changes they were not contracted with [health plan], and then I called CCS and they said that the vendor should be contracted and expected me to call and figure out who they are contracted with. Then finally, I got a list for three places in [my county], and they all said was “we don’t know why they keep referring you here, we don’t offer those services.” Then I finally called [health plan] and they were explaining she didn’t qualify for drugs. I had to go back to the original vendor to get the list of what they sent her in the past, and I had to go to the MD to get an authorization. **Why do I have to keep asking for something that they know my daughter has a lifetime need for?** They didn’t even have my daughter’s chart in front of them. That is what the state is paying for. Do they want to pay for people that aren’t sufficient at their job? Or just cut everything? It is almost like they want to hide it from you, I feel like they’re not really there for you, why do I have to fight so hard? I have to fight a battle every day.”

Families describe problematic practices:

- One mother describes experiencing medical fraud: “I was charged for medications that were covered by Medi-Cal and then the place I was getting the medications was closed.”

Durable Medical Equipment (DME)

DME is inconsistent across organizations, and lack of access to it outside of PT or MTU can result in a delay of development for some CYSHCN:

- “Most of the programs seem to be working well. The guidelines are constantly changing for CCS, and they don’t inform you. I went to college, but even for me it is confusing. The biggest issue that I had is that a lot of the treatments are not consistent—there was a period of time when my daughter did not get any therapy (5 years old, cerebral palsy) and I was given all of the excuses in the book. One thing is that they only allow you to get one necessary medical equipment and then are only granted one when the child is actively able to use it, for example a gait trainer. I had to get the regional center involved asking for medical equipment that CCS would not grant us (a light gate trainer). In therapy—they give her all kinds of equipment to use and then they tell the parents to duplicate it at home, but CCS won’t give them more than one piece of equipment—how are parents supposed to duplicate therapy at home so that she doesn’t lose what she has gained. Single mother, has nobody else to help. Other children w/ private insurance are surpassing my daughter and we lost a year because of CCS. A lot of the “prescriptions” they grant have to be signed off by an MD and there are always delays due to this. Long wait between prescription and administration, MDs sometimes don’t return authorizations don’t carry over, have to go back to the new MD for a new authorization.”

Some families have positive experiences with CCS in regards to DME:

- “CCS helped us to get a wheelchair and delivered to the CCS office. [Our case manager] who was mentioned by two other parents today—very helpful with getting a proper wheelchair timely.”

Access to Medical Equipment, DME, and Supplies

Many families of CYSHCN experience delays, a lot them because Medi-Cal denies it or vendors don’t want to wait for Medi-Cal to authorize:

- “This center has received so many calls because CCS and Medi-Cal has been taking so long and has been sending denial after denial after denial. Long wait times, lots of denials. Families are desperate to get appropriate equipment.”
- “Savings spent on diapers because it took forever to get Med-iCal to pay.”
- “I have also had trouble getting MDs to authorize diapers for my child with cerebral palsy.”
- “For the feeding pump we had issues—CCS said they just let them “borrow” the machine, but Medi-Cal said that the family should own the machine. CCS kept coming to switch it and then they ended up with no feeding machine, and then we would have had to wait 5 years to get approved for another—I had to call many people and one pharmacist helped and gave it to me. CCS did not help me find the right person to get the feeding machine, other moms helped too.”

Sometimes when they do get access to equipment, it is not the right equipment or it is broken equipment or they won’t cover costs to fix equipment:

- “Inappropriate or faulty equipment, dangerous and then there is no back up and it will take months for appropriate.”

- “When my child was younger, they would fix her wheelchair all the time. But now we can’t fix anything until the vendor can accommodate and sometimes she goes months without the wheelchair because CCS rules don’t allow us to find a new vendor.

Sometimes parents have to take alternate measures to get their child the equipment they need:

- “Had to get a used bathroom chair and also gait trainer from a “covert” program through private therapy. CCS does not have an official lending or re-use program for equipment, but private insurance will take and give. This is important because gait trainers can cost \$3K. **CCS could benefit from something like this”**

A few families had largely positive experiences with getting DME through traditional CCS:

- “CCS helped a lot and we didn’t experience delays or issues.”
- “Received everything we needed, even if sometimes it took time.”

The biggest complaint with Health Plans is around supplies, but some haven’t experienced any DME issues with them:

- “Diaper issues—they sent pads so she could wear diapers longer. It was inappropriate.”
- “Haven’t had an issue yet—haven’t had to ask for any yet since Whole Child Model implementation.”
- “Still getting medications and the same amount of medications.”

Getting Care from Specialists and Specialty Care Centers:

Family’s experiences with specialists varies...

Some experience **a great deal of trouble and delays in getting appointments with specialists:**

- “Lots of trouble with getting an appointment with a specialist, **7 months it took to make the appointment**—if they switch doctors they have to start that wait time over. Even if this is for a life-saving procedure, DME or medication.”
- “Neurologist Specialist said that they don’t see children with autism so it took one woman **a whole year before seeing her son**. One specialist lost the results and so I waited two hours for them to have the results faxed—then the doctor gave the results in front of other people (not in private or confidential).”
- “I tried to see a specialist at [local children’s hospital] and they flat out told me that there were no appointments there at all. [Hospital] told me that she was better off going somewhere else because they don’t have any appointments at [local children’s hospital] with specialists at all.”
- “**It took me six months to find out that my daughter didn’t have a brain tumor that would cause her to lose her sight—all because they didn’t have enough appointments.**”
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Some families have **positive experiences with most types of specialists, but most families have trouble with dentists or optometrists that are not well equipped to handle CYSHCN:**

- “We have had mostly good experiences with specialists EXCEPT for dentists and optometrists.”
- “**I had to wait five months for glasses that a 5 year old needed to see**, Medi-Cal didn’t explain that if someone could call the specialist on their own and pay cash, they will be seen.”
- One person had to wait five months for glasses that a 5 year old needed to see, Medi-Cal didn’t explain that if someone could call the specialist on their own and pay cash, they will be seen.

Family relationships with specialists vary, but they are best when specialists treat family members/caregivers like part of the child’s care team, and they are best when they can establish trust:

- “The neurologist gave my granddaughter medication even when both me and my daughter disagreed that the medication was right for her, and told her just to give her the medication, even though it messes up her stomach. She [my daughter, the child’s mother] explained this to another doctor that would answer her questions and this new doctor [a new doctor that was not the neurologist that gave her granddaughter the medication that upset her stomach] **said that the medication would have killed her granddaughter because it kills people with Mito.**” *Note: Mito is short for a particular mitochondrial disease that this person was referring to.*
- “My son has always seen specialist. Takes a long time to get the pharmacies to get approval for special formulas—pharmacies sometimes have made me pay out of pocket before authorization. My specialist always sends things before approval because she knows my son needs it.”

Changes to services provided by Specialists as a result of Whole Child Model:

- “It used to be great. WCM doesn’t guarantee that the specialists will stay. Specialists don’t want to bill a million different medical plans.”
- “I was told that I had to call the specialists and tell them that they had to work with the PCP. It didn’t used to be that way. In the past CCS, my case manager, they handled all that. We were able to see specialists when they needed to.”
- “In the past I had a case manager that helped me to get to specialists. Now I have a pediatrician that keeps trying to make referrals that don’t get authorized.”

Access to Mental and Behavioral Healthcare (for CYSHCN & their Families)

Families experience a lot of difficulties getting mental and behavioral health care for CYSHCN:

- **Sometimes this is because there is a lack of quality providers in general, and specifically a lack of providers within a child’s insurance network and mental and behavioral health providers that can specialize in CYSHCN conditions:**
 - “I called numerous times to get psychology or therapy for my son and I haven’t been able to find a good one, I found one once that works in the regional center and she told my son that he was “almost graduated from autism,” and even though she was nice and she gave him good tools I didn’t see a difference. CCS sent two new references to me by email, but one didn’t answer my calls and the other was difficult to get into contact with. It is hard to find a therapist for my son.”
 - “There is no psychiatric facility here and parents have to sit in the hall at the ER until they have a placement somewhere. Apparently they just built a facility. Still 35-20 minutes.”

- “The entire mental health system in [county] is very poor. So many parents have called and they get no help. Even with suicidal, self-harm children. We do have adults that are threatening to harm themselves and they only give them a hold for an hour and then turn them out.”
- “The assessment they asked me about if she is depressed, but I don’t know if I could figure that out because she is non-verbal.”
- Other times this is because **behavioral health conditions are not covered, or the mental health condition is not considered part of the CCS condition:**
 - “My daughter has multiple conditions that began with ADHD—it took six years to get proper machines for breathing at night—we’ve had issues with specialists saying that my child’s needs are not medical, just behavioral. They have told me all my children’s lives that if they didn’t have physical indicators of disability that they are not a priority—many of my children have attempted suicide—many employers won’t hire them with their disabilities. [Health insurance] has been one of the better places to bring them for mental and behavioral health issues where this is covered by Medi-Cal.”
 - “When my daughter tried to commit suicide, no hospital would take her for a psyche hold because she is autistic.”
 - “Not for my CCS child. CCS has said that it is not up to us to decide issues in mental health. CCS does not cover autism.”
 - “Children with schizophrenia and bi-polar disorder are not being served by CCS and they are having a hard time.”

Most seek out mental and/or behavioral healthcare from the county rather than CCS:

- “Sees county psychiatrist. Not CCS, Medi-Cal covers cost of psychiatrist only once a month.”

Most families have found that parents and family members are not offered mental and behavioral health care through CCS or Health Plans:

- “I saw someone at [health plan] and my son did too through [county clinic] to help my son and I had to leave [health plan] in order for my son to get mental health care. [County clinic] does 20 minute appointments and you wait for hours.”
- “I don’t even know if I could get services.”
- “Nobody asks me about my mental health.”
- “The only people that asked me were my HHS workers when she was born and then the CCS, nobody at the [health plan]. It was helpful in the beginning because I was depressed.”
- **“Our grief continues, am I sad about my child every day? No, they bring great things. Then there are those sneak attacks of grief that come and take you to the floor. So I think that mental health services would be great, especially for our young parents. Their wounds haven’t scabbed over even though it will never really heal.”**
- “Sometimes, but other times I’ve felt that I needed therapy and had no way of getting it. Social workers at [hospital] give personal cell phone sometimes to help with my child. But not for me personally to get access to therapy.”
- “I have a therapist that is literally just helping me with paperwork to coordinate my child’s care, but we don’t talk about my issues or how to cope with everything and keeping everything afloat.”

Case Management

Many families have or had special relationships with their CCS case managers:

- “They really care”
 - “We have had a good case manager, even though my daughter lost a year of therapy, she was really good at communicating with me and advocating for me. Her limitation is that she is only able to authorize specialist appointments and medications, nothing beyond that.”
- “We have a good one at the moment. But they need to advocate for us.”

Families have also had negative experiences with case managers or CCS clearly communicating what to expect in regards to case management:

- “My care coordinator doesn’t do much at all. My daughter had an emergency and they knew but they did nothing, they didn’t even care. After she was discharged I was the one that coordinated anything.”
- “Nobody else knows how to get a case manager or if they have one.”
- “When I got CCS they didn’t send a welcome letter or intro—they never said “here is your Case Manager” or anything.”
- “CCS never told us that we could also be with regional center—another parent at CHLA told us that when my daughter was a year. She should have been with regional center at birth.”
- “My daughter’s case manager, an RN that had no idea what the medical conditions or treatments for my daughter’s diagnosis were—she didn’t understand them at all and it is her job to authorize treatments. She would never know what the diagnoses were, I had to end up calling up above her for adequate help. The PICU wouldn’t release my daughter without out proper DME—and the case manager had no knowledge about it and we had to wait and pay for expensive equipment and an expensive hospital bed until I spoke with the MD directly.”
- “First case manager that I had was male and he was very good, he helped with moving medical equipment. The one I have now seems like she hates her job and she doesn’t care, she doesn’t do anything to help, and she doesn’t try to communicate with us. Not only she doesn’t want to help, she doesn’t want to let the therapist help. Once her daughter lost a whole week of school because the breaks on the wheelchair were broken and my case manager said she didn’t care. The first one was very knowledgeable and helpful.”

Like some other aspects of CCS, families feel that the shift to Whole Child Model Health Plans has caused many changes to Case Management:

- **They feel that they don’t have as much familiarity with case managers anymore, and their role has become unclear and inconsistent (and sometimes confused with care coordination):**
 - “Who has a [health plan] case manager?”
 - “Haven’t heard from them”
 - “If you are really involved and complex, then you get a nurse case manager. They make assessments about whether you are high or low risk. Everyone else gets a care coordinator, who doesn’t really know anything or do much.”
 - “I have a care coordinator and they are polite, but they don’t do much at all. Now I know that I am going to be doing a lot of leg work.”
 - “Most case managers were relocated or ‘retired’ when [health plan] came in. They tried to explain how to care for kids, but the [health plan] didn’t listen. I’m not saying that they aren’t trying, but they didn’t educate themselves in advance.”

- **However, in some cases, case management/care coordination has been positive with Health Plans:**
 - "...This is one thing that might be positive; the DME is more smoothly covered. Better than getting the state to pay the vendors."
 - "I do know who our case manager is, they are very good and when we needed her she was there, but now I don't need much from her. We talk on the phone."

Care Coordination

Most parents feel that they are primarily responsible for coordinating care for their child—but occasionally MTUs and MDs (specifically specialists) will have a care plan, when asked who coordinates care and if their child has a care plan that makes sense, these were some of the responses:

- "We do! Parents coordinate care for their children. But beyond that, **MTUs seem to have yearly care plans**. Physicians have **care plans for specific diagnoses**, but not specific to the child. **CCS never provides us with a care plan.**"
- "Individual therapists coordinate care, MDs sometimes are very good at coordinating care."
- "For very rare disease child, the specialist coordinates the care."
- "Used to have ICP meetings, definitely don't now."
- "It used to be that they knew us, now there is a lot of turnover. But now I have an amazing person to work with there and they have a plan."

Parents also mentioned that regional centers can sometimes fill in the gaps in care coordination:

- "I love the regional center, they have a plan for me for my daughter maybe going to school. They continue to help me."

Comments about care coordination and care plans with Health Plans after Whole Child Model Implementation:

- **Some families have really excellent providers:**
 - "Our pediatrician is in communication with us all the time. If my younger child gets sick, then he works with us on a plan for preventing my CCS child from getting sick."
- **Others have had shockingly bad experiences where the Health Plan or provider didn't understand the needs of their child:**
 - "I take it personally that Whole Child Model and [health plan] wanted her [my daughter] to sit in her diapers for longer, and it makes me sad that instead of focusing on things that really need improvement they [instead decide that they will] will reduce diapers for CYSHCN."

Families feel that they are not being heard on what their child needs for care coordination and care planning:

- "I also want a plan so that my son can be connected to the feeding tube at night because he hates it during the day and I haven't found an MD or provider that can help me to coordinate this to help provide better care for my son."

***No families had heard of the Shared Plan of Care model**

Provider to Provider Communication

Most families experiences with communication between providers is that they have lot of restrictions that prevent them from communicating or they leave this up to the parents:

- “In general, they don’t know about it or how to do it. [Health plan] keeps throwing HIPPA in their faces.”
- “Sometimes we see OT and PT talking to each other about my child’s care. But it was mostly casual and not with intention.”
- “MTU used to do that, now there is a big line in the sand between [health plan] and MTUs.”
- “Providers just ask us to get paperwork from one provider and bring to another. “
- “MDs never talk to each other, have parents bring documentation.”
- **“Honestly, if we did what all of our specialists tell us what to do, our children would never get to live and they don’t understand that because the providers don’t speak to each other to look at the big picture.”**
- “EMR sometimes allows intra medical communication with other MDs. Regional center to CCS to IEP, it is just parents that do the communicating and coordinating. Some parents feel that communicating between the three is dangerous and works against them because sometimes IEP holds it against you and then the regional center takes services away.”

There is also a theme of concern that CCS services will be taken away if families seek outside therapy due to the way that some providers are communicating with families:

- “There is no actual coordination between providers. Also, my child has to have two separate goals for CCS and regional center and it is scary because I worry my child will be kicked out of CCS if they get outside therapy or talk about other therapies.”
- “There was a UCLA therapist saying “you need to decide which is priority CCS or UCLA?” because I was struggling to get to both appointments. Also their favorite line to use is “she’s taking up the space of another kid so move it along” as children get older their priority status lessens.”
- “Parents are afraid to share information with professionals because they don’t want it to be used against them.”

Culturally Sensitive Care

Most families have had positive experiences with providers in this regard, although it is most difficult when there are language barriers:

- “I have Only have dealt with respectful providers.”
- “When we tried to get everything translated, we found that the translators were not accurately translating everything well enough for us for we prefer to speak in English to make sure we are getting the most consistent care. This presents a language barrier.”

Transition to Adult Care

Many families in focus groups did not have children that were at the age of transition yet, if they were above 14, most hadn’t been spoken to about it, but many were concerned what it would mean for their CYSHCN:

- “Granddaughter is 12, we haven’t discussed transition at all.”
- “16 year old son—nobody has talk to me about transition, nobody has talked to him about that.”
- “If my child were left to his own devices he would probably discontinue his care because he hates his treatment, he hates wearing his leg braces, maybe it is because he is a teenager—but still, this would make transition difficult. We choose CCS because they helped us diagnose him at 14.”
- CCS support and in-depth explanations would be helpful.

Some parents just handled the transition themselves, some with the help of county case managers:

- “For us, it went smooth. We were not able to find an adult provider though; I pick up where medical leaves off. I found the PCP for her, the pediatrician gave three recommendations and none of them would take her because of her need. The equipment that they gave us after transition was good quality enough and we haven’t had a need for DME. This was before Whole Child Model, our case manager made sure that we had every bit of equipment we needed when she aged out.”

Family Support

Families shared their experiences of family support from CCS or Health Plans, most did not receive much and many felt that CCS created unnecessary barriers to family support:

- “Not nearly enough to cover all of the gaps.”
- **“We are to a certain degree, but just lately it has been a lot of difficult. It scares me because my job is to take the best care of my daughter and I have to go on FMLA and I also need to work and having to do CCS’s job for them. And now I have to go home and worry about a million different things. How can I give her the best care if they are putting up all of these road blocks. I don’t have the energy, I’m tapped out and tired.”**
- “In-home support makes a world of difference. But there are huge issues with IHSS being verbally abusive and then not having IHSS respond or deal with any of the issues.”

Being able to access respite care more easily would be very helpful, especially for single parents:

- “There are so many parents that don’t have the energy. Some moms with no family and nobody at all, taking care of child 24/7 with no respite. You can’t hire your own respite person anymore, they made it very hard. Because of the fraud, Our families are not frauding.”

Other services, such as Family Resource Centers (FRCs), can sometimes help with family support:

- “Here the FRC is helping us to get what we need.”

Families suggested support that would be helpful:

- “Support in the form of childcare because sometimes if you pay respite care a little extra for other children they might take care of them.”

- “Finding a nurse that can work on off hours like Friday or Saturday night so that I can have time for myself. **They give me around 40 respite hours, but nobody is ever available during the times that I would use them.** The agency changes nurses all of the time and never notifies us so if we do find a good, reliable nurse, we lose them often. I have to vet agencies for myself. Yesterday was one nurse’s first day and then today she called in sick after months of not having a nurse.”
- “Some of our respite aides don’t have to change diapers or pick up children so what is even the point?”
- “What would we like to have? **Therapy, even if it is just a phone conversation to touch base with the parent to see how they are doing on a human level.** It would be great every month, which is probably idealistic, maybe even after 3-6months. Even just meeting the nurse case manager from CCS.”
- “Male figures support—hard to find.”

Final Comments & Suggestions for the Future of CCS

Suggestions for improvement for CCS in general:

- “There used to be a parent-friendly guide booklet to CCS and we would like this again! They never recreated it.”
- “I would like a ‘welcome packet’ that introduces us to CCS and tells you what will happen, and what they cover”
- “Consistency among providers about recommendations for medications and treatment.”
- “If CCS has a re-use program for equipment.”
- “I wish it was more fun to go to CCS places, they are very clinical looking.”
- “My daughter’s condition is a lifelong condition, it would be great if they didn’t make us get proof every year that she isn’t “meeting the progress” and making sure that she still has this obviously lifelong disease. There is a PT and OT appointment every year where they do this. This doesn’t benefit my child at all, especially when they make us come up with new goals each year when she hasn’t met the goals. **Does it always have to be measurable; can’t her yearly goal just be to “walk better” over time?** She is only ever going to make small improvements. This doesn’t allow children to guide what they do, which is an important part of their treatment.”
- “Appointments need to be more consistent so that we can establish relationships with PT and OT. Because the hours are so hard to get you just get the therapist that you get. There isn’t a lot of continuity of care.”
- “Would love if they had sit down meetings where parents could take part in decision making about how to care for their child. Also if they brought parents in to discuss how to improve the system as a whole.”
- “Parent advisory committees to talk about transition overall.”

Positive feedback on CCS:

- “I would like to extend my heartfelt gratitude for the CCS program and everyone that worked with us. It was a well-oiled machine and worked here even if not everywhere.”

Suggestions for Health Plans as Whole Child Model is implemented:

- “Don’t make us eligible for something that we cannot use. Make the state aware that they have abandoned us and set us up for something that we can’t even use...They practically stripped it before we got it in the end.”
- “I would suggest that they pay more attention to what the CCS program says instead of acting like they know everything.”
- “I’ve never really spoken to them. So I want communication because I don’t know what I don’t know. You guys are talking about all of these things and I don’t know.”
- “Finding MDs and finding good care and services with [health plan] is very hard. They don’t cover anything it seems. [Health plan] will fill in the gap as a secondary insurance. I don’t think there is any malice involved here, they just need to listen to their people.”
- “I would like to have a case manager.”
- “It would be nice to get a phone call every couple of months to talk about what will happen down the road. “

Comments on what has worked well with the Health Plans:

- “Good at covering expensive medications for my diabetic son, it sometimes takes a long time to find the right thing and I have a lot of hunting, but once I find it they’ll cover it.”

Comments on the Whole Child Model:

- “I just feel, why did they try to fix something that wasn’t broken? They wasted thousands of dollars trying to train people that don’t know anything. Just to let them know that we are humans and we try to do our best and if you don’t provide the services that we need, our children’s health is going to suffer. We are rural families and children that need help.”
- “[Health plan] can’t take care of my non-special needs kids, how are they going to take care of special needs kids?”
- “The Whole Child Model is NOT working, [health plan] can’t get MDs to come here.”

Suggestions for the next five years:

- “Make it function more like private insurance, less paperwork, more people and providers”
- “Provide clarity and consistency around eligibility criteria.”
- “Not take away CCS when a child doesn’t meet a goal, but also don’t take it away and not tell them about regional center if that happens.”
- “CCS needs to re-do their website, they have so much to offer and they aren’t putting themselves out there to demonstrate that. Most of the parents here today didn’t know about CCS until someone told them and they had to find out on their own how to apply. CCS is the ‘best kept secret’.”
- “Once a year if someone could come and visit the house to see how everything is working, and see what services are needed and how the family is doing. CCS never does review for at least two of these parents.”

- “Help with finding housing that is handicapped accessible, our social worker was not helpful in the past they gave us phone numbers that didn’t work. Our PT helped us get a wheelchair to climb stairs to work around this.”
- “Maybe co-locating someone from CCS within the hospital. CCS hospital liaisons or reps.”
- “Proper case or care coordination.”
- “DIS, designated structural services.”