Focus Group Results: Transition to Whole Child Model

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Focus Group Facilitation Provided By:

COMMUNITY INVESTMENT STRATEGIES
CONNECTING PASSION TO ACTION

OCC3 for Kids Facilitated By:

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Introduction

Orange County Care Collaborative for Kids (OCC3 for Kids) is a cross-agency, cross-sector collaborative that is working to improve systems of care for children with special health care needs (CSHCN). Funding to support this partnership is provided by Lucile Packard Foundation for Children's Health along with in-kind contributions of staff support from those who participate on OCC3 for Kids. More than 20 organizations are part of the collaborative.[1]

In the Fall of 2020, OCC3 for Kids received a grant from the Lucile Packard Foundation for Children's Health to explore the transition of California Children's Services (CCS) to the Whole Child Model (WCM) in Orange County. Under the WCM, CCS-eligible children in 21 counties began receiving all of their CCS and non-CCS services through Medi-Cal managed care organizations in 2018. As part of this award cycle, OCC3 for Kids conducted case reviews and focus groups to identify system issues related to the transition from fee-for-service under CCS to managed care under CalOptima. The focus groups were meant to validate and better understand the system issues uncovered in the case review process, and to hear directly from various key stakeholder groups, including and especially parents.

The focus group facilitator, Patricia Sinay, facilitated nine focus groups with a total of 65 participants:
- Physicians: 9 participants
- 4 Parent focus groups (2 in Spanish & 2 in English): 22 participants
- Health Administrators: 4 participants
- Case Managers: 9 participants
- MTUs: 11 participants
- Vendors: 10 participants

The focus groups were held via Zoom and were approximately one hour long. Parent/guardian participants received a $50 Target gift card to thank them for their time and input. Focus group questions were all open-ended, resulting in in-depth, qualitative information that was analyzed for themes across stakeholder groups as well as within each group. While there was consistency in some of the questions asked, the questions were tailored for each group.[2] This report includes the findings from the focus group process. Overall, CalOptima has, on average, over 11,000 monthly WCM members.[3] While the focus groups represent a small portion of these, the purpose of focus groups is not to capture population-level data but rather to better understand strengths and challenges to inform opportunities for improvement. It is important to remember that focus group findings may sometimes be a function of *perception* or *stakeholder understanding* of WCM. In cases where a finding is inconsistent with how WCM actually works, it may highlight an opportunity for education and outreach.

Discoveries

All stakeholders involved in the focus groups expressed a deep understanding of and compassion for CSHCN and their families. Focus group participants' comments were always focused on what could be best for the patient (the child) and their families.

The consistent challenges related to the transition to WCM that were shared by all stakeholder groups fell under four overarching themes:

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[1] See Appendix A on page 9 for a list of organizations participating in OCC3 for Kids
[2] See Appendix C on page 11 for a list of focus group questions by stakeholder group
[3] See Appendix B on page 10 for more context re: CalOptima Whole Child Model members

1) Key challenges lead to interruption of care for patients
2) Not all networks are equal in terms of WCM
3) It is unclear who supports systems navigation support for parents
4) Orange County is isolated with WCM relative to surrounding counties

In some cases, stakeholder groups had different perspectives on the same theme. This report will go further into each of these themes and how they manifested for the various stakeholders. Parents were very clear that a successful system would serve their children when needed and support them as caregivers. As one parent shared, she was happy with WCM because, *"We found the right doctor, at the right hospital, that is near us."*

1) Key challenges lead to interruption of care for patients

The first theme, interruption of care for patients, was shared in different ways by all stakeholder groups. Focus group participants shared four key challenges that led to interruptions in care:
- Out-of-network challenges
- Annual redeterminations
- Re-authorizations
- Silos and missing information within networks and across the WCM system

Out-of-Network Challenges
A primary challenge expressed across all stakeholders was **out-of-network contracts**. The challenges with out-of-network contracts included the need for:

- More specialists so families have a choice and can obtain second opinions
- Faster approval for out-of-network referrals
- Smoother payment to vendors and providers who are out-of-network
- Continuity of care

"Getting approval for out-of-network referrals is tough. We have a family with a 7-year-old with brain cancer who is very sick. They want to go to San Francisco, and it has taken a long time to get the ok. She does not have the time." – Health Plan Administrator

"Contracting is the biggest challenge [with WCM]. Under CCS, they could go anywhere, and with WCM, they must go with who we have contracted. I have one parent who refuses to leave UCLA. She is going to need to change her healthcare plan or move to one of our contracted providers." – Case Manager

"I found a specialist for my daughter by searching and he was at Stanford. There are doctors who know more about individual conditions outside of OC. It shouldn't be a fight to get to see the correct specialist. They need to listen to the doctors making the referral. I have had times when a doctor has found the right fit for my child and then they [WCM] redirect me back to OC." - Parent

Annual Redetermination/Re-authorizations
Annual redetermination and 90-day reauthorization were the second most discussed challenges across all focus groups. While annual redetermination and reauthorization are two completely different things, they were often talked about together, particularly by parents. Annual redetermination is a once per year process that determines a child's eligibility for CCS whereas reauthorizations are more frequent (and the frequency can vary by health network) and are for authorization of durable medical equipment (DME) and other needed supplies. The challenge for families is that it can feel like they are constantly being asked to prove that their child has a disability and needs services and supplies.

"CCS authorization was for a year; currently, all plans ask for authorization every three months; CHOC Health Alliance has expanded to six months if you specifically ask for it." - Vendor

"It is frustrating that we continually need to prove our child's disability. My child will not get better; they will have the same disability for life, so why do we need to reclassify and ask for a new referral? We lose the therapist and other providers." - Parent

"The parents were used to a year, and now we need to reauthorize every three months, which delays some of the services for the patients." - Vendor

"My daughter will get comfortable with a therapist (behavioral health), and then she is forced to go to a new therapist. She has had three therapists in the past year and a half, which is very difficult for an 11-year-old. The social worker needs to resubmit a referral to continue the care – each time he resubmits, they change her therapist." - Parent (referring to annual redetermination and 90-day reauthorizations)

Silos Within Health Networks & Across the WCM System

Silos within health networks in Orange County and across the WCM system is another hurdle that was shared by focus group participants. Focus group participants explained that differing policies and procedures and lack of access to a shared patient data platform create these silos among health networks (and sometimes within health networks). Some of the consequences shared include:
- Service providers not getting needed medical information on patients
- Delay in services or obtaining equipment
- Challenges with changing service providers

"Sometimes I have parents calling me to ask about the status of equipment or AFO. In the past, I could look that up because it was all coordinated with CCS. Now I don't know what to tell them; I have to tell them to call their health plan. They come to me for help, but I feel like my hands are tied." – MTU Therapist

"I wish it wasn't so difficult to change therapists and other services. I had to apply to five or six companies. It frustrated me," - Parent

We also learned that communication with patients was more difficult for some health networks because the different departments are not on the same technology platform.

"… it is frustrating that I need to rely on another team – like UM (utilization management) – I can only see [in their computer system] what we are working on, but I can't give the family more information on what is delaying the approval because it is not in my lane." - Case Manager

2) Not all networks are equal in terms of WCM

Another concerned shared is that there are differences across health networks, including:
- Different levels of experience with CSHCN
- Different approval processes

"There is no consistency between counties, and there is no consistency among the different medical groups. So it really puts us in a bad situation with parents. The parents are friends [with other parents] and know what each other gets." - Case Manager

Experience with CSHCN

All stakeholder groups were concerned that the level **of specialization and experience with CSHCN** was inconsistent across different health networks.

"There is a huge disparity in Medicare managed care networks and their ability to deal with CCS children… other managed care plans that only have like four CCS kids and they are not equipped to really help them. There needs to be more transparency around what constitutes a good plan for kids, so parents know what they are signing up for." - Physician

"When I am in crisis, I have found that people are not prepared to help me. People need to be better trained and prepared to serve children with special needs in emergency rooms." - Parent

"Vendors need some education. I am not sure if they received any training [regarding WCM and children with special needs]." – Case Manager

"The worse job you do for the patient, the more you get paid. The better job you do, the less you get paid. It feels like a cost cutting race to the bottom. We want better care. Some networks are doing a lot better than others...this increases costs for plans that are doing it well because patients move to them. If you do a crappy job, expensive patients leave." – Physician (referring to concern about a "reverse incentive")

Different Approval Processes
The frustration with the **different approval processes** came up by all the service providers. One lamented that WCM did not adopt the CCS-approved categories. There was also a **perception that different systems had different lists of pre-approved services and items**.

"Things that were covered aren't now. [We need to get] authorizations for things that didn't need it before." – Physician

"Before we got CSAGS (Conditional Specific Authorization Groups), everything had to be individually authorized... That was a BIG burden… [a specific health network] has allowed us to create CSAGS for equipment and routine procedures. A lot of the other health plans do not have this, so it is a lot of work. It can take months to get things done." – Case Manager

"There have been changes in our vendors/providers, and the parents have had a hard time connecting with the vendor. Some children need specific brands because they have allergies, and the vendors do not carry all brands, and that is a challenge." – Health Network Administrator

"Not sure why this is happening because we are still using the same manufacturing list that CCS used, so the product should be the same." – Vendor

In regard to technology, the Vendors were very appreciative of "the Portal". They all agreed that approvals through the Portal with CalOptima and CHOC Health Alliance [CHA], which takes approximately three days, is quicker than the system they had with CCS. It is important to note, as one health network administrator explained, that the turnaround time requirements [for approval] of 72 hours is true for all authorizations requested to any of the managed care Medi-Cal networks. Having said that, the Portal that vendors praised is only accessible if a patient is covered by CHA, and vendors agreed that the approval process was not as efficient with other health networks.

3) It is unclear who provides system navigation support for parents

The challenge of supporting parents to navigate the system was raised throughout the focus groups. A few key issues emerged:
- Parents are hungry for education, community and support
- Parents don't always know or know how to leverage the Patient Care Coordinators (PCCs)

- Increased burden on other parts of the system to support families
- Concerns shared about caseloads

"The happiest parents are those who attend the family meetings before the transition and use their care coordinator." - Health Network Administrator

Parents Are Hungry for Education, Community & Support
During the focus groups, parents networked with each other and asked the facilitator many questions, making it clear that parents are hungry for education, community, and support. The reality for parents of CSHCN is complicated, and the parents encouraged each other to seek parent training classes, to get mental health support for themselves, and connect with the resources that exist in Orange County. There is a perception that under CCS, parents received more support than under WCM. In addition, parents who felt supporting in navigating the system usually said they had a good pediatrician who helped them.

"Support groups would be helpful especially for rare conditions that they (healthcare providers) don't know a lot about. With a support group, parents could share what they have learned so we can be better advocates for our kids." - Parent

"You feel like you have no life, and it is very difficult. It is hard to enjoy your children. You have other children and the household." - Parent

"The system they have here in California is very good. The therapist can help you. They will open doors for you. The first few years are tough. It took me a few years to acknowledge my child's special needs. I have two. The therapists care about the kids with special needs, and it is they who made the best recommendations. Ask them for help. Please take the time to ask them and take parenting classes. It will help you have a better home and more peace." - Parent

"I used to have a great case manager under CCS. She helped me with everything. When we transitioned to WCM, I was told she was not trained in WCM, so she could no longer help me. I have a nurse and a case manager, but neither are very helpful. The case manager said she could only help me submit for payment if I travel." - Parent

"I like our pediatrician. I just happened to pick the right doctor. He has been great in helping my son. He gave us all the information we needed and referrals we required." – Parent (After the parent shared this information, the other parents quickly asked for the name of her pediatrician and if he was taking new patients)

Parents don't always know or leverage the Patient Care Coordinators (PCCs)
As expressed by the physicians and the MTUs, the challenge is that families don't necessarily know how to leverage their PCC. We learned from the health network administrators that all patients are offered support by a call and/or letter. Some focus group participants shared that the burden is put on the parents to <u>opt in</u> to be assigned a "navigator" (though focus group participants use different words for this role). Other related focus group findings included:
- There is a perception that more responsibility is put on the parent as an MTU shared,
- There are different names, roles, and policies for the navigators depending on the health network. The names include care coordinator, patient care coordinator, personal care coordinator, case manager and others
- How to access the support services is not clear to parents or, in some cases, to the service providers
- Additionally, families have different levels of need for PCCs and other system navigation resources

"Families don't necessarily know their patient care coordinator (PCC). Meetings [with the PCC] have been helpful, but they are far and few." – Physician

"I think some staff felt some relief that some work was put on the parents but on the other hand some are concerned about the quality of care." – MTU Therapist

Increased burden on other parts of the system
Physicians shared that there is an increased burden on other parts of the system because patients depend on their pediatricians, MTUs, and the Regional Center to help with navigation.

"I think the primary care role is severely undervalued. When they [parents] can't get diapers they need, seizure med, denial, etc…. they call me. I don't think insurance carriers value the work of primary care. It is overwhelming to care for these patients. We want to care for them. They take a ton of manpower, and we don't get paid as much as other patients. We had to close our panel for these kids," - Physician

Concerns about caseloads
Focus group participants shared concerns about navigator's caseloads. Again, families have different levels of need for support.

"I would like to touch base more with my families than I have." – Health Network Administrator

"I wonder sometimes are we doing our members as well as a service as we can. Some days I work on one issue for only one member, and I can't do anything for other members." – Case Manager

4) Orange County is isolated with WCM relative to surrounding counties

Focus group participants shared challenges related to Orange County being the only Southern CA county that has implemented WCM. The counties that surround Orange County are still under CCS.

"With the CCS model, families had the option of choosing what specialist best met their child's needs. Now they are not permitted to see a specialist in San Diego or LA unless there is a specific situation. Now with WCM, they are limited to Orange County." - Parent

"We have access to specialists, but not as many providers as we would like." - Parent

"Kiddos are very special and need pediatric specialty doctors and need choices." – MTU Therapist

Other challenges cited by focus group participants included:
- There are not enough choices of specialists in Orange County
- There is a perception that providers in other counties do not want to see Orange County WCM patients
- Vendors work across counties and are operating under different guidelines
- It is a difficult transition for children who move to or out of Orange County
- Children who live in two different counties (e.g. due to divorced parents) have difficulty accessing services since not all counties are part of the same system
- Some Orange County specialists, because there are a limited number, cannot see clients in a timely fashion
- Parents attending two of the four focus groups shared that it was difficult to access dental care for CSHCN

"Some CHOC specialists are not as available - can't see patients for three months down the line." – Case Manager

"There is no one in OC that takes Denti-Cal who does oral surgery and has time." – Parent

Priority Issues by Stakeholder Group

The four themes outlined above include the key findings across the six stakeholder groups that participated in the focus groups. The top issues *per* stakeholder group are outlined below.

Parents
- Need for more options/availability of specialists, including ability to go outside OC
- Clarity on how and what services exist
- Need to reduce barriers, including 3-month reauthorization & annual redetermination
- Lots of questions when you have to go to emergency room or to a new provider
- Need for more education, community, & support

Physicians
- Concerns about reverse incentive (if you do a bad job with WCM patients, they leave and networks that do a better job have higher costs)
- Parents need more information on what is the best health network for their child (increased transparency)
- Complete patient records with summaries (could be a care coordinator who knows the patient history)

Health Network Administrators
- Out of network contracting is the biggest challenge (this includes outside of OC)
- Not being able to access all patient information because there are different data platforms across the system and within health networks
- Annual redetermination

Vendors
- Change from yearly to 3-month for authorization
- Working with health plans that they are not contracted with
- Some health plans do have the needed expertise for working WCM patients

MTUs
- Increase options of specialist doctors/providers including being able to go outside of health plan or outside Orange County
- Better contact with care coordinators

Case Managers
- Lack of CSAGS (condition specific authorization groups) & reauthorization every 3-months
- Not all medical groups are providing the same level of service and care for WCM patients; difficult to get patient information
- Continuity of care: families should be able to continue seeing service providers outside OC WCM

Next Steps

The next step is for OCC3 for Kids to select a WCM system issue to work on together to address. When doing so, it is important to develop criteria to help select the issue to work on. Some of the issues that arose during the focus groups could be broader system issues that existed prior to the implementation of WCM. In addition, there could be WCM challenges that are a function of state-wide policies that OCC3 for Kids may not be able to change locally. These factors should be kept in mind while reviewing these findings and agreeing on next steps for OCC3 for Kids. As a next step, OCC3 for Kids will determine how to move forward together based on these findings.

Appendix A: Organizations Participating in Orange County Care Collaborative for Kids (OCC3 for Kids)

- CalOptima
- California Children's Services (CCS)
- Center for Autism and Neurodevelopmental Disorders
- First 5 Orange County
- Comfort Connection
- CHOC Primary Care
- CHOC Health Alliance (CalOptima Network)
- CHOC Case Management
- Dayle McIntosh
- Family Support Network
- Family Voices of CA
- Help Me Grow, Orange County
- Orange County Department of Education
- Orange County Health Care Agency, Public Health Nursing
- Orange County Health Care Agency, Children & Youth Behavioral Health, Family Health
- Regional Center of Orange County
- Social Service Agency
- State Council on Developmental Disabilities
- Children's Health Initiative of Orange County
- Priority Center

Appendix B: Additional Context re: CalOptima Whole Child Model (WCM) Members

The table below includes the average monthly number of CalOptima WCM members, the average monthly number of providers, and the average monthly number of providers and vendors combined that are serving WCM members under the age of 21. This information provides some context for the universe of WCM children served by CalOptima and CalOptima contracted networks, providers and vendors in Orange County.

Average Monthly Number of WCM CalOptima Members	11,407
Average Monthly Number of WCM Providers	777
Average Monthly Number of Providers/Vendors Serving less than 21 Years Old WCM Members	8,825

Source: Provided by CalOptima, May 2021

Appendix C: Focus Group Questions

Parents:
1) If your child's therapy and healthcare needs were fully met, what would it be like? How would you access CCS services?
2) As you think of the dream situation for your child, what gives you hope right now that your child's needs are being met well? In short: What is working well?
3) If you have questions about CCS, where would you go for answers?
4) Areas where the CCS currently could improve: What is still needed to achieve your vision for your child?
    a) When getting your child's needs met, what are some of the challenges? What makes you frustrated? What takes too much time?
    b) Are there things that could be better?
5) In closing, of all the challenges and frustrations mentioned, what would make the biggest difference?

Physicians:
1) How were you informed of changes associated with Whole Child Model? Did you feel adequately prepared when WCM went live?
2) What has been the largest impact on patients and their families? What's working better since WCM has been implemented? What isn't?
3) Review of list of system issues identified in case review process. Have you experienced any of these with your patients? Which come up most frequently?
4) What has been the impact on you (or other physicians you have talked to)? What is working well with WCM? What isn't?
5) From our discussion, what aspects of Whole Child Model do you think are MOST IMPORTANT to address/fix for the benefit of patients and their families? For the benefit of system coordination?

Health Network Administrators & Case Managers:
1) Can you share about your roles as it relates to working with families with children that are part of Whole Child Model?
2) How has the interface / communication with parents and the various players in the system changed with the transition to Whole Child Model?
    a) E.g. Case managers, care coordinators, social services, pharmacy, health network administrators, CalOptima
    b) How has it improved from your perspectives?
    c) Is there anything that is more challenging now?
3) Do you feel prepared to work with / help WCM families?
    a) In what areas, if any, do you need additional support to help families?
4) From our discussion, what aspects of the Whole Child Model do you think are MOST IMPORTANT to address/fix for the benefit of children and their families? For the benefit of system coordination?
5) Anything else we have not discussed?

Vendors:
1) Are you familiar with the transition of California Children's Services (CCS) to Whole Child

Model?
   a) How did you hear about it?
   b) Did you/do you feel prepared?
   c) In general, what has worked well and what challenges have you encountered?
2) Have you seen any change in the way you bill or get authorizations for supplies?
   a) What have changes been? Do they make things easier or more difficult? In what ways?
   b) Are you familiar with MediCal and non-MediCal codes?
3) What is the vendor's role/responsibility with regard to billing and authorizations under the WCM system?
   a) If they say it is the parents responsibility, how would parents know the proper codes to use?
4) How do you communicate with families (or do you primarily address issues with the payor)?
5) Is there anything that would help you, as a vendor, better meet the needs of children that are part of Whole Child Model?

MTUs:
1) From your perspective, how has the transition to Whole Child Model gone? What has worked well? What has been challenging?
2) What has been the largest impact on patients and their families?
3) Review of list of system issues identified in case review process. Have you experienced any of these with your patients? Which come up most frequently?
4) From our discussion, what aspects of Whole Child Model do you think are MOST IMPORTANT to address/fix for the benefit of patients and their families? For the benefit of system coordination?
5) Anything else that we haven't discussed?