

Family Engagement and California's Whole Child Model

Lessons Learned from the Implementation of Family Advisory Committees

Author: Caroline Davis, MPP



About the Author

CAROLINE DAVIS, MPP, is president of Davis Health Strategies, which provides strategic and analytical services, including government/public policy/regulatory strategy and analysis, managed care program development and implementation, strategic planning, and meeting facilitation to health care organizations focused on improving care for vulnerable and safety-net populations.



THE LUCILE PACKARD FOUNDATION FOR CHILDREN'S HEALTH unlocks philanthropy to transform health for all children and families – in our community and our world. Support for this work was provided by the Foundation's Program for Children with Special Health Care Needs. We invest in creating a more efficient system that ensures high-quality, coordinated, family-centered care to improve health outcomes for children and enhance quality of life for families. The views presented here are those of the authors and do not reflect those of the Foundation or its staff. Learn more at: lpfch.org/CSHCN

Table of Contents

4	Executive Summary
6	Background
7	WCM/FAC Implementation
8	FAC Implementation: Findings and Lessons Learned
13	Discussion & Recommendations
14	Conclusion
15	Footnotes

Executive Summary

Across California, approximately 180,000 children under age 21 are enrolled in the California Children's Services (CCS) program, which provides diagnostic and treatment services, medical case management, and physical and occupational therapy services to children with CCS-qualifying conditions. Historically, for CCS-eligible children enrolled in Medi-Cal, the child's Medi-Cal health plan covers all non-CCS services, while CCS specialty services are carved out of the health plan's responsibility and managed by the county.

In 2016, California Senate Bill (SB) 586 created the CCS Whole Child Model (WCM) for CCS-eligible children enrolled in Medi-Cal in 21 counties served by five County Organized Health Systems (COHS): CalOptima, CenCal Health, Central California Alliance for Health (CCAH), Health Plan of San Mateo (HPSM), and Partnership HealthPlan of California (PHC). Under the WCM, these health plans provide integrated Medi-Cal and CCS services to children enrolled in both programs. In keeping with the whole child focus of SB 586, the statute required the participating health plans to create a family advisory committee (FAC). The purpose of the FACs is to ensure that the health plans engage with CCS families and caregivers to bring their voices into the design, implementation, and ongoing management of the WCM, as well as the care provided to CCS enrollees.

This report captures the lessons learned in the process of establishing and managing the FACs during the early phases of WCM implementation. Individual, structured interviews were conducted with staff from each of the five WCM health plans, FAC family representatives, and other stakeholders, including CCS county staff and community advocates. In addition, respondents were asked twice to provide information via e-mail on any changes made to the FACs over the 6-12 months following the interviews.

Key themes and lessons include:

- **FAC structure varies by health plan.** Four of the FACs are chaired by a family representative. Within the health plans, management of the FAC typically resides either with staff from the Member Services department or the Health Services department. Depending on internal health plan policies, several of the health plans require a quorum for the FAC meetings, which can be challenging to achieve.
- **Member recruitment and retention has been challenging.** Most of the health plans and FAC representatives identified recruitment of family members to join the FACs as a significant, ongoing challenge. WCM family members find it challenging to commit the time and effort required to participate on the FAC, particularly given existing caregiving, family and work obligations.
- **Some health plans provide orientation or training to new FAC family representatives.** The health plans vary in whether they provide formal orientation or training to family representatives when they join the FAC or become the FAC chair or vice chair. Several respondents noted the importance of helping family representatives understand their role on the FAC, which is to represent the needs of all WCM families rather than the needs of their individual child.
- **Health plans provide support for FAC members in a variety of ways.** All of the health plans provide some supports and accommodations to help family representatives participate on the FACs. Examples include providing translation services, offering food at meetings, and allowing parents to bring their children to meetings. In addition, all of the health plans provide a stipend of between \$50-\$100 per meeting to their FAC family representatives. A number of the health plans, particularly those that operate across multiple counties, offer family representatives options for how to participate in the FAC meetings (e.g., by hosting meetings simultaneously at satellite offices via videoconference or allowing members to join via phone). Due to the pandemic, every health plan adopted the use of videoconferencing for their FAC meetings.
- **FAC members collaborate on the development of meeting agendas.** All of the FACs use a collaborative process to develop meeting agendas with health plan staff and FAC members (typically the FAC chair) working together. In several cases, the FAC chair and/or vice chair solicit input from the other family representatives on agenda items. This ensures that the agenda reflects topics and issues of importance to the families.
- **Common meeting topics have emerged as the WCM has moved beyond initial implementation.** Initially, the FACs typically focused on start-up activities, including gathering feedback on member communications. Following implementation, the FACs transitioned to focus on operational issues of concern to the health plans, the FAC family representatives, or both. Common agenda items across the FACs have included discussion of member grievance data, care coordination issues, service authorization trends, and pharmacy benefit issues.

-
- **Bi-directional information sharing between the FAC and health plan leadership is important to ensure success.** For some of the FACs, health plan senior leadership, including the CEO, attend the meetings. Several interviewees noted that having senior leadership attend signals that the health plan takes the work of the FAC seriously. In other cases, health plan staff attend the FAC and share information afterwards with senior plan leadership.
 - **FACs have had meaningful impacts on health plan operations.** In their first 18-24 months, the FACs tackled a range of topics and provided meaningful input that has helped to improve the WCM and led to changes in health plan operations. For example, one health plan worked with FAC members to revise and streamline the process for parents and caregivers to be reimbursed for travel costs related to a medical service or appointment. FAC members made recommendations on improvements to the layout and content of the reimbursement request form as well as the process for submission of the form to make it easier and faster for the health plan to process. Another health plan worked with the FAC to develop a preferred vendor program for incontinence supplies to address access and quality issues identified by FAC family representatives.
 - **COVID-19 has impacted the FACs.** The shift to meeting virtually via videoconference was identified as one of the pandemic’s “silver linings” as it allowed FAC members to attend meetings more easily, resulting in improved attendance. Some families, however, find it challenging to use a health plan’s videoconference platform if it requires learning to use a different system from the one they typically use.

The FACs provide health plans with the opportunity to engage directly with families on a regular basis and provide families with an avenue to ensure that they have a voice in how the WCM operates. Respondents identified several key components to ensure that the FACs are effective:

- **Reduce barriers to family participation.** Family recruitment, retention, and participation in the FACs has been challenging across all of the health plans. Each FAC has developed strategies to support recruitment of new members.
- **Assist families to understand their role on the FAC.** Several respondents commented on the importance of training families about how to advocate for all WCM children rather than the unique needs of their child.
- **Allow the FAC to evolve over time.** It is important to be flexible in terms of the FAC structure and content of the meetings, as priorities are likely to shift over time.
- **Communicate the value of the FAC. Make sure families on the FAC feel heard.** Almost all respondents stressed the importance of making sure the family representatives on the FAC feel heard and understand their value. This was viewed as critical to sustained participation by families and, over the long run, to the sustainability of the FACs.
- **Understand time and resources required from health plan to ensure the FAC’s success.** Managing the FAC requires significant work and commitment on the part of the health plan to manage the meetings (e.g., develop agendas, arrange for meeting rooms, prepare materials, etc.), follow up on any action items identified during the meetings, and assist FAC members in maintaining meaningful engagement.

Meaningful family engagement can lead to improved care delivery, quality of care, and patient and family satisfaction. For the WCM, the health plans and family representatives worked together to establish the FACs, which help ensure that the family (and patient) experience is reflected in the management of the program. The FACs provide the families with the opportunity to share information and offer input into health plan operations, and to raise issues affecting WCM enrollees. Launching an FAC and ensuring its long-term viability requires commitment on the part of both the health plan and the WCM families to continually evaluate the structure of the FAC and make adjustments as needed. The FACs’ long-term success also depends on ensuring that the families feel heard by the health plans and understand the value they bring to improving the WCM model and the care provided to their children.

Background

Across California, approximately 180,000 children under age 21 are enrolled in the California Children’s Services (CCS) program. CCS provides diagnostic and treatment services, medical case management, and physical and occupational therapy services to children with CCS-qualifying conditions. Administration of the CCS program has historically been shared between the California Department of Health Care Services (DHCS) and the counties. For CCS-eligible children enrolled in Medi-Cal, the child’s Medi-Cal health plan covers all non-CCS services, while CCS specialty services are carved out of the health plan’s responsibility and managed by the county.

In 2016, California Senate Bill (SB) 586 created the CCS Whole Child Model (WCM) for CCS-eligible children enrolled in Medi-Cal in the 21 counties served by five of the state’s County Organized Health Systems (COHS).² Under the WCM, the five COHS plans – CalOptima, CenCal Health, Central California Alliance for Health (CAAH), Health Plan of San Mateo (HPSM), and Partnership HealthPlan of California (PHC) – provide integrated Medi-Cal and CCS services to children enrolled in both programs. HPSM was the first county to pilot the WCM, launching its program in 2013. Following enactment of SB 586, the WCM was implemented on a rolling basis between July 2018–July 2019 (see Table 1).³

Table 1. Whole Child Model Health Plans

COHS	County(ies)	WCM Implementation Date
CalOptima	Orange	July 2019
CenCal Health	San Luis Obispo, Santa Barbara	July 2018
Central California Alliance for Health	Merced, Monterey, Santa Cruz	July 2018
Health Plan of San Mateo	San Mateo	July 2018
Partnership HealthPlan of California	Del Norte, Humboldt, Lake, Lassen, Mendocino, Marin, Modoc, Napa, Shasta, Siskiyou, Solano, Sonoma, Trinity, Yolo	January 2019

In keeping with the whole-child focus of SB 586, the statute required the participating health plans to create a family advisory committee (FAC). Evidence shows that consumer engagement leads to better health outcomes and higher patient and family satisfaction.⁴ The purpose of the FACs is to ensure that the health plans engage with CCS families and caregivers to bring their voices into the design, implementation, and ongoing management of the WCM. The FACs provide a regular forum for the health plans to partner with families and caregivers to discuss and address issues affecting the WCM and the families served by the program.

This report captures the lessons learned in the process of establishing and managing the FACs during the early phases of WCM implementation.

Methodology

To collect information on the five FACs, initial structured, telephonic interviews were conducted with representatives from the five COHS, family members serving on each FAC, and other stakeholders, including CCS county staff and community advocates. Interviews were conducted individually with health plan staff and family members. Respondents also were asked twice to provide information on any changes made to the FACs over the 6–12 months following the interviews. This information was gathered via e-mail. Interviews were conducted from March 2019–March 2020, and the additional information was gathered between October

2019–October 2020. The COVID-19 pandemic began after most of the data collection had been completed; however, information about the impact of the pandemic on the FACs was collected from health plans and FAC members in the fall of 2020 and has been incorporated into this report.

WCM/FAC Implementation

As part of WCM implementation, DHCS issued guidance to the WCM plans that incorporates the requirements included in SB 586 regarding the FACs.⁵ Specifically, the FACs must meet quarterly and comprise families that reflect a range of CCS enrollees’ conditions, disabilities, and demographics. The FACs also must include providers. Required providers include parent centers (e.g., family resource centers), family empowerment centers, and parent training and information centers. Under SB 586, the health plans may offer a stipend to FAC members to support in-person participation in meetings. Within these parameters, the health plans established their FACs. As shown below in Table 2, each WCM plan varies somewhat in terms of the composition of the FAC membership, meeting frequency, and whether the health plan staff or the families serve as FAC chair and vice chair.

Table 2. Key FAC Characteristics

COHS	FAC Composition	Meeting Frequency	FAC Chair & Vice Chair (Family representatives or health plan staff)
CalOptima	<ul style="list-style-type: none"> 7 family representatives Health plan staff 2 consumer advocates 2 community-based organizations 	Every other month	Family representatives
CenCal Health	<ul style="list-style-type: none"> 8-9 family representatives Health plan staff County CCS Medical Therapy Program (MTP) supervisor 	Quarterly	Health plan
Central California Alliance for Health	<ul style="list-style-type: none"> Up to 6 family representatives per CCAH county (total of 18) Health plan staff County CCS staff CCAH Board member Representatives from 4 community-based organizations 	Every other month	Family representatives
Health Plan of San Mateo	<ul style="list-style-type: none"> 10 family representatives Health plan staff County CCS staff 	Quarterly	Family representatives
Partnership HealthPlan of California	<ul style="list-style-type: none"> 28 family representatives (2 per PHC county) Health plan staff County CCS staff 	Every other month	Family representatives

PHC, which provides Medi-Cal coverage in 14 counties, initially planned to create two FACs – one for the northern counties in its service area and one for the southern counties. As discussed below, FAC recruitment has been challenging for all of the WCM plans. In PHC’s case, they decided to start with one FAC and launch a second FAC at a later date. While PHC would like to have 28 family representatives (i.e., two from each county) participating on the FAC, it currently has 14.

FAC Implementation: Findings and Lessons Learned

Based on the interviews and other information provided, a number of key themes and lessons emerged, which are discussed below.

FAC Structure Varies by Health Plan

All of the FACs include both health plan staff and family representatives. In addition, as required by state statute, the FACs include provider representatives as well as community-based organizations. Several respondents noted the importance of having county CCS staff attend the FAC meetings, as they continue to work closely with the families (e.g., the counties remain responsible for CCS eligibility determinations and continue to operate CCS’s Medical Therapy Program).

Leadership of the FAC varies by health plan. Three of the FACs have been chaired by a family representative since they began meeting, with health plan staff filling this role as needed when the chair (or vice-chair) position is vacant. Another FAC was chaired initially by health plan staff before transitioning to having family representatives serve in the FAC leadership roles within the six months following the WCM launch. The fifth FAC is chaired by a health plan representative. Two health plans initially established the chair and vice chair positions with one-year terms but moved fairly quickly to two-year terms. As one respondent noted, “it takes time to learn the chair and vice chair roles, so it does not make sense to serve for just one year.”

Across the health plans, management of the FAC typically resides either with staff from the Member Services department or the Health Services department. Two of the health plans reported that they had moved responsibility from one area of the health plan to another during the first 12-18 months following implementation. In one case, the FAC was initially overseen by Health Services before responsibility moved to Member Services. In the other, Member Services was responsible for the FAC initially before it was moved to Health Services. The health plan lead typically is responsible for managing FAC meeting logistics, development and dissemination of meeting materials, agenda development, and building relationships with the families.

Depending on internal health plan policies, several of the health plans require a quorum for the FACs, and respondents noted this can be challenging to achieve. One health plan noted that even offering multiple ways for FAC members to participate (e.g., in-person, by phone or by videoconference) does not guarantee a quorum will be reached. Another health plan made the decision to stop requiring a quorum to encourage participation and ensure that feedback and discussion can occur even without a quorum.

Member Recruitment and Retention is Challenging for Most Health Plans

Most of the health plans and FAC representatives identified recruitment of family members to join the FACs as a significant, ongoing challenge. Respondents commented on the importance of educating family members about the role of the FAC and its value as a way of encouraging individuals to join the FAC. WCM family members find it challenging to commit the time and effort required to participate on the FAC given existing caregiving, family, and work obligations. In particular, caring for a CCS-eligible child can mean coordinating multiple, ongoing medical appointments, therapy visits, and medications, as well as providing in-home care and managing non-medical supports. As one interviewee noted, “families have a hard time adding one more thing to their plates.” Another said, “when you’re trying to tread water, it can feel impossible” to take on another responsibility. Interviewees also noted that FAC members will transition off when their children “age out” of CCS at age 21, and no longer qualify for the program.

“When you’re trying to tread water, it can feel impossible.”

To recruit family representatives initially, the health plans relied on different strategies. Several plans worked with their county CCS colleagues and CCS MTP staff to identify family members, commenting on the importance of face-to-face recruiting. Two health plans relied on WCM stakeholder groups, established to help with planning for WCM implementation, to identify potential FAC members. Health plans also recruited members through their local family resource centers (FRCs), which provide support to children with disabilities and their families. FRCs work closely with CCS families, making them another good avenue for identifying and recruiting FAC members. Health plans also worked with local providers to identify FAC members. One health plan worked with its case management staff to help identify potential FAC members, and trained Member Services staff to recruit family representatives. Finally, health plans partnered with community-based organizations, such as Family Voices of California and their local Regional Centers, to identify FAC members.

Several of the health plans require interested family representatives to complete an application to join the FAC. While this demonstrates an individual's interest in, and commitment to, serving on the FAC, the application process, itself, also can serve as a barrier for family members who may not believe they have the bandwidth to participate on the FAC. Some health plans use the application to help ensure that the FAC represents local community needs, the diversity of the CCS population, and the range of CCS conditions. As one interviewee commented, “we wanted to ensure that not a single voice or issue was dominant” on the FAC.

“ We wanted to ensure that not a single voice or issue was dominant. ”

Following the initial establishment of the FACs, some health plans looked to the family representatives to help identify other individuals to join. This included FAC members soliciting new family representatives directly through social media or local community groups. One health plan revised its website to highlight the FAC and recruit new members, advertised for new members in the health plan's member newsletter, and shared information about the FAC and new member recruitment with the health plan's Consumer Advisory Committee. Another health plan mailed recruitment flyers to enrollees and included FAC and recruitment information in its member newsletter. Health plan leadership also reached out directly to community-based organizations and other local partners to request assistance with recruitment.

For four of the health plans, the roles of FAC chair and vice chair are filled by family representatives. Several respondents noted how difficult it is to keep these roles filled given their added responsibilities. In some cases, the positions take a long time to fill once the incumbent leaves the FAC. In other cases, family representatives cycle through the position, resulting in a lack of consistency in the leadership of the FAC.

A number of interviewees noted the importance of having diverse family representation to ensure that the FACs are representative of the entire CCS population (e.g., ethnicity, non-English speakers, age of child, diagnoses) served by the health plan. Even so, interviewees also noted that this goal can be challenging to achieve. Several interviewees commented on the “concerted” effort needed to ensure that FACs are diverse. One interviewee shared that it may take time to build an FAC that reflects the composition of the CCS population, noting that their FAC initially had no Spanish-speaking members but worked to change the membership until Spanish-speaking members comprised half of the FAC.

Orientation for FAC Family Representatives Offered by Some Health Plans

The health plans vary in whether they provide formal orientation or training to family representatives when they join the FAC or become the FAC chair or vice chair. For the health plans that provide training, some provide an overview of the FAC and the WCM, while others include information about meeting structure and process. New member orientation also may offer training to families to help them feel confident and comfortable speaking during the meetings. Several respondents noted the importance of helping

family representatives understand their role on the FAC, which is to represent the needs of the WCM families rather than the needs of their own child. One health plan requires new FAC members to complete compliance training. This training is reportedly designed for health plan staff and covers topics that are not directly related to the WCM or the FAC. The training is lengthy to complete (60-90 minutes), and the health plan was considering whether to provide a stipend to families to complete it.

A few health plans relied on convenings conducted by the Lucile Packard Foundation for Children's Health and Family Voices to bring the FACs together (both health plan staff and family representatives) rather than offer their own FAC training. Another health plan asked one of the FAC members from a local community-based organization to provide training for families on member expectations. One health plan respondent commented that the health plan "does not want to bombard families with WCM information;" instead, they want to "lead by example" to show the families how to participate on the FAC.

The challenges noted above with retaining FAC members also impact FAC training. As one respondent noted, "there is a new family at almost every meeting, which makes it hard to manage training needs."

Health Plans Support FAC Family Representatives in Different Ways

All of the health plans provide supports and accommodations for family representatives to participate on the FACs. This includes translation services (e.g., interpreters, translation of materials) as needed, depending on the composition of the FAC. In addition, all health plans provide a stipend to FAC family representatives: most of the health plans provide a \$50 stipend per meeting, with one providing a stipend of \$100. The stipends are intended to help cover any costs for family members to attend the meetings. Offering a stipend also demonstrates the health plans' commitment to the WCM families and their participation on the FAC. In addition to a stipend, some health plans provide support for transportation costs (e.g., by offering mileage reimbursement or bus passes).

Scheduling the FAC meetings based on family representatives' input and availability is another accommodation provided by the health plans. For example, one of the FACs meets in the evening because that worked best for the family representatives. Other WCM plans hold the FAC meetings during the workday, which could limit the participation of the family representatives. One health plan surveyed families and learned that daytime meetings would be the most convenient since their children are in school. Parents also shared that they are more likely to have nursing or respite care available during the day. One health plan moved the meeting from the late afternoon to the morning because the families found it challenging to meet later in the day, after school ends. Some of the health plans also provide food at the FAC meetings (e.g., dinner or lunch depending on the meeting time). A few health plans allow parents to bring their children to the FAC meetings, and one health plan was considering whether to offer childcare to family representatives.

A number of the health plans, particularly those that operate across multiple counties, offer family representatives options for how to participate in the FAC meetings. Some host FAC meetings simultaneously at satellite offices via videoconference. (As discussed below, all of the health plans adopted the use of videoconferencing due to COVID-19.) In many cases, family representatives can join via phone as well. As one interviewee noted, "face-to-face meetings are always better, but videoconferencing gives access to more people." One health plan shared that they meet at a central location in their county that was selected by the parents.

“Face-to-face meetings are always better, but videoconferencing gives access to more people.”

FAC Members Collaborate on Agenda Development

All of the FACs use a collaborative process to develop meeting agendas, with health plan staff and FAC members (typically the FAC chair) working together. At one health plan, FAC agendas are developed collaboratively between the health plan, FAC chair (a family representative) and county CCS staff. At another health plan, the chair and vice chair (both held by family representatives) determine the

agenda topics, with the health plan adding items as time allows. In several cases, the FAC chair and/or vice chair solicit input from the other family representatives on agenda items. This ensures that the agenda reflects topics and issues of importance to the families. One health plan solicits agenda items from FAC members via e-mail and then shares the draft agenda with the FAC for feedback. Health plans also collect future agenda items from FAC members at each meeting.

Common Meeting Topics Have Emerged

The topics covered at FAC meetings have evolved over time. During the initial meetings (occurring prior to, or shortly after, WCM implementation), agendas typically focused on start-up activities, including gathering feedback on member communications and the structure of WCM “town hall” meetings with families. In addition, the health plans provided background information to FAC members about the health plan and the WCM at the early meetings. One health plan reported that the members of the FAC worked together initially to develop the roles and responsibilities for FAC members and a glossary of health plan and WCM terminology. For another health plan, the initial FAC meetings also included discussion of operational issues and family concerns (e.g., how to ensure coordination of benefits, how service authorization requests would transfer from the county to the health plan following implementation).

Following implementation, the FAC agendas transitioned to focus on operational issues of concern to the health plans, the FAC family representatives, or both. As one respondent commented, “topics have evolved greatly since the start of the FAC when members were still learning about the WCM and the health plan. Now, they [family representatives] are ready to tackle benefits, topics, and processes that are meaningful to families and beneficiaries.”

“Topics have evolved greatly since the start of the FAC when members were still learning about the WCM and the health plan. Now, they [family representatives] are ready to tackle benefits, topics, and processes that are meaningful to families and beneficiaries.”

Common agenda items across the FACs have included discussion of member grievance data, care coordination issues, service authorization trends, and pharmacy benefit issues. FAC agendas may include standing updates from senior health plan leadership, including the chief executive officer (CEO).

Over time, specific topics have emerged that impact WCM enrollees across the health plans. These have included access to pediatric shift-nursing services and durable medical equipment-related issues (e.g., access to incontinence supplies). Issues related to CCS MTP also are discussed at FAC meetings. Another common topic for the FACs involves the transition process for WCM enrollees when they age out of the program and are no longer eligible for CCS. Community partners also may be invited to present at FAC meetings. One FAC invited Pacific Gas & Electric Company (PG&E) to provide an update to the FAC on emergency preparedness for families of WCM enrollees who use medical devices that require electricity.

Several respondents noted that their FAC includes a “goal statement” on the agenda or asks a family representative to read the FAC’s mission statement at the start of each meeting. This helps the FAC remain focused on its goals and purpose during the meeting. One FAC developed a 12-month “road map” to guide its work, including the selection of agenda topics for discussion by the FAC.

Bi-Directional Information Sharing between FACs and Health Plan Leadership Is Important

Bi-directional communication between the FACs and health plan leadership is critical to the success of the FACs. For some of the FACs, health plan senior leadership, including the CEO, attend the meetings. Several interviewees noted that having senior leadership attend signals that the health plan takes the work of the FAC seriously. In other cases, health plan staff attend the FAC and share information afterwards with senior plan leadership (e.g., by sending the meeting minutes to the executive team). FAC meeting minutes also may be shared with the health plan's provider or quality committees.

Health plan FAC lead staff ensure that appropriate staff attend the meetings to address issues raised by the families in advance. For at least one of the health plans, the FAC chair (who is a family representative) provides regular updates to the health plan's board of directors. The health plans also follow up on action items or issues identified by the FAC and report back at a subsequent meeting to ensure that FAC members know how issues are resolved.

FACs Make Meaningful Impacts on Health Plan Operations

In their first 18-24 months, the FACs tackled a range of topics and provided meaningful input that has helped to improve the WCM. Respondents noted that the FACs helped “put a face” on their children and their challenges for the health plans. One health plan respondent noted that “the FAC members help the plan to understand the unique needs of [the CCS] population through story sharing and discussion of agenda items.”

“The FAC members help the plan to understand the unique needs of [the CCS] population through story sharing and discussion of agenda items.”

As noted earlier, the health plans seek the FAC's input on member communications and outreach, including the content of written materials, call center scripts, and timing for WCM-related events. One respondent commented that “FAC input is always sought to ensure family-friendliness for any outreach activities.” Based on feedback from the FAC, one health plan added a link to the WCM intranet webpage to allow families to share information with the FAC, and any information submitted through this link is sent directly to health plan staff for review.

The FACs have provided important input and suggestions on other topics as well, leading to changes in health plan operations. This includes one health plan that worked with FAC members to revise and streamline the process for parents and caregivers to be reimbursed for travel costs. The health plan commented that FAC members were “vital” in the redesign of the form to request reimbursement for gas mileage, tolls, and parking related to a medical service or appointment. FAC members made recommendations on improvements to the layout and content of the form and on submission of the form to make it easier and faster for the health plan to process.

Access to appropriate transportation services is a critical issue for WCM enrollees and their families. One health plan revised the information provided to its transportation vendor to include notes about the WCM enrollee's complex needs and whether both parents would need to go with the child to an appointment. The same health plan sought the FAC's input on a review and assessment of the Treatment Authorization Request (TAR) process. As a result, work is underway to identify opportunities to improve and streamline this process.

Another health plan worked with the FAC to develop a preferred vendor program for incontinence supplies, to address access and quality issues identified by FAC family representatives. The same health plan created a value-based purchasing program for shift-nursing services to help improve access for WCM families. Under this initiative, the health plan provides an enhanced payment to providers that is tied to improved access and quality of care.

Based on input from an FAC member, one health plan revised the onboarding process for new WCM families. When a child eligible for CCS is identified at local hospitals, a nurse case manager or another health plan representative meets with the family in person at the hospital to help coordinate care and identify other resources for the child.

Impact of COVID-19 on the FACs

When the pandemic began in the Spring of 2020, the FACs transitioned quickly to meeting virtually via videoconference. Respondents identified this change as one of the pandemic's "silver linings" as it allowed FAC members to attend meetings more easily, resulting in improved attendance. For health plans that require a quorum, this has been particularly noteworthy. One respondent noted, however, that some families find it challenging to use a health plan's videoconference platform if it requires learning to use a different system from the one they typically use. For at least one FAC, the pandemic changed the timing of the FAC meetings: the health plan moved the meeting to later in the afternoon in response to a request from the families to meet following the end of the virtual school day.

Respondents also reported that FAC agendas have added COVID-19 as a regular topic. One health plan includes time on the agenda to allow families to share their experience with, and concerns about, COVID-19. One respondent commented on the need to shorten their meeting agenda to accommodate the ability to allow for translation of the discussion in a virtual environment. When the meetings are held in person, the translator can translate the discussion in real time; however, in the virtual format, the discussion must pause after every sentence to give the translator time to translate from English to Spanish or Spanish to English.

Based on feedback from the FAC, one health plan developed a flyer for WCM families about COVID-19. While the health plan had posted information about COVID-19 on its website, the FAC recommended mailing the flyer out to families so they could "put [it] on the fridge," making it easy to find information quickly without having to access the Internet.

Discussion & Recommendations

The FACs provide health plans with the opportunity to engage directly with families on a regular basis and provide families with an avenue to ensure that they have a voice in how the WCM operates. Respondents identified several key components to ensure that the FACs are effective:

- **Reduce barriers to family participation.** Family recruitment, retention, and participation in the FACs has been challenging across all of the health plans. Each FAC has developed strategies to support recruitment of new members. The health plans also provide supports (e.g., stipends, travel reimbursement) to encourage family representatives to join the FACs and make it easy to participate.
- **Assist families to understand their role on the FAC.** Several respondents commented on the importance of training families about how to advocate for all CCS children rather than the unique needs of their child. While both perspectives are important, addressing individual concerns during the FAC can take the meeting off topic.
- **Allow the FAC to evolve over time.** It is important to be flexible in terms of the FAC structure and content of the meetings, as priorities are likely to shift over time. For example, several FACs reported changing the frequency of their meetings in response to health plan needs and/or families' input. Other WCM plans transitioned FAC leadership from health plan staff to the families. The topics covered at the FAC meetings also have evolved. Finally, all of the FACs moved to use videoconferencing for their meetings during the pandemic.
- **Communicate the value of the FAC.** Make sure families on the FAC feel heard. Almost all respondents stressed the importance of making sure the family representatives on the FAC feel heard and understand their value. This was viewed as critical to sustained participation by families and, over the long run, to the sustainability of the FACs. Follow-through by the health plans on issues raised at the meetings was noted as particularly critical. This demonstrates the WCM plans' respect for the families, which is essential

to building trust between the families and health plans. Offering stipends to FAC family representatives also communicates the value health plans place on family participation. Many WCM families were concerned that the health plans would not be their allies and were skeptical that they would accept family input and feedback. By partnering to address issues, however, the WCM plans and their families can build strong relationships and improve family satisfaction and the quality of care provided.

- **Understand time and resources required from health plan to ensure the FAC's success.** Managing the FAC requires significant work and commitment on the part of the health plan to manage the meetings (e.g., develop agendas, arrange for meeting rooms, prepare materials, etc.), follow up on any action items identified during the meetings, and assist FAC members to maintain meaningful engagement.

Conclusion

Meaningful family engagement can lead to improved care delivery, quality of care, and patient and family satisfaction. For the WCM, the health plans and family representatives worked together to establish the FACs, which helps ensure that the family (and patient) experience is reflected in the management of the program. The FACs provide the families the opportunity to share information and offer input into health plan operations, and to raise issues affecting the WCM enrollees. In several cases, the FACs have been instrumental in establishing operational changes that improve the WCM experience for families. The FACs are a partnership between the health plans and the families, and they have evolved over time as both parties better understand how to work together and what is necessary to make each FAC successful. Launching an FAC and ensuring its long-term viability requires commitment on the part of both the health plan and the WCM families to continually evaluate the structure of the FAC and make adjustments as needed. The FACs' long-term success also depends on ensuring that the families feel heard by the health plans and understand the value they bring to improving the WCM model and the care provided to their children.

Footnotes

¹ California State Senate, Chapter 625, Statutes of 2016.

² The 21 counties included in the WCM program include: Del Norte, Humboldt, Lake, Lassen, Marin, Mendocino, Merced, Modoc, Monterey, Napa, Orange, San Luis Obispo, San Mateo, Santa Barbara, Santa Cruz, Shasta, Siskiyou, Solano, Sonoma, Trinity, and Yolo.

³ In 2013, HPSM launched a pilot, in collaboration with DHCS, to test a CCS model similar to the WCM.

⁴ Holly Henry, PhD, Allison Gray, MA, and Edward Schor, MD, “How California Children’s Services Programs in the 21 Whole-Child Model Counties Engage with Families,” Lucile Packard Foundation for Children’s Health, March 2018, https://www.lpfch.org/sites/default/files/field/publications/ccs_family_engagement_3.16.18.pdf; Priscilla Marbell, MD, MPH, “Engaging Families in Improving the Health Care System for Children with Special Health Care Needs,” Lucile Packard Foundation for Children’s Health, November 2017, https://www.lpfch.org/sites/default/files/field/publications/engaging_families_in_improving_the_health_care_system.pdf

⁵ California Department of Health Care Services, “California Children’s Services Whole Child Model,” All-Plan Letter 18-023, December 23, 2018, <https://www.dhcs.ca.gov/formsandpubs/Documents/MMCDAPLsandPolicyLetters/APL2018/APL18-023.pdf>.