Lucile Packard Foundation
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Case Study

# Tackling Systems Change to Improve Access to Incontinence Supplies for Children with Special Health Care Needs

## Orange County Care Coordination Collaborative for Kids

Prepared By

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**ABOUT THE AUTHOR**:

**Leslie Linton, JD, MPH,** is a research and evaluation consultant based in San Diego, California. She has led evaluation activities for the California Community Care Coordination Collaborative (5Cs) and its county coalitions across three phases of the program. A former lawyer, Leslie has a special interest in the impact of policy and systems on public health. In addition to her interest in systems change to support children with special health care needs and their families, she continues to investigate how policy and environment can support active living and healthy eating to prevent childhood obesity.

The author gratefully acknowledges the generosity of each of the interviewees (see Appendix: List of Interviewees) in sharing their time and expertise.

Lucile Packard Foundation *for* Children's Health

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**ABOUT THE FOUNDATION**: The Lucile Packard Foundation for Children's Health is a public charity, founded in 1997. Its mission is to elevate the priority of children's health, and to increase the quality and accessibility of children's health care through leadership and direct investment. Through its Program for Children with Special Health Care Needs, the foundation supports development of a high-quality health care system that results in better health outcomes for children and enhanced quality of life for families. The Foundation works in alignment with Lucile Packard Children's Hospital Stanford and the child health programs of Stanford University.

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"We have struggled for years with the authorization process. My daughter's diagnosis has not changed and, barring a miracle, it never will. The multiple layers of insurance make this a nightmare." – *Mother of a 22 year-old daughter.*

"People think it is so simple to get diapers for your child who has outgrown Pampers. It is so convoluted. It depends on the child's diagnosis. It depends on what services the child has. It depends on whether the child has a waiver, if they have Medi-Cal, if they are getting that through their primary care doctor. Most primary care insurance doesn't cover diapers. But you need a denial. And you are ping-ponged." – *Family representative at OCC3 for Kids.*

"If a child has been in diapers for 8, 10, 12 years, why do we have to keep filling out paperwork or telling people that yes, they're still incontinent. It should almost be a 'no-brainer.' Why is it we have to keep doing these referrals and these authorizations if we know this is a condition that is not going to change?" – *Family representative at OCC3 for Kids.*

## Setting: Orange County, California

With an estimated population of 3,175,700, Orange County is the third most populous county in California and the sixth most populous county in the United States.[1] Children under the age of 18 make up 21.7% of the population.[1] In Orange County, 15.1% of these children have special health care needs.[2] For many of these children, health care needs are profound. As of 2014, more than 13,000 children were served by California Children's Services (CCS), a statewide program that provides funding for treatment of children with certain physical limitations and chronic health conditions or diseases.[3] The medical director at Orange County's CCS estimates that 14,000 children were being served by her agency as of 2019.[4] Of these children, 13,000 also were beneficiaries of Medi-Cal, California's Medicaid program.[5]

Medi-Cal in Orange County is administered by a single health plan, CalOptima.[6] Health care coverage is provided through 13 networks contracted with CalOptima.[5] At the time of this writing, Orange County was one of 21 counties in California scheduled to implement the "Whole Child Model." The Whole Child Model incorporates services currently covered under the state CCS program for Medi-Cal eligible children into a Medi-Cal managed care plan contract.[7] In Orange County, CalOptima will have this contract to administer CCS services previously administered by Orange County for the benefit of children who are Medi-Cal eligible.[5] The hoped-for results of the legislatively authorized Whole Child Model are "improved care coordination for primary, specialty and behavioral health services for CCS and non-CCS conditions."[8]

# OCC3 for Kids: A Collaboration of Agencies Serving Children with Special Health Care Needs

Beginning in 2013, with the assistance of a grant from the Lucile Packard Foundation for Children's Health (LPFCH),[9] the Orange County Care Coordination Collaborative for Kids (OCC3 for Kids) began working to improve systems of care for children with special health care needs (CSHCN).[10] OCC3 for Kids is a partnership that has grown to include more than 18 public and private organizations, including CCS, CalOptima, Regional Center of Orange County, Family Support Network and many other key partners, all coming together voluntarily on behalf of children with special health care needs.[10] Key personnel throughout the program have been Rebecca Hernandez, Principal Investigator and Program Manager of lead agency, Help Me Grow (rhernan2@uci.edu) and Lisa Burke, Burke Consulting, who served as a group facilitator from the inception of OCC3 for Kids' until 2019.[11]

Since 2013, OCC3 for Kids has met continuously, with monthly meetings for the general membership and periodic workgroup or stakeholder meetings of interested partners on specific issues of interest. Some of the group's successes have included piloting of a care coordination measurement tool, an outreach program to provider groups to increase referrals to an OCC3 for Kids case coordinator/public health nurse (a program that is no longer in operation due to funding changes), and workgroups focused on policy changes relating to the Newborn Intensive Care Unit (NICU) discharge, provider education, and in-home support services.

All partners in OCC3 for Kids were surveyed at the end of 2017 and again at the end of 2018 about their experience in participating in the coalition. Partners identified the top two aspects of the collaboration each year to be "bringing together diverse stakeholders" and "exchanging info/knowledge." Both years, large majorities of partners responding to the survey agreed or strongly agreed that partnership with OCC3 for Kids:

- increased our organization's ability to network and collaborate with other organizations [100% in 2017 and 2018]
- provided a place to bring some difficult challenges to help find solutions [(2017: 77%) (2018: 84%)]
- enhanced our training and awareness of other services in the county [(2017: 95%) (2018: 95%)]
- provided a place to present our services/clarify misunderstandings [(2017: 95%) (2018: 94%)]
- provided a place to advocate for services for Children with Special Health Care Needs (CSHCN) [(2017: 91%) (2018: 89%)]
- allowed us to better serve our clients [(2017: 82%) (2018: 89%)].

## Coalition Process

During the summer of 2017, the coalition applied for and was selected to receive a grant of $12,000 from LPFCH as part of LPFCH's "Phase 3" funding for the program known as 5Cs, the California Community Care Coordination Collaborative.[9] Part of the grant's scope of work was to identify a specific system-level issue for the group to address during the one-year grant period from August 1, 2017 to August 31, 2018, in addition to their ongoing networking and education meetings of the coalition. The group initially articulated their chosen issue fairly broadly:

1. Explore opportunities for increased coordination among CalOptima (managed Medi-Cal), California Children's Services and Regional Center, for the purpose of reducing children's wait times for services, referral or products and reducing the burden on parents to access/secure these services/products.

2. Develop a cooperative approach for gaining understanding of initial authorization and payment of services among CalOptima, California Children's Services and Regional Center, and increased coordination of payment for those services that do not fall "cleanly" under one agency's purview.

3. Pilot implementation of cooperative approach.

OCC3 for Kids had several specific situations/models in mind as the group sought to further refine the specific system change/coordination challenge they wished to pursue. With at least three family representatives actively participating in the coalition, they had developed an ongoing interest in the problems that parents of CSHCN experience in securing durable medical equipment and supplies for their children. In the past, the group had invited consultant Maryann O'Sullivan to meet with the collaborative on this issue to consider possible advocacy strategies to pursue in support of CSHCN.[12]

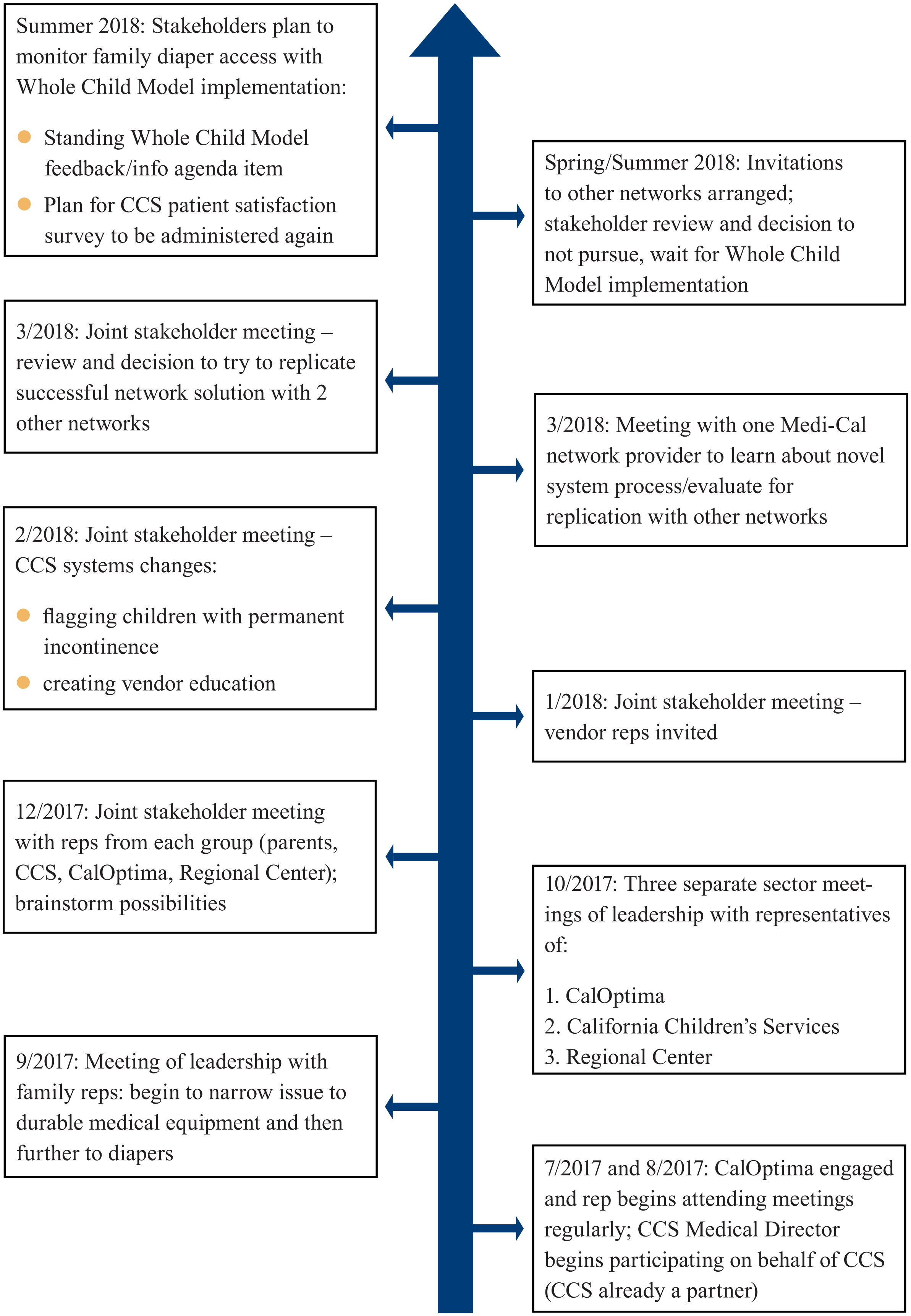
The collaborative had also been introduced to a model practice followed in Kern County,[13] whereby, in situations wherein the responsible payer was unclear, one of the parties (e.g. California Children's Services or the Medi-Cal plan) would agree to pay upfront for needed supplies/equipment with an agreement between care providers/insurers to provide reimbursement between the parties later on if the party that paid upfront was not ultimately determined to be the responsible party. The concept was to ensure that families did not wait while the issue of responsibility was bounced around between payers.

With this background, collaborative partners decided to narrow the type of equipment/supplies. They chose diapers and other incontinence supplies needed on an ongoing basis by children as a consequence of a medical condition. Partners made this decision following a meeting with the collaborative's three family representatives, all of whom were intimately acquainted with the types of problems faced by parents, either because they worked as family mentors, they were parents of a child with special health care needs, or both. Diapers became the focus:

> "We started with diapers because diapers are relatable to everyone. Everyone who's ever had a child understands the necessity. It's so much easier to be disassociated from other things – like neurological needs."
>
> *– Maura Byron, OCC3 for Kids Partner, parent and Program Coordinator for Family Support Network*

Working with stakeholders, OCC3 for Kids leadership determined that the best process, having chosen a narrowed issue and type of supply, was to meet separately with each key stakeholder (family representatives, CalOptima, CCS, and Regional Center), for the purpose of learning about their administrative processes, listening to any concerns and exploring possible solutions before bringing the entire group together again. A timeline appears as Figure 1.

**Figure 1. OCC3 for Kids Timeline: Systems Change for Access to Incontinence Supplies**



Summer 2018: Stakeholders plan to monitor family diaper access with Whole Child Model implementation:

- Standing Whole Child Model feedback/info agenda item
- Plan for CCS patient satisfaction survey to be administered again

Spring/Summer 2018: Invitations to other networks arranged; stakeholder review and decision to not pursue, wait for Whole Child Model implementation

3/2018: Joint stakeholder meeting – review and decision to try to replicate successful network solution with 2 other networks

3/2018: Meeting with one Medi-Cal network provider to learn about novel system process/evaluate for replication with other networks

2/2018: Joint stakeholder meeting – CCS systems changes:

- flagging children with permanent incontinence
- creating vendor education

1/2018: Joint stakeholder meeting – vendor reps invited

12/2017: Joint stakeholder meeting with reps from each group (parents, CCS, CalOptima, Regional Center); brainstorm possibilities

10/2017: Three separate sector meetings of leadership with representatives of:

1. CalOptima
2. California Children's Services
3. Regional Center

9/2017: Meeting of leadership with family reps: begin to narrow issue to durable medical equipment and then further to diapers

7/2017 and 8/2017: CalOptima engaged and rep begins attending meetings regularly; CCS Medical Director begins participating on behalf of CCS (CCS already a partner)

The OCC3 Leadership met individually with CalOptima, CCS, and Regional Center before they brought the parties together again to brainstorm possible solutions. At the suggestion of the CCS Medical Director, Dr. Hoda Kaddis, they invited a number of vendors who supply diapers among other medical supplies to a joint stakeholder meeting to understand vendor procedures and considerations. The workgroup continued brainstorming potential solutions to the problems expressed by parents under different scenarios in several subsequent meetings.

## Outcomes

Key partners engaged in a rich exchange about the different diagnoses/insurance scenarios presented by different patients. The key stakeholders universally agreed that this exchange increased understanding about the complex processes at other agencies as well as the frustrations suffered by parents.

> "There was some value in having the key partners at the table and explaining their system and eligibility criteria – how to navigate the system and where the handoff takes place."
>
> – *Tiffany Kaaiakamanu, Manager, Community Relations, CalOptima*

Significantly, there were specific systems changes that developed from the coalitions efforts:

- The CCS Medical Director adopted an institutional change at her agency. She changed the CCS authorization process for children who have lifelong incontinence, by flagging those cases:

> "I instructed my case managers to make that decision once and for all. Chances are this child is the same and is going to continue to be the same and we do not need to revisit that decision. The case managers will put that decision on an alert with a notation that this child has been determined to receive diapers through CCS until they age out. This makes the process much faster, and at the same time, it's making the network's job a little easier because now they know – this child is going to be covered by CCS."
>
> – *Hoda Kaddis, MD, Medical Director, Orange County CCS*

This change also was expected to speed the process for the incontinence supply vendors because they had knowledge that the child will be covered by CCS. Before this, vendors had been double submitting (to both CCS and to the Medi-Cal network) in the face of uncertainty.

- The CCS Medical Director also responded to feedback from vendors about their processes and determined that it was important to institute specific trainings for vendors to allow them to better understand CCS procedures and avoid errors that could cause delays. She developed and delivered a new training for vendors and an additional training was also scheduled.

OCC3 for Kids has also initiated some process changes, moving forward, to allow the organization to continue to monitor problems encountered by parents in acquiring incontinence supplies, and more broadly with delays and care coordination issues. These changes are discussed below in the "Challenges in Seeking Change" and "Moving Forward" sections.

## Key Stakeholder Roles

Family representatives were key to identifying the issues and frustrations suffered by parents of CSHCN. Based on their collective personal experiences, as well as their professional experience in mentoring parents, they were able to guide leadership to draft flow charts that documented the complexity of seeking something as simple as diapers. They also wrote family stories that allowed the group to share real life stories with partners, thereby highlighting problems and challenging partners to devise solutions.

CalOptima was an important and committed partner in this process, as well, and was able to find data about numbers of patients with different circumstances and network affiliations to guide decisions about where to focus the coalition's attention. The community representative who participates in the coalition was heavily engaged throughout and was able to bring in other CalOptima personnel when needed to explain their processes. Before July 2017, CalOptima had only been peripherally involved in the collaboration. Their strong participation at this time was and is beneficial for both the collaboration and CalOptima in light of the pending implementation of the Whole Child Model and the reciprocal information exchange.

Regional Center engaged in the process as planned, as well, and has been a steady member of the coalition on an ongoing basis. During this time period, their Chief Operating Officer participated in the stakeholder workgroup along with their Intake Manager. Regional Center comes into play as a payer for families that don't have private or public (Medi-Cal) insurance, and pay for services as the "payer of last resort," including when Regional Center families are in limbo waiting for a decision by CalOptima and CCS about who is the responsible payer.

California Children's Services was a fully engaged stakeholder in this process. The Medical Director participated in meetings to seek solutions to the struggles of families seeking diapers, and especially those with lifelong disabilities. She specifically identified ways to make a difference and instituted system change on an institutional level by flagging cases involving lifelong incontinence to reduce wait time. As recognized by Maryann O'Sullivan, a family advocate who has extensively studied family challenges to securing durable medical equipment (DME) and medical supplies:

> "Avoiding continual reauthorization is a real win. The opportunity to educate the vendors is a big deal. And [the coalition] should really be acknowledged and recognize these wins."
>
> *– Maryann O'Sullivan, J.D., author and consultant on advocacy and DME for CSHCN*

## Challenges in Seeking Change

The implementation of the Whole Child Model represents a significant challenge to the process. It is hoped that some of the care coordination challenges faced by parents may be resolved when CalOptima is responsible for much of the care currently administered by CCS. As the process of working toward system change unfolded, the impending transition to the Whole Child Model in Orange County led to speculation. Would the changes the group was working toward become a short-term "stop gap" that would soon no longer be necessary? At the time this work was under way, the implementation date was January 1, 2019, but toward the end of 2018 the implementation date was extended until July 1, 2019.[8]

An example of how the pending change challenged the process came toward the end of the coalition's execution of their workplan. The stakeholder workgroups discovered that the largest of the 13 provider networks providing care under CalOptima had already arrived at a solution that significantly benefited families. That network, CHOC Health Alliance, had an agreement in place with their primary vendor of incontinence supplies. The vendor had agreed to supply diapers to families, in advance, without knowing who the final payer would be (CCS or CalOptima, depending on whether the child's incontinence was related to a CCS condition). Once the final responsible payer was identified, the vendor billed the responsible payer and payment was made quickly. In many ways, this was an improvement on the Kern County model because there was no need for reimbursement of the party initially fronting the payment by the party ultimately responsible. It did, of course, require the vendor to ship without payment and assume that risk, and the group had heard from smaller vendors that the process was one that could only be undertaken by the larger vendors.

To the stakeholders, this represented an option worthy of sharing and potentially piloting with other networks. A plan was made to approach two additional networks to demonstrate the CHOC Health Alliance model and encourage its adoption. However, as the process progressed, the collaboration's stakeholders questioned the value of investing further time and effort due to the relatively small numbers of affected families covered by these two additional networks and the networks' focus on transition to the Whole Child Model.

> "Even if we did implement a new process, it would take time to integrate it into the system and reeducation of parents. It would all take a long time. And knowing that the CCS transition [Whole Child Model] was on the horizon, we kind of stepped back from there."
>
> *– Tiffany Kaaiakamanu, Manager, Community Relations, CalOptima*

Despite frustration at not being able to advance the CHOC Health Alliance model with other networks, OCC3 for Kids leadership recognized that it may be unwise to use their initial introduction to these previously uninvolved networks if the focus on Whole Child Model was going to serve as a distraction to the process.

## Lessons Learned

### *The power of a strong coalition, with a complement of invested partners.*

OCC3 for Kids is a strong and mature collaboration. The group has been able to attract and retain major agencies and organizations. When pursuing specific systems changes to ease access to diapers, they were able to recruit the key stakeholders whose processes impact children. Even vendors of incontinence supplies who are not partners were willing to come to the table to discuss possible change. This systems change project, together with the fact that the Whole Child Model was about to be implemented in Orange County, enabled them to recruit their managed Medi-Cal plan, CalOptima, to engage more closely with the coalition than had been true in the past. They were able to engage the California Children's Services medical director, who had the power to implement system change, as well as the chief operating officer at Regional Center who explained and examined that agency's responsibilities for payment related to this issue.

### *Creating a safe environment to discuss change.*

The word "safe" has been mentioned repeatedly by partners, both in surveys and interviews in reference to the OCC3 for Kids' meetings. This may be partly due to the fact that its leaders are relatively neutral conveners. So, for instance, in the context of the system changes under consideration, they did not have an affiliation with a stake in the outcome. One reflection on leadership illustrates this point:

> "They are very non-confrontational. Also, they don't cater to politics. They are very neutral – safe. And, they provide a safe environment, as well as education....You can rely on them to use the information diplomatically and not to ruin my relationship with other entities. You can trust them."
>
> *– Hoda Kaddis, MD, Medical Director, Orange County CCS*

### *Simplifying the issue helped clarify and maintain interest.*

The complexities of care coordination for CSHCN can be dizzying, even for those intimately involved with its intricacies. Narrowing the issue to DME and then further to incontinence supplies helped move an overwhelming set of variables into something much more manageable and readily understandable. It helped focus the discussion. No specialized medical knowledge is needed to sympathize with a family caught in the struggles of being bounced among different potential payers.

## Moving Forward

A key to sustaining and building on systems change is ongoing monitoring of the experiences of families with special health care needs. OCC3 for Kids is doing this now. With three active family representatives as partners, the coalition has an ear to the experiences of local families. With a relatively full complement of partners from different sectors serving children, the collaboration has a window into how procedural change in the delivery of health care is impacting the systems that deliver care. The monthly meetings of the full membership of partners now include a standing agenda item relating to the transition to the Whole Child Model, and this will allow partners to be updated by CalOptima. But it will also allow for feedback about how the Whole Child Model transition is impacting families and affected organizations. Having family representatives who are active in 5Cs who will also serve on CalOptima's Family Advisory Committee should contribute to rapid communication between OCC3 for Kids and CalOptima, as well as interested organizations representing families.

> "Having updates and also feedback about what is working and what is not working [will be valuable.] Whatever concerns our members are experiencing, we want to be aware so that we can make changes. I will continue to provide updates....CalOptima also has a Family Advisory Committee. There are some members who are members of both OCC3 for Kids and CalOptima's Family Advisory Committee. A rep from that group will be at our CalOptima Board meetings. That's good because the Board is where the changes take place."
>
> *– Tiffany Kaaiakamanu, Manager, Community Relations, CalOptima*

Collaborations such as OCC3 for Kids can provide some of the strongest and important feedback about the effectiveness of the transition to the Whole Child Model:

> "[Concerning OCC3 for Kids' ongoing role]: We need to keep these people at the table. This should happen even if CalOptima is going to have a Family Advisory Group....There need to be eyes on the outside...[OCC3 for Kids] are tenacious and smart and the organization should be kept in place to watch, and there should be other [similar coalitions] around the state, as well....There is something about the leadership at OCC3 for Kids – they have been together for a while and they work very well together."
>
> *– Maryann O'Sullivan, J.D., author and consultant on advocacy and DME for CSHCN*

OCC3 for Kids also learned that Orange County CCS conducted periodic surveys of families of CSHCN. One of the questions asks if the child received assistance during the last 12 months for getting medical supplies (e.g. urinary catheters, diavpers, syringes) and inquiries about satisfaction.

Results for the surveys distributed and due at the end of June 2018 included 1,387 responses, with 21% (294) indicating that they had received assistance from CCS in getting medical supplies. Of these, 284 responded about their level of satisfaction. "Very satisfied" was the response of 64% of respondents, "satisfied" was checked by 32%. Only 4% (10) checked that they were "dissatisfied" (3%) or "very dissatisfied" (1%). An open-ended option allowed respondents to explain their reasons. Of those who indicated dissatisfaction, the reasons expressed included mention of delays and one mentioned the need to purchase diapers on Amazon until the situation was straightened out.

OCC3 for Kids is hoping that the survey can continue to be administered as another means of getting ongoing feedback on the specific issue of medical supplies, generally, and diapers, in particular. The CCS medical director noted that she is unsure if she will be permitted to continue to distribute the survey to families who are no longer receiving CCS services. If Managed Medi-Cal plans such as CalOptima that are part of the Whole Child Model are required to distribute patient satisfaction surveys, it would be very helpful if specific questions about DME/Medical Supplies and diapers could be included to provide ongoing measures of family challenges in obtaining incontinence supplies.

OCC3 for Kids does plan to review Orange County data that are scheduled to be collected from local families via the Family Survey planned in connection with CCS Needs Assessment process being conducted by the Family Health Outcomes Project at the University of California, San Francisco.[14] A question is expected to appear in that survey that is similar to the series of questions asked in the CCS survey described above, and should offer another objective measure of family experiences.

OCC3 for Kids has continued its work over the following year with a new focus – on transition of CSHCN from pediatric to adult care. The group found that Orange County has a lack of adult primary and specialty care providers who are trained and/or comfortable serving CSHCN as they transition into adulthood. There is a significant need for coordination, connection and networking between pediatric providers serving CSHCN, and the health plans and adult health care providers that may "receive" these transitioning CSHCN.

Building on the model that they successfully used in addressing access to incontinence supplies, the coalition continues to engage key stakeholders in a smaller workgroup, building on existing relationships and engaging additional partners with key roles in addressing transition challenges. The coalition surveyed key stakeholders to better understand existing agency and provider practices and challenges, as well as to identify best practices that can be shared. Ultimately, they assembled and modified existing resources into a toolkit for providers and have provided educational forums for providers and related stakeholders. As always, the larger coalition is playing a key role in informing the progress of the workgroup and in disseminating the work to a broad range of parties working with CSHCN.

## Appendix: List of Interviewees

**Lisa Burke,** Facilitator for OCC3 For Kids
Burke Consulting

**Maureen Byron,** Parent Partner at OCC3 For Kids; Parent and Program Coordinator
Family Support Network, Orange County

**Rebecca Hernandez,** Program Manager
Help Me Grow Orange County
OCC3 For Kids Leadership Team

**Tiffany Kaaiakamanu,** Manager of Community Relations
CalOptima

**Hoda Kaddis, MD,** Medical Director
California Children’s Services, Orange County Health Care Agency

**Maryann O’Sullivan, JD,** Independent Health Policy Consultant

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