HMG Affiliate Summary of Evaluations

HMG Study 1	
Responder Information	Name: Heather Little Affiliate: California
Status (select one)	Completed In process
Study Focus (select one)	HMG independent HMG in combination with other initiative Independent evaluation that calls out HMG
Model Relevance (Select one)	HMG Call Center Physician Outreach Family Engagement Community Outreach Developmental Screening Other (please specify):
Study Framework (Describe each)	Primary research question: How to help parents navigate California's referral system by identifying and making necessary improvements. Target population: 0-21 Sample size (if applicable): Study design: Interviews, online surveys, working groups of established coalition partnerships for document review
Key Findings	Please provide a written of key findings and take aways from this study. The regions supported by the Foundation to date have established strong coalitions composed of committed partners. While they have continued to operate with primarily in-kind support from participating agencies, they struggle with sustainability. Support for staff to communicate with members and organize and run meetings is a particular need. • A stipend for families would make it easier for them to participate in coalition activities. • A 24-month grant period for coalitions is preferred over 18 months to support development of member relationships and systems change. • The 5Cs Statewide Learning Collaborative is considered one of, if not the most valued aspect of 5Cs participation. It provides synergy for the work of the individual coalitions

	as well as informs the Foundation about the critical systems issues impeding families of CSHCN. Local coalitions also find that their association with the Foundation provides them with added credibility with agency partners and encourages participation. • Coalitions are hopeful that, even if they are not granted funding to run their local coalition, they would be able to attend the Statewide Learning Collaborative meeting, and continue to characterize themselves as a 5Cs coalition or be "the 5Cs in association with Lucile Packard." They point to their connection with the Foundation and the Statewide Learning Collaborative as important for recruiting and retaining coalition members. • Future convening could also include a statewide or regional meeting that would demonstrate the work of the 5Cs coalitions to other regions and encourage replication. • Evaluation activities should be enhanced in future 5Cs activities and will assist local coalitions in securing agency participation. Offering evaluation support to coalition teams, particularly as projects are being designed, could produce richer outcome data. In addition, a uniform assessment tool could be designed with the help of coalition leaders to measure aspects such as the extent of the networks and relationships built locally and how coalition members are deploying the information learned at meetings. • Elevate systems change at the state level. The Foundation is uniquely qualified to be "the voice."
Other *Please describe other relevant information such as budgets, consults, etc.*	

CALIFORNIA COMMUNITY CARE COORDINATION COLLABORATIVE

AN EVALUATION REPORT FOLLOWING PHASE 2

SUBMITTED TO: LUCILE PACKARD FOUNDATION FOR CHILDREN'S HEALTH
PREPARED BY: LESLIE S. LINTON, MPH, HEALTH POLICY CONSULTING GROUP
February 22, 2017

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Executive Summary

> *"The many eligibility requirements of each agency are extraordinarily frustrating to a parent. . . . You have to understand, legally and procedurally, all of the rules and laws of every different system you are entering into. . . . You get exhausted and lost."*
> [Parent of a child with special health care needs who is also a 5Cs local coalition leader]

Recognizing the fragmented systems of health care that California's families of children with special health care needs (CSHCN) must navigate, the Lucile Packard Foundation for Children's Health (LPFCH) provided two rounds of funding from 2013-2016 for the California Community Care Coordination Collaborative (5Cs). Ten local coalitions were formed across the state to bring together previously siloed agencies with the goal of improving local care coordination services and identifying needed changes to systems that serve CSHCN.

To leverage and support the work of the local coalitions, the Foundation initiated and staffed a Statewide Learning Collaborative that brought together leaders from all of the local coalitions four times during each 18-month grant cycle, and additionally offered joint webinars and technical assistance to the individual local coalitions.

To assess the 5Cs experience to date and inform consideration of a future iteration of the 5Cs, the Foundation retained an outside evaluator. The evaluation included an online written survey of 24 leaders of the 10 local coalitions and in-person group interviews with leaders from each local coalition.

Findings: Local Coalitions

- Local coalitions successfully recruited relevant agencies (typically 20-25 members) to join monthly meetings.
- Meetings included presentations from agencies about their services, eligibility, and referral methods. Meetings often included presentations about complex cases with discussion and brainstorming to find solutions.
- Nine of the ten coalitions continue to meet in 2017, notwithstanding the end of LPFCH funding, due to strong interest from participating agencies.
- The development of relationships between agencies was highly valued by all coalitions. Here are some descriptions of the value of these relationships in the words of the leaders:

- *Because I come to this meeting, I know who to contact - - where to refer and not refer. . . . We problem solve. What could we have done? What was the gap and why couldn't they get the service they needed?*
- *We have networking and sharing. It feels like it is the strongest it has ever been. It is its most highly functioning.*
- *Everyone is equal in the room. With that trust, we can build solutions.*
- *Know[ing] about the whole circle of services . . . is what helps protect the families from bouncing against agencies and trying to figure things out . . . the providers, too . . . don't really understand the rules . . . [and] were equally as frustrated as the family.*
- *[5Cs activities] also identified a lot of where we were dropping the ball in our county. It would show us patterns of things happening more than once.*
- *Agencies developed protocols for working with each other.*

- As a result of these meetings, there is evidence of systems change at the local level. In addition to the institution of coalition meetings, local examples include new agency protocols between agencies that frequently work with each other, trainings for agency staff to improve referrals and quality of care, embedding of system care coordinators at county public health departments by leveraging Federal Financial Participation funds, and formation of 5Cs policy subcommittees to address recurring local systems issues.
- Coalitions valued family participation in their 5Cs coalitions.
- Leaders stressed that building a coalition and developing trust among agencies takes time. Achieving local systems change takes even longer.
- Leaders foresee multiple challenges in the immediate future, including the potential repeal of the Affordable Care Act and related threats to the State's Medi-Cal program. They expect these changes to disproportionately affect California's CSHCN. They see an important role for the 5Cs coalitions to connect agencies, share rapidly changing information, identify new gaps in the safety net for CSHCN, and provide information channels to help allocate public resources at the local and state levels.
- Every respondent to the online survey agreed, "The 5Cs project has had a positive impact on my community." And 96% responded "yes" to the question, "Has the Foundation's support helped develop sustainable collaboration within your community?"
- Notwithstanding the determination of local coalitions to continue to operate 5Cs meetings, sustainability challenges remain.
- The coalitions were repeatedly challenged by systems issues they could not solve at a local level.
    - *We are working on the symptoms. But some things need to be resolved at the state level.*

    - *Coordination between agencies about who will pay for what - - but again, all at state level. It is a nightmare, always.*
- The strong consensus is that LPFCH should take the lead in working for systems change at the state level. While the coalitions are aware of ongoing state level efforts by LPFCH, some leaders said they were unclear about how the information they brought to the Statewide Learning Collaborative was being used to influence change.

Findings: Statewide Learning Collaborative

- Every leader who attended the Statewide Learning Collaborative meetings described them as "useful" or "very useful." A typical comment from interviews was, "*The learning we had from all the other communities - - I will be very sad to have it disappear, particularly because of the statewide learning collaborative. If I had to pick the most unique thing about their funding, that is it. And the greatest value add."*
- Leaders particularly valued the opportunity to exchange information and brainstorm with other coalitions. They learned how other regions were engaging hard-to-reach partners, billing for care coordination, and dealing with common systems issues. Coalitions shared tools that they had developed with each other, creating a toolbox to allow regions to start with a template that was right for their jurisdiction. Relationships built at the in-person meetings continued outside of meetings. "*We were free to and did go to other counties [for help]. We were all in this. We learned from every single 5Cs community."*
- Meetings were also an opportunity for coalition leaders to share with each other and the Foundation about persistent state-level systems issues and how these were impacting children and families in their communities.
- Expert presentations at the Statewide Learning Collaborative meetings in areas such as advocacy, communications, goal setting, and system design were highly valued by grantees.
- *"The meetings reinvigorated our systems work. We took people's examples and brought them back to the local level."*

Conclusions and recommendations

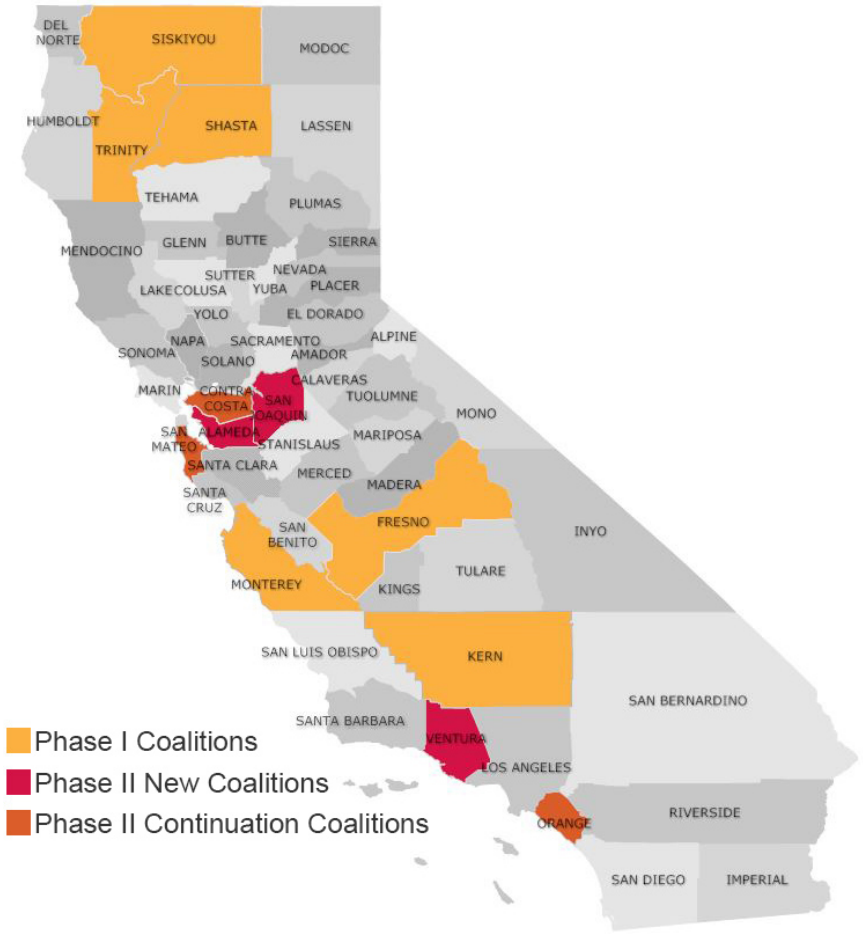
Coalition leaders foresee multiple challenges in the immediate future, including the potential repeal of the Affordable Care Act and related threats to the State's Medi-Cal program. They expect these changes to disproportionately affect California's CSHCN. They see an important role for the 5Cs coalitions to connect agencies, share rapidly changing information, identify new gaps in the safety net for CSHCN, and provide information channels to help allocate public resources at the local and state levels.

- The regions supported by the Foundation to date have established strong coalitions composed of committed partners. While they have continued to operate with primarily in-kind support from participating agencies, they struggle with sustainability. Support for staff to communicate with members and organize and run meetings is a particular need.
- A stipend for families would make it easier for them to participate in coalition activities.
- A 24-month grant period for coalitions is preferred over 18 months to support development of member relationships and systems change.
- The 5Cs Statewide Learning Collaborative is considered one of, if not the most valued aspect of 5Cs participation. It provides synergy for the work of the individual coalitions as well as informs the Foundation about the critical systems issues impeding families of CSHCN. Local coalitions also find that their association with the Foundation provides them with added credibility with agency partners and encourages participation.
- Coalitions are hopeful that, even if they are not granted funding to run their local coalition, they would be able to attend the Statewide Learning Collaborative meeting, and continue to characterize themselves as a 5Cs coalition or be "the 5Cs in association with Lucile Packard." They point to their connection with the Foundation and the Statewide Learning Collaborative as important for recruiting and retaining coalition members.
- Future convening could also include a statewide or regional meeting that would demonstrate the work of the 5Cs coalitions to other regions and encourage replication.
- Evaluation activities should be enhanced in future 5Cs activities and will assist local coalitions in securing agency participation. Offering evaluation support to coalition teams, particularly as projects are being designed, could produce richer outcome data. In addition, a uniform assessment tool could be designed with the help of coalition leaders to measure aspects such as the extent of the networks and relationships built locally and how coalition members are deploying the information learned at meetings.
- Elevate systems change at the state level. The Foundation is uniquely qualified to be "the voice."

The Foundation has created a strong network of community coalitions supported by a vigorous Statewide Learning Collaborative. Building on that structure in the coming years should prove invaluable to the State's families of children with special health care needs and to the regional agencies and individuals that serve them.

Background.

In 2013, Lucile Packard Foundation for Children's Health (LPFCH) initiated and funded a pilot project known as the California Community Care Coordination Collaborative (5Cs). Recognizing the fragmented system of health care that California's children with special health care needs (CSHCN) and their families must navigate, LPFCH sought to improve local systems of care through organization and support of local coalitions of agencies serving CSHCN and creation of a Statewide Learning Collaborative. The initial project supported development of six local coalitions and the initiation of the Statewide Learning Collaborative and ran for 18 months, from 2013-2014. A second phase of the project, initiated in 2015, provided support for three of the original coalitions to build on their first phase accomplishments and for three new coalitions to form and join the Statewide Learning Collaborative, with paired mentoring assistance from previously funded coalitions.



The rationale behind the 5Cs approach is reflected in LPFCH's second Request for Proposals:

> Although care coordination is not covered by Medi-Cal and often is not covered by private health insurance, many public programs for children with special health care needs do provide some care coordination. However, in these cases, care coordination resources often are reported to be both inadequate and ironically, duplicated among programs. Further, existing efforts are remarkably fragmented by different administrative processes, eligibility, and payment streams. This likely reflects a lack of planning, funding, and collaboration by policymakers, community agencies, and service providers.
>
> While better policies and enhanced payment would go a long way toward improving care coordination, in the absence of community-based, collaborative planning and action it is unlikely that care coordination would compensate for the fragmentation that exists. Consequently, high quality, responsive care coordination services need to be developed locally in order to best utilize existing resources, respond to local circumstances and meet the needs of children and families.

Phase 2 of the 5Cs project ended in June 2016 and a third phase is under consideration by the Foundation. Health Policy Consulting Group was invited to assist in developing and conducting an evaluation that would offer insight about the performance of the 5Cs to date and inform the Foundation's consideration of a future iteration of the 5Cs.

Methodology.

Structured interviews.

The Foundation was particularly interested in securing qualitative information from the leadership of the county coalitions to allow an insightful overview of the ten coalitions' experience on a local level and as participants in the statewide learning collaborative facilitated by the Foundation four times during each grant cycle in Palo Alto. The evaluator developed a structured interview outline, with feedback and suggestions from Foundation staff. Topic areas included:

- Update about coalition activities following grant completion
- Coalition successes, including systems/policy change
- Challenges to coalition functioning
- Continued systems issues at local, state, and national levels
- Coalition tools created and exchanged with other coalitions; mentoring experience
- Evaluation process during grant and future needs
- Statewide learning collaborative assessment and ideas for possible future convening
- Experience with other Foundation technical assistance services
- Success with sustainability and
- Vision for the future.

Foundation staff identified two or three leaders for each county coalition and contacted them to introduce the evaluator and request their participation in the interview process. The evaluator followed up to schedule a joint interview for each group at a location selected by each coalition team. The evaluator conducted two-hour interviews with each team. She advised participants that the information they shared would not be attributed to them or their coalition, but that it could be possible for the Foundation to identify which county had offered information, given the unique nature of some of the coalitions' activities and experiences[1]. In all, 24 leaders were identified by the Foundation and all 24 participated in interviews. A list of those interviewed is attached as Appendix 1. Interviews were recorded by the evaluator and transcribed. Qualitative participant responses were classified by topic area and digested in Appendix 2.

Online written survey.

Foundation staff were particularly interested in feedback from coalition leaders about their experience with technical assistance offered by the Foundation during the 5Cs project. The 5Cs Statewide Learning Collaborative was a major technical assistance component of the project. To supplement the qualitative interviews, the evaluator constructed an online survey, and

fielded it prior to the interviews through SurveyMonkey (www.surveymonkey.com) with the same 24 leaders designated by the Foundation. The survey requested ratings of the usefulness of various aspects of the Statewide Learning Collaborative and other forms of technical assistance provided during the grant process and also solicited suggestions for future Statewide Learning Collaborative meetings and other technical assistance. Like the interviews, participants were advised that their responses would be kept confidential but advised that the nature of their information might reveal which coalition they were affiliated with. Results are summarized in the report narrative section about the Statewide Learning Collaborative and qualitative comments are attached to the report as Appendix 3.

In addition to specific questions about technical assistance, the survey included three questions that were posed to leaders of the 10 coalitions in November 2015 as part of a survey fielded by the Public Health Institute. Results appear in Appendix 3.

Document review.

The Foundation shared collaborative meeting slides, evaluations from learning collaborative meetings, RFPs, grantee proposals, grantee and Program Officer reports, and "Collaborative Checklist" summaries prepared by coalitions at the beginning and end of their projects. A review of these documents provided context and background for interviews.

Overall structure of 5Cs.

The program is comprised of two major elements: the establishment and operation of local coalitions and the participation of those coalitions in a series of joint activities of the Statewide Learning Collaborative.

Local coalitions.

Funded coalitions are summarized below. Four coalitions received funding during both funding cycles. One of these, Kern, was a preexisting care coordination coalition and was funded during the first phase to give technical assistance to 3 counties to replicate successful aspects of Kern's coalition and during the second phase to participate in the Statewide Learning Collaborative. Three additional coalitions participated in both phases; two coalitions were part of Phase 1 only; and three coalitions were part of Phase 2 only. Monterey County was not funded during either phase, but asked to join the Statewide Learning Collaborative and was also given technical assistance from Kern County.

County	**Phase 1 (4/1/13-9/30/14)**	**Phase 2 (1/1/15-6/30/16)**
Fresno	Funded prior to start of 5Cs but asked to participate	
Shasta, Siskiyou, Trinity	x	
Contra Costa	x	x
Kern	Funded to do replication	Funded to participate in Statewide Learning collaborative
Orange	x	x
San Mateo	x	x
Alameda		x
San Joaquin		x
Ventura		x
Monterey	Unfunded, received technical assistance and participated Statewide Learning Collaborative	Unfunded, received technical assistance

Local coalitions were required to meet regularly, with most meeting once per month. Typically, meetings consisted of informational presentations from stakeholder agencies, and often included presentations of one or more complex care coordination cases, followed by brainstorming around the table of potential solutions to those cases. Many of the coalitions

also had a separate monthly meeting of coalition leaders to plan and organize the main meeting, outreach to new partners, and construct tools and deliverables. The number of agencies participating in coalition activities was typically 20-25, but the range is represented by one coalition that has 50 members (a preexisting coalition that predates the 5Cs) and one that has just 12-15 active members. Meeting length ranged from 1.5 hours to 2.5 hours and was frequently scheduled over the lunch hour to maximize attendance.

Local coalitions each had their own target population. While some were broadly focused on the 0-21 age range, including two that were focused on mental health, others focused on the 0-5 age group. Lead agencies included county public health (4), First 5 and Help Me Grow (2), and family-focused nonprofit agencies (4).

Most of the coalitions either drew membership from existing coalitions or created their coalition as a subcommittee of an existing structure. However, one coalition had to create their coalition "from scratch." All coalitions recruited additional members to join their mission.

All funded coalitions (9) were required to choose goals, design and update workplans, and submit interim and final reports to the Foundation. All funded coalitions were required to complete an assessment at the beginning of their project and again at the close. The assessment was a Collaborative Checklist that was adapted from The Bridgespan Group.[2] Several coalitions conducted internal assessment activities during Phase 1, and all coalitions that participated in Phase 2 were required to select and execute internal evaluation activities. The Foundation Program Officer obtained further information from coalitions during regular check-in calls and coalitions provided periodic updates on their activities to other coalitions as part of their Statewide Learning Collaborative activities, via webinars and meetings at the Foundation.

5Cs Statewide Learning Collaborative.

During both phases, the technical assistance activities of the Statewide Learning Collaborative fell into five categories, including in-person meetings at the Foundation, online webinars, one-on-one telephone check-ins with the Program Officer, site visits, and "other" forms of technical assistance.

In-person meetings at the Foundation.

The Foundation hosted and facilitated four in-person meetings during each of the two phases. The day-long meetings were attended by all coalitions, and each coalition was invited to send three representatives. Typically, participants included primary leadership staff, but the third attendee was often a rotated agency member of the coalition, for example, a member of the

Medi-Cal managed care plan, an Early Start Coordinator, a pediatrician, and a Legal Aid attorney. The meetings included presentations from each coalition about current activities, successes, and challenges, followed by discussion among the coalitions to exchange information and brainstorm solutions to challenges based on the collective experience of the group. In addition to discussing process challenges (e.g., how to recruit participation by certain agencies), the group also identified common systems challenges they were identifying in their local coalitions. Each meeting included at least one presentation/training by experts. The Program Officer designed the agenda and chose experts based on the current status of the coalitions and feedback and requests from coalition members. Examples of expert presentations include process improvement and evaluation activities, the pediatrician's role in care coordination, California Children's Services (CCS) changes and reimbursement strategy, uses for kidsdata.org, communications planning and strategies, and advocacy planning.

Technical assistance webinars.

The Foundation produced webinars that featured expert presentations on topics of specific importance to grantees, and also provided an opportunity for updates from each coalition and dialogue among grantees. Expert presentations included state and local experts speaking on issues including financing and reimbursement for care coordination, experiences in engaging regional centers, opportunities to use telehealth to improve care coordination, and CCS regulatory changes.

Check-in telephone conference calls.

Periodic, scheduled conference calls with the Program Officer allowed the coalitions to review progress as well as ask questions and receive guidance from the Program Officer concerning challenges.

Site visits.

Site visits were scheduled to allow the Program Officer to attend a monthly coalition meeting of each coalition during each phase of the grant. It also provided an opportunity for detailed planning and review of the coalition's progress and challenges.

Other forms of technical assistance.

Curated by the Program Officer and other staff, the Foundation website includes a number of reference materials concerning care coordination for CSHCN and also includes a selection of the tools developed by the local coalitions that may be used by other local coalitions to facilitate their work: http://www.lpfch.org/cshcn/community-engagement.

Some coalitions also received expert assistance. During the first phase, for example, three coalitions received intensive assistance in replicating the strategies previously developed and implemented in Kern County. In consultation with the Program Officer, experts from LPFCH and external experts (e.g., communications and advocacy specialists) presented at local coalition meetings or held workshops for coalition membership.

Outcomes: Local Coalitions.

Success in coalition organization and meetings.

All ten coalitions successfully recruited agency members and convened coalition meetings during the terms of their grants. Although not every coalition had case sharing, most did. Although some had separate meetings for case sharing, sometimes designated as "Roundtables," there was also a process for sharing systems issues with the larger 5Cs group. A common "formula" for the joint 5Cs meetings was described by one leader:

> *We have an agency presentation in the first hour and then we have a case presentation. We ask agencies to present what services they provide, what their eligibility criteria are, how to refer to them, and what some common misconceptions are about their agency.*

Meetings of the 5Cs coalitions, and especially the development of relationships among agencies, were highly valued by all coalitions.

> *Because I come to this meeting, I know who to contact - - where to refer and not refer. . . . We problem solve. What could we have done. What was the gap and why couldn't they get the service they needed. When you look at all the problems, they fell in one of two areas - - either a lack of knowledge of the role of each agency, or those gaps - - when people do not fit.*

> *We have this tighter web of contacts and call each other and say, here's the situation. Who should we call. The silos aren't gone, but we have the contacts within the silos to call and find the best person to call.*

> *Getting agencies to the table to talk to each other that have not done so effectively in a long time was a huge success. Those networks that got built [were critical]. This was especially true with what I call the "big four" . . . and they developed protocols for working with each other about certain things - - and then they would do it again.*

We bring in a speaker on a relevant topic. We have networking and sharing. It feels like it is the strongest it has ever been. It is its most highly functioning.

You need to know about the whole circle of services. This is what helps protect the families from bouncing against agencies and trying to figure things out. And it is not just families - - it is providers, too. They really didn't understand the rules. Why is managed care kicking us back to CCS who is kicking us back to managed care? They were equally as frustrated as the family.

The rich, rich discussions that occur is really what's of value - - there have been remarkable discussions [for instance] from children's behavioral health specialists.

It's a safe and trusted group - - I think that's because we've been meeting so long. We are all there for the same reason - - that agencies don't say "no" to be mean, etc.

Someone may know the loophole that I never knew.

Our relationship with our children's hospital improved dramatically.

Everyone is equal in the room. With that trust, we can build solutions.

Case reviews were valued as a part of the 5Cs mission to identify common systems issues. For groups that were able to review significant numbers of cases, they also offered the opportunity to collect specific data about systems problems.

The group can learn what's going on - - can identify gaps. The group may have ideas about resources. It's almost a support group. Then the person doing the review will go back and try to implement suggestions and report on that.

It also identified a lot of where we were dropping the ball in our county. It would show us patterns of things happening more than once.

People who were at first skeptical came around and thought it was very helpful. Word got out that this was not a "gotcha" meeting.

New agencies started coming at the end because they heard we had good resources. They also wanted to do case sharing. We had organizations that presented [about their agency] and then flipped around and presented a case [for review].

Some of the coalitions used outside facilitators for their meetings. Although there was some expression of skepticism at the outset, outside facilitation was viewed as helpful. One coalition leader remarked that it freed her to participate more fully in the meeting process. One leader commented that it was hard to find someone willing to work within their budget, but when they did locate someone, they found it to be helpful to the process. It was also helpful that the facilitator did not know any of the people involved in the meeting.

Sustaining function after LPFCH funding ended.

Coalitions that were funded during Phase 1, only, had LPFCH funding end September 30, 2014. Phase 2 coalitions had funding end June 30, 2016 (although a couple of coalitions continued on no-cost extensions for a few months). One coalition that participated in the Statewide Learning Collaborative and received technical assistance never had LPFCH funding at all. Notably, all except one of the coalitions continue to hold meetings.

One of the coalitions that had funding terminate at the end of Phase 1 continued functioning with in-kind support from the local First 5 for almost two years before a realignment of funding priorities put their 5Cs group meetings "on hold" for the present. That group describes continued benefits, however, from their 5Cs work, noting that relationships among agencies remain and many agencies continue to participate in the county's umbrella systems change group. Additionally, that coalition's leaders report that their own agency's case managers continue to use the information and strategies learned during 5Cs funding to help them field calls to their agency that involve care coordination. The other grantee that has not had LPFCH funding since 2014 continues to run their 5Cs meetings, but have changed to a quarterly schedule with hosting responsibilities rotating among participating agencies. They are also initiating outreach to new partners, including tribal health entities.

All of the other coalitions continue to function, although many cite the challenge of continuing to seek support. The coalitions that have been running the longest and had funding through two grant cycles have been particularly successful in embedding their 5Cs work into their counties.

We continue to meet monthly. People are very committed to it. Funding ended 6/16 but the core group has remained the same. Individuals changed, the agencies have remained the same.

We have First 5 funding now. We have renamed the group to reflect that.

We continue to meet and have continued engagement from a lot of people. Our Care Coordinator is still 16 hours per week. The County stepped up to the plate to support her position. She's a public health nurse, and there are Federal Financial Participation funds. Leadership and organization is in-kind from Help Me Grow and First 5 and facilitation is supported, so far, through the hospital's foundation from a private grant. These funds are for about a year and we will have to keep looking for support.

Among the counties that received funding during the second phase only, all continue to function. One coalition continues to meet enthusiastically, but has slightly changed its format and has transferred leadership to a key partner - - a nonprofit agency supporting families that is offering leadership time in-kind. Another also continues at full force, but has noticed that some agencies are not attending as often or are sending lower-level managers, citing the end of the grant funding. A leader of that group commented, however, "I don't feel these connections are going to go away." She noted the power of the fact that they could tell agency participants that their group was supported by a grant from LPFCH ("that name has such gravitas around here"), and wondered if there was a possibility that their coalition could continue to have some status as "affiliated with LPFCH" or could participate in the Statewide Learning Collaborative as a means of demonstrating their ongoing alignment with the Foundation and its goals.

But, there are expressions of concern about the ability to continue. One of the groups that received funding during Phase 2, only, continues with support from their lead agency, for now, but has been given until June of this year to find another funding source.

Local successes – specific examples.

Asked to identify their primary successes, nearly every coalition leader cited the successful networking and building of member agency relationships and the functioning of monthly coalition meetings. The coalitions also offered specific examples of local successes.

Alameda County – Alameda County Children's Services Mental Health Initiative – Stakeholder Committee

Alameda County has identified gaps in accessing mental health services and worked on systems change to improve access for clients and families of the CCS program. The coalition, which specifically recruited family participation, raised awareness broadly among a group of agencies participating in the coalition, and within CCS by creating trainings for staff to learn how to identify mental health issues and refer clients. Coalition leaders have shared their experience

and tools through presentations to regional and state CCS leadership, to Family Voices of California, and to a State Senate Select Committee. Coalition leaders have plans to offer assistance to the Department of Health Care Services to revise the current CCS "Numbered Letter" on mental health benefits that would more clearly direct providers to be reimbursed. This would affect the entire CCS program statewide.

Contra Costa County – 7Cs Coalition

The 7Cs coalition, now led by the Care Parent Network, continues to meet with consistent participation from agency members. The members, who have been meeting since 2013 as the 7Cs, have "a network - - a safe and trusted group." With the sunset of the Early Childhood Leadership Alliance (ECLA), the 7Cs remains as the sole collaborative to identify and address systems issues in care coordination for CSHCN in Contra Costa County. Two Roundtables, preexisting groups that conduct case reviews, meet separately, but refer systems issues to the 7Cs, with some intersecting membership. The 7Cs recently developed and implemented a Family Experience which allowed small group meetings of 2-4 coalition members to meet with families of CSHCN and hear, first-hand, about their struggles to secure services on behalf of their children.

Fresno County – Central California Care Coordination Project

Fresno County's coalition was part of Phase 1 funding from December 2012 through September 2014. The care coordination coalition acted as a subcommittee of an existing county group, the Model of Care Partner Oversight Committee (MOCPOC). The subcommittee continued meeting monthly through July 2016 when the local First 5 Commission changed its funding focus and the group was put on hold. The coalition succeeded in bringing attention to the intense need for care coordination with the medically fragile pediatric population in Fresno County. Valley Children's Hospital, which had become a valued coalition member, simultaneously expanded their care coordination services to better serve the same population. The staff at Exceptional Parents Unlimited, who acted as care coordinators during the term of the grant, continue to assist when care coordination questions come to the One Call for Kids call line, and many of the new partners in the care coordination coalition have continued to participate by attending the "parent" organization's meetings (MOCPOC).

Kern County – Medically Vulnerable Care Coordination Project

The MVCCP, begun in 2008, has evolved to include a full-time care coordinator and a part-time project director, with biweekly meetings of the participating agencies. The coalition was recently recognized as a "promising practice" by the Association of Maternal and Child Health Programs' Innovation Station. Kern County was funded as part of the 5Cs to replicate its work in new counties, by sharing MVCCP tools and experience. Kern's Project Director worked with

three counties to explore their unique needs and the potential for adapting parts of the model employed by Kern, including the structure for leveraging Federal Financial Participation funds to enhance care coordination services for CSHCN.

Monterey County – Monterey County Caring Partners

Monterey County asked to participate in the Statewide Learning Collaborative even though it was not a funded grantee. With technical assistance and guidance from the 5Cs and a Kern County leader, Monterey County built a coalition and established a position for a public health nurse to act as a care coordinator. The coalition is currently working to fill the posted position, and continues to meet regularly to identify and address systems issues and to review cases. The coalition has constructed a case review and referral form, as well as a participating agency summary (PAS). The coalition is exploring ways to make the PAS available to coalition members. They are also considering partnering with a local agency to upload information into a searchable database, which will be used by local providers seeking referral sources for children with special health care needs.

Orange County – Orange County Care Coordination Collaborative for Kids (OCC3 for Kids)

OCC3 for Kids was successful in developing a part-time system care coordinator position within the county health department. The system care coordinator is a public health nurse, and the county is able to secure Federal Financial Participation to reimburse much of the work she does. OCC3 for Kids developed an evaluation plan, which it has executed over the course of two phases of Foundation funding, and a care coordination measurement tool (adapted from a Boston Children's Hospital instrument), which allows the system care coordinator to track system issues as well as care coordination activities and child demographics. Following a communications workshop at the Statewide Learning Collaborative, OCC3 for Kids leaders developed an outreach plan to four provider groups which they have been carrying out to increase referrals to OCC3 for Kids. A toolkit for professionals that includes information about OCC3 for Kids, referral form, authorization form, outreach letter, and flyers is posted on OCC3 for Kids' webpage: http://www.helpmegrowoc.org/occ3-referral/. Policy workgroups have formed following presentations at OCC3 for Kids monthly meetings, including groups to address NICU discharge issues, provider education, and in-home support services (IHHS). The IHSS group is planning to explore ways to support parents in securing services that are covered, but underused, possibly by developing time logs to demonstrate need.

San Joaquin County – San Joaquin 5Cs

Families of CSHCN frequently must travel outside San Joaquin County for surgery and specialty care. The San Joaquin County coalition planned to prepare a guide identifying available transportation resources for families, but learned in the process of contacting the 26 licensed

vendors that only one, and, at one point, no vendors were willing to actually provide these services. The vendors cited low reimbursement rates and a preference for local trips because payment did not include reimbursement for waiting time. The Coalition prepared a memo about this lack of resources and circulated it widely, putting the issue on the agenda for a number of agencies. The County is now negotiating with Uber and Lyft with the possibility of providing direct payment. The Coalition also engaged with the Council of Governments and the local Regional Transit District in an effort to secure a bus stop along a route to hospitals from Stanislaus County. Negotiations are seen as promising and the coalition attributes their success to shining a light on the issue and engaging partners they would not have thought to include at the beginning of their 5Cs journey. The San Joaquin group also held a San Joaquin County Forum for Children with Special Health Care Needs in May 2016, attracting 135 attendees.

San Mateo County – San Mateo County Systems Change Group for Children with Special Health Care Needs and their Families

Although San Mateo County had an existing medical community case discussion roundtable, participation as a 5Cs grantee allowed county partners to refocus their energy on systems change to benefit CSHCN. Expanding their outreach to new provider partners, including pediatricians and the local Human Services Agency, as well as the local Regional Center, the group developed a number of tools that were shared with the Statewide Learning Collaborative and adapted by other county coalitions, including a map of care coordination resources. The group's convening has allowed them to respond quickly to policy opportunities with partners such as Legal Aid at the table. Policy partners like Children Now offer policy updates to the coalition. The coalition's policy workgroup considered a number of care coordination systems issues, ultimately advocating for a new level of access for the community - - a centralized telephone access for care coordination, for which the group is seeking funding.

Shasta, Siskiyou, and Trinity Counties – Rural Children's Special Health Coalition

Although this coalition's funding ended more than two years ago, agency participation has continued and meetings of local agencies are held quarterly. The group is working to expand participation to include tribal agencies, smaller community health clinics, and Rancherias. Last year, the Coalition produced a health conference (with partial funding from LPFCH) focused on rural health issues including mental health, telehealth services, and state advocacy issues, attracting participants from six counties.

Ventura County – VC-Pact – a pact between Ventura County agencies to promote the continuum of care for children with special health care needs

Following the conclusion of 18 months of funding in June 2016, VC-Pact members chose to continue monthly meetings, featuring presentations by participating agencies and case reviews.

Leadership is confident that the coalition is helping to alleviate challenges faced by families with CSHCN by increasing knowledge of available resources and the eligibility criteria of each agency and creating a better network among agencies. Highlighting gaps suffered by families has helped create systems/policy change. Examples include the creation of workgroups between agencies, such as a transition team between CCS and the local Medi-Cal managed care plan to ease transition issues when a child falls off CCS, and improvement in information-sharing so that Probation can access children's care information in the transition from Juvenile Hall. VC-Pact has support to continue operating through June 2017 and is able to leverage Federal Financial Participation to support some functions. Leadership is working with Epidemiology to select indicators and develop metrics to demonstrate the coalition's value to the community.

Policy and systems change on a local level.

Coalition leaders were mostly modest in claiming to have achieved systems change on a local level, but as can be seen from the examples of accomplishments above, there are existing examples of policy/systems change locally and plans to continue on that path. Interview data about specific issues dealt with by the coalitions illustrate more about how local "systems" changed after 5Cs local coalitions began to meet.

> *While we have a long way to go, we are the only County directly addressing the mental health needs of clients and families. That is a specific change. In the past, the nurses were so focused on authorizing the necessary medical care that even if they were in actual crisis they weren't really thinking about referring the behavior health - - it wouldn't be automatic.*

> *We are partnering with behavioral health in a way that we never have before. It is not so much policy yet as practice, but more operations. We had 20 people on an email chain this week to help save a young man. It never would have happened but for this [5Cs] mental health initiative.*

> *It can be difficult to sort out if something was a direct correlation to the 5Cs, but those agencies all knew what the rules were and many of them knew there was a problem [with transportation]. And it didn't get brought to the table. I sat at the table for 20 years. I only heard it discussed in the last 18 months. It turns out it was a much bigger problem than what they had been saying. What did happen was the light being shined on the issue. They don't want the Packard Foundation to find out about this.*

One of the difficulties was that families would have appointments scattered out over the week. Then they would have missed appointments, and CCS would get involved because of medical neglect. [After hearing about these issues] the hospital made it a point to look at how they were scheduling appointments. They made an effort to clump all of their appointments together. That was a big first step. And they put together their own care coordination team.

There was considerable frustration expressed about needed systems changes that were beyond the power of the local coalition.

We are working on the symptoms. But some things need to be resolved at the state level.

Coordination between agencies about who will pay for what - - but again, all at state level. It is a nightmare, always.

There was a strong consensus that the Foundation was in a strong position to take the lead on issues that continue to need attention at the state level.

The Packard team helped us with what we were doing here [locally] and they shared information, but they should really take the lead politically for state-level change. If you want to talk about mental health, it would look like them starting some discussions with the state about modifying that numbered letter. And that would have a complete impact across the state in terms of accessing mental health. And you could have them do that with other care coordination issues. Transitioning into adult health care, etc.

But [the Foundation] also ha[s] a reputation of doing things by killing with kindness instead of yelling and screaming. They fund things that promote collaboration and better services. It's all about improvement. It's not about showing that one agency screwed up. They are known for that - - how to work together. That goes a long way with agencies that are afraid of being "outed." And that helps at the state level where everything is about turf wars. There's policy and then there's change. If you really want change you better step away from the policy sometimes.

Additional discussion of these issues appears below in the section about the Statewide Learning Collaborative.

Sharing among coalitions – tools.

Phase 1 coalitions developed a number of products to assist in forming and running coalitions. These were catalogued in a Foundation issue brief following the conclusion of Phase 1.[3] Many of the tools are also posted on the Foundation's website. One of the goals for Phase 2, as expressed in the RFP, was that new coalitions would pilot and adapt resources developed by

existing coalitions. New coalitions reported many instances of reviewing and adapting these documents, including evaluation documents (e.g., surveys of agency members), acuity screening tools, interagency information-sharing authorization documents, and service system mapping and referral pathways. Leaders described the availability of documents and information developed by other coalitions as "a very important benefit of being a part of the learning collaborative." During Phase 2, many new tools were developed as well, and they have been shared through the Statewide Learning Collaborative, the website, and by specific request from other counties. Examples include:

- A toolkit of care coordination information for providers including documents such as a Payer of Last Resort Summary and a service system map [adapted from Phase 1];
- Items concerning county-specific resources, such as a participating agency summary and needs assessments;
- A mental health fact sheet for posting in medical provider offices; a staff training plan to teach CCS staff how to identify and refer mental health issues; service system map;
- Evaluation documents such as a logic model to help focus evaluation efforts and a care coordination measurement tool (adapted from a tool developed at Boston Children's Hospital to track cases and help identify systems issues and currently in use by a coalition system care coordinator).

Sharing among coalitions – mentoring.

The coalitions spoke extensively and very positively about the importance of being able to share with other coalitions via the Statewide Learning Collaborative. However, the structure of Phase 2 also included a requirement that the three new coalitions be mentored by one of the three continuing coalitions that was receiving ongoing support. The consensus among the participating counties was that the mentoring aspect was not particularly helpful. The paired mentoring was variously described as "not particularly helpful," "we had different populations than they did," and "a little bit of a forced fit."

> *Every county is different. I'm not sure the mentorship worked. I think the statewide community worked better than trying to pair us up.*

The other complaint about the requirement was that there was insufficient time and budget to do site visits with the other county. This may have reflected a sense that there was a lot to accomplish with their grants as well as a sense that it might be more efficient to contact whichever county seemed to have history and potential assistance to offer the coalition on specific needs. Given the practice of generous sharing created by participating in the Statewide Learning Collaborative, the need for a designated mentor may have felt less compelling. Two

counties offered that if mentorship was going to be required, a training in how to offer it might be beneficial.

Challenges – coalition process.

Many systems challenges arose for the coalitions, and those that were named by multiple coalitions as being statewide issues are discussed in the section on the Statewide Learning Collaborative. For the counties that were trying to replicate the use of a system care coordinator as had been successfully done in Kern County, two succeeded in getting a public health nurse position to act as the coalition's system care coordinator, at least on a part-time basis. For one county, however, the challenge has been to fill the approved and posted position. A nursing shortage and competition from a local hospital, combined with the coalition's desire to find someone who is familiar with the range of resources available to CSHCN, has proved challenging. For a third county, many months of working with county administrators did not ultimately succeed. "The concept was supported. Where it stopped was fiscal."

Other process challenges expressed in interviews included the difficulty for a rural coalition to get buy-in, early on, from other counties and getting distant agencies to drive to coalition meetings. An open telephone line partially addressed this and successful meetings have encouraged more participation from distant members.

Several coalitions cited difficulties in getting agencies other than the lead agency to do referrals and bring cases for presentation at 5Cs coalition meetings. They theorized that this may have reflected reluctance to fill out the coalition's acuity tool or may have had to do with a sense of protectiveness. One county cited difficulty getting agreement on consent forms for case reviews as the reason that they could not do the number of case reviews they had projected.

Although some counties found their physician participants to be some of the most enthusiastic and important among their partners, others found physician engagement to be a significant challenge, and attributed the amount of time needed for the meeting as a likely barrier.

Some coalitions felt there was not enough staff time available to the coalition. Some leaders were able to work in-kind hours on behalf of the coalition due to the closely related work of their employing agency, but at least one leader did not have that ability, and also did not have clerical support for the same reason.

Lessons learned: advice for future coalitions.

- Coalitions recommended continued family participation.

  We usually had about five parent participants at our meetings and they really participated. It helped us understand the varied needs of the kids and their families. For our policy people to hear what worked and what didn't was helpful. They went back to their offices and knew they needed to talk to their staff. What helped was there was a stipend for the families to participate. There's value in having a number of families. When there is just one family it is very intimidating. . . . Some our families [had been] through advocacy training. Maybe if families didn't have that level of empowerment, it would be difficult.

  It is the family's stories that administrative people don't always know. Getting the parent there may be difficult because they need to provide care. Transportation and childcare are an issue. So, there needs to be a stipend like [the stipend] Family Voices [provides] so they can participate.

  One of things that was stunningly successful was bringing in families and setting up meetings with [coalition] members and just having them listen. It was one of the best days we've had. [Note: this was a specially scheduled meeting in small breakouts between a family and several coalition members. It was not a regular meeting of the coalition.]

  The pro-parent in me says of course you should always have the parents participate. But the realist in me says that there are some agencies that will not talk in front of parents because they are afraid of where it's going to go. So, it may depend on the parent.

- Have decision-makers at the table. But there's an important role for frontline staff that know families, too.

  Be sure you have decision-makers coming to the meeting - - who can decide, then and there, to make a change.

  In some cases, it is okay when the managers can't come. The front-line people, in a way, may be more important because they are serving the parent directly. This made it easier to resolve the case issue but perhaps not generate a policy change.

There are people who come to meetings with significant authority. I think that is part of our success. Having a mix of people is important. Day-to-day reality of life for a family is different than day-to-day life of care providers. Having those two realities to be able to discuss things is important.

Hire a dedicated coordinator. I would have failed without her. She put in more than 20 hours. Find the right skill set. At least when trying to get up and running.

- Coalitions recommend having the meeting on the same day of every month or at least scheduling the meetings well into the future - - even 12 months in advance - - so agencies can plan to attend. Schedule the meeting over the lunch hour so more can attend, and if possible, have food available.

- Do monthly presentations from participating agencies, even if it seems like everyone already has that information. There is a lot of misunderstanding about eligibility and services.

- Make sure everyone has an opportunity to participate, not just the major players in the front row.

- Have separate meetings of the leadership group to maintain a targeted meeting and avoid "muddying the waters."

- Leverage what you have. Build your coalition on existing groups and connections, if possible.

Reflections about the 5Cs grant: amount of support and 18-month timeframe.

Almost all coalitions thought that the 18-month grant period was too short unless a second round of funding could be expected, citing the considerable effort required to form the coalition and gain momentum. One Phase 2 grantee remarked, "we're just hitting the ground running now." A 24-month grant cycle was considered more feasible, and even then, coalitions that functioned through two grant cycles were emphatic that achieving systems change on a local level is a lengthy process. As summed up by one 2-cycle grantee, "We're still working on it!" Some coalitions acknowledged that it was helpful to have short deadlines and that it propelled them to move forward quickly. Some said that if the grant period was two years, it would be important to have one-year workplans to stay focused.

Grants for first-time coalitions in both the first and second rounds totaled $45,000. For continuing coalitions, the award was $25,000, in recognition that a task for the initial round of funding was to work toward sustaining the functions of the coalition. Concerning the sufficiency of the grant amounts, a number of grantees noted that the availability of matching federal funds allowed them to function with a much larger, more feasible budget. One remarked that it would be difficult for smaller counties to undertake a similar arrangement. Matching funds were not accessed by all counties. Two grantees, both from parent-focused nonprofits, found the grant amount to be sufficient. Others, however, lamented that a great deal of in-kind work was required from leadership in order to carry out grant obligations. They characterized their grants as "underfunded." Staffing was often cited as the most important element to support the coalition, and the most costly.

New challenges for community care coordination on the horizon.

Coalition leaders foresee multiple challenges, including problems posed by the Whole Child Model and elimination of much of CCS function. Uncertainty about the potential repeal of the Affordable Care Act and related threats to the State's Medi-Cal expansion were cited by almost every coalition as a source of serious concern. Other concerns relate to the uncertainty of future support of public health functions and potential cuts to a range of services as well as threats to investments in medical training. The inability to plan on the part of state and local government until the federal picture is more clear is another concern.

> *We are concerned. I'm starting to get information from the managed care plan about what the impact on the community will be. If ACA is pulled back, 80,000 people in the 3 counties will be without insurance any more. They will be in a safety net situation. ERs, etc. will be impacted. If you have a lot of people losing health care coverage, one of the concerns will be delayed identification and entry into health care service. This may be especially true for CSHCN. We'll see a lot more cases in the ER because things weren't identified early enough. In the midst of this, CHDP [Child Health and Disability Prevention] is unraveling because they are pulling state funding for a population that is now covered. California can continue to cover this group. But the managed care plan won't be responsible for them. There is also fear about being deported. Maybe people won't appear in the ER until the very last minute because of fear and incurring cost they can't pay. They may worry - - "will I be put on the radar?" This fear could also result in less prenatal care.*

Every coalition expressed the belief that these uncertainties elevate the importance of local community coalitions.

The uncertainty is definitely a reason to keep the 5Cs programs so we can navigate these changes. This is especially true where we are because there are so many undocumented children and migrant workers. Sometimes they are afraid to get services for fear of getting deported.

Having a care coordinator and a collaborative - - It's already of great importance, but it may be an even greater importance. [During upcoming potential changes} having agencies identify how impacted they are and us [County public health] being able to identify the higher need, see duplications, identify resources. This could help us with resource allocation.

Evaluation.

Collaboration checklist.

During the course of the two grants, there was one common assessment tool used, a Collaboration Checklist. The instrument was completed by coalition members at the outset of the grant cycle and at the conclusion, for each phase of grant funding. The checklist asked members to rate various aspects of the collaborative on a five-point scale from "low" to "high" in categories such as operating principles, characteristics of success, and ability to thrive. The checklist was distributed by the Program Officer via email and during Statewide Learning Collaborative meetings with directions to distribute to coalition members and return tabulated results.

Overall, coalition leadership did not find the instrument to be helpful, saying that they did not think the topics to be rated on were very helpful and that "it was too vague to really convey much." Other limitations on the interpretation of these data include: a) the fact that some of the coalitions were already existing prior to the 5Cs grant; b) the instrument was not necessarily completed by the same people at the outset and at the end of the grant period; and c) there were administration inconsistencies, with some leaders indicating that they filled out the form themselves and did not distribute, collect, and tally information from members, as intended. For these reasons, it is not very useful to use these data to look across the range of coalitions, some of which were funded for only 18 months versus others that have operated over two grant cycles.

The tool was useful, however, as a measure of self-reflection for some coalitions. One organization that used the tool at the beginning and end of each phase, analyzed several of the topic areas that seemed relevant to members, including the topic area assessing "effective leadership and governance: keeping the decision-makers at the table" and several other

assessments of staff function. At the beginning of Phase 1, measurements tended to be in the low to medium categories. However, at the end of Phase 1 and continuing through Phase 2, their self-assessments were between medium and high function. The same analysis showed consistent performance in other leadership measures over time, but with a slight drop toward the end of Phase 2 in a communications measure. The coalition said that had been helpful self-reflection for leadership.

Coalition self-evaluation.

Coalitions were required to incorporate evaluation elements as part of their workplans, and for Phase 2 grantees, there was a requirement of a specific evaluation plan. The focus area and measurement complexity was variable and ranged from simple counts of meetings and agency participation to the design and use of a relatively sophisticated care coordination measurement tool that tracks demographic information for each child, activities of the care coordinator and the types of systems issues encountered in the course of working that case. Several coalitions surveyed their membership about the value of meetings and found that to be helpful. Asked to describe measures that might be helpful for the future, a leader of that coalition noted:

> *I think the most important question we asked on our survey of committee members was, "do you think you are better able to serve families now?" And the overwhelming answer was "yes." And they are training other staff. You could extrapolate and figure out the caseload for each person who has been trained. So, then you could say 1300 kids were impacted. That way we can say we touch this many agencies and they touched this many children.*

Some coalitions attempted to measure cases that came before the coalition and the outcomes that followed. One coalition remarked that they "let go of" this because there was difficulty getting people to tackle this task, in part because there were different people following the child over time. Another coalition had focused their evaluation on tracking the number of cases reviewed, but then experienced many difficulties getting the number of cases they had projected. They lamented,

> *In retrospect, what we should have been focusing on is the relationships at those [case review] meetings. The goals we had had to do with systems. But I think what really made the difference was the relationships. It would have been good to be able to measure more about that.*

Another coalition echoed the theme that relationships among members should be a focus area, suggesting that one possibility would be to measure "connectedness" but also stressed that this

would be hard to do midstream and would need to be initiated early. Other suggestions for future evaluation included the comment that there was better data at the state level that could be brought to them at the county level, such as Medi-Cal reimbursement data. Another comment suggested that the true question was whether parents get what they need, when they need it, for their child, and that finding a measure of "security" was the most important goal. Another comment was that hospitals have more capacity to collect and evaluate data, and that perhaps coalitions with strong hospital partners could seek support there. Several coalition leaders also commented that more training about evaluation and evaluation support would be helpful for grantees, and that this could potentially be most helpful at the very beginning of the grant and possibly before the first meeting of the Statewide Learning Collaborative.

> *I would be thrilled to do more data but I would need more support on that. We are program people - - I'm not an "epi" person.*

Role of community-level care coordination.

Asked if having a community-level care coordination coalition helps alleviate challenges faced by families with CSHCN, every coalition enthusiastically agreed. Some typical responses include:

> *Our 5Cs grant absolutely changed lives and changed perspectives. I think we changed the lives of everybody we touched after being together as a group.*

> *Absolutely. We accomplished things with that group that a family would never be able to get done on their own. Why? No one would talk to them or if they did, they weren't listening. We got the ear of the person who can make the decision. Our community is still benefiting.* [Phase 1 grantee]

Grantees agreed that a local coalition was the minimum level of care coordination needed for a community,

> *What's the minimum needed? A resource available such as a coalition or a collaboration that care coordinators within agencies can turn to for support, networking, information, and communication. The idea is to build a system - - not take over case management.*

The online survey data were consistently positive on this issue, with all 23 respondents responding “yes” to the statement, “The 5Cs project has had a positive impact on my community.” Twenty-two of 23 responded “yes” to the question “Has the Foundation’s support helped develop sustainable collaboration within your community?’

The Statewide Learning Collaborative.

The 5Cs collaborative was composed of several activities: in-person group meetings of coalition leaders hosted by the Foundation in Palo Alto; educational webinars; technical assistance from the project staff in the form of site visits (1 per phase), monthly check-in calls, and informal calls and correspondence in response to requests for assistance. In some cases, technical assistance was also offered by outside consultants.

To begin to assess the value of the Learning Collaborative to participants, 24 leaders representing the 10 coalitions were asked if they had accessed a number of forms of technical assistance that had been available to them during their grant cycle. Twenty-three leaders completed the online written survey. For each type of technical assistance they had used, respondents were asked to use ratings of "very useful," "useful," "not very useful," or "not useful at all." As shown in Table 1 below, among those who had accessed each aspect of technical assistance, facilitation and hosting of the Learning Collaborative, hosting of webinars, answering one-on-one questions, connecting coalition leaders to expert information and research from the field, and connecting coalitions to each other were all rated as "very useful" or "useful" by all coalition leaders.

Table 1. Q4: Please rate the usefulness of the following types of technical assistance offered by Lucile Packard Foundation for Children's Health (LPFCH) in connection with your participation in the California Community Care Coordination Collaborative (5Cs).

	Did not access this form of technical assistance	Not useful at all	Not very useful	Useful	Very useful	Total	Weighted Average
a. Facilitating the Learning Collaborative meetings.	8.70% 2	0.00% 0	0.00% 0	21.74% 5	69.57% 16	23	4.43
b. Hosting the Learning Collaborative at the Foundation.	8.70% 2	0.00% 0	0.00% 0	26.09% 6	65.22% 15	23	4.39
c. Hosting webinars.	4.35% 1	0.00% 0	0.00% 0	69.57% 16	26.09% 6	23	4.13
d. Answering one-on-one questions and providing expertise.	4.55% 1	0.00% 0	0.00% 0	18.18% 4	77.27% 17	22	4.64
e. Connecting coalition leaders to expert information and research from the field.	4.35% 1	0.00% 0	0.00% 0	43.48% 10	52.17% 12	23	4.39
f. Connecting coalitions with each other.	4.55% 1	0.00% 0	0.00% 0	27.27% 6	68.18% 15	22	4.55
g. Helping address project challenges that arose.	8.70% 2	0.00% 0	4.35% 1	43.48% 10	43.48% 10	23	4.13
h. Assisting with grant administration (reporting, budget issues, etc.).	26.09% 6	0.00% 0	4.35% 1	21.74% 5	47.83% 11	23	3.65
i. Supporting coalitions in presenting work at external conferences, meetings, or webinars.	27.27% 6	0.00% 0	9.09% 2	22.73% 5	40.91% 9	22	3.50

While there was not a lot of variability, "hosting webinars" was mostly rated as "useful" as contrasted to hosting and facilitating the learning collaborative, answering one-on-one questions, connecting coalitions to each other, and connecting coalition leaders to expert information and research from the field, which were primarily rated as "very useful." Interview data offered more insight about webinars. While many leaders mentioned them in a very positive light, and described them as "very effective," others observed that people did not tend to join in the discussion as much as they did at the in-person meetings. Some leaders confessed to not being a "fan of webinars" and admitted, "I'm much more engaged in the actual in-person conversations."

Every coalition described the Statewide Learning Collaborative in-person meetings as very helpful and very highly valued. One leader summed up "this was the greatest value add." "The benefit is someone creating the venue, deciding focus of discussion, identifying best practices, and the results of groups trying them. "

> *What we really got from the 5Cs group was hearing the challenges those counties were having and hearing how they resolved some of those challenges. And then hearing some*

of the things they were doing that we have not thought of. It's an evolutionary process. First you build that foundation and then you get involved in the more intricate issues instead of just holding the group together.

One other tangible thing that we took from the learning collaborative was how to network with hard-to-reach agencies or partners. A lot of that is really nuanced. It's the kind of stuff you have to get through conversation - - there is no manual. So, having a hard time engaging our local Regional Center, for example. Hearing people brainstorm and troubleshoot this - - those conversations happened regularly at these meetings. And then I would have one more thing in my toolkit the next time I wanted to approach that entity.

It made you feel like you were part of something bigger. Focusing on CSHCN is not a common topic, so being around other people who understand this topic and want to make an improvement - - Packard elevated the case. It gave us momentum and made us feel we could really make an impact. If you feel like you're doing it in isolation, it's a little hard.

We really took away info from the Family Resource Centers in the three northern counties and EPU in Fresno. We had not engaged families. We always had that hope. It has now made us more dedicated to reaching out through different avenues to parents. We tend to have professional parents who wear multiple hats.

The connections between counties were an essential aspect of the Statewide Learning Collaborative, both during the Statewide Learning Collaborative meetings and outside the meetings. "Everyone has always been very willing to share."

My mind was blown by the learning collaborative. I think we are doing things decently well and we're not at the beginning. But then I was like "wow," I would never have even thought of that. The thing for me that was such an "aha" was the way that people are billing for care coordination. To hear in depth how people were doing this. The different federal funding streams that we could draw down. It has moved our thinking and our intention for the future. I feel very hopeful that we're going to be able to make that change.

We were free to and did go to other counties [for help]. We were all in this. We learned from every single 5Cs community.

People [at our local coalition] would have questions about what other counties were doing. We could send that question up and get answers and bring it back to the group. Having that connection was key.

[The meetings] reinvigorated our systems work. We took people's examples and brought them back to the local level.

Expert presentations were also a highly valued part of the Statewide Learning Collaborative. Internal experts like Ed Schor and kidsdata.org personnel offered useful tools. External experts in the areas of advocacy, communications, PDSA cycle, goal setting, systems design, and others all offered targeted expertise and strategies that coalitions said they were able to take back to their counties and use.

Coalition leaders were equally emphatic about the assistance they received on a one-to-one basis from the Foundation. The project team was praised repeatedly for responding rapidly and thoroughly to requests and providing helpful research and connections to other counties and expertise. They were described as being extraordinarily knowledgeable, as well as understanding and committed to the success of each coalition. Leaders also appreciated being "kept in the loop" by newsletters, and report continuing to rely on the research and reporting about status of legislation, learning opportunities, and the like. Coalitions especially appreciate the Program Officer's participation in coalition meetings during site visits, noting that it helped to reinforce the Foundation's interest in their project, which increased commitment and interest on the part of coalition partners.

External technical assistance was also appreciated. Speaking of Marc Thibault, who worked to help replicate some of the successful strategies employed in Kern County,

[He] shared the vision of systems level look at care coordination. He became our best friend. He helped create the context in which our group started working. He really helped me understand what our mission should be and provided a lot of great tools for doing case reviews and to look at systems issues.

Systems Issues.

One of the roles of the Statewide Learning Collaborative was to identify state and local systems issues that were being seen by the local coalitions and to explore potential solutions. A lengthy list of issues, many of which were raised by coalition leaders again during interviews, are summarized in the issue brief about Phase 1: http://www.lpfch.org/cshcn/blog/2014/10/30/lessons-learned-local-care-coordination-

california. The umbrella topic areas of systems issues garnered from interview discussions, can be categorized as:

1. Transportation (to specialists and medical centers, particularly). This issue particularly affects families who live some distance from children's specialty hospitals.
   -Leaders described the shortage of specialists as well as more basic expertise such as occupational therapy.
   -Funding is needed to support families' travel.
   -Coordination is needed to consolidate appointments for those who must travel.
2. Use of telehealth to support care coordination.
   -This is important in rural communities, in particular.
   -When available, however, there are often reimbursement issues because there are three parties for each consult: the specialist, the primary care doctor who may need to prescribe, and the nurse/facilitator who attends the appointment with the child and family locally.
3. Foster care and CSHCN.
   -NICU discharge issues: determining who may authorize care, communications issues.
4. Mental health and CSHCN.
   -One example is seen in the division between categories of mental health needs in some counties into "mild to moderate" (handled by Medi-Cal managed care) and "moderate to severe" (handled by county behavioral health) with some finding that the latter category is more likely to get timely care. Delays in care are seen and patients may have further difficulties when their diagnosis changes, resulting in the need to enter a new system.
   -Integration between primary care and behavioral health is an issue.
   -There are breakdowns between the referring and referred-to organizations and insufficient or no feedback.
   -There are waiting lists for "mild to moderate" cases because there are not enough providers in some areas who will accept low reimbursement rates.
5. Payment for care coordination services.
6. Payment and financing systems.
   -Difficulties in identifying payer of last resort, leaving families to deal with the issue.
   -Example is durable medical equipment.
7. "Other"

- Early Start community care licensing regulation creating a gap: if children were not in the program before age 2, they could not qualify until after they were age 3.
- Shift nursing: lack of available nurses willing to accept low reimbursement rates, particularly when authorization is only for 2-3 hours.
- Applied Behavior Analysis (ABA) treatment availability.

Systems change as the focus of 5Cs.

Systems change has been a focus of the 5Cs. The local coalitions have worked on a local level to achieve this. At the Statewide Learning Collaborative, the coalitions come together to discuss these changes and to also identify needed changes at the state level. In interviews, coalition leaders support the goal of systems change at a local level, describing it as a "really good goal" and stressing the unique needs of the counties and importance of being able to tailor their work and changes to meet those needs. "We need to keep funding at a local level."

> *Systems level change is a place to be working, but it is a lofty goal. When we can't change - - when it is beyond our capacity or capability - - we can influence, but . . . there has to be some reality in that, too. And you have to look at small successes as systems change too.*

The coalitions have described their work as "working on the symptoms" of state-level systems problems. When it comes to advocacy for state-level changes, at least one coalition that may have influence within the CCS agency is exploring ways to influence changes in eligibility and billing issues. The strong consensus is that LPFCH should take the lead in working for systems change at the state level. While the coalitions are aware of some state-level efforts by LPFCH, a number of leaders said they were unclear about how the information they brought to the Statewide Learning Collaborative was being used to influence change: "It always felt like there were people working on state policy, but I never understood how it fully connected to [our] work."

> *[There should} be the ability to distill a policy agenda to work at the state level. Those of us that are government-funded can't be advocating.*
>
> *[LPFCH has] the research and the ability to message that. If they can be loud at a state level. CA is a thought leader. Then you have an impact at a federal level.*
>
> *A role LPFCH could play is as convener - - to get the state players to come together to discuss certain issues. They could say we have these three issues and see how they impact this one child in multiple ways. The 5Cs could bring the stories.*

There was also a strong expression of concern for the families that continue to be caught in systems issues problems. Two coalitions expressed concern that there should be some level of direct service available to parents, especially until state systems issues are better resolved.

Suggestions for the future.

While many of the grantees are hopeful that the Foundation will continue to support their efforts as a local coalition, there was particularly vigorous support for the continuation of the Statewide Learning Collaborative meetings. Some voiced the hope that formerly funded coalitions would be able to attend, and perhaps continue to characterize themselves as a 5Cs coalition or be "the 5Cs in association with Lucile Packard" or similar. They hope for the continued opportunity to attend the statewide meetings and point to this connection with the Foundation as important for recruiting and retaining coalition members.

Other suggestions included:

- Adding a half day in advance of the regular meeting for new grantees.
- Developing documents or a presentation that would introduce newer people to the laws and policies that affect CSHCN and how these affect the counties' ability to deliver services. There could be an issue brief, for instance, on transportation and why it is such an issue.
- Offering coalitions Powerpoint slide presentations from experts to assist them in sharing what was learned at the statewide meetings.
- Adding time at the end of the meeting for focused one-on-one time to develop workplans in consultation with LPFCH staff.
- Providing technical assistance with sustainability and helping to find creative ways for counties that aren't able to get matching funds or county funding for staffing.
- Adding trainings in facilitation, evaluation, working with youth.
- Arranging meetings with leaders in the field (state CCS leaders, etc.).
- Offering even more one-on-one TA.

Several leaders talked about the potential for adding or changing some of the meetings.

- There could be regional meetings of the Statewide Learning Collaborative. This would reduce travel and also potentially allow for more members of local coalitions to attend – perhaps 6 or 7 instead of 3. "It will build the core members' experience, knowledge, and commitment to the group."
- A number of leaders spoke of the possibility of inviting other counties to attend a special statewide or regional meeting.

- *Coordinate a statewide conference that invites those with collaboratives and other counties that don't - - it could be a resource to help people build. Having a conference like that (statewide) might help to educate those areas [outliers away from specialty hospitals] about the possibilities, writing grants, resources out there like MCAH [Maternal, Child and Adolescent Health] or First 5. It would be a place where you could get the formula and hear the players that you want to have at your table. Here are best practices and the context for getting started.*
- *Do a large-scale conference that could share these things [care coordination insights, need for changes]. They [the Foundation] may not have the people to do this meeting organization. There is an organization called CRISS - - Children's Regional Integrated Service System. They would have the capacity to hire people to do this.*

❖ If a statewide or regional conference is held to share what the 5Cs have learned, make sure there are continued opportunities for sharing among coalitions. This could take the form of a smaller breakout session for funded or formerly funded grantees, for instance. "There's value in having those focused smaller conversations." "The intimacy and protection [of the meetings of the past is important.]"

Conclusion and recommendations.

The local coalitions that make up the California Community Care Coordination Collaborative have succeeded in establishing strong coalitions on the local level that are making a difference in their respective counties. Their successful recruitment of relevant agencies and ongoing work to improve local care coordination is, in itself, a system change for those counties. The accomplishments of the coalitions include a number of specific changes to local policies and systems, as well. Of the 10 counties that have participated in the Statewide Learning Collaborative, nine continue to meet, notwithstanding the end of LPFCH funding.

❖ Future support of existing coalitions. The Foundation has built a movement by fostering these 10 coalitions. While these groups have successfully leveraged resources within their respective counties, ongoing support to continue their work may help ensure that they thrive. The need for community-level care coordination for CSHCN is even more urgent now given scheduled changes in health care systems on a state level and the potential for major changes on a federal level with threatened repeal of the Affordable Care Act. 5Cs coalitions can serve an important purpose in their communities during times of profound change. Foundation support could take various forms:

- The 5Cs Statewide Learning Collaborative is highly valued by all coalitions. Continuing to convene and support coalitions to take part will serve both the local coalitions in their work and the state's CSHCN by identifying systems issues that require attention at a state level.
- Continued strategic support of local coalitions' staffing could take the form of direct funding, either via contract or through an RFP process. Needs and goals vary, and the potential to leverage federal participation funds is a tool that should be maximized. Smaller counties or counties with financial and/or political constraints may not be able to take advantage of that opportunity, however, so the Foundation could consider other means of supporting these regions, especially given the special challenges facing these areas (transportation, lack of specialty care, etc.). This could include support for formation and continuation of coalitions, educational opportunities such as support to attend a statewide convening, or other learning opportunities.
- The Foundation could additionally employ strategies to assist coalitions in sustaining and leveraging the networks that have already been created. This might include:
  - Working to promote the coalitions with First 5 and other parts of local government, including public health departments, that may be able to provide direct or in-kind support. First 5 has been an active partner with a number of the existing 5Cs coalitions, and First 5 California's 2017-18 policy agenda is closely aligned with the 5Cs mission, specifically seeking to "support coordination across the health care system."[4]
  - Considering co-funding opportunities or "marketing" to other funders with related missions, particularly those that support community collaborations. This might include Kaiser Family Foundation, California Endowment, and others.
  - Providing continued sustainability training and advice directly to coalitions to assist them in seeking support from outside sources.
  - Devising a means to allow existing coalitions to promote themselves as affiliated with the Foundation in some capacity, even if direct grant funding has ended. A number of leaders have stressed that their participating agencies come to the 5Cs table (and stay there) specifically because of the involvement of LPFCH.

❖ Elevate and advocate for resolution of systems issues at the state level. While this is already happening on multiple levels, there may be ways to make this strategy more clearly connected to the work of the 5Cs. Consider convening groups of agency leaders at a state level to illustrate dysfunction and suggest change. 5Cs coalitions may be

partners in this effort by bringing their stories and experience in support of change. Connecting LPFCH supported advocacy programs to the 5Cs program could provide synergistic benefits.

- Share the collective knowledge of the 5Cs and promote replication. A statewide conference could demonstrate what has been learned and "prime the pump," particularly for counties with the capacity to undertake their own coalitions. The Foundation could offer targeted technical assistance and promote another round of funding for new coalitions if timing and resources permit. The conference could serve as an opportunity to recruit and assist prospective grant/contract recipients.
- Expand evaluation.
    - The ultimate outcome measure will be whether or not families are able to secure appropriate services in a timely and efficient manner. Consider devising questions to "tack on" to existing statewide surveys of families of CSHCN that will allow ongoing monitoring of family experience and the state of care coordination. A field that identifies respondents' county of residence could provide region-specific information and assist the coalitions.
    - Monitor and promote the availability of expanded data availability, "big data," and work toward making it available to coalitions. Those data may prove useful in prioritizing and promoting needed changes to state systems. Databases have expanded, particularly with the rise of electronic health records. LPFCH evaluators and academic partners may be able to map data elements that could be useful in measuring care coordination and explore means for making de-identified data available. Ultimately, robust data could demonstrate cost savings from effective care coordination strategies which could, in turn, build the case for reimbursement for care coordination.
    - Expand measurement of the value of coalitions. All coalitions stressed the value of the networks and relationships that are created, as well as the care coordination improvements that happen outside of meetings as a result of member participation in 5Cs. Some of the coalitions constructed surveys of agency members. A working group of coalition leaders, working with evaluation support, could develop and pilot a survey to gather specific information about the extent of the networks, the relationships built, and how coalition members are deploying the information learned at meetings. This could include quantitative information about cases influenced, trainings of agency staff with 5Cs learnings and tools, etc. This working group could also modify (if needed) the current Collaboration Checklist, or recommend more uniform ways to administer it to help coalitions measure the function and growth of the coalition.

- Support 5Cs local coalitions with evaluation assistance. Coalitions, including their leadership and agency participants, need data to justify continued participation. Recruiting local hospitals with large data systems and evaluation support into coalitions could help supplement capacity. Another strategy would be to recruit academic partners, including residency programs in community health, public health, and epidemiology that may have residents or doctoral students with expertise to offer. Offering evaluation support to coalition teams, particularly as projects are being designed, could produce richer outcome data.
- For promising evaluation instruments, such as the care coordination measurement tool employed in Orange County, consider expanding the pilot of the tool with care coordinators who have a rich caseload to test it on. Per the suggestion of the local coalition, explore the potential for public health nursing to employ the tool and provide data.

Every 5Cs meeting around the State depends on in-kind participation by interested agencies. The 5Cs "formula" has been effective, because it continues to engage participation. The Foundation has created a strong network of community coalitions supported by a vigorous Statewide Learning Collaborative. Building on that structure in the coming years should prove invaluable to the State's families of children with special health care needs and to the regional agencies and individuals that serve them.

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[1] "Coalition successes" were described on page 15. These include the name of each coalition along with a description of a few of the accomplishments named by the team in their interview. In light of the agreement that statements would not be attributed to them, the evaluator prepared the paragraph for each coalition and reviewed it with the leadership group to insure accuracy and an understanding that the information would appear in this report with the coalition's name attached.

[2] Jolin, M., Schmitz, P. and Seldon, W. Needle-moving community collaboratives: A promising approach to addressing America's biggest challenges. Retrieved from https://www.bridgespan.org/insights/initiatives/transformative-scale/needle-moving-community-collaborative-s-a-promising

[3] http://www.lpfch.org/cshcn/blog/2014/10/30/lessons-learned-local-care-coordination-california.

[4] First 5 California, 2017-18 Children's Policy Agenda. Retrieved from: http://www.ccfc.ca.gov/pdf/about/leg/2017-18_Childrens_Policy_Agenda.pdf