THE 5CS: CALIFORNIA COMMUNITY CARE COORDINATION COLLABORATIVE

AN EVALUATION REPORT FOLLOWING PHASE 4

SUBMITTED TO: LUCILE PACKARD FOUNDATION FOR CHILDREN'S HEALTH

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Executive Summary

In 2013, the Lucile Packard Foundation for Children's Health (LPFCH) initiated and funded 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 a statewide learning collaborative 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 accomplishments and for three new coalitions to form and join the statewide collaborative. At the conclusion of the second phase, an evaluation was conducted. (California Community Care Coordination Collaborative: An Evaluation Report Following Phase 2, February 22, 2017.)

Thereafter, LPFCH supported Phases 3 and 4 of the 5Cs (2017-2019), providing funding to two of the coalitions that participated earlier to pursue specific systems-level changes needed and identified by the coalition communities. The participating coalitions were the same for both phases and included Orange County Care Coordination Coalition (OCC3) for Kids (Orange County) and San Joaquin County 5Cs. Evaluation activities during Phases 3 and 4 included case studies of the system change process undertaken by each coalition during Phase 3 and a survey of individual partners in each coalition administered at the beginning of Phase 3, at the end of Phase 3, and at the end of Phase 4 (Partner Survey).

The purpose of the current evaluation report is to:

1. Summarize the primary outcomes from evaluation activities during Phases 3 and 4; and
2. Summarize the "top level" findings across the four Phases of the 5Cs' evaluation activities.

Case studies: learning about the process of pursuing systems change

The evaluator followed the progress of the coalitions in their pursuit of systems change during Phase 3 activities and interviewed those who participated, documenting the process. Final reports were prepared:

- *Tackling Systems Change to Improve Access to Incontinence Supplies for Children with Special Health Care Needs: Orange County Care Coordination Collaborative for Kids*
- *Partnering to Create Transportation Options for Families of Children with Special Health Care Needs: San Joaquin County 5Cs*

While the systems changes pursued by the two county coalitions were very different, two common themes emerged:

1. Having committed partners from a broad range of agencies and sectors was key to securing meaningful systems change; and
2. Committed coalition leadership created an open, non-confrontational, and collaborative environment for participation. This collaborative approach to problem solving made change possible.

Partner surveys: learning about coalition function over time from the vantage point of participating agencies, organizations and individuals

Surveys were sent by the evaluator via SurveyMonkey to each coalition partner annually, which allowed three separate survey administrations representing the beginning and end of each phase (Phases 3 and 4). By including a common set of questions, we were able to monitor changes in partner perceptions over time.

Benefits of participation for partners.

The survey provided a list of potential benefits of coalition participation and partners were invited to rate their agreement on a 5 point scale, with 1 indicating STRONGLY DISAGREE and 5 indicating STRONGLY AGREE. For both coalitions, there was a progressive increase over the three survey administrations in the percentage of partners who STRONGLY AGREED that their organization's partnership with the coalition:

- "Increased our organization's ability to network and collaborate with other organizations"
- "Increased our organization's visibility among other organizations / providers"
- "Enhanced our training and awareness of other services in the county"
- "Provided a place to present our services / clarify misunderstandings"
- "Allowed us to better serve our clients"

This is a consistent finding with another question in the survey that asked partners to rate the top three aspects of collaboration that have most contributed to the coalitions' success. Every year, both coalitions rated "bringing together diverse shareholders" and "exchanging information and knowledge" as top reasons for their success as a coalition.

Evaluation outcomes across four Phases

Success was observed through multiple evaluation perspectives:

Systems change success – documented by objective assessment. Changes in systems have the potential to benefit many families as well as the overall health care system and larger community by minimizing fragmentation and duplication and facilitating access. Early phase examples involved systematizing the function of the coalitions. As coalitions continued their work, patterns of systems-level problems emerged and the coalitions often formed smaller working groups within the coalition to investigate and facilitate systems change. As relationships developed and trust grew, systems changes affecting broad groups of CSHCN emerged from the work of the coalitions. In San Joaquin County, for example, in Phase 2, the coalition identified lack of out-of-county transportation as a critical access problem for CSHCN in the rural county. In Phase 3, the coalition advocated with transportation authorities to secure authorization and funding for non-emergency medical transportation services for CSHCN to travel out-of-county for specialized care. They partnered with the regional transportation provider to market newly created van and bus services. At the beginning of Phase 3, coalition members had identified lack of transportation as the most difficult challenge to effective care coordination in the county. By the end of Phase 4, transportation access had dropped to tenth out of eleven local challenges.

Coalition success through network of relationships built – documented by surveys of partners and interviews of coalition leadership. The value of the relationships built through the coalition network was cited repeatedly in interviews and surveys, including the independent survey fielded by Public Health Institute in 2015. For example, a partner mentioned "the 5Cs project has helped all of the collaborative partners to understand the need to act on the systems gaps and barriers that have been identified and increased the communication and positive relationships that are needed to create systems change."

Contributions to CSHCN by supporting the work of coalition member organizations – documented by surveys of partners. The Partner surveys also substantiated the hypothesis that the agencies and organizations that participate in the coalitions are able to improve their own services to families as a result of their participation. For example, 2019 data from partners who provide direct services to families showed:

- 81% said they had "shared contacts or other information gained through coalition participation with families of children with special health care needs."
- 77% agreed that the coalition "provided a place to bring some of our most difficult challenges and help find solutions."
- 94% agreed that the coalition "enhanced our training and awareness of other services in the county."
- 87% agreed that the coalition "allowed us to better serve our clients."
- 94% agreed that the coalition "provided a place to advocate for services for CSHCN."

The evaluations of the Coalitions during Phases 3 and 4 illustrated the success of the groups in leveraging their relationships and collaborative process to bring about local systems change, while supporting partner organizations to elevate their direct services to families of CSHCN.

Background.

In 2013, Lucile Packard Foundation for Children's Health (LPFCH) initiated and funded 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 collaborative, with paired mentoring assistance from previously funded coalitions. At the conclusion of the 18 months of the second phase, Health Policy Consulting Group designed and conducted an evaluation of the initial two phases of the 5Cs and prepared a report. (California Community Care Coordination Collaborative: An Evaluation Report Following Phase 2, February 22, 2017.)

Thereafter, LPFCH supported Phases 3 and 4 of the 5Cs, providing funding to two of the coalitions that participated earlier to pursue specific systems-level changes needed and identified by the coalition communities. Phase 3 extended from September 2017-August 2018, with Phase 4 running directly thereafter from September 2018-August 2019. The participating coalitions were the same for both phases and included OCC3 for Kids (Orange County) and San Joaquin County 5Cs. Table 1 outlines phases and dates, participating counties, focus of phases, and evaluation activities.

Table 1. California Community Care Coordination Collaborative (5Cs) Funded Phases

	Phase 1 4/1/13-9/30/14 18 months	**Phase 2** 1/1/15-6/30/16 18 months	**Phase 3** 9/1/17-8/31/17 12 months	**Phase 4** 9/1/18-8/31/19 12 months
County coalitions	Orange, Contra Costa, Fresno, San Mateo, North combo (Shasta, Siskiyou & Trinity) [Monterey unfunded but participated]	Orange, San Joaquin, Contra Costa, San Mateo, Alameda, Ventura [Kern funded to participate in Statewide collaborative]	Orange San Joaquin	Orange San Joaquin
Coalitions' focus	Formation, convening, local goals, Statewide collaborative participation	Formation (for new counties) convening and local goals, Statewide collaborative participation	Continued convening of coalition, specific system change target, meetings at LPFCH	Continued convening of coalition, specific system change target, meetings at LPFCH
Statewide collaborative	X	X	X (smaller group with invited guests)	X (smaller group with invited guests)
Evaluation: Post Phase 2		Surveys, in-person interviews (Report 2/22/17)		
Evaluation: Case study			Case study of Phase 3 systems change begins	Completion of Phase 3 case study
Evaluation: Partner survey			Nov/Dec 2017	Nov/Dec 2018 Sept/Oct 2019

Leslie Linton (Health Policy Consulting Group), who had conducted the post Phase 2 evaluation, assisted in planning and executing evaluation activities during Phases 3 and 4. Detailed reports

and presentations summarized the specific findings of those activities and provided feedback to the coalitions and to the Foundation during the course of Phases 3 and 4.

The purpose of the current evaluation report is to:

1. Summarize the primary outcomes from evaluation activities during Phases 3 and 4; and
2. Summarize the "top level" findings across the four Phases of the 5Cs' evaluation activities.

Phases 3 & 4: The coalitions pursue defined systems changes.

For Phase 3, a Request for Proposals was extended to the existing coalitions, previously funded during the first two phases. Those coalitions had already recruited partners and were continuing to meet on a regular basis to address local care coordination challenges. Phase 3 ran for 12 months with the potential, following application and submission of a new workplan, to continue systems change work for an additional 12 months during Phase 4. Each coalition, in consultation with its partners, undertook a specific system change to address a problem faced by that county's families of CSHCN. Each was successful during Phase 3 and developed a new scope of work to continue systems change during Phase 4 in a new area.

Orange County: Phase 3.

The Orange County Care Coordination Collaborative for Kids (OCC3 for Kids) wanted to reduce wait times and administrative run-arounds suffered by families as a result of multiple layers of payers. With multiple parent representatives as coalition partners providing guidance, the coalition chose to explore system changes to ease the burden on families whose children had an ongoing need for diapers and other incontinence supplies due to medical conditions. The group convened separate meetings with key stakeholders / potential payers who were already part of the coalition [CalOptima (Medi-Cal managed care plan), California Children's Service (CCS), and Regional Center of Orange County] as well as vendors of incontinence supplies to explore the intricacies of the system that caused families so much ongoing stress. Systems changes that emerged as a result of their work included a change in CCS procedure that would flag cases for children who have lifelong incontinence. This provided more certainty about who would pay and created less delay and authorization hassle for families.

Orange County: Phase 4.

The coalition identified the issue of transition from pediatric to adult care for CSHCN as the overall system issue they wished to tackle during this 12-month period. OCC3 for Kids' initial focus was on development of a toolkit to assist health care providers. Partners and leadership reviewed and analyzed existing toolkits, identified an existing toolkit to modify, and designed changes and additions, including a local resource list to make it useful to Orange County providers. The coalition also facilitated connections between pediatric and adult providers while

introducing and promoting use of the coalition's toolkit. http://www.helpmegrowoc.org/occ3-for-kids/

Partner members of the coalition such as Regional Center of Orange County and CalOptima (Medi-Cal managed care plan with responsibility of children in the California Children's Services Program Whole Child Model) have undertaken internal system changes to improve transition, including creation of brochures to routinely inform families as children approach transition age. A survey of partners in the coalition in September and October 2019 revealed that 76% had shared information about the Toolkit and/or resource list with others, 38% had used the Toolkit and/or resource list in their work, and 43% intended to use or disseminate the Toolkit/resource list in the future.

San Joaquin County: Phase 3.

The county does not have a local children's hospital and suffers a shortage of specialists in many fields. For families of CSHCN, this means they must travel outside the county for specialty care, often to the Bay Area which is a two-hour trip by car, each way. Many local families lack reliable, affordable transportation, resulting in missed appointments. For Phase 3, the coalition chose to pursue system changes to increase transportation opportunities for families with CSHCN. In a survey of the coalition's partners at the beginning of Phase 3, lack of transportation was identified as the top challenge to effective care coordination for CSHCN in San Joaquin County.

Coalition leaders approached the San Joaquin Council of Governments (SJCOG) which oversees changes to local transportation systems. They joined committees within SJCOG to learn and follow processes for change, collected surveys to document residents' needs, gathered letters of support, and organized testimony before decisionmakers, eventually winning approval and funding for the Regional Transportation District (RTD) to plan services. Once authorized, coalition members partnered with RTD to design and market a trial system of van and bus services for the benefit of county families. As the new system was successfully launched, regulations changed to require health plans to secure and provide transportation to families, and the newly launched RTD services became far less in demand. Still, the efforts of the coalition serve as an example of the power of the collaborative to work toward profound system change.

San Joaquin County: Phase 4.

With the goal of increasing access to behavioral health for CSHCN, the coalition recruited new behavioral health partners and conducted a needs assessment and review of existing services. Based on their needs assessment, the coalition was particularly interested to locate and describe services that decreased violent or frightening behaviors in the home, decreased suicide risk, and improved family functionality and wellness at home and in the community. The coalition ultimately decided to help address gaps and barriers and improve the system of care by including

the information they developed in an updated 2020 Mental Health Directory of the County's Public Health Department with descriptions of agencies and program descriptions relevant to CSHCN. To further increase accessibility, they added program updates to their local 2-1-1 network. To train future parent advocates and increase meaningful participation of families in local agencies and organizations affecting CSHCN, 12 coalition members and community leaders participated in a Project Leadership training (train the trainer). https://www.familyvoicesofca.org/project-leadership/

When partners in the San Joaquin 5Cs were surveyed in September and October of 2019, 100% indicated that their knowledge of mental health resources had increased. One partner offered a specific example of how the project had changed, ". . . we now have a resource from CAPC [Child Abuse Prevention Council] to refer children ages 0-5 that may need a mental health evaluation and/or family support."

Phases 3 & 4: Evaluation planning.

Working with LPFCH staff, we decided on two strategies to evaluate the work of the coalitions. For Phase 3, we decided to conduct case studies of the targeted systems changes. The case studies would tell the story of the evolution of change through the efforts of the coalitions. By tracking the coalition process throughout the year of activities, it would allow a deeper understanding of the change process. It would include lessons learned to inform other organizations seeking to undertake similar changes, and it had the potential to provide broader lessons about systems change by a community coalition. Finally, it could aid the ongoing work of the coalition by documenting success to assist in recruiting future coalition partners as well as showing prospective funders a proven track record.

Because the coalitions are collaboratives of diverse community agencies, organizations and individuals serving CSHCN, we also wanted to evaluate the coalition by directly securing the perceptions of the partners who were participating and to observe any changes occurring over time. By surveying individual partners, it was hoped that we could learn more about the value of the coalition relationships within and among the member organizations. We chose to design and implement a Partner Survey, to be fielded online, via SurveyMonkey with each of the coalitions' partners on a yearly basis.

Case studies (Phase 3): What have we learned about the process of pursuing systems change?

A case study for each coalition was conducted by the evaluator in cooperation with the coalitions. Data was collected during the work plan year for Phase 3 and was completed during

Phase 4. A detailed case study report was generated to document the work of each coalition and to distill the lessons learned during the process.

- *Tackling Systems Change to Improve Access to Incontinence Supplies for Children with Special Health Care Needs: Orange County Care Coordination Collaborative for Kids*
- *Partnering to Create Transportation Options for Families of Children with Special Health Care Needs: San Joaquin County 5Cs*

During the course of Phase 4 meetings of coalition leadership at LPFCH, leaders decided that brief 2-page summaries of the case studies would assist them in highlighting accomplishments of the coalitions in a variety of settings such as recruiting new partners and securing financial and agency support for the continuation of the coalitions' work. LPFCH staff led a process to distill the lengthy case studies into 2-page documents for use by the coalitions.

- *Issue Brief – A Success Story: How a Coalition Improved Children's Access to Lifelong Incontinence Supplies; and*
- *Issue Brief – Improving Access to Care for Families of Children with Special Health Care Needs in San Joaquin County.*

Although the systems changes pursued by the two county coalitions were very different, looking closely at how the coalitions used their time and resources to produce change suggests at least two common themes.

1. Having committed partners from a broad range of agencies and sectors was key to securing meaningful systems change.

Orange County.

Broad range of agencies and sectors. The coalition's parent representatives were able to distill a common and relatable problem and identify the payors who were involved in authorization and payment for incontinence supplies. Those payors included the Medi-Cal managed care plan (CalOptima), California Children's Services, and Regional Center of Orange County, all of which were already active partners in the coalition. These partners helped hash through and understand the scope of the problem and identify potential solutions. The coalition was also able to recruit and meet with vendors of incontinence supplies who were not previous partners to find ways to involve them, as major players, in the solution.

Committed partners. Coalition representatives came to the table to solve the problem. They sent representatives to meetings who were knowledgeable about their own agency's internal procedures and who were authorized to implement change. By way of example, California

Children's Services was represented by the Medical Director who was able to investigate and explain her agency's internal procedures. Ultimately, after interacting with the coalition, she was able to modify internal procedures and create trainings for vendors that would go on to implement meaningful systems change.

San Joaquin County.

Broad range of agencies and sectors. When the coalition determined to create transportation options for local families that needed to travel outside the county for care, they knew they needed to join with agencies in the transportation sector to understand how to create options and to help guide the outcome to benefit CSHCN. They did this by joining and working on several committees of the San Joaquin Council of Governments who would ultimately agree that there were unmet transportation and funding needs. Once funded on a trial basis, coalition members partnered with the Regional Transportation District (RTD) to design and market the services that were created. Coalition members became active partners at each step in the transportation sector processes, and the coalition, in turn, invited RTD staff to join meetings of the coalition. This partnership was also highlighted in the Public Health Department accreditation process.

Committed partners. Identifying the needs of county families for expanded transportation options was only the beginning. Coalition members embedded themselves in the process of a sector that were heretofore completely foreign to them. They served on committees of the regulatory body for more than two years. They rallied the entire coalition membership to circulate transportation surveys to document need. They rallied influential coalition members to attend hearings before decision makers and speak up on behalf of families. And they did the behind the scenes work to help identify and address the barriers to implementation including payment logistics and marketing.

2. Committed coalition leadership created an open, non-confrontational, and collaborative environment for participation. This collaborative approach to problem solving made change possible.

Orange County.

When a system is complex, involves multiple players, and is not functioning well, the natural inclination may be defensiveness and faultfinding. But solutions require a clear and unbiased understanding of the facts without blame. The collaborative manner and approach at OCC3 for Kids was described by one partner in an interview for the case study,

> "*They are very non-confrontational. Also, they don't cater to politics. They are very neutral – safe. And, they provide a safe environment, as well as education. . . .You can*

rely on them to use the information diplomatically and not to ruin my relationship with other entities. You can trust them."

San Joaquin County.

Collaborating with new partners in the transportation field required coalition members from the health and social services sectors to learn an entirely new vocabulary, culture, and regulatory framework. It required demonstrating a commitment to collaborate rather than simply insisting on change as an outsider with a grievance. That collaboration was demonstrated by active, consistent, working participation on committees of the San Joaquin Council of Governments for over a year. Later, it required a close partnership with the Regional Transportation District to design and market the newly authorized transport services to families of CSHCN. The support of the individual coalition members who were doing this work by their agencies' leadership is significant, also, because their agencies were grounded in public health and social services, a seeming far cry from transportation.

Partner Surveys (Phases 3 & 4).

From the evaluation at the end of Phase 2 we know that all of the coalitions have placed a high value on the network of relationships that they created and sustained. Evaluation planning at the beginning of Phase 3 determined that periodic surveys (yearly) of the partners in each coalition would provide a better understanding of how the coalitions were performing over time and provide feedback to the coalitions and LPFCH to guide future planning. The evaluator worked collaboratively with Foundation staff and leadership for each coalition to design the initial survey to be administered in SurveyMonkey. The second and third yearly surveys incorporated questions specific to workplan goals, but also maintained a core set of consistent questions that allowed reflection about how partners were changing perspectives over time.

The evaluator sent a survey invitation to each partner in both coalitions using email addresses furnished by coalition leadership. Several reminders were sent to partners who did not initially respond. Surveys were gathered from the coalitions during these timeframes:

1. November 2017 – December 2017.
2. November 2018 – December 2018.
3. September 2019 – October 2019.

Response rates and characteristics of partners who responded.

- **Response rates** ranged between 44% and 63% for the 6 administrations of the survey (three times for each of the two coalitions).

- The **number of invitations issued** varied over three administrations:
    - Between 43-45 in Orange County.
    - Between 21-44 partners in San Joaquin County. There, the focus of the coalition changed with each systems change workplan, and partnership membership changed, accordingly. That is why there were smaller numbers of partners for the 2018 survey than for the 2017 survey and even fewer in 2019.
- **Length of membership**. Most of the partners who responded to the surveys had been coalition members for 2 years or more. (Range: 52%-73%).
    - But coalitions also got feedback from newer members, as well, with between 12% and 32% of partners having joined during the year preceding the survey.
- **Meeting participation**. The vast majority of partners who responded were those who attended regular coalition meetings.
    - In San Joaquin County, 89% of members attended 2-6 meetings of the full coalition (they met every other month) in 2018 and 100% of respondents did so in 2019.
    - In Orange County, 11 meetings of the full coalition were held each year and 63% of respondents attended 6 or more meetings in 2018 and 68% did so in 2019. Additional partners attended 2-5 meetings in 2018 (21%) and in 2019 (18%).
- **Sectors represented**. Beginning in 2018, the survey asked respondents to classify the sector that best described their representation in the coalitions. The coalitions used different categories in their respective partner surveys. Orange County's coalition in 2019 was comprised of 41% "health care provider," 21% "public agency," 14% "community-based organization," 9% "parent," 5% "education," and 9% "other." San Joaquin's coalition in 2019 was comprised of 31% "education, early education & developmental services," 23% "social services and welfare," 15% "health services," 8% "parent or caregiver," and 23% "other."
- **Direct service providers**. In 2018 and 2019, when the question was asked, at least 80% of partner representatives said they either provide direct services to CSHCN or their organization does so.

Benefits of participating in the coalition.

The evaluation provided a list of potential benefits of coalition participation and asked partners to consider the extent of their agreement with each on a five-point scale ranging from strongly disagree to strongly agree. While there was consistent agreement among partners over all three years with the entire list of statements of potential benefits, there is one change over the three years of surveys that stands out. For a number of listed benefits to the organizations, there was a progressive increase in each of the three years in the percentage of partners who STRONGLY AGREED. This is shown in Table 2 below.

Table 2. Please indicate your agreement with each statement. My organization's partnership with [coalition name] has. . .

	% of partners who "STRONGLY AGREE" increased each year	
	San Joaquin County	Orange County
• Increased our organization's ability to network & collaborate with other organizations.	⇑⇑⇑⇑	⇑⇑⇑⇑
• Provided place to bring some difficult challenges to help find solutions.		
• Increased our organization's visibility among other organizations / providers.	⇑⇑⇑⇑	⇑⇑⇑⇑
• Provided key information that has saved us staff time handling cases.	⇑⇑⇑⇑	
• Enhanced our training and awareness of other services in the county.	⇑⇑⇑⇑	⇑⇑⇑⇑
• Provided place to present our services / clarify misunderstandings.	⇑⇑⇑⇑	⇑⇑⇑⇑
• Provided a place to advocate for services for CSHCN.	⇑⇑⇑⇑	
• Allowed us to better serve our clients.	⇑⇑⇑⇑	⇑⇑⇑⇑

In order to understand more about how partners have used the information they have gained as a result of their participation, the Partner Survey asked how often partners used various types of information gained during their coalition participation. Partners were asked to select, "never," "almost never," "occasionally," "fairly frequently," or "frequently" for each option. Again, while partners offered positive ratings for all options in both coalitions over all three years, as depicted in Table 3 there was an increased percentage of partners selecting "FREQUENTLY" every year for a number of categories.

Table 3. Thinking back over the last three months, consider how often you have used information that you gained as a result of participating in [coalition name].

	% of partners who said "frequently" increased each year	
	San Joaquin County	Orange County
• I have communicated with contacts I gained through the coalition to get information about a member agency.	⇑⇑⇑⇑	⇑⇑⇑⇑
• I have worked with contacts I gained through the coalition to assist specific families of CSHCN.	⇑⇑⇑⇑	⇑⇑⇑⇑
• I have shared contacts or other information gained through coalition participation with fellow staff members in my organization.	⇑⇑⇑⇑	⇑⇑⇑⇑
• I have shared contacts or other information gained through coalition participation with families of CSHCN.	⇑⇑⇑⇑	⇑⇑⇑⇑

These results were consistent with another question that asked partners to rate the top three aspects of collaboration that have most contributed to the coalition's success. Every year, both coalitions rated "bringing together diverse stakeholders" and "exchanging information and knowledge" as top reasons for their success as a coalition.

Rating local care coordination challenges.

The Partner Survey also asked partners each year to rate a number of listed challenges to effective care coordination for CSHCN in their respective communities. The survey used a 10-point scale with "1" being "not really a challenge in our community" and "10" being "one of the greatest challenges in our community." While some challenges were consistently rated "one of the greatest challenges in our community" in both coalitions, there were also differences between the two coalitions. For each coalition, there were also differences observed over the three years the survey was fielded.

- **Similarities between coalitions**:
  - "Services for mental health and physical health are not integrated," was one of the top four challenges in both communities all three years. (Range: 7.4-9.4).
  - "Regulations and processes to determine which entity is responsible for payment for some services and/or supplies are confusing and cumbersome," was one of the top five challenges in both communities all three years. (Range: 7.5-8.1).
  - "Care coordination requires a great deal of time for providers," was one of the top five challenges for both communities except one year. (In 2017, it was the sixth rated challenge in Orange County).

- **Differences between the coalitions reflect their unique circumstances**:
    - "Specialty care is unavailable or scarce / there is no major medical center in our community," was the top rated challenge in San Joaquin County in 2018 and 2019 and the third highest challenge in 2017. (Range 8.1-9.4). This challenge was the lowest rated challenge in Orange County all three years. (Range: 4.1-5.8).
    - "Transition of CSHCN from pediatric to adult care suffers from lack of training and coordination among providers and health plans," was rated the top challenge in the community in Orange County in 2018 and 2019. (Range: 8.6-9.0) While this was also a highly rated challenge in San Joaquin County, it was not part of the top five rated challenges either year. Note: this challenge did not appear on the list in 2017 and was added for later years at the suggestion of the coalitions.
- **Changes within the coalitions over the years**:
    - "Families have difficulty securing transportation to needed services," was the top rated challenge (rated 9.5/10) in San Joaquin County in 2017 and was the impetus for the system change that the coalition pursued in 2017 and 2018. By 2019, when system change had been realized, (see Case Study description page 8), the partners' initial rating of this as the top challenge dropped to tenth on the list of relative challenges.
    - "Transition to the Whole Child Model," was added as a potential challenge on the list of ratings for the Orange County coalition (only) in light of their migration to the Whole Child Model in July 2019. The survey was fielded just a few months after implementation, but it did not register at that time as a major concern for coalition partners with a rating that did not put it among the most significant relative challenges in the community.

Partner organizations: seeking input from parents.

In 2018 and 2019, the survey added a question about the ways that partner organizations (as distinct from the coalition) seek input from parents. Asked to check "all that apply," the most frequently observed ways of seeking input from parents included:

- "As members of advisory groups / task forces" (Range: 40%-78%)
- "Via surveys / satisfaction surveys" (Range: 27%-68%)
- "Via partnerships with family organizations" (Range: 27%-41%).

Evaluation outcomes across four Phases.

Success was observed through multiple evaluation perspectives:

- Objective assessment of systems changes;

- Building a relationship network - perceptions of coalition leaders as expressed in interviews and surveys;
- Contributing to CSHCN by supporting the work of coalition member organizations - perceptions of coalition partners as expressed in yearly partner surveys (2017-2019).

Systems change successes.

The first two phases of the program brought together new coalitions and refocused groups that had already formed. Coalition workplans included organization of the coalitions, including recruitment of critical partners, convening of meetings, and development of interagency working arrangements and protocols. However, the program has always placed a major emphasis on setting measurable and specific systems change goals. Changes in systems have the potential to benefit many families as well as the overall health care system and the larger community, by minimizing fragmentation and duplication and facilitating access to needed services. Early examples involved systematizing the function of the coalitions:

- Adoption of standardized referral forms among all child and family service providers in a community;
- Creation of inter-agency memoranda of understanding that delineate procedures for the sharing of client information;
- Establishment of case review procedures including forms and protocols for presentation and review by the coalition;
- Creation of care coordinator positions/functions to systematize case review and resolution and track broader patterns of systems disfunction beyond individual cases;
- Leverage of financial support for care coordination positions through use of Federal Financial Participation funds (Kern County, Orange County, Ventura County).

As coalitions continued their work, patterns of systems-level problems emerged, and the coalitions often formed smaller working groups within the coalition to investigate and facilitate change. Examples have included:

- Policy workgroups to address NICU discharge issues, provider education and in-home support services (Orange County);
- A transition team created between CCS and a local Medi-Cal managed care health plan to ease transition when a child falls off CCS (Ventura County);
- A workgroup to increase information sharing so that probation can access medical records from Juvenile Hall (Ventura County);

As relationships were built within coalitions and trust was built, systems changes affecting broad groups of CSHCN emerged from the work of the coalitions. Examples include:

- Creating new systems and training within CCS to routinely consider behavioral health as well as medical needs and make appropriate referrals (Alameda County – Phase 2);
- Identifying lack of transportation out-of-county as a critical access problem for CSHCN in a rural county and creating documentation of the problem in order to advocate for change with decisionmakers. (San Joaquin County – Phase 2).
- Advocating with transportation authorities to secure authorization and funding for emergency medical transportation services (van and bus) for CSHCN to travel out-of-county for specialized care that was not offered locally. Partnering with the regional transportation provider to market newly authorized and created transportation services to families of CSHCN. (San Joaquin County – Phase 3).
- Through facilitation of information exchange between key partners (parent representatives, CCS, Regional Center, and managed MediCal health plan) as well as vendors, inspiring change of local CCS systems by the Medical Director to allow longer term authorization for incontinence supplies for children with ongoing medical needs. (Orange County – Phase 3).
- Creating tools to facilitate systemic change at various levels of the health care system such as:
    - A county specific transition toolkit, including forms and local resource information as well as trainings to assist providers and insurers in creating a smoother transition of children from pediatric providers to adult providers. (Orange County – Phase 4);
    - Revising and updating a Mental Health Directory maintained by the local health department using resources gathered from a needs assessment and survey of existing programs; also updating the county's 2-1-1 program with program updates based on the information developed by the coalition. (San Joaquin County – Phase 4).

Coalition success: network of relationships built and contributions to partner organizations' success.

While systems change has been a program focus, all of the coalitions have continuously stressed that the relationships built within the coalitions have been invaluable to the communities they serve. [Interviews of coalition leaders (post Phase 2); post Phase 2 evaluation online survey of coalition leadership; online surveys of coalition partners in 2017, 2018, and 2019; and a LPFCH cross program survey from Public Health Institute in September 2015].

In an independent written survey to LPFCH grantees fielded by Public Health Institute in September 2015, current and former coalition leaders agreed (8 out of 9) that Foundation grant support had helped develop sustainable collaboration within the coalition's community.

"I see the networking that has been created through the collaborative having a long-lasting effect in our community."

"As a result, in part, of Foundation support, my institution is part of a large national collaborative study of system change for CSHCN."

In the same survey, 8 out of 9 leaders think the 5Cs project has had a positive impact in their community. Typical comments include:

"The 5Cs project has helped all of the collaborative partners to understand the need to act on the systems gaps and barriers that have been identified and increased the communication and positive relationships that are needed to create systems change."

"We have established relationships between agencies and those relationships have led to improved communication and problem resolution in care coordination issues."

Interviews of coalition leaders after Phase 2 underlined the importance of the coalition networks and relationships:

"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. 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."

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"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 that room. With that trust, we can build solutions."

The same sentiment was echoed in the comments offered in the Partner Surveys (organizations that are members of the coalition). For example,

> [The coalition] "*represents an ongoing forum for diverse community organizations to get to know each other & develop relationships, learn about specific available resources, brainstorm solution both specific and general, discuss wider need for change, and create a collective culture of caring and advocacy."* [Partner Survey, 2019.]

The Partner surveys also substantiated the hypothesis that the agencies and organizations that participate in the coalitions are able to improve their own services to families as a result of their participation. (See pp. 10-11). For instance, when we consider the data from the 2019 survey from those partners in both Phase 4 coalitions that provide direct services (personally, or someone in their agency does; n=31) we see strong evidence of improved benefits for families:

- 94% said they had frequently, fairly frequently or occasionally "worked with contacts I have gained through the coalition to assist specific families of CSHCN."
- 81% said they had frequently, fairly frequently or occasionally "shared contacts or other information gained through coalition participation with families of children with special healthcare needs."
- 77% agreed or strongly agreed that the coalition "provided a place to bring some of our more difficult challenges and help find solutions."
- 94% agreed or strongly agreed that the coalition "enhanced our training and awareness of other services in the county."
- 97% agreed or strongly agreed that the coalition "provided a place to present / explain how our services are delivered, clarifying any misunderstandings about them."
- 94% agreed or strongly agreed that the coalition "provided a place to advocate for services for CSHCN (children with special health care needs).
- 87% agreed or strongly agreed that the coalition "allowed us to better serve our clients."
- As expressed in a partner's open-ended response, "we are able to network with others and collaborate with services. We have helped numerous families due to this connection and helped them get the right services."

Families are benefiting from coalition efforts.

Given the 5Cs' goal to improve local systems of care for children and families, we would hope to find greater access to care and greater satisfaction among families of CSHCN as a result of the work of the 5Cs coalitions. We know the initial problem – the one that inspired the 5Cs program in the first instance:

> *"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."* [Interview, post Phase 2 of parent of a CSHCN who was a Phase 1 coalition leader].

While the data suggest that the structure of the coalition is designed to smooth out the systems barriers that have frustrated parents for so long, we have also heard from parent partners / coalition members that the coalitions have achieved success from the parent perspective.

> *"OCC3* [the coalition] *has provided an excellent opportunity for community partners to get together and share information about their agencies/organizations. Initially, I believe most organizations knew what they did to provide services in the community but knew very little about what the other organizations did. Now, I see an improvement across the community in communication and knowing how to connect clients to outside agencies/organizations. As a parent, I believe that the primary case manager is, and likely always will be, the parent. Now, since the agencies we work with have a better understanding of what the others do, things are easier to navigate."* [Partner Survey, 2019, from Partner/parent].

Moving forward.

The coalitions have enjoyed success from all of the perspectives we have examined, including review of objective systems change, the perspectives of coalition leadership, and the perspectives of coalition partners, including family representatives participating in the coalitions. The systems changes achieved during Phases 3 and 4 reflect the maturity of the coalitions involved and their flexibility to continue the ongoing work of the coalition, while simultaneously engaging partners in the pursuit of targeted system change.

Clearly, the work of the coalitions is not "done," and families continue to struggle as result of the deeply fragmented system of health care. As expressed by a parent partner in a coalition,

> "*The care of the CSHCN in our community requires a real unified approach. The opportunities provided from groups such as [our coalition] are critical to developing working relationships, however the issues of insurance coverage, denial/approval*

processes, doctors willing to provide care to young adults with special needs, Regional Center responsibilities hindering the long term care of the individual, limits on day programs, etc, etc. There are many issues that are being addressed as individual issues when, in actuality, they are all intertwined and one thing effects another. It's extremely frustrating. There is also very little attention given to the caregiver – and these individuals suffer with PTSD, depression, anxiety, etc. There is much work to do."

While this sentiment suggests a future agenda for some issues that are within the influence of the coalition, they also suggest another role – as potential voices and advocates for the community of affected families in other jurisdictions where policy is made and changed.