Lucile Packard Foundation *for* Children's Health

Report

An Experiment in Local Care Coordination:

Lessons Learned from Phase I of the California Community Care Coordination Collaborative

April 2013-September 2014

Prepared By

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ABOUT THE FOUNDATION: The Lucile Packard Foundation for Children's Health is a public charity, founded in 1997. Its mission is to elevate the priority of children's health, and to increase the quality and accessibility of children's health care through leadership and direct investment. The Foundation works in alignment with Lucile Packard Children's Hospital Stanford and the child health programs of Stanford University School of Medicine.

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Executive Summary

Prior to 2013, the medical director of the California Children's Services program in one large California county had never laid eyes on the medical director of the local Regional Center for individuals with developmental disabilities.

That lack of interaction between agencies serving children with special health care needs is not unusual, and would have come as no surprise to families in the area. Although children with complex and chronic conditions almost always require services from a wide range of providers, few reliable mechanisms are in place for organizations to interact with one another and share information about their mutual clients. Consequently, care tends to be fragmented and costly, and quality may be jeopardized. Families and care providers alike feel frustrated by how the system is organized.

This state of affairs began to change in several California counties in 2013, with the launch of the California Community Care Coordination Collaborative (5Cs). This pilot project, initiated and funded by the Lucile Packard Foundation for Children's Health, was designed to test whether bringing together previously siloed agencies could result in: a) better-coordinated services for children with special health care needs and their families; and b) collaboration among agencies in identifying ways to improve the care systems that serve these children.

With $40,000 in funding for 18 months, six organizations around the state stepped up to help form and lead local coalitions composed of agencies and organizations serving children with special health care needs.

Local coalitions were formed in six regions in April 2013:

- Contra Costa County
- Fresno County
- Kern County
- Orange County
- San Mateo County
- Shasta/Siskiyou/Trinity Counties

A seventh unfunded coalition in Monterey County asked to join the 5Cs and was added in August 2013.

Each local coalition was required to include representatives from its local California Children's Services program, Regional Centers, and Family Resource Centers. Additional members in the coalitions included pediatricians, public health nurses, special education and mental health professionals, and representatives of other community-based organizations.

The local coalitions met monthly in their counties, and leaders from each coalition also took part in monthly statewide activities as part of a learning collaborative. The local coalitions offered an opportunity for members to find innovative ways to connect and work together on client and policy issues.

At the inception of the pilot project, Foundation staff members had been disheartened by the lack of prior interaction and collaboration across organizations in many of the participating counties. But after 18 months the project was evaluated internally by Foundation staff, and the results offered some positive responses related to the questions the pilot was designed to test:

- The 5Cs statewide learning collaborative became a fully functioning body that met regularly. Information was shared broadly and a number of common policy issues were identified by local coalition members.
- All local coalitions, with an average of 25 members, were established and held fixed meetings that were well attended. Each coalition established goals, and many developed useful tools that were shared statewide.
- Inter-agency cooperation within the seven coalitions helped to initiate improvements in local systems of care coordination, benefiting individual children and their families.
- All seven local coalitions continue to meet, four without continuing funding from the Foundation.

As a result of this initial progress, the Foundation expanded the 5Cs project in 2015, funding three additional local coalitions, in Alameda, San Joaquin, and Ventura counties. To date, 10 local coalitions are operating throughout the state. This report outlines how the learning collaborative and local coalitions were structured and how they functioned. The findings may serve as an example of how other regions might organize their activities to encourage improvements in their local systems of care coordination. Materials developed and shared by learning collaborative members are available at www.lpfch.org/cshcn/community-engagement.

Introduction

Children with special health care needs (CSHCN)[1] require services from a wide array of providers, yet in most California counties few reliable mechanisms exist for providers to share information about their mutual clients.

This limited communication means that families may be unaware of available services, confused as to who is responsible for providing and financing care, and frustrated by the lack of planning, continuity of information, and comprehensiveness of care. Indeed, the top priority identified by families in a 2012 survey[2] was for more and better care coordination among the multiple agencies from which they receive services. Similarly, representatives of health and community service organizations lament that they do not know professionals in other organizations and do not know what services they offer or fund, which limits their capacity to coordinate care.

Although a myriad of definitions exist,[3] care coordination ideally involves a family-centered process aimed at meeting the needs of a patient through active planning and collaboration among all organizations involved in care, with one individual designated as the team leader. This care coordinator generally manages all the interrelated medical, social, developmental, behavioral, educational, and financial needs of patients and their families.

Among families in California who need care coordination, nearly half report they do not receive it.[4] Instead, families become the default care coordinators—tracking billing and payment across insurance programs, facilitating communication between providers, coordinating appointments and transportation, and researching available services. Many programs, agencies, and health plans that serve CSHCN employ care coordinators, but families reflect, "Who coordinates the coordinators? I do."

To relieve this burden, care coordination services need to be improved at the multiple levels at which coordination takes place. These range from coordination by service providers for individual families, to local coalitions coordinating across agencies and planning services, to county government implementing state-sponsored programs. It also includes state government determining who may receive and provide care coordination, as well as how it is paid for and which quality standards will be applied and monitored.

To begin to address these issues, the Lucile Packard Foundation for Children's Health in 2013 provided grant funding for the development of a statewide learning collaborative that would bring together previously siloed agencies. The goal was to encourage better care coordination for children

1 McPherson, M., Arango, P., Fox, H., Lauver, C., McManus, M., Newacheck, P.,… Strickland, B. (1998). A new definition of children with special health care needs. *Pediatrics*, 102(1): 137–140.

2 Henry, H. (2015). Key elements of care coordination for children with special health care needs and their families. Palo Alto, CA: The Lucile Packard Foundation for Children's Health.

3 Bachman, S., Comeau, M. & Jankovsky, K. (2015). The care coordination conundrum and children and youth with special health care needs. Palo Alto, CA: The Lucile Packard Foundation for Children's Health.

4 Child and Adolescent Health Measurement Initiative. (2016, January 13). National Survey of Children with Special Health Care Needs. As cited on www.kidsdata.org, a program of the Lucile Packard Foundation for Children's Health. Retrieved from www.kidsdata.org

at the local level, while also identifying needed system changes for which learning collaborative members could collectively advocate.

This pilot program, known as the California Community Care Coordination Collaborative (5Cs), was launched with grants to six organizations around the state. These lead organizations formed and led local coalitions in six regions: Contra Costa County; Fresno County; Kern County; Orange County; San Mateo County; and Shasta/Siskiyou/Trinity counties. A seventh unfunded local coalition in Monterey County asked to join the learning collaborative and was added in August 2013. Each coalition received approximately $40,000 over 18 months. This funding could not be used for direct services.

All local coalitions included representatives from their local California Children's Services programs, Regional Centers and Family Resource Centers. Additional coalition members varied throughout the state, but frequently included pediatricians, public health nurses, special education and mental health professionals, and representatives of other community-based organizations.

The local coalitions met regularly in their counties, and most also had a monthly leadership meeting to plan future activities. The coalition goals were to improve communication across agencies and service providers, share information, and collaborate to improve services and policies. Leaders from each coalition also took part in several statewide activities of the learning collaborative.

After 18 months, Foundation staff evaluated the work of the 5Cs to assess its initial effects on care coordination.

5Cs Structure and Function

The California Community Care Coordination Collaborative (5Cs) functioned at two levels: the learning collaborative that brought together leaders from the local coalitions, and the local coalitions that operated in the seven regions around the state.

Learning Collaborative

The collaborative was structured around four main activities: quarterly in-person meetings at the Foundation; quarterly technical assistance webinars; monthly check-in calls with the 5Cs Program Officer; and a day-long site visit with the 5Cs Program Officer.

In-Person Meetings

The Foundation hosted four in-person meetings for the 5Cs project. Up to three members from each of the seven local coalitions attended. In the first half of the meeting each coalition provided project updates and noted successes and challenges, which was followed by an open discussion. Afternoons included at least one guest speaker.

Technical Assistance Webinars

Five technical assistance webinars supported the 5Cs project, most of which involved presentations by national and/or state experts. Topics for the webinars included:

- An overview of the 5Cs goals, participating local coalitions, planned activities, and available resources
- Financing and Reimbursement for Care Coordination
- Challenges and Opportunities to Improve Care Coordination
- Experiences Engaging Regional Centers in Improving Local Systems of Care Coordination
- Opportunities to Use Telehealth to Improve Care Coordination in California

Check-In Calls

The 5Cs Program Officer conducted standardized check-in calls with local coalition leadership from each region in the months when there were no other 5Cs activities. These calls lasted approximately 30 minutes and included a discussion of upcoming grant deliverables, as well as current challenges the leaders were facing. Calls also provided a chance to review the project work plan and ensure that it was progressing adequately. Many informal calls and electronic communication also occurred between the Program Officer and local coalition leaders over the course of the grant period.

Site Visits

The 5Cs Program Officer visited each local coalition during the course of the grant period. Day-long site visits were organized to coincide with the monthly coalition meeting. The remainder of the day was spent touring sites of lead agency members and planning with coalition leadership.

Local Coalitions

Each local coalition met on a regular basis, and most also hosted a monthly leadership meeting. Coalitions had approximately 25 members. On average, local coalitions met 17 times during the 18-month grant period, ranging from a high of 36 to a low of six quarterly meetings, though those meetings were of longer duration. Four local coalitions added anonymous case reviews to illustrate system challenges as an activity of this project. An average of nine cases were reviewed per local coalition during the grant period.

To monitor their progress, coalition leaders each completed two interim reports and final narrative and financial reports. Leaders also submitted quarterly worksheets outlining the next steps for their coalition, along with anonymous evaluations of 5Cs learning collaborative activities. Local coalition members completed an assessment of the functioning of their coalition at the beginning (April 2013) and the end (September 2014) of the grant period. The assessment tool, titled the Collaborative Checklist, was adapted from the Bridgespan Group[5] and is included as Appendix A of this report. Finally, leaders provided periodic information to the 5Cs Program Officer during their check-in calls. Several local coalitions also conducted additional internal evaluation activities to monitor their progress and impact.

5 Jolin, M., Schmitz, P. & Seldon, W. Needle-moving community collaboratives: A promising approach to addressing America's biggest challenges. Retrieved from http://www.bridgespan.org/getmedia/7da1eafe-f85a-4798-8774-7386058f2ce4/needle-moving-community-collaboratives-report.aspx

Project Outcomes

At the end of the 18-month initial grant period, the Foundation conducted an evaluation to assess three aspects of the 5Cs project:

1) How well the learning collaborative was functioning; 2) The extent to which the goals of each local coalition were being met; and 3) The extent to which the Foundation's goals for the 5Cs were being met.

Goal 1—Functionality of the Learning Collaborative

The goal of the learning collaborative was to provide a structured opportunity for local community coalitions to learn from one another, identify areas of shared need, discuss emerging challenges, and connect with others engaged in improving care coordination for CSHCN. The learning collaborative functioned well, but there were challenges to overcome and thus many lessons were learned.

Accomplishments

Though it required a significant investment of time to prepare presentations and suggest issues to discuss for each of the learning collaborative activities (i.e., webinars, in-person meetings, calls, site visits), local coalition leaders were actively engaged in helping structure the time. Throughout the project, active participation in the learning collaborative helped local coalition leaders problem-solve, innovate, and share ideas and frustrations. One of the 5Cs participants commented in a grant report, *"we are so much stronger working together as the 5Cs than we could be individually."*

An illustration of shared learning within the learning collaborative was evident in the use of the Federal Financial Participation (FFP) program. FFP enables Local Health Jurisdictions to claim reimbursement for activities that assist eligible clients to apply for Medi-Cal or access Medi-Cal providers, care, and services. One local coalition had been using this funding mechanism to support some non-5Cs organizational activities. A leader from another local coalition then used this approach to leverage funding to support a public health nurse active in their coalition. Consequently, two additional local coalitions have used FFP to support public health nurses as Service System Coordinators, and other coalitions are planning to do the same.

When participants were asked to describe what was most valuable about the in-person learning collaborative meetings, they consistently made comments such as, *"gaining new insights into what other counties are doing that could be applied to our project"* and *"being able to hear others are having similar issues and how they are dealing with it."* Ratings of "excellent" by 85% of the in-person meeting participants added evidence that the process served its function.

Lessons Learned

- Establishing a schedule well in advance for 5Cs activities, e.g., collaborative meetings, webinars, check-in calls, etc., helped attendance and participation.
- Networking among collaborative members required ongoing facilitation by Foundation staff; only a small amount of communication occurred outside of structured activities.
- The greatest degree of interaction among collaborative members occurred during face-to-face meetings. Virtual interactions via webinars and conference calls, though they allowed many more coalition members to participate, were valued but were less productive of generative discussions.
- Consistent participation by the same individuals contributed to the productivity of in-person meetings.
- The collaborative process was enhanced when external experts participated in the meetings, calls, and webinars. They not only brought expertise, but reinforced the importance of the process.
- Technical assistance in addition to using outside experts, including sharing materials and doing site visits, was also valued by the collaborative members.

Systems Issues Identified

One goal of the 5Cs project was to identify problems inherent in the service delivery systems that might be addressed by changes in state policies or programs. Members of the learning collaborative highlighted the following system-level issues:

- **The system of care is fragmented.**
  - There are multiple points of entry into the system of care for CSHCN.
  - No point person or agency is designated to "coordinate the coordinators" in complex situations.
  - Parents may (and often do) serve as the primary care coordinator, although they may not have the necessary information, health literacy, supports or energy to adequately access services for which their children are eligible.
  - Assessment and referral processes for services can be cumbersome, duplicative, and challenging.
- **No systematic communication or feedback occur between providers, community service agencies, and families.**
  - Lack of communication between payers causes complications—local coalition case reviews showed that children covered by multiple payers (for example, private insurance and California Children's Services) seemed more likely to have delays in care due to determination of appropriate payer.

- There is a lack of knowledge about available services and eligibility criteria, on the part of both providers and families.

- **Children and families experience significant delays in care for a number of reasons**, including:
  - Approval process: paperwork is incorrect or not signed by the right party (for example the primary care physician) or not received at the right place in the right time frame to facilitate services.
  - Insurance: a referral is not generated in a timely manner, or paperwork is not completed correctly, or there is lack of knowledge about what is covered.
  - Eligibility: children with some conditions are not eligible for services for which they are referred, or their condition is not described in a way to ensure eligibility for services.
  - Long wait times: there can be considerable waiting periods for assessments and appointments with specialists.

- **Services specific to CSHCN are lacking**, including:
  - Primary care physicians with expertise in caring for CSHCN (even more pronounced in rural areas).
  - Specialty care physicians and particularly those who accept Medi-Cal.
  - Mental, behavioral, and oral health providers who accept Medi-Cal and have experience with CSHCN.
  - Transportation, particularly to specialty care for rural and low-income families.
  - Preventive services for children with mild-to-moderate needs.

- **Financial barriers prevent coordinating care, both on the individual and systems levels.**
  - Care coordination services are not often reimbursed.
  - Codes to bill for care coordination are not accepted in California.
  - The decrease in funding for First 5 programs across the state will have a significant impact on CSHCN and must be addressed.
  - Families must provide denials from one insurer before they can pursue other modes of payment.

- **Challenges coordinating care are exacerbated during times of transition.**
  - When CSHCN move between counties, they have difficulties accessing services.
  - Significant changes in services for CSHCN occur at age 3; for example, children move from Early Start programs to Special Education.
  - The hospital discharge process may not include coordination with community services.
  - Little information is available for families of CSHCN transitioning into adulthood in California.

Goal 2—Extent to Which Local Coalition Goals Were Met

During the application process, each local coalition developed goals for its project. Since each local coalition began its work at a different stage of readiness and dealt with unique local circumstances, each coalition's goals were distinct and specific to their community. Overall, the goals of each coalition were met.

Local Coalition Accomplishments

Perhaps the best indicator of success for this project has been that although only three of the local coalitions received continuing funding, *all* seven local coalitions continue to meet. Three of the coalitions (Contra Costa County, Orange County, and San Mateo County) were selected to receive continued funding as part of Phase II of the 5Cs project, and each is also receiving additional private sector support. Three other local coalitions from Phase I are receiving external funding to continue their work, and the seventh coalition is receiving in-kind support from member agencies.

> **"We are finding that, presently, there is a 'non-system' of care coordination. The simple yet intentional act of bringing people and agencies together is creating greater understanding of services, mechanisms for referrals, barriers to services, and gaps in services."**

Each local coalition had several individual accomplishments in relation to their goals, some of which are described below.

- **Contra Costa County – Seven Cs Coalition**

  In Contra Costa County, a major accomplishment was the development of the Children's Service System Resolution Process. This process directs service system concerns from County Roundtable meetings, which are designed to discuss new referrals to the system of care, to the Seven Cs coalition, and, as needed, to the Early Childhood Leadership Alliance (ECLA), a group of directors of child-serving county programs that has been in existence for several years, for problem-solving. This process results in resolution or information being communicated back to the Roundtable participants. The coalition has been successful in revitalizing the existing County Roundtable meetings and has also been able to use their ECLA to address systems issues more effectively.

- **Fresno County – Central California Care Coordination Project**

  The coalition in Fresno County built on its prior experience at the Exceptional Parents Unlimited Children's Center coordinating care for children with developmental problems to meet the care coordination needs of children with complex medical issues. The coalition attributes its success in convening an inter-agency coalition to having project funds come from an outside foundation rather than from an individual county agency.

- **Kern County – Medically Vulnerable Care Coordination Project**

  Kern County has a strong history of collaboration on a number of issues. This history was important for its success in care coordination. The local coalition has been active since 2008 and became a part of the 5Cs through funding from the Foundation to replicate its work in new counties. The coalition leader believes "many important connections across agencies and individuals have been forged as a result of these coalition meetings … participants now simply pick up the phone or send an email to a personal contact when there is an issue with a family, rather than having to bring it before the case review team to have concerns addressed." The relationships that have developed as a result of the group have led to real-time coordination of services for individual families.

- **Monterey County – Medically Vulnerable Infant and Children's Care Coordination Collaborative**

  The Monterey County coalition asked to join the learning collaborative after it was already under way. Although members did not receive any grant funds, they were able to receive technical assistance from the Kern County project leaders. Their coalition is continuing to meet and is using Federal Financial Participation (FFP) to fund some of its work.

- **Orange County – OC Care Coordination Collaborative for Kids**

  The Orange County coalition conducted monthly case reviews to understand how the experiences of individual families may shed light on systems issues. Over half of the cases reviewed were for challenges faced by the families of children who were discharged from a Neonatal Intensive Care Unit (NICU) without a relationship with a primary care pediatrician established. As a result of being involved in the coalition, the Children's Hospital of Orange County started a new primary care clinic for children to improve the handoff between being discharged from the NICU and beginning to be seen in a medical home. In addition, the clinic needed a risk assessment tool to use with families and because of their connection with the coalition was able to pilot one that the group had recently adapted.

- **San Mateo County – Care Coordination Learning Community**

  The coalition in San Mateo County focused on care coordination policy recommendations. As a result of these discussions, a new set of trainings on the Health Insurance Portability and Accountability Act (HIPAA) and the Family Educational Rights and Privacy Act (FERPA) were developed and are now shared during ongoing county Roundtable meetings, a pre-existing group of organizations that discusses high-needs cases as part of the Watch Me Grow Demonstration site in the county.

- **Shasta/Siskiyou/Trinity Counties – Rural Children's Special Health Coalition**

  Prior to the 5Cs project, no inter-agency coalition was active in these rural northern counties. There is now an active group working on improving the system of care in the region. From relationships forged during coalition meetings, the coalition leader is now a Community Board member for the Medi-Cal managed care company in the county and also on the Board of the local Community Health Center.

Products Developed by Local Coalitions

A variety of materials were developed and shared by learning collaborative members. Resources and tools developed by local coalitions are available at www.lpfch.org/cshcn/community-engagement.

Coalition Establishment:

- Coalition outreach process with introductory letter
- Kickoff meeting agenda and PowerPoint presentation
- Trifold leaflet to describe coalition and purpose to community partners
- Sample coalition meeting agenda
- Sample list of coalition goals as wall chart for use at each meeting
- Sample vision, mission, and value statements
- Coalition role descriptions and responsibilities: i.e., facilitator, care coordinator, evaluator

Case Review:

- Protocol for case review
- Template for case review
- List of 18 identifiers of private health information under HIPAA as wall chart for reference during case reviews
- Inter-agency consent form for sharing client information
- Sign-in sheet that serves as a statement of confidentiality for case reviews

Care Coordination Tools:

- County-specific CSHCN trend report
- CSHCN risk assessment tool
- Assessment and referral protocol for pediatric primary care clinic
- Sample community resource lists, both physical and online, for providers, agencies, and families
- Care coordination policy recommendations
- Sample survey of parent experiences with inter-agency care coordination coalition
- Memorandum of understanding for participating agencies and organizations

Lessons Learned

> **"Being coalition members made us realize that if we aren't talking together about the needs of the whole child and family, we aren't doing our job."**

- Each coalition is working with extremely complex and siloed systems that experience significant staff turnover. This turnover can hamper developing inter-professional relationships. In some communities, coalition building is also hampered by a lack of trust between agencies, a lack of time, or a lack of interest of agency staff to attend coalition meetings. Incorporating rotating monthly agency presentations into coalition meetings bridged some of these issues.
- Case reviews were intended to uncover service issues that could be addressed by system changes, yet coalition members frequently found it difficult to identify those potential changes.
- Many of the improvements in care coordination rested on new interagency relationships that were made through coalition participation rather than system changes.
- Even absent system change, relationships among coalition members can streamline and expedite referrals across systems. Overall functioning and understanding of the system are enhanced when coalition members know key contact points, eligibility criteria, referral processes, expected time frames, and available services.
- Measuring the success of community coalitions in improving inter-agency collaboration and care coordination is a continuing, difficult challenge. Achieving financial sustainability was a challenge for all of the coalitions. Although several coalitions were successful in accessing outside funding, they continue to struggle with how to "show the value" of their coalitions and to identify ongoing sources of support.
- Universally, coalitions found that system change happens at a slow pace. One coalition leader described that the process requires *"patience, perseverance, and significant relationship building."*
- Coming together as a coalition to work on systems issues is valuable, but coalition leaders indicated that the duties ought to be included in the leader's regular job so that the work involved is not in addition to other full-time responsibilities.
- The involvement and perspective of families were essential in understanding how systems can influence care coordination.
- Coalitions must include decision-makers so that the systems issues that are discovered can be acted upon.
- Coalitions require designated staff to be effective. Staff responsibilities may include convening regularly scheduled informational and case review meetings; receiving, tracking, and evaluating case results; leveraging funds; performing outreach to new partners; and maintaining clear vision.
- Community service agencies benefit from having designated care coordinators on their staff. One coalition leader felt that *"agencies with care coordinators on staff are often more successful at gaining access to services for the families they serve"* than other agencies.

- A coalition leader noted, *"There is the communication, process, and progress that occurs at the formal project meetings, and there is the communication, process, and 'progress' that occurs outside of the formal project meetings. The coalition leader needs to attend to both."*
- A number of factors contributed to successful inter-agency coalition meetings:
  - Use of meeting facilitator who was not the project director to keep the meeting on schedule and develop action items,
  - Provision of refreshments,
  - Adequate meeting length for discussion—approximately 1.5 hours appeared ideal,
  - Standard agenda items for each meeting,
  - Participation of the major health plans in the county,
  - Project director having relationships with members of the coalition and asking them, by name, to assist with tasks, and
  - Smaller leadership meetings separate from the coalition meetings for planning.

Goal 3—Extent to Which Foundation Goals Were Met

The Foundation had three goals for the 5Cs project:

- **Provide a structured opportunity for community coalitions to learn from one another, identify areas of shared need, discuss emerging challenges, and connect with others engaged in improving care coordination for CSHCN.**

  ***Outcome**:* Coalitions have formal, regular venues for sharing information, identifying areas of shared need, discussing challenges, and connecting with one another. In addition, coalition leaders have developed individual relationships with one another and continue their information-sharing informally and outside of the collaborative. Membership in the inter-agency coalitions has increased over time. Identifying appropriate agency representatives was time-consuming, but accomplished. Many coalition members, leaders of agencies serving CSHCN and their families at the county-level, did not know each other or had not met face-to-face prior to the 5Cs initiative. Building relationships was a necessary step in accomplishing the first goal of the initiative.

- **Improve local systems of care coordination for CSHCN.**

  ***Outcome**:* Great progress has been made toward improving local systems of care coordination. Inter-agency coalitions seem firmly ensconced in their communities, with fixed monthly meetings, regular membership, and structured meeting formats.

- **Develop care coordination models with the potential to be replicated in other parts of the state.**

  ***Outcome**:* Coalitions have developed a number of tools and processes that are improving their local systems of care coordination and aiding in the replication of their work in other parts of the state. Much of the initial replication effort has come from within the learning collaborative, as members share and adapt the tools they are using.

A lesson from colleagues at the William and Flora Hewlett Foundation regarding evaluation of community changes is important to note here: *"Recognize, measure, and track a full range and continuum of outcomes, including changes in capacities and behaviors, instead of categorizing results as processes vs. products or rejecting 'soft' outcomes."*[6]

Lessons Learned

This project provided many opportunities for learning about community-based activities both for the collaborative participants and Foundation staff members:

- Each community is different. Some communities lack a history of communication and interaction across agencies serving CSHCN. Coalition meetings served as opportunities for service providers to first meet others serving the same populations and families. Other communities had well established linkages and patterns of cooperation in support of identified objectives.
- Where community coalitions did not previously exist, the first step to implementing a project is to focus on community development and engagement. The project, in this case care coordination for CSHCN, was the topic around which the community rallied and relationships formed.
- Relationships are critical to the success of community-based initiatives and cross-agency collaboration. A second lesson from the William and Flora Hewlett Foundation about funding projects to promote community change provides context: *"Allow room for the definition of success to shift and evolve as people learn what is possible and effective, as relationships deepen, and as the work matures."*[7]
- Adequate and consistent participation of community agencies and service providers is essential to the success of collaborative work. So, too, is meaningful incorporation of family representatives and family participation.
- The timeline for community-based projects needs to be conservative. Even the most collaborative of communities require time to recruit participants, get buy-in from key stakeholders, and reach consensus on goals and processes.
- Communities in California are interested in collaborating around care coordination for CSHCN. Some of this interest is generated when coalition participants speak publicly about their experiences or when information and tools are made freely and easily available.
- Community-based initiatives are a useful vehicle for foundations to increase their visibility and signal their interest in a topic.
- Collaborative, community-based work is in part an advocacy activity, as it helps identify policy priorities that can be used by advocates to improve services and outcomes for CSHCN.

6 Brown, P. & Fiester, L. (2007). Hard lessons about philanthropy and community change from the Neighborhood Improvement Initiative. Menlo Park, CA: The William and Flora Hewlett Foundation.

7 Ibid.

Conclusion

The 5Cs model of local coalitions whose leaders are part of a statewide learning collaborative is helping to develop stronger local systems of care coordination in California. Community coalitions have used multi-stakeholder meetings to identify barriers to effective care coordination, and have used their evolving relationships to help overcome these barriers. Materials and tools developed by coalitions have been shared within the broader collaborative. Identifying and addressing the need for policy changes has proven more challenging than addressing isolated, cross-agency collaboration. With the addition, in 2015, of three new coalitions, there are now 10 inter-agency care coordination coalitions functioning across the state. Having 10 functioning local coalitions should help in prioritizing policy changes.

The next steps for the project include continuing to support existing and new care coordination coalitions, developing and refining measures of the impact of care coordination activities, identifying and disseminating key components of successful care coordination activities, and facilitating the adoption of new policies to support improved community-level care coordination. Current products and information about the 5Cs are available through the Foundation website at: www.lpfch.org/cshcn/community-engagement.

Appendix A: Collaborative Checklist

A. Operating Principles	Low		Medium		High	Comments
1. Commitment to long-term involvement						
2. Involvement of key stakeholders across sectors						
3. Use of shared data to set the agenda and improve over time						
4. Engagement of community members as substantive partners						
B. Characteristics of Success	**Low**		**Medium**		**High**	**Comments**
1. Shared vision and agenda						
2. Effective leadership and governance: keeping decision makers at the table						
3. Alignment of resources: using data to continually adapt						
4. Dedicated staff and appropriate structure						
• Convening						
• Facilitation						
• Data collection						
• Communications						
• Administration						
5. Sufficient funding: targeted investments						

C. Ability to Thrive	Low		Medium		High	Comments
1. Increasing the visibility and legitimacy of collaborative work						
2. Supporting policy and system change						
3. Providing knowledge and implementation support						
4. Funding for infrastructure and implementation support						
5. Pushing for greater community partnership						

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