



Stories from the Field:

Building a Transformative Partnership with Families and Clinicians

December 11, 2019

Today's Moderator



Allison Gray

Senior Program Officer

Lucile Packard Foundation for Children's Health

Meet Today's Speakers



Elaine Linn

Project Leadership Manager, Family Voices of California



Alison Beier

Special Needs Advocate, Autism Society of Los Angeles
Project Leadership Graduate, Family Voices of California



Jennifer Baird, PhD, MPH, MSW, RN, CPN

Director, Institute for Nursing and Interprofessional
Research at Children's Hospital Los Angeles

Ask Questions!

We look forward to a lively discussion with our audience.
Enter questions in the GoToWebinar question box.



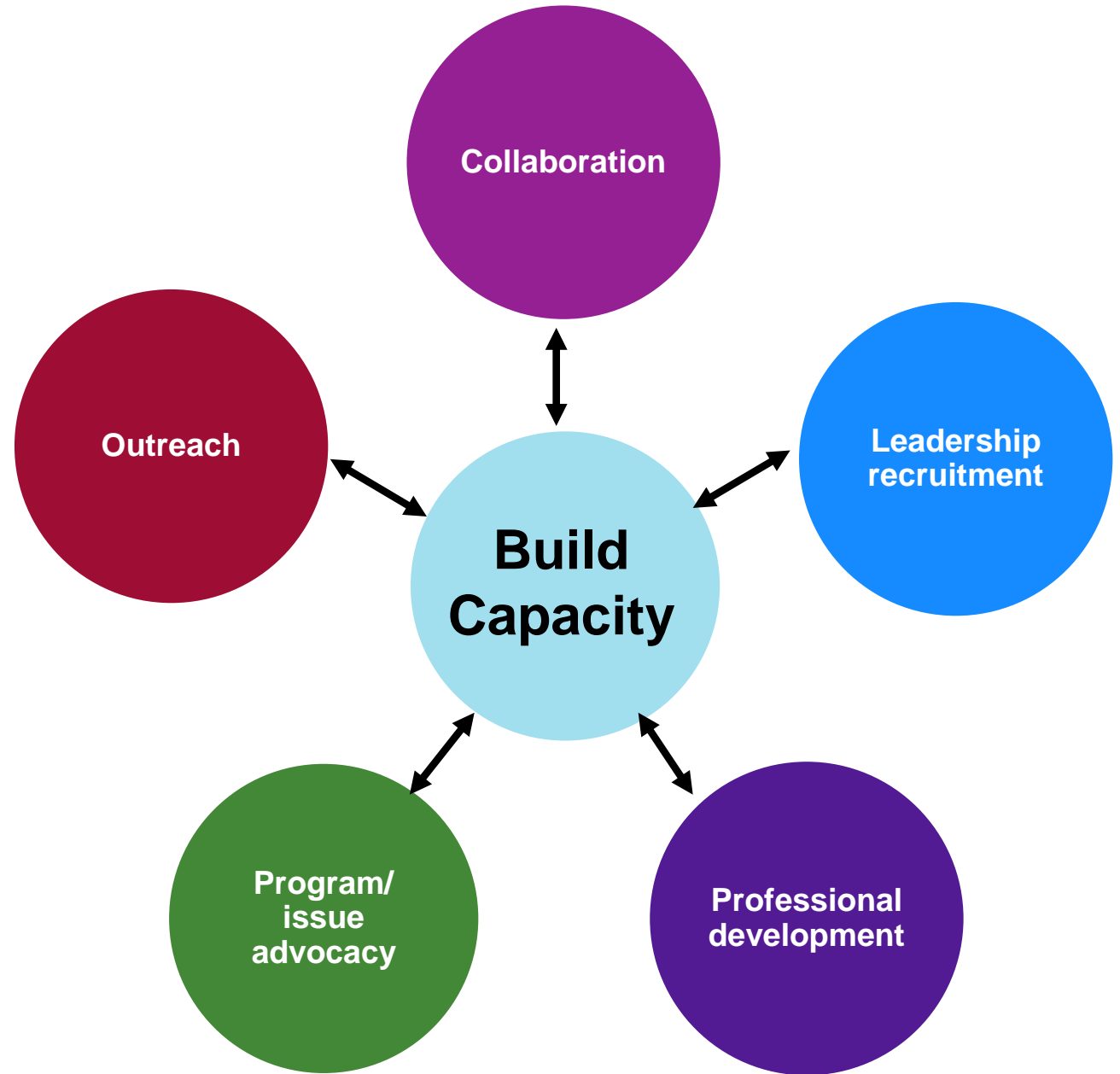
Project Leadership

Advocacy and leadership training

Family-professional partnerships

Engagement for health systems improvements

Family Engagement for Systems Improvement



Project Leadership in Action

Congratulations to our Project Leadership trainer Maria Magana at Central CA Center for Independent Living and local Project Leadership grads for their advocacy efforts and successful passage of an important policy for CYSHCN.



Shifting the conversation:
Plastic straw ban exemption

Improving access:
Dental care rates



Transforming perceptions:
California-based Nurse-led Discharge Learning (CANDLE) Collaborative

Changing protocol:
Code Sepsis



Elevating Advocacy

Our ongoing support and mentoring plays a strong role in families' ability to participate in leadership roles



65% of graduates have participated in one or more groups focused on children with special health care needs



More graduates participated in state or federal level advocacy in 2018



Approximately 60% of graduates contacted their legislators

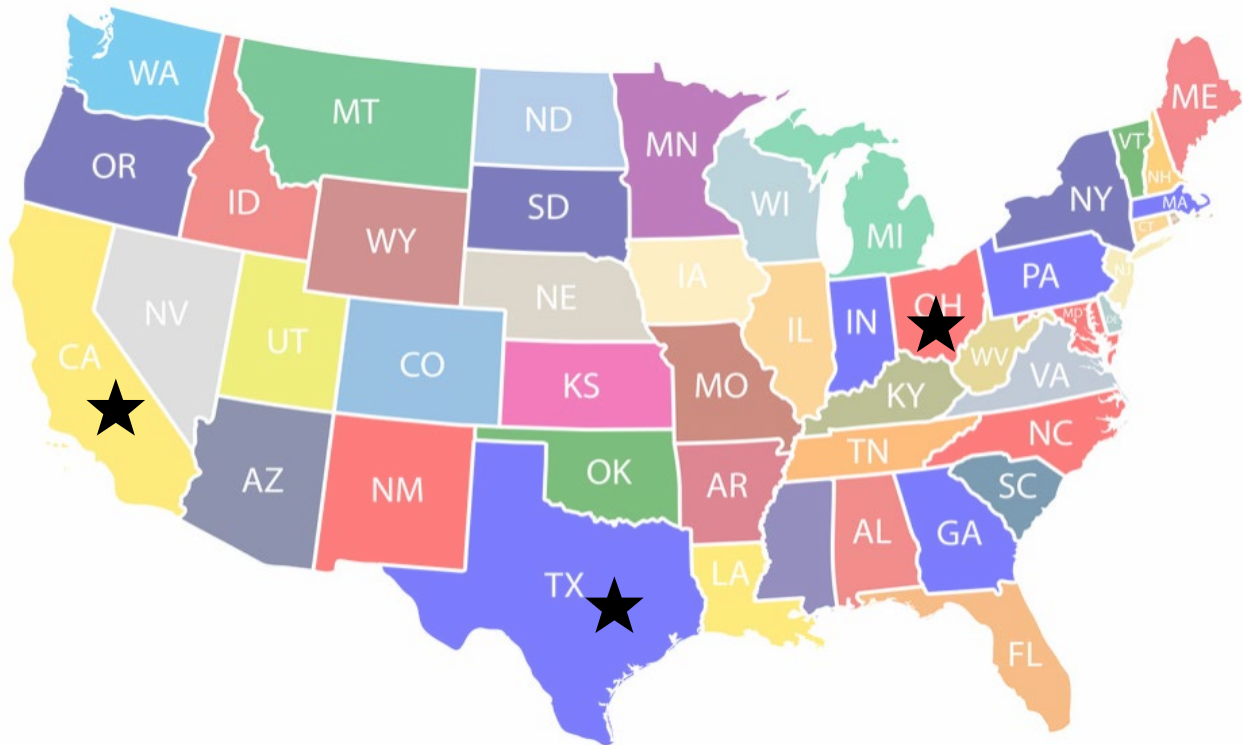


Use Project Leadership skills in their work with committees, boards, media, etc.

67% of these reported a policy or systems improvement occurring or under consideration

2020: Project Leadership Expansion

By 2020 facilitator training will expand to California's rural counties and two additional regions across the U.S.



Training of Trainers Workshops

- January – Visalia, California (full – registration closed)
- October – Cincinnati, Ohio
- November – Austin, Texas

Sign up to learn about upcoming workshops:
bit.ly/ProjectLeadershipUS-2020

ALISON BEIER

Mother of Two

FVCA Project Leadership Alumna

Special Needs Advocate



EVAN, 10
TEAGAN, 4

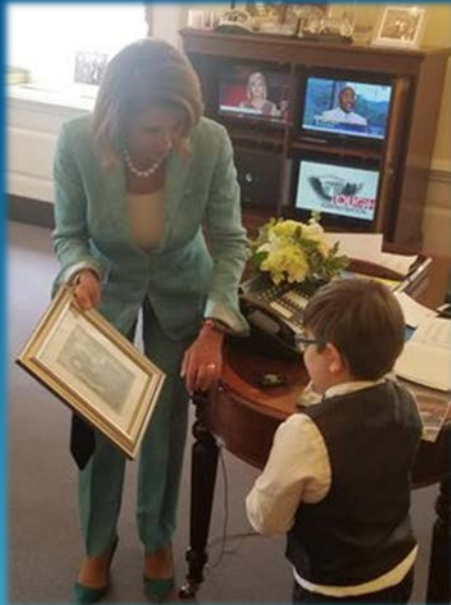


LOCAL & STATE ADVOCACY

- UCLA Mattel Children's Parent Advisory Council
2011 – present
- UCLA Re-Igniting the Spirit of Caring
2018 – present
- Autism Society of Los Angeles
- FVCA Health Summit & Legislative Day Participant
2017 – 2019
- FVCA Health Summit Panel Speaker
2018
- Established Relationships with Legislators

FEDERAL ADVOCACY

Speak Now for Kids Family Advocacy Day, 2017



CANDLE COLLABORATIVE





CANDLE
Collaborative

**California-based Nurse-led Discharge
Learning (CANDLE) Collaborative**

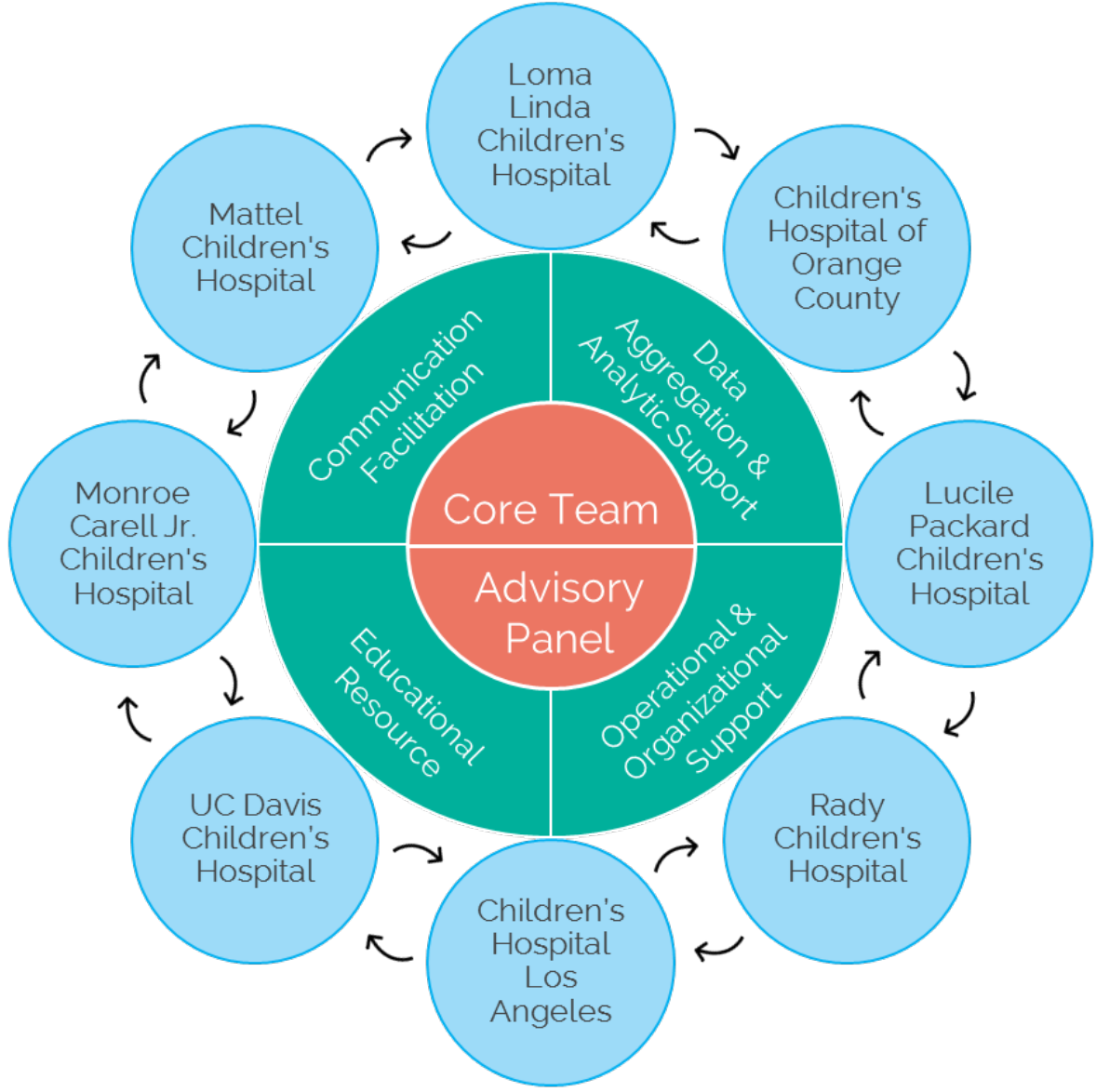
Lighting the way for a brighter future.

Mission



WE AIM TO

- **ADVANCE** systems-level changes in discharge care delivery for hospitalized children throughout and outside of California **THROUGH** the joint piloting and refining of local quality improvement interventions that support new evidence-based standards of pediatric discharge care.



Collaborative Structure

LOCAL TEAMS

Local Teams are the site-specific teams that will lead local discharge activities. They are interdisciplinary and led by a nurse site lead and an allied health professional co-lead.



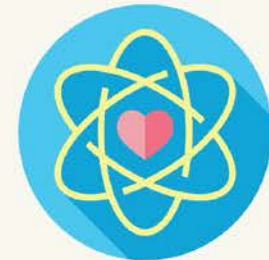
SITE PAIRS

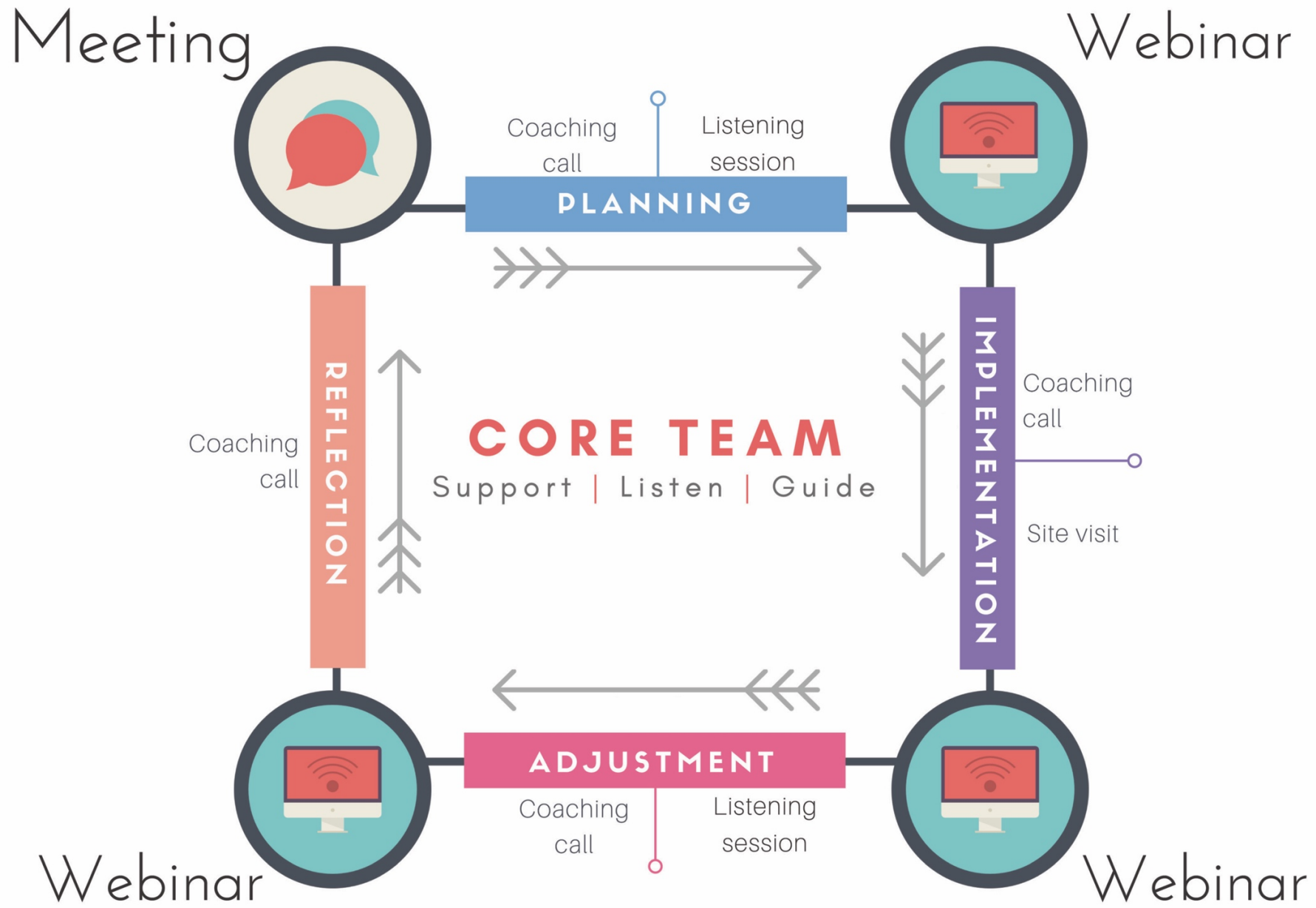
Two Local Teams are paired for the duration of the Collaborative. Offline, they hold formal and informal meetings to discuss individual project barriers, implementation strategies, and logistical successes.



CORE TEAM

The Core Team facilitates tailored & structured learning opportunities for Collaborative members. Additionally, it offers them hands-on guidance in designing and developing local projects, as well as provides them with ongoing operational, managerial, and analytic support.





Family Engagement



"[Being a part of the Collaborative helped us to] really strive to [partner] with parents throughout the entire process...CANDLE really drove home the importance of having the parents' voice in any changes that you make - which I knew was important, but CANDLE really drove that home: really ask every step of the way. That has actually changed my practice and all practice changes that I make now. I make sure that we go to the parents and get their voice and their opinion first, and then try to work towards [a solution] step by step, which I don't know if I would have done as thoroughly or systematically before. I think it might have taken me a couple years to figure that out on my own."

Panelist Q&A

*Submit your questions through the
GoToWebinar question box*



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We pursue a system that works for children with special health care needs.

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