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

- Collaboration
- Outreach
- Leadership recruitment
- Program/issue advocacy
- Professional development

Build Capacity
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
- 89% 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

FAMILY VOCI ES of California
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
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
California-based Nurse-led Discharge Learning (CANDLE) Collaborative

Lighting the way for a brighter future.
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.
“[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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Director, Institute for Nursing and Interprofessional Research at Children’s Hospital Los Angeles
We pursue a system that works for children with special health care needs.

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