

# The Impact of the Iowa Family Leadership Training Institute on Families, Communities, and Systems

University of Iowa Division of Child and Community Health

Child Health Specialty Clinics

Martha Hanley, Diane Brenneman, Rachel Charlot, Alejandra Escoto

## Child Health Specialty Clinics

The Division of Child and Community Health (DCCH) administers Iowa's Maternal and Child Health Title V Program for Children and Youth with Special Health Care Needs (CYSHCN). DCCH has a network of 14 regional centers and 4 satellite locations across Iowa.

## Iowa Family Leadership Training Institute

### IFLTI

- Provides training to Iowa parents and primary caregivers of CYSHCN to develop their leadership skills and become better advocates
- Four, in-person training sessions
- Framed by the Maternal and Child Health Leadership Competencies

### Program Objectives

- Teach trainees how to work with partners
- Guide trainees on how to develop individual paths to leadership
- Help trainees identify strategies for advocacy
- Help trainees discover how to impact communities and systems

### Funding Sources

- This project has been funded in whole or in part with Federal funds from the National Library of Medicine, National Institutes of Health, Department of Health and Human Services, under Grant Number 1UG4LM012346 with The University of Iowa



## Significance of Family Training

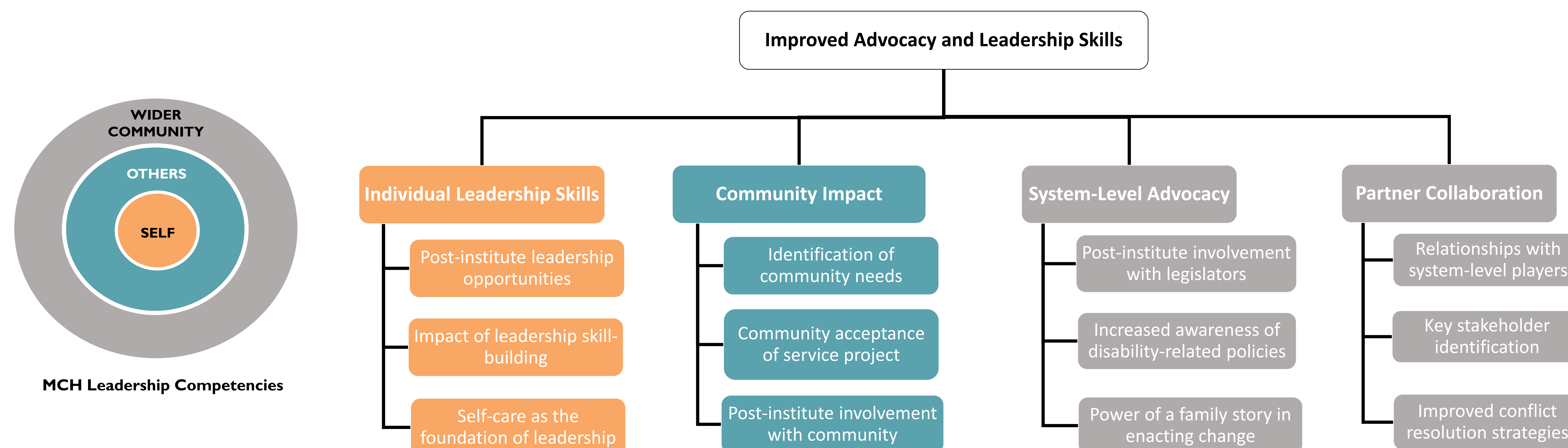
- While parents and caregivers of CYSHCN have significant life experience, they may not have the training and experience to partner with professionals at all levels<sup>1</sup>
- Family leadership training increases the capacity of caregivers to communicate better with providers, to join with community partners to identify gaps and create solutions to fill them, and to help make health care systems more family centered and culturally competent<sup>1</sup>

## Research Objectives

- Use qualitative and quantitative methods to explore the effectiveness of the IFLTI and identify if the IFLTI is effectively training participants on:
  - Working with partners
  - Developing individual paths to leadership
  - Identifying strategies for advocacy
  - Identifying and executing methods of impacting communities and systems

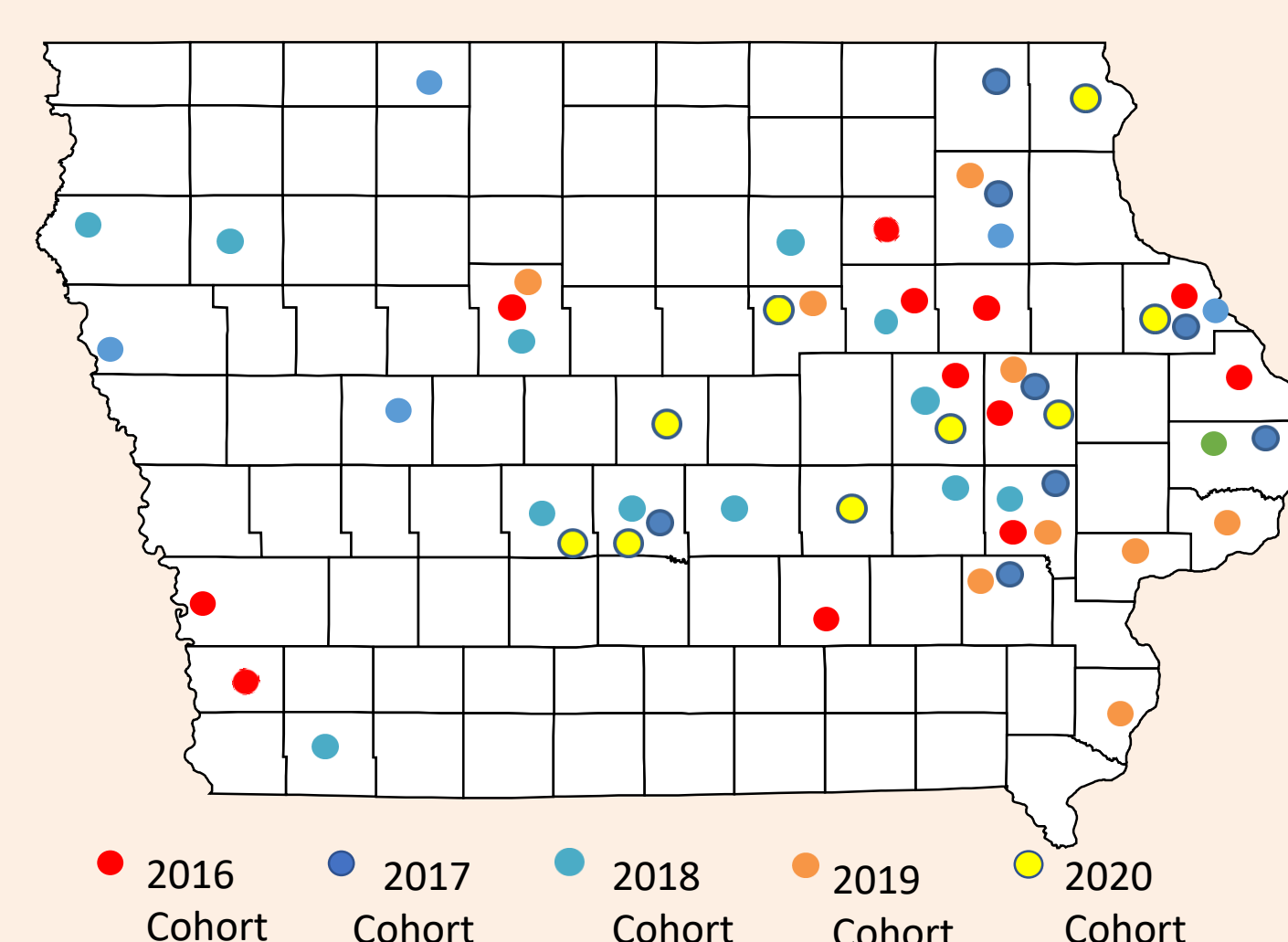
<sup>1</sup> Johnson B, Abraham M, Conway J, Simmons L, Edgman-Levitan S, Sodomka P, Schlacter J, Ford D. (2008). Partnering with Patients and Families to Design a Patient- and Family-Centered Health Care System. Institute for Patient- and Family-Centered Care.

## IFLTI Graduate Interviews



## Methodology

- Graduates from the IFLTI program were asked to participate in phone interviews
- Phone interviews were conducted with 15 IFLTI graduates from 2016 – 2019 during the summer of 2019
- A thematic summary was completed on the interview notes



## Results

### Individual Leadership Skills

- 100% of participants reported having at least one leadership opportunity since completing the IFLTI
- True Colors and Servant Leadership sessions helped graduates understand others' perspectives and explore options of how to respond to them

*"I learned that I'm not just a mom with a special needs child, and that I have other purposes. I learned that if I don't take care of myself I am not taking care of my family."*

### System-Level Advocacy

- 11 of the 15 (73%) of participants reported having increased involvement with legislators since the IFLTI
- Graduates reported being more informed of legislation affecting CYSHCN since the IFLTI

*"Developing an elevator speech is best when talking to legislators. Telling every detail can muddy things up, so you need to keep it short and sweet."*

### Community Impact

- Graduates reported using techniques learned through the IFLTI to better identify needs within their community
- Many graduates reported continued involvement in disability-related projects in their communities

*"The people I've reached out to in the community to gain perspective for my project have been really supportive and they feel like this is something we need in the community."*

### Partner Collaboration

- Graduates reported that they have continued building relationships with key stakeholders in the CYSHCN world after their training session

*"I feel more empowered to ask questions and interact with conflicting perspectives. It's good to have the ability to look at situations not as confrontational things and work with them in a less aggressive manner."*

## IFLTI Trainee Pre-/Post-Assessment

Selected Questions <small>Adapted from FamilyVoices California</small>	Pre-Test (n=42)	Post-Test (n=34)
How confident did you feel that you had a good understanding of the service systems that your child is involved in?	52%	71%
How often did you have ideas about how the service system for children could be improved?	48%	68%
How confident did you feel about telling your child's story in a way that informed people with decision-making power about why they needed to change policies and systems?	33%	47%

## IFLTI Graduate Survey

- **90%** of graduates strongly agreed or agreed that the IFLTI increased their confidence in their leadership skills
- **90%** of graduates strongly agreed or agreed that the IFLTI increased their advocacy skills
- **80%** of graduates strongly agreed or agreed that the IFLTI increased their ability to form partnerships

## Conclusions

- The IFLTI trained participants to recognize and develop their own leadership skills and expertise as parents of CYSHCN
- The IFLTI participants gained the confidence and skills to develop community and system-level partnership
- The IFLTI encouraged continuing connectedness among cohorts
- While family training positively impacts the system of care for CYSHCN, more research is needed to measure impact over time