



# Florida Family Leader Network (FFLN): A Family Led Statewide Initiative to Build a Network of Family Leaders in Florida

A Collaboration between the UF Pediatric Pulmonary Center and Florida Department of Health Children's Medical Services(CMS) (Florida Title V Agency)

This project is/was supported by the Health Resources and Services Administration (HRSA) of the U.S. Department of Health and Human Services (HHS), under grant #T72MC00002/University of Florida Pediatric Pulmonary Center/PI: Wagner. This information or content and conclusions are those of the author and should not be construed as the official position or policy of, nor should any endorsements be inferred by HRSA, HHS or the U.S. Government.

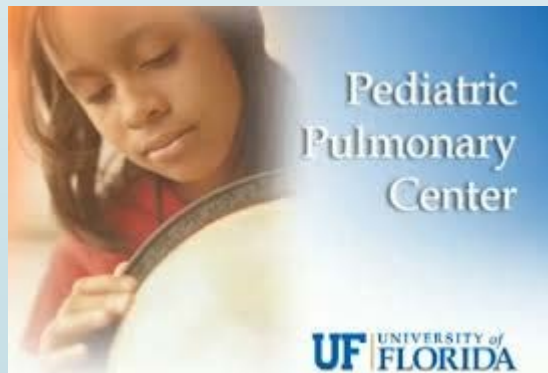
# Introductions

Angela Miney

Family Partner

University of Florida

Pediatric Pulmonary Center



Family Voices 2019

Joane White

Title V Family Leader

Florida Dept. of Health

Children's Medical Services





# Objectives

DISCUSS

Discuss the creation of the Florida Family Leader Network which can serve as a model for other states

Outline

Outline strategies for building and sustaining a network

Review

Review leadership training resources to build capacity and skills of family leaders

# *Network, Network, Network*





# Our Plan For Today:

1

Tell you about Florida DOH CMS is interested in fostering family engagement

2

Tell you how the Florida Family Leader Network has come about

3

Tell you about what we have done so far and what we will do to sustain the network



## Time Out:

- So you told the person next to you your name:
- The state you come from
- Now tell them the agency you work with
- Your title

# Florida Department of Health Children's Medical Services



# Florida Department of Health Children's Medical Services



***It's a New Day in Public Health.***

The Florida Department of Health works to protect, promote & improve the health of all people in Florida through integrated state, county, & community efforts.

Our **mission** at CMS is to protect, promote and improve the health of children up to age 21 with chronic and serious physical, developmental, behavioral, or emotional conditions through a comprehensive system of care.





# Changes to delivery model for Children's Medical Services

- CMS Health Plan has partnered with WellCare of Florida, Inc. (WellCare) to provide managed care services to our members. WellCare is a licensed Florida health plan.
- CMS Florida Title V Maternal and Child Health.
- CMS is developing and training regional teams to lead health care initiatives.
- Each team consist of Title V consultants and a Family Leader



# Children's Medical Services Health Plan

— Operated by WellCare —

This plan is for children with special health care needs. It provides a comprehensive system of care that's centered around the family.

CMS Health Plan has partnered with WellCare of Florida, Inc. (WellCare) to provide managed care services to our members. WellCare is a licensed Florida health plan.



# Children's Medical Services Health Plan

- ▶ Eligibility



The CMS Health Plan is for children who:



Are under age 21 and eligible for **Medicaid** or



Are under age 19 and eligible for **Florida KidCare**, and



Have special health care needs that require extensive preventive and ongoing care



# Title V MCH Block Grant Program FLORIDA

## ► Program Overview

- The Florida Department of Health is responsible for administering the Title V Maternal and Child Health Block Grant, encompassing the Maternal and Child Health (MCH) and Children and Youth with Special Health Care Needs (CYSHCN) programs. These programs fall within the auspices of the Division of Community Health Promotion and the Office of Children's Medical Services (CMS) Managed Care Plan and Specialty Programs.



# Title V MCH Block Grant Program FLORIDA

- ▶ In Florida, Title V programs serve a large, diverse population. Florida is the third most populous state in the country, with an estimated population of 21 million citizens, of which 77.6 percent are white; 16.8 percent black; and 5.5 percent are other races, mixed race, or unknown. The racial, ethnic, and cultural diversity of Florida's population creates unique challenges as well as increased opportunities. Diversity helps us recognize and respect the customs, behaviors, and traditions of others, allowing for bridges of trust, respect, and understanding to be built across cultures.

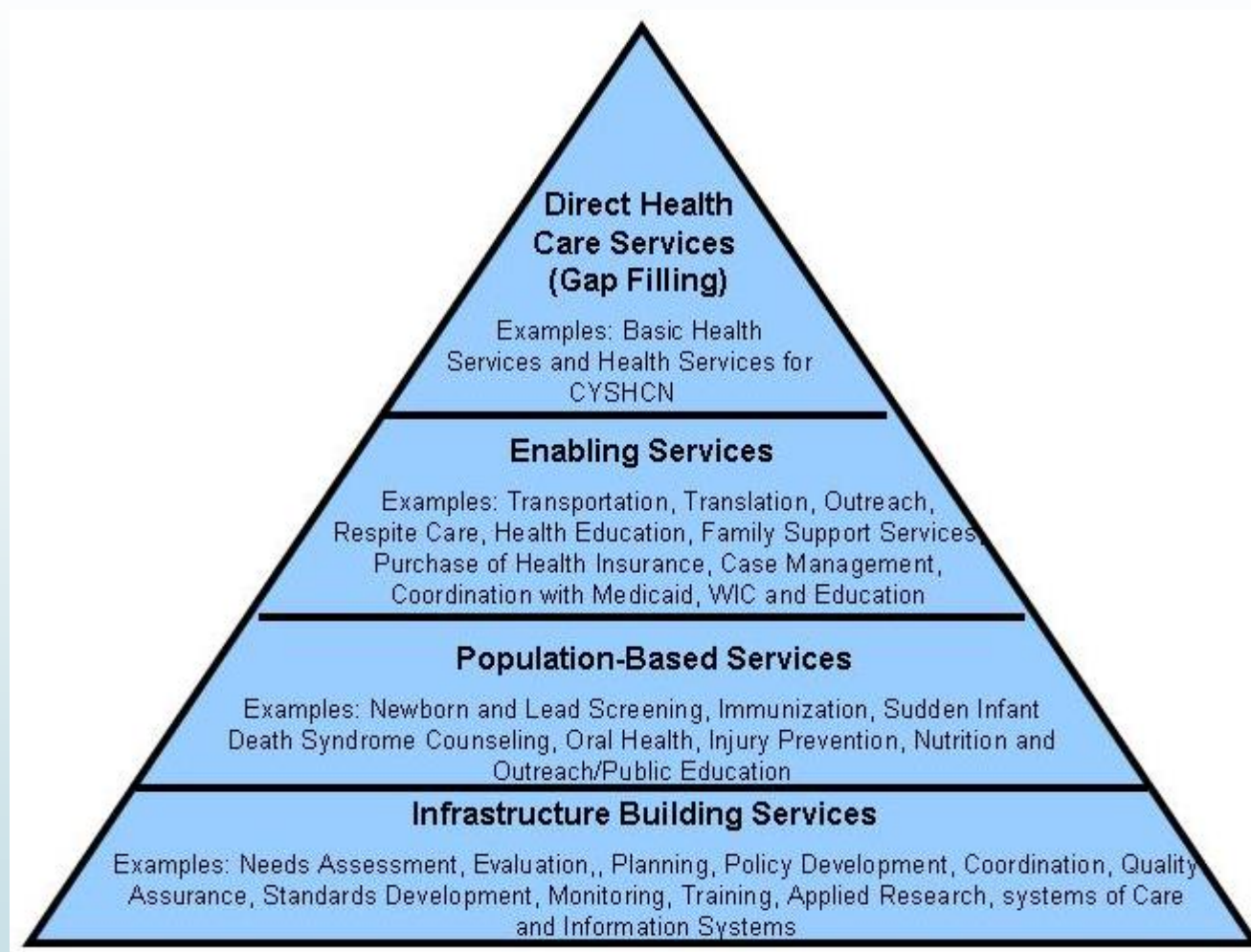
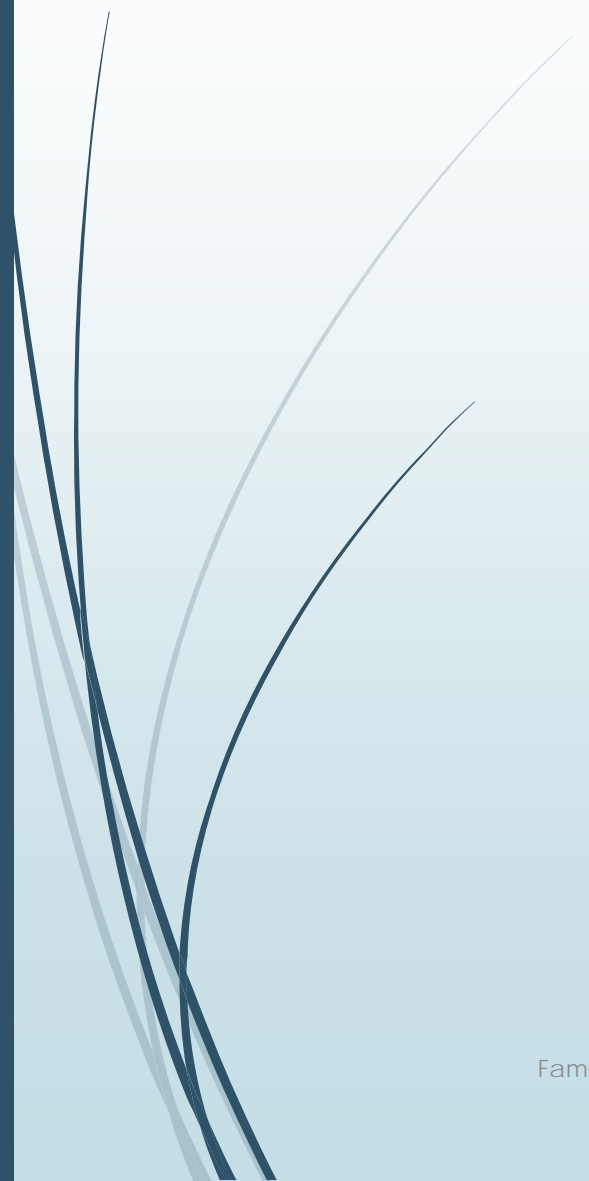


# Children's Medical Services Maternal and Child Health Title V

## Goals

Title V team members will receive training on change management to support change in role from direct service to population health.

Title V team members will gain the skills to demonstrate confidence in communicating population health initiatives to stakeholders.



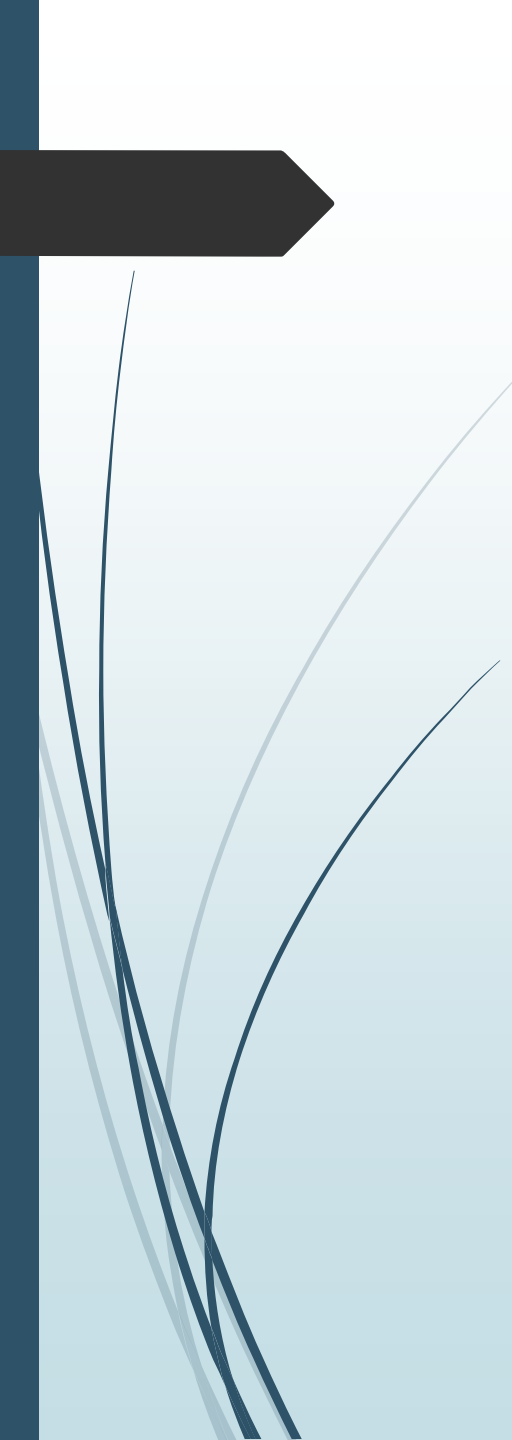


# CMS Title V

## Under construction....

- ▶ Currently preparing Title V staff with evidenced-based knowledge of best practices, models, and standards of care regarding Patient-Centered Medical Home, Health Care Transition, and Integrated Behavioral Health.
- ▶ Using the knowledge gained during training, Title V staff will be able to provide technical assistance to internal and external stakeholders regarding these initiatives.

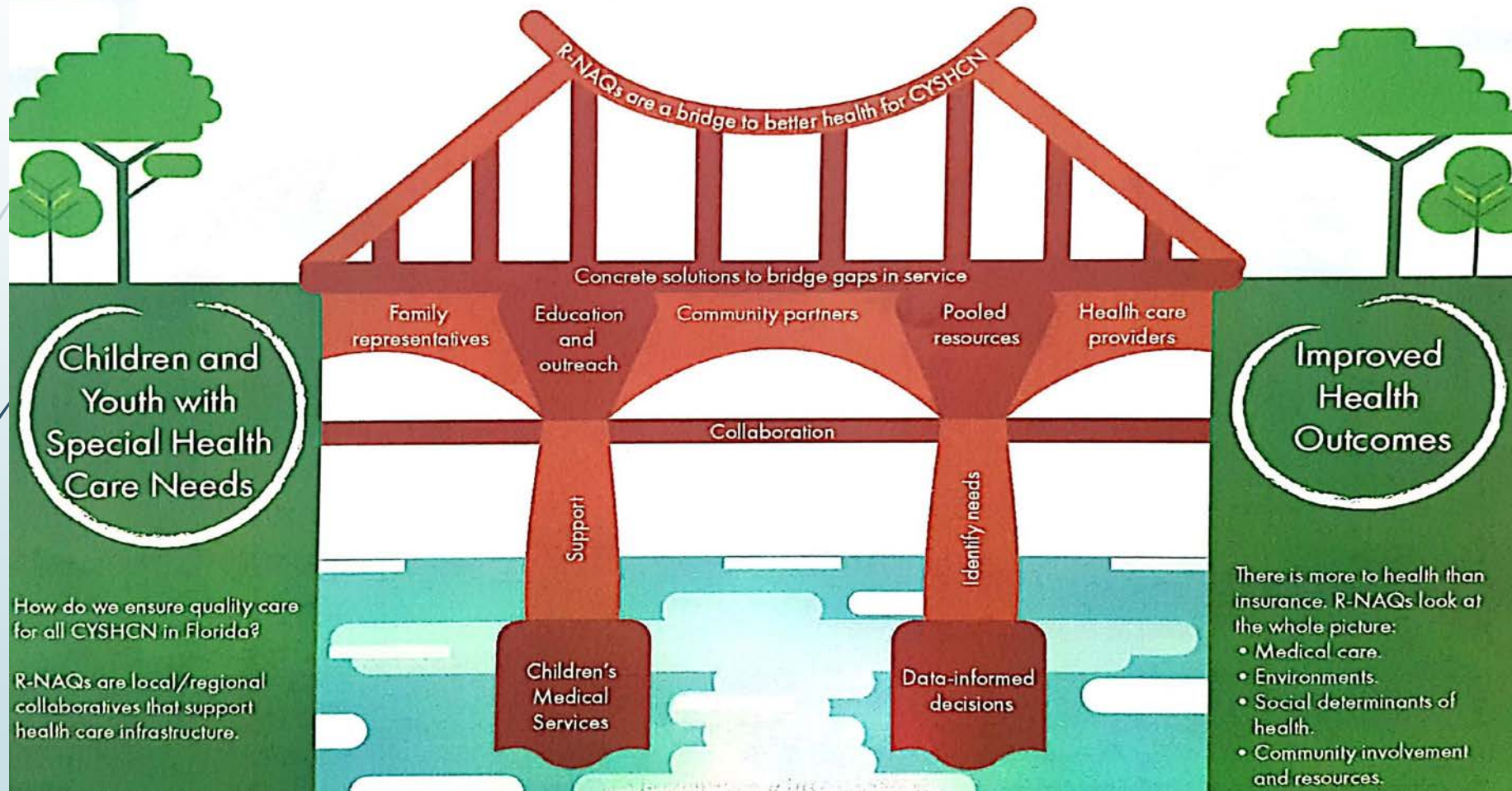


- 
- ▶ The Department's Office of Children's Medical Services Managed Care Plan administers Florida's Title V Children with Special Health Care Needs Program.
  - ▶ This program focuses on several priorities:
  - ▶ Increasing access to medical homes and primary care for children with special health care needs;
  - ▶ Improving health care transition for adolescents and young adults with special health care needs to all aspects of adult life; and
  - ▶ Improving access to appropriate mental health services to all children.

Presenting the Florida Department of Health's

## **REGIONAL NETWORKS FOR ACCESS AND QUALITY (R-NAQ)**

R-NAQs aim to improve health care access and quality for children and youth with special health care needs (CYSHCN), especially those with medical complexity, no matter what their insurance is or where they live. Through collaboration, R-NAQs bridge the gaps in care for the 800,000+ CYSHCN in Florida.





# Title V Regional Teams

- ▶ Reporting to a CMS Regional Nursing Director;
- ▶ Nurse, Title V Consultant
- ▶ Social Worker, Title V Consultant
- ▶ Family Leader, Title V Consultant



# CMS Title V Family Leaders

- ▶ The role and experience of the Family Leader is unique and cannot be learned in any training or course. Self-advocates, parents, guardians, care givers of children and youth with health care needs may have a Family Leader role to bring the family perspective, family voice to the agency or program.
- ▶ The CMS office may designate specific Title V Family Leaders duties as each office may have unique needs directly related to geographical area and the services available.



# CMS Title V Family Leader Workforce Development

- ▶ Family Leaders as Equal Partners
- ▶ Value Member Participation
- ▶ Create an Inclusive Environment
- ▶ Clear expectations
- ▶ Ongoing Supports



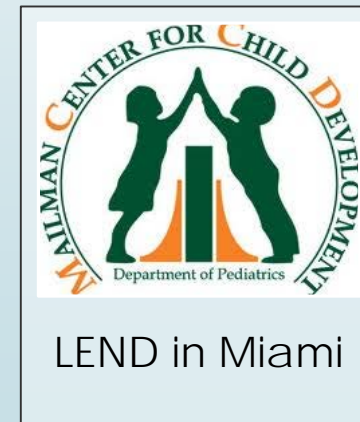
## Time Out:

- ▶ How connected do you feel?
  - ▶ Within your organization
  - ▶ In your state
  - ▶ Nationally

# The Florida Family Leader Network (FFLN)



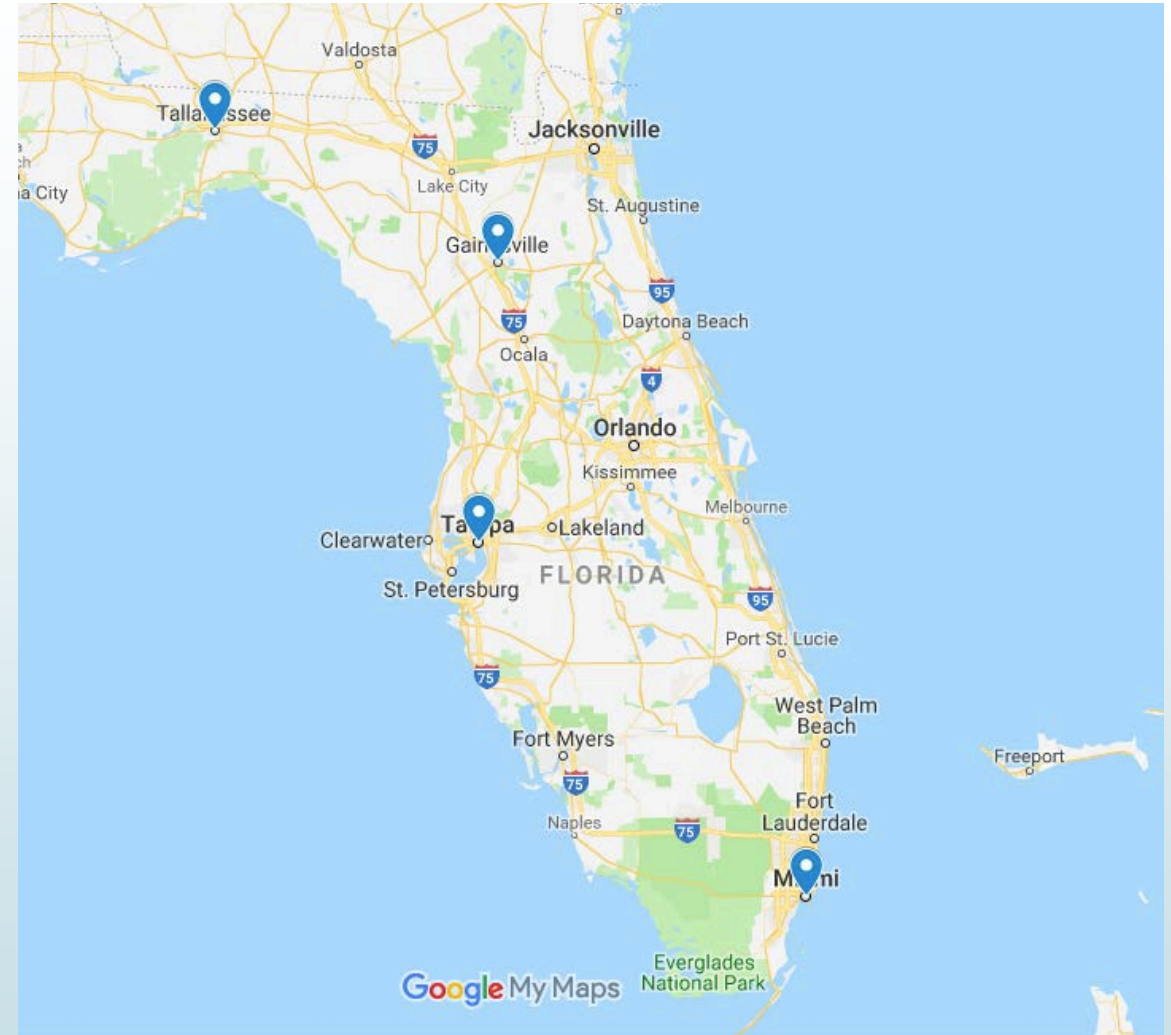
# Florida: Three MCHB Programs and DOH Children's Medical Services





# Challenges

- ▶ Geography
  - ▶ Tallahassee is:
    - ▶ 140 miles from Gainesville
    - ▶ 276 miles from Tampa
    - ▶ 483 miles from Miami
  - ▶ Changes in Leadership at DOH CMS
  - ▶ Diverse State

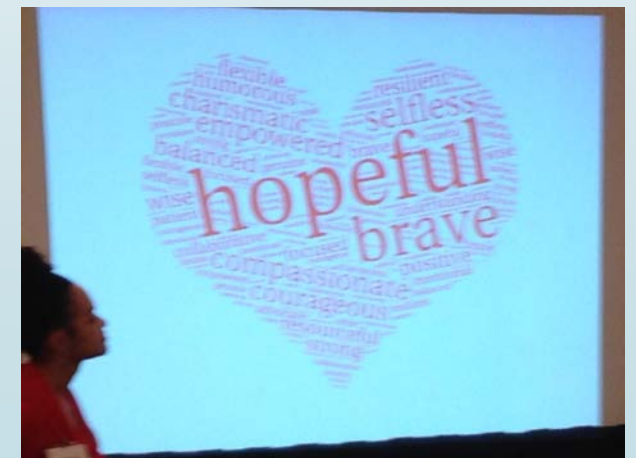


# MCHB Programs and DOH Meet Annually

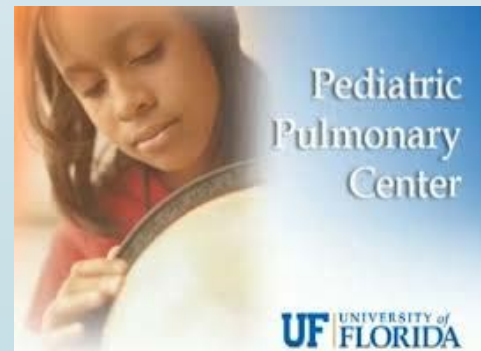
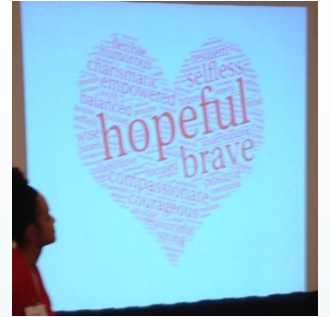
- ▶ Themes of our meeting:
  - 2013: ACA
  - 2014: Transition
  - 2015: Online Training on Disparities
  - 2016: Family Leadership

# 2016: Family Leadership

- Goals:
  - Identify the characteristics found in family leaders
  - Address the training needs for family caregivers to move into family leadership positions
  - *Identify preliminary steps to build a family leadership network in Florida*
- Participants - 33
  - MCH Faculty
  - MCH Trainees
  - *13 Family Leaders*
  - Florida Department of Health Children's Medical Services (CMS)
  - *PPC Family Leaders from Arizona and Alabama*



# 2016 Meeting of the MCHB Programs: Family Leadership



# What did we learn at this meeting:



The traits that family leaders bring to the table



The gap in their skills



The hunger for networking across health related systems in the state

Family leaders feel isolated in their agencies because they are the only ones  
Leads to burn out and compassion fatigue



# The traits family leaders bring to the table

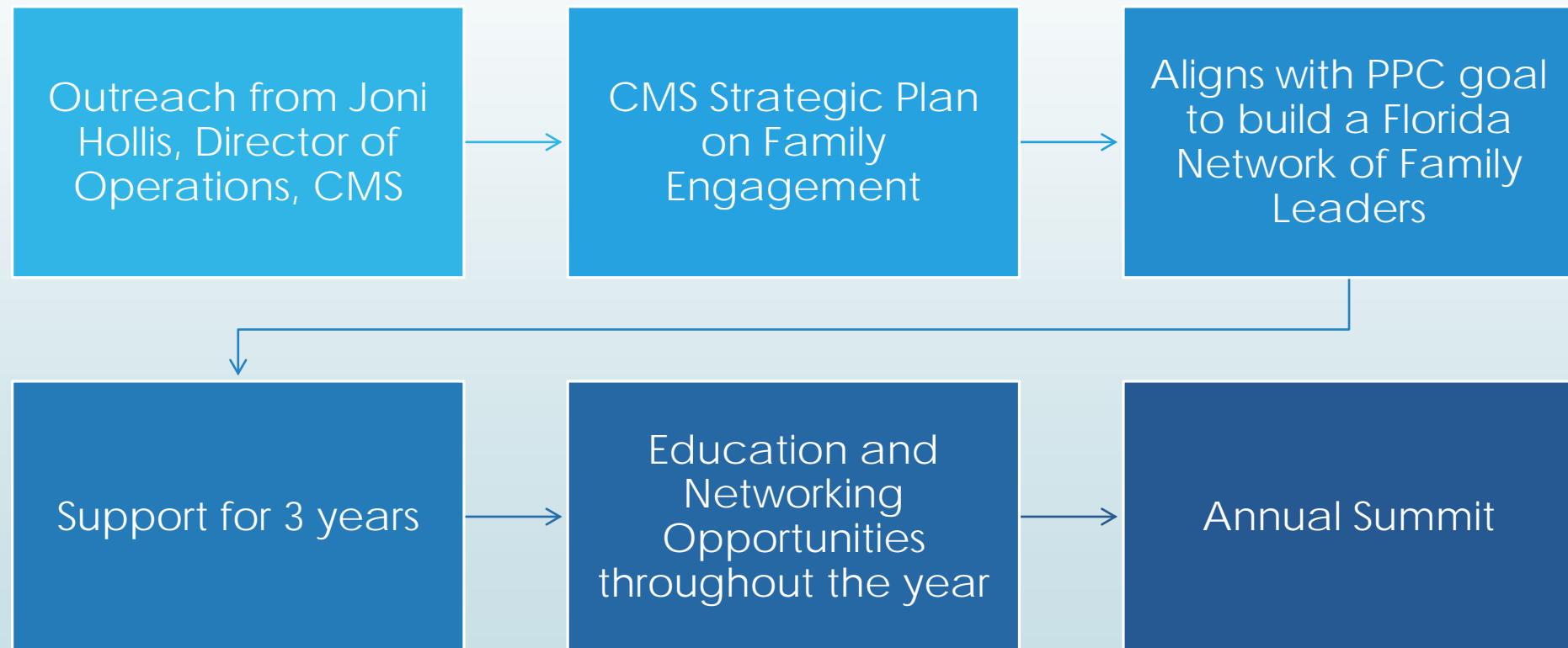
- ▶ Emotional Intelligence
- ▶ Self confidence
- ▶ Self Awareness
- ▶ Competence in literacy and communication skills
- ▶ Ability to be open minded
- ▶ Ability to be positive and encouraging
- ▶ They are resourceful
- ▶ They know when to compromise and negotiate
- ▶ Assertive without being aggressive
- ▶ Recognize their limitations and ask for help
- ▶ Accept their personal situation – do not bring an agenda
- ▶ Are engaged in their community
- ▶ Represent the diversity of their community
- ▶ They are compassionate towards the *professionals* with whom they work
- ▶ They are very patient and very passionate
- ▶ ***They know they need to be kind to themselves***



# To be successful, we need to know

- ▶ The needs of the organization we work in
- ▶ The strategic goals for the organization
- ▶ Acronyms
- ▶ The specific populations the family leader represents
- ▶ Patient and Family Centered Care – in depth knowledge of the theory and practice
- ▶ Personal development training – create a leadership IEP
  - ▶ Communication training
  - ▶ Compassion Fatigue training
  - ▶ Cultural Competence training
  - ▶ Conflict resolution and negotiation
  - ▶ *MCH competencies*
- ▶ Create or join a local network
- ▶ ....and Network

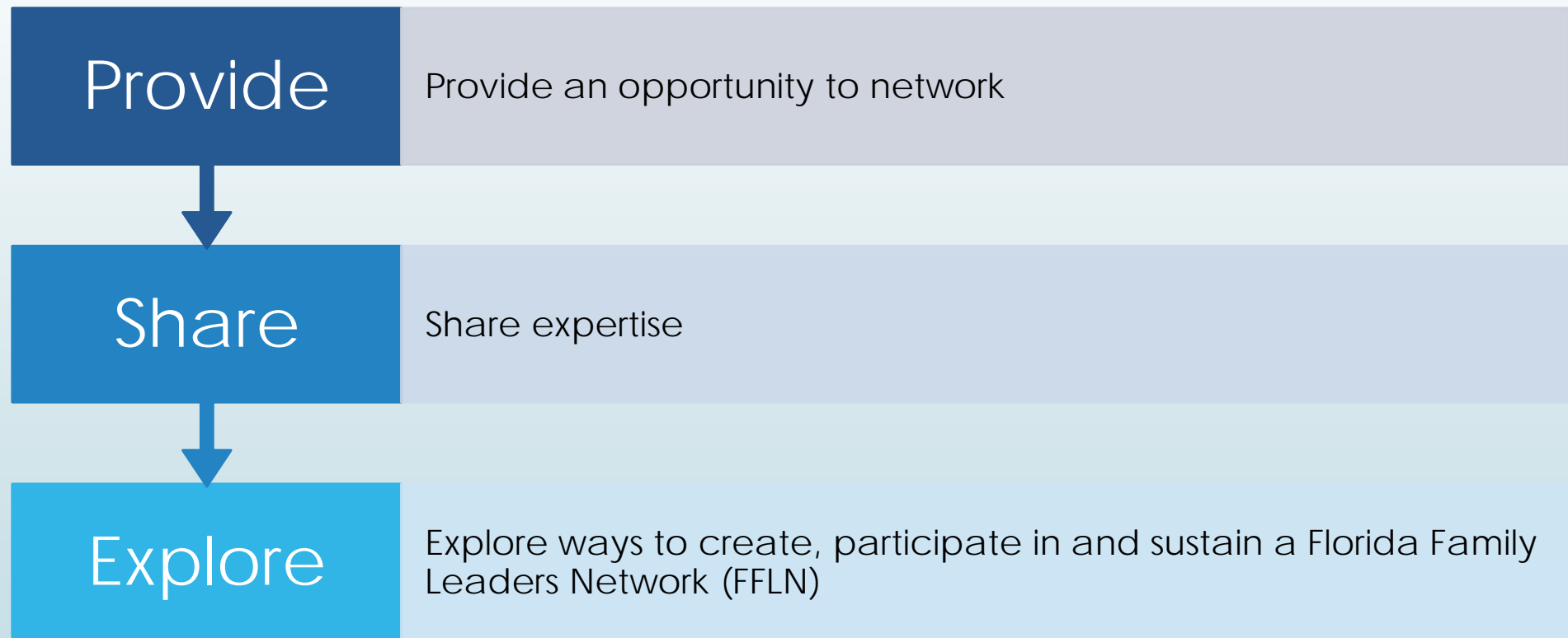
# 2018: Florida Family Leader Network (FFLN)







# 2018: Florida Family Leader Summit Goals

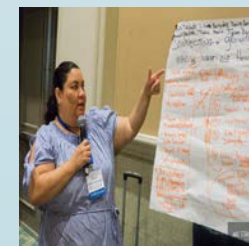




## Time Out:

- ▶ Can you teach people how to network?

# 2018: Florida Family Leader Summit



Orlando Florida  
September 2018

# Participants from all over the state

82 Participants

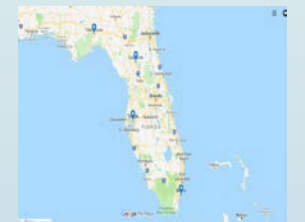
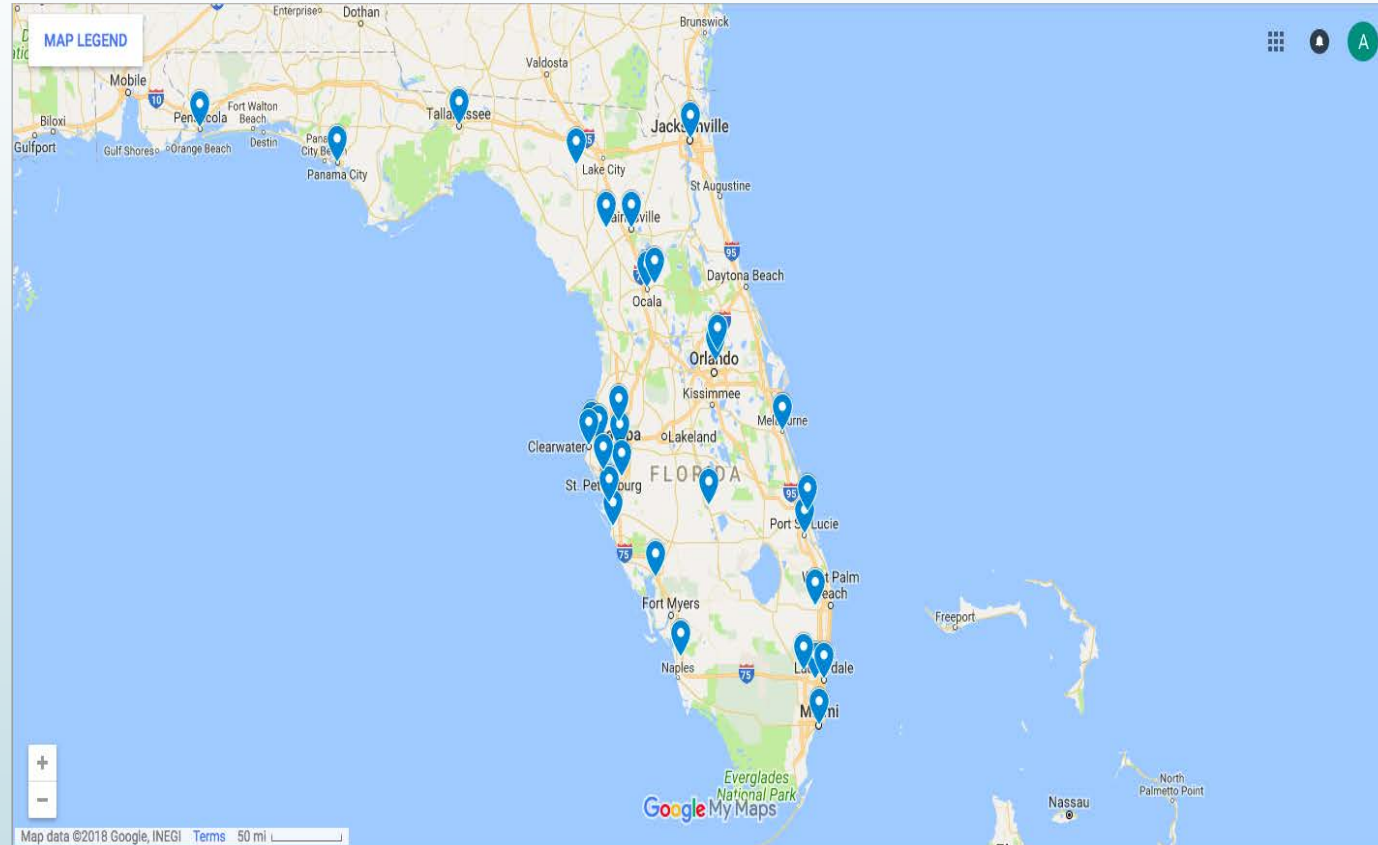
**43 Family Leaders**

27 Champions

11 Emerging

Professionals

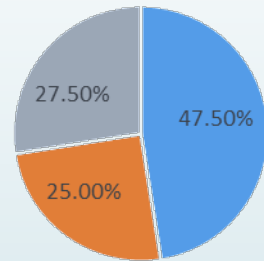
1 *Facilitator*





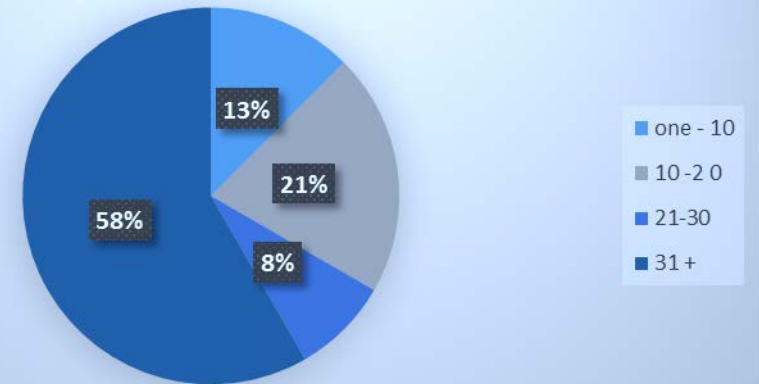
# Demographics

Paid/volunteer positions as Family Leader/SA



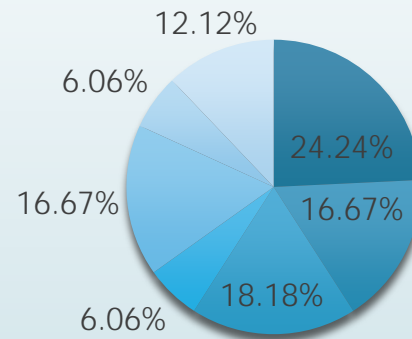
- Are you in a paid position as Family Leader or Self-Advocate, or
- Are you a volunteer?
- Other/Comments

Hours employed as FL or SA  
n= 40



# Demographics contd:

## Activities Family Leaders or Self-Advocates have participated in



- Individual advocacy
- Consultation/Committee membership
- Presentations
- Other
- Local, state or national advocacy/policy change
- Grant Writing
- Publications

# Two National Experts

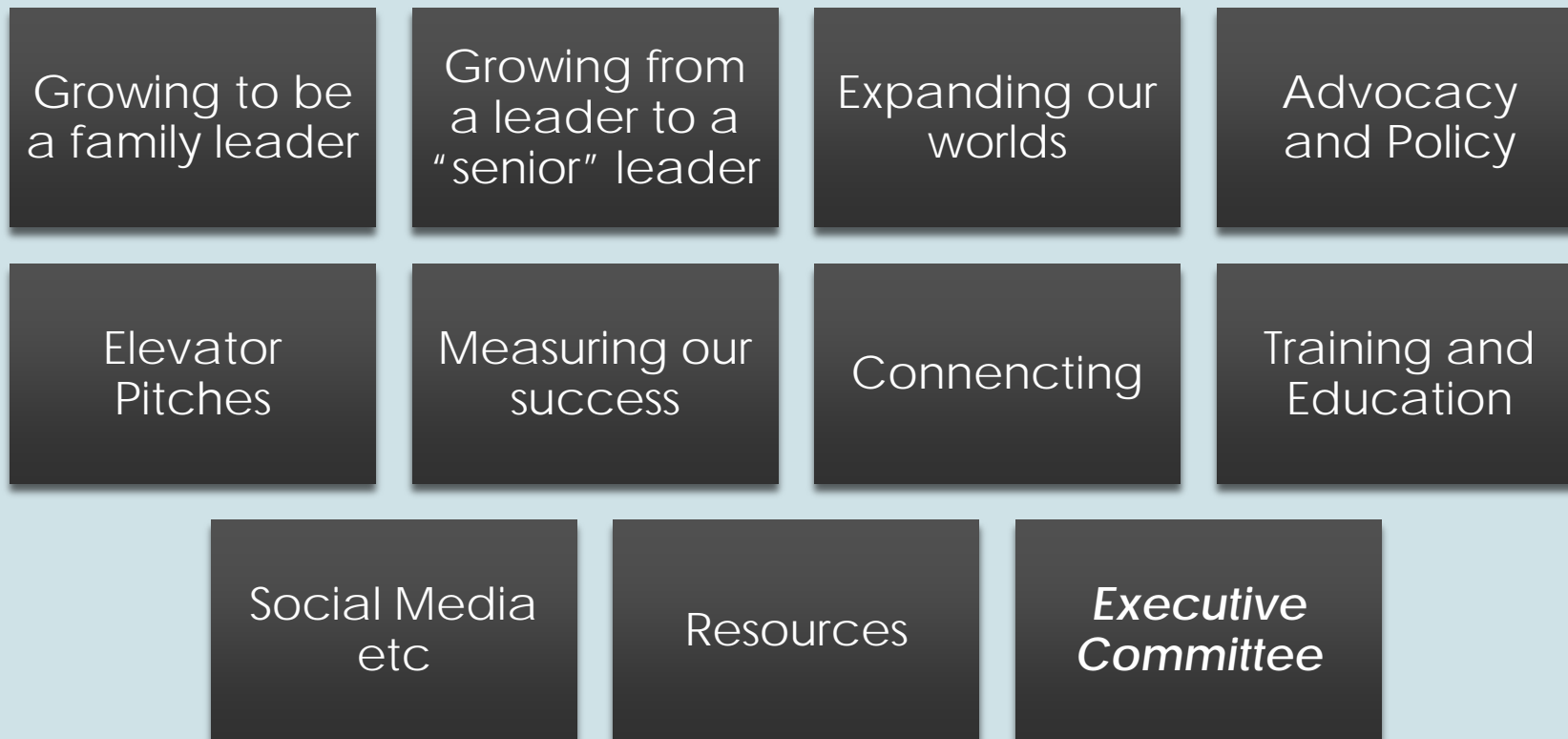
- ▶ Shannon Haworth: former LEND trainee
- ▶ Rylin Rodgers





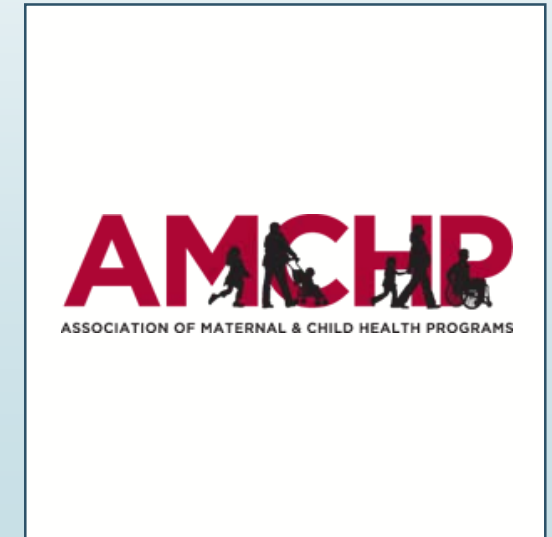


# Outcomes: Executive Committee and Working Groups



## Currently:

- ▶ Executive committee meeting every other month
- ▶ Subcommittees meeting, collaborating and networking
- ▶ Abstracts submitted to 3 conferences:
  - ▶ AMCHP
  - ▶ Family Voices
  - ▶ Family Café
- ▶ Webinar Series:  
*“The Changing Landscape of Patient and Family Centered Care”*
- ▶ Facebook Group
- ▶ Planning 2019 Summit





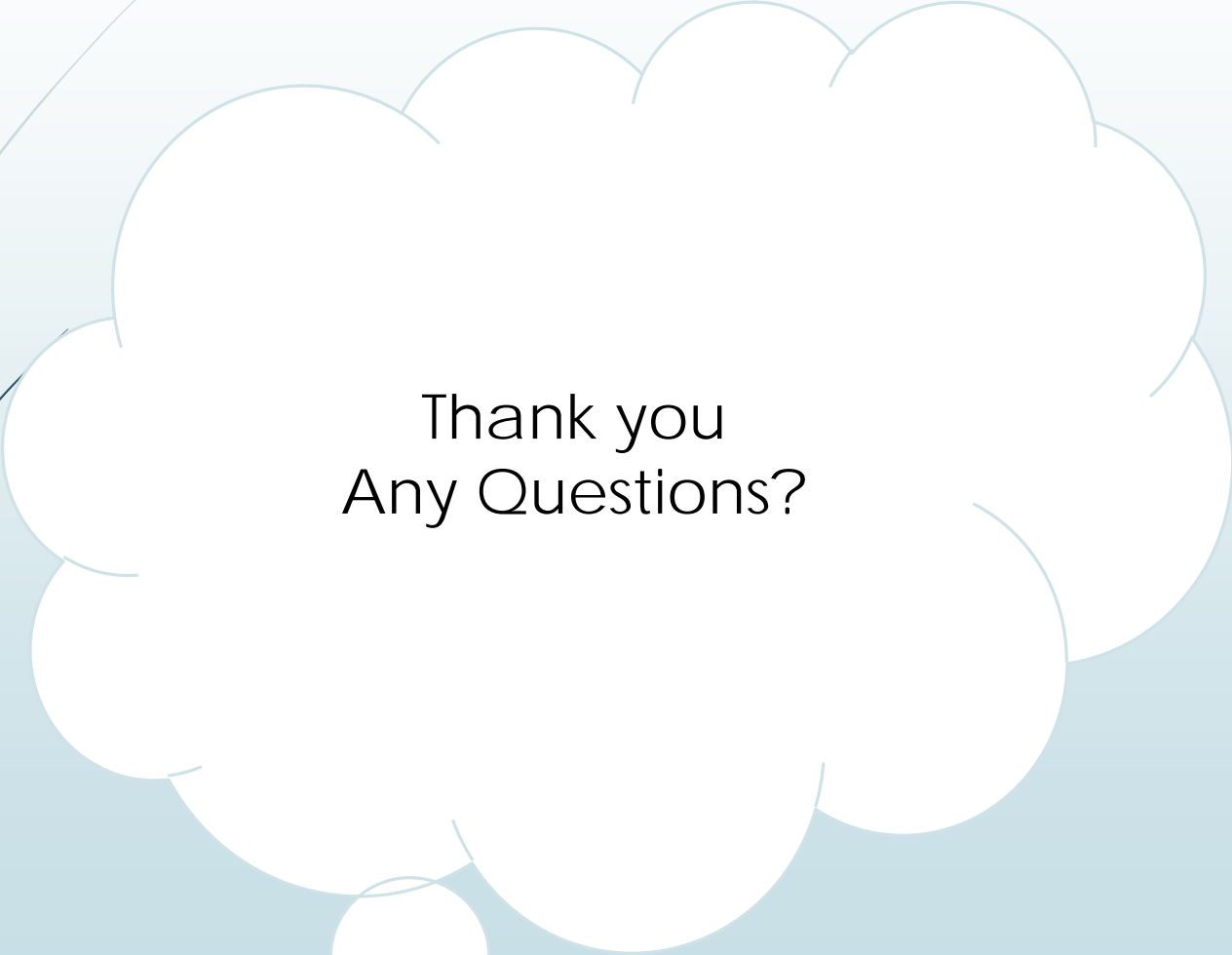
# Lessons Learned So Far

- ▶ Build capacity
  - ▶ In numbers
  - ▶ In education
  - ▶ Across settings – especially healthcare settings

A dark blue arrow points to the right from the left edge of the slide. Below it, several thin, curved lines in shades of blue and grey sweep across the left side of the slide.

# Leadership Learning Opportunities

- ▶ Webinar Series
- ▶ Some of the educational/ leadership opportunities that we have offered



Thank you  
Any Questions?



## Time Out:

- Challenge you to share you contact information with at least one person in the room today

# Resources:

Compassion Fatigue: A 5-part webinar series for Family Leaders:

<https://pulmonary.pediatrics.med.ufl.edu/education/training-program/current-activities-in-the-news/>



“The Changing Landscape of Patient and Family Centered Care”

Elise Bloch, Co-chair Joe DiMaggio Children’s Hospital and Associate Professor at Nova Southeastern University.

[https://ufl.zoom.us/recording/play/6iU7orlCiJTRSSR\\_Kx0qQUXlxk97CBrsyrX0srDd-EwEwvhdwpp0lQHvOP3Im5hC?continueMode=true](https://ufl.zoom.us/recording/play/6iU7orlCiJTRSSR_Kx0qQUXlxk97CBrsyrX0srDd-EwEwvhdwpp0lQHvOP3Im5hC?continueMode=true)