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

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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

I WANT YOU...
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
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
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 consists of Title V consultants and a Family Leader.
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.
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.

Family Voices 2019
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.
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.
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.

**R-NAQs are a bridge to better health for CYSHCN**

**Concrete solutions to bridge gaps in service**
- Family representatives
- Education and outreach
- Community partners
- Pooled resources
- Health care providers

**Children and Youth with Special Health Care Needs**

How do we ensure quality care for all CYSHCN in Florida?

R-NAQs are local/regional collaboratives that support health care infrastructure.

**Improved Health Outcomes**

There is more to health than insurance. R-NAQs look at the whole picture:
- Medical care
- Environments
- Social determinants of health
- Community involvement and resources
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
The role and experience of the Family Leader is unique and cannot be learned in any training or course. Self-advocates, parents, guardians, caregivers 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
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

- Florida Health
- PPC in Gainesville
- Center for Excellence in Maternal and Child Health in Tampa
- LEND in Miami
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 burnout 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)

- Outreach from Joni Hollis, Director of Operations, CMS
- CMS Strategic Plan on Family Engagement
- Aligns with PPC goal to build a Florida Network of Family Leaders
- Support for 3 years
- Education and Networking Opportunities throughout the year
- Annual Summit
2018: Florida Family Leader Summit Goals

**Provide**
- Provide an opportunity to network

**Share**
- Share expertise

**Explore**
- Explore ways to create, participate in and sustain a Florida Family Leaders Network (FFLN)
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

Family Voices 2019
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

- 58% one - 10
- 21% 10 - 20
- 8% 21 - 30
- 13% 31 +
Activities Family Leaders or Self-Advocates have participated in

- Individual advocacy: 24.24%
- Consultation/Committee membership: 16.67%
- Presentations: 16.67%
- Publications: 6.06%
- Grant Writing: 6.06%
- Other: 12.12%

Family Voices 2019
Two National Experts

- Shannon Haworth: former LEND trainee
- Rylin Rodgers
Outcomes: Executive Committee and Working Groups

- Growing to be a family leader
- Growing from a leader to a “senior” leader
- Expanding our worlds
- Advocacy and Policy
- Elevator Pitches
- Measuring our success
- Connecting
- Training and Education
- Social Media etc
- Resources
- Executive Committee

Family Voices 2019
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
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 your 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/6iU7or1Cj_TRSSR_Kx0qQUXlxk97CBrsvrX0srDd-EwEwvhdwpp0lQHvOP3lm5hC?continueMode=true

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