





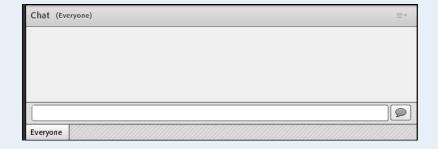
Preparing Families to Participate

Webinar 3 of a 3-webinar learning series February 12, 2020

Welcome

- Please mute your line by using the mute function on your phone or by using *6 to mute/un-mute.
- To Ask a Question
 - Please type your questions into the chat box (shown right).
- At the end of the presentation, there will be time for additional questions and to share strategies you have used to engage diverse and medically underserved families in Title V programs & activities





If you need technical assistance, contact lan at iwhitney@familyvoices.org

Support for this work

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Agenda

- Welcome
- Iowa Example
- Utah Example
- Q & A and discussion

Objectives

- 1. Participants will two state's examples of strategies they use to prepare families to participate in Title V programs and activities
- 2. Participants will have an opportunity to share additional strategies and resources

PREPARING FAMILIES TO PARTICIPATE: IOWA'S FAMILY NAVIGATOR NETWORK

Martha Hanley, MA, FPSS Child Health Specialty Clinics, Iowa

FAMILY NAVIGATOR PROFILE

Parent or primary caregiver of a child or youth with special health care needs (CYSHCN)

Work with parents of CYSHCN to provide

- Emotional support
- Systems navigation
- Connection to community resources

HISTORY OF THE NETWORK



First "Parent Consultant" in 1984: Julie Beckett



Training developed as funding became available



Family Navigator designation, 2010



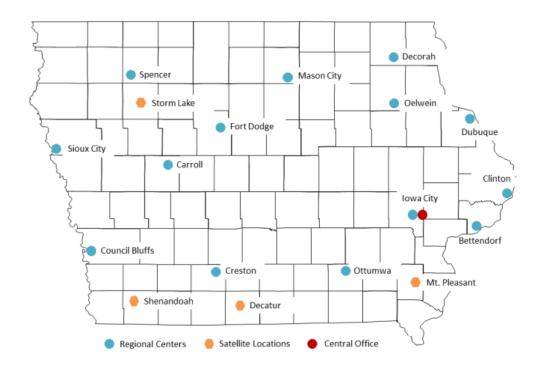
Deployed for the first time in primary care practices, 2014



Developed EMR Consult, 2015



Certification, 2019



2020 SNAPSHOT, CHSC FAMILY NAVIGATOR NETWORK

- 14 Regional Centers
- 30 Family Navigators
- 23 Certified FNs
- 8 Programs
- 10 Funding Sources

1. IDENTIFYING CAPACITY FOR ROLE

Distance from diagnosis

Empathy

Team player

Knowledge of community resources

Experience negotiating for services

Committed to the greater good

Strengths-based view of families

Follow-through

Inclusive

Ability to maintain professional boundaries

2. PREPARE WITH INTENTIONALITY

Make connections with several mentors

Provide skill-building training

Provide inspiration for the role

Monitor, visit and support

TOWA PEER SUPPORT AND FAMILY PEER SUPPORT **SPECIALIST** TRAINING **PROGRAM**

Developed curricula

Educated supervisors

Provided continuing education

Made recommendations for certification

Developed with funding from Iowa Department of Human Services in collaboration with ASK Resource Center, NAMI Iowa, and the UI National Resource Center for Family-Centered Practice

https://iowapeersupporttraining.org/about-us-2/

EMBRACING DIVERSITY

Leverage relationships with local communities to create pools of candidates

Educate staff

Involve cultural brokers

Translate materials

Recognize pioneers

Provide peer mentoring

3. PROVIDE ONGOING EDUCATION/SUPPORT

Encourage/provide time for continuing education

Support problem-solving

Promote self-care

Continue to clarify role

Provide leadership opportunities

Appreciate

4. ADVOCATE FOR THE FAMILY NAVIGATOR ROLE

Educate new staff, stakeholders, policymakers

Assess impact

Communicate supporting research

VALUE OF PARENT PEER SUPPORT

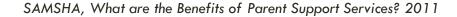
Increased sense of collaboration

Increased sense of self-efficacy

Increased empowerment to take action

Recognition of the importance of self-care

Decreased internalized blame



QUESTIONS?

Martha Hanley

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PREPARING FAMILIES TO PARTICIPATE

With Title V & Beyond

Gina Money – Utah gina.ufv@gmail.com

IT'S OKAY TO BLEND IN, AND THEN IT'S NOT

Focus Groups

Surveys

Meetings

NPMs, SPMs, ESMs, NOMs, etc.

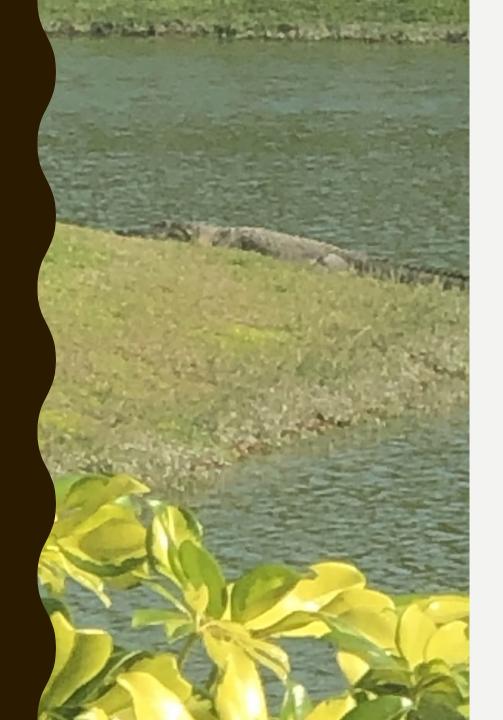
Needs Assessment

Individual families

Family Organizations

Staff





EVIDENCE BASED VS. REALITY BASED

- Creating a
 Culture of Family
 Engagement
- Levels of Family Engagement

- Sustaining and Diversifying Family Engagement
- Evaluating Family Engagement

MEANINGFUL PARTNERSHIPS

Policy

Meet families where they are

Trust

Document, document, document

Close the loop

Validate needs

Make it meaningful



OUTSIDE OF THE BOX IDEAS AND CREATIVE **SOLUTIONS ARE NOT ONLY WELCOMED BUT ENCOURAGED**



FREEDOM TO GIVE INPUT BASED ON FAMILY EXPERIENCE AND EXPERTISE



RESOURCES



- https://www.nichq.org/insight/roadmap-authentic-community-engagement
- https://familyvoices.org/fesat-request-form/
- http://www.amchp.org/programsandtopics/family- engagement/SiteAssets/Pages/default/Family%20Engagement%20Executive%20Summary%20v107.pdf
- https://www.mchnavigator.org/transformation/family-engagement.php

Supporting Family Engagement

- Family engagement policy
- Clear "ask"
- Family-friendly materials
- Provide mentoring & Support
- Convenient meeting times
- Provide compensation or other support
- Close the loop
- Partner with family/youth-led organizations and others focused on family/youth engagement

Q&A

Thank you & Feedback Please



https://www.surveymonkey.com/r/PrepFamiliesParticipate