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 Ian 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
<table>
<thead>
<tr>
<th>Event</th>
<th>Year</th>
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<tbody>
<tr>
<td>First “Parent Consultant” in 1984: Julie Beckett</td>
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<tr>
<td>Training developed as funding became available</td>
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<tr>
<td>Family Navigator designation, 2010</td>
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<td>Deployed for the first time in primary care practices, 2014</td>
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<td>Developed EMR Consult, 2015</td>
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<td>Certification, 2019</td>
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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
IOWA 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

SAMSHA, What are the Benefits of Parent Support Services? 2011
QUESTIONS?

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PREPARING FAMILIES TO PARTICIPATE

With Title V & Beyond

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

<table>
<thead>
<tr>
<th>Focus Groups</th>
<th>Surveys</th>
<th>Meetings</th>
<th>NPMs, SPMs, ESMs, NOMs, etc.</th>
<th>Needs Assessment</th>
<th>Individual families</th>
<th>Family Organizations</th>
<th>Staff</th>
</tr>
</thead>
</table>
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
- Trust
- Close the loop
- Validate needs
- Make it meaningful
- Document, document, document
- Meet families where they are
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://familyvoices.org/fesat-request-form/
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
Thank you & Feedback Please

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