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Training Coordinator

August 13, 2020
AMCHP/SPHARC
Peer to Peer Exchange

IOWA FAMILY PEER SUPPORT SPECIALIST TRAINING PROGRAM

If you can't fly then run
If you can't run then walk
If you can't walk then crawl,
But do whatever you have to do to
keep moving forward

Martin Luther King, Jr.



TRAINING IOWA FAMILIES SINCE 1984

Julie Becket was Iowa's first
Family Navigator, hired in 1984

Iowa has been training families
for 36 years



IFLTI

Agency Support

Funding and Staff Interest

Access to Families

National Models

JUMPING INTO
2016
LEADERSHIP
TRAINING



TECHNICAL
ASSISTANCE FOR
2017 TRAINING





PROGRAM OBJECTIVES

Developed to provide parents and caregivers of children and youth with special health care needs the opportunity to develop leadership and advocacy skills

1. Understand how to work with partners
2. Become aware of one's own path to leadership
3. Discover strategies for advocacy
4. Develop a Community Service Project

MATERNAL AND CHILD HEALTH LEADERSHIP COMPETENCIES

SELF

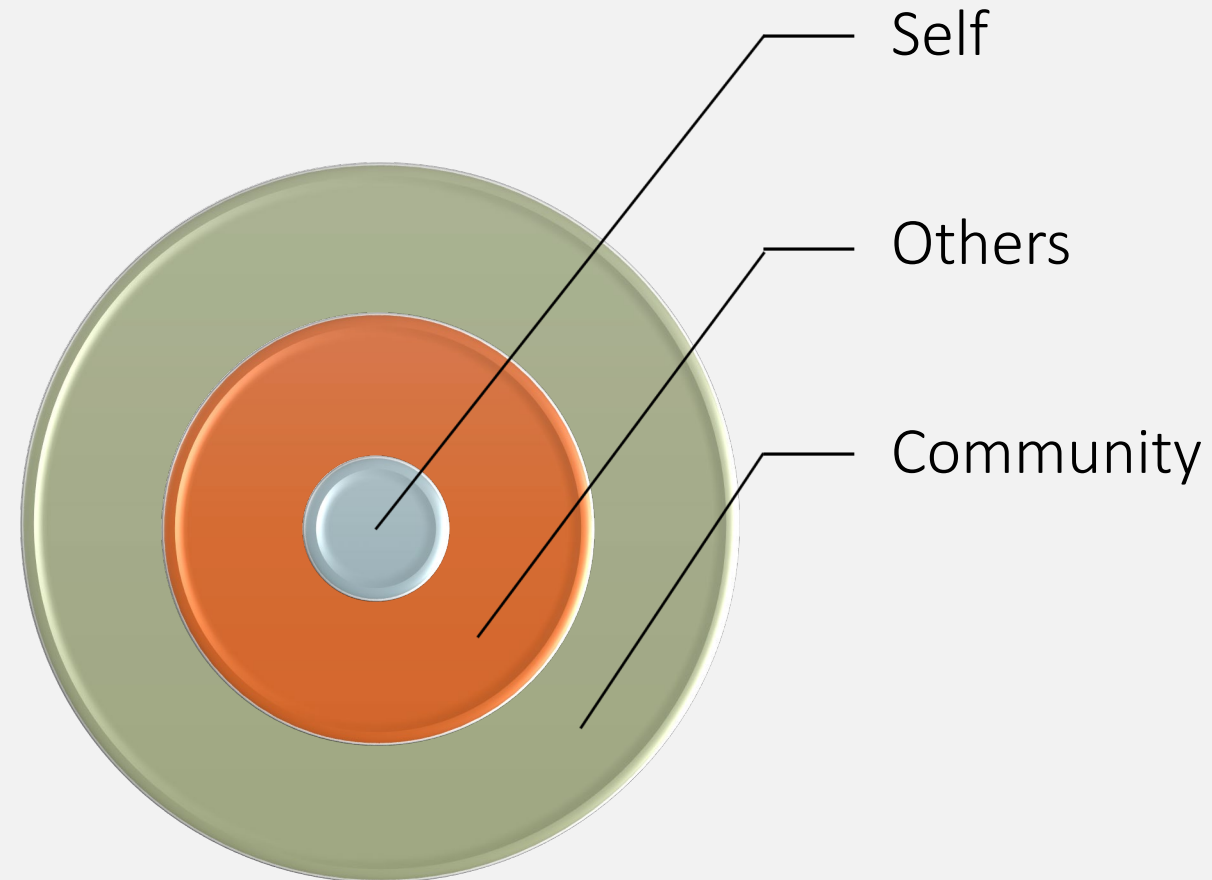
MCH Knowledge Base
Self Reflection

OTHERS

Communication
Negotiation and Conflict Resolution
Family-Centered Care

COMMUNITY

6. Working with Communities and Systems
7. Policy and Advocacy



RECRUITING

Identify the “ideal” participant

Not every family is able to participate in this kind of training

Don't have to accept all applicants

Cast a wide net

Host call for our staff with last year's participants



SCREENING

Can't spend too much time on this step

- ✓ Application
- ✓ References
- ✓ Interview

Staff rated each candidate

Saying no to some applicants ensures a strong cohort

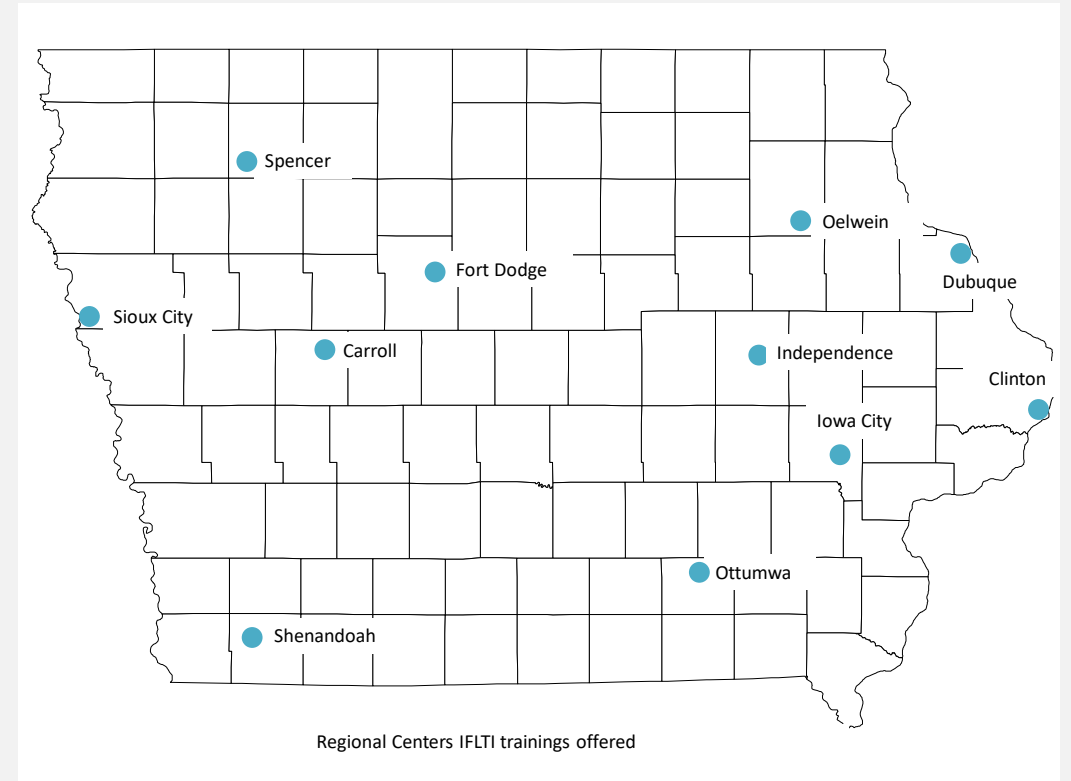


REGIONAL CENTER TRAINING

El Grupo Manantial

Topics include:

- ✓ Communication
- ✓ Conflict Management
- ✓ Finding Evidence-based
- ✓ Resources
- ✓ Care Coordination
- ✓ Family-Centered Care



TRAINING FORMAT

Four sessions over four months

Friday evening to Saturday afternoon

12-15 participants per cohort

Individual mentors

Local experts

- The History of the Disability Movement
- Servant Leadership
- True Colors™
- Storytelling
- Communication and Conflict Management
- Health Information Resources
- Advocating with Policymakers
- Working with Data to Support Storytelling
- Transition to Adulthood
- Self-Care and Resilience

A group of people is sitting on a grassy hill, looking out over a city at sunset. The scene is bathed in the warm, golden light of the setting sun. In the foreground, a man in a blue t-shirt is sitting with his back to the camera, his hands on his head. Next to him, a woman in a black top is also sitting with her back to the camera. They are surrounded by other people, some sitting and some standing, all enjoying the view. The city below is visible in the distance, with buildings and a bridge. The sky is a mix of orange, yellow, and blue. A large, dark tree is on the left side of the frame. A brown rectangular box with a white border is overlaid on the image, containing the text 'COMMUNITY SERVICE PROJECTS & MENTORING' in white, uppercase letters.

COMMUNITY SERVICE PROJECTS & MENTORING

- Seasoned family leaders provide individual mentoring to participants
- Keep trainees on task
- Improve quality of work
- Determine impact

COMMUNITY SERVICE PROJECTS

- Support Groups
- Facebook pages
- Newsletters
- Resources Guides
- Participation on advisory board
- State legislation
- Training
- Community activities



DIVERSE FAMILY LEADERS

Recruiting may take
additional effort

Interpretation costs

Great impact



ENGAGEMENT POST- TRAINING

Ongoing mentoring for six months

Facebook Page

Advocacy Day with legislators at the state
Capitol

Occasional webinar

Iowa Family Leadership Training Institute
Newsletter

THE NEWS LETTER

April 2020



IOWA FAMILY
LEADERSHIP TRAINING
INSTITUTE

A Note from Staff...

Dear Iowa Family Leadership Training Institute graduates,

We, IFLTI staff, are thinking of you as you hunker down and try to get through the COVID-19 shutdown. We have confidence in your leadership, your cohesion as cohorts, and your ingenuity as you weather this storm. Please know we are here to listen, to strategize and to bolster your resilience as needed.

Please let us know if you are in need of anything we might direct you to.

We, parents of children and youth with special health care needs, know how to make lemons from lemonade. But we also know we do that best in a team. Lean on us, and one another.

Take good care of yourselves,

IFLTI Core Team Staff

Martha Hanley, Rachel Charlot and Diane Brenneman

Resources for Wellness

As we navigate through the Coronavirus disease pandemic, self-awareness and wellness are more pertinent than ever before. The IFLTI staff have shared two resources to assist with wellness and provide you with a little break from the crazy world we are in.

Wellness for children, [click here](#).

Wellness for adults, [click here](#).

Additional resources (all are linked):

[COVID-19 in Iowa](#), a site sponsored by the State and IDPH

[Iowa Department of Public Health](#)

[Centers for Disease Control and Prevention \(CDC\)](#), Coronavirus Page

#stayhome
#staysafe
#staypositive

News You Can Use

Diane Zaerr Brenneman,
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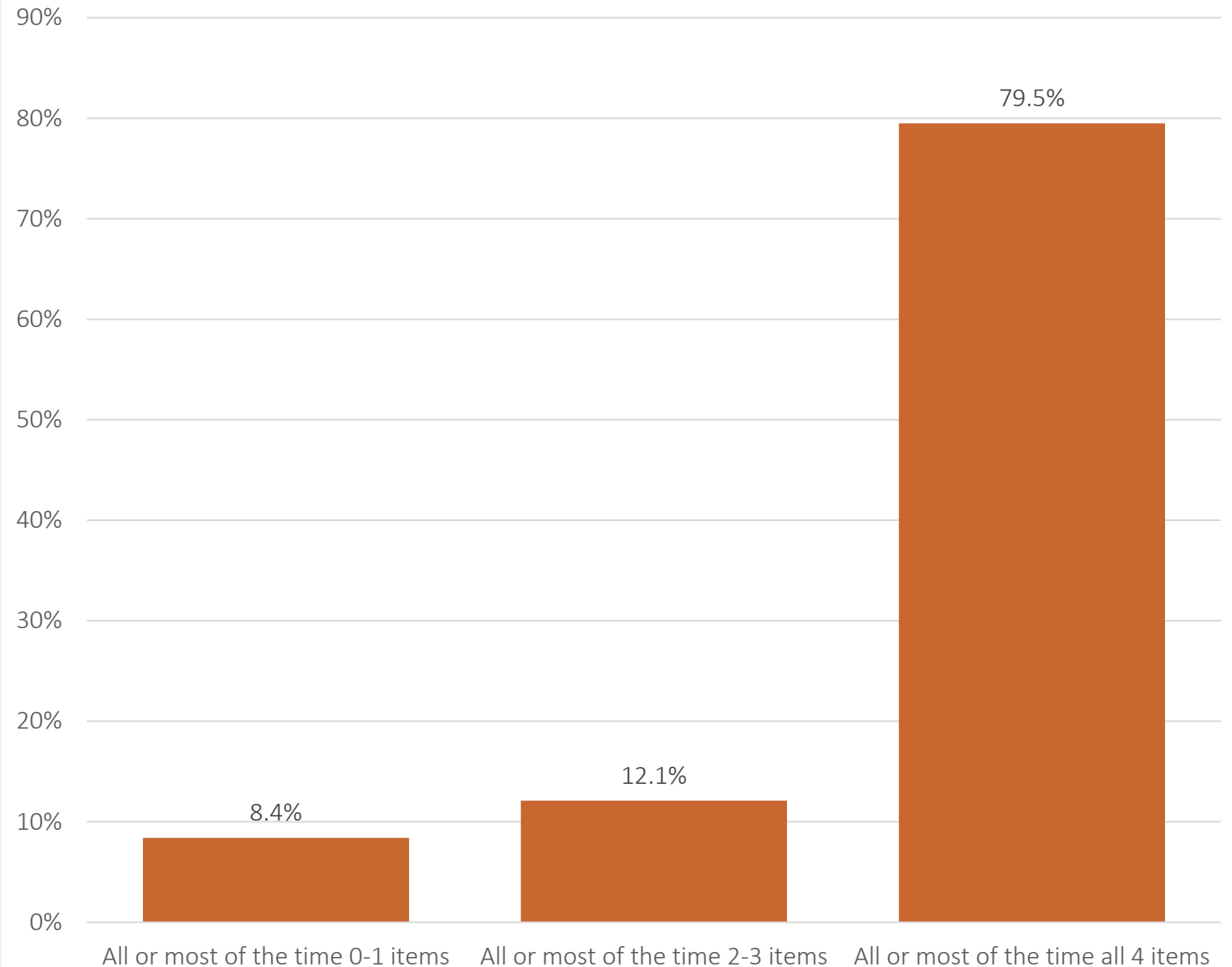
Sarah Foley
2018 IFLTI Grad, Newsletter
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WHY CONTINUE THE TRAINING?

According to the [2016 National Survey of Children's Health](#), only 80% of Iowa families report demonstrating all four qualities of resilience when facing problems:

1. Talk together about what to do
2. Work together to solve problems
3. Know we have strengths
4. Stay hopeful in difficult times

Family Resilience Composite Measure
Iowa Families of Children age 0-17 years



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!
- 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!

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

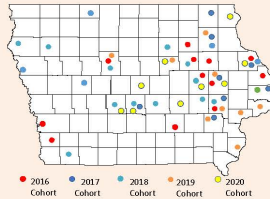
1. Johnson B, Abraham M, Conway J, Simmons L, Edgman-Levitan S, Sodomka P, Schlucter J, Ford D. (2008). Partnering with Patients and Families to Design a Patient- and Family-Centered Health Care System. Institute for Patient- and Family-Centered Care.

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

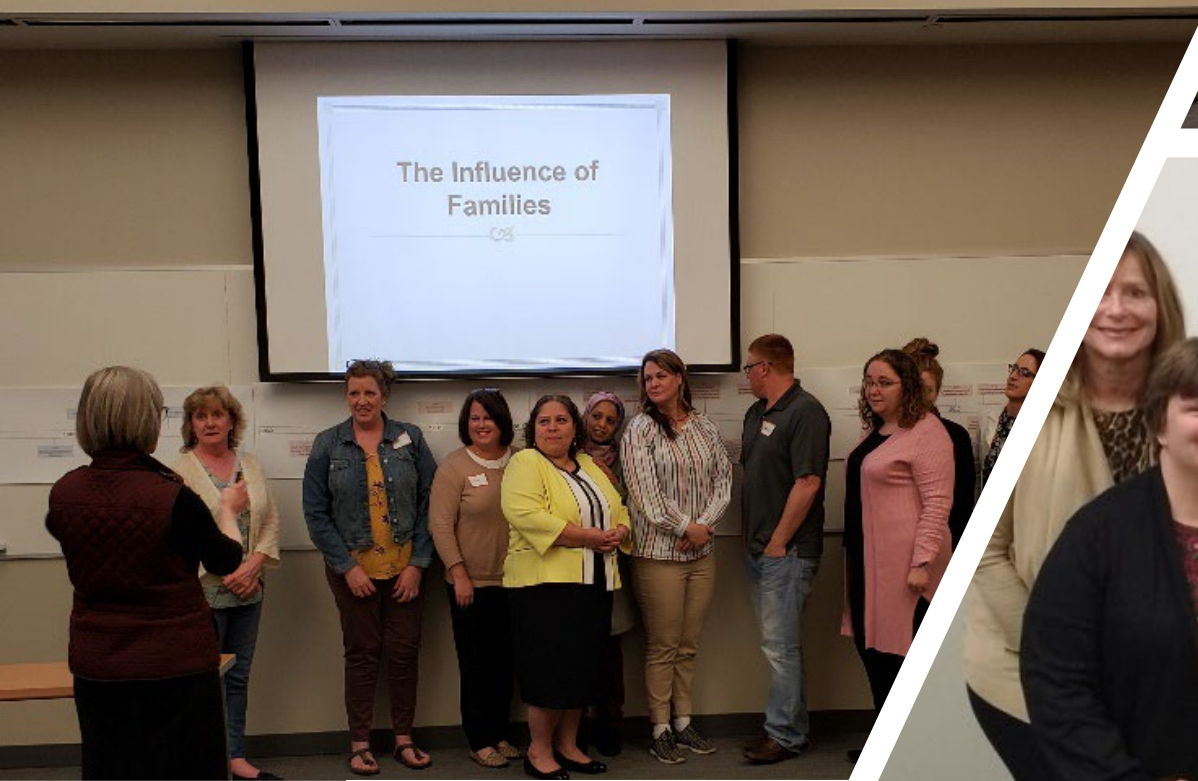
Selected Questions <small>Adapted from FamilyVoices California</small>	Pre-Test (n=42)	Post-Test (n=34)
How confident did you feel that you had a good understanding of the service systems that your child is involved in?	52%	71%
How often did you have ideas about how the service system for children could 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



INNOVATION STATION TOOLKIT

AMCHP's Implementation Toolkit for **National Performance Measure 11**

To increase the percent of children with and without special health care needs who have a medical home



How to Use This Toolkit

This toolkit contains resources and tools that Title V programs and public health professionals can use to address NPM 11. The strategic approaches below are informed by evidence and include resources from the [National Resource Center for Patient/Family-Centered Medical Home](#), Title V MCH programs, and national professional organizations.

The strategic approaches below are aligned with and link to the desirable characteristics of a medical home, found in the American Academy of Pediatrics' (AAP) [Medical Home policy statement](#). Please click on the strategic approaches below to learn more.

Intended User

This toolkit is intended for Title V staff to use as well as share with relevant partners and other stakeholders.

44

states and territories
selected NPM 11 in 2019.

(highlighted in mint green)



GU AS MP PW MH FM

PR VI

Visit the [TVIS website](#) to obtain contact information for Title V MCH and CYSHCN Directors for each state and territory.

Strategic Approaches

QUESTIONS?

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Jill Stevenson

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