A New Approach to Assessing Family Engagement in Health Care Systems

Webinar
January 23, 2019 at 10 am PST
Today’s Moderator:

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President and Chief Executive Officer,
Institute for Patient- and Family-Centered Care
A Framework for Assessing Family Engagement in Systems Change

April 2018 Issue Brief

Access the brief and more at: lpfch.org/cshcn

Abstract

Families of children and youth with special health care needs (CYSHCN) have unique perspectives about the complexities of systems of care because they are involved with so many aspects of these systems. As their children’s primary caregivers, families are deeply affected by systems-level issues, such as care fragmentation, which are often a direct result of ineffective or outdated health-care policies and practices. Families’ lived experiences make them uniquely qualified to partner in shaping systems-level policies that can improve systems of care for all children, especially CYSHCN.

Family Voices is a national, non-profit, family-led organization that works to promote quality health care for all children and youth, particularly those with special health care needs and those from diverse communities. To explore strategies for ensuring, enhancing, and supporting the meaningful engagement of families at the systems level of health care, Family Voices conducted an environmental scan of existing literature and a series of key informant interviews with family leaders and professionals.

This Issue Brief summarizes what we learned from these activities, describing barriers to effective family engagement and identifying four domains and corresponding key criteria that provide a framework for considering how well organizations and agencies are engaging families.

Introduction

In December 2015, the Lucile Packard Foundation for Children’s Health hosted a symposium, “Designing Systems That Work for Children with Complex Health Care Needs,” where families and professionals shared experiences and visions for improving care for CYSHCN.

Discussion topics ranged from care planning and coordination to insurance issues and costs. A key issue was the fragmentation of care for children served by an array of health care providers and programs that work independently with little communication or coordination.

In each session, families and professionals alike recognized that, “working closely with families may be the best way to affect health care outcomes.”

Existing evidence shows that family engagement with health care professionals improves care coordination and health outcomes.
Meet Our Speakers

Beth Dworetzky
Project Manager, Family Voices

Nanfi Lubogo
Co-Executive Director, PATH Parent to Parent/Family Voices of Connecticut

Susan Chacon
President, Association of Maternal and Child Health Programs
Title V Director for Children’s Medical Services, Children and Youth with Special Health Care Needs Program, New Mexico
Ask Questions!
We look forward to a lively discussion with our audience.
Enter questions in the GoToWebinar question box.
Beth Dworetzky

Project Manager, Family Voices
Systems-level Family Engagement
Systems-Level Family Engagement

- **Meaningful partnerships** between organizations and family-led or community-based organizations

- **Meaningful collaboration** between organization staff and family leaders who reflect the diversity of the communities they represent
Domain: Commitment

Key Criteria:
- Champion
- Win-Win
- Create opportunities
- Work together to create mission, strategic plan, other programmatic documents
- Provide support
- Provide compensation

Commitment

Families are included in all systems-level initiatives that impact the organization’s policies, programs, services, and practices.

FAMILY VOICES®
Domain: Transparency

Key Criteria
- Use data
- Shared understanding of work
- Provides training & support
- Cultural awareness
- No jargon
- Convenient meetings

Transparency
Family leaders can easily access and understand the information they need to participate effectively.

FAMILY VOICES®
Domain: Representation

Key Criteria
- Partners with family-led or community-based organizations to recruit families
- Race/ethnicity, Culture
- Language
- Age
- Gender
- Disability
- Geographic Area

Representation
Family leaders reflect the diversity of the community served by the organization.
Domain: Impact

Key Criteria
- Choosing goals
- Involved in implementation
- Engaged in evaluation
- Influenced programmatic options
- Engagement $\rightarrow$ improved services

Family leaders’ ideas are incorporated at the systems level to improve policies, programs, services, and practices.
Family Engagement in Systems Assessment Tool (FESAT)
For systems of care that serve children, youth and families

- **Assess** how well an organization engages families & youth
- **Guide** the design of systems-level activities to ensure family & youth engagement
- **Improve** efforts over time towards meaningful family & youth engagement
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Assessing Family Engagement

Nanfi N. Lubogo
Co-Executive Director
PATH Parent to Parent/Family Voices of CT (PATH/FVCT)
CT Family to Family Health Information Center
Our mission is to promote and improve health and social well-being of those with inherited conditions through collaborations among public health professionals, private health professionals, educators, consumers and advocates in Maine, New Hampshire, Vermont, Massachusetts, Rhode Island and Connecticut.

**Continuous Quality Improvement Project**

Improve access to genetic services for diverse and medically underserved individuals

Family Voices State Affiliate Organization

Parent to Parent Alliance Member

CT Family to Family Health Information Center

Health Insurance Marketplace Champion for Coverage

CT KASA (Kids as Self Advocates)

Project ECHO for Family Engagement Training
Partnerships

• Across all 6 New England states

• Hospital outreach to ensure representation from diverse and medically underserved families

Compensation

• NERGN’s budget included funding for the family-led organizations
Transparency

Creating shared language

• Genetics 101 training to PATH/FVCT staff

• Revised materials (no jargon, no acronyms) for families.

• Reviewed website: negenetics.org

• 37 genetic conditions information available at: gemsforschools.org
Improving access

• PATH/FVCT & NERGN worked together to improve access to genetic services to families

• Follow up calls, genetics webinars, satisfaction surveys, resources and technical assistance
Commitment

Long-term investments

• F2Fs included in grant proposal

• Supported both NERGN and family-led organization staff time to implement the Genetics 101 training
“We join others even as we ask others to join us.”

Trish Thomas/Roberto Chene
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Susan Chacon

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Title V Director for Children’s Medical Services, Children and Youth with Special Health Care Needs Program, New Mexico
Meaningful Family Engagement in the Title V Needs Assessment

New Mexico Story
New Mexico Population Statistics

- 45% Hispanic
- 41% White, Non-Hispanic
- 10% Native American
- 26% under 18 live below the poverty level
- Border MCH health issues related to communities in Southern NM and proximity to Northern Border of Mexico.
- 19 Pueblos and 3 Reservations
Title V Needs Assessment: Representation

- Data sets-compilation of data on CYSHCN from multiple sources such as:
  - NSCH
  - NSCHSN
  - IDEA-Part B and Part C
  - EPSDT
  - NM specific data sets

1st prioritization meeting with CYSHCN expert stakeholders

All members involved in the decision making process and decisions accurately reflected the consensus of the group.
Title V Needs Assessment: Transparency

What are families saying in addition to our community based partners:

- Survey developed based on priorities selected by expert panel to collect additional information from families and consumers of care

- Spanish and English versions

- We need to go to the places that families are gathering and convening to collect additional input.
CMS outreach clinics
PRO Family Leadership Conference
EPICS Family Leadership Conference
F2F HIC Listserv
Title V Needs Assessment: Impact

Addressing Top Issues of Concern for Families:

1. Child abuse and neglect, 62%
2. Behavioral Health, 47.7%
3. Medical Home, 30.3%
Engaging Diverse Family Leaders in Title V Block grant process is essential for our work

- EPICS
- Hands & Voices
- Asian Family Center
- Tribal Home Visiting programs
- Family Voices
- Parents Reaching Out F2F HIC
- Navajo Family Resource Center
Thank you!
Submit your questions in the question box

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Upcoming Events

Introducing the FESAT: A Tool to Enhance Family Engagement in our Health Care System
AMCHP Annual Conference, March 11

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