

# FAMILY VOICES

Leadership in **F**amily and **P**rofessional **P**artnerships



*FV Leadership in Family and Professional Partnerships:  
What It Is and How You Can Benefit!*

October 10, 2019

## Mission

**Family Voices** is a national organization and grassroots network of families and friends of children and youth with special health care needs and disabilities that **promotes partnership with families**—including those of cultural, linguistic and geographic diversity—in **order to improve healthcare services and policies for children.**

## Vision

With families at the center of health care, all children and youth reach their full potential and health disparities are eliminated.

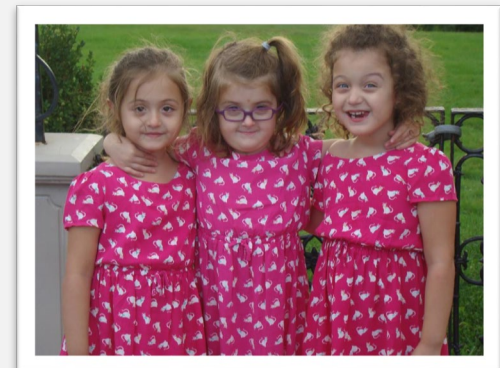


# Leadership in Family and Professional Partnerships

Family Voices (FV) is funded by HRSA Maternal and Child Health Bureau (MCHB) as the Leadership in Family and Professional Partnerships (LFPP) project for the period: **June 1, 2019 – May 31, 2022**

Family Voices has been funded to provide assistance on family-professional partnerships since 1999.

For the current cooperative agreement, FV has contracted with SPAN to co-lead the project.



# Our Team

## Co-Directors



Nora Wells



Bev Baker



Diana Autin

## Family Voices Staff and Consultants

## Extended team: F2F and FVAO networks



# Our Team

## TA/Training Providers

Beth Dworetzky  
 Maria Isabel Frangenberg  
 Glenn Gabbard  
 Clarissa Hoover  
 Mary Jo Paladino  
 Nicole Pratt  
 Luisa Soaterna  
 Allysa Ware

## Program Management & Support

Ayo Bajomo  
 Carolyn Fisher, External Evaluator  
 Lisa Maynes  
 Ashlee Richey  
 Ian Whitney

## Communications, Resources & Policy

Cara Coleman  
 Janis Guerney, Public Policy Director  
 Melissa Vickers

## Regional Coordinators

Tara Townsend, Region A  
 Keishawna Smith, Region B  
 Tami Allen, Region C  
 Susan Wood, Region D

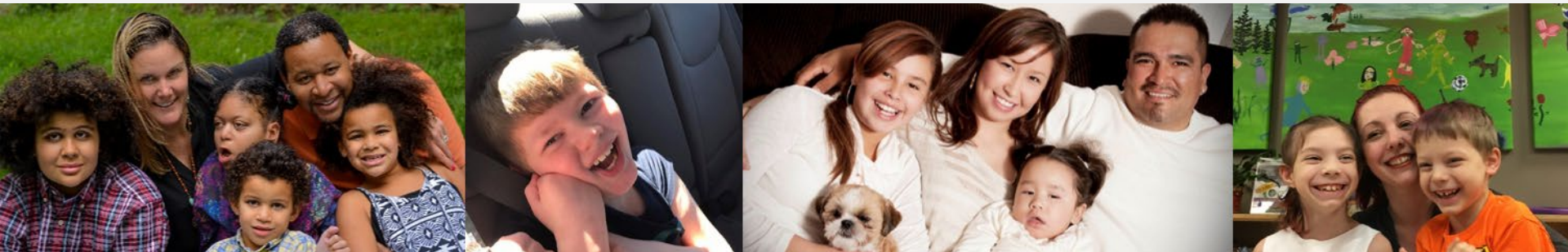


# Purpose

**To increase family engagement at all levels of health care, including:**

- direct patient care,
- organizational design and governance, and
- program and policy,

**in order to strengthen the health care systems serving children and youth with special health care needs (CYSHCN) and improve the health and well-being of CYSHCN and their families.**



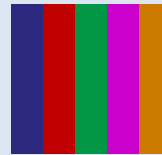
# What & For Whom?

## LFPP ACTIVITY

Connection of the national F2F network



National resource promoting family engagement; national leadership on engaging families in health care.



Technical assistance and training.



National CYSHCN public policy analysis.



Partnership building with other organizations serving CYSHCN.



Best practices on family engagement.



## CYSHCN STAKEHOLDERS

**Family organizations, including F2Fs and FVAOs**

**State agencies including Title V**

**Other MCHB-funded programs**

**Other organizations serving diverse CYSHCN**

**Families, clinicians, and others**



# Training, Sharing, Collaboration

For ALL CYSHCN Stakeholders

**Annual face-to-face convening** promoting family/professional partnerships

*Year 1 – co-located with 2020 AMCHP Conference (March 2020)*

*Year 2 – National Family Voices Leadership Conference (Spring 2021)*

*Year 3 – TBD based on stakeholder input (2022)*

**Virtual learning opportunities**

**Sharing of best practices and resources** via website, social media and email lists





# Training & Technical Assistance

FAMILY VOICES  
LFPP

For Family Organizations

## Serving on Groups Train-the-Trainer Facebook Live Workshops

to prepare family organizations to develop family leadership, especially diverse family leadership, to participate on decision making groups at the systems level. Follow-up mentoring/support is also available for trainers.



# Training & Technical Assistance

For Family-to-Family Health Information Centers (F2Fs)  
and Family Voices Affiliate Organizations (FVAOs)

*Online organizational capacity self-study workshops*

*Data support for F2F program with data definitions, collection, reporting, and national program analysis*

*Monthly drop-in calls on developing and supporting family engagement*

*Opportunities and mentorship for diverse family/youth to serve as partners on national and regional initiatives*

*Ongoing connection through national F2F/FVAO listservs, quarterly regional calls*

*Individualized TA*



## For Title V/Other State Agency and Family Organization Leaders

### **Leading by Convening webinar series**

on effectively engaging diverse stakeholders at systems and policy level

### **Leading by Convening follow-up support**

**State Collaborative Action Team Process:** A facilitated cohort on family engagement for 4-5 state teams of family organizations and state agency partners that have attended Serving on Groups (family organizations) and Leading by Convening (state, professional, and family organizations) workshops

**F2F peer-to-peer matching** to connect in-person or virtually with another F2F. Option for F2F to invite their state partners to participate.

For ALL CYSHCN Stakeholders

## Trainings on validated tools to assess/ measure Family Engagement:

**Family-Centered Care Assessment Tool (FCCA)** to assess family-professional partnerships at the individual level

**Family Engagement in Systems Toolkit (FESAT)** to assess family-professional partnerships at the program and/or systems level

# Public Policy Analysis

For ALL CYSHCN Stakeholders

Inform of emerging state and federal trends, legislation, regulations and other relevant policy impacting CYSHCN and their families.



# Connect to LFPP

For ALL CYSHCN Stakeholders

Family Voices Website

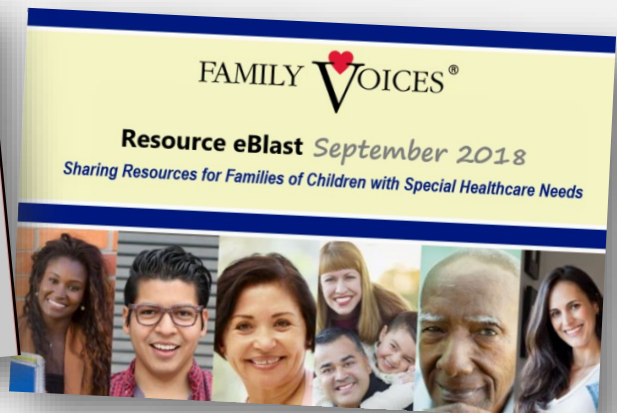
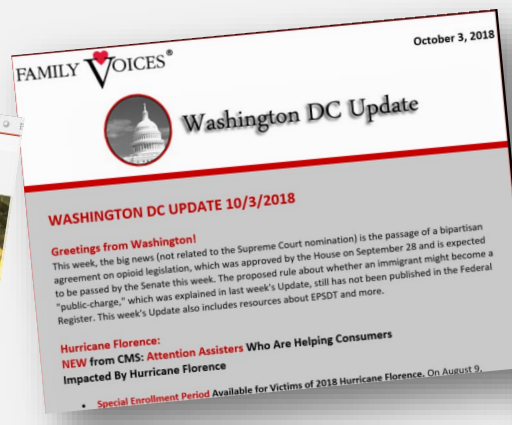


/FVNational



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Newsletters and Email Communications



## For Family Organizations

- ❖ [How Family Organizations can Help Shape and Implement the Title V Block Grant](#)
- ❖ [Collaborating with Non-Traditional Partners to Develop Diverse Family Leaders](#)

## For Title V and Other State Agency Leaders

- ❖ [Engagement of Family Leader Organizations in Non-CSHCN Initiatives](#)
- ❖ [Tips for Title V Programs: Partnering with Families](#)

## For Families and Youth

- ❖ Partnering with Your Child's Provider [English/Spanish](#)
- ❖ [Working with a Group](#): tip sheet series created by Youth As Self Advocates

## For ALL CYSHCN Stakeholders

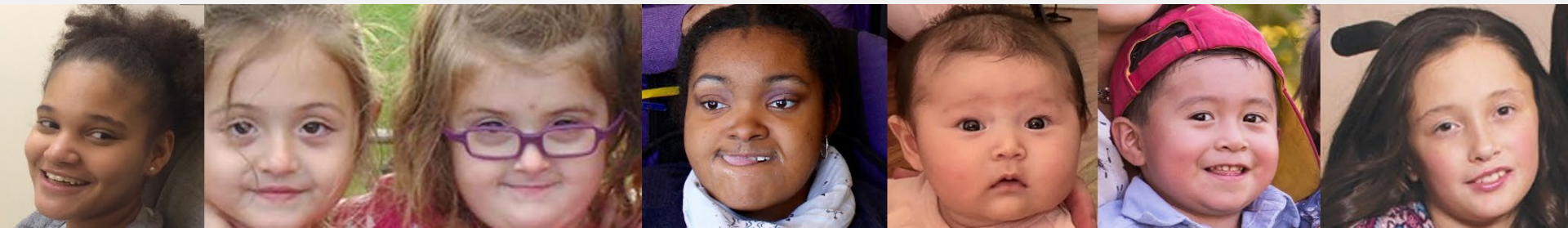
- ❖ [Framework for Assessing Family Engagement](#)
- ❖ [Model for Meaningful Family Engagement:](#)

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## *Questions?*

Before you go! [Please complete a QUICK feedback survey](#)





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*Thank You*

