

Celebrating 25 Years

FAMILY VOICES®



FAMILY LEADERSHIP CONFERENCE 2017

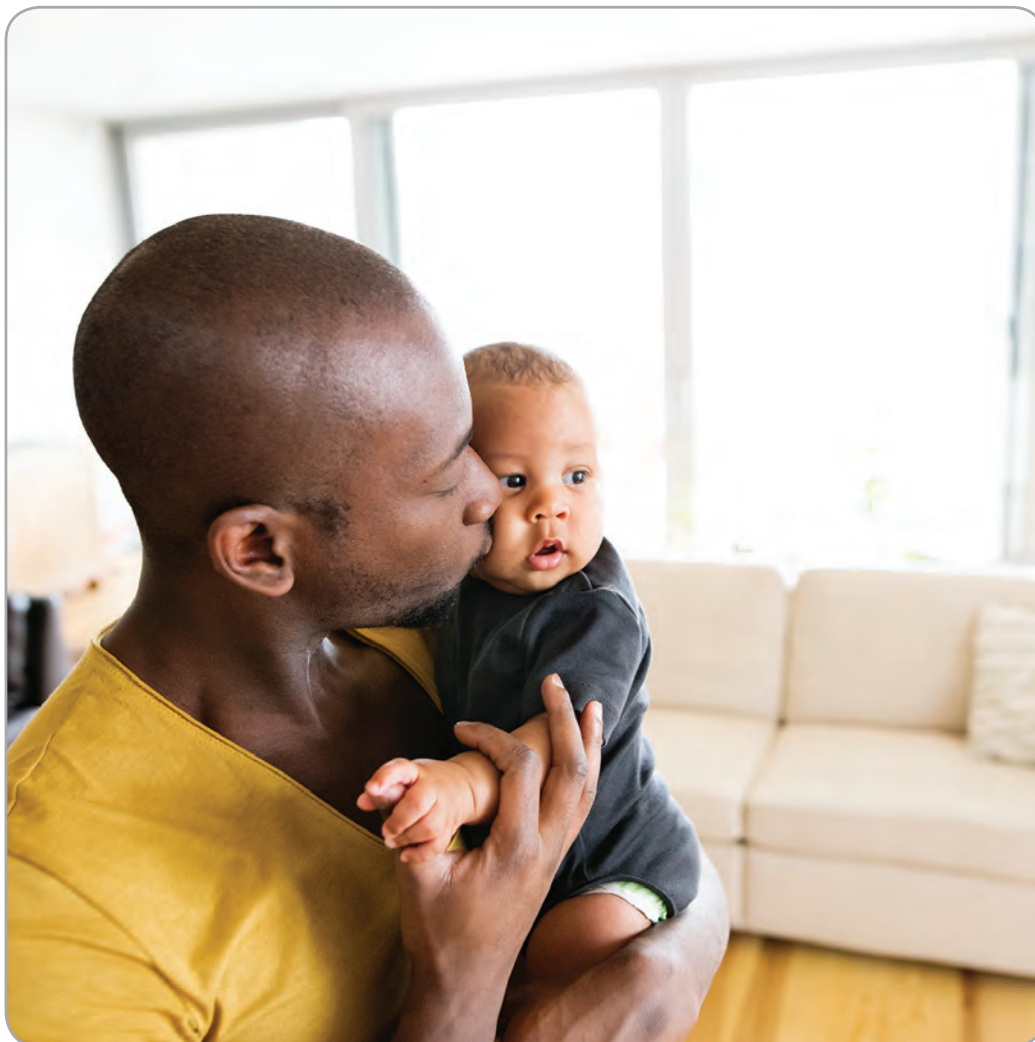
Weaving a Tapestry of Strength through Diversity



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November 15-17, 2017

The Conference Center at
The Carnegie Endowment for International Peace
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FAMILY LEADERSHIP
CONFERENCE | 2017

*Weaving a Tapestry of
Strength through Diversity*

Welcome to the 2017 National Family Leadership Conference!

We want to sincerely thank the sponsors who have made this Reception and Conference possible. Their partnership will make our movement stronger, and our capacity to share family perspectives has much to contribute to their work.

This year marks the 25th anniversary of Family Voices. We have come a long way since our creation in 1992 as a volunteer network to bring “family voices” to debates around President Clinton’s health care reform. The continued and vital importance of the Family Voices’ vision was reinforced this fall with the extraordinary success of families in educating elected officials about the impact that proposed healthcare reforms would have on children with special needs and disabilities. Our connected network of family organizations, family leaders, and many national partner organizations, continues to be a great source of strength in keeping families at the center of children’s healthcare.

Our conference theme, Weaving a Tapestry of Strength through Diversity, reflects our commitment to ensuring that families of all races, ethnicities, backgrounds and locations are supported to partner at all levels of healthcare. Our diversity as a network and as a country is the foundation of our strength.

We know that fully realizing our vision will be challenging. However, as President Barack Obama reminded us, *change will not come if we wait for some other person or some other time. We are the ones we’ve been waiting for. We are the change that we seek.* We hope that this gathering will provide each of you with many opportunities for support, energy and inspiration.

Thank you for being part of our vibrant network.



Marcia J. O'Malley
Marcia O'Malley, President



Nora Wells
Nora Wells, Executive Director

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Family Network on Disabilities

Liz Healey and family
Federation for Children with Special Needs
Oklahoma Family Network
Family Voices of Tennessee
Family Voices of California
New Hampshire Family Voices
Rhode Island Parent Information Network
Family Voices of Illinois
PATH Parent to Parent/Family Voices of Connecticut



Schedule at a Glance

WEDNESDAY, NOVEMBER 15, 2017

The Conference Center at The Carnegie Endowment for International Peace

9:00-5:00 Pre-conference Serving on Groups Train-the-Trainer Workshop* *Butler Room*

Russell Senate Office Building

5:30-7:30 Family Voices 25th Anniversary Celebration *Kennedy Caucus Room*

THURSDAY, NOVEMBER 16, 2017

The Conference Center at The Carnegie Endowment for International Peace

9:00-10:45 Welcome, Keynote: Jeanné Isler *Root Room*

Leadership from the Heart: Courage in Threatening Times

10:45-11:00 Break

11:00-12:15 Breakout Sessions

- Ensuring Access to Invisible Populations: A Guide to Successful Outreach *Choate Room*
- Mental Health: Creating Supports When the System is Lacking *Root Room*
- Executive Directors: Got Staff? Now What? *Butler Room*

12:15-1:00 Lunch

1:00-1:45 Speed Dating for Collaboration *See insert for descriptions of these networking sessions*

1:45-1:55 Break

1:55-3:15 Breakout Sessions

- Organizational Development for Diversity Initiatives *Choate Room*
- Stories of Transition *Root Room*
- Family Leaders and Medicaid: Working Together *Butler Room*

3:15-3:30 Break

3:30-5:00 Breakout Sessions

- Family Leadership in the Digital Age: Let's Do It! *Choate Room*
- Diverse Family Leaders in Research *Butler Room*
- Supported Decision-Making: From Theory to Practice *Root Room*

FRIDAY, NOVEMBER 17, 2017

The Conference Center at The Carnegie Endowment for International Peace

8:30-9:00 Native American Moving On Ceremony *Root Room*

9:00-4:30 Leading by Convening Workshop* *Choate Room*

9:00-10:00 Policy Panel: What Lies Ahead and the Power of the Grassroots *Root Room*

10:00-10:10 Break

10:10-11:10 Claire McAndrew, The Power of Families' Voices in Defending and Transforming our Health Care System *Root Room*

11:10-11:20 Break

11:20-12:20 Breakout Sessions

- Diverse and Underserved Communities and the Power of Project ECHO *Butler Room*
- Deeper Dive: Choose from Mental Health, Transition & SDM, or Diversity *Root Room* or Evaluation *1st Floor Foyer*

12:20-1:00 Lunch and Closing Remarks

* Requires Specific Pre-Registration

Agenda

THURSDAY, 9:00-10:45

WELCOME

Nora Wells, *Family Voices Executive Director*

Merrill Friedman, *Senior Director, Disability Policy Engagement, Anthem*



Laura Kavanagh, M.P.P.,
Acting Associate Administrator, Maternal and Child Health Bureau (MCHB), Health Resources and Services Administration (HRSA)



Joan Scott, *Acting Director, Division of Services for Children with Special Health Needs, MCHB, HRSA*

Treeby Williamson Brown, M.A., *Chief, Integrated Services Branch, Division of Services for Children with Special Health Needs, MCHB, HRSA*

Tigisty Zerislassie, *Project Officer for the National Center for Family Professional Partnerships (NCFPP) and Family-to-Family Health Information Center (F2Fs), MCHB, HRSA*

KEYNOTE



Jeanné Isler, *VP and Chief Engagement Officer, National Committee for Responsive Philanthropy*

Leadership from the Heart: Courage in Threatening Times



SongRise, *a DC-based, women's social justice a cappella group.*

THURSDAY, 11:00-12:15

BREAKOUT SESSIONS

Ensuring Access to Invisible Populations: A Guide to Successful Outreach

Maria Isabel Frangenberg, *Project Coordinator, Family Voices*

Olga M. Lopez, *Latino Outreach Coordinator, Federation for Children with Special Needs*

Mariela Pijem, *F2FHIC Coordinator, Parents Reaching Out*

Family organizations are historically sought out by partners because of their deep seeded connections to underserved populations. In these changing times, family organizations have had to become more creative to ensure effective outreach to hidden populations, such as undocumented families. During this session, we will hear from two F2F's who will share their successes and lessons learned, with opportunities for questions and a planning activity.

Mental Health: Creating Supports When the System is Lacking

Shauna Signorini, *Parent Partner/Trainer, Oregon Family to Family Health Information Center*

Many communities are unable to completely support children and youth who experience mental health challenges but there are ways we can help. Learn new strategies and resources for building resilience and wellness, linking key programs, and developing partnerships to maximize outcomes.

Executive Directors: Got Staff? Now What?

Rene Averitt-Sanzone, *Executive Director, The Parents' Place of MD*

There are many great things about being the leader of an organization! Being passionate about the mission and the work, working with like-minded folks, to name a few, but then reality hits – we have staff! Come to this interactive session to learn or get a refresher on current HR laws and share your experience. This session will also address strategies around the challenges and successes of leading a team.



FREE WI-FI is available at the conference. To access: select **ceipguest** and enter your name when prompted.



THURSDAY, 1:00-1:45

Speed Dating for Collaboration

This networking session of short encounters is designed to enable family leaders to meet new organizations, leaders and/or projects to become familiar with their work and resources, and explore opportunities to collaborate. Choose three organizations, leaders and/or projects from the list of potential “dates” and move between them for brief 10 minute timed encounters. See the list of topics in your conference folder.

THURSDAY, 1:55-3:15

BREAKOUT SESSIONS

Organizational Development for Diversity Initiatives

Maria Isabel Frangenberg, *Project Coordinator, Family Voices*

Lisa Maynes, *Family Support Director, Vermont Family Network*

Karen Thompson, *Executive Director, ASK Resource Center, Inc.*

Dana Yarbrough, MA, MS, *Director, Center for Family Involvement*

This session brings lessons learned from several F2F/FV SAOs on organizational structuring to build and sustain diversity initiatives that focus on essential aspects of culture including: seminal values; organizational demands for conformity in thought, interpersonal style, and action; power structure and power dynamics; employee participation; and inclusion/exclusion issues.

Stories of Transition

Margie Austin, *Advocate for People with IDD and Autism, Public Health Management Corporation*

Dr. Josie Badger, CRC, DHCE, *Co-Director, RAISE*

Ceil Belasco, MEd, *Parent, Educator, Sibling, Former Director of Training, PEAL Center*

Cara Coleman, JD, MPH, *Consultant, Family Voices*

Roseani Sánchez Algarín, *Coordinadora de Servicios de Apoyo a la Familia, APNI, Inc.*

Life is full of transitions. Time, friends, school, job, where you live; your health, financial situation and beliefs will influence each individual and family decision. For CYSHCN, transitions are often met with resistance and are very emotionally charged. What do we do when the tools designed to guide

difficult transitions don't seem to fit? How do we move forward with transitions for CYSHCN when individual needs, cultures, and beliefs are so varied? Later there will be time for solutions; we invite you to come to this session to listen, absorb and be moved to act.

Family Leaders and Medicaid: Working Together

Tamara Bakewell, *Family Involvement Coordinator/Project Coordinator, Oregon Center for Children and Youth with Special Health Needs*

Kau`i Rezentes, *Ho`okele Kokua (Parent Navigator), Hilopa`a Family to Family Health Information Center*

Matt Salo, *Executive Director, National Association of Medicaid Directors*

This workshop will focus on ways families can give meaningful input into their states' Medicaid programs. We will discuss a range of opportunities from attending one-time hearings to serving as the Medicaid Ombudsman. We will help family leaders consider what Medicaid policies they want to influence, identify ways to search out what platforms to use, and how to support having people's voices heard by policy makers. This will be an interactive session, so please come prepared to share how your organization has participated in Medicaid policy making activities.

THURSDAY, 3:30-5:00

BREAKOUT SESSIONS

Family Leadership in the Digital Age: Let's Do It!

Ceil Belasco, MEd, *Parent, Educator, Sibling, Former Director of Training, PEAL Center*

Liz Healey, *Former Executive Director, PEAL Center*

Rylin Rodgers, *Family Leader, Family Voices of Indiana*

Effective and innovative use of electronic communication and social media is critical to all aspects of our work. Bring your WiFi-enabled device and come ready to expand your skills in digital family-to-family support, information dissemination, professional partnership, and advocacy at local, state and national levels by exploring Facebook, Twitter, Instagram, video chat and related tools and platforms.

Diverse Family Leaders in Research

Rosario Beagarie, *Bilingual Parent Education Coordinator, Idaho Parents Unlimited*

Angela Lindig, *Executive Director, Idaho Parents Unlimited*

Dorey Nez, *Parent Advocate, Navajo Nation Tribal Member*

Yolanda Sandoval-Nez, *Parent Advocate/Community Advocate, Navajo Nation Tribal Member*

Trish Thomas, *Director of Diversity and Outreach, Family Voices*

This session will address the cultural adaptations needed to bring about diverse family engagement in research. We will talk about migrant farm workers in Idaho and the process used to partner with families to design a healthy eating and exercise research project. We will share the process used to build the relationship between the Mountain States Regional Genetic Collaborative and the Navajo Nation, which currently has a moratorium on genetics research due to a history of research abuse.

Supported Decision-Making: From Theory to Practice

Morgan K. Whitlatch, JD, *Legal Director, Quality Trust for Individuals with Disabilities*

Elver Ariza, *Bi-Lingual Advocate Outreach Specialist, Quality Trust for Individuals with Disabilities*

Supported Decision-Making is a process that people with disabilities can use to make their own decisions by receiving the help they need. This presentation will discuss what Supported Decision-Making means in practical, everyday terms; why it is important; its cultural implications; and how it is emerging in practices within the United States. Come learn about this alternative to adult guardianship and how it is being implemented in DC and beyond.



PLEASE SILENCE YOUR PHONE
out of respect for the presenters
and participants. Thank you!



FRIDAY, 8:30-9:00

Native American Moving On Ceremony

Dorey Nez, *Parent Advocate, Navajo Nation Tribal Member*

Yolanda Sandoval-Nez, *Parent Advocate/Community Advocate, Navajo Nation Tribal Member*

Trish Thomas, *Director of Diversity and Outreach, Family Voices*

We invite you to take part in this unique cultural event designed to assist those facing hurt, loss, challenge or bitterness in their lives to symbolically free themselves, move beyond the pain, and start anew.

FRIDAY, 9:00-10:00

PUBLIC POLICY PANEL



Elena Hung
Parent Advocate
Co-Founder of Little Lobbyists



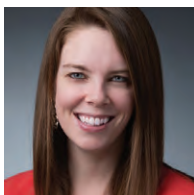
Michael Gamel-McCormick, PhD
Disability Policy Director
Office of Senator Bob Casey (PA)



Andrew J. Imparato, JD
Executive Director
AUCD

FRIDAY, 10:10-11:10

KEYNOTE



Claire McAndrew, *Director of Campaign Strategy, Families USA*
The Power of Families' Voices in Defending and Transforming our Health Care System

FRIDAY, 11:20-12:10

BREAKOUT SESSIONS

Diverse and Underserved Communities and the Power of Project ECHO

Clarissa G. Hoover, MPH, *Project Coordinator, Family Voices National*

Jill McCormick, *Director Family to Family Health Information Center/Family Voices of Washington, PAVE Partners for Action Voices for Empowerment*

Eric J. Moody, PhD, *Assistant Professor, University of Colorado & University of Wyoming*

We will demonstrate Project ECHO in action, with a project presentation by PAVE, the Washington State F2F, and a group discussion of outreach to diverse communities in Washington. We will also learn how the Wyoming Institute for Disabilities has used Project ECHO to support families of children with autism. This session will serve as the first meeting of Family Voices' Family Wisdom learning collaborative, and is open to all conference attendees.

CONFERENCE EVALUATION

Please complete the short paper session evaluation after EACH SESSION and the OVERALL conference evaluation using this link:
www.surveymonkey.com/r/2017FVConferenceFeedback



At the heart of every health care decision are people who care.

We're proud to be a part of the Family Voices 25th Anniversary Family Leadership Conference. Together, we're committed to supporting families of children with special needs, helping them navigate and thrive within the complex health care system.



General Information

Conference Feedback

We need to hear from you! At the end of each session you will be asked to complete a very brief evaluation. At the conclusion of the conference please complete the online overall conference evaluation at www.surveymonkey.com/r/2017FVConferenceFeedback.

Internet Access

Wifi is available on-site at the conference. Choose the "ceipguest" network, and enter your name when prompted.

Connect With First Time Conference Participants!

Be on the lookout for the participants with a red heart on their name badge. These are first time Family Voices Family Leadership Conference participants, and we want to extend them a special welcome. Please introduce yourself and welcome them to our fantastic network!

Community Activities

We hope you will contribute to our symbolic Tapestry of Strength and Strands of Peace! These are visual testaments to the power of our diverse and connected network. See your registration packet for materials.

Conference and Reception Planning Committee Members:

Our sincere gratitude to the many in our network of family leaders who contributed ideas, personnel, and resources to make this conference a reality. In addition to the work of Family Voices staff and consultants, we extend a special thank you to the F2F and FV SAO network members and Family Voices board members who have served on conference and reception planning committees:

Program Planning

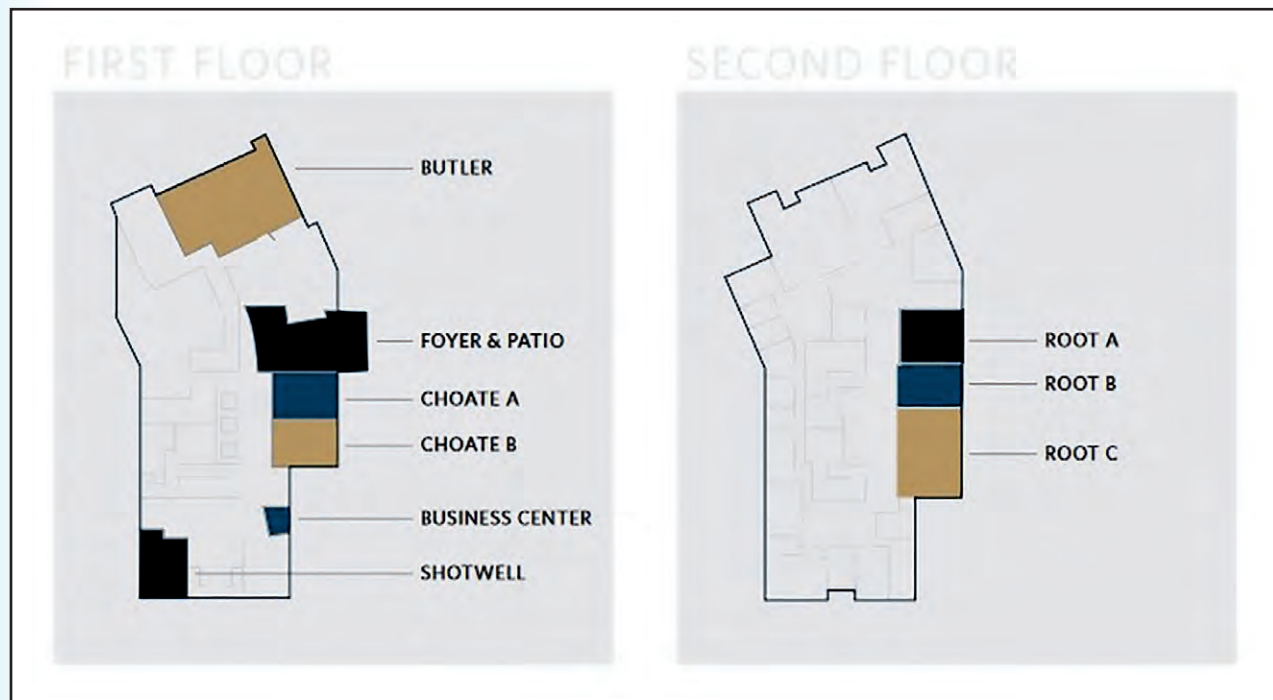
Tamara Bakewell, OR
Nithya Narayan, OH
Heather Pike, OK

Logistics and Hospitality

Tami Allen, KS
Doreen Hodges, DC

Reception Planning

Julie Beckett, IA
Donene Feist, ND
Lisa Gordon Cook, MI
Tom Rose, CO
Peters Willson, DC





CONGRATULATIONS FAMILY VOICES

The American Board of Pediatrics congratulates Family Voices on 25 years of successfully advocating for family-centered care for all children and youth with special health care needs.

The ABP invites all families to explore ways board certification helps your pediatrician provide better care for children at:

www.MyCertifiedPediatrician.org





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Grace Pushparany
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PATH P2P/FV of Connecticut, CT

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(PAVE), WA

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CT Council on Developmental Disabilities, CT

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**Promoting
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Congratulations on 25 Years of Leadership



Strategic Plan

VISION

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

MISSION

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

VALUES

Family Voices believes in:

- Social justice and the promotion of health equity
- Authentic family-centered care that recognizes family as the center of a child's life and as an equal partner in decision-making about all aspects of the child's care
- Effective family/professional partnerships at the local, state, and national level
- Inclusion and connection of underserved families representing the cultural, linguistic and geographic diversity of the population
- Connected and informed Family Leaders and Youth Leaders as powerful change agents
- Children and youth with special needs and their families becoming empowered self-advocates
- Family engagement in prevention, health and wellness in clinical and community settings.

GOALS

- Develop family and youth leaders, particularly those from underserved and underrepresented populations
- Maintain and strengthen Family Voices' leadership role for children and youth with special health care needs (SHCN) and disabilities through advocacy and partnerships
- Create and support policy positions for children and youth with SHCN and disabilities
- Connect and enhance a vibrant national network of family organizations that reflect the diversity of the population they serve
- Maintain and strengthen organizational structure and capacity

OUR NATIONAL NETWORK OF FAMILY ORGANIZATIONS

At the core of Family Voices are grassroots families supported by MCHB-funded Family-to-Family Health Information Centers (F2Fs) and Family Voices State Affiliate Organizations (FV SAOs). These family organizations provide critical support to families caring for children and youth with special health care needs (CYSHCN), including families of children with complex needs and those from diverse communities. Our network collectively reached almost 1 million families and 350,000 professionals nationwide in the last funding year. F2Fs and FV SAOs also work at state, regional, and national levels to improve systems and policies that affect children and families, and they prepare and support new and diverse families of CYSHCN to participate in systems change. This vibrant and connected network of family organizations--sharing resources, strategies, and peer support--keeps the voices of families at the heart of children's health care.

■ Both F2F & FV SAO ■ FV SAO ONLY ■ F2F ONLY

AK Stone Soup Group	MA Massachusetts Family Voices @ the Federation for Children with Special Needs	OH Ohio Family-to-Family Health Information Center
AL Family Voices of Alabama		OK Oklahoma Family Network, Inc.
AR Arkansas Disability Coalition	MD The Parents' Place of Maryland	OR Oregon Family-to-Family Health Information Center
AZ Raising Special Kids	ME New Directions for Maine Families	PA Parent Education & Advocacy Leadership (PEAL) Center
CA Family Voices of CA @ Support for Families of Children with Disabilities	ME Maine Parent Federation	RI Rhode Island Parent Information Network (RIPIN)
CO Family Voices Colorado	MI Michigan Family Voices @ The Arc of Michigan	SC Family Connection of South Carolina, Inc.
CT PATH Parent to Parent / Family Voices of Connecticut	MI Michigan Public Health Institute	SD South Dakota Parent Connection, Inc.
DC Advocates for Justice and Education	MN Family Voices of Minnesota	TN Family Voices of Tennessee @ Tennessee Disability Coalition
DC Family Voices of DC	MN PACER Center, Inc.	TX Texas Parent to Parent
DE Delaware Family Voices, Inc.	MO Missouri Family to Family Resource Center @ UMKC-IHD	UT Utah Family Voices Health Information Center
FL Family Network on Disabilities	MS Family Voices of Mississippi, U of Southern MS	VA Family to Family Network of Virginia - Center for Family Involvement @ VCU
GA Parent to Parent of Georgia	MT Parents Let's Unite for Kids (PLUK)	VT Vermont Family Network
HI Hilopa'a Family-to-Family Health Information Center	NC Exceptional Children's Assistance Center (ECAC)	WA PAVE/Family Voices of Washington
IA Family Voices of Iowa @ ASK Resource Center	ND Family Voices of North Dakota, Inc.	WI Family Voices of Wisconsin, Inc.
ID Idaho Parents Unlimited, Inc.	NE PTI Nebraska	WV West Virginia PTI
IL Family Voices of Illinois/ The Arc of Illinois	NH New Hampshire Family Voices	WY UPLIFT - Wyoming Family Voices
IN Family Voices Indiana	NJ Statewide Parent Advocacy Network (SPAN)	WY Wyoming Institute for Disabilities (WIND)
KS Families Together, Inc.	NM Parents Reaching Out (PRO)	
KY Family Voices of KY/KY Family-to-Family Health Information Center	NV Family TIES of Nevada	
LA Bayou Land Families Helping Families	NY Family Voices New York @ Parent to Parent of NYS	

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The American Academy of Pediatrics recognizes that perspectives and information provided by **families, children, adolescents, and young adults** are essential components of collaborative decision-making in the delivery of high-quality, safe, and compassionate health care.

American Academy of Pediatrics

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The Catalyst Center is delighted to support our friends and colleagues at the Family Voices Network and their 2017 Family Leadership Conference!



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WITH SPECIAL HEALTH CARE NEEDS



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voices to policy!**



Thank you

FAMILY  VOICES

for 25 years of advocacy for
children and youth
with special health care needs and
their families.

Liz, Mike and Bevin Healey

Congratulations

to Family Voices for
25 years of advocacy
on behalf of children with
special health care needs
and disabilities

Massachusetts
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SPAN is proud to partner
with Family Voices on the
National Center for Family
Professional Partnerships.



We warmly recognize Family Voices on its
25th anniversary of working to ensure that
"families are at the center of children's healthcare."



Providing the resources and support families need to
help their children fully participate in and contribute
to our communities.

Empowering families and involving professionals in the healthy
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Congratulations to Family Voices on this impressive milestone!

For 25 years you have led the charge in promoting quality health care for YSHCN, ensuring that the family perspective is front-and-center.

Keep up the great work!

FAMILY  VOICES
of California

FVCA wishes to honor and recognize Lucile Packard Foundation for Children's Health for their unwavering support of parents as partners and leaders as well as their tireless devotion to improving the lives of CYSCHN.



Lucile Packard Foundation
for Children's Health



Congratulations to Family Voices

for 25 years of steadfast
focus on what matters!



NCHAM supports family-professional
partnerships within EHDI systems



Congratulates
Family Voices
on 25 years of supporting
family organizations and
ensuring excellence in
services of families of
children and youth with
special health care needs
and disabilities!



Family to Family Health
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Faye Manaster, M. Ed.
Project Director

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And the
2017 Family Voices Leadership Conference.

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★ ★ ★ **DARA V. HOWE** ★ ★ ★

**DIRECTOR OF THE FIRST STATE CHAPTER
OF FAMILY VOICES**


FND 
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ON DISABILITIES**

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Thank you
for keeping families
at the center of health
care for 25 years!

*We are honored to support the
Family Voices Network and the
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