FAMILY LEADERSHIP CONFERENCE 2017
Weaving a Tapestry of Strength through Diversity

November 15-17, 2017
The Conference Center at
The Carnegie Endowment for International Peace
1779 Massachusetts Avenue NW • Washington, DC 20036

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Proud to be a supporting sponsor of the 2017 Family Voices Family Leadership Conference

Anthem
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 O’Malley, President
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.

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**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, MSED, 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, MSED, 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
OUR LEADERSHIP

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Tom Rose
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Peters D. Willson
Association of American Medical Colleges, DC
Molly Cole, Past-President of BOD,
CT Council on Developmental Disabilities, CT

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Rylin Rodgers
Mercedes Rosa
Yolanda Sandoval
Matthew Shapiro
Luisa Soaterna
Allysa Ware
Ian Watlington
**FAMILY VOICES®**

**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.

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<th>Both F2F &amp; FV SAO</th>
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<td>AR Arkansas Disability Coalition</td>
<td>ME New Directions for Maine Families</td>
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<td>MT Parents Let’s Unite for Kids (PLUK)</td>
<td>VA Family to Family Network of Virginia - Center for Family Involvement @ VCU</td>
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<td>GA Parent to Parent of Georgia</td>
<td>NC Exceptional Children’s Assistance Center (ECAC)</td>
<td>VT Vermont Family Network</td>
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<td>WA PAVE/Family Voices of Washington</td>
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<td>IN Family Voices Indiana</td>
<td>NM Parents Reaching Out (PRO)</td>
<td>Wyoming Institute for Disabilities (WIND)</td>
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There's nothing more impactful than dedicated people working toward a common goal. Healthcare Banking at MUFG salutes those whose commitment is helping create a better future—for all of us.

WE'RE PROUD TO SUPPORT FAMILY VOICES

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

Learn more about health care coverage and financing of care for children and youth with special health care needs:

Visit our website - www.catalystctr.org
Follow us on Facebook and Twitter

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Congratulations to Family Voices for 25 years of bringing child and family 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 FAMILY VOICES
a project of the
FEDERATION FOR CHILDREN WITH SPECIAL NEEDS

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inclusion  dignity  respect  equity
justice  health  well-being

AUCD
ASSOCIATION OF UNIVERSITY CENTERS ON DISABILITIES
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 development and education of our children and youth.

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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

got transition

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!
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!

“Your Statewide Health Information Resource for Families of Children and Youth with Special Health Care Needs!”

Is honored to support The Family Voices Network And the 2017 Family Voices Leadership Conference.
Congratulations
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 2017 Family Leadership Conference

FAMILY VOICES
Board of Directors