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Family Voices

20 | LEADERSHIP 19 | CONFERENCE

FAMILIES AS PARTNERS SHAPING SYSTEMS CHANGE | MAY 8-10 2019



FHI 360 Conference Center
1825 Connecticut Ave, NW, 8th Floor
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UnitedHealthcare is happy to support Family Voices in all the hard work they do to support families of children with special health care needs.





Welcome to the 2019 National Family Leadership Conference!

We are very pleased that you are joining us in Washington at this important conference! Attendees have traveled from every state, from territories, and from tribal groups, each bringing perspectives to share and a willingness to learn from each other. Our collective expertise as family members and professionals with first-hand experience caring for our children and youth with special healthcare needs is increasingly recognized as a critical component in improving systems of care. Thank you for taking this time to meet together focused on: "Families as Partners Shaping Systems Change."

We are excited to welcome new family leaders from across the country, and especially to welcome family leaders from eight new Family-to-Family Health Information Centers (F2Fs), five serving territories and three serving tribal communities. F2F funding for the tribes and territories represents the achievement of a long held Family Voices goal. We look forward to hearing about, and working together to meet, the needs of the communities these new F2Fs serve.

The conference program is rich with opportunities to learn and share best practices on topics critical to family leadership. We hope you will be inspired by those you meet, and what you learn in the plenary and breakout sessions, speed dating, posters, exhibits, legislative reception, and numerous additional networking and learning opportunities.

Our sincere thanks to our sponsors and donors for their support of the conference and reception. Without their generous contributions, our convening would not be possible. Please visit with the sponsors who are conference participants, stop by their exhibits, and thank them for their essential contributions to our work.

Realizing the Family Voices vision, "with families at the center of health care, all children/youth reach their full potential and health disparities are eliminated," will be a challenge. We know that "there is no greater power than a community discovering what it cares about" (Margaret Wheatley). We are such a community. We hope that the next few days will provide each of you with many opportunities for support, energy, and inspiration.

Thank you for being part of this gathering.



Deborah Klein Walker

Deborah Klein Walker, President



Nora Wells

Nora Wells, Executive Director



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General Information

Exhibitors

Be sure to stop by the exhibit tables in the lounge and foyer, available throughout the conference.

Connect With First-time Family Leader Participants ♥

Be on the lookout for the family leaders with a red heart on their name badge. These are first time Family Voices Leadership Conference participants, and we want to extend them a special welcome.



We lovingly remember the children and adults of the Family Voices network who are no longer with us. Their light guides our work into the future.

Thank You to our Conference and Reception Planning Volunteers!

In addition to the work of Family Voices staff and consultants, we extend a special thank you to the F2F and FVAO network members, partners, and Family Voices board members who have served on conference and reception planning committees:

Tami Allen, KS
Julie Beckett, IA
Alisa Bentley, SC
Susan Colburn, AL
Donene Feist, ND
Tracie Haywood, SC
Lisa Maynes, VT
Jill McCormick, WA

Pat Nemia, MA
Ann Phillips, DE
Shauna Signorini, OR
Keishawna Smith, MS
Tara Townsend-Hayes, RI
Kristi Wees, PA
Peters Willson, DC

A special thank you to FV Conference Planning Consultant, Liz Healey, for her dedication to making this a great conference for everyone.

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2019 Schedule at a Glance

TUESDAY, MAY 7, 2019 FHI 360 Conference Center

1:00-5:00 Preconference Leading by Convening Workshop

For those who have not taken the Leading by Convening workshop before.

WEDNESDAY, MAY 8, 2019 FHI 360 Conference Center

9:30-11:30 Preconference Serving on Groups Technical Assistance session

For those who have taken the Serving on Groups Train-the-Trainer Workshop.

10:00-11:00 Preconference How to Do a Hill Visit (It's Easy!)

11:00-12:30 Conference Registration Opens

11:00-11:30 Welcome Session for First-time Attendees

12:30-2:30 Opening Plenary

Welcome from Family Voices

Keynote: The Health Care Justice Movement: Our Time is Now! Frederick Isasi, Families USA

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

Welcome from MCHB

Words from our Sponsors

2:30-2:45 Break

2:45-3:45 Breakout Sessions

1. Providing Support for CYSHCN at School | Room: **Angle A/B**

2. Title V Five-Year Needs Assessment: Opportunities for Families and Family-led Organizations to Partner with Title V | Room: **Academy**

3. Meaningfully Engaging Families in Newborn Screening Education | Room: **Angle C**

4. Including Youth with Special Health Care Needs at Every Level of Your Organization | Room: **Vista A**

5. Well Child Care--An Oxymoron for CYSHCN? No! Bright Futures for Every Child! | Room: **Vista B**

3:45-4:00 Break

4:00-5:00 Breakout Sessions

6. Developing and Supporting Remote Work Teams | Room: **Vista A**

7. We Can't Do This Without You! One F2F's Authentic Partnership with Their State's Title V CYSHCN Program | Room: **Angle A/B**

8. Family Partners in Research | Room: **Angle C**

9. Family Wisdom, Diverse and Underserved Communities and the Challenges of Intersectionality | Room: **Academy**

10. History of Family Voices | Room: **Vista B**



THURSDAY, MAY 9, 2019 FHI 360 Conference Center

9:00-9:45 Keynote: *Perspectives from the Maternal and Child Health Bureau*
Dr. Michael Warren, MCHB

9:45-9:55 Break

9:55-11:00 Breakout Sessions

- 11. LEAD: Staff Leadership Exploration and Development | Room: **Angle C**
- 12. Consumer Engagement in a Virtual World | Room: **Academy**
- 13. Cultural Broker/Model to Implement in Human Services Agencies | Room: **Vista B**
- 14. Charting the LifeCourse: Path to the GOOD Life Throughout the Lifespan | Room: **Angle A/B**
- 15. Important Intersections Between CYSHCN & the Child Welfare System: Policy & System Navigation Implications for F2Fs and SAOs | Room: **Vista A**

11:00-11:10 Break

11:10-12:30 Breakout Sessions

- 16. Executive Directors' Session: Successful Staff Recruitment & Retention | Room: **Angle C**
- 17. Social Media: New Low-cost Tools for Effective Outreach | Room: **Angle A/B**
- 18. Sharing Community-Based Cultural Signals - Through a Diné Lens on the Navajo Nation
Room: **Vista B**
- 19. Supported Decision-Making: How to Create a Supportive Network | Room: **Vista A**
- 20. Florida Family Leaders' Network: A Family-led Statewide Initiative to Build a Network of Family Leaders in Florida | Room: **Academy**

12:30-1:30 Lunch

1:30-2:45 Speed Dating for Partnership & Poster Sessions

3:00-3:45 Hill visits *Capitol Hill*

4:00-5:00 Policy Panel *Capitol Hill, Dirksen Senate Office Building, Room SD-G50*

5:30-7:30 Family Voices Awards Reception *Capitol Hill, Hart Senate Office Building, Room 902*

FRIDAY, MAY 10, 2019 FHI 360 Conference Center

9:00-10:15 Partnership Opportunities Panel

10:15-10:25 Break

10:25-11:55 Breakout Sessions

- 21. Family Engagement Strategies for Health Systems Change | Room: **Academy**
- 22. Partnering in the MCH Block Grant: From Start to Finish to Starting Again! | Room: **Angle A/B**
- 23. Innovative Ways to Use the Care Map | Room: **Vista A**
- 24. Child and Adolescent Health Measurement Initiative (CAHMI) Data in Action and Family Engagement Resources | Room: **Vista B**
- 25. Assessing Family Engagement in Systems-level Initiatives | Room: **Angle C**

11:55-12:05 Break

12:05-1:00 Closing Keynote: *The State of the Disability Union 2019*
Rebecca Cokley, Center for American Progress

Agenda

WEDNESDAY, 12:30-2:30

OPENING PLENARY

Welcome from Family Voices



Keynote *Health Care Justice Movement: Our Time is Now!*
Frederick Isasi, Executive Director,
Families USA



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



Joan Scott, MPP
Deputy Associate Administrator,
MCHB

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Jennifer Kyle, *United Healthcare*

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out of respect for the presenters and
participants. Thank you!

WEDNESDAY, 2:45-3:45

BREAKOUT SESSIONS

1. Providing Support for CYSHCN at School

Pattie Archuleta, *Family Engagement and Training Specialist, Maryland Coalition of Families*
CYSHCN often require a variety of supports at school. Learn the importance and application of using Individual Health Plans and Emergency Action Plans; provisions for providing accommodations under Section 504; strategies to identify the need for supports under Present Levels of Performance in the IEP; and approaches to establish health-related goals in the IEP.

2. Title V Five-Year Needs Assessment: Opportunities for Families and Family-led Organizations to Partner with Title V

Kate Marcell, MS, *Public Health Analyst and Ellen Volpe, MHS*, *Chief, Eastern Branch, DSCH/MCHB/HRSA*
Focusing on the upcoming Title V Maternal and Child Health (MCH) Block Grant Five-Year Needs Assessment, presenters will share an overview of the needs assessment process and will discuss opportunities for families and family-led organizations to partner with Title V in this process.

3. Meaningfully Engaging Families in Newborn Screening Education

Annie Evans, MPH, *Program Development Specialist, Genetic Alliance*
Learn about the Genetic Alliance's new education training program tailored for families entering or embarking on a journey in the newborn screening system. The program teaches families skills to help them advocate, share stories, and make informed decisions. Join this session to learn about successful education strategies and partnership opportunities.

4. Including Youth with Special Health Care Needs at Every Level of Your Organization

Matthew Shapiro, *Chair KASA Board, KASA (Kids as Self-Advocates)*, **Wednesday Eanes**, *KASA Board*; **Hamza Jaka**, *KASA Board*; **Elisabeth (Lis) Harkins**, *KASA Board*; **Emily Robinson**, *KASA Board*
Members of Family Voices' KASA project will share their experiences serving as youth leaders in their communities. This interactive session is an opportunity to hear youth discuss how they are affecting systems change in every corner of the country and to learn best practices for meaningfully including YSHCN in your programs and organizations.



5. Well Child Care –An Oxymoron for CYSCHN? No! Bright Futures for Every Child!

Jane Bassewitz, MA, Senior Manager, AAP Bright Futures National Center; **Cara L. Coleman, JD, MPH**, Consultant, Family Voices; **Ashley Bates-Crowley**, Executive Director and Founder, Team Josiah 2K22 Foundation; **Yetta Myrick**, President/Founder, DC Autism Parents; **Norman A. Ospina Quintero**, Dad/Spanish & English Interpreter & Translator; **Allysa Ware, MSW**, Project Director, Family Voices

Overview of the American Academy of Pediatrics Bright Futures Guidelines for Health Supervision of Infants, Children, and Adolescents and an opportunity to creatively brainstorm ways to use Bright Futures materials in conversations about hot topics such as social media use, sexuality, and social determinants of health.

WEDNESDAY, 4:00-5:00 PM

BREAKOUT SESSIONS

6. Developing and Supporting Remote Work Teams

Naomi Sandweiss, MA, Executive Director, Parents Reaching Out, NM; **Christopher Tiffany**, Executive Director, Raising Special Kids, NM
Learn how organizations can support remote work teams using high-tech, low-tech and high-touch tools on a minimal budget. You will learn about organization policy considerations, accountability, physical space and professional standards for staff working remotely, or telecommuting. We will cover communication practices and strategies for staying connected with remote staff and cultural considerations, specifically with remote staff that serve Native American communities.

7. We Can't Do This Without You! One F2F HIC's Authentic Partnership with Their States Title V CYSHCN Program

Susan Colburn, BS, CRS State Parent Consultant and Family Voices of AL Co-Director; **Vera L. Spinks**, Parent Consultant, Alabama Department of Rehabilitation Service- Children's Rehabilitation Service
Authentic family engagement in Alabama's Title V CYSHCN program has been enhanced by the strong partnership with the F2FHIC. Presenters will detail the history of this partnership and specific activities that are mutually beneficial to both programs, including data collection efforts and involvement in the Title V Block Grant process. This interactive session will provide time share your partnerships and consider new collaborative opportunities.

8. Family Partners in Research

Charlene Shelton, Program Manager, University of Colorado Anschutz; **Karen Kulthau**, Associate Professor of Pediatrics, Harvard Medical School; **Debbi Harris**, Parent Liaison, Family Voices of MN; **Carolyn Allshouse**, Executive Director, Family Voices of MN; **Tim Edison**, Rivergate Pediatrics; **Amy Hess**, Nationwide Children's Hospital

Increasingly, child health and medical researchers are being urged to partner with families in their research projects. This session will explore what elements are important in successful partnerships; what are "research networks" and what sets network research apart from other types of medical research; examples of family engagement from the Autism Intervention Research Network on Physical Health (AIR-P) and Children and Youth with Special Healthcare Care Needs Research Network (CYSHCN); family engagement innovations developed by the CYSHCN team; and the joys and challenges of braving new frontiers in family engagement.

9. Family Wisdom, Diverse and Underserved Communities, and the Challenges of Intersectionality

Alexandra Fogarty, Program Director, Stone Soup Group; **Brenda Lamkin, M.Ed.**, Executive Director of WVPTI; **Mary Scott, M.Ed.**, Administrative Assistant, WVPTI; **Dana Yarbrough**, Community Supports Specialist, VCU Center for Family Involvement
The Family Wisdom learning collaborative has provided an opportunity for F2Fs and Family Voices affiliates nationwide to share their experiences working with diverse and underserved communities. This session will discuss diverse and underserved communities and intersectionality with the CYSHCN community, illustrated by case studies from learning collaborative participants.

10. History of Family Voices

Betsy Anderson, Former Project Director, Family Voices and Former co-chair AAP FPN and **Julie Beckett**, Co-founder, Family Voices, Family Voices, Board Member; **Nora Wells**, Executive Director, Family Voices

What was happening in health care for families of CYSHCN in the 1960s, 70s, and 80s? What roles did families play in encouraging change? This session will include discussion of the origins of Family Voices and the roles of many partners working with families who have led us to where we are today.

THURSDAY, 9:00-9:45



Keynote *Perspectives from the Maternal and Child Health Bureau*

Dr. Michael Warren, Associate Administrator, MCHB

THURSDAY, 9:55-11:00

BREAKOUT SESSIONS

11. LEAD: Staff Leadership Exploration and Development

Dana Yarbrough, M.S., M.A., Director, Center for Family Involvement @ VCU
Family-led organizations often hire parents for their wisdom and experience. Our job as teammates and supervisors is to build the next generation of family leaders. This interactive session focuses on the who, how and why of leadership development. Attendees will practice using leadership skill assessments and tools, discuss why energy management is more important than time management, and look at generational communication.

12. Consumer Engagement in a Virtual World

Kristi Wees, MSChem, Consumer Engagement Director and Social Media Coordinator, Mountain States Regional Genetics Network
In today's fast past, virtual world, face-to-face in-person meetings and connections with consumers and families are going the way of the dinosaurs (becoming extinct, fast!). While many say this is a travesty, others may find a benefit to this new world of consumer engagement. Learn how to harness today's tools to engage families in a virtual world using video, social media and the importance of real, personal connections.

13. Cultural Broker/Model to Implement in Human Services Agencies

Asha Abdullahi, Somali Cultural, Somali Development Centers; **Olga M. Lopez**, Information Specialist Latino Outreach Coordinator, Federation for Children with Special Needs; **Pat Nemica, MA, PT**, Project Director, Federation for Children with Special Needs
Increasing parent representatives from diverse communities is important. This panel of two cultural brokers from the Somali and Spanish communities will share insights, successes, and challenges of including diverse parent leaders in meaningful ways, and discuss strategies to broaden outreach to diverse communities.

14. Charting the LifeCourse: Path to the GOOD Life Throughout the Lifespan

Crystal Bell, Coordinator, Missouri Family to Family; **Sheri Romblad**, CT Parent to Parent Program Coordinator; **Dylan Maldonado**, CT KASA Co-Chair
The Charting the LifeCourse (CtLC) framework helps individuals and families at any age or stage of life think about what they need to know, identify how to develop integrated supports, and discover what it takes to live the lives they want to live now and in the future. This interactive workshop provides a foundation, practice time, and real-life examples of the successful use of the CtLC Framework.

15. Important Intersections Between Children with Special Health Care Needs and the Child Welfare System: Policy and System Navigation Implications for F2Fs and SAOs

Brooke Lehmann, MSW, JD, Partner, Capitolworks, LLC; **Javi P. Dolif**, Family Navigator, Family Voices Colorado; **Tom Rose**, Chief Executive Officer, CBR YouthConnect

When considering the important intersections between children with special health care needs and the child welfare system, the question to be contemplated is: are all children in the welfare system also children with special health care needs? If they are, what policy changes could/should be made? In addition to these discussions, this session will share tools to help family organizations better support Foster Families parenting children with special healthcare needs, and cover the Family First Prevention Services Act and Kinship Navigation.

THURSDAY, 11:10-12:30

BREAKOUT SESSIONS

16. Executive Director Session: Successful Staff Recruitment & Retention

Rene Averitt-Sanzone, Executive Director, The Parents' Place of MD
Have great staff? How do we keep them? Need great staff? How do we recruit them? All challenging questions that today's leaders need to answer. The work is very rewarding but very hard. Today's workforce looks very different than it did ten or even five years ago. Explore, through interactive discussion, how we recruit and keep staff that make our teams highly effective and advances the mission of our organization.



17. Social Media: New Low-cost Tools for Effective Outreach

Joe La Belle, *Director of Program Impact/Co-Director of FND Social, Family Network on Disabilities*
FND Social, a project of Family Network on Disabilities, develops and implements social media strategies with the goal of achieving inclusive communities. Learn hands-on how to enhance your community reach through social media, whether it's families, students, or other professionals. Social media is no longer optional; it's the new standard.

18. Sharing Community-Based Cultural Signals - Through a Diné Lens on the Navajo Nation

Elvira Dennison, *Family Mentor and Coordinator, Navajo Family Voices, Indian Country Grassroots*; **Josephine Foo, BA, JD, CCSVANW**, *Program Administrator, Navajo Family Voices, Indian Country Grassroots Support*; **Hazel James**, *Diné Community Coordinator, San Juan Collaborative for Health Equity*; **Beverly Maxwell**, *Traditional Mentor, Navajo Family Voices, Indian Country Grassroots*
This session explores culturally responsive practices and acknowledges not only the distinct cultural characteristics, experiences, and perspectives of tribal communities that the presenters are part of and serve in, but subtleties and sensitivities needed in moving back and forth between tribal communities, the larger society and institutions serving them. Presenters will share particular situations and how they are viewed through a whole Diné lens as well as fractured lenses, and concrete examples about what "culturally responsive" means within the principle of k'é.

19. Supported Decision-Making: How to Create a Supportive Network

Jodie Hall, *Southern Maine Regional Support Coordinator*; **Robin Levesque**, *Northern Maine Regional Support Coordinator*; **Carrie Woodcock**, *Executive Director, Maine Parent Federation*
Learn about the least restrictive options to full guardianship with a concentration on Supported Decision-Making. In this interaction session, you will learn about information, workshops, activities, and tools used when working with both the supporters and the youth being supported.

CONFERENCE EVALUATION

Please complete the short paper session evaluation after EACH SESSION and the OVERALL conference evaluation using this link:
www.surveymonkey.com/r/2019FVLC

20. Florida Family Leaders' Network: A Family-Led Statewide Initiative to Build a Network of Family Leaders in Florida

Angela Miney, *Family Partner, University of Florida Pediatric Pulmonary Center*; **Joane White, CCHW**, *Florida Title V Family Leader, DOH FL, Children's Medical Services*

Learn about the Florida Family Leaders' Network (FFLN), a network of Family Leaders and those who support them across community and health care settings. The FFLN shares best practices and provides leadership training to family leaders that enhances the skills they possess as caregivers of CYSHCN. A significant accomplishment of the Network was the inaugural Florida Family Leaders' Summit, a meeting of family leaders and their champions from across Florida.

THURSDAY, 1:30-2:30

Speed Dating for Partnership & Poster Sessions. See conference folder for details.

THURSDAY, 4:00-5:00

Public Policy Panel

Location: Capitol Hill, Dirksen Senate Office Building, Room #SD-G50

Ryan Martin, *Senior Human Services Advisor, Senate Finance Committee*; **Ann Dwyer**, *Senior Health Counsel, Senate Finance Committee*; **Rick Van Buren**, *Health Counsel, House Energy and Commerce Committee*; **Caleb Graff**, *Professional Staff, House Energy and Commerce Committee*; **Stuart Portman**, *Health Policy Advisor, U.S. Senate Committee on Finance*

Take advantage of a rare opportunity to listen to a panel of senior bi-partisan, bi-cameral staff as they discuss health policy priorities in this new Congress. This dynamic panel will share critical information about health care priorities in this new Congress, including F2F funding, as well as provide an opportunity for attendees to share their stories and ask questions of staff about broader health topics. This is a unique forum for a dialogue with staffers whose fingers are on the pulse of the health policies that touch you and your family every day. Come to listen, learn, question, and share.

THURSDAY, 5:30-7:30

Family Voices Reception

Capitol Hill, Hart Senate Office Building, Room 902

FRIDAY, 9:00-10:15

PARTNERSHIP OPPORTUNITIES PANEL



Christina Boothby, *Systems of Care and Medical Home Initiatives, American Academy of Pediatrics*



Margaret Comeau, *Catalyst Center*



Lynda Gargan, *Federation of Families for Children's Mental Health*



Peggy McManus, *Got Transition*



Jonathan Webb, *Association of Maternal and Child Health Programs*

FRIDAY, 10:25 – 11:55

BREAKOUT SESSIONS

21. Family Engagement Strategies for Health Systems Change

Elaine Linn, *Project Leadership Manager, Family Voices of California*
Learn about Family Voices of California's Project Leadership parent advocacy training program and post-training family engagement. This interaction session will share highlights of the project curriculum, implementation, and impact; best practices for improving authenticity in parent engagement with key decision-makers; and how to integrate Project Leadership curriculum into local programming.

22. Partnering in the MCH Block Grant: From Start to Finish to Starting Again!

Diana MTK Autin, *Executive Co-Director, SPAN Parent Advocacy Network*; **Mercedes**

Rosa, *Director, Family to Family Health Information Center, SPAN Parent Advocacy Network*; **Jeannette Mejias**, *Director, Special Education Volunteer Advocates Project, SPAN Parent Advocacy Network*

The Maternal and Child Health block grant guidance is clear: states must partner with families and family organizations in all aspects of the block grant process. This workshop will provide participants with strategies to (a) demonstrate their value-add; (b) engage a wide variety of family and youth perspectives in the block grant process; (c) secure resources to support their meaningful

participation; (d) have the greatest possible influence on the block grant process; and (e) develop a block grant involvement "action plan."

23. Innovative Ways to Use the Care Map

Olga Goncharova-Zapata, *Parent Advocate, Delaware Family Voices* and **Ann Phillips**, *Executive Director, Delaware Family Voices*

Learn about the care map, its original purpose, and the innovative way we have found to effectively use it to help individual families and achieve needed systems change.

24. Child and Adolescent Health Measurement Initiative's (CAHMI) Data in Action and Family Engagement Resources

Christina Bethell, PhD, MBA, MPH, *Johns Hopkins Bloomberg School of Public Health*, **Narangerel**

Gombojav, PhD, MD, *Johns Hopkins Bloomberg School of Public Health*, **Mary Wahl**, MPH, *Johns Hopkins Bloomberg School of Public Health*

Participants will learn to put data from the National Data Resource Center for Child and Adolescent Health into action for improved family and child health at the state and national levels. Participants will also be introduced to family engagement tools that aim to engage families, children, and youth before, during, and after well, routine and chronic care child visits, including the: Well-Visit Planner, Promoting Healthy Development Survey, and CARE-PATH for Kids.

25. Assessing Family Engagement in Systems-level Initiatives

Beth Dworetzky, *Associate Director of Programs, Family Voices*, **Kasey L. Dudley**, *Family to Family-Regional Coordinator, SPAN Parent Advocacy Network*

Family Voices developed a Framework for Assessing Family Engagement and a Family Engagement in Systems Assessment Tool (FESAT) to be released in summer 2019. The FESAT was designed to promote, support, assess, and guide efforts for authentic partnerships between organizations and family leaders working together to develop and implement improved policies, programs, services, and practices. Participants will see a preview of the tool, hear examples of how the tool has been used to date, and hear families' experiences using the tool.

FRIDAY, 12:05 – 1:00

CLOSING



Keynote *The State of the Disability Union 2019*

Rebecca Cokley, *Center for American Progress*



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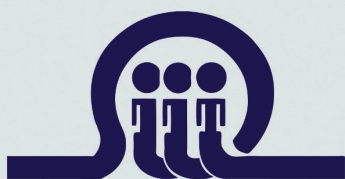
OUR NATIONAL NETWORK OF FAMILY ORGANIZATIONS

At the core of Family Voices are grassroots families supported by MCHB-funded Family-to-Family Health Information Centers (F2Fs) and Family Voices Affiliate Organizations (FVAOs). 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. F2Fs and FVAOs 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.

Family Voices is pleased to welcome F2F grantees in 5 U.S. territories* and 3 F2Fs serving tribal nations**, newly-funded in 2018.

Both F2F & FVAO FVAO ONLY F2F ONLY

AK Stone Soup Group	MA Massachusetts Family Voices @ the Federation for Children with Special Needs	NY Family Voices New York @ Parent to Parent of NYS
AK Alaska Native/American Indian Family to Family @ Stone Soup Group**		OH Ohio Family-to-Family Health Information Center
AL Family Voices of Alabama	MD The Parents' Place of Maryland	OK Oklahoma Family Network, Inc.
AS American Samoa Department of Health*	ME Maine Parent Federation	OR Oregon Health and Science University
AR Arkansas Disability Coalition	MI Michigan Family Voices @ The Arc of Michigan	PA Parent Education & Advocacy Leadership (PEAL) Center
AZ Raising Special Kids	MI Michigan Public Health Institute	PR University of Puerto Rico Medical Sciences Campus*
AZ Indian Country Grassroots**	MN Family Voices of Minnesota	RI Rhode Island Parent Information Network (RIPIN)
CA Family Voices of CA @ Support for Families of Children with Disabilities	MN PACER Center, Inc.	SC Family Connection of South Carolina, Inc.
CO CBR YouthConnect	MO University of Missouri Kansas City Developmental Disabilities Resource Center	SD South Dakota Parent Connection, Inc.
CT PATH Parent to Parent / Family Voices of Connecticut	MP Northern Mariana Islands Commonwealth Healthcare*	TN Tennessee Disability Coalition
DC Advocates for Justice and Education	MS Family Voices of Mississippi, University of Southern Mississippi	TX Texas Parent to Parent
DE Delaware Family Voices, Inc.	MT Parents Let's Unite for Kids (F2F until 5/31/19)	UT Utah Family Voices Health Information Center
FL Family Network on Disabilities of Florida, Inc.	MT University of Montana (beginning 6/1/19)	VA Family to Family Network of Virginia - Center for Family Involvement @ VCU
GA Parent to Parent of Georgia	NC Exceptional Children's Assistance Center (ECAC)	VI Virgin Islands Developmental Disabilities Council, Inc.*
GU Guam Department of Public Health & Social Services*	NC Family Resource Center South Atlantic	VT Vermont Family Network
HI Hilopa'a Family-to-Family Health Information Center	ND Family Voices of North Dakota, Inc.	WA Washington PAVE
IA Family Voices of Iowa @ ASK Resource Center	NE PTI Nebraska	WI Family Voices of Wisconsin, Inc.
ID Idaho Parents Unlimited, Inc.	NH New Hampshire Family Voices	WV West Virginia University's Center for Excellence in Disabilities
IL Family Voices of Illinois/ The Arc of Illinois	NJ Statewide Parent Advocacy Network (SPAN)	WV West Virginia Parent Training and Information (WVPTI)
IN Family Voices Indiana	NM Parents Reaching Out (PRO)	WY UPLIFT - WY Family Voices
KS Families Together, Inc.	NM Parents Reaching Out/ Raising Special Kids (AZ)**	WY Wyoming Institute for Disabilities (WIND)
KY Family Voices of KY/KY Family-to-Family Health Information Center	NV Family TIES of Nevada	
LA Bayou Land Families Helping Families		



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Greetings from
The Arc of Illinois
Family-to-Family Health
Information Center



**Congratulations to Family Voices
on its continued success!**

For over 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!

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programs designed to
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understand the issues
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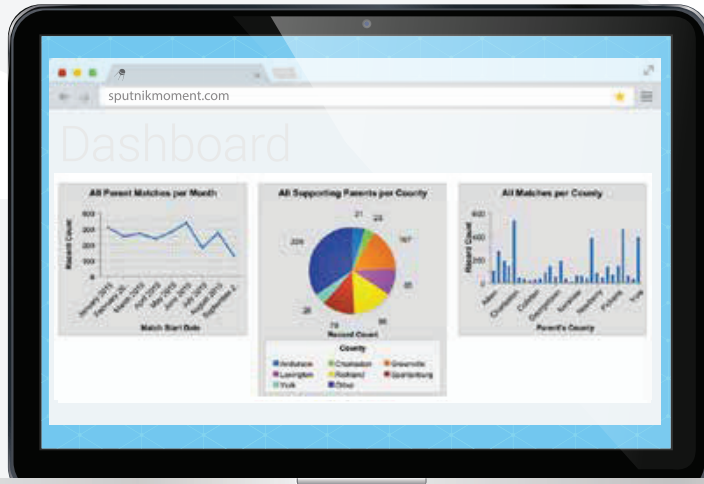
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Life Course Intervention Research Network (LCI-RN)

MCHB recently (2018) funded the Life Course Intervention Research Network (LCI-RN) to create a multisite research infrastructure for designing, testing, and scaling innovative life course interventions.

Anchored by a National Coordinating Center located at UCLA, the LCI-RN includes six Collaborating Research Entities, with a diverse group of experts from research institutions and MCH stakeholder groups.

Leveraging the collective intelligence of a growing life course intervention research community, the LCI-RN will identify better ways of improving life course trajectories for children and families, with a particular emphasis on reducing health disparities among diverse and vulnerable populations. The LCI-RN will be prioritizing family focused interventions that have the potential to improve and optimize health development trajectories.

Over the 5-year grant, the LCI-RN will:

- Design, develop, publish, disseminate, and regularly update an LCI Research Agenda
- Develop and operate an Innovation and Impact Incubator that enables the development of LCI studies
- Launch new multisite LCI research studies
- Provide training on priority topics to network members and cultivate a new generation of LCI researchers through an LCI Scholars Program
- Better understand the role of families, family interventions, and family development in life course health development
- Work to meaningfully engage families in both agenda-setting and the design, implementation, and evaluation of interventions
- Utilize a website, e-newsletters, webinars and publications to accelerate the timely translation of LCI research
- Develop and implement an outreach, engagement, and fundraising plan to ensure network growth and sustainability

In partnership with:



For more information, and to join the LCI-RN, please contact:

Neal Halfon, MD, MPH (Principal Investigator) at nhalfon@ucla.edu or Ericka Tullis, MPP (Project Manager) at etullis@mednet.ucla.edu



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Coverage and Financing of Care for
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Thank you to our colleagues at
Family Voices for the critical work
you do in shaping systems
change on behalf of children and
youth with special health care
needs and their families!

Boston University School of Social Work
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NCHAM is funded in part by a cooperative
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Resources and Services Administration
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Health and Human Services.



Powerful Partnerships

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with thanks to
Allen Fisher

Family Voices Staff are proud to support the Family Voices Affiliate Organizations and F2Fs.

Thank you for all you do for families!



HILOPA'A



God couldn't be everywhere, and therefore He made Mothers.

-Kipling

Josie & Puna, you will always be in our hearts...

Mahalo for your aloha

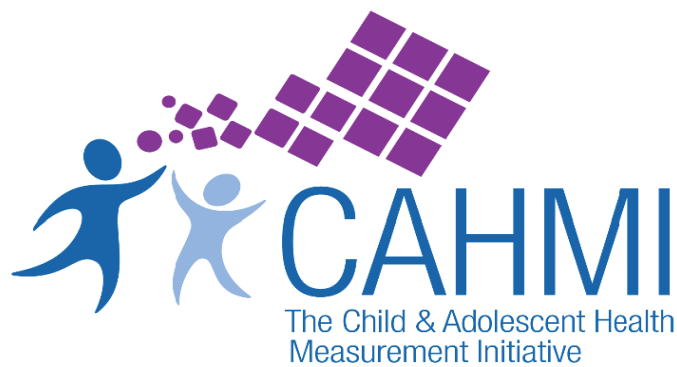
A	Akahai – kindness expressed with tenderness
L	Lōkahi – unity, expressed with harmony
O	Olu'olu – agreeable, expressed with pleasantness
H	Ha'aha'a – humility, expressed with modesty
A	Ahonui – patients, expressed with perserverance



Lei aloha na'u, lei makamae

Josephine Callahan Woll March 29, 1941 – May 17, 2018

Leonetta Keolaokalani Kinard December 29, 1925 – May 15, 2018



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Data In Action



The CAHMI works to provide hands-on access to maternal and child national, state and regional data findings so that individuals can utilize the data for advocacy, policy work, and education. The **Data Resource Center (DRC)** allows users to access data from population-based surveys to improve child, youth, family and community health and well-being in the nation. Visit the DRC online www.childhealthdata.org.



The **Maternal Child Health Measurement Research Network (MCH-MRN)** provides a platform to support and advance efforts related to MCH measurement to improve outcomes and systems performance for the nation's children, youth, and families. The **MRN Compendium** features 1000+ measures on maternal, child, adolescent, and family health. Visit the MRN online at www.mch-measurement.org.

Putting Families at the Center

CAHMI's work is focused on giving families a voice in their health care at all levels. The **Cycle of Engagement** tools build the provider and family relationship through engaging families in the well-visits of their children. These tools include the **Well-Visit Planner** and the **Promoting Health Development Survey**. The CAHMI is developing the **CARE_PATH for Kids** model and tools to engage families with children with special health care needs in building shared plans of care focused on family's priorities, goals and needs.





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

We warmly recognize Family Voices during their 2019 Leadership Conference as they help *"Families as Partners Shaping Systems Change"*




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*We are honored to support the
Family Voices Network and the
2019 Family Leadership Conference*

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