

2016

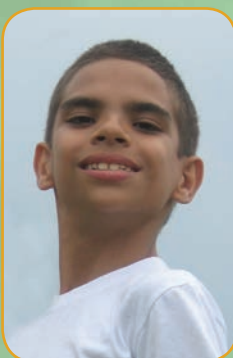
FAMILY LEADERSHIP CONFERENCE

Expanding our Reach, Impacting the Future



Wednesday & Thursday
March 30-31, 2016

HRSA Headquarters
5600 Fishers Lane
Rockville, MD





Sometimes
making a
difference
makes
all the
difference
in the
world.

Proud sponsor of the
**2016 National Family
Leadership Conference**



2016 NATIONAL FAMILY LEADERSHIP CONFERENCE

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FAMILY LEADERSHIP CONFERENCE

Welcome to the 2016 National Family Leadership Conference: Expanding our Reach, Impacting the Future!

We are delighted that you have joined us.

We thank MCHB for providing this lovely new conference space and for their support through the FamilyVoices National Center for Family Professional Partnerships (NCFPP) and the Family-to-Family Health Information Centers (F2F HICs). We also thank the many sponsors who helped to make this conference possible.

We are excited to welcome 78 participants who indicated that this is their first FamilyVoices or Family Leadership Conference. Whether you are new to this conference, or a seasoned veteran, be sure to meet someone new and learn about their work, explore shared goals, challenges and vision.

The focus of this conference, expanding our reach, impacting the future, was determined by input from family leaders across the county. We hope you will experience many opportunities to learn from your peers and partners as you participate. An important element of the meeting are sessions around engaging and supporting family leaders from diverse communities. This reflects a shared belief that the participation of families of all racial, ethnic and socio-economic groups at a new level of leadership is critically important to improving the health disparities so many families experience.

During the meeting, we will pause to reflect on the legacy of four extraordinary MCHB Champions of Children's Health whose authentic and profound belief in the importance of partnership with families has helped us reach where we are today. Great progress has been made toward their vision of a family-centered community based system of care, yet more remains to be done. We applaud MCHB's ongoing commitment to authentic partnership with family leadership as key in this progress. At a Reception on the Hill, we recognized Champions of Children's Health who laid essential policy groundwork for improved health care for children and families. The MCHB and family leaders here today know that the vision and passion to carry this work forward is now in our hands. In the words of President John F. Kennedy, ***"the torch has been passed to a new generation."***

It is especially timely that we are meeting in our nation's capital to share our talents and passion. 2016 is the 10th anniversary of the Family Opportunity Act that provided funding for F2F HICs in every state and the District. Millions of families of children with special health care needs have been helped by the F2F HICs! Much progress in policies and programs has been made. Nevertheless, many challenges remain. We all know that these challenges will not be overcome without family leaders and many partners working together.

We hope you enjoy the next two days and take away innovative strategies and renewed passion that will strengthen our collective impact on systems serving the health care needs of children with special needs and all children.

As Helen Keller said, "Alone we can do so little; together we can do so much."

Thank you for coming and enjoy the meeting!

g!



Marcia O'Malley, President

A handwritten signature in black ink that reads "Marcia J. O'Malley".



Nora Wells, Executive Director

A handwritten signature in black ink that reads "Nora Wells".

CONFERENCE SPONSORS

FamilyVoices gratefully acknowledges the support of the Health Resources and Services Administration, Maternal and Child Health Bureau, Division of Services for Children with Special Health Needs for providing funding for this meeting through cooperative agreement #U40MC00149, the National Center for Family/ Professional Partnerships. We also thank the Health Resources and Services Administration for donating the beautiful conference space. This meeting would not have been possible without the generous support of our sponsors:

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Speak Now for Kids is a national online network of parents, grandparents, teachers, nurses, doctors, hospital workers, teens – **people like you** who care about how kids' health care affects our future.

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to partner with**
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of children, youth, and families.**



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FAMILY LEADERSHIP CONFERENCE

SCHEDULE AT A GLANCE

Tuesday, March 29:

5:30-7:30 pm

Dirksen Senate Office Building, Room 562

Honoring Champions of Children's Health Reception

Wednesday, March 30:

8:00am – 5:00pm

8:00am – 9:00am

9:00am – 9:30am

9:30am – 10:45am

10:45am – 11:00am

11:00am – 12:15pm

12:15pm – 1:00pm

1:00pm – 1:45pm

1:50pm – 3:15pm

3:15pm – 3:30pm

3:30pm – 5:00pm

Pavilion, HRSA Headquarters, 5600 Fishers Lane, Rockville, MD

Registration

Continental Breakfast

Welcome from Family Voices and the
Maternal and Child Health Bureau

Plenary

Break/Networking

Breakout Sessions

Networking Lunch

Plenary: MCHB Legacy and Award Celebration

Breakout Sessions

Break/Networking

Breakout Sessions

Thursday, March 31:

8:00am – 2:00pm

8:00am – 9:20am

9:10am – 9:20am

9:20am – 10:30am

10:30am – 10:40am

10:40am – 11:50am

11:50am – 12:25pm

12:25pm – 12:45pm

12:50pm – 1:50pm

1:50pm – 2:00pm

Pavilion, HRSA Headquarters, 5600 Fishers Lane, Rockville, MD

Registration

Continental Breakfast - Roundtable Discussions

Break/Networking

Plenary

Break/Networking

Plenary

Networking Lunch

Lunchtime Presentation

Regional Breakouts

Adjourning Remarks

SCHEDULE

Tuesday Evening, March 29, 5:30-7:30pm:

FROM THE HEART: HONORING CHAMPIONS OF CHILDREN'S HEALTH RECEPTION

Dirksen Senate Office Building, Room 562, Washington, DC

Family Voices celebrates the outstanding leadership of three individuals who have been true policy champions of the rights of families of children and youth with special health care needs.

2016 marks the 10th anniversary of the Family Opportunity Act, which included funding for Family-to-Family Health Information Centers (F2F HICs) in every state and DC. F2F HICs help millions of families of children with special health care needs navigate health care systems, take on critical roles as partners in their children's care, and participate at the systems level to improve health care for children.

We are very pleased to honor Ms. Garner, Mr. Whitlock, and Ms. Mann for the fundamental roles they have each played in championing the roles of families as key partners in ensuring quality health care for children, including supporting F2F HICs and other programs and policies that benefit children with special health care needs or disabilities and their families.

Families of children with special health care needs across the country thank Ms. Garner, Mr. Whitlock and Ms. Mann, recognizing the profound impact of their work on the daily lives of children and families!

Family Voices gratefully acknowledges the reception supporters:



***The Honorable Charles Grassley
United States Senate (Iowa)***

Anthem

Children's Hospital Association

***Lucile Packard Foundation
for Children's Health***

CONNIE GARNER



Former Policy Director for Disability and Special Populations to the U.S. Senate Committee on Health, Education, Labor and Pensions (HELP) and staff to the late Senator Edward M. Kennedy of Massachusetts

RODNEY WHITLOCK



Former Health Policy Advisor and Acting Health Policy Director for Senator Chuck Grassley of Iowa, Chair of the Senate Finance Committee

CINDY MANN (in absentia)



Former Deputy Administrator and Director of the Center for Medicaid and CHIP Services and founder and Director of the Center for Children and Families at the Georgetown University Health Policy Institute

FAMILY LEADERSHIP CONFERENCE

SCHEDULE

Wednesday, March 30, 2016:

FAMILY LEADERSHIP CONFERENCE

Pavilion, HRSA Headquarters, 5600 Fishers Lane,
Rockville, MD 20852

➤8:00am – 5:00pm

REGISTRATION OPEN

➤8:00am - 9:00am

CONTINENTAL BREAKFAST

➤9:00am - 9:30am

WELCOME FROM FAMILY VOICES AND THE MATERNAL & CHILD HEALTH BUREAU (MCHB)

Marcia O'Malley, President, Family Voices Board of Directors
Nora Wells, Executive Director, Family Voices
Debra Waldron, MD, MPH, FAAP, Director, MCHB Division of Services for
Children with Special Health Needs (DSCSHN)
LaQuanta Smalley, Public Health Analyst, MCHB DSCSHN
Tigisty Zerislassie, Public Health Analyst, MCHB DSCSHN

➤9:30am - 10:45am

GREETINGS FROM THE MCHB OFFICE OF THE ASSOCIATE ADMINISTRATOR

Laura Kavanagh, Deputy Associate Administrator, MCHB

FAMILY LEADERSHIP MOVING FORWARD: COLLABORATION AND THE IMPORTANCE OF CONSTITUENT VOICES IN SYSTEMS CHANGE

Family leaders know the importance of having the voice of families at the table. In order for systems to effectively meet the needs of those they are intended to serve, we need to hear from those impacted by that service or policy. How do we effectively engage those family and youth voices? In this session we will hear from expert presenters from Community Catalyst, a renowned national advocacy organization dedicated to engaging constituents, a state F2F, and a state Medicaid program who will each share ways to successfully engage families of children and youth with special health care needs (CYSHCN) at all levels of a system.

Facilitator:

Josie Thomas, Executive Director, Parents Place of Maryland

Speakers:

Eva Marie Stahl, Project Director, Community Catalyst Alliance for Children's Health
Joni Bruce, Executive Director, Oklahoma Family Network
Nico Gomez, Chief Executive Officer for the Oklahoma Health Care Authority (virtual participation)

➤10:45am - 11:00am

BREAK/NETWORKING



➤ 11:00am – 12:15pm

BREAKOUT SESSIONS (Choose one of three)

1) RECRUITING, TRAINING, & SUPPORTING UNDERSERVED FAMILIES IN LEADERSHIP

With the growing diversity of the US population, many family leader organizations are making efforts to achieve workforce diversity and to support family leaders in representing the needs of diverse communities in systems. There are wonderful benefits to employing individuals with different cultural, racial and linguistic backgrounds and supporting diverse leaders to serve in meaningful systems change. However, engaging families from diverse backgrounds can present what may seem, at first, to be a daunting challenge. In this session, F2Fs and SAOs who have faced these challenges will share successful strategies they have used to recruit, train and provide ongoing mentorship to culturally, racially and linguistically diverse and underserved families that serve in leadership roles for CYSHCN. They will also provide insight on overcoming challenges they have encountered.

Facilitator:

Rita Maldonado, Public Health Analyst, MCHB Division of MCH Workforce Development

Speakers:

Jennifer Akers, Project Director, Family Voices Indiana

Aura Roblero, Bilingual Specialist, Family Voices Indiana

Leolinda Parlin, Director, Hilopa'a Family-to-Family Health Information Center and Hawai'i MCH LEND Program (virtual presentation)

2) CULTURAL IMPLICATIONS OF HEALTH LITERACY

Health literacy is the degree to which individuals have the capacity to obtain, process, and understand basic health information and services needed to make appropriate health decisions. Health Literacy often impacts far more than we realize; it is much more than the wordsmithing of a website or brochure. Today, for many Americans, everyday signs, medical directions, school notices, applications, social service information and other print and web based material are daily challenges. When you add to this challenge race, ethnicity, cultural and linguistic differences you often have the cocktail for a true cultural health literacy barrier. Learn about how culture impacts health literacy.

Facilitator:

Christine Ramey, Deputy Director, HRSA Office of Health Equity

Speaker:

Eva Marie Stahl, Project Director, Community Catalyst Alliance for Children's Health

3) SUPPORTED DECISION MAKING (SDM)

Most people are not aware that, under Article 12 of the United Nations Convention on the Rights of Persons with Disabilities (<http://www.un.org/disabilities/convention/conventionfull.shtml>), people with disabilities enjoy legal capacity—capacity for rights and capacity to act—on an equal basis with others in all aspects of life. States have a duty to provide persons with disabilities access to the supports they may require to exercise their legal capacity. States must ensure that these measures provide for safeguards to prevent abuse that are both proportional and tailored to the individual's circumstances. As youth move into more independent lives, parents may struggle with this concept and how to most effectively support an emerging adult. The National Center on SDM will discuss an effective approach to maximize the capacity of youth and young adults with disabilities to make decisions within a supportive team – “supported decision-making,” a model that honors the personhood of people with disabilities and that represents an alternative to guardianship. The NJ F2F will discuss how they have encouraged the use of Supported Decision Making in New Jersey, particularly in school IEPs and Individual Support Plans for youth and young adults.

Facilitator:

Bev Baker, Co-Director of the National Center for Family/Professional Partnerships (NCFPP), Family Voices

Speakers:

Jonathan Martinis, Esq., Senior Director for Law and Policy, Burton Blatt Institute at Syracuse University

Diana Autin, Esq., Executive Co-Director, Statewide Parent Advocacy Network (SPAN), New Jersey

FAMILY LEADERSHIP CONFERENCE

➤ 12:15pm – 1:00pm

NETWORKING LUNCH

➤ 1:00pm – 1:45pm

PLENARY: MCHB LEGACY AND AWARD CELEBRATION

Special remarks from Dr. Michael C. Lu, MD, MS, MPH, Associate Administrator, MCHB, will honor family leaders and supporting leaders from the past, present, and future. Remarks delivered on behalf of Dr. Lu by speaker:

Laura Kavanagh, Deputy Associate Administrator, MCHB

The extraordinary development of family leadership in health as we know it today would not have been possible without the visionary leadership and support of influential leaders within MCHB. Please join us in remembering this legacy and recognizing and honoring the significant contributions of four of those leaders: Merle McPherson, MD; Bonnie Strickland, PhD; Diana Denboba; and Kathy Bishop, PhD (posthumous).

Nora Wells, Executive Director, Family Voices

Kau'i Rezentes, Ho'okele Kokua, Hilopa'a F2F HIC

Jennifer Bolden Pitre, Program Coordinator, Family Voices

Tara Townsend, Family Voices Coordinator, Rhode Island

Parent Information Network

HONOREES

MERLE MCPHERSON, M.D., M.P.H.



Dr. Merle McPherson is a legend and hero to Family Voices and scores of others involved in the world of children with special health care needs (CYSHCN). From 1987 until 2007, Merle directed the Division of Services for Children with Special Health Needs (DSCSHCN) at the Maternal and Child Health Bureau (MCHB). She played a revolutionary role – under her leadership, the MCHB program for “crippled children” evolved into a program focused on a family-centered, coordinated community based system of services. She brought families in to this revolutionary process as partners and co-creators. To Merle we owe thanks for MCHB funding of family-led initiatives and MCHB respect for authentic partnership with families. Merle’s leadership was a catalyst and an inspiration for the establishment of Medical Homes, a definition of CYSHCN, six core components of a system of services, a national survey of families. In 2001 Merle received the Presidential Rank of Distinguished Executive for fostering partnerships and community solutions. Her vision and goals live on in the family and professional networks she helped to create. The torch has been passed to each of us striving to achieve family-centered care for all children through effective partnerships. Family Voices is humbled to honor Merle as a “Champion of Children’s Health”, as her visions continue to lead our way forward toward better systems of care for children and families.

BONNIE STRICKLAND, PH.D.



Bonnie Strickland has worked in the service of children and youth with special health care needs and their families for over two decades as a project officer, branch chief, and ultimately Director of the Division of Services for Children with Special Health Care Needs in the Maternal and Child Health Bureau. In each role, Bonnie used her many talents to build a national framework for robust systems of services for these children and families. She advocated, developed national implementation programs, and authored numerous publications to promote family-professional partnerships; the medical home; early and continuous screening and intervention; adequate health care financing; access to community services; and transition to adult health care, work and independence. She played key roles in the design and development of the National Survey of Children with Special Health Care Needs, always seeking family input, and oversaw analyses and refinements in the survey to more effectively monitor the care experience of children with special health care needs and provide national and state level prevalence estimates using a common definition. Bonnie has received numerous awards for her outstanding dedication to children and families. We are honored to present her with this Family Voices award to recognize her enormous contributions to improving systems of care for children with special health care needs. She is truly a “Champion for Children’s Health.”



In memory of Polly Arango and Katie Beckett and in honor of all families of children with special health care needs, Family Voices of North Dakota hosts a Parent Leadership Institute (Empowering Parents as Leaders), a seven-month training program to prepare families to take next steps in policy/advocacy work.

DIANA DENBOBA



Diana Denboba is the retired Branch Chief of the Integrated Services Branch of the Division of Services for Children with Special Health Needs at the Maternal and Child Health Bureau (MCHB). From her earliest work – as a Head Start teacher and day care consultant in migrant camps, Diana valued families as partners, ensuring that they were partners in the programs she oversaw. During her tenure at MCHB, Diana worked tirelessly to operationalize family-centered care, cultural competence and family-professional partnerships. She collaborated with the Centers for Medicare and Medicaid Services to manage the early Family-to-Family Health Information Centers (F2Fs) and skillfully nurtured this program to maturity, resulting in an F2F in every state. She was the Program Director for Family/Professional Partnerships, Family Centered Care and Cultural Competence and the Project Officer for the Family Voices National Center for Family/Professional Partnerships as well as National Centers on Cultural Competence and Inclusive Communities and the 51 F2Fs. In retirement, Diana continues to make the world a better place – through work with the National Congress of Black Women and its Culture of Disabilities Committee, and the Family Voices Board Subcommittee on Health Equity/Cultural Competence. Family Voices honors Diana as a “Champion for Children’s Health” with deep gratitude for her dedication, leadership and idealism.

KATHY BISHOP, PH.D. (posthumous)



The Family Voices network was deeply saddened by Kathy’s recent passing. A passionate advocate for families and visionary leader at the Maternal and Child Health Bureau (MCHB), Kathy believed that everyone had the capacity and should be given the chance to speak for his or her self, and her life reflected this philosophy. Kathy dedicated her life to social justice. Kathy first worked in the MCH Genetics Program, helping to create strong relationships with the families it served. Working with Merle McPherson, she helped to change the DSCSHCN program orientation from serving “crippled children” to developing a comprehensive system of services for children with special needs. She played a lead role in conceptualizing “family-centered care.” Together with Merle, Kathy encouraged the creation of Family Voices and served on the Family Voices Board for many years, sharing her wise counsel and confidence in families. Kathy then joined academia in the field of social work. Her colleagues noted, “Her contributions as a social work educator, scholar, researcher, consultant, agency adviser, advocate, coalition builder, program developer, and direct service provider were... quite simply ‘amazing.’” Family leaders and the families they serve owe a huge debt of gratitude to Kathy’s vision, dedication and incredible caring. Family Voices honors Kathy as a true “Champion for Children’s Health.”

FAMILY LEADERSHIP CONFERENCE

➤ 1:50pm - 3:15pm

BREAKOUT SESSIONS (Choose one of three)

1) RECRUITING, TRAINING, & SUPPORTING DIVERSE YOUTH LEADERS

The engagement of today's technologically savvy and diverse youth leaders requires a certain skill set and presents particular challenges. F2Fs and Family Voices SAOs who are working with youth will share successful strategies used to recruit, train, and support culturally, racially, and other underserved youth to serve in leadership roles.

Facilitator:

Marie Mann, MD, MPH, Senior Medical Advisor/ Acting Chief, Integrated Services Branch, MCHB DSCSHN

Speakers:

Carmina Cirioli & Nanfi Lubogo, Co-Directors, PATH Parent to Parent/Family Voices, Connecticut

Susan Wood, Ho'okele Kōkua, Hilopa'a Family-to-Family Health Information Center, Hawai'i

Karin Harvey-Olson, Youth Transition Coordinator and Zach Hastings, Youth Advisor, YEAH council, NH Family Voices (virtual participation)

2) DIVERSIFYING FUNDING STREAMS

It is often said that successful businesses have diverse funding sources. Like successful businesses, nonprofits need a sustainable and healthy business model with funding from a variety of sources. This session will address (a) effective approaches to secure funding from a range of sources including grants, contracts, fee for service, events, and individual donors, and (b) how family organizations have used the F2F funding to leverage other funding.

Facilitator:

Todd Rundle, Program Manager for Family Services, West Virginia Family-to-Family Health Information Center

Speakers:

Laura Warren, Executive Director, Texas Parent to Parent

Tami Allen, Program Director, Families Together, Inc., Kansas

3) CULTURAL RECIPROCITY/RESPONSIVENESS DISCUSSION

The cornerstone of a discussion about Cultural Reciprocity is an in-depth analysis of cultural self-awareness and examination of desired outcomes. This session will engage participants in a facilitated discussion about the essential responsibility of family organizations to be responsive to the needs of all families from diverse cultures, races, socio-economic status and other underserved populations, and how we should define our work in this area.

Speakers:

Diana Denboba, National Congress of Black Women, Prince George's County Chapter; FV Cultural Competence Board Committee member (retired Integrated Services Branch Chief, MCHB)

Note Taker:

Kau'i Rezentes, Ho'okele Kōkua, Hilopa'a Family-to-Family Health Information Center



➤ 3:15pm - 3:30pm

BREAK

➤ 3:30pm - 5:00pm

BREAKOUT SESSIONS (Choose one of three)

1) FAMILY/PROFESSIONAL PARTNERSHIPS FOR SYSTEMS CHANGE

When families and professionals work together to share their expertise and knowledge, systems begin to work more effectively for those the system was intended to support. This panel of experts from family-led organizations will share effective strategies, including advocacy and collaboration that they have used to engage others in systems change.

Facilitators:

Tigisty Zerissassie, Public Health Analyst, MCHB DSCSHN
LaQuanta Smalley, Public Health Analyst, MCHB DSCSHN

Speakers:

Gina Pola-Money, Director, Utah Family Voices Health Information Center
Ann Phillips, Executive Director, Delaware Family Voices
Lisa Rossignol, Healthcare Liaison, Parents Reaching Out, New Mexico



2) DEVELOPING & SUSTAINING “VALUE ADD” PARTNERSHIPS

Family organizations can be inundated with “opportunities” to partner with professional organizations, including state and local government agencies. This session will help participants understand the value and nature of the knowledge, skills, and expertise they bring to partnerships; share tools and processes to determine whether potential partnerships add value to their work; and make decisions about which partnerships are “value add.”

Facilitator:

Sylvia Sosa, Public Health Analyst, MCHB Office of Policy and Planning

Speakers:

Diana Autin, Executive Co-Director, Statewide Parent Advocacy Network (SPAN), New Jersey
Doreen Hodges, Director, Family Voices of DC
Kristal Wortham, Executive Director, National Alliance on Mental Illness (NAMI), DC

3) PROMISING PRACTICES IN WORKING WITH DIVERSE FAMILIES

The Family Voices NCFPP Promising Practices initiative is focused on family-identified promising practices in family/professional partnerships that engage perspectives and effectively support families from underserved racial, ethnic, and rural communities. The Family Voices Family Wisdom Project, funded by the Patient Centered Outcomes Research Institute (PCORI), has engaged families from American Indian and Spanish-speaking populations in research around culturally appropriate healthy weight promotion. Each of these initiatives has worked to identify effective practices that may lead to a reduction in disparities in health outcomes and improved access to healthcare and other services in underserved communities. A panel of Family Voices SAOs that have participated in these projects will share what they have learned in their work with diverse, underserved populations.

Facilitator:

Leticia Manning, Public Health Analyst, MCHB DSCSHN

Speakers:

Tami Allen, Program Director & Molika Jenious, Parent Information Specialist, Families Together, Inc., Kansas
Ginger Kwan, Executive Director, Open Doors for Multicultural Families (virtual participation)
Jill McCormick, Director Washington PAVE
Julie Lucero, PhD, MPH, Assistant Professor, UNR (virtual participation)
Angela Lindig, Executive Director, and Rosario Beagarie, Parent Leader, Idaho Parents Unlimited

FAMILY LEADERSHIP CONFERENCE

SCHEDULE

Thursday, March 31, 2016:

FAMILY LEADERSHIP CONFERENCE

Pavilion, HRSA Headquarters, 5600 Fishers Lane,
Rockville, MD 20852

➤8:00am – 2:00pm

REGISTRATION OPEN

➤8:00am - 9:20am

CONTINENTAL BREAKFAST

➤8:00am - 9:10am

ROUNDTABLE DISCUSSIONS

Roundtable discussions offer further opportunities for networking and sharing of resources including ideas generated in the breakout sessions and around other topical areas of interest.

➤Best Practices in Recruiting, Training, & Supporting Underserved Families in Leadership

How has your family organization supported leadership development for diverse families? Do you struggle with knowing where to begin? Let's learn together about approaches that have worked for others.

Facilitators:

Mercedes Rosa, Director, Family-to-Family Health Information Center, Statewide Parent Advocacy Network (SPAN), New Jersey

Deepa Srinivasavaradan, Family Resource Specialist, Statewide Parent Advocacy Network (SPAN), New Jersey

➤Family/Professional Partnerships for Systems Change

Are you engaging families in systems change? What are some of the partnerships that have been successful in your state? Join us to share your strategies and learn what your fellow family organizations have accomplished.

Facilitator:

Gina Pola-Money, Director, Utah Family Voices Health Information Center

➤Best Practices in Recruiting, Training, & Supporting Diverse Youth Leaders

Trying to get a youth group off the ground? Come share your strategies and learn how others have managed to successfully engage youth.

Facilitators:

Robin deAlmeida, Marketing & Outreach Manager, New Hampshire Family Voices

➤Supported Decision-Making for Youth/Young Adults with Special Healthcare Needs

Supporting our young adult children to move into adult lives is a common challenge for parents. How do we help parents to make decisions within a supportive team and find alternatives to guardianship?

Facilitators:

Dana Yarbrough, Director, Center for Family Involvement, Virginia Commonwealth University

Kathy Brill, Executive Director, Parent to Parent USA



➤ **Developing & Sustaining “Value Add” Partnerships**

Come prepared to share partnerships you have developed, or learn from others the creative approaches they have used to develop partnerships that make a difference.

Facilitator:

Diana Autin, Esq., Executive Co-Director, Statewide Parent Advocacy Network (SPAN), New Jersey

➤ **Diversifying Funding Streams**

Family organizations frequently struggle with too much work and not enough funds. Join us to learn from others and share your strategies for leveraging other funding.

Facilitator:

Tami Allen, Program Director, Families Together, Inc., Kansas

➤ **Cultural Implications of Health Literacy**

Do you have strategies for helping families understand basic health information and services in order to make appropriate health decisions? Join us to share those strategies and to learn what works to overcome cultural barriers in health literacy.

Facilitator:

Wendy Jones, Director, Children & Youth with Special Health Care Needs Project, National Center for Cultural Competence

➤ **Parent Leaders as Block Grant Reviewers**

Family involvement in block grant reviews is a valuable resource to Title V programs. Learn what others are doing and how to get positioned to be a reviewer.

Facilitators:

Trish Thomas, Director of Diversity and Outreach, Family Voices

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

Chris Dykton, Western Branch Chief, Division of State & Community Health, MCHB

➤ **Implications of Adverse Childhood Experiences (ACEs) Research & Implications for Families of Children with Special Healthcare Needs**

Adverse Childhood Experiences are potentially traumatic events that can have negative, lasting effects on health and well-being. These experiences range from physical, emotional, or sexual abuse to parental divorce or the incarceration of a parent or guardian. Come learn about the Child and Adolescent Health Measurement Initiative's (CAMHI) work in this area and share your thinking and experience about this important issue.

Facilitators:

Christina Bethell, PhD, MPH, MBA, Director, Child and Adolescent Health Measurement Initiative

Michele Solloway, PhD, Senior Research Associate, Child and Adolescent Health Measurement Initiative



FAMILY LEADERSHIP CONFERENCE

➤ 9:10am – 9:20pm

BREAK/NETWORKING

➤ 9:20am -10:30am

PLENARY: YOUTH LEADERSHIP DEVELOPMENT

Professionals and families recognize the importance of having the voice of youth at the table. This panel of four diverse young adult advocates from youth/young adult advocacy organizations will share their personal advocacy and leadership journeys as well as their “tips” for family organizations to more effectively work with, mentor, and support the development of youth leaders and their engagement in advocacy.

Facilitator:

Patience White, MD, Co-Director, Got Transition: The Center for Health Care Transition Improvement

Speakers:

Jennifer Thomas, Youth Development Specialist, National Collaboration on Workforce and Disability for Youth (NCWD)

Ian Watlington, Consultant, Family Voices Kids As Self Advocates (KASA)

Natalia Rivera Morales, Leadership Programs Coordinator, Autistic Self-Advocacy Network (ASAN)

Antonio Robinson, Youth Advocate, Youth MOVE (Motivating Others through Voices of Experience)



➤ 10:30am -10:40am

BREAK/NETWORKING

➤ 10:40am -11:50am

PLENARY: LESSONS LEARNED IN DEVELOPING & SUPPORTING DIVERSE PARENT LEADERS

The Family Voices Polly Arango Mentoring Initiative was established as a legacy to Polly's lifelong commitment to leadership development of families from diverse cultural and linguistic backgrounds. Last year, four Family Voices State Affiliate Organizations (FV SAOs) were awarded funds to develop mentorship programs to build the leadership skills of such families in their states. Three of the participating FV SAOs will present lessons learned from their Arango projects and how the Arango Mentoring Initiative impacted their organization's work with diverse families.

Facilitator:

Jennifer Bolden Pitre, Esq., Program Coordinator, Family Voices

Speakers:

Marlyn Wells, NC Family Voices Program Coordinator, & Magnolia Elquere, Family Leader, Exceptional Children's Assistance Center (ECAC), North Carolina

Karen Thompson, Executive Director, & Anahi Abarca, Family Support Coordinator/Hispanic Outreach Coordinator, ASK Resource Center, Iowa

Mary J. Elam, Executive Director, Stone Soup Group, Alaska



➤ 11:50am – 12:25pm

NETWORKING LUNCH

➤ 12:25pm - 12:45pm

LUNCHTIME PRESENTATION: FAMILY LEADERSHIP WITHIN TITLE V AND MCH WORKFORCE DEVELOPMENT

MCHB Divisions and Offices work collaboratively to increase inclusion of family leadership within each of its program areas. Specifically, the MCHB Division of State and Community Health partners with State agencies to administer the Title V Block Grant program, through which family engagement is a key program requirement. In addition, the Division of MCH Workforce Development provides leadership and oversight of several programs that offer leadership development opportunities for aspiring and seasoned family leaders, including the Leadership and Education in Neurodevelopmental Disabilities (LEND) program and the Workforce Development Center (WDC). Specifically, the WDC works to increase the workforce capacity for State Title V program leaders and partners to meet current public health MCH policy and programmatic imperatives. Division directors will share their perspectives of Title V and family leaders working together to support family leadership within MCH workforce at all levels.

Facilitator:

Tamara Bakewell, Project Coordinator, Family-to-Family Health Information Center, Oregon Health and Science University

Speakers:

Ellen Volpe, Eastern Branch Chief, Division of State and Community Health, MCHB
Lauren Ramos, Director, Division of Workforce Development, MCHB

➤ 12:50pm - 1:50pm

REGIONAL BREAKOUTS

The Regional Breakout sessions will provide time for family leaders and partners to network, and share ideas and accomplishments. Participants will have the opportunity to: share with family leaders in their region the ongoing work of reaching out and engaging youth and family leaders, especially from diverse communities; recognize and acknowledge where the work is innovative and making positive contributions to the MCH workforce; and identify technical assistance needs to enhance efforts to engage emerging youth and family leaders. MCHB staff have been invited to attend these regional breakouts to learn about the many initiatives in which family organizations are engaged.

Facilitators:

Region 1: Zayli Bocanegra, Latino Outreach Coordinator and Mercedes Rosa, Director, NJ Family to Family Health Information Center, Statewide Parent Advocacy Network (SPAN)

Region 2: Bryan Cozart, Director, Arkansas Disability Coalition and Keishawna Smith, Family to Family Coordinator, Institute for Disability Studies, The University of Southern Mississippi

Region 3: Barbara Katz, Co-Director, Family Voices of Wisconsin

Region 4: Kau'i Rezendes Ho'okele Kōkua, Hilopa'a Family-to-Family Health Information Center and Donene Feist, Executive Director, Family Voices of North Dakota



➤ 1:50pm - 2:00pm

ADJOURNING REMARKS

Nora Wells, Executive Director, Family Voices

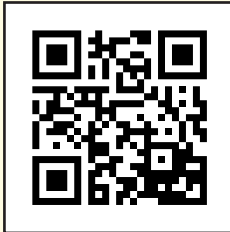
FAMILY LEADERSHIP CONFERENCE

GENERAL INFORMATION



Meeting Feedback

Your feedback about this event is **IMPORTANT** to us! At the end of each session, you will be asked to complete a very brief evaluation. At the conclusion of the conference, please provide your overall feedback online at: <https://www.surveymonkey.com/s/2016FLConf> or scan the QR code above.



Throughout the conference, we encourage you to use the "Take Aways" form included in your registration packet to record key ideas, information, and strategies that you want to remember or take action on later



Participate in our Video Feedback Pilot while here at the conference!

During the conference we are piloting a new method of gathering stories, input, and feedback using interactive video technology. Take 5 minutes to participate in this fun opportunity! See the flyer in your registration packet for more details.



Internet Access

While inside the HRSA building, you may access the internet by connecting to the "HRSA-GUEST" wireless network.



First Time Participants

Is this your first time attending a Family Leadership conference? Welcome! We are very excited to have many new family leaders or first time attendees join us for this event. If this is your first time attending a FamilyVoices or Family Leadership meeting, please let us know at the registration table so we can provide a heart sticker for your name tag. This will let others know and encourage them to introduce themselves to you. Family Voices staff are also available to introduce and connect you to others in your state, region or with a similar interest. Let us know how we can help you feel welcome and included.

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FAMILY LEADERSHIP CONFERENCE

ABOUT FAMILY VOICES

OUR MISSION

Family Voices aims to achieve family-centered care for all children and youth with special health care needs and/or disabilities. Through our national grassroots network, we provide families with resources and support to make informed decisions, advocate for improved public and private policies, build partnerships among families and professionals, and serve as a trusted resource on health care.

OUR VISION

Every child and youth with special needs receives family-centered care.

OUR PRINCIPLES

- **Family-centered care.** Because families are at the center of a child's life, they must be equal partners in decision-making and all aspects of the child's care. Family-centered care is community-based, coordinated, culturally and linguistically competent, and guided by what is best for each child and family.
- **Partnerships.** Family-centered care is based upon strong and effective family-professional relationships built within the context of families' and professionals' cultural values and practices to improve decision-making, enhance outcomes, and assure quality.
- **Quality, access, affordability and acceptability.** Children with special needs deserve primary and specialty health care that is of high quality, affordable, within geographic reach and respectful of family and community culture.
- **Health systems that work for families and children.** Health policies and systems built on a foundation of family-centered, culturally and linguistically competent care must be the standard for all children.
- **Informed families/strong communities.** Like their peers, children with special needs deserve every opportunity to enjoy a happy and healthy childhood at home in their communities. Families equipped with reliable, accurate information about ways to support their child's health, education and social development will help them grow into productive adults as defined by their personal, family and community cultural beliefs and values.
- **Self-advocacy/empowerment.** When informed and supported, young people with disabilities can make choices and advocate for themselves.



OUR WORK

Family Voices is a national family-led grassroots organization that works to keep families at the center of children's healthcare. Incorporated in 1992, Family Voices has been built by a dynamic network of family and youth leaders and friends across the country. It brings a respected family perspective to improving health care programs and policies, ensuring that health care systems include, listen to, and honor the voices of families. Family leaders in every state provide information, assistance, and support to other families of children and youth with special health care needs and/or disabilities across a wide spectrum of diagnoses and health conditions. This network of family leadership is connected and supported by a national Family Voices Board of Directors, staff, and experienced peer leaders. Targeted efforts focus on leadership development of families in the most underserved and diverse communities. Youth leadership is encouraged through Kids as Self Advocates (KASA), a youth self-advocacy project. Under a cooperative agreement with the Maternal and Child Health Bureau, Family Voices provides technical assistance to 51 Family-to-Family Health Information Centers around the country through information-sharing, listservs, social media, webinars, distance and on-site peer technical assistance, meetings, partnership opportunities and publications. Family Voices has strong partnerships with provider and professional groups through which we work to promote quality family-centered care and to bring family perspectives to decision making arenas. Family Voices monitors federal and state legislation and provides information to help families and family leaders understand and influence legislation and policy at the state and national levels to support the complex needs and situations of families.

OUR PROJECTS

NATIONAL CENTER FOR FAMILY/PROFESSIONAL PARTNERSHIPS (NCFPP)

Funded through a cooperative agreement with the Maternal Child Health Bureau (MCHB), the National Center for Family/Professional Partnerships (NCFPP) strives to improve health care delivery and quality of life for all children with special health care needs and their families through promoting effective partnerships between families and professionals. The project assists family organizations such as F2Fs serving families of children and youth with special health care needs (CYSHCN), connecting them for peer support and helping them partner with state Title V programs and other partners to work toward full implementation of the Affordable Care Act (ACA), a strengthened workforce, and improved family access to a system of services. Through a one year supplement, the NCFPP is gathering information about family leadership development needs and activities across other MCHB funded national projects such as Leadership Education in Neurodevelopmental and Related Disabilities (LEND) programs, MCH Workforce Development and Association of Maternal and Child Health Programs (AMCHP) as well as convening family leaders in a national conference.

KIDS AS SELF ADVOCATES (KASA)

Currently funded through private donations, KASA is a national, grassroots network created by youth with special health care needs and/or disabilities for youth. KASA youth are leaders in their communities. They share information to help youth to become more independent and learn advocacy and leadership skills. KASA youth work with health care professionals, policymakers, and other adults in their states to voice their issues, leading to discussions about how to help youth succeed.

POLLY ARANGO MENTORING INITIATIVE

Funded by private donations, this initiative supports Family Voices State Affiliate Organizations (SAOs) in preparing families from diverse cultural and linguistic backgrounds to join a new generation of family leaders that reflects the growing diverse populations within states and our nation, while building the leadership and advocacy of SAOs at the state level. The first cohort included SAOs in Alaska, Iowa, Minnesota, and North Carolina. The second and current cohort includes SAOs in Vermont, Tennessee, and New Mexico.

FAMILY WISDOM RESEARCH PROJECT:

Funded by the Patient-Centered Outcomes Research Institute (PCORI), this project is using peer-led learning to identify approaches to improve healthy weight for children in American Indian and Spanish-speaking communities in Washington and Idaho. A diverse Oversight Committee of collaborators and stakeholders is developing comparative effectiveness research (CER) questions that will drive future research. Research partners include Idaho Parents Unlimited, Washington Partners for Action Voices for Empowerment, community members, researchers, and pediatric healthcare providers.

PARTNERSHIP WITH FRIENDS IN SUPPORT OF the NATIONAL CENTER ON BIRTH DEFECTS AND DEVELOPMENTAL DISABILITIES (NCBDDD)

With funding from Centers for Disease Control (CDC) through the Association of University Centers on Disability, Family Voices supports families in the disability community to act as liaisons to the Executive Committee of the Friends of NCBDDD and to CDC leadership. Family Voices advises the Friends on strategies to enhance communication between families and key target audiences of the Friends including policy makers, non-government organizations, and service providers.



FAMILY LEADERSHIP CONFERENCE

PARTNERSHIP WITH AMCHP ON FAMILY LEADERSHIP:

Family Voices assists AMCHP, through funding from an MCHB cooperative agreement, meeting regularly regarding areas to collaborate around family professional partnerships including educating families about Block Grant reviews; gathering feedback from family Block Grant reviewers; and mentoring and supporting AMCHP Family Scholars within their states.

NATIONAL DISABILITY NAVIGATOR RESOURCE COLLABORATIVE (NDNRC)

Partnering with the American Association on Health and Disability (AAHD), this project is funded by the Robert Wood Johnson Foundation. Family Voices assists selected Family Voices SAOs to collaborate on Community Outreach in their states for increasing the enrollment of people with disabilities in ACA marketplace plans. Participating SAOs share lessons learned with family organizations across the country. FV SAOs in Washington, Indiana, Rhode Island, Colorado, North Dakota, Arizona, Louisiana, Nevada, and Texas are partners in this initiative. Family Voices also created a fact sheet on CYSHCN and the ACA to help Navigators across the country identify issues that families of CYSHCN face in choosing health coverage. The fact sheet is available on the NDNRC and Family Voices websites.

PARTNERSHIP WITH THE AMERICAN ACADEMY OF PEDIATRICS ON EMERGENCY/DISASTER PREPAREDNESS

Family Voices is assisting the AAP in this project funded by the CDC around developing materials to enhance the partnership between families and pediatricians in emergency preparedness. Family Voices is working with family leaders in states with recent experience with disasters to pilot test materials, identify and implement effective dissemination strategies and develop strategies for other effective means to enhance family pediatrician partnerships about preparedness.

PARTNERSHIP WITH CHILD AND ADOLESCENT HEALTH MEASUREMENT INITIATIVE (CAHMI)

Family Voices assists CAHMI in this initiative funded by MCHB and other sources, in their efforts to ensure that children, youth, and families are at the center of quality measurement and improvement efforts. Family Voices provides family perspective by: serving on the Data Resource Center (DRC) National Advisory Committee; providing input from diverse family leaders on the redesign of the DRC website; disseminating information about the DRC and other CAHMI products; providing input from diverse family leaders on materials and uses of the Well Visit Planner; and providing family perspectives on discussions of Adverse Childhood Experiences (ACEs).

ALLIANCE FOR INNOVATION ON MATERNAL AND CHILD HEALTH PROGRAMS (AIM) PROJECTS

Family Voices is advising 5 partners who have funding from MCHB through the AIM initiative, with the purpose of bringing a family perspective to this initiative. The overall purpose of the initiative over the project term is to engage teams from 21 states in activities within MCHB focus areas of improving access to health coverage for pregnant women and children, increasing the implementation of Bright Futures and improving services for CYSHCN.

Family Voices encourages family participation at all levels of the project and the connection of AIM state teams to family organizations. Family Voices participates as invited in project meetings and provides family perspective/family engagement and expertise, as well as disseminates work products to Family Voices audiences. Activities with specific partners are:

Partnership with the American Academy of Pediatrics (AAP) includes helping AAP disseminate a survey to collect information on problems patients/families identify having with access to health care and coverage and collecting more detailed information through phone interviews with selected families in each state participating in the AIM initiative. This information collecting is undertaken through SAOs and F2Fs within states who have indicated their willingness to develop state teams to participate in one of the AIM target areas in their state.

Partnership with National Congress of State Legislators (NCSL) includes advising NCSL on publications and other written work that concern CYSHCN and Bright Futures guidelines for children, including project products that focus on state policies.

Partnership with the Association of State and Territorial Health Officers (ASTHO) includes developing an infographic/case study illustrating successful models of care coordination and services for CYSHCN and a checklist on strategies that State Health Departments can use to help families, especially those from culturally and linguistically diverse families, in the implementation of Bright Futures Guidelines. Family Voices will also develop a

survey to identify family perspectives of Bright Futures Guidelines to assist Public Health and Primary Care training programs.

Partnership with the Association of Maternal and Child Health Programs (AMCHP) includes developing vignettes descriptive of family experiences obtaining coverage under the ACA collected from families in the states.

Partnership with the National Association of State Health Policy (NASHP) includes providing guidance on areas for family engagement, participating in an in-person meeting of state Title V CYSHCN directors, Medicaid agency representatives, families/consumers, provider groups and other leaders to address how to improve access to care for CYSHCN populations, identifying families of CYSHCN to participate and present on project webinars and identifying families of CYSHCN to participate in a focus group conference call to advise on the content of a project issue brief.

SOCIETY FOR GENERAL INTERNAL MEDICINE (SGIM) CONFERENCE PLANNING PROJECT

Funded by Patient-Centered Outcomes Research Institute (PCORI), Family Voices is participating in two cycles of planning for two SGIM international conferences on strategies to improve partnerships between providers and patients and patient roles in patient centered outcomes research. Topics include learning about healthcare systems, the role of the patient advocate, creating a sense of safety for patients engaged in research, validation, accommodation for patients with special healthcare needs, and listening and learning from patients.

SUPPORTED DECISION-MAKING PARTNERSHIP WITH NATIONAL RESOURCE CENTER FOR SUPPORTED DECISION-MAKING (NRC-SDM)

Family Voices, along with Parent to Parent USA, is partnering with Quality Trust for Individuals with Disabilities to establish the NRC-SDM, funded by Administration on Intellectual and Developmental Disabilities/Administration for Community Living (AIDD/ACL). The project is dedicated to increasing the use of Supported Decision-Making for older adults and people with disabilities. Family Voices advises the project by providing input into planning and implementation of activities, conducts outreach to families, and shares resources and training opportunities developed through the project to better inform family leaders, families, and the professionals who support families and youth with special health care needs and disabilities.



FAMILY LEADERSHIP CONFERENCE

OUR PARTNERSHIPS with STATE FAMILY LEADER ORGANIZATIONS

At the core of Family Voices are grassroots families supported by Family-to-Family Health Information Centers (F2Fs) and State Affiliated Organizations (SAOs.) Through this extensive network of family organizations, Family Voices connects to families in communities from whom we gather information about needs and to whom we disseminate important information. The network allows Family Voices to disseminate critical policy information and guidance. We provide technical assistance and opportunities on a wide range of topics and encourage sharing of resources, mentorship, and peer support. This vibrant and sophisticated network keeps the voices of families at the heart of children's health care.

F2Fs are family-staffed organizations that provide information, education, technical assistance and peer support to families of Children and Youth with Special Health Care Needs (CYSHCN) and the professionals who serve them. They work at state, regional and national levels to improve systems and policies that affect children and families, with a particular focus on families of CYSHCN. The F2F network is comprised of organizations in every state and the District of Columbia, each of which receives funding from the Health Resources and Services Administration, Maternal Child Health Bureau through a competitive grant process. F2Fs are supported with technical assistance, training, and resources through the Family Voices National Center for Family/Professional Partnership.

SAOs are nonprofit, family-led advocacy organizations committed to the mission, vision, and principles of Family Voices. There is one SAO per state, which must be a family-led organization with a majority Board of Directors who are families. SAOs engage in systems change in their state and at the national level to improve the quality of health care for CYSHCN and their families. There are currently 44 SAOs. Most F2Fs are also SAOs.

KEY Both SAO & F2F, SAO ONLY, F2F ONLY

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

OUR LEADERSHIP

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OUR LEADERSHIP

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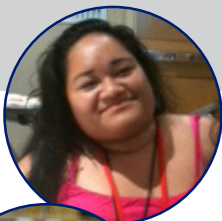
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Promising Practices in Family/Professional Partnerships *Supporting Underserved Racial, Ethnic, and Rural Communities*



The Promising Practices initiative identifies, documents, and shares information about family-identified promising practices in family/professional partnerships and family-centered care that effectively support families from underserved racial, ethnic, and rural communities. The criteria for identifying promising practices were created by a diverse group of family leaders and the selection process was carried out through a process established by this diverse group. The selected practices have been written up to encourage other organizations to adopt these practices, with the potential to reduce disparities in access to healthcare and other services for underserved communities.

Four family-identified Promising Practices that effectively support families from underserved racial, ethnic, and rural communities have been identified. They are:

- Washington's Open Doors for Multicultural Families,
- Families Together, INC., (Kansas);
- North Carolina's Exceptional Children's Assistance Center (ECAC) and
- Texas Children's Health Plan.

Learn more about three of these organizations in a breakout session on Wednesday from 3:30 – 5:00.

Descriptions of the selected initiatives can be found on the Family Voices display table and are posted on our website at <http://www.fv-ncfpp.org/activities/promisingpractices/>.

We invite you to submit an application for a Promising Practice through April 22nd. Applications can be found on the Family Voices display table. Selections will be made and organizations contacted to arrange more in-depth interviews by May 6th.



FAMILY LEADERSHIP CONFERENCE

POLLY ARANGO Mentoring Initiative

The Polly Arango Mentoring Initiative has provided funding for two cohorts of Family Voices State Affiliates to prepare families from diverse cultural and linguistic backgrounds to join a new generation of family leaders reflecting the growing diverse populations within our nation, while building the leadership and advocacy capacity of Family Voices' State Affiliate Organizations (SAOs) at the state level.

Polly Arango, beloved mother, friend and founder of Family Voices, was a passionate advocate for children with special health care needs and their families. Polly served as the first Family Voices Executive Director.

Polly's vision for a nationwide, empowered and vocal voice of families includes the voices of families from diverse cultural and linguistic backgrounds. Polly cultivated new leaders and envisioned the leadership of Family Voices at the state and national levels to reflect the richness and diversity of our nation. Leadership development through mentoring was one of Polly's long-standing passions. To establish a lasting memorial to Polly, Family Voices has used funds from the Polly Arango Memorial Fund and other donations to establish a mentoring program. This mentoring program supports the development and support of emerging family leaders from culturally and linguistically diverse backgrounds.

In 2015, four SAOs were awarded funds to develop mentorship programs to build the leadership skills of underserved families. Family Voices provided guidance and technical assistance to these four SAOs through a learning collaborative that meets monthly to share challenges and strategies to overcome difficulties. Year one recipients and their activities are:

- **Stone Soup Group (SSG) in Alaska** partnered with Alaska's Partners in Policymaking Program (PIP) to facilitate the MAP (Mentor, Advocate, and Partner) Family Project. The training for the project was jointly developed by Stone Soup Group and Alaska PIP following a review of existing curricula from SPAN-NJ, National Family Voices, California's Family Leadership Training, SSG's Navigator Curriculum and PIP's self-advocacy curriculum. Sixteen participants from rural or frontier areas and diverse backgrounds and cultures were trained on topics such as: "Understand Where We've Been to Know Where We're Going," "Telling Your Story," and "Rules of the Road."
- **Access for Special Kids (ASK) in Iowa** hired a bilingual project coordinator to structure outreach activities to identify Spanish-speaking parent leaders. Training was provided to develop an infrastructure of mentors and leaders to increase project sustainability.
- **Exceptional Children's Assistance Center (ECAC) in North Carolina** worked with community partners to identify Spanish-speaking parent leaders. Parent leaders participated in an initial training based on an adapted and translated curriculum and have formed a group, Angeles de Esperanza (Angels of Hope). Mercedes Rosa of SPAN of NJ provided mentorship and support.
- **Family Voices of Minnesota** contracted with a Somali parent volunteer who participated in a training that included project administration, computer instruction, and leadership development on family-centered care, medical home, and communicating effectively with health providers. This parent leader connects with other FV of Minnesota Parent Support Navigators and an international group of Somali women on an ongoing basis and provides support and outreach to other Somali parents.



In 2016, three additional SAOs have recently begun participating in this initiative:

- **Vermont Family Network** is working with former refugees living in Vermont including Somali-Bantu and Bhutanese-Nepali communities with the goal of broadening outreach efforts and connections, and earning the trust of more families from diverse cultural communities.
- **Family Voices of Tennessee** will provide culturally and linguistically effective outreach to families and professionals who serve or support CYSHCN, particularly families from underrepresented and diverse communities with a particular focus on Kurdish and the West African communities.
- **Parents Reaching Out, New Mexico** is providing support for New Mexico families of children and youth with special health care or education needs, especially those who have challenges accessing current systems in rural and frontier Hispanic (monolingual Spanish-speaking) and Native American families.

Learn more about these initiatives in the Thursday morning plenary:
Lessons Learned in Developing & Supporting Diverse Parent Leaders



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Congratulations to Merle, Bonnie, Diana, and Kathy for a lasting legacy of contributions toward the well-being of children with special health care needs.

Paul Newacheck, DrPH



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national youth transitions center

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The Family Voices Staff thanks all of the family leaders, family members, and professionals for the work you do every day realizing our mission - family-centered care for all children and youth with special health care needs and/ or disabilities.



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NOTES

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