



Wednesday, May 8th

12:30-2:30 PM

Welcome, Nora Wells, *Family Voices*

Opening Keynote: The Health Care Justice Movement: Our Time is Now!

Frederick Isasi, JD, MPH,
Executive Director, Families USA

SongRise Performance

Joan Scott, MPP, *Deputy Associate Administrator, MCHB*

Words from our sponsors:

Jennifer Kyle
United Healthcare

Merrill Friedman
Anthem

2:45-3:45 PM

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, MHSA, 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 CYSHCN? 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*

Featuring a panel of diverse family leaders with CYSHCN, this session will provide an overview of the 4th Edition 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 on hot topics such as social media use, sexuality, and social determinants of health. Your input will help shape the future of the FV Bright Futures Family Pocket Guide.

Wednesday 4:00-5:00 PM

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's Authentic Partnership with Their State's Title V CYSHCN Program

Susan Colburn, BS, *CRS State Parent Consultant and Family Voices of AL Co-Director* and **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 their strong partnership with the Alabama F2F. 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 to 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 Minnesota*; **2 parents, coming soon**

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 (CYSHCNet); family engagement innovations developed by the



CYSHCNet 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, West Virginia Parent Training & Education; **Mary Scott, M.Ed.**, Administrative Assistant, West Virginia Parent Training & Information, **Dana Yarbrough**, Community Supports Specialist, Virginia Commonwealth University 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; **Julie Beckett**, Co-founder, Family Voices, Family Voices Board Member; **Nora Wells**, Executive Director, Family Voices
Description coming soon.

Thursday, May 9th

9:00-9:45 AM

Keynote: Dr. Michael Warren, Associate Administrator, MCHB
Perspectives from the Maternal and Child Health Bureau

Thursday 9:55-11:00 AM

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-paced, 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 and **Pat Nemia, MA, PT**,

Project Director, Federation for Children with Special Needs

Including parent representatives from diverse communities in the work of the organization improves the organizations effectiveness. 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/LifeCourse Ambassador* and **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 session provides a foundation, practice time, and real-life examples of the successful use of the CtLC Framework, including a self-advocate who utilized the Charting the LifeCourse framework to build his great life.

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 AM-12:30 PM

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. We 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 interactive session, you will learn about information, workshops, activities, and tools used when working with

both the supporters and the youth being supported.

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* and **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 healthcare settings. The FFLN shares best practices and provides leadership training to family leaders that enhance the skills they possess as caregivers of CYSHCN. A significant accomplishment was the inaugural Florida Family Leaders' Summit; a meeting of family leaders and their champions from across Florida.

Thursday 4:00-5:00 PM

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*

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 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 families every day. Come to listen, learn, question, and share.

Thursday 5:30-7:30 PM

Family Voices Reception

Location: Capitol Hill, Hart Senate Office Building, Room 902

Friday, May 10th

9:00-10:15 AM

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

10:25-11:55 AM

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, NJ*

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 ways 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 PM

Closing Keynote:

Rebecca Cokley, *Director, Disability Justice Initiative, Center for American Progress*

The State of the Disability Union 2019