



# Presenter Biographies

## Asha Abdullahi

Somali Cultural, Somali Development Centers  
[asha.abdullahi35@gmail.com](mailto:asha.abdullahi35@gmail.com)

### **18:** Cultural Broker/Model to Implement in Human Services Agencies

Asha Abdullahi is a former refugee from Somalia, and a mother of a child on the Autism Spectrum. As a member of the nonprofit Somali Development Center (SDC), Asha assists Somali and East African refugee communities in accessing services and education in the context of acculturation. She is also a former Diversity LEND Fellow and engaged in research around identifying signs and milestones of disabilities including Autism. Ms. Abdullah organizes workshops about family engagement and mental health issues with the goal of decreasing cultural myths about disabilities and uses of psychotropic or other medications.

## Betsy Anderson

Former Project Director, Family Voices  
 Former co-chair AAP FPN  
 AAP Family Partnerships Network; Family Voices, MA  
[Betsy11Anderson@gmail.com](mailto:Betsy11Anderson@gmail.com) and (503) 896-8866

### **10:** History of Family Voices

Betsy Anderson is the parent of 3 now adult children, one of whom has substantial special health care needs. Ms. Anderson has worked in health care advocacy for children with special needs for many years and was formerly the Family Voices IMPACT Project Director, funded by the Maternal and Child Health Bureau, with special focus on Bright Futures and Title V initiatives. Currently she works with the American Academy of Pediatrics and is past co-chair of the Family Partnerships Network. She has a long-term interest in family-professional collaboration.

## Patti Archeletta

Family Engagement and Training Specialist  
 Maryland Coalition of Families  
[downtoearthdesign@comcast.net](mailto:downtoearthdesign@comcast.net)

### **I:** Providing Support for CYSHCN at School

Pattie Archuleta develops and implements programs focused on raising the family voice and aimed at improving systems of care for children and youth with behavioral and/or special health care needs. She is active on a variety of local, state, and national initiatives, including a gubernatorial appointment to the Maryland State Autism Workgroup and serving as an advisory committee member to the American Academy of Pediatrics Coordinating Center on Epilepsy. Pattie is also experienced in peer support program development, implementation, and management. She is the parent of a young man with an autism spectrum disorder and a history of epilepsy.

## Diana MTK Autin, JD

Executive Co-Director  
 SPAN Parent Advocacy Network, NJ  
 973-642-8100 x 105, [diana.autin@spanadvocacy.org](mailto:diana.autin@spanadvocacy.org)

**Pre-Conference:** Leading by Convening and  
 Serving on Groups training

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



Diana Autin co-directs the SPAN Parent Advocacy Network and its regional projects, the Navigating Excellence-Parent TA Center and REACH for Transition as well as the National Center for Family Professional Partnerships. She directs the National Center for Parent Leadership, Advocacy, and Community Empowerment (National PLACE), and serves as a Wisdom Council member for the National Center for Cultural Competence, and a consultant for the National Center for Systemic Improvement. She worked with the IDEA Partnership to develop Leading by Convening and the Creating Agreement collection. She serves on the Board of the National Federation of Families for Children's Mental Health (FFCMH) and is on the Advisory Committee for the Region 1 Equity Assistance Center. She recently received the Reclaiming Children Award from the FFCMH in 2018. She is a parent with direct experience navigating systems for CYSHCN. She is of Cajun and Native American (Sioux, Cherokee, and Houma) background.

### **Rene Averitt-Sanzone**

Executive Director

The Parents' Place of MD

[rene@ppmd.org](mailto:rene@ppmd.org)

#### **II: Executive Director Session: Successful Staff Recruitment & Retention**

Rene has served as the Executive Director at Parents' Place of Maryland since June of 2017. Prior to that she worked as the Regional Technical Assistance Co-Director for the OSEP-funded parent centers in the mid-south region. She has held a variety of roles in the field of special education: Parent Educator, Early Childhood Behavior Specialist, Evaluator, and Charter School Administrator. Rene has an undergraduate degree in Psychology and a masters in Organizational Change Management. She is the parent of two grown daughters who are deaf.

### **Jane Bassewitz, MA**

Senior Manager, AAP Bright Futures National Center

American Academy of Pediatrics

#### **5 Well Child Care—An Oxymoron for CYSCHN? No! Bright Futures for Every Child!**

Ms. Bassewitz serves as the Senior Manager of the American Academy of Pediatrics (AAP) Bright Futures National Center, managing the activities of the Bright Futures Initiative. Previously, as the Manager of the Bright Futures Training Intervention Project, Ms. Bassewitz worked with 15 practices across the country, using quality improvement approaches, to test a systems change package addressing the delivery of preventive services. As the Manager for AAP's Healthy Tomorrows Partnership for Children Program (HTPCP), Ms. Bassewitz provided individualized assistance to community-based programs working to increase the access and quality of care to children and their families.

### **Ashley Bates-Crowley**

Executive Director and Founder

Team Josiah 2K22 Foundation

[ashley@teamjosiah2k22foundation.com](mailto:ashley@teamjosiah2k22foundation.com)

#### **5: Well Child Care—An Oxymoron for CYSCHN? No! Bright Futures for Every Child!**

Ashley D. Bates-Crowley is the Executive Director and founder of Team Josiah 2K22 Foundation, the first non-profit for autism awareness in Northwest Kansas. She networks, representing diversity, in her rural KS community, regionally, statewide, and nationally to educate and raise awareness of the rights and needs of children and families living the challenges of autism and other exceptionalities. She is a parent trainer and education advocate for Families Together Inc. She serves on the Family Partnership Network of the American Academy of Pediatrics and is involved in the Kansas local chapter. Ms. Bates-Crowley is a devoted mother of twin eight-year-old boys with special needs.

**Julie Beckett**

Co-founder, Family Voices  
Family Voices, Board member  
AAP Family Partnerships Network; Family Voices. IA  
[waivermom@earthlink.net](mailto:waivermom@earthlink.net)

**10 History of Family Voices**

Julie Beckett's daughter Katie was the first person to have access to the home and community-based waiver program in the United States. Prior to Katie receiving this benefit, Medicaid did not pay for home care services. In 1991, Julie, Polly Arango, and Josie Woll started Family Voices, a non-profit organization speaking on behalf of children with special health care needs. At that time, most Family Voices staff were volunteers. Through the support of MCHB and foundation funding, Family Voices has become a nationally known organization.

**Crystal Bell**

Coordinator  
Missouri Family to Family, MO  
[bellcd@umkc.edu](mailto:bellcd@umkc.edu)

**19 Charting the LifeCourse: Path to the GOOD Life Throughout the Lifespan**

Crystal Bell is the coordinator for Missouri Family to Family and a mother of three children, two of whom have a developmental disability. Crystal has served in various advisory roles, representing the family perspective and has focused much of her education and training around family life and leadership. She is a Certified Charting the LifeCourse Trainer, specializing in Family Leadership and Education. Through her extensive training and daily implementation of the Charting the LifeCourse Tools and Framework in her personal and professional life, Crystal and her family have experienced the first-hand transformations that occur when families are given the permission to dream.

**Christina Bethell, PhD, MBA, MPH**

Johns Hopkins Bloomberg School of Public Health  
[cbethell@jhu.edu](mailto:cbethell@jhu.edu)

**24: Child and Adolescent Health Measurement Initiative's (CAHMI) Data in Action and Family Engagement Resources**  
Dr. Christina Bethell is a Professor at Johns Hopkins Bloomberg School of Public Health and the founding director of the Child and Adolescent Health Measurement Initiative (CAHMI), which leads the National Data Resource Center for Child and Adolescent Health, among other initiatives, aiming to advance family and child health efforts.

**Christina Boothby, MPH**

Senior Manager, Systems of Care and Medical Home Initiatives  
American Academy of Pediatrics  
[cboothby@aap.org](mailto:cboothby@aap.org) or 630/626-6311

**Opportunities for Partnership Panel**

Christina Boothby is Senior Manager, Systems of Care and Medical Home Initiatives at the American Academy of Pediatrics (AAP) and the Principal Investigator of the National Resource Center for Patient/Family-Centered Medical Home (NRC-PFCMH). In this role, she provides support and strategic direction to the NRC-PFCMH, health care providers, Title V programs, and other key stakeholders in developing integrated, community-based, family-centered systems of care initiatives that improve access to health care services for children and youth with special health care needs via medical home.



## Rebecca Cokley

Director, Disability Justice Initiative  
Center for American Progress

### Keynote: The State of the Disability Union 2019

Rebecca Cokley is the Director of the Disability Justice Initiative at the Center for American Progress. She joined CAP after leading the National Council on Disability, an independent agency charged with advising Congress and the White House on disability policy. From 2009-2013 she worked in the Obama Administration at the Departments of Education, Health & Human Services, and the White House where she oversaw diversity and inclusion. Rebecca began her advocacy at the Institute for Educational Leadership, building tools and resources to empower and educate disabled youth. Rebecca serves on the boards of Common Cause, the Community Justice Reform Coalition, and ACLU DC. She has been featured on CNN, Vox/Netflix's "Explained" and "Last Week Tonight with John Oliver." In 2015 she was inducted into the Disability Mentoring Hall of Fame and received the Frank Harkin Memorial Award by NCIL. In 2008 she helped lead the first Presidential Campaign Disability Policy Advisory Board, for then-Senator Obama. She has spoken at Netroots Nation, New York City Comic-Con, Google, and the U.S. Commission for Civil Rights. Rebecca has a B.A in Politics from UC Santa Cruz, is the proud spouse of Patrick and mother of three and is writing her first two books.

## Susan Colburn

CRS State Parent Consultant and  
Family Voices of AL Co-Director, AL  
[susan.colburn@rehab.alabama.gov](mailto:susan.colburn@rehab.alabama.gov)

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

Susan Colburn has been an advocate for children with special health care needs for over 20 years. She has served since 1996 as the State Parent Consultant for the Children's Rehabilitation Service, Alabama Department of Rehabilitation Services, (Alabama's Title V Program for CSHCN). Previously Ms. Colburn worked in Alabama's Early Intervention System as a District Service Coordinator. She is the co-coordinator of Family Voices of AL, (home of Alabama's Family-to-Family Health Information Center) and served two terms as the co-Regional Coordinator for the 8 state Southeast Region. In 1987, Ms. Colburn co-founded Friends for Life, a support group for families and friends of children with special needs. She has served as vice-chair of the Family and Youth Leadership Committee of the Association of Maternal and Child Health Programs.

## Cara L. Coleman, JD, MPH

Consultant  
Family Voices National  
[ccoleman@familyvoices.org](mailto:ccoleman@familyvoices.org)

### 5 Well Child Care—An Oxymoron for CYSCHN? No! Bright Futures for Every Child!

Cara is a mom, attorney, author, and advocate. She consults for Family Voices, IPFCC and teaches medical students at the INOVA regional campus of VCU medical School.

## Margaret (Meg) Comeau, MHA

Senior Project Director  
Catalyst Center  
[mcomeau@bu.edu](mailto:mcomeau@bu.edu)

### Opportunities for Partnership Panel

Meg Comeau, MHA is a senior project director at the Center for Innovation in Social Work & Health (CISWH). She is a nationally recognized expert on the impact of Medicaid and federal health care reform for children with special health care needs, medically complex conditions, and disabilities. She brings more than 15 years of health care delivery and



financing experience to her role as principal investigator for the [Catalyst Center](#), a project focused on improving insurance coverage and financing of care for children and youth with special health care needs.

### **Diana Denboba**

Former Branch Chief and Program Director of the Integrated Services Branch, Division of Children with Special Health Needs (DSCSHCN), Maternal and Child Health Bureau (MCHB)/Federal Health Resources and Services Administration (HRSA)

[addisqueen1@yahoo.com](mailto:addisqueen1@yahoo.com)

#### **Preconference: Leading by Convening**

Diana Denboba is a member of the National Congress of Black Women, Inc. and its' Disability Committee; member of Health Care is a Human Right; mentor and Wisdom Council member for the National Center for Cultural Competence; a member of the Health Equity subcommittee for Family Voices Board; and a member of Friends of New Carrollton, MD Police Department.

### **Elvira Dennison**

Navajo Family Voices, a program of Indian Country Grassroots

[Elvira@navajofamilies.org](mailto:Elvira@navajofamilies.org)

#### **13 Sharing Community-Based Cultural Signals - Through a Diné Lens on the Navajo Nation**

Elvira Dennison is the Family Mentor and Coordinator of Indian Country Grassroots Support's Navajo Family Voices program. She is Salt Water clan, born for Many Hogans, and is a CYSHCN parent of two. For the last fifteen years, she has been a volunteer advocate for parents and families of children and youth with special healthcare needs in the Naschitti-Newcomb Navajo Nation area, using her own parental experiences to help parents work with medical providers, schools, and community leaders. She presently serves the New Mexico Public Education Department Secretary's Family Cabinet and has served on the community first responder team, and trained in search and rescue as a first level tracker, as a Naschitti chapter representative, and as parent representative on school committees including the Naschitti Elementary School Bilingual Parent Activities Committee.

### **Javi P. Dolif**

Family Navigator

Family Voices Colorado

[jdolif@familyvoicesco.org](mailto:jdolif@familyvoicesco.org)

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

Born and raised in Santiago, Chile, Javi has lived in the US for over 20 years and has over 4 years' experience in advocacy. She is the mother of 2 boys. The oldest (10yrs old) has learning and processing disabilities. She is new to this role but loves it!

### **Kasey L. Dudley**

Family to Family-Regional Coordinator

Parent Advocacy/SPAN

[Kdudley@spanadvocacy.org](mailto:Kdudley@spanadvocacy.org)

#### **25: Assessing Family Engagement in Systems-level Initiatives**

Kasey currently serves as a contracted employee for the Autism Medical Home Program at Hackensack University Medical Center in NJ. She holds dual roles as the SPAN Family Resource Specialists and Outreach Coordinator. Kasey is a trained Support Coordinator, for N.J. Division of Developmental Disabilities, a certified lactation counselor, and licensed Clinical Massage Therapist specializing in sensory integration for individuals with autism. Kasey is a trusted advocate, helping individuals with navigating the complex health and education systems that support families of children with special needs to live their best lives.



## **Beth Dworetzky**

Family Voices

[bdworetzky@familyvoices.org](mailto:bdworetzky@familyvoices.org)

### **25: Assessing Family Engagement in Systems-level Initiatives**

Beth Dworetzky, MS, Family Voices. Beth joined the national Family Voices staff in January 2018 and manages several projects that focus on building the capacity of systems of care to better serve CYSHCN and promoting meaningful family engagement at all levels of the systems that serve all children.

## **Anne Dwyer**

Senior Health Counsel

Senate Finance Committee

[Anne\\_Dwyer@finance.senate.gov](mailto:Anne_Dwyer@finance.senate.gov)

### **Public Policy Panel**

Anne Dwyer serves as senior health counsel for the United States Senate Finance Committee under Ranking Member Ron Wyden. As Senior Health Counsel, her portfolio includes Medicaid, the Children's Health Insurance Program, women's health, mental and behavioral health, and prevention. Prior to joining the committee as professional staff, Ms. Dwyer was a David A. Winston Health Policy Fellow. Before arriving in Washington, D.C., she spent time with Blue Cross and Blue Shield of Minnesota, the Minnesota Disability Law Center, and the State of Wisconsin. As a Midwest native, Ms. Dwyer received a JD with a concentration in health law and bioethics from the University of Minnesota Law School, MPH in Public Health Administration and Policy from the University of Minnesota School of Public Health, and BA from the University of Wisconsin.

## **Wednesday Eanes**

Board Member

KASA

### **4: Including Youth with Special Health Care Needs at Every Level of Your Organization**

Wednesday Eanes is a KASA board member, poet and creative writer from Denver, CO. She graduated from Jefferson County Open School in 2015 and is pursuing a career in Human Rights Advocacy.

## **Annie Evans, MPH**

Program Development Specialist

Genetic Alliance

[aevans@geneticalliance.org](mailto:aevans@geneticalliance.org) and phone 202-966-5557

### **3: Meaningfully Engaging Families in Newborn Screening Education**

Passionate about helping families find good quality healthcare that transcends cultural and language barriers, Annie Evans works to creatively engage different stakeholders in Expecting Health at Genetic Alliance's programs through outreach efforts, development of practical tools, and monitoring of impact for quality improvement. She focuses on engagement initiatives from both a technical and conceptual perspective. Annie currently manages Expecting Health's new Newborn Screening Family Education Program. Annie received a bachelor's degree in Biology from Penn State in 2015 and a Master of Public Health from George Washington University in Global Health Program Design, Monitoring, and Evaluation in 2017.

**Alexandra Fogarty**

Program Director

Stone Soup Group

[alexandraf@stonesoupgroup.org](mailto:alexandraf@stonesoupgroup.org)**9: Family Wisdom, Diverse and Underserved Communities, and the Challenges of Intersectionality**

Alexandra Fogarty has many years of experience working in nonprofit leadership roles and with diverse groups. Alex is responsible for managing the Stone Soup Group's core programs, including grant management, program activities and training. Prior to joining Stone Soup Group, Alex was the program director for an organization working with school districts in Colorado to improve the health of students. Alex got her start at a health care research firm working in a graphic design department in Washington, D.C.

**Josephine Foo**

Program Administrator

Navajo Family Voices, a program of Indian Country Grassroots Support

[josey@navajofamilies.org](mailto:josey@navajofamilies.org)**13: Sharing Community-Based Cultural Signals - Through a Diné Lens on the Navajo Nation**

Josephine Foo is co-founder and Executive Director of Indian Country Grassroots Support (ICGS). She is a Malaysian ethnic Chinese immigrant who has been an advocate for indigenous Diné individuals and families for 20 years, serving as a teacher, community organizer, and lawyer in legal services and Navajo Nation government. As an attorney in the Navajo Nation Office of the Chief Justice, Josey was responsible for setting up the Judicial Branch grants program and the websites of the tribal court system. She is project attorney for ICGS's Small Trust Land User Research and Assistance Project and Program Administrator of Navajo Family Voices. From 2000-2006, she served with DNA People's Legal Services in their Tuba City, Shiprock and Farmington offices. She graduated from the University of Pennsylvania Law School, Brown University (MFA) and Vassar College. She is a Sustainable Economies Law Center Fellow, specializing in innovative cooperative formation suitable for Indian Country small land users.

**Lynda Gargan, PhD**

Executive Director

Federation of Families for Children's Mental Health

[lgargan@ffcmh.org](mailto:lgargan@ffcmh.org) 240-403-1901**Opportunities for Partnership Panel**

Dr. Lynda Gargan serves as the Executive Director for the National Federation of Families for Children's Mental Health. Throughout her career, she has worked nationwide providing technical assistance and training to ensure that all individuals are afforded the opportunity to live in the community of their choice. She recently served as CEO for an agency specializing in Intensive In-Home Family Therapy services. Dr. Gargan has a wealth of experience in community-based behavioral health at the local, state, and national levels. She has a rich background in field research, including longitudinal studies in multiple class action law suits. Dr. Gargan currently serves as a partner in the national evaluation of System of Care grantees. Under her guidance, the National Federation has fully operationalized the Parent Support Provider Certification Initiative, an innovative peer support workforce initiative that utilizes the lived experience and specialized training of parents to assist and empower families who are raising children and youth with behavioral health challenges.



### **Narangerel Gombojav, PhD, MD**

Johns Hopkins Bloomberg School of Public Health  
[ngomboj1@jhu.edu](mailto:ngomboj1@jhu.edu)

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

As an assistant scientist with the CAHMI team at Johns Hopkins Bloomberg School of Public Health, Dr. Narangerel Gombojav's research goals include improving family and child health outcomes through data-driven online tools and resources. Dr. Gombojav is also an internationally trained pediatrician.

### **Olga Goncharova- Zapata**

Family advocate/volunteer  
Delaware Family Voices, DE  
[ogzapata2@gmail.com](mailto:ogzapata2@gmail.com)

#### **23: Innovative Ways to Use the Care Map**

Olga Goncharova-Zapata is a 17-year veteran of medical complexity, having been the primary caregiver for her son, Victor, since the onset of symptoms related to his diagnosis of PNKP gene mutation, in 2001. During this period in addition to this full-time role, Olga has pursued numerous posts as a parent advocate at the local and state levels including serving as a founding member of Delaware Medicaid's Committee on Medically Complex Children. As part of this group, she helped to author the Delaware's Plan for Managing the Health Care Needs of Children with Medical Complexity. Olga also serves as a member of the Parent Advisory Committee of Al DuPont Hospital for Children and as a parent volunteer with Delaware Family Voices. She is currently enrolled in the Delaware LEND program, studying leadership practices with a diverse cohort of professionals and family members who support people with neurodevelopmental disabilities.

### **Caleb Graff**

Professional Staff  
House Energy and Commerce Committee  
[Caleb.Graff@mail.house.gov](mailto:Caleb.Graff@mail.house.gov)

#### **Public Policy Panel**

Caleb Graff is currently Professional Staff for Energy & Commerce. He handles Medicaid, CHIP, and 340B. He has been with the Committee since January 2017. Before that, he spent a year with the House Budget Committee and before that a year and a half with Speaker Boehner. Caleb has a Masters from Claremont Graduate University in American Politics and Public Policy, and received his undergraduate degree from Bethel University in St. Paul, Minnesota.

### **Jodie Hall**

Regional Support Coordinator, Southern Maine  
Maine Parent Federation  
[jhall@mpf.org](mailto:jhall@mpf.org)

#### **I4: Supported Decision-Making: How to Create a Supportive Network**

In 2003, Jodie graduated from The University of Connecticut with a B.S. in Human Development and Family Studies. After college, she worked as a Case Manager for children with behavioral challenges and assisted families in accessing resources that supported the family as a whole. In 2004, her son was born with Down syndrome and several accompanying medical diagnoses. Subsequently, her role shifted from being a provider of services, to one who navigated them on behalf of her son. In 2017 - 2018, Jodie had the privilege of filling the role as a trainee for the New Hampshire - Maine Leadership Education in Neurodevelopmental Related Disabilities (LEND) Program. Shortly after completing the LEND Program, she joined the staff of Maine Parent Federation and now provides outreach and trainings to Southern Maine.





## Elisabeth (Lis) Harkins

Board Member

KASA

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

Lis is from SC and is 19 years old. She has been on the KASA board for 1 year. She attends Aiken Technical College and will be transferring to Clemson University after next year. She is active with my local Center for Independent Living and Girl Scouts. She's also taking sign language classes.

## Clarissa G. Hoover, MPH

Project Director

Family Voices

[choover@familyvoices.org](mailto:choover@familyvoices.org)

### 8: Family Leadership in CYSHCNet Research

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

Clarissa Hoover started advocating for patients, families, and quality healthcare shortly after her daughter's diagnosis with cystic fibrosis in 2005. She is currently a project director for Family Voices, a national, nonprofit, family-led organization promoting quality health care for all children and youth, particularly those with special health care needs. Ms. Hoover directs the Family Wisdom project and partnerships with the Children and Youth with Special Healthcare Needs Research Network (CYSHCNet) and Lifecourse Interventions Research Network (LCI-RN).

## Frederick Isasi, JD, MPH

Executive Director

Families USA

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

Frederick Isasi was selected to be Families USA's second-ever Executive Director in January 2017 because of his life-long commitment to achieving high-quality, affordable health care for all. Mr. Isasi is a well-known national speaker on Medicaid, state innovation, health system transformation, behavioral health, and the social determinants of health as well as health care quality, payment, and equity issues. Mr. Isasi's passion for health care reform began when he was growing up in North Carolina as the son of Cuban immigrants. There, he saw firsthand many of the barriers to health care experienced by the poor, people of color, people with language barriers, and rural communities. Before joining Families USA, Mr. Isasi served as the Health Division Director at the bipartisan National Governors Association's (NGA) Center for Best Practices. Prior to NGA, Mr. Isasi served as Vice President for Health Policy where he founded its Health Policy Department. Prior to this work, Mr. Isasi served as Senior Legislative Counsel for Health Care on both the U.S. Senate Finance Committee and Senate Committee on Health, Education, Labor, and Pensions (HELP) for former Senator Jeff Bingaman (D-NM), the only Democrat serving on both committees during the creation of the Affordable Care Act. Earlier in his career, Mr. Isasi served as a health care attorney with Powell Goldstein, where he worked closely with states on Medicaid reforms and represented public hospitals; prior to that, he served as Senior Policy Advisor to the District of Columbia Primary Care Association. Mr. Isasi holds a JD from Duke University, an M.P.H. from the University of North Carolina, and a B.S. in Cellular Biology and a second major in Spanish from the University of Wisconsin.

## Hamza Jaka

Board Member

KASA

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

Hamza Jaka is a KASA member, recent law school graduate, Berkeley Law and newly licensed attorney. He's the founder of Project Lead, a nonprofit that supports people with disabilities in Pakistan.

**Hazel James**

Tribal Liaison

Indian Country Grassroots Support

[hazbah4nm@gmail.com](mailto:hazbah4nm@gmail.com)**I3: Sharing Community-Based Cultural Signals - Through a Diné Lens on the Navajo Nation**

Hazel James is Diné, of the Zuni Edgewater People; Born for Black Streak through Wood People; Maternal Chei/grandfather is Big Water; Nali/Paternal grandfather is Salt People. She is a proud wife, a mother of four, a grandmother of four grandsons, and a happy gardener who has dedicated her life to advocating for her people with love and compassion. Hazel honors Diné values, principles, and wisdom learned from her parents and grandparents by applying cultural protocols to carry out her work as the San Juan Collaborative for Health Equity-Coordinator. Hozho go na ada /Dine' Research and Evaluation uses a Diné/Indigenous Lens to carry out a unique process, revitalizing Dine' knowledge and language, to effect positive change centered on unity and healing, to combat systemic injustices and to nurture food security, water security, racial healing, environmental justice and economic sustainability.

**Karen Kulthau**

Associate Professor of Pediatrics

Harvard Medical School

**8: Family Leadership in CYSHCNet Research****Joe Labelle**

Director of Program Impact/Co-Director of FND Social

Family Network on Disabilities

[joe@fndfl.org](mailto:joe@fndfl.org)**I2: Social Media: New Low-cost Tools for Effective Outreach**

Joe LaBelle is a self-advocate with learning disabilities and ADHD. He has presented as Co-Director of FND Social to OSEP's symposium on reaching families and OSEP's national leadership conference. He works with OSEP-funded Part D programs across the country, helping them reach their goals using social media. Joe is also the Director of Programs Impact at Family Network on Disabilities, helping to oversee 4 federally funded programs, providing information, resources, and support to families who have children with special needs and complex medical needs across Florida.

**Brenda Lamkin, M.Ed.**

Executive Director

West Virginia Parent Training &amp; Information, WV

[Brendalwvpti@aol.com](mailto:Brendalwvpti@aol.com)**9: Family Wisdom, Diverse and Underserved Communities, and the Challenges of Intersectionality**

Brenda Lamkin is the Executive Director of West Virginia's Parent Training and Information Center. Brenda's experience working with children started with her child and developed through obtaining degrees to expand her knowledge of the world as a parent and professional. As the Executive Director of WVPTI, which serves infants through age 26, she knows firsthand the importance of everyone working together for the benefit of the child. Brenda has extensive experience in parent training and leadership by serving on state, local, and national advisory councils. She holds a master's degree in Education and has 15 years of experience working with families of children with disabilities.

**Brooke Lehmann, MSW, JD**

Partner, Capitolworks, LLC

[Brooke@capitolworksllc.com](mailto:Brooke@capitolworksllc.com)**I5: 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 is a clinical social worker and public interest attorney whose professional expertise is in the areas of children's health, education, and child welfare. Ms. Lehmann has spent two decades providing direct clinical and advocacy services to children and families while simultaneously working to improve the systems that administer these services through policy development and legislative advocacy. As the Founder and President of Childworks, LLC, Ms. Lehmann has managed multi-million dollar local, state, and federal advocacy campaigns, providing legislative analysis and strategy expertise to clients serving vulnerable populations of children, youth, and families. As a national expert, Ms. Lehmann provides consultation on the design, development, and reform of pediatric health/mental health services and special education and child welfare systems.

### **Robin Levesque**

Regional Support Coordinator, Northern Maine

Maine Parent Federation

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#### **I4: Supported Decision-Making: How to Create a Supportive Network**

Robin Levesque has worked at Maine Parent Federation for 10 years as the Regional Support Coordinator for Northern Maine. Previous to her work at MPF she worked in banking and at her families business. For many years she was a stay-at-home mom raising her 3 sons. Her eldest son was diagnosed with Bipolar Disorder and her youngest was born with Cerebral Palsy, Angelmen's Syndrome, Autism, and Epilepsy. Through her work at MPF she has had the privilege of sharing her experience with families and providing them support and assistance navigating the various systems of care.

### **Elaine Linn**

Project Leadership Manager

Family Voices of California, CA

[elinn@familyvoicesofca.org](mailto:elinn@familyvoicesofca.org)

#### **2I: Family Engagement for Health Systems Change**

Elaine Linn has spent more than 25 years uniting nonprofit, community, public, and corporate partners in public health policy efforts. She has worked with diverse stakeholders in pharmacy, psychiatry, and ophthalmology, as well as diabetes, sepsis, social work, disability, and women's and children's health to engage communities, promote awareness, and increase access to care. In her role as Family Voices of California Project Leadership Manager, Elaine oversees the Project Leadership parent advocacy training program, which educates, supports and engages organizations, parents, and caregivers for leadership and advocacy activities to improve health systems for CYSHCN. She also monitors policy issues, develops communications, and is a liaison with statewide policy and stakeholder organizations. Elaine is the parent of two sons with special health care needs and disabilities.

### **Olga M. Lopez**

Information Specialist Latino Outreach Coordinator

Federation for Children with Special Needs, MA

[olopez@fcsn.org](mailto:olopez@fcsn.org) or <https://www.facebook.com/Federacionlatino/>

#### **I8: Cultural Broker/Model to Implement in Human Services Agencies**

Originally from Medellin Colombia, Olga is the Information Specialist Latino Outreach Coordinator at the Federation for Children with Special Needs. Olga developed, implemented and coordinated the first cohort of the Latino Parent Leadership Program. She is also a former LEND Fellow from the Eunice Kennedy Shiver Center/Massachusetts Medical School and has a Special Education Master's degree from Cambridge College.



## Dylan Maldonado

Connecticut KASA Youth Leader

PATH Parent to Parent/Family Voices Connecticut

### I4: Charting the LifeCourse

Dylan Maldonado is a 15 ½ year old young man from Connecticut. He is a Youth Leader and is the Co-Chair for Connecticut KASA (Kids As Self Advocates). Dylan also is the Youth Ambassador for Charting the LifeCourse, which he has benefited from and charted his own course. You will find Dylan throughout CT representing CT KASA at many events and also presenting at conferences. In April of 2018, he founded a program called Kids in Care Luggage of Love (KICLLOL). Dylan hopes that this will help provide children in foster care with an alternative to garbage and shopping bags used to transport a child's belongings during an emergency removal from home.

## Kate Marcell, MS

Public Health Analyst, DSCH/MCHB/HRSA

[kmarcell@hrsa.gov](mailto:kmarcell@hrsa.gov), 301-443-4656

### 2: Title V MCH Block Grant Five-Year Needs Assessment: Opportunities for Family Partnership

Kate Marcell has worked for the Health Resources and Services Administration (HRSA), Department of Health and Human Services (DHHS) since 2002, and for the Maternal and Child Health Bureau (MCHB) since 2010. She currently serves as a Public Health Analyst in the Eastern Branch of the Division of State and Community Health (DSCH). In this role, she supports the work of the Title V Maternal and Child Health (MCH) Block Grant program by serving as the Project Officer for the Region III states. Ms. Marcell also provides oversight for MCHB's cooperative agreements with CityMatCH and AMCHP to support the work of State and Urban MCH leaders.

## Ryan Martin

Senior Human Services Advisor

Senate Finance Committee

[Ryan\\_Martin@finance.senate.gov](mailto:Ryan_Martin@finance.senate.gov)

### Public Policy Panel

Ryan Martin is the Senior Human Services Advisor for Senate Finance Committee Chairman Chuck Grassley of Iowa. In this role, he assists with the development and advancement of legislation to reduce poverty, protect children, improve maternal and child health, and ensure social programs achieve results. Before joining the Committee in 2017, he worked for the House Committee on Ways and Means in a similar capacity. Prior to joining the Ways and Means Committee, Ryan served as the Executive Officer for the Office of Family Assistance, U.S. Department of Health and Human Services, which administers Temporary Assistance for Needy Families (TANF)—the nation's primary cash welfare program designed to help low-income families achieve self-sufficiency.

## Beverly Maxwell

Fiscal Manager

at Indian Country Grassroots Support

[beverlymaxwell@hotmail.com](mailto:beverlymaxwell@hotmail.com)

### I3: Sharing Community-Based Cultural Signals - Through a Diné Lens on the Navajo Nation

Beverly Maxwell is a multi-generational Navajo Nation Shiprock farmer, a sergeant in the U.S. Marine Corps, and a Blue Star mom. She is the Fiscal Manager at Indian Country Grassroots Support, traditional farming advocate, and traditional family mentor. Beverly serves on several committees and boards, including as Secretary/Treasurer of the Shiprock Community Development Corp. She is also a Community Organizing Fellow with Growing Partners of SW Colorado. The mother of 3 sons one of whom is in the U.S. armed forces, she is a family disability, health, and farm sustainability advocate. She mentored Northern Arizona University Navajo students in scientific lab and field biological data collection methods and is an accomplished scientific researcher. Her focus is on traditional Navajo farming methods and crops, on sharing traditional cultural knowledge and practices, and supporting affordable nutrition for the wellbeing of children.



### **Peggy McManus**

Co-Project Director

Got Transition

[mmcmanus@thenationalalliance.org](mailto:mmcmanus@thenationalalliance.org)

#### **Opportunities for Partnership Panel**

Ms. McManus is the President of The National Alliance to Advance Adolescent Health, a nonprofit organization dedicated to improving the delivery and financing of health care for adolescents. With Dr. White, she is responsible for overall project management. Ms. McManus has over 25 years of experience directing national and state projects on child and adolescent health. These research and policy projects have addressed health care transition, public and private health insurance, the Affordable Care Act, integrated primary and behavioral health care, patient-centered primary care, and pediatric workforce issues. Ms. McManus has a Masters in Health Sciences from Johns Hopkins School of Public Health.

### **Jeannette Mejias**

Director, Special Education Volunteer Advocates Project

SPAN Parent Advocacy Network, NJ

[jmejias@spanadvocacy.org](mailto:jmejias@spanadvocacy.org)

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

Jeannette Mejias is the Director of Special Education Volunteer Advocates which provides support to families who have the most challenges advocating for quality inclusion and transition to adulthood services for their children with developmental disabilities. She serves as the Bilingual Family Support Integration Specialist on the Family to Family Health Information Center providing parents and professionals with best practices to ensure ongoing collaboration, communication, and engagement across systems. Jeannette is a NJ LEND Fellow and the recipient of the 2015 young Maternal Child Health professional award for Region II.

### **Angela Miney**

Family Partner

University of Florida Pediatric Pulmonary Center. FL

[aminey@peds.ufl.edu](mailto:aminey@peds.ufl.edu) and 352-273-8508

**15 Florida Family Leaders' Network: A Family Led Statewide Initiative to Build a Network of Family Leaders in Florida**  
Angela Miney, the parent of a young adult with a chronic health condition, is the Family Partner at the University of Florida Pediatric Pulmonary Center, (UFPPC), a federally funded Maternal and Child Health Bureau (MCHB) program. As family faculty, Angela trains emerging healthcare professionals, to fulfill the MCHB mission to deliver care that is community based, family centered and culturally competent. She shares her experiences as a consumer, navigating the complexity of the healthcare system. She is a founding member of the UF Health Pediatric Family Advisory Council (FAC), a member of the UF Health Patient Advisory Council and a member of the UF Health Board Quality Committee. Angela is leading the UFPPC team in their collaboration with the Florida Department of Health to develop the Florida Family Leader Network (FFLN).

### **Yetta Myrick**

President/Founder

DC Autism Parents

[ymyrick@dcautismparents.org](mailto:ymyrick@dcautismparents.org)

#### **5: Well Child Care—An Oxymoron for CYSCHN? No! Bright Futures for Every Child!**

**Yetta Myrick** is the mother of a teenage son with ASD and ID. She is the Founder/President of DC Autism Parents, Community Outreach Coordinator at the Center for Autism Spectrum Disorders at Children's National and serves as the CDC's Act Early Ambassador to the District of Columbia.



### Pat Nemia, MA, PT

Project Director

Federation for Children with Special Needs

[pnemia@fcsn.org](mailto:pnemia@fcsn.org)

#### **18 Cultural Broker/Model to Implement in Human Services Agencies**

Pat Nemia is the Project Director of Mass Family Voices/F2F Health Information Center at the Federation for Children with Special Needs. In her role at FCSN, Pat educates and empowers families through 1:1 assistance and trainings in health care access in a medical home, healthcare financing, impact of health care on education and healthcare transition. Pat works closely with the Outreach Program at the Federation for Children with Special Needs, using a Train the Trainer Model, to reach underserved communities. She serves on numerous statewide committees to represent the family voice in Massachusetts. Pat has many years of experience in healthcare as a physical therapist, educator, administrator, and parent.

### Norman Ospina

Norman A. Ospina Quintero

Dad/Spanish & English Interpreter & Translator. Preferred pronouns: he, his & him

[mirupacha@gmail.com](mailto:mirupacha@gmail.com)

#### **5: Well Child Care—An Oxymoron for CYSCHN? No! Bright Futures for Every Child!**

Born in Colombia in 1971, Norman is the son of two textile workers, and the youngest sibling of nine. He was forced to immigrate to the U.S. in 1981, and graduated from the University of R.I. with a degree in Sociology in 1996. He migrated to Oakland, CA, in July of 2010, and witnessed the birth of his son, Rajon Amaru, in early 2011. “First and foremost, I’m a Dad to a child who is full of Spirit, loves Nature, and is curious about the Universe - and one who is presently living & thriving with Spina Bifida.”

### Ann Phillips

Executive Director

Delaware Family Voices

[annp@defv.org](mailto:annp@defv.org)

#### **23: Innovative Ways to Use the Care Map**

Ann Phillips is a parent of an adult son with disabilities and special health care needs. Ann has been involved with the F2F since 2008 and established DE FV as a non-profit in 2010. She is an advocate for CSHCN statewide and sits on many councils and committees. She also has appointments as chair of Delaware’s Brain Injury Committee, a member of the State Council for Persons with Disabilities and serves on its Executive Committee. She is the facilitator of the monthly Medicaid Managed care call and appointed to the Medical Care Advisory Council, serves on the Children with medical complexity committee, and Chairs the Family Leadership Advisory Council. Ann would like to see families at every table where policy is made that affects children.

### Stuart Portman

Public Policy Panel

### Raquel Quezada

Mother /producer/host /creator

Cambiando El Mundo de necesidades especiales/Changing the world of special needs, Haverhill, MA

[cambiandoelmundo04@gmail.com](mailto:cambiandoelmundo04@gmail.com)

#### **POSTER SESSION: How to Use Media Platforms and Different Avenues to Educate Parents**

Raquel Quezada is Latina from Dominican Republic and mother of 4 children, one with Cerebral Palsy and other medical complex needs. She is a former LEND fellow (2017-18) and Crocker Fellow (2018-19), ICI, and UMASS. She has experience in communications, radio, and TV in her country. She believes there is a lot of need to inform parents and



relatives about how to help, and educate them about the concerns and needs of a disabled member. All the knowledge as a mother of a disabled child and the education she received on different types of disabilities and situations is what motivated her to have her own radio show to better help others.

### **Emily Robinson**

KASA Board Member

#### **4: Including Youth with Special Health Care Needs at Every Level of Your Organization**

Emily Robinson is a 24 year old head strong advocate. She is involved with her SILC, KASA, CASA, NCIL Youth Caucus, NCIL Education subcommittee, and she is a troop leader for girl scouts. WVSILC is in the middle of creating their first YLF to empower youth to advocate for themselves. Emily loves what she does and she wants to continue to advocate for all people that have disabilities. She recently graduated from West Virginia State University where she was President of Student Access Advocates and CHOICES Peer Educators.

### **Sheri Romblad**

Parent to Parent Program Coordinator

PATH Parent to Parent/Family Voices of CT

[sromblad@pathct.org](mailto:sromblad@pathct.org)

#### **I4: Charting the LifeCourse**

Sheri Romblad is the Parent to Parent Program Coordinator for PATH Parent to Parent/Family Voices of CT. She is an active member of the CT Governor's Advisory Board to Persons who are Deaf and Hard of Hearing, CT EHDI (Early Hearing Detection and Intervention) Task Force, CT Core Team of LifeCourse Ambassadors, Co-Chairs CT LifeCourse Family Mentoring & Leadership Committee, serves as a family leader for the DEC/ECPC (Division of Early Childhood/Early Childhood Personnel Center) and has served as a Family Liaison for NCBDDD (National Center on Birth Defects and Developmental Disabilities). She is a 2014 graduate of Partners in Policymaking, upon graduation she introduced two bills in CT regarding hearing screenings in school aged children. Sheri has a Bachelor of Science in Media Communication and has spent most of her career in NYC working in media advertising. She resides in Madison, CT with her husband of 20 years and their two children.

### **Mercedes Rosa**

Director, Family to Family Health Information Center

SPAN Parent Advocacy Network

[addisqueen1@yahoo.com](mailto:addisqueen1@yahoo.com)

Pre-conference: Leading by Convening

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

Mercedes Rosa directs SPAN's Family-to-Family Health Information Center and is a diverse family leadership coach on the National Center for Family Professional Partnerships and a Family-Centered Services TA/Coach on SPAN's NE-PACT/Region A Parent TA Center project. Rosa also serves on the Catalyst Center's Advisory Board.

### **Tom Rose**

Chief Executive Officer

CBR YouthConnect

Family Voices Colorado by CBR, CO

Phone: (303) 691-6095 Cell: (720) 775-9341

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

Tom Rose is the President of the Colorado Boys Ranch

Foundation (CBR), Chief Executive Officer of CBR YouthConnect, and Executive Director of Family Voices Colorado by CBR.

CBR YouthConnect programs provide services focused on keeping children in the child welfare and juvenile justice systems safe in their homes, and services that help keep families together. CBR programs focus on mentoring, positive



family relationships, and services that help keep families together. Tom currently serves on more than a dozen Colorado boards, commissions, task forces, and committees focused on healthcare policy affecting children in the Child Welfare system and children with disabilities. Mr. Rose is also a Board Member and Treasurer of Family Voices National, an Executive Committee Member of the AAP Family Partnership Network, and a member of the Georgetown University Community of Practice for Cultural and Linguistic Competence in Developmental Disabilities.

### **Naomi Sandweiss, MA**

Executive Director

Parents Reaching Out, AZ

[nsandweiss@parentsreachingout.org](mailto:nsandweiss@parentsreachingout.org), 505-247-0192

#### **6: Developing and Supporting Remote Work Teams**

Naomi Sandweiss is Executive Director of Parents Reaching Out. She supervises two FFHIC projects, one as the state of NM FFHIC and another FFHIC in conjunction with Raising Special Kids in Arizona to serve Native American populations. Naomi is on the board of National Place. She is a parent of two young adults and experienced at advocating on their behalf.

### **Mary Scott, M.Ed.**

Administrative Assistant

West Virginia Parent Training & Information, WV

[marywvpti@gmail.com](mailto:marywvpti@gmail.com)

#### **9: Family Wisdom, Diverse and Underserved Communities, and the Challenges of Intersectionality**

Mary has a Bachelor's Degree and Master's Degree in Education. For over thirty years, she has assisted parents and families who have children with disabilities in the educational system. Currently, she assists children and youth who have special needs to find resources and to advocate for their needs.

### **Matthew Shapiro**

Chair KASA Board

KASA (Kids as Self-Advocates)

[matthew.shapiro@6wheelsconsulting.com](mailto:matthew.shapiro@6wheelsconsulting.com)

#### **4: Including Youth with Special Health Care Needs at Every Level of Your Organization**

Matthew Shapiro is a 2013 graduate of VCU where he completed a Bachelors of Interdisciplinary Studies degree. Throughout college he participated in several internships including opportunities with The White House, The U.S. Department of Transportation, and with several Virginia area disability organizations. In 2014, he developed a disability consulting company called 6 Wheels Consulting whose is to work with businesses of all types to help advance their understanding of disability culture. In his free time, he enjoys learning about politics, watching sports, and hanging out with his dog, VP.

### **Charlene Shelton**

Program Manager

University of Colorado Anschutz

#### **8 Family Leadership in CYSHCNet Research**



**Vera L. Spinks**

Parent Consultant

Alabama Department of Rehabilitation Service- Children's Rehabilitation Service, AL

[vera.spinks@rehab.alabama.gov](mailto:vera.spinks@rehab.alabama.gov) and 205-562-1802**7: We Can't Do This Without You! One F2F HIC's Authentic Partnership with Their States Title V CYSHCN Program**

Vera Spinks is a Family Leader living in Tuscaloosa, Alabama, with her husband and three children. All three children were born prematurely, and currently Adlen is a talented teen; Kylie thrives with Cerebral Palsy and other complex medical conditions; and Xan is an active boy and has a diagnosis of laryngomalacia. Vera has over 16 years of experience partnering with programs and systems in Alabama serving CSHCN as a consumer and three years as a Parent Consultant in Children's Rehabilitation Service's Tuscaloosa Office. Vera serves on many committees including the Alabama Disability Advocacy Program's Protection and Advocacy for Persons with Developmental Disabilities Advisory Council and Alabama's State Community of Practice implementing the Life Course Framework. Vera completed the AMCHP Leadership Lab in the Family Leader Cohort and as a Parent and Family Leader within Alabama's Title V CSHCN Program strives to inspire and bring people together to achieve sustainable results to improve lives.

**Christopher Tiffany, MA. Ed.**

Executive Director

Raising Special Kids

[christophert@raisingspecialkids.org](mailto:christophert@raisingspecialkids.org)**6: Developing and Supporting Remote Work Teams**

Chris came to Raising Special Kids in 2010 from the public school system in central Phoenix where he was a dedicated Special Education teacher and facilitator. Chris and his wife, Paulina, are parents to their only son who was diagnosed with Autism at the age of two. Moving into the role of Executive Director in 2018, Chris is dedicated to the mission of supporting Arizona families who are raising children, of all ages, with special health care needs.

**Rick Van Buren**

Health Counsel

House Energy and Commerce Committee

[Rick.Vanburen@mail.house.gov](mailto:Rick.Vanburen@mail.house.gov)

Public Policy Panel

Rick Van Buren is a Health Counsel focusing on Medicaid and CHIP with the majority staff of the House Energy and Commerce Committee. Prior to joining the Committee, he was a senior analyst at the Medicaid and CHIP Payment and Access Commission where he focused on policies relating to the Medicaid Drug Rebate Program and Medicaid Managed Care. He also previously served in the Centers for Medicare & Medicaid Services Office of Legislation and as Legislative Counsel for Senator Sheldon Whitehouse. He is a graduate of Georgetown Law and the University of Pittsburgh.

**Ellen Volpe, MHSA**

Chief, Eastern Branch

DSCH/MCHB/HRSA

[evolpe@hrsa.gov](mailto:evolpe@hrsa.gov), 301-443-6320**2: The Title V Five-Year Needs Assessment: Opportunities for Families and Family-led Organizations to Partner with Title V**

Ellen Volpe has worked in the Maternal and Child Health Bureau since 2006, serving as Chief of the Eastern Branch, Division of State and Community Health since 2010. In this role, Ellen oversees staff who support the Maternal and Child Health (MCH) Block Grant program in Regions 1-5. Prior to joining MCHB, Ellen spent 5 years with the National Health Service Corps (NHSC) as Chief of the Application and Award Branch, awarding \$120 million annually in scholarship and loan repayment support to more than 2,000 students and clinicians committed to serving in underserved areas. Before working with the NHSC, Ellen worked in HRSA's Bureau of Health Professions, managing



student loan and scholarship programs designed to address national health care workforce needs, with a focus on access, diversity and workforce distribution.

### **Mary Wahl, MPH**

CAHMI Research Program Manager  
Johns Hopkins Bloomberg School of Public Health  
[mwahl8@jhu.edu](mailto:mwahl8@jhu.edu)

**24:** Child and Adolescent Health Measurement Initiative's (CAHMI) Data in Action and Family Engagement Resources  
Ms. Mary Wahl is a Research Program Manager with the CAHMI at Johns Hopkins Bloomberg School of Public Health and has public health experience at the local, county, and national level with a focus on improving health outcomes for children, families, and their communities.

### **Allysa Ware, MSW**

Project Director  
Family Voices  
[anware@familyvoices.org](mailto:anware@familyvoices.org)

#### **5: Well Child Care—An Oxymoron for CYSCHN? No! Bright Futures for Every Child!**

Allysa Ware is a Project Director with Family Voices. Allysa has spent the last decade working to improve access to education, medical services, and community supports for children with special health care needs and their families. Allysa received her master's degree in social work from The Catholic University of America (CUA) and is currently pursuing her Ph.D. in social work at CUA with a research focus of autism diagnosis and treatment in the African-American community. She is licensed by the Association of Social Work Boards as a Licensed Graduate Social Worker (LGSW) in Washington, DC, and Maryland. Allysa is also the proud parent of a 16-year-old daughter with an autism spectrum disorder.

### **Dr. Michael Warren**

Associate Administrator  
Maternal and Child Health Bureau

#### **Keynote: Welcome and Sharing MCHB Vision and Goals on Family Partnership**

Dr. Michael Warren became Associate Administrator of the Maternal and Child Health Bureau (MCHB), part of the U.S. Department of Health and Human Services' Health Resources and Services Administration, on October 15, 2018. Dr. Warren manages MCHB's \$1.33 billion budget, providing vision and direction to ensure programs are planned and carried out effectively to achieve results. Dr. Warren's impressive career in public health clearly demonstrates his passion and commitment to improving maternal and child health outcomes. Before assuming his current role as MCHB's Associate Administrator, Dr. Warren served as the Deputy Commissioner for Population Health at the Tennessee Department of Health. In this role, he made improvements in maternal and child health across the state in the areas of safe sleep policies, breastfeeding rates, decreased early elective deliveries, newborn screening transit times, electronic systems for WIC and vital records registration, and establishing the first-ever real-time public health surveillance system for neonatal abstinence syndrome. As a board-certified pediatrician, Dr. Warren previously served as the Tennessee Department of Health Assistant Commissioner for Family Health and Wellness and as the Director of Maternal and Child Health. Prior to joining the Department of Health, he served as an Assistant Professor in the Department of Pediatrics at Vanderbilt and as Medical Director in the Governor's Office of Children's Care Coordination.

Dr. Warren graduated Summa Cum Laude with Honors in Psychology from Wake Forest University and earned his medical degree from the Brody School of Medicine at East Carolina University, where he was inducted into the Alpha Omega Alpha Honor Medical Society. He completed his pediatrics residency, Chief Residency, and fellowship in Academic General Pediatrics at Vanderbilt, where he also obtained a Master's in Public Health. He is a fellow of the American Academy of Pediatrics.



Dr. Warren has served as President for the Association of Maternal and Child Health Programs (AMCHP), the national professional organization for maternal and child health professionals. He was also appointed by the United States Department of Health and Human Services to the Secretary's Advisory Committee on Infant Mortality (SACIM).

### **Jonathan Webb, MBA, MPH**

Chief Executive Officer

Association of Maternal and Child Health Programs

[jwebb@amchp.org](mailto:jwebb@amchp.org)

#### **Opportunities for Partnership Panel**

Mr. Webb has spent more than 15 years in the public health space promoting community health outcomes; addressing the social determinants of health; and tackling a number of epidemics including childhood obesity, diabetes, and CVD. Jonathan's professional experience includes work for two local health departments including work within the Office of Epidemiology of the City of Chicago and leading the Community Health Division of the City of Evanston. Additionally, Mr. Webb has spent more than nine years in the nonprofit space leading strategy; building meaningful partnerships; fundraising; and implementing programming for organizations such as the McGaw YMCA, Feed the Children, and the American Osteopathic Association. Most recently he served as the vice president of corporate alliances, grants and social enterprise for the American Diabetes Association. With the current fundraising climate keenly focused on strategic philanthropy, Mr. Webb has been working on effective collaboration and identifying those mutually beneficial partnerships that drive the mission of the organization forward.

### **Kristi Wees, MSChem**

Consumer Engagement Director and Social Media Coordinator

Mountain States Regional Genetics Network

[kwees@mountainstatesgenetics.org](mailto:kwees@mountainstatesgenetics.org)

#### **17: Consumer Engagement in a Virtual World**

Prior to joining MSRGN 6 years ago, Kristi was a parent advocate who served on the 2012 Consumer Task Force for Baby's First Test. She brings previous experience working in a laboratory and research setting as a chemist as well as scientific sales and marketing experience after completing her master's degree in chemistry from UCLA. For the last 6 years, Kristi has utilized social media to provide focused outreach to an audience of mothers of children with special needs. Kristi's daughter was suspected of a mitochondrial disorder that was not diagnosed at birth. She helps other families navigate the medical system through her patient advocacy work.

### **Nora Wells**

Executive Director

Family Voices

[nwells@familyvoices.org](mailto:nwells@familyvoices.org)

#### **10: History of Family Voices**

Nora Wells has worked with Family Voices since its inception in 1992, leading multiple initiatives, in partnership with professionals, around the design and delivery of family-centered quality health care services. She has most recently served as the Director of Programs and as the Director of the Family Voices National Center for Family/Professional Partnerships (NCFPP) before becoming the Family Voices Executive Director in 2014. Through the years she has provided extensive training and technical assistance to family leaders and professionals throughout the country; testified in Congress; and collaborated with numerous federal and private agencies, task forces, and national initiatives, providing the family perspective on policy and practice issues. Nora was the 2015 recipient of the Merle McPherson Leadership Award for her dedication and service. Nora holds a MS Ed degree, and previously worked for the Massachusetts Federation for Children with Special Needs focusing on health and special education. Nora brings a deeply personal commitment to our work as the parent of a son with a disability.

**Joane White, CCHW**

Florida Title V Family Leader  
DOH FL, Children's Medical Services  
[Joane.White@flhealth.gov](mailto:Joane.White@flhealth.gov)

**I5: Florida Family Leaders' Network: A Family Led Statewide Initiative to Build a Network of Family Leaders in Florida**  
Joane serves as the Title V Family Leader for the Florida Department of Health Children's Medical Services (CMS) where she is a liaison and advocate for families within the CMS Network. She assists with related CMS Title V Program initiatives and activities which include Patient Centered Medical Home, Behavioral Health Integration, and Transition. She is also a Certified Community Health Worker and serves on state and local committees, including as family faculty at the University of South Florida Maternal and Child Health Center of Excellence.

**Carrie Woodcock**

Executive Director  
Maine Parent Federation, ME  
[cwoodcock@mpf.org](mailto:cwoodcock@mpf.org) and 207-588-1933

**I4: Supported Decision-Making: How to Create a Supportive Network**

Carrie Woodcock is the parent of a 12-year-old daughter with Down Syndrome and a 14-year-old son with Dyslexia and ADHD. She has been at Maine Parent Federation for 5 years and in the Executive Director capacity for 2 years. Her passion and inspiration come from watching her children overcome obstacles and achieve success.

**Dana Yarbrough, M.S., M.A.**

Director  
Center for Family Involvement @ VCU, VA  
[dvyarbrough@vcu.edu](mailto:dvyarbrough@vcu.edu) and 804-828-0352

**9: Family Wisdom, Diverse and Underserved Communities, and the Challenges of Intersectionality****I6: LEAD: Leadership Exploration and Development**

Dana Yarbrough is the Assistant Director of Strategic Initiatives for the Partnership for People with Disabilities, Virginia's University Center for Excellence in Developmental Disabilities located at Virginia Commonwealth University. Among her many roles at VCU, Dana serves as the Principal Investigator for the Center for Family Involvement and its initiatives statewide to support diverse families of children and adults with developmental disabilities to become effective advocates for their children and leaders for systems change. She also oversees the work of the Partnership to build youth leaders. Dana brings family wisdom and experience to her work as the mother of a 24-year old daughter who in spite of significant support needs for physical, intellectual, and sensory disabilities, owns her own dog boarding business. Dana holds masters' degrees in non-profit transformational leadership and special education secondary transition.