

FCC TASKFORCE WEBINAR

SEPT 10
11:30AM - 12:30PM PT



PREGNANCY & DISABILITY: INTRODUCING THE ACCESSIBLE PREGNANCY ACTION PLAN

Kara Ayers, PhD (she/her)

*Associate Professor,
Cincinnati Children's Hospital Medical Center
NICU Parent*



SUPPORTING PARENTS WITH DISABILITIES: INCLUSIVE, MULTIDISCIPLINARY CARE FOR LACTATION & BEYOND

Alesha Thomas, BS, IBCLC (she/her)

*Founder & Executive Director,
Adaptive Parent Project
NICU Parent of Nolan*



RETHINKING DISABILITY IN THE NICU

Amy RL Rule, MD, MPH, FAAP (she/her)

*Associate Professor of Pediatrics,
Newborn & Hospital Medicine
Director, GHOP Pediatric Residency Track
Co-Director, Center for Maternal Infant Health*

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Webinar Etiquette

Thank you for helping us make FCC Taskforce Webinars a safe & brave space for all!

By participating, you are agreeing to the following guidelines:

1. Please mute your microphone when you aren't speaking
2. Please turn off your camera if multitasking
3. All questions & comments spoken and written in the chat should be respectful, non-discriminatory, and non-judgmental

Topics discussed may illicit strong emotions and feelings. Please reach out to us if you need support.



September is NICU Awareness Month

NICU AWARENESS MONTH

Join us in honoring NICU families
and the healthcare professionals
who care for them.



Dates to Remember:

September 15th: Neonatal Nurses Day
September 26th: NICU Remembrance Day
September 28th: NICU Staff Appreciation Day
September 29th: NICU Sibling Support Day
September 30: NICU Awareness Day

National Neonatal Nurses Week:

September 12-18

International Neonatal Therapy Week:

September 20-26



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This Webinar is Dedicated to Nolan



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All-In Meeting

- Break down the hierarchy
- Integrate patient-families
- Prioritize funds to support patient-families
- Intentionally elevate the voices of women, diverse groups, and individuals with rare or unique experiences
- Make it relevant and personal
- Provide support to disabled individuals during in-person meetings
- Invest in building relationships
- Support and include breastfeeding mothers/parents
- Demonstrate the impact, progress, and opportunities
- Capitalize on the expertise in the room
- Remain receptive and responsive to constructive criticism



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OF A HEALTHIER WORLD



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Family-Led Organizational Partners

- Adaptive Parent Project
- Adult Premie Advocacy Network
- Cooper Steinhauser Foundation
- Alliance for Black NICU Families
- Canadian Premature Babies Foundation
- Connected Forever
- Dear Fathers
- Empowering NICU Parents
- FreeArm
- Generation O
- GLO Preemies
- Graham's Foundation
- Hand to Hold
- Hope for HIE (Hypoxic Eschemic Encephalopathy)
- ICU baby
- Love for Lily
- Miracle Babies Foundation
- NEC Society (Necrotizing Enterocolitis)
- Neonatal Butterfly Project
- NICU Alumni
- The NICU Dad
- NICU Neuroscience
- NICU Parent Network
- PPROM Foundation (Preterm Premature Rupture of Membranes)
- PremieWorld
- Saul's Light
- Project NICU
- Skylar Project
- Today is a Good Day
- Zaky (Nurtured by Design, Inc.)



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Healthcare-Based Organizational Partners

- 4th Trimester Project
- AAP Organization of Neonatal Training Program Directors (ONTPD)
- AAP Section on Neonatal Perinatal Medicine (SoNPM)
- AAP Section on Newborn Pediatric Hospital Medicine Hospitalists (nPHM)
- AAP Trainees and Early Career Neonatologists (TECaN)
- California Association of Neonatology (CAN)
- California Perinatal Quality Care Collaborative (CPQCC)
- Care for NICU Families
- Caring Essentials Collaborative
- Children's Hospital Neonatal Consortium (CHNC)
- Colorado Perinatal Care Quality Collaborative (CPCQC)
- Council of International Neonatal Nurses, Inc. (COINN)
- Creative Therapy Consultants
- DEFINE Colorado
- Engage, Grow, Thrive
- Georgia Perinatal Quality Collaborative (GAPQC)
- Global Foundation for the Care of Newborn Infants (GFCNI)
- Illinois Perinatal Quality Collaborative (ILPQC)
- Institute for Patient- and Family-Centered Care (IFPCC)
- Irish Neonatal Health Alliance (INHA)
- March of Dimes
- Measure the Placenta
- Missouri Perinatal Quality Collaborative (MOPQC)
- National Association of Neonatal Nurses (NANN)
- National Association of Neonatal Therapists (NANT)
- National Association of Perinatal Social Workers (NAPSW)
- National Coalition for Infant Health
- National Institute for Children's Health Quality (NICHQ)
- National Network of Neonatal Psychologists (NNNP)
- National Perinatal Association (NPA)
- Nebraska Perinatal Quality Improvement Collaborative (NPQIC)
- Neonatal Research Network of Japan
- Neonates Foundation of India
- Neonatology Today
- New York State Perinatal Quality Collaborative (NYSPQC)
- Newborn Brain Society
- NIDCAP Federation International, Inc. (Newborn Individualized Developmental Care and Assessment Program)
- Not on My Watch
- Prematuridade
- Perinatal Advisory Council: Leadership, Advocacy, and Consultation (PAC/LAC)
- Perinatal-Neonatal Quality Improvement Network of Massachusetts (PNQIN)
- Perinatal Resource Collaborative (PRC)
- Preventing Blindness
- Ronald McDonald House Resource Link
- Sensory Beginnings
- South Dakota Perinatal Quality Collaborative (SDPQC)
- Synapse Care Solutions
- Tennessee Initiative for Perinatal Quality Care (TIPQC)
- Tiny Baby Collaborative
- T.E.N.D.E.R. Services
- Union of European Neonatal and Perinatal Societies (UENPS)



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New Organizational Partnerships



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Resource Link



Equal Representation in Leadership

Leadership Team



Malathi Balasundaram, MD
Founder & Executive Director
Neonatologist



Morgan Kowalski
Director of Operations
NICU Parent



Keira Sorrells
Director of Impact & Strategy
NICU Parent

Executive Council of Family Partners



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Lellis Bauza Vernon, SQIL



Latoya Blueford



Sahra Cahoon



Jennifer Canvasser, MSW



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Marybeth Fry, M.Ed.



Yamille Jackson, PhD,
PE, PMP



Mia Malcolm, BS, CDFT



Erika Mendence



Lenette Serio



Misti Staley



Katrina Moline



Kimberly Novod, MPH



Betsy Pilon



Alex Zavala

Executive Council of Healthcare Partners



Jessi Barnes, MSN, RN,
RNC-NIC, NPD-BC, C-ELBW



Anisha Bhatia Attawala,
MD, FAAP



Cameron N. Boyd, MD



Marsha Campbell-Yeo, RN,
BN, NNP-BC, PhD, FAAN



Mary Coughlin, MS,
NNP, NCC-E



Jessica Daigle, MD



Christy Gliniak, PhD,
OTR/L, CNT, CPXP, NTMTC



Henry Lee, MD



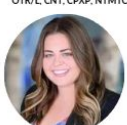
Ramya Kumar, MS, CCC-SLP,
BCSS, CNT, IBCLC, NTMTC, SBOS



Lily Lou, MD, FAAP



Alon Metrikin-Gold



Angelica Moreyra, PsyD



Andrea C Morris, DNP,
RNC-NIC, CCRN-K, CNS



Nicole Nyberg, MSN,
APRN, NNP-BC



Amanda Yastou-
Massey, MD, FACOG

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Pittsburgh, PA
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Division of Neonatology
Children's Hospital Los Angeles
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Neonatology Today*



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Co-Chair,
Family Advocacy Network
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Ashley Omwando, MBA
*FCC Committee Member
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NICU Parent*



Jadene Wong, MD
*Neonatal Hospitalist,
Lucile Packard Children's Hospital
Clinical Associate Professor,
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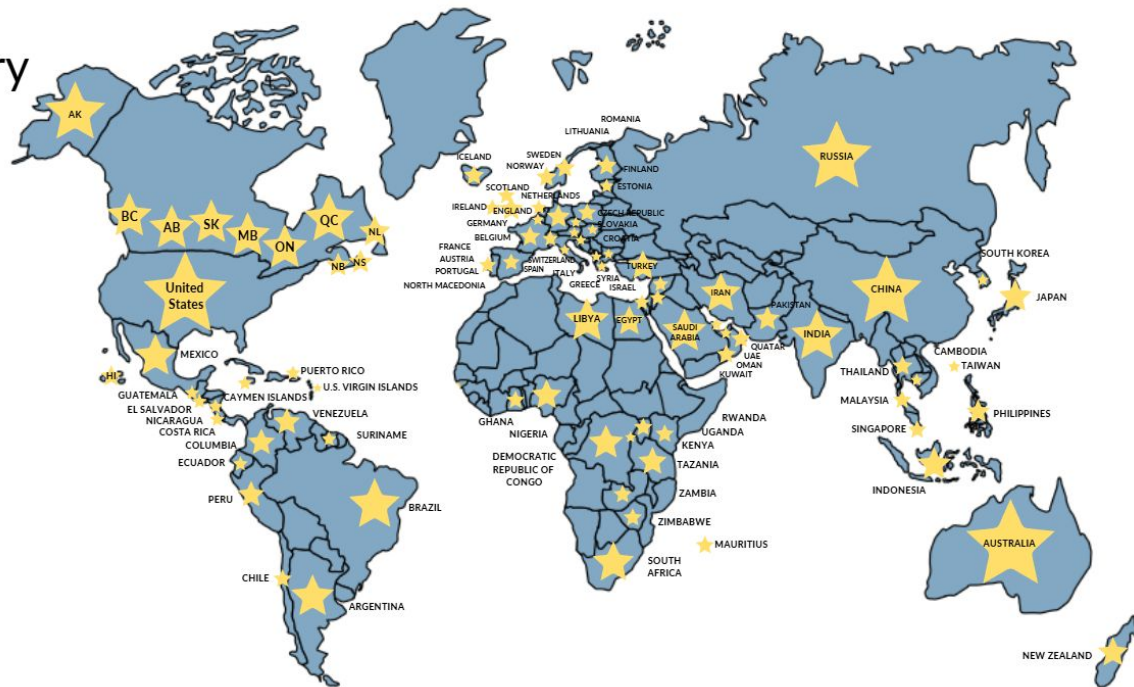
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Family-Centered Care Around the Globe!

The FCC Taskforce began in February 2022 with just 50 members.

Over the last three years,
our membership has increased to:

- more than **3,700** members
- **50** U.S. States & Puerto Rico
- **9/10** Canadian Provinces
- **81** Countries!!!



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September POLL

**Help us understand how your NICU navigates
social determinants/influencers of health.**



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FCC COMMUNITY EXCHANGE OPEN FORUM

SEPTEMBER 17, 11AM PT/2PM EST

***BEYOND "DIFFICULT": UNDERSTANDING WHAT
FAMILIES CARRY INTO HEALTHCARE***



Mary Coughlin, MS, NNP, NCC-E
Founder & President,
Caring Essentials Collaborative



Mia Malcolm, CDFT, NICU Parent
Community Engagement Specialist,
Ollie Hinkle Heart Foundation
Co-Chair,
FCC Taskforce EDIBJ Committee
NICU Parent of Gavin



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Presence Study Toolkit



Recognizing
parents as essential
partners in care,
strengthening their
role at the bedside,
and prioritizing both
infant outcomes and
family well-being

Presence Study Toolkit

Support for adopting a true
family-centered approach
• NICU teams • Healthcare organizations
• Educators • Family support networks



Toolkit developed collaboratively by family and healthcare partners from the Family-Centered Care Taskforce, the MOM-LINC Lab, and the Canadian Premature Babies Foundation's Presence Study team

The Toolkit is designed to:

- *Support more consistent, informed care*
- *Bring research into real-world use*
- *Reflect both clinical and family perspectives*
- *Be practical, not theoretical*
- *Be shared across teams, sites, and systems*

Recognizing parents as essential
partners in care, strengthening
their role at the bedside, and
prioritizing both infant outcomes
and family well-being



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CPBF Canadian Premature
Babies Foundation



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A Family Inclusive Taskforce for Improving NICU Quality of Care

FAMILY PARTNERSHIPS | JULY 14 2026

A Family-Inclusive Taskforce for Improving NICU Quality of Care

FREE

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 Split-Screen

 Views 

 PDF

 Share 

 Tools 

Keira Sorrells, Family Partner



- Avoid relying on one family partner to speak on behalf of all families.
- Seek out a diversity of stories to inform the development of family-centered care practices.

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RESEARCH

Invasive Ventilation Effectiveness Against Pediatric Death

A. J. S. S. et al.

Second-Session Impact of Menstrual Immunization

B. M. et al.

Pathogen-Specific Respiratory Infection Symptoms

A. J. S. S. et al.

Estimating Inappropriate Postoperative Antibiotics

A. J. S. S. et al.

Neural Targeted cDNA Screening

A. J. S. S. et al.

Prophylactic CMV at Cesarean in Preterm Neonates

A. J. S. S. et al.

Neonatal Screening for Oral Cleft Disorders

A. J. S. S. et al.

Parental Anxiety Over 2 Years After NICU Discharge

A. J. S. S. et al.

Telemedicine vs Telephone in Pediatric ID

A. J. S. S. et al.

A Brief Test to Predict Adherence to the 40

A. J. S. S. et al.

Pediatric Care in Pediatric Hospital

A. J. S. S. et al.

Trends in Pediatric Transfers: 2008–2023

A. J. S. S. et al.

New Technology Transitions in Pediatric Trauma Patients

A. J. S. S. et al.

Quality of Pediatric Primary Care Language Services

A. J. S. S. et al.

Interventions in Pediatric Liver Transplantation

A. J. S. S. et al.

Enhancing Physical Activity for Children With CP

A. J. S. S. et al.

Neurologic Impairment and Technology Assistance Behaviors

A. J. S. S. et al.

Barriers to NICU for Infants in Primary Care

A. J. S. S. et al.

Correlates of Perceptions on Postpartum in OBG

A. J. S. S. et al.

A Brief Care Intervention in Pediatric Practice

A. J. S. S. et al.

Child Welfare System Involvement: 2016–2022

A. J. S. S. et al.

Disrupting Health Inequities and Safety Data Disparities

A. J. S. S. et al.

Food and Nutrition in Pediatric ID Patients: Results

A. J. S. S. et al.

PEDIATRICS PERSPECTIVES

Personalizing Change in Children's Media Use

A. J. S. S. et al.

A Response to Individualized and Personalized ID

A. J. S. S. et al.

FAMILY PARTNERSHIPS

Collaborative Taskforce Improving NICU Quality of Care

A. J. S. S. et al.

FEATURE

Pediatric Imaging Progress in Southeast Asia

A. J. S. S. et al.

Disparities in Menstrual Update

A. J. S. S. et al.

Minimally Assisted Transfer

A. J. S. S. et al.

Trends in Low-income Use for Asthma

A. J. S. S. et al.

Head Loss Testing in Pediatric

A. J. S. S. et al.

REVIEW ARTICLE

Machine Learning for Treating Bacterial Infections

A. J. S. S. et al.

STATE-OF-THE-ART REVIEW

Neurological Function and Neurodevelopmental Status

A. J. S. S. et al.

SPECIAL ARTICLE

Building the Foundations for AI in Pediatrics

A. J. S. S. et al.

ETHICS ROUND

Gen Treatment by Withhold Because of Disability

A. J. S. S. et al.

HEALTH POLICY

Impacts of AI and Family Leave on Perinatal Health

A. J. S. S. et al.

QUALITY REPORTS

Improving Race and Ethnicity Data in the NICU

A. J. S. S. et al.

Establishing an Inclusive Breast Assessment Guideline

A. J. S. S. et al.

CASE REPORTS

Cardiogenic Shock in a Toddler With Malaria

A. J. S. S. et al.

Hyperdynamic Regeneration After Stroke Underlying

A. J. S. S. et al.

Spontaneous Epithelial Tumor in an Infant

A. J. S. S. et al.

FROM THE AMERICAN ACADEMY OF PEDIATRICS

Special Committee on High-Risk Neonatal Care Delivery

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Equity, Diversity, Inclusion, Belonging, and Justice Position Statement



Family-Centered Care Taskforce Equity, Diversity, Inclusion, Belonging, and Justice Position Statement

Position Statement

The Family-Centered Care (FCC) Taskforce affirms and advocates for the principles of **equity, diversity, inclusion, belonging, and justice (EDIBJ)** as foundational to high-quality, compassionate, and just neonatal care. We believe that every family in the neonatal intensive care unit (NICU) deserves care that honors their identity, recognizes their individual needs, and promotes trust, healing, and resilience.

Background

Having an infant in the NICU is universally traumatic, exhausting, and emotionally taxing. However, for families that have been intentionally and historically marginalized, this experience is often compounded by systemic inequities (i.e., racism, classism, misogyny, etc.), bias, and cultural disconnects. When families do not see themselves represented among the medical team caring for their baby, it can create mistrust, fear, and a sense of alienation—emotions that hinder the foundation of family-centered care.

Disparities based on race, gender identity, language, family composition, socioeconomic status, and other dimensions of identity can lead to additional harm. Families who feel unseen, undervalued, and/or misunderstood often experience isolation, defensiveness, and exhaustion. At this critical moment in time—when identities are being denied, families are being divided, and inclusion is under threat—the neonatal community must rise to protect our most vulnerable patients and their families.

The FCC Taskforce therefore reaffirms its unwavering commitment to equity, diversity, inclusion, belonging, and justice in all aspects of NICU care, culture, and education.

Equity

Equity means providing individuals and families with **what they need** to achieve optimal outcomes—not necessarily providing the same resources or support to everyone. Equality assumes sameness; equity recognizes difference.

Just as precision medicine tailors treatments to each patient's biological needs, family-centered care must respond to each family's social, cultural, and emotional needs. True fairness emerges not from identical treatment, but from intentional and individualized support. By identifying and addressing systemic inequities, we can begin to level the playing field for all NICU families. Each family's journey is unique, and our care must reflect that truth.

Ultimately, family-centered care is rooted in centering the individual needs of each family and providing culturally conscious, concordant care that allows families to achieve the best possible outcomes for their infants.

Figure 1 on Page 2 uses a street-crossing analogy to illustrate the difference between equality and equity. In the NICU, this same concept applies to many care practices, such as safe sleep, that are often taught and discussed in a strict binary way (i.e., right or wrong). This approach of either/or framing takes away our ability to see the fullness of a family's experience—their abilities, capabilities, beliefs, cultural practices, fears, community/familial norms—rendering equity impossible.

The FCC Taskforce affirms and advocates for the principles of equity, diversity, inclusion, belonging, and justice (EDIBJ) as foundational to high-quality, compassionate, and just neonatal care.

We encourage you to read and share this information with your team and explore how your unit can mitigate harm for marginalized families.



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