

FCC Taskforce Webinar

September 11, 2025

11-12:30pm PT

Screening Now: Standardizing Mental Health
Assessments for NICU Parents



Megan Paulsen

MD (she/her)
Neonatologist &
NICU Parent,
Children's Hospital
Minnesota



Sarah Swenson

MD, DPhil, FAAP (she/her)
Assistant Professor,
Division of Neonatology
University of Nebraska
Medical Center
Children's Nebraska

Long-Term Outcomes:
Preparing Families for Future Health



Lauren Ingledow

(she/her)
Co-Founder and
Director,
Adult Preemie
Advocacy Network
CIC (APAN)



Michelle M. Kelly

PhD, CRNP, FAANP, FAAN
(she/her)
Professor, Villanova
University, M. Louise
Fitzpatrick College of
Nursing
Pediatric & Neonatal Nurse
Practitioner

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This Webinar is Dedicated to Peter & Nathaniel



Remembering 9/11



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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.



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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Organizational Partners



FCC Taskforce Core Leadership Team

Co-Chairs

Program Manager



Malathi Balasundaram, MD

*Clinical Professor,
Stanford School of Medicine
Attending Neonatologist &
FCC Committee Chair,
El Camino Health, CA*



Keira Sorrells

*Founder &
Executive Director,
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Trauma-Informed
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*Associate Professor of Pediatrics &
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NICU Parent*



Morgan Kowalski

*Family Liaison,
American Academy of
Pediatrics Committee
on Hospital Care
NICU Parent*

Executive Council of Family Partners



Fabiana Bacchini



Lelis Bauzá Vernon



Latoya Blueford



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Jennifer Canvasser



Nishan Degnarain, MPA



Amy Finn



Molly Fraust-Wylie



Marybeth Fry



Yamille Jackson, PhD



Erika Goyer



Mia Malcolm



Necole McRae



Erika Mendence



Katrina Moline



Kimberly Novod



Betsy Pilon



Elizabeth Simonton



Alex Zavala

Executive Council of Healthcare Partners



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RNC-NIC, NPD-BC, C-ELBW



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Jessica Daigle, MD



Jessica Fry, MD



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Henry Lee, MD



Lily Lou, MD, FAAP



Kerri Machut, MD



Nicole Nyberg,
MSN, APRN, NNP-BC



Dharshi Sivakumar, MD



Vincent Smith, MD, MPH



Kimberly Stobbe, LCSW



Bob White, MD



Emily Whitesel, MD

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 **2,600** members
- **49/50** U.S. States & Puerto Rico
- **8/10** Canadian Provinces
- **71** Countries!!!



Advocacy Committee

Co-Chairs

Kerri Machut, MD

*Attending Neonatologist,
Lurie Children's Hospital
Associate Professor*

*Feinberg School of Medicine at
Northwestern University*

Nicole Nyberg, MSN, APRN, NNP-BC

*Neonatal Nurse Practitioner,
Cone Health*

Founder,

*Empowering NICU Parents &
Empowering NICU Parents Podcast*



Presence Study Toolkit

The spark:

The negative impact of restrictive parental presence policies in NICUs during the COVID-19 pandemic.

Dilemma

- Hospitals restricted parental access, leaving babies without a parent or a support person, even during extreme illness or death.
- Significant variations existed in parental access policies, even in the same city.
- Parents reported higher negative health outcomes during the visit.

The response:

Co-created best evidence practice recommendations regarding parental in NICUs during pandemics caused by respiratory pathogens such as COVID-19

How we got there:

Consensus Panel: A diverse group of individuals with expertise related to the project.

Values, preferences, and evidence guided our recommendations

1. Gathered input into a national survey, parent caregivers, healthcare providers, and NICU.
2. Identified 50 potential recommendations.
3. Conducted two rounds of Delphi surveys. Participants (n=20) rated and ranked each item on importance.
4. Round 1: Rated 50 items on a scale of 1-5.
5. Round 2: Rated the top 20 items of Round 1.
6. Presented rapid evidence synthesis of the top 20 items to the panel.
7. Consensus Panel: Each item has a Strength of Consensus recommendation, based on strength of evidence.
8. Award panel members. Do you agree with this item as a national recommendation?

Consensus recommendations based 80% of the panel agreement



Consensus practice recommendations regarding parental presence in NICUs during pandemics caused by respiratory pathogens such as COVID-19

Parents/Caregivers should have:

- 1. Status for parent/caregiver(s) as essential caregivers
- 2. Unrestricted access to provide skin-to-skin contact for their infant in the NICU
- 3. Unrestricted access to breastfeed and to receive breastfeeding supports (lactating only, non-exclusively pumping, lactation encouragement, and lactation support) for their infant in the NICU
- 4. Unrestricted access to mental health and psychosocial support services while their infant is admitted to the NICU
- 5. Unrestricted access to attend medical rounds while their infant is admitted to the NICU
- 6. Inclusion in co-decisioning/decision-making for parent-requested NICU policies (e.g., infection control, medical equipment, housing/NICU cleanliness and advocates)
- 7. Unrestricted access to provide feeding touch for their infant in the NICU
- 8. Unrestricted access to provide holding touch for their infant in the NICU
- 9. Unrestricted, in-person access to attend medical rounds while their infant is admitted to the NICU. Virtual care services may be preferred. Contact on the local context or if parent health or preference warrants it.
- 10. Unrestricted, in-person access to attend medical rounds and psychosocial support services while their infant is admitted to the NICU. Virtual care services may be preferred, based on the local context of parent/caregiver preference warrants it.
- 11. Unrestricted access for two parent/caregivers to be present while their infant is admitted to the NICU
- 12. Unrestricted access to fractional allocated space to visit/attend to their infant is admitted to the NICU
- 13. Unrestricted access to use communication devices that are on hospital grounds for remote communication and support (text/pictures, video, phone, etc.) while their infant is in the NICU (with staff approval)

Call to Action: Consensus practice recommendations based on evidence and parent/caregiver preferences should be implemented to support the health and well-being of infants and their parents, ensure equitable care, and optimize future infection control efforts.

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Equity, Diversity, Inclusion, & Belonging Committee

Co-Chairs



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

*Neonatal Outreach Coordinator,
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Mia Malcolm, BS, CDFT

*Community Outreach & Programs Care Manager,
Ollie Hinkle Heart Foundation*
Senior Research Coordinator,
Washington University School of Medicine
Clinical Research Coordinator,
Stanford University School of Medicine

Work in Progress:

- Executive Council Demographics Survey
- Equity, Diversity, Inclusion, and Belonging Position Paper
- Nonverbal Messaging in the NICU



Marketing & Communications Committee

Co-Chairs

Daphna Barbeau, MD
*Attending Neonatologist,
Director, Neurodevelopment &
Palliative Care,
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Family Leader,
Vermont Oxford Network*



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How You Can Help:

- **Follow us!** Even if you're not active on social media, giving The FCC Taskforce a follow boosts engagement and drives traffic to our profiles!
- **Tag us!** Tagging us makes it faster and easier to share and repost your content.



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Newsletter Committee

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Former Associate Director,
West Penn Hospital NICU*

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All Issues

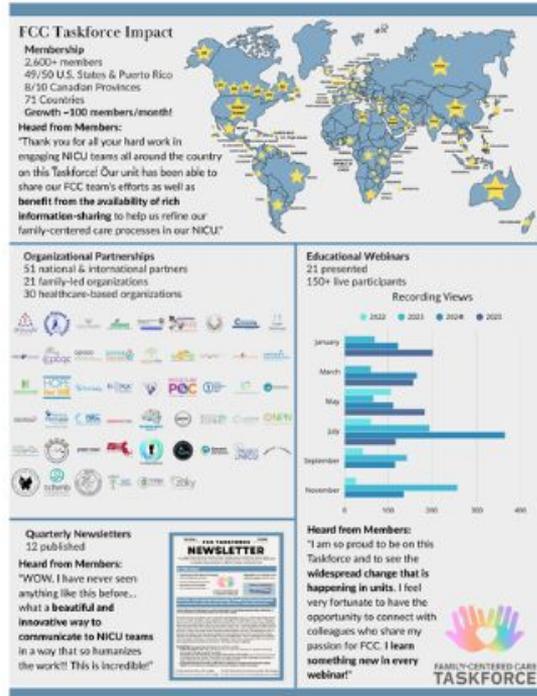


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Monthly Poll

Our September Poll asks for your feedback!

Please share what you love about the FCC Taskforce, where we can improve, and what we can offer to help you learn about and implement FCC in your NICU.



All poll responses can be found here!



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FCC Taskforce Office Hours

Who?

Facilitated by one Healthcare Partner and one Family Partner from our Executive Council and attended by members like you!

What?

An informal meeting where members can bring their unit's specific challenges and barriers around implementing family-centered care practices and brainstorm solutions for overcoming them with their peers.

Where?

Zoom! These sessions are not recorded so folks can feel safe sharing.

Why?

Don't reinvent the wheel! Modify what's worked for other units to suit your own.

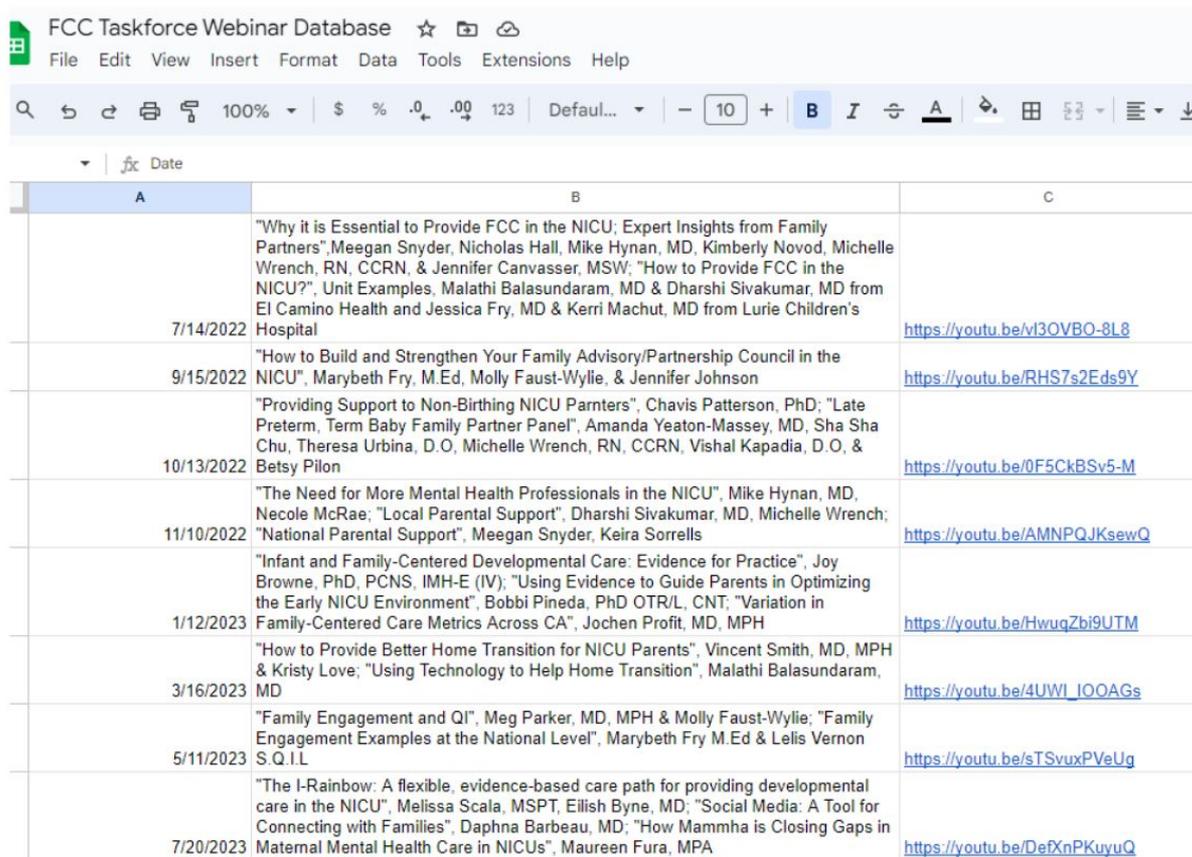
Heard from Members: **"Hearing real life experiences is so impactful for us all as clinicians who have never lived in the shoes of NICU families!** Thank you all for your vulnerabilities and sharing so that we can all learn."

Register Here



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Database of Webinar Recordings & Topics



A	B	C
7/14/2022	"Why it is Essential to Provide FCC in the NICU; Expert Insights from Family Partners", Meegan Snyder, Nicholas Hall, Mike Hynan, MD, Kimberly Novod, Michelle Wrench, RN, CCRN, & Jennifer Convasser, MSW; "How to Provide FCC in the NICU?", Unit Examples, Malathi Balasundaram, MD & Dharshi Sivakumar, MD from El Camino Health and Jessica Fry, MD & Kerri Machut, MD from Lurie Children's Hospital	https://youtu.be/vI3OVBO-8L8
9/15/2022	"How to Build and Strengthen Your Family Advisory/Partnership Council in the NICU", Marybeth Fry, M.Ed, Molly Faust-Wylie, & Jennifer Johnson	https://youtu.be/RHS7s2Eds9Y
10/13/2022	"Providing Support to Non-Birthing NICU Parnters", Chavis Patterson, PhD; "Late Preterm, Term Baby Family Partner Panel", Amanda Yeaton-Massey, MD, Sha Sha Chu, Theresa Urbina, D.O, Michelle Wrench, RN, CCRN, Vishal Kapadia, D.O, & Betsy Pilon	https://youtu.be/0F5CkBSv5-M
11/10/2022	"The Need for More Mental Health Professionals in the NICU", Mike Hynan, MD, Necole McRae; "Local Parental Support", Dharshi Sivakumar, MD, Michelle Wrench; "National Parental Support", Meegan Snyder, Keira Sorrells	https://youtu.be/AMNPQJKsewQ
1/12/2023	"Infant and Family-Centered Developmental Care: Evidence for Practice", Joy Browne, PhD, PCNS, IMH-E (IV); "Using Evidence to Guide Parents in Optimizing the Early NICU Environment", Bobbi Pineda, PhD OTR/L, CNT; "Variation in Family-Centered Care Metrics Across CA", Jochen Proffit, MD, MPH	https://youtu.be/HwuqZbi9UTM
3/16/2023	"How to Provide Better Home Transition for NICU Parents", Vincent Smith, MD, MPH & Kristy Love; "Using Technology to Help Home Transition", Malathi Balasundaram, MD	https://youtu.be/4UWI_JOOAGs
5/11/2023	"Family Engagement and QI", Meg Parker, MD, MPH & Molly Faust-Wylie; "Family Engagement Examples at the National Level", Marybeth Fry M.Ed & Lelis Vernon S.Q.I.L	https://youtu.be/sTSvuxPVeUg
7/20/2023	"The I-Rainbow: A flexible, evidence-based care path for providing developmental care in the NICU", Melissa Scala, MSPT, Eilish Byne, MD; "Social Media: A Tool for Connecting with Families", Daphna Barbeau, MD; "How Mamma is Closing Gaps in Maternal Mental Health Care in NICUs", Maureen Fura, MPA	https://youtu.be/DefXnPKuyUQ



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The Gravens Conference
on the Environment of Care
for High Risk Newborns

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“Sensitive Issues in Sensational Times”

*New date & location, same great topics,
workshops, abstracts, and networking for those
who work in Newborn Intensive Care Units.*

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June 16th, 17th, and 18th, 2026

at University of Notre Dame
Notre Dame, Indiana

Pictured: Baby Kole with his Dad



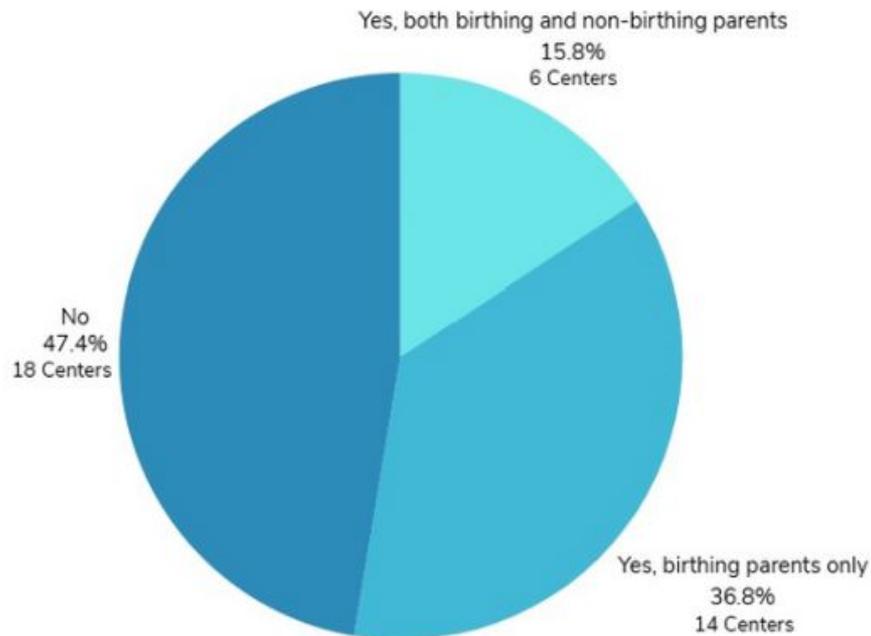
**Abstracts Due
February 15th, 2026**

To learn more and register,
visit our website:



Mental Health Screenings in the NICU

Does your unit screen NICU families for perinatal mood disorders and anxiety disorders?
(ex. PMAD Ex Edinburgh Scale)



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Does preterm birth status matter after the NICU?

Michelle M. Kelly, PhD, CRNP, FAANP, FAAN
Professor, Villanova University,
M. Louise Fitzpatrick College of Nursing



Disclosures: We have nothing to disclose

Warning: We will try very hard to convince you to think differently about preterm birth as a lifelong part of health

All children catch up by 2 years of age

All developmental delays will be evident by age 2.

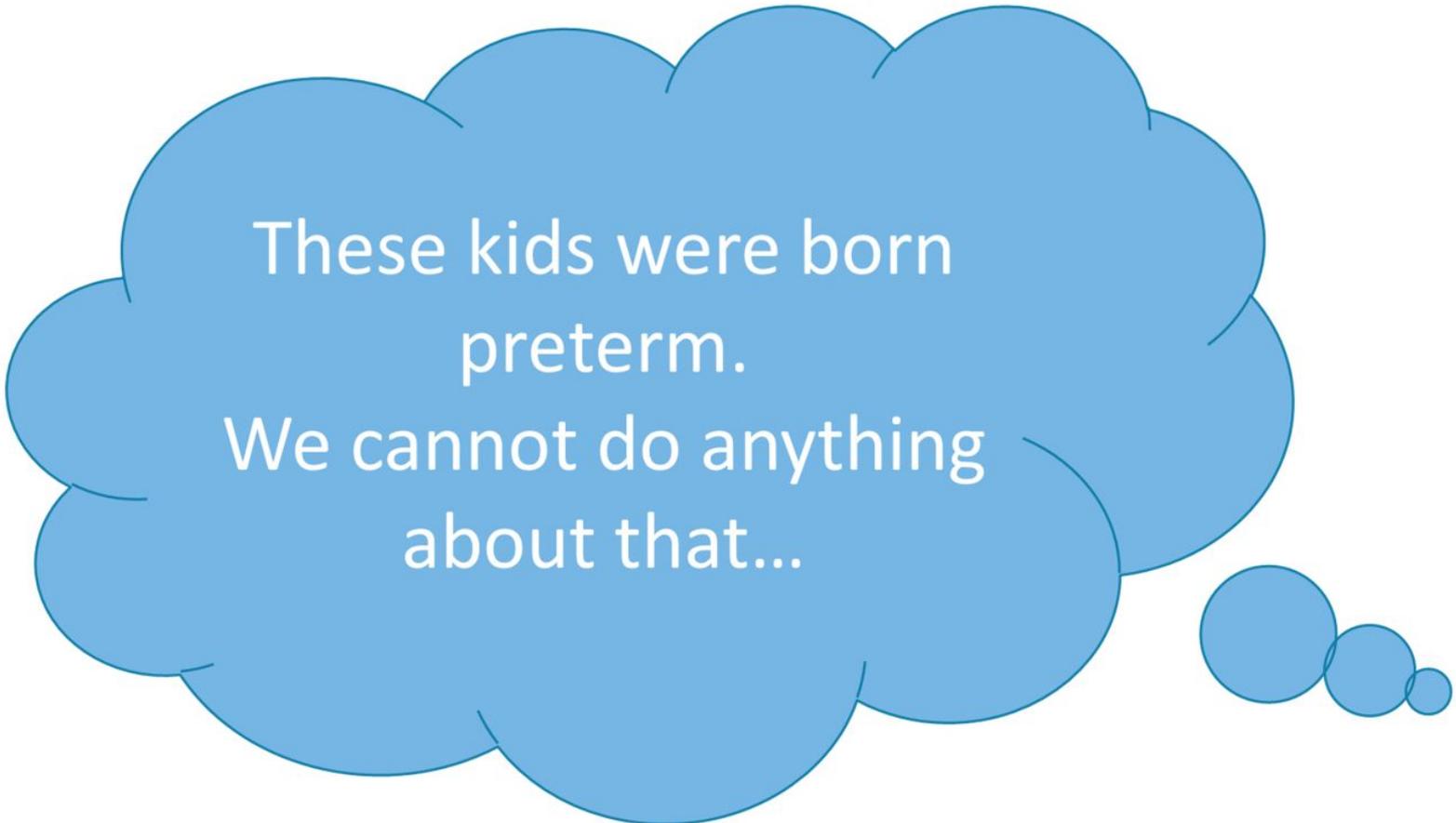
Preterm birth history only matters until age ...4?

People born at 32...34... weeks are “not really” preterm

MYTHS
BUSTED

The image features the word "MYTHS" in large, bold, black, sans-serif capital letters. A red, distressed, rectangular stamp with rounded corners is placed over the letters "T", "H", and "S". Inside the stamp, the word "BUSTED" is written in a similar bold, sans-serif font. The stamp has a grainy, ink-like texture.

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These kids were born
preterm.

We cannot do anything
about that...



Long-Term Healthcare Outcomes of Preterm Birth: An Executive Summary of a Conference Sponsored by the National Institutes of Health

Tonse N. K. Raju, MD¹, Victoria L. Pemberton, MS², Saroj Saigal, MD³, Carol J. Blaisdell, MD², Marva Moxey-Mims, MD⁴, and Sonia Buist, MD⁵, on behalf of the Adults Born Preterm Conference Speakers and Discussants*

The conference, “**Adults Born Preterm: Epidemiology and Biological Basis for Adult Outcomes**” was presented on August 13–14, 2015, Rockville, Bethesda, MD, and was funded by the National Institutes of Health, *Eunice Kennedy Shriver* National Institute of Child Health and Human Development, National Heart, Lung, and Blood Institute, and the National Institute of Diabetes and Digestive and Kidney Diseases.

Pulmonary

- Higher rates of wheezing, with or without BPD
- Wheezing rates worsen with excessive weight gain in 1st year of life
- Decreased pulmonary function & increased airflow obstruction



Cardiovascular

- Elevated systolic BP, risk increased for females
- Increased risk of diabetes, hypertension

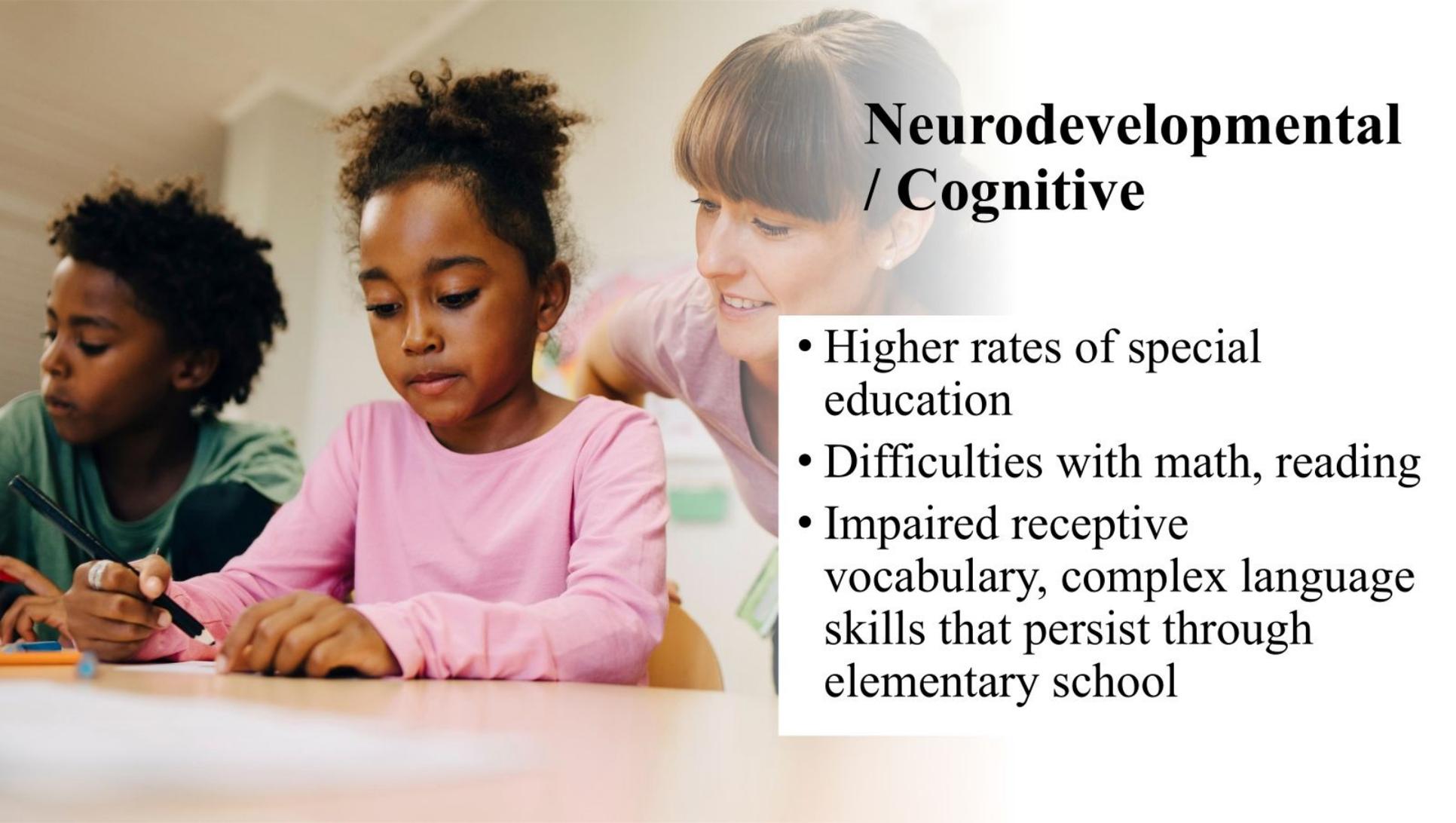


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Mental / Behavioral Health

- Increased risk of ASD
- Increased risk of ADHD (**inattentive type**)
- Increased risk for **internalizing** or externalizing behaviors
- Increased risk for impaired social competence / adjustment

A photograph of a classroom scene. A female teacher with brown hair and bangs, wearing a pink shirt, is leaning over a desk, smiling and looking at a young girl. The girl has dark curly hair and is wearing a pink long-sleeved shirt. She is holding a black pen and looking down at a piece of paper on the desk. To the left, another young girl with dark curly hair, wearing a green shirt, is also looking down at her work. The background is a bright, slightly blurred classroom setting.

Neurodevelopmental / Cognitive

- Higher rates of special education
- Difficulties with math, reading
- Impaired receptive vocabulary, complex language skills that persist through elementary school

Addressing Preterm Birth History With Clinical Practice Recommendations Across the Life Course



Michelle M. Kelly, PhD, CRNP, CNE, Jane Tobias, DNP, CPNP-PC, &
Patricia B. Griffith, MSN, CRNP, ACNP-BC





**What is the
NICU team's
role in this new
paradigm?**

Somewhere between
this...



And this...



We need to talk about
how to maximize health



A white sticky note is pinned to a light-colored surface with an orange pushpin. The note has the words "Work in progress" written in black, casual handwriting. The note is slightly wrinkled and has a soft shadow cast to its left. The entire scene is framed by a thin, light gray circular border.

Work
in
progress



ADULT PREEMIE
—ADVOCACY NETWORK—

Lauren Ingledow
CO-FOUNDER / DIRECTOR
ADULT PREEMIE ADVOCACY NETWORK CIC



+



Me

- 26 weeks gestation
- 430g
- Pre-eclampsia

- Medical follow up at 3yo
- Mum's concerns dismissed by HCP's "over-anxious" / mental health.

- Childhood: Throat and chest infections

- Adulthood – Diabetes and Chronic Kidney Disease
- Need for mum to advocate

345+ Adults born preterm

APAN Survey – Adults Born Preterm

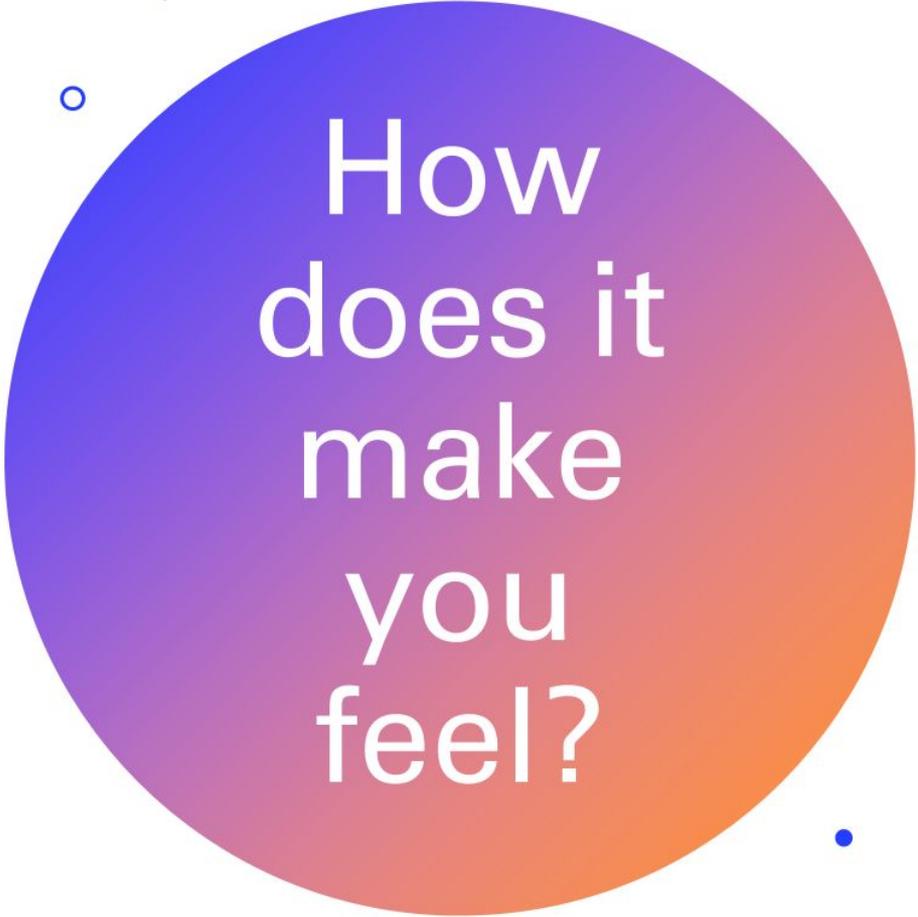
20% - report their primary care provider does consider their preterm birth as relevant and pro-actively monitors their health.

Do you feel prematurity impacts your current health?

- Yes – 84.3%
- Not sure – 15.7%



* Parents proactively stepping in to advocate for their adult children



How
does it
make
you
feel?

- “Prematurity is irrelevant”
 - “Lazy / poor lifestyle choice”
 - “You made it out of NICU – you’re fine now”
 - “health anxiety”
- 

Parent Support Network



Psychological
provision
NICU and on-going
availability

Support / encourage
families to share
with siblings, and
the individual as
they grow up.

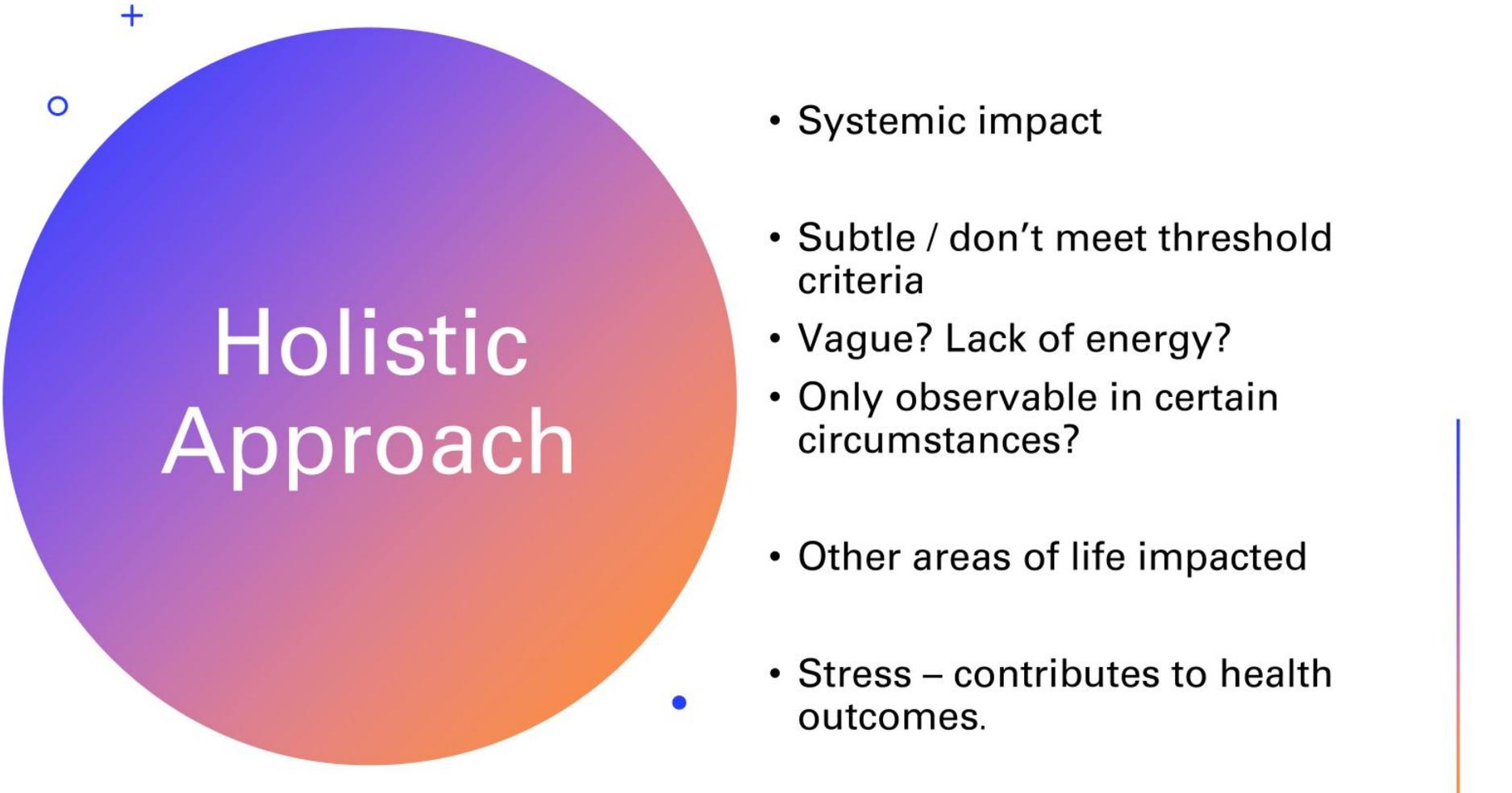


What is in a word?

- “Ex”
- “Former”

Are we giving the right message?

- Birth History & Time in NICU matters
- Included in records



Holistic Approach

- Systemic impact
- Subtle / don't meet threshold criteria
- Vague? Lack of energy?
- Only observable in certain circumstances?
- Other areas of life impacted
- Stress – contributes to health outcomes.

What can we do?

- Translate evidence into practice
- Awareness of risks
- Discharge summary – include a follow up plan & recommendations.
- Thorough follow up – mitigates risks & promotes informed discussion / choices.



Questions? Please Reach Out!



Image from Microsoft PowerPoint 365

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