

# JULY 2024 WEBINAR

## FCC TASKFORCE WEBINAR

July 11, 2024

11:00am - 12:30pm PT



### FAMILIES AS NEUROPROTECTORS IN THE NICU

**Paige Terrien Church, MD** (she/her)

- Director, NICU Grads Program, Boston Children's Hospital, Beth Israel Deaconess Medical Center
- Assistant Professor, Harvard Medical School

### DELIVERING HOPE THROUGH WORDS: THE POWER OF EFFECTIVE COMMUNICATION IN THE NICU

**Mia A. Malcolm, BS, CDFT** (she/her)

- NICU Parent of Gavin
- DEIB Facilitator and Consultant



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GAVIN MALCOLM



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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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# 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.



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# FCC Taskforce Core Team

## Co-Chairs



**Malathi Balasundaram, MD**

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



**Keira Sorrells**

Founder & Executive  
Director,  
NICU Parent Network  
Trauma-Informed  
Professional



**Colby Day, MD**

Assistant Professor of Pediatrics &  
Medical Director,  
Golisano Children's Hospital NICU  
University of Rochester  
Medical Center

## Program Manager



**Morgan Kowalski**

Family Partner



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# Executive Council - Family Partners



**Fabiana Bacchini**



**Lelis Bauzá Vernon**



**Jennifer Canvasser**



**Amy Finn**



**Molly Fraust-Wylie**



**Marybeth Fry**



**Lauren Ingledow**



**Yamille Jackson, PhD**



**Kelli Kelley**



**Kristy Love**



**Mia Malcolm**



**Necole McRae**



**Kimberly Novod**



**Betsy Pilon**



**Elizabeth Simonton**



**Meegan Snyder**



**Alex Zavala**

# Executive Council - Healthcare Partners



**Daphna Barbeau, MD**



**Joy Browne, PhD**



**Robert Cicco, MD**



**Mary Coughlin,  
MS, NNP, NCC-E**



**Jessica Daigle, MD**



**Jessica Fry, MD**



**Vargabi Ghei, MD**



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



**Mitchell Goldstein, MD**



**Luann Jones,  
DNP, APRN, NNP-BC, NE-BC**



**Henry Lee, MD**



**Lily Lou, MD, FAAP**



**Kerri Machut, MD**



**Nicole Nyberg,  
MSN, APRN, NNP-BS**



**Tim Palmer, MD**



**Jochen Profit, MD**



**Aida Simonian,  
MSN, RNC-NIC, SCM, SRN**



**Dharshi Sivakumar, MD**



**Bob White, MD**



**Emily Whitesel, MD**

# Welcome New Executive Council Members!



**Fabiana Bacchini**  
NICU Parent of Gabriel (26 Weeker & Surviving Twin)  
Executive Director, Canadian Premature Babies Foundation



**Jessica Daigle, MD, FAAP**  
NICU Parent of Liam (31 Weeker)  
Founder, Mom & Me MD



**Lauren Ingledow**  
Former Premie (26 Weeker)  
Co-Founding Director, Adult Premie Advocacy Network



**Lily Lou, MD, FAAP**  
Co-Chair, SONPM Advocacy Committee  
Former Chair, AAP Section on Neonatal-Perinatal Medicine



# FCC Taskforce Committee Chairs

## Marketing & Communications Committee Co-Chairs



**Daphna Barbeau, MD**

*Attending Neonatologist,  
HCA University Hospital  
Director,  
High Risk Infant Follow Up Clinic*



**Alex Zavala, Family Partner**

*Founder,  
The NICU Dad &  
The NICU Dad Podcast  
PFAC Chair,  
Dell Ascension NICU Network  
Family Advisor,  
Vermont Oxford Network*

## Newsletter Committee Co-Chairs



**Vargabi Ghei, MD**

*NICU Medical Director,  
HCA East Florida Northwest  
Medical Center*



**Morgan Kowalski, Family Partner**

*Program Manager,  
Family-Centered Care Taskforce  
Family Partner,  
Golisano Children's Hospital NICU  
University of Rochester Medical  
Center*

## Advocacy Committee Co-Chairs



**Kerri Machut, MD**

*Attending Neonatologist,  
Lurie Children's Hospital  
Associate Professor,  
Feinberg School of Medicine,  
Northwestern University*

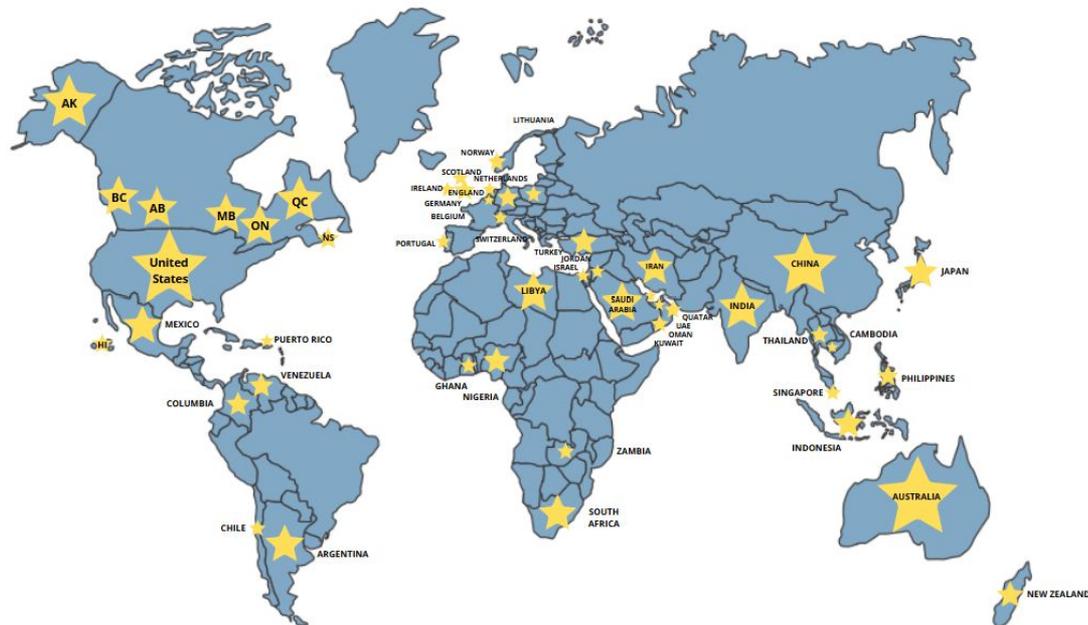


**Nicole Nyberg, NNP &  
Family Partner**

*Neonatal Nurse Practitioner,  
Cone Health  
Founder,  
Empowering NICU Parents &  
The Empowering NICU Parents  
Podcast*



# Family-Centered Care Around the Globe!



Over 1,200 members!  
48/50 U.S. States & Puerto Rico  
41 Countries



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📅 Date

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 Canvasser, 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	<a href="https://youtu.be/vI30VBO-8L8">https://youtu.be/vI30VBO-8L8</a>
9/15/2022	"How to Build and Strengthen Your Family Advisory/Partnership Council in the NICU", Marybeth Fry, M.Ed, Molly Faust-Wyllie, & Jennifer Johnson	<a href="https://youtu.be/RHS7s2Eds9Y">https://youtu.be/RHS7s2Eds9Y</a>
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	<a href="https://youtu.be/0F5CkBSv5-M">https://youtu.be/0F5CkBSv5-M</a>
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	<a href="https://youtu.be/AMNPQJKsewQ">https://youtu.be/AMNPQJKsewQ</a>
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 Profit, MD, MPH	<a href="https://youtu.be/HwuqZbI9UTM">https://youtu.be/HwuqZbI9UTM</a>
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	<a href="https://youtu.be/4UWI_J0OAGs">https://youtu.be/4UWI_J0OAGs</a>
5/11/2023	"Family Engagement and QI", Meg Parker, MD, MPH & Molly Faust-Wyllie; "Family Engagement Examples at the National Level", Marybeth Fry M.Ed & Lelis Vernon S.Q.I.L	<a href="https://youtu.be/sTSvuxPVeUg">https://youtu.be/sTSvuxPVeUg</a>
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 Mammha is Closing Gaps in Maternal Mental Health Care in NICUs", Maureen Fura, MPA	<a href="https://youtu.be/DeFxnPKuyuQ">https://youtu.be/DeFxnPKuyuQ</a>



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# June 2024 Poll

**For those who have successfully implemented FCC practices:**

(NICU-specific FCC Committee, NICU-specific Family Partnership Council, paid Family Partner position(s), parental mental health support, unlimited caregiver access, etc.)

**How did you obtain senior leadership/administration buy-in for FCC practices in your unit?**



**All poll responses  
can be found here!**



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# FCC Taskforce Office Hours



Join us for Office Hours **Thursday, 7/25**  
**at 9am PT** to with Aida Simonian and  
Yamile Jackson.



**Yamile Jackson, PhD,  
PE, PMP**

*CEO, Nurtured by Design*  
NICU Parent of Zachary



**Aida Simonian, MSN,  
RNC-NIC, SCM, SRN**

*CEO, PAC/LAC*



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# 2024 FCC NICU Measures REDCap Survey & Benchmarking

- Collaborated with Family Partners to **create NICU FCC Measures in seven categories**
- Created **comprehensive REDCap survey** to be completed by clinicians and their teams
- **NICU FCC Measures Survey**
  1. NICU Framework/Infrastructure (8)
  2. Family Support (18)
  3. Family Integration into Care (16)
  4. Family Integration into QI & Processes (1)
  5. NICU Environment (7)
  6. Staff Education (2)
  7. Balancing Measures (4)

## Why should your unit participate?

- Immediate unit performance score upon survey completion
- Benchmark unit performance with participating NICUs (all identifying data kept anonymous) at end of study
- Collaborate with participating NICUs on topic-specific QI work

## Please reach out to receive our survey!



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Paige Terrien Church, MD

# Land Acknowledgement

I have nothing to disclose

I would like to acknowledge the unceded land on which I work, which is the traditional land of the Massachusetts, Pawtucket, Wampanoag, & Nipmuc peoples and express my respect and appreciation for the past present and future.



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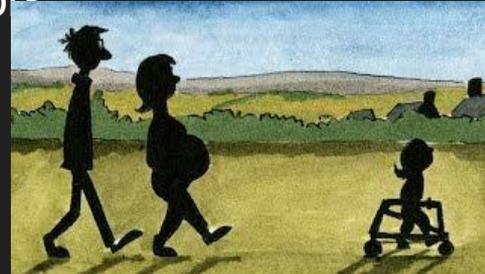
# GOALS

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1. Review what we know about longterm outcomes of preterm birth
2. Impact of NICU environment on babies & families
3. Strategies to build families as neuroprotectors



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# UNPACKING THE BURDEN OF CARE FOR INFANTS IN THE NICU

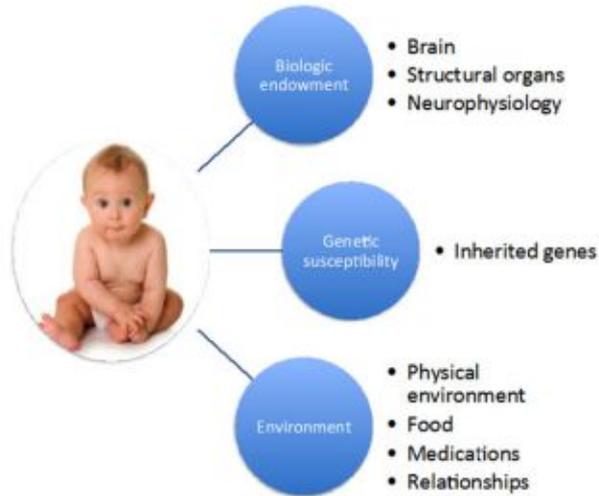
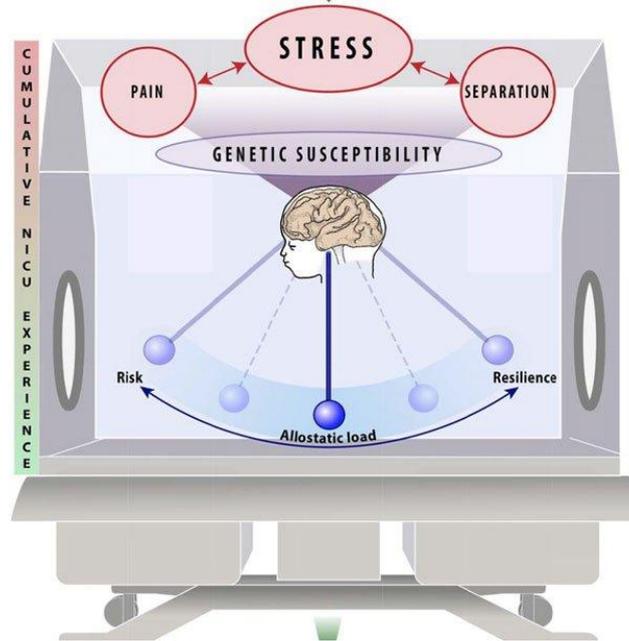


FIGURE 1. The human template.



# Long-term Neurodevelopmental Phenotype of

## Preterm Birth

Early findings 1-25%

- Cerebral Palsy
- Vision/Hearing differences
- Cognitive challenges
- Autism



- “Minor morbidities” 50-90%
  - Behavioral (ADHD, executive fxn)
  - Mental health (anxiety, depression)
  - Learning (processing, visual spatial)

- Motor (DCD, graphomotor)
- Language (receptive, expressive)
- Socioemotional skills / social communication



Church PT, Banihani R, Luther M, Maddalena P, Asztalos E. (2018). Premature Infants: the Behavioral Phenotype of the Preterm Survivor. In H. Needleman, B. Jackson (ed) *Follow-Up for NICU Graduates: Promoting Positive Developmental and Behavioral Outcomes for At-Risk Infants* Cham, Switzerland: Springer International Publishing AG.

“Distress is the companion of everyone in NICU” (Hynan 2015)

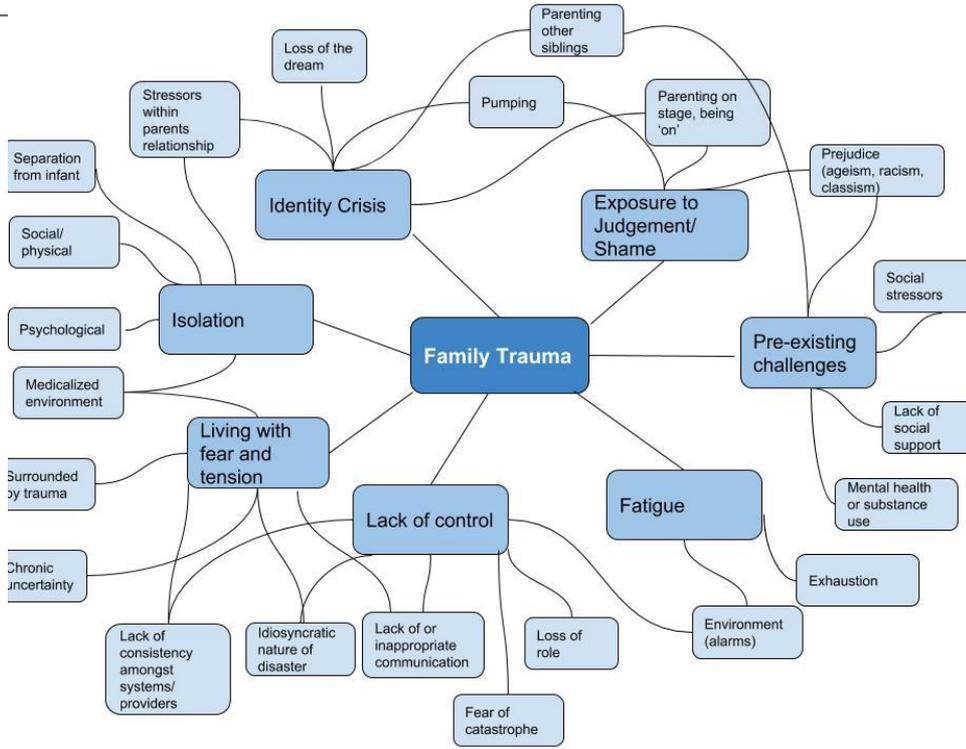
## Emotional Cauldron of NICU



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Jack Maypole, Children,  
2024



McLaughlin V, 2016

Pediatrics  
January 2018, VOLUME 141 / ISSUE 1 MeetingAbstract  
Section on Neonatal-Perinatal Medicine Program

### Traumatization During Birth and Nicu Experience: Comparing Mothers' and Partners' Report

Tammy Pham, Alexandra Hua, Regina Spinazzola, Jill Sonnenklar, Diana Li, Nicol R. Awadalla, Ruth Milanaik

[Eur J Psychol.](#) 2016 Nov; 12(4): 604–621.

Published online 2016 Nov 18. doi: [10.5964/ejop.v12i4.1093](https://doi.org/10.5964/ejop.v12i4.1093)

## Mothers and Fathers in NICU: The Impact of Preterm Birth on Parental Distress

Pediatrics  
April 2005, VOLUME 115 / ISSUE 4  
Article

### Helping Parents Cope With the Trauma of Premature Birth: An Evaluation of a Trauma-Inventive Psychological Intervention

Pediatrics  
July 2014  
Article

### Prevention of Traumatic Stress

Richard J. Shaw, Nick St John, Emily Li

## Unexpected: an interpretive description of parental traumas' associated with preterm birth

International Journal of Psychology and Behavioral Science  
p-ISSN: 2163-1948 e-ISSN: 2163-1956  
2017; 7(1): 27-31  
doi:10.5923/j.ijpbs.20170701.05

[Open Access](#)

### Parental Stress Experiences with Preterm Birth in a Neonatal Intensive Care Centre

Neetika Ashwani<sup>1</sup>, Neela Aruna Rekha<sup>2</sup>, C. Ashwini<sup>3</sup>

<sup>1</sup>Special Newborn Care Unit (SNCU), Niloufer Hospital, Hyderabad

<sup>2</sup>Department of Gynaecology and Obstetrics, Niloufer Hospital, Hyderabad

<sup>3</sup>Department of Neonatology, Niloufer Hospital, Osmania Medical College, Hyderabad

Gerri C Lasiuk ✉, PhD

<sup>^</sup>Deceased

*BMC Pregnancy and Childbirth*

<https://doi.org/10.1186/s12884-017-1211-1>

Published: 31 January 2017



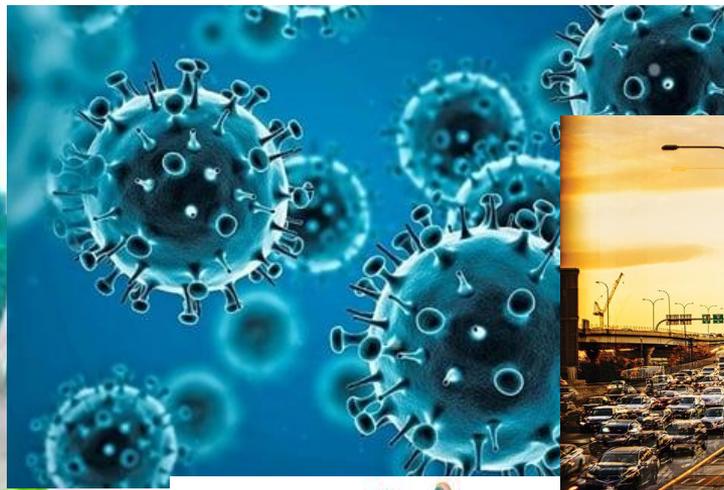
**Children's National**  
Health System

45 percent of parents experience depression, anxiety and stress when newborns leave NICU





“You are going to work at your job...I am in hell”



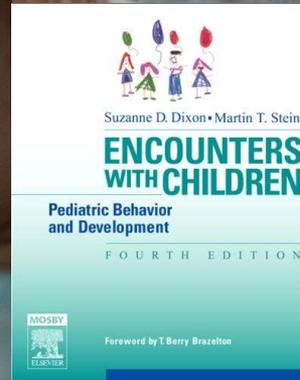


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Premature Parents

Intellectualization

Attachment competition



# The Why and How of Family-Centered Care

Theresa Urbina, DO,\* Malathi Balasundaram, MD,<sup>†</sup> Mary Coughlin, MS, NNP, RNC-E,<sup>‡</sup> Keira Sorrells, BSFCS,<sup>§</sup>  
Caroline Toney-Noland, MSc,<sup>¶</sup> Colby Day, MD<sup>||</sup>

\*Department of Pediatrics, Uniformed Services University of Health Services, Bethesda, MD

<sup>†</sup>Division of Neonatology, Department of Pediatrics, Stanford Medicine Children's Health, Stanford, CA

<sup>‡</sup>Caring Essentials Collaborative, LLC, Boston, MA

<sup>§</sup>NICU Parent Network, Lanesville, IN

<sup>¶</sup>Family Centered Care Taskforce, Oregon Health and Science University, Portland, OR

<sup>||</sup>Division of Neonatology, Department of Pediatrics, University of Rochester Medical Center, Rochester, NY



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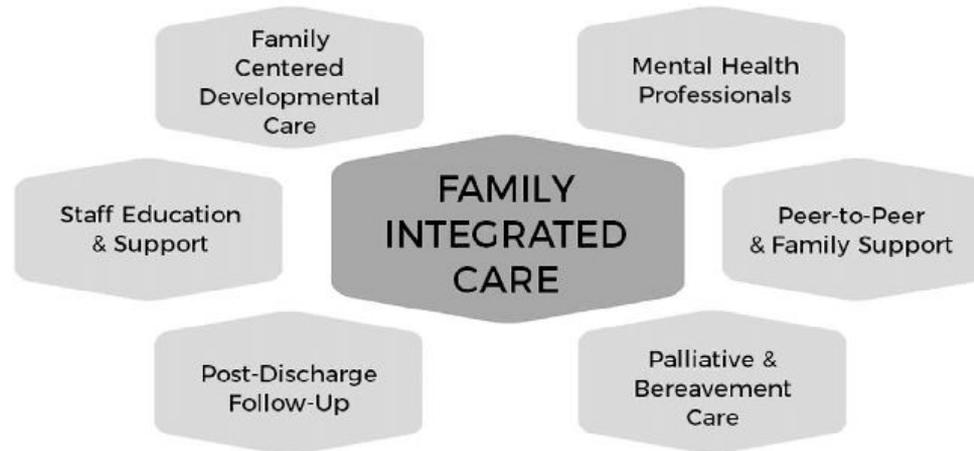


Figure 1. The core principles of trauma-informed care.

# The neonatal intensive parenting unit: an introduction

SL Hall<sup>1</sup>, MT Hynan<sup>2</sup>, R Phillips<sup>3</sup>, S Lassen<sup>4</sup>, JW Craig<sup>5</sup>, E Goyer<sup>6</sup>, RF Hatfield<sup>7</sup> and H Cohen<sup>8</sup>

## Components of Comprehensive Family Support in the NICU



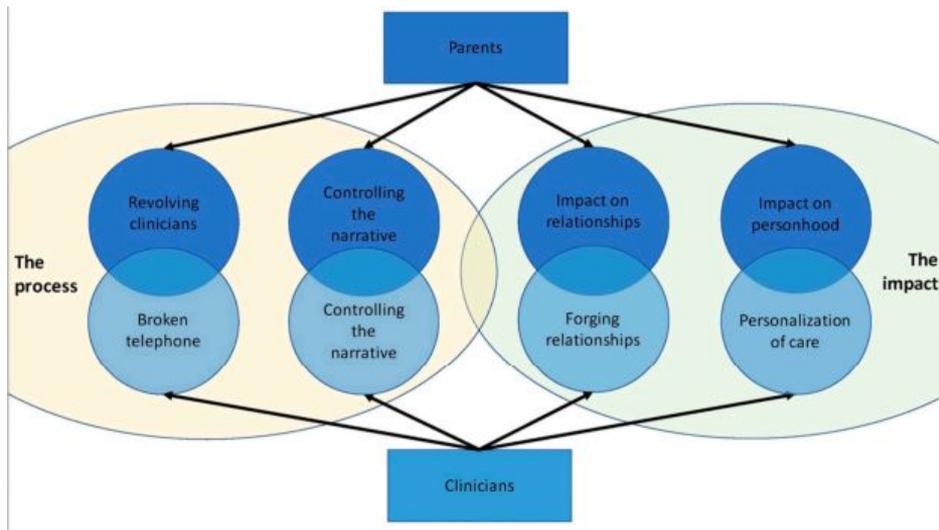
Journal of Perinatology (2017) 00, 1–6



Article

# Understanding the Family Context: A Qualitative Descriptive Study of Parent and NICU Clinician Experiences and Perspectives

Maya Dahan <sup>1,2,\*</sup>, Leahora Rotteau <sup>3</sup>, Shelley Higazi <sup>2</sup>, Ophelia Kwayke <sup>2</sup>, Giselle Lai <sup>2</sup>, Wendy Mouldsdaie <sup>2</sup> , Lisa Sampson <sup>2</sup>, Jennifer Stannard <sup>2</sup>, Paige Terrien Church <sup>1,2</sup> and Karel O'Brien <sup>1,4</sup>



# Family Snapshot Tool

Standards of Care Neonatal Consult Assessments Interventions Note Spells Nurturing Encounters Family Downtime Key Event

Vital Signs Ventilation Lines, Tubes & Drains IV Record Feed Trends Fluid Balance Diagnostic/Therapies Transfusion Labs P & C Skin/Wound Record Clinical Trends Shift Overview Family Snapshot Social Work Nutrition Pharmacy BFRN PT / OT Key Events Discharge Planning NICU Portal

Show sessions log    << <    New Session    > >>    [Print]

Include error sessions    ... 03/18/2022 09:45    [Refresh]

Demographics	Family Details	Communication
<p>Name of Parent <input type="text"/></p> <p>Preferred Pronoun(s) and Name <input type="text"/></p> <p>Occupation <input type="text"/></p> <p>Name of Parent <input type="text"/></p> <p>Preferred Pronoun(s) and Name <input type="text"/></p> <p>Occupation <input type="text"/></p> <p>Infant First Name <input type="text"/></p> <p>Primary Language <input type="text"/></p> <p>Need for Interpreter <input type="checkbox"/> Yes <input type="checkbox"/> No</p>	<p>Concerns, Hopes, and Important Family Values <input type="text"/></p> <p>Family and Home Situation <input type="text"/></p> <p>Key Supports <input type="text"/></p> <p>Spiritual, Religious, and/or Cultural Beliefs <input type="text"/></p> <p>Other Important Information About the Family <input type="text"/></p> <p>Communication Preferences <input type="text"/></p>	<p>Document Family Communication</p> <p>Document Care Conference</p> <p>Document Additional Family Meeting</p>
Additional Details		
<p>Obstacles to Spending Time with Baby / Additional Stressors <input type="text"/></p> <p>Family Time Routine <input type="text"/></p> <p>Social Worker Assigned <input type="text"/></p>		

Article

# NICU Language, Everyday Ethics, & Giving Better News: Optimizing Discussions about Disability with Families

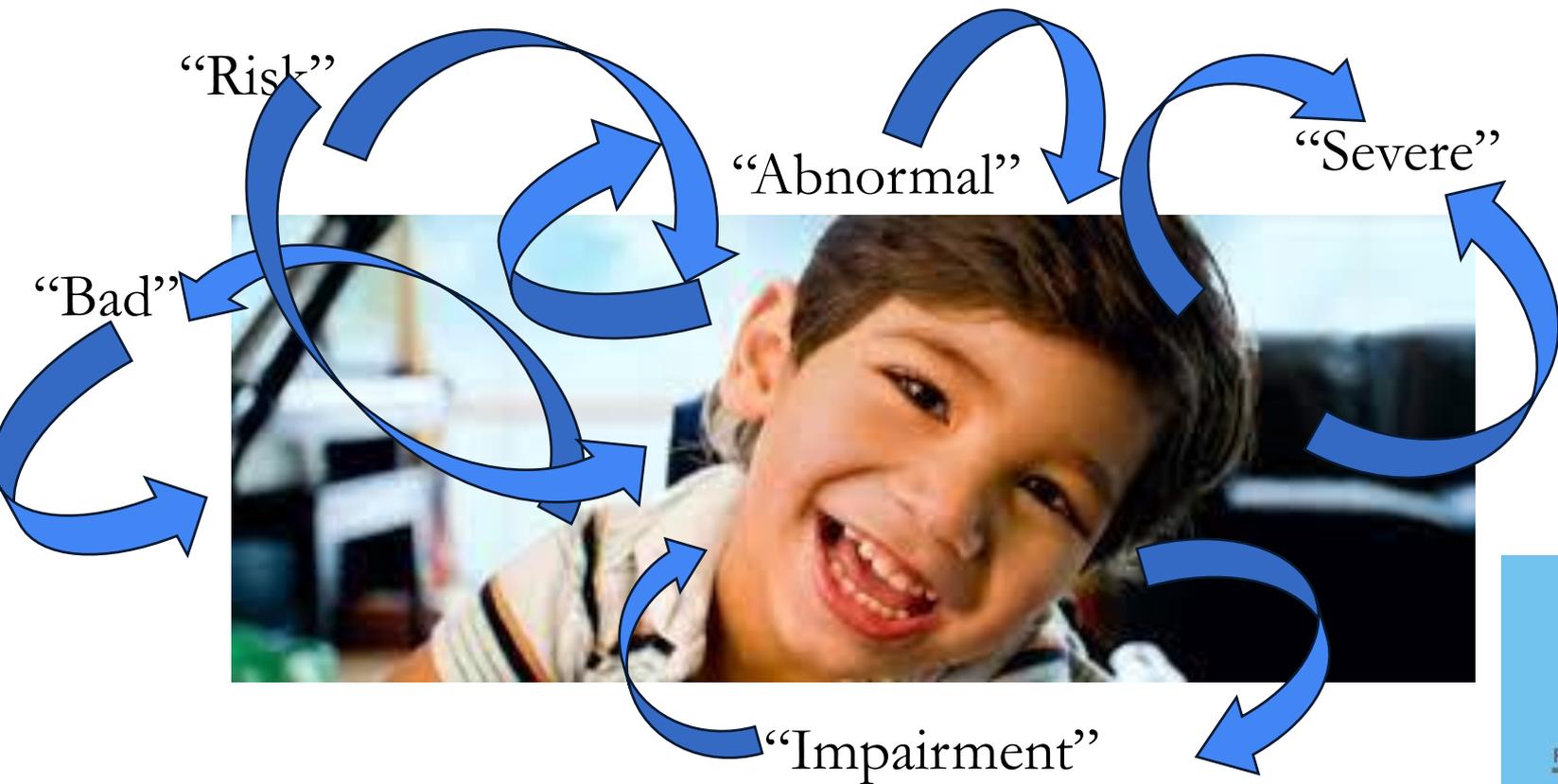
Paige Terrien Church, MD<sup>1\*</sup>; Maya Dahan, MD<sup>2</sup>; Amy Rule, MD<sup>3</sup>; Annie Janvier, MD, PhD<sup>4</sup>; Jane E. Stewart, MD<sup>1</sup>; John S. Maypole, MD<sup>5</sup>; Darcy Fehlings, MD<sup>6</sup>; Jonathan S. Litt, MD<sup>1</sup>; and Rudaina Banihani, MD<sup>2</sup>

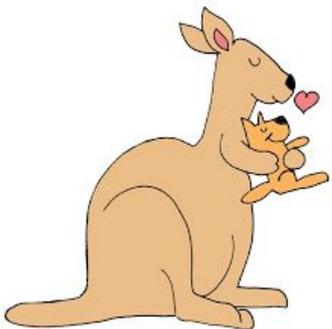


John S. Maypole MD, 2024



# Relational Frame Theory / Microethics



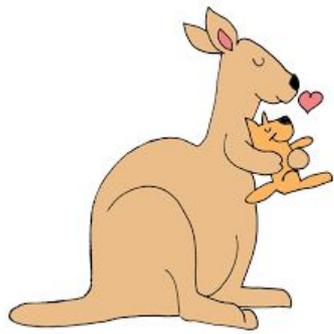


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STEVE RUSSELL/TORONTO STAR

Melissa Amer snuggles her twin daughters born prematurely five weeks ago. The stress of the birth affected Amer's milk supply, so Billie, left and Isabella, have



# Twenty-year Follow-up of Kangaroo Mother Care Versus Traditional Care

Nathalie Charpak, MD,<sup>a</sup> Rejean Tessier, PhD,<sup>b</sup> Juan G. Ruiz, MD, MSc,<sup>c,d</sup> Jose Tiberio Hernandez, PhD,<sup>e</sup> Felipe Uriza, MD, MSc,<sup>c,d</sup>  
Julieta Villegas, MD, MSc,<sup>a</sup> Line Nadeau, PhD,<sup>b</sup> Catherine Mercier, PhD,<sup>b</sup> Francoise Maheu, PhD,<sup>f</sup>  
Jorge Marin, MD,<sup>g</sup> Darwin Cortes, PhD,<sup>f</sup> Juan Miguel Gallego, PhD,<sup>h</sup> Dario Maldonado, PhD<sup>e</sup>

## Kangaroo mother care had a protective effect on the volume of brain structures in young adults born preterm

Nathalie Charpak<sup>1</sup>  | Rejean Tessier<sup>2</sup> | Juan Gabriel Ruiz<sup>3</sup> | Felipe Uriza<sup>4</sup> |  
José Tiberio Hernandez<sup>5</sup> | Darwin Cortes<sup>6</sup> | Adriana Montealegre-Pomar<sup>1,4</sup>

Positive association between KC duration and GM volume,  
basal nuclei, cerebellum and WM organization

Functionally this translated to measured differences in:

Infant IQ

Parenting behavior with greater protectiveness and nurturing

Decreased school absenteeism

Decreased hyperactivity and aggressiveness

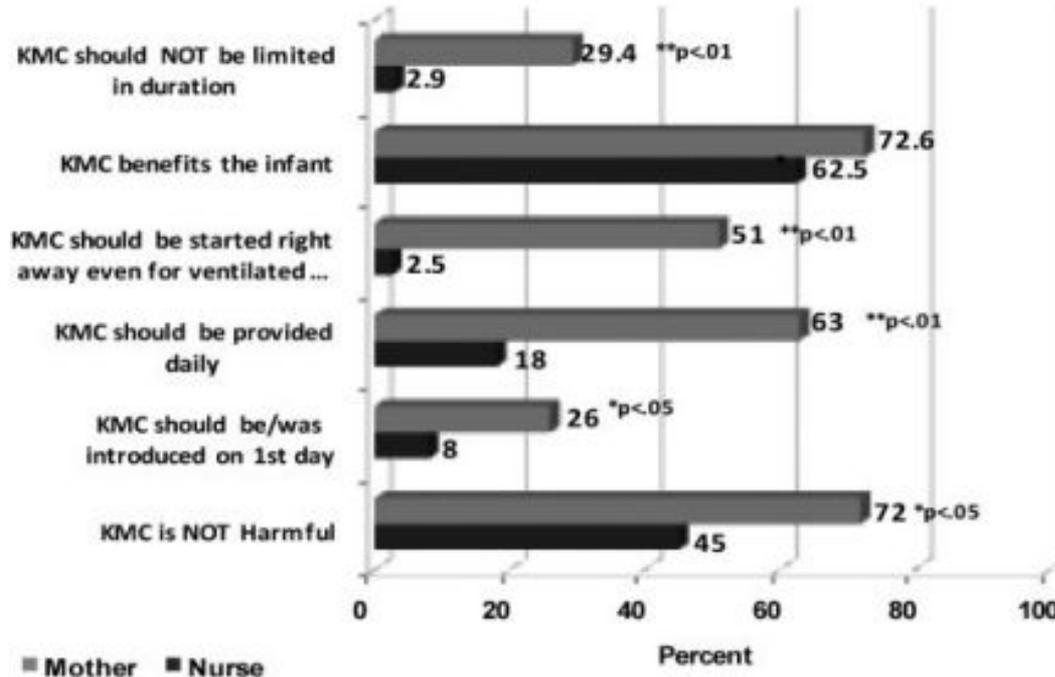


## Maternal and Neonatal Nurse Perceived Value of Kangaroo Mother Care and Maternal Care Partnership in the Neonatal Intensive Care Unit

Karen D. Hendricks-Muñoz, MD, MPH<sup>1</sup>, Yihong Li, DDS, MPH, DrPH<sup>2</sup>, Yang S. Kim, MD<sup>3</sup>, Carol C. Prendergast, EdD<sup>3</sup>, Roslyn Mayers, RN<sup>4</sup>, and Moi Louie, MD<sup>3</sup>



FAMILY-CENTERED CARE  
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# Number and Frequency of Routinely Applied Painful Procedures in University Neonatal Intensive Care Unit

Manal Kassab, RN, MSN, PhD<sup>1,2</sup>,  
 Afnan A. Alhassan, MSP<sup>3</sup>,  
 Karem H. Alzoubi, PhD<sup>1</sup>,  
 and Yousef S. Khader, BDS, MSc, MSPH, MHPE,  
 FFPH, ScD<sup>1</sup>



**Table 4.** Number of Procedures during the First 7 Days of Admission by General Characteristics of Neonates.

Variable	M ± SD	p value
Gender		
Male	103.05 ± 55.92 <sup>a</sup>	.184
Female	91.42 ± 50.49 <sup>a</sup>	
Gestational age at birth (week)		
≤27	135 ± 21.21 <sup>a</sup>	<.001
28-31	129.92 ± 52.66 <sup>b</sup>	
32-36	98.95 ± 52.66 <sup>c</sup>	
≥37	70.75 ± 49.79 <sup>d</sup>	
Birth weight		
≤1,000	150.75 ± 65.35 <sup>a</sup>	<.001
1,001-1,500	130.46 ± 51.82 <sup>a</sup>	
1,501-2,500	94.66 ± 49.21 <sup>b</sup>	
≥2,501	72.63 ± 44.18 <sup>c</sup>	

Note. Different superscript indicate statistical difference across categories of each variable.

# Effectiveness of Family Integrated Care in neonatal intensive care units on infant and parent outcomes: a multicentre, multinational, cluster-randomised controlled trial

Karel O'Brien, Kate Robson, Marianne Bracht, Melinda Cruz, Kei Lui, Ruben Alvaro, Orlando da Silva, Luis Monterrosa, Michael Narvey, Eugene Ng, Amuchau Soraisham, Xiang Y Ye, Lucia Mirea, William Tarnow-Mordi, Shoo K Lee, for the FiCare Study Group and FiCare Parent Advisory Board\*

Annie Janvier<sup>a,b,c,d,e,f,g,h,\*</sup>, Michael-Andrew Asaad<sup>a,b</sup>, Martin Reichherzer<sup>b</sup>, Catherine Cantin<sup>b,h</sup>, Maia Sureau<sup>i</sup>, Josée Prince<sup>i</sup>, Thuy Mai Luu<sup>a,c</sup>, and Keith J Barrington<sup>a,b,c</sup>

<sup>a</sup>Department of Pediatrics, Université de Montréal, Montréal, Canada

<sup>b</sup>Division of Neonatology, Hôpital Sainte-Justine, Montréal, Canada

<sup>c</sup>CHU Sainte-Justine Research Center, Montréal, Canada



“INDIVIDUALIZED”



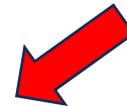
## Family Integrated Care (FiCare): Positive impact on behavioural outcomes at 18 months

Paige Terrien Church<sup>a,b</sup>, Ruth E. Grunau<sup>c,e</sup>, Lucia Mirea<sup>d</sup>, Julie Petrie<sup>e</sup>,  
Amuchou Singh Soraisham<sup>f</sup>, Anne Synnes<sup>c,e</sup>, Xiang Y. Ye<sup>d</sup>, Karel O'Brien<sup>b,d,g,\*</sup>

**Table 3**

Comparison of outcomes measured at 18–21 months without adjustment.

Outcomes	Non-FiCare n = 62	FiCare n = 123	p-Value
Internalizing Total score, mean (sd)	45.7 (8.0)	47.0 (9.5)	0.34
Externalizing Total score, mean (sd)	49.2 (7.6)	48.6 (9.1)	0.67
Dysregulation Total score, mean (sd)	46.6 (12.8)	41.7 (9.0)	0.01
Competence Total score, mean (sd)	47.0 (9.7)	48.2 (9.8)	0.42



# Systematic review of developmental care interventions in the neonatal intensive care unit since 2006

Sara Burke 

## Do NICU developmental care improve cognitive and motor outcomes for preterm infants? A systematic review and meta-analysis

Farin Soleimani<sup>1</sup>, Nadia Azari<sup>1</sup>, Hesam Ghiasvand<sup>1,2</sup>, Amin Shahrokhi<sup>1</sup>, Nahid Rahmani<sup>3</sup> and Shiva Fatollahierad<sup>1\*</sup> 

## Effectiveness of interventions on early neurodevelopment of preterm infants: a systematic review and meta-analysis

Marilyn Aita<sup>1,2,3\*</sup> , Gwenaëlle De Clifford Faugère<sup>1,2</sup>, Andréane Lavallée<sup>1,2</sup>, Nancy Feeley<sup>3,4,5</sup>, Robyn Émilie Rioux<sup>1,8</sup> and Marie-Hélène Proulx<sup>1</sup>

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FAMILY-CENTERED CARE  
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## Early developmental interventions for infants born very preterm – what works?

Peter J. Anderson<sup>a,b,\*</sup>, Karli Treyvaud<sup>b,d</sup>, Alicia J. Spittle<sup>b,c</sup>

<sup>a</sup> Turner Institute for Brain and Mental Health & School of Psychological Sciences, Monash University, Melbourne, Australia

<sup>b</sup> Murdoch Children's Research Institute, Melbourne, Australia

<sup>c</sup> Department of Physiotherapy, School of Health Sciences, University of Melbourne, Melbourne, Australia

<sup>d</sup> Department of Psychology and Counselling, La Trobe University, Melbourne, Australia



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# Understanding family-centered care in the NICU: a scoping review protocol

Maria E. Franco Fuenmayor<sup>1</sup> • Andrea Fawcett<sup>2,3</sup> • Katherine E. Schwartz<sup>4</sup> • Susan Horner<sup>2,5,6</sup> •  
Malathi Balasundaram<sup>7</sup> • Barbara Lawlor Burke<sup>8</sup> • Katherine A. Bean<sup>5,6</sup> • Laura N. Russell<sup>9</sup> • Elizabeth Simonton<sup>10</sup>  
• Kerri Z. Machut<sup>5,6</sup> • Jessica T. Fry<sup>5,6</sup>

# The STEP Program—A Qualitative Study of the Supportive Therapeutic Excursion Program and Its Effect on Enabling Parental Self-Efficacy and Connectedness after the Stress-Experience of the NICU

Makini McGuire-Brown <sup>1</sup>, Rudaina Banihani <sup>2</sup>, Jo Watson <sup>2</sup>, Eugene Ng <sup>2</sup>, Colleen Rocha <sup>2</sup>, Laura Borges <sup>2</sup> and Paige Terrien Church <sup>2,\*</sup>



*“I was [now] in charge of my child. And that it was up to me to decide how to be safe or not safe. And to give myself a little bit of self-confidence, and I think that’s important for moms, especially when you’re getting closer to discharge, it’s the lack of self-confidence and knowledge in your own capabilities of being a mother because it’s stripped from you right at the door.” Participant 12 (parent)*



**FAMILY-CENTERED CARE  
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# Acceptance and Commitment Therapy for Children with Special Health Care Needs and Their Parents: A Systematic Review and Meta-Analysis

Arpita Parmar<sup>1,2</sup>, Kayla Esser<sup>1,2</sup>, Lesley Barreira<sup>1,2,3</sup>, Douglas Miller<sup>3</sup>, Leora Morinis<sup>4</sup>, Yuen-Yu Chong<sup>5</sup> , Wanda Smith<sup>3</sup>, Nathalie Major<sup>6</sup>, Paige Church<sup>7</sup>, Eyal Cohen<sup>1,2,8,9</sup> and Julia Orkin<sup>1,2,9,\*</sup>

## Coached, Coordinated, Enhanced Neonatal Transition (CCENT): protocol for a multicentre pragmatic randomised controlled trial of transition-to-home support for parents of high-risk infants

Julia Orkin,<sup>1,2,3</sup> Nathalie Major,<sup>4</sup> Kayla Esser ,<sup>3</sup> Arpita Parmar,<sup>3</sup> Elise Couture,<sup>5</sup> Thierry Daboval,<sup>4</sup> Emily Kieran,<sup>6</sup> Linh Ly,<sup>7</sup> Karel O'Brien,<sup>8</sup> Hema Patel,<sup>9</sup> Anne Synnes,<sup>6</sup> Kate Robson,<sup>10</sup> Lesley Barreira,<sup>3</sup> Wanda L Smith,<sup>11</sup> Sara Rizakos,<sup>3</sup> Andrew R Willan,<sup>12</sup> Maryna Yaskina,<sup>13</sup> Myla E Moretti,<sup>14,15</sup> Wendy J Ungar,<sup>3,15</sup> Marilyn Ballantyne,<sup>16</sup> Paige Terrien Church,<sup>2,17</sup> Eyal Cohen  <sup>1,2,3</sup>



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## Edinburgh Postnatal Depression Scale<sup>1</sup> (EPDS)

Name: \_\_\_\_\_ Address: \_\_\_\_\_

Your Date of Birth: \_\_\_\_\_

Baby's Date of Birth: \_\_\_\_\_ Phone: \_\_\_\_\_

As you are pregnant or have recently had a baby, we would like to know how you are feeling. Please check the answer that comes closest to how you have felt **IN THE PAST 7 DAYS**, not just how you feel today.

Here is an example, already completed.

I have felt happy:

- Yes, all the time  
 Yes, most of the time      This would mean: "I have felt happy most of the time" during the past week.  
 No, not very often      Please complete the other questions in the same way.  
 No, not at all

In the past 7 days:

- |  |  |
|--|--|
| <p>1. I have been able to laugh and see the funny side of things</p> <p><input type="checkbox"/> As much as I always could<br/> <input type="checkbox"/> Not quite so much now<br/> <input type="checkbox"/> Definitely not so much now<br/> <input type="checkbox"/> Not at all</p> <p>2. I have looked forward with enjoyment to things</p> <p><input type="checkbox"/> As much as I ever did<br/> <input type="checkbox"/> Rather less than I used to<br/> <input type="checkbox"/> Definitely less than I used to<br/> <input type="checkbox"/> Hardly at all</p> <p>*3. I have blamed myself unnecessarily when things went wrong</p> <p><input type="checkbox"/> Yes, most of the time<br/> <input type="checkbox"/> Yes, some of the time<br/> <input type="checkbox"/> Not very often<br/> <input type="checkbox"/> No, never</p> <p>4. I have been anxious or worried for no good reason</p> <p><input type="checkbox"/> No, not at all<br/> <input type="checkbox"/> Hardly ever<br/> <input type="checkbox"/> Yes, sometimes<br/> <input type="checkbox"/> Yes, very often</p> <p>*5. I have felt scared or panicky for no very good reason</p> <p><input type="checkbox"/> Yes, quite a lot<br/> <input type="checkbox"/> Yes, sometimes<br/> <input type="checkbox"/> No, not much<br/> <input type="checkbox"/> No, not at all</p> | <p>*6. Things have been getting on top of me</p> <p><input type="checkbox"/> Yes, most of the time I haven't been able to cope at all<br/> <input type="checkbox"/> Yes, sometimes I haven't been coping as well as usual<br/> <input type="checkbox"/> No, most of the time I have coped quite well<br/> <input type="checkbox"/> No, I have been coping as well as ever</p> <p>*7. I have been so unhappy that I have had difficulty sleeping</p> <p><input type="checkbox"/> Yes, most of the time<br/> <input type="checkbox"/> Yes, sometimes<br/> <input type="checkbox"/> Not very often<br/> <input type="checkbox"/> No, not at all</p> <p>*8. I have felt sad or miserable</p> <p><input type="checkbox"/> Yes, most of the time<br/> <input type="checkbox"/> Yes, quite often<br/> <input type="checkbox"/> Not very often<br/> <input type="checkbox"/> No, not at all</p> <p>*9. I have been so unhappy that I have been crying</p> <p><input type="checkbox"/> Yes, most of the time<br/> <input type="checkbox"/> Yes, quite often<br/> <input type="checkbox"/> Only occasionally<br/> <input type="checkbox"/> No, never</p> <p>*10. The thought of harming myself has occurred to me</p> <p><input type="checkbox"/> Yes, quite often<br/> <input type="checkbox"/> Sometimes<br/> <input type="checkbox"/> Hardly ever<br/> <input type="checkbox"/> Never</p> |
|--|--|

Administered/Reviewed by \_\_\_\_\_ Date \_\_\_\_\_

<sup>1</sup>Source: Cox, J.L., Holden, J.M., and Sagovsky, R. 1987. Detection of postnatal depression: Development of the 10-item Edinburgh Postnatal Depression Scale. *British Journal of Psychiatry* 150:782-786 .

<sup>2</sup>Source: K. L. Wisner, B. L. Parry, C. M. Piontek, Postpartum Depression N Engl J Med vol. 347, No 3, July 18, 2002, 194-199

Users may reproduce the scale without further permission providing they respect copyright by quoting the names of the authors, the title and the source of the paper in all reproduced copies.



# Take Away Messages

Family = Neuroprotectors

BUT...

Parents preterm too

Need to create environment where they:

- Feel safe
- Can explore parenting
- Develop capacity



# FCC TASKFORCE WEBINAR

July 11, 2024

11:00am – 12:30pm PT



## FAMILIES AS NEUROPROTECTORS IN THE NICU

**Paige Terrien Church, MD** (she/her)

- Director, NICU Grads Program, Boston Children's Hospital, Beth Israel Deaconess Medical Center
- Assistant Professor, Harvard Medical School

## DELIVERING HOPE THROUGH WORDS: THE POWER OF EFFECTIVE COMMUNICATION IN THE NICU

**Mia A. Malcolm, BS, CDFT** (she/her)

- NICU Parent of Gavin
- DEIB Facilitator and Consultant



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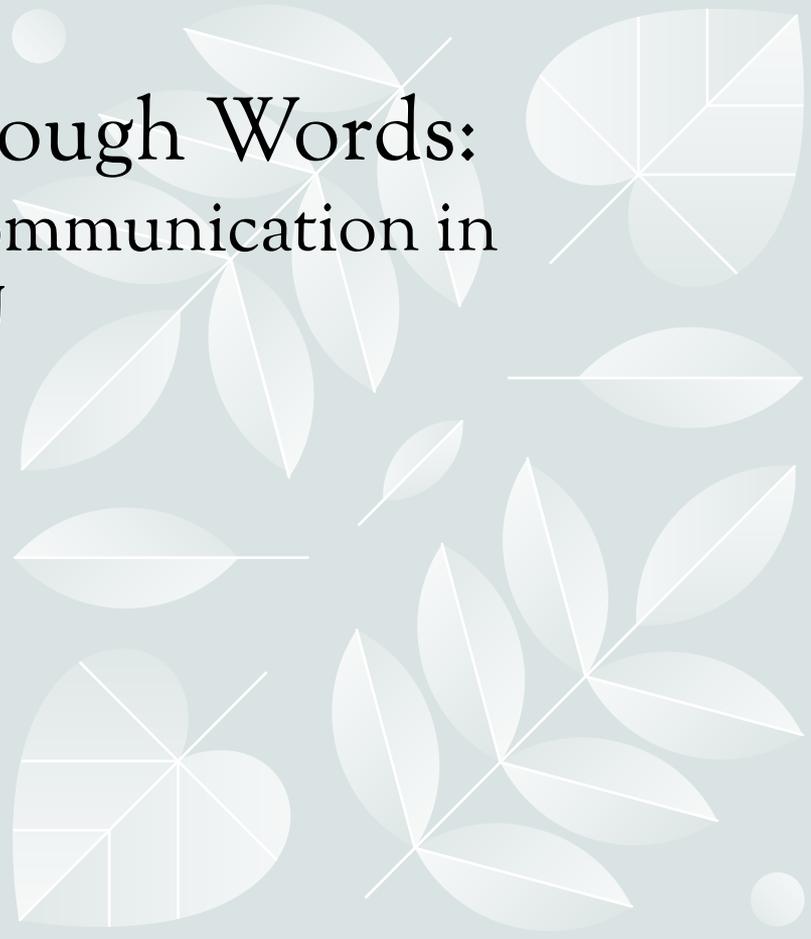
MeadJohnson  
Nutrition



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# Delivering Hope Through Words: The Power of Effective Communication in the NICU

The background features a light green color with a pattern of stylized, white-outlined leaves and circles of varying sizes scattered across the right side and bottom.

---

Mia Malcolm (she/her), B.S., CFDT

DEIB Facilitator/Advisor

NICU Mom

# LAND ACKNOWLEDGEMENT

WITH RESPECT, WE HONOR, THAT THE LAND I AM ON TODAY, IN ST. LOUIS, IS THE TRADITIONAL AND ANCESTRAL HOMELANDS OF THE **CAHOKIA, ILLINIWEK (ILLINI) CONFEDERATION, MISSISSIPPIAN, MA "ZHA" (OSAGE), OTOE-MISSOURIA, MYAAMIA (MIAMI), AND OČETI ŠAKÓWID (SIOUX) PEOPLES.**

WE RECOGNIZE THE INDIGENOUS PEOPLES AS ORIGINAL STEWARDS OF THIS LAND AND ALL THE RELATIVES WITHIN IT. THE PROCESS OF KNOWING AND ACKNOWLEDGING THE LAND WE STAND ON IS A WAY OF HONORING AND EXPRESSING GRATITUDE FOR THE ANCESTRAL PEOPLE WHO WERE ON THIS LAND BEFORE US.



# #NeverForget

EFFECTIVE COMMUNICATION WITH PATIENTS  
AND FAMILIES AFFECTS PATIENT OUTCOMES,  
PATIENT SAFETY, AND PERCEPTIONS OF  
QUALITY OF CARE.

EFFECTIVE COMMUNICATION IS THE  
CORNERSTONE OF PATIENT AND FAMILY  
CENTERED CARE

# WORDS



words have  
direct and  
indirect impacts

# MATTE R

on the people  
who hear or  
read them



24 weeks, 5 days

1lb, 8oz □ 680g

Gavin  
aka  
Big G



# LET'S TALK LANGUAGE



## Failure

Failure to  
thrive

Failed  
extubation

Failed \_\_\_  
intervention

# LET'S TALK LANGUAGE



## Misbehaving

He/she was  
being bad/  
misbehaving

# LET'S TALK LANGUAGE



## Difficult

Difficult  
families

Difficult  
stick/airway

# LET'S TALK LANGUAGE

Disengaged

Absent or  
Inattentive  
Parents



# LET'S TALK LABELS & EXPECTATIONS

## Good Parents

- **Gracious**
- **Present\***
- **Invisible\***
- **Accommodating/Agreeable**

# LET'S TALK LABELS & EXPECTATIONS

## Bad Parents

- **Obnoxious**
- **Intimidating**
- **Demanding**
- **Overbearing**

# BARRIERS TO EFFECTIVE COMMUNICATION

1



## Intentionality

- WHAT DOES IT MEAN TO BE INTENTIONAL WITH YOUR WORDS?
- WHAT DOES IT COST YOU WHEN YOU ARE NOT?
- INTENTION VS IMPACT

2



## Sympathy

- EMPATHY VS SYMAPTHY
- GATEWAY TO COMPASSION

3



## Listening

- TWO PART PROCESS
- QUESTIONING VS. ASKING QUESTIONS
- SELF-RELFECTION

4



## Storytelling

“Power is the ability not just to tell the story of another person, but to make it the definitive story of that person.”

~The Danger of a Single Story TED Talk – Chimamanda Adichie

# HOW WE FOSTER HOPE:

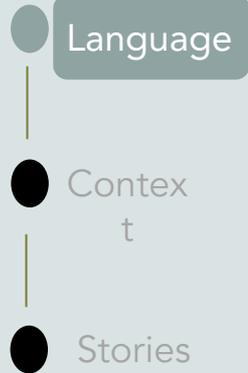
UNDERSTANDING BARRIERS TO EFFECTIVE COMMUNICATION

“People in trauma are often relying on strangers for compassion, during their darkest moments.”

~ unknown

# HOW WE FOSTER HOPE:

UNDERSTANDING BARRIERS TO EFFECTIVE  
COMMUNICATION



When words fail,  
disease sets in.  
~Shawn Corey  
Carter (Jay Z)

HOW WE FOSTER  
HOPE:  
UNDERSTANDING BARRIERS TO EFFECTIVE  
COMMUNICATION

● Language

● Context

● Stories

Words are never  
good or bad on  
their own, context  
makes them so.  
~unknown

# HOW WE FOSTER HOPE:

UNDERSTANDING BARRIERS TO EFFECTIVE  
COMMUNICATION

● Language

● Context

● Stories

Stories can also  
repair broken  
dignity.  
~ Chimimanda  
Ngozi



Thank you

---

Mia Malcolm (she/her)

[mia.malcolm@outlook.com](mailto:mia.malcolm@outlook.com)

# UPCOMING WEBINARS

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## September 12th:

→ Improving Family Engagement in the NICU: The Colorado Experience

**Susan Hwang, MD, MPH, PhD**

→ Title TBD

**Elizabeth Simonton, JD and Co-Founder/CEO,  
ICU Baby**

## November 14th:

→ Title TBD

**Rafi Mendelson, MD, Neonatologist, Tel Aviv**

→ Title TBD

**Fabiana Bacchini, Executive Director,  
Canadian Premature Babies Foundation**

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