

# COURAGEOUS COMMUNICATIONS

*Intentionally Creating  
Diverse & Inclusive Spaces*



Saturday, October 14, 2023 | Louisville, Kentucky

[nicuparentnetwork.org](http://nicuparentnetwork.org)

2023

- Gigi Khonyongwa-Fernandez
- Tieast Leverett *She / Her*
- Erika Goyer *She / They*



How we will

# ENGAGE

- OPEN HEARTS  OPEN MINDS  CURIOUS
- LISTEN TO UNDERSTAND, NOT TO RESPOND
- EVERYONE PARTICIPATES, NO ONE DOMINATES

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**W.A.I.T.** WHY AM I TALKING?  
WHY AREN'T I TALKING?



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# PROMPTS:

**DISCUSSION**

**ANY INSIGHTS?**

**DO YOU HAVE  
RESOURCES TO SHARE?**



How we will

**MANAGE US**

**E.L.M.O.**

**Enough.**

**Let's move on.**



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**WHAT IS SAID HERE  
STAYS HERE**

**WHAT IS LEARNED HERE  
LEAVES HERE**



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**DOES THIS WORK  
FOR EVERYONE?**

**WHAT ARE YOUR  
EXPECTATIONS?**



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# Why?

- create **community**
- be more **inclusive**
- limit **harm, understand impact**



# What?

- bring greater **awareness, identifying gaps**
- expand **understanding**
- promote **health**



# How?

- **case studies**
- **tools**
- **collaborators**





Why?



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# Impact

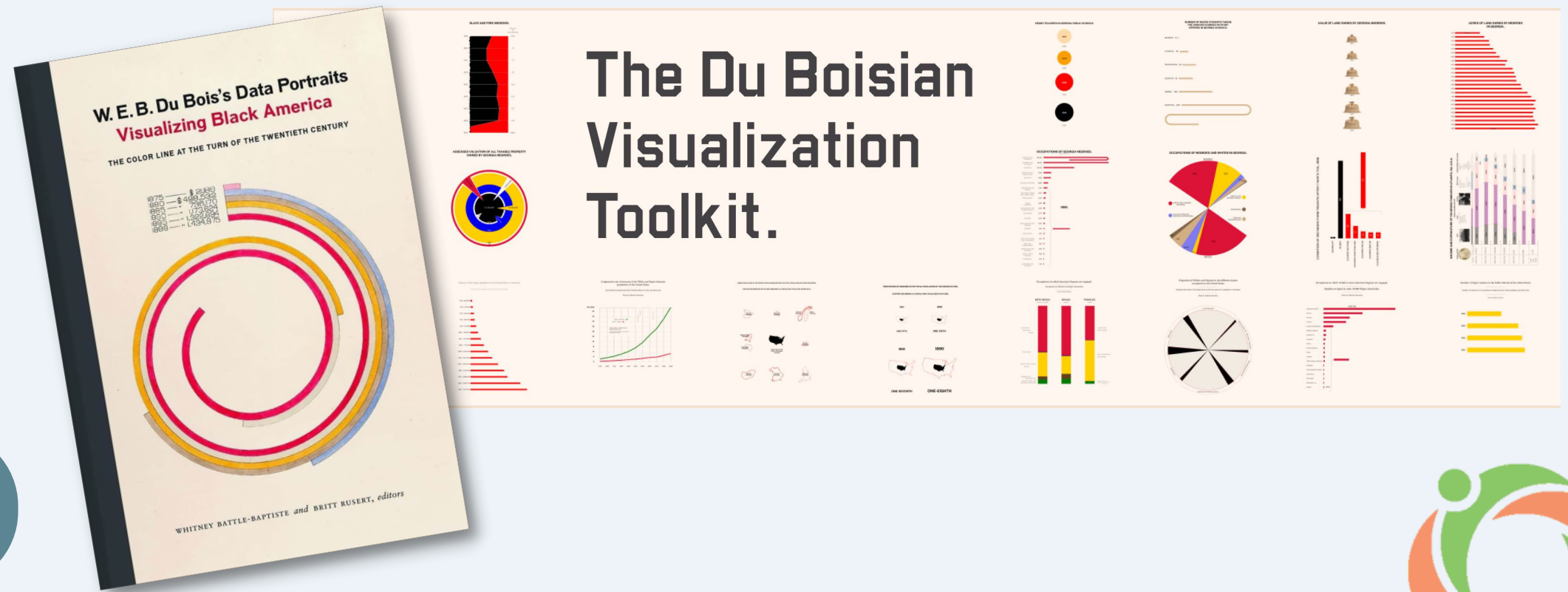
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“The matter of sickness is an indication of social and economic position... Negro death rate and sickness are largely matters of condition and not due to racial traits and tendencies.”



W.E.B. Du Bois 1868–1963



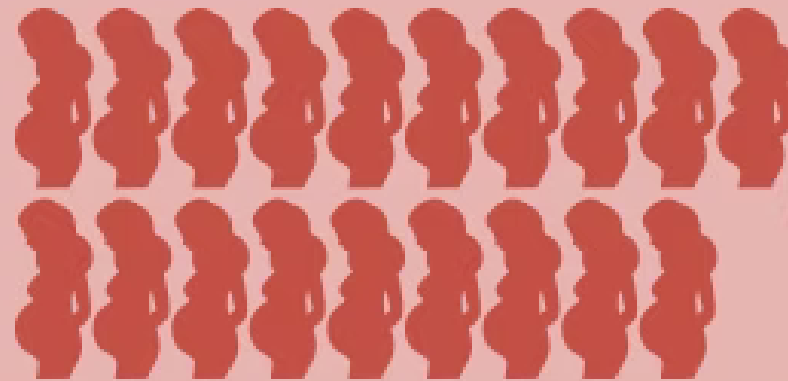
# Black Women Face **Three Times** the Maternal Mortality Risk as White Women



Black mothers: **55**



White mothers: **19**



Hispanic mothers: **18**



\*Deaths per 100,000 live births

Source: <https://www.cdc.gov/nchs/data/hestat/maternal-mortality/2020/maternal-mortality-rates-2020.htm>

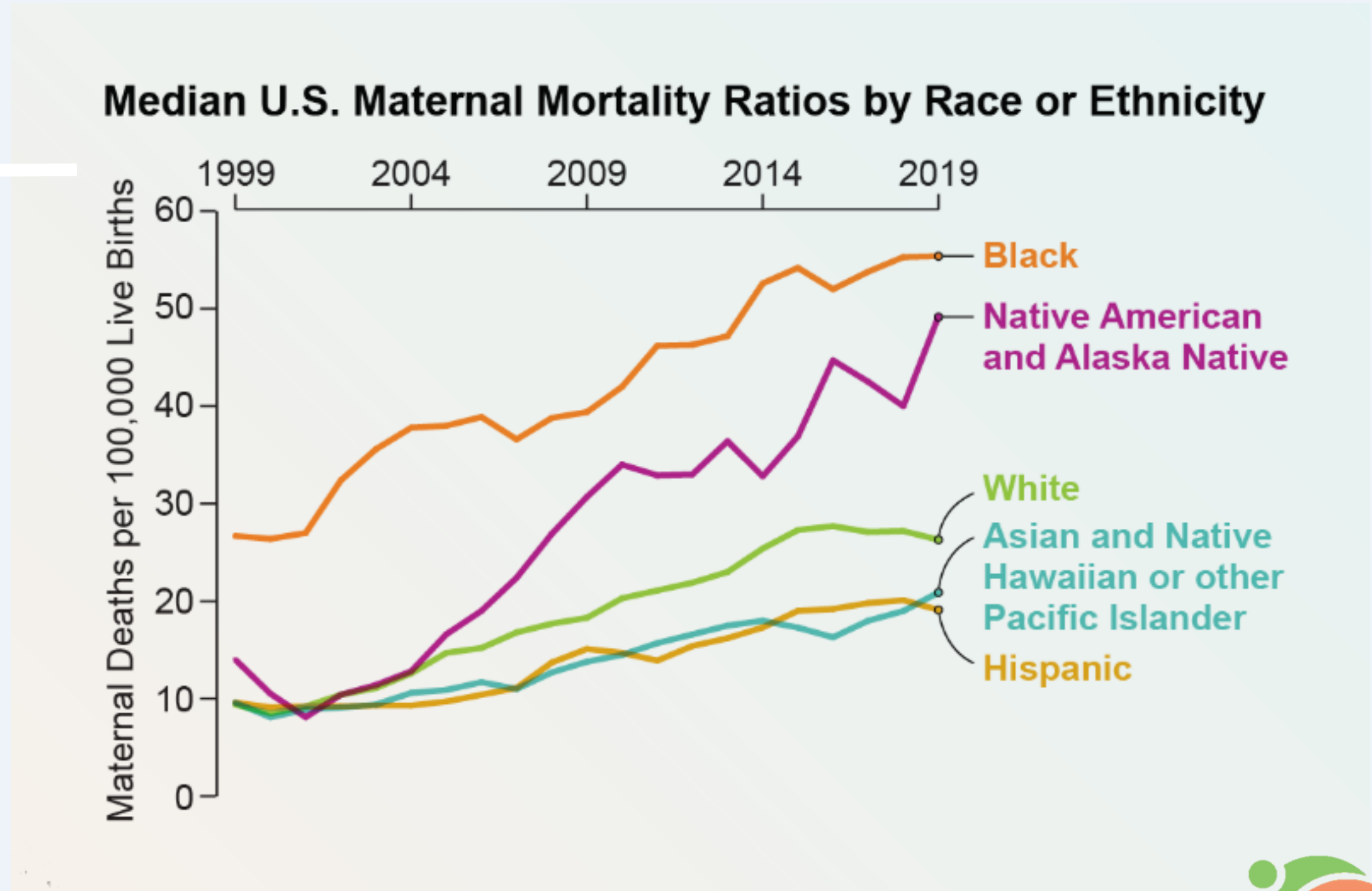
This is the **LEGACY**  
of **RACISM** and **CLASSISM**

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# OUTCOMES

CONCEPTION  
PREGNANCY  
BIRTH  
MORTALITY  
DEVELOPMENT  
MENTAL HEALTH



Credit: Amanda Montañez; Source: "Trends in State-Level Maternal Mortality by Racial and Ethnic Group in the United States," by Laura G. Fleszar et al., in *JAMA*, Vol. 330, No. 1; July 3, 2023



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# NICU

PREMATURITY  
DISABILITY  
QUALITY OF CARE  
FOLLOW UP  
MENTAL HEALTH  
MORTALITY

## Racial/Ethnic Disparities in Neonatal Intensive Care: A Systematic Review

Krista Sigurdson, PhD,<sup>1,2,3</sup> Briana Mitchell, BS,<sup>4,5</sup> Jessica Liu, PhD,<sup>6,7</sup> Christine Morton, PhD,<sup>8</sup> Jeffrey B. Gould, MD, MPH,<sup>9</sup> Henry C. Lee, MD, MS,<sup>10</sup> Nicole Capdarest-Arest, MA, LIS, AHIP,<sup>11</sup> Jochen Proffitt, MD, MPH<sup>12</sup>

**CONTEXT:** Racial and ethnic disparities in health outcomes of newborns requiring care in the NICU setting have been reported. The contribution of NICU care to disparities in outcomes is unclear.

**OBJECTIVE:** To conduct a systematic review of the literature documenting racial/ethnic disparities in quality of care for infants in the NICU setting.

**DATA SOURCES:** Medline/PubMed, Scopus, Cumulative Index of Nursing and Allied Health, and Web of Science were searched until March 6, 2018, by using search queries organized around the following key concepts: "neonatal intensive care units," "racial or ethnic disparities," and "quality of care."

**STUDY SELECTION:** English language articles up to March 6, 2018, that were focused on racial and/or ethnic differences in the quality of NICU care were selected.

**DATA EXTRACTION:** Two authors independently assessed eligibility, extracted data, and cross-checked results, with disagreements resolved by consensus. Information extracted focused on racial and/or ethnic disparities in quality of care and potential mechanism(s) for disparities.

**RESULTS:** Initial search yielded 566 records, 4/0 of which were unique citations. Title and abstract review resulted in 382 records. Appraisal of the full text of the remaining 88 records, along with the addition of 5 citations from expert consult or review of bibliographies, resulted in 41 articles being included.

**LIMITATIONS:** Quantitative meta-analysis was not possible because of study heterogeneity.

**CONCLUSIONS:** Overall, this systematic review revealed complex racial and/or ethnic disparities in structure, process, and outcome measures, most often disadvantaging infants of color, especially African American infants. There are some exceptions to this pattern and each area merits its own analysis and discussion.

<sup>1</sup>Perinatal Epidemiology and Health Outcomes Research Unit, Division of Neonatology, Department of Pediatrics, School of Medicine, Stanford University and Lucile Packard Children's Hospital, Palo Alto, California; <sup>2</sup>Department of Social and Behavioral Sciences, School of Nursing, University of California, San Francisco, San Francisco, California; <sup>3</sup>California Perinatal Quality Care Collaborative, Palo Alto, California; <sup>4</sup>California Maternal Quality Care Collaborative, Palo Alto, California; and <sup>5</sup>University of California, Davis, Davis, California

Dr Sigurdson conceptualized and designed the study, ran the search strategy, drafted the initial manuscript, and revised the manuscript; Ms Mitchell conceptualized and designed the study, ran the search strategy, assisted in drafting the initial manuscript, and revised the manuscript; Dr Liu assisted in drafting the initial manuscript and revised the manuscript; Drs Morton, Gould, and Lee assisted in running the search strategy and revised the manuscript; Ms Capdarest-Arest designed the search strategy, assisted in drafting the initial manuscript, and revised the manuscript; Dr Proffitt conceptualized and designed the study and reviewed and revised the manuscript; and all authors approved the final manuscript as submitted and agree to be accountable for all aspects of the work.

Ms Mitchell's current affiliation is Department of Obstetrics, Gynecology and Reproductive Sciences, University of California, San Francisco, San Francisco, CA.

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PEDIATRICS Volume 144, number 2, August 2019:e20183114

abstract



REVIEW ARTICLE

Journal of Perinatology  
<https://doi.org/10.1038/s41372-018-0057-3>

QUALITY IMPROVEMENT ARTICLE

## Disparities in NICU quality of care: a qualitative study of family and clinician accounts

Krista Sigurdson<sup>1,2,3</sup> · Christine Morton<sup>4</sup> · Briana Mitchell<sup>1,2</sup> · Jochen Proffitt<sup>1,2</sup>

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**Abstract**

**Objective** To identify how family advocates and clinicians describe disparities in NICU quality of care in narrative accounts. **Study design** Qualitative analysis of a survey requesting disparity stories at the 2016 VON Quality Congress. Accounts from 4) were from a sample of RNs ( $n = 114$ , 35%), MDs ( $n = 109$ , 34%), NNP's ( $n = 55$ , 17%), RN other ( $n = 4$ , 1%), and other ( $n = 25$ , 7%), family advocates ( $n = 16$ , 5%), and unspecified ( $n = 1$ , <1%). **Results** Accounts (324) addressed non-exclusive disparities: 151 (47%) language; 97 (30%) culture or ethnicity; 72 (22%) gender; 41 (13%) SES; 28 (8%) drug use; 18 (5%) immigration status or nationality; 16 (4%) sexual orientation or family structure; 14 (4%) disability. We identified three types of disparate care: neglectful care 85 (26%), judgmental care 85 (26%), or systemic barriers to care 139 (44%). **Conclusions** Nearly all accounts described differential care toward families, suggesting the lack of equitable family-centered

**Introduction**

of-care delivery across neonatal intensive care units (NICUs) varies greatly [1], and vulnerable populations may be at risk for receiving suboptimal care, translating into

The content is solely the responsibility of the authors and does not necessarily represent the official views of the Eunice Kennedy Shriver National Institute of Child Health and Human Development or the National Institutes of Health.

**Supplementary material** The online version of this article ([10.1038/s41372-018-0057-3](https://doi.org/10.1038/s41372-018-0057-3)) contains supplementary material which is available to authorized users.

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15 April 2018

suboptimal outcomes. We recently demonstrated statistically significant racial/ethnic variations in quality of care both between NICUs and within NICUs [2]. These findings reflect multiple mechanisms that create overall disparity. First, minority infants may be more likely to receive care in poor quality NICUs [1–7]. Very low birth weight (VLBW) infants born in high-black concentration hospitals have higher rates of infection, discharge without breast milk, and nurse understaffing [3] and these structural barriers likely translate to higher risk-adjusted VLBW infant mortality and morbidity rates [4–6]. Second, minority infants may be more likely to receive suboptimal care within a given NICU [2, 8–10]. Hispanic mothers have been found to be less likely than whites to receive antenatal steroids [9] and human breast milk feeding [10] at discharge within a given institution. Further, qualitative research [8] found that black non-Hispanic women have reported limited breastfeeding education and support in the NICU. However, breastfeeding at discharge may be a complex measure of NICU quality, given that non-NICU breastfeeding at NICU discharge are key in establishing breastfeeding at NICU discharge [11].

The breastfeeding example highlights that the quality of NICU care is intricately linked to how NICU clinicians engage with families and their social attributes. Little is known regarding the interaction of these factors that contribute to disparities in

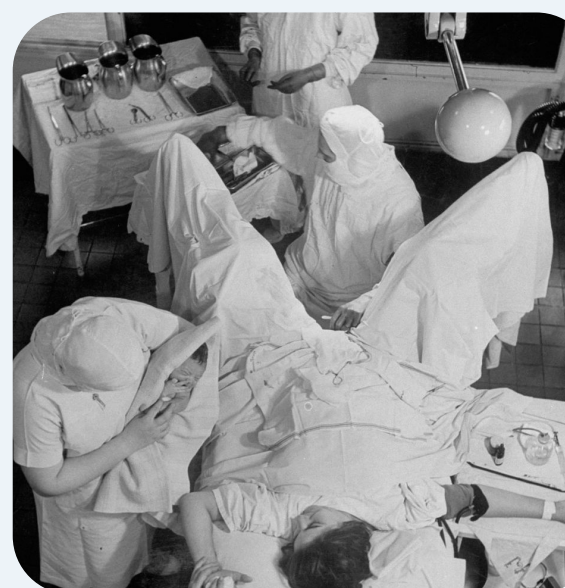
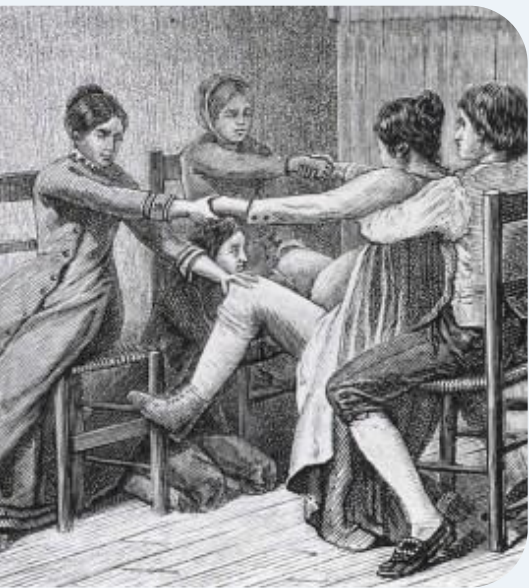


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*The system was built this way.*

Bringing Midwifery Back to Black Mothers | Retro Report

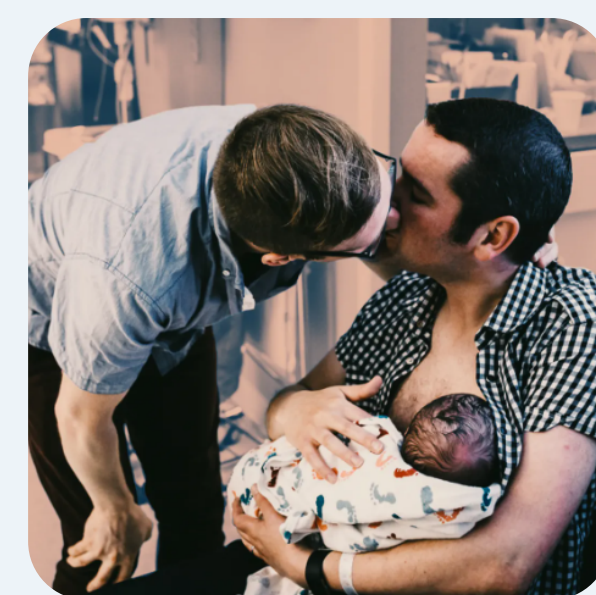


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# We need to DISMANTLE RECLAIM REBUILD



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# DESIGNING for COMMUNITIES

## Case Study:

In 2018 at a Summit, during the final day of member discussion, a NICU Parent Leader, who had not yet become a member, stood up and said **"I want you to know that as a fullterm NICU mom, I wasn't sure PPA was for me, because of the name. But after being here, meeting everyone and learning from many of you, I know that I have found my community in this season of my life building and leading an organization. Thank you for being so open and welcoming."**

I was stunned - While we had been meticulous and intentional about our messaging we had neglected our actual BRAND! I walked over to her, gave her a big hug, and said **"Of course, you belong!"** We reached out to the members we had at the time who were parents of full-term NICU babies and asked for their honest feedback. We asked if they felt like they belonged if there were instances where they had felt like outsiders, and what they would want to see done differently. **We took the feedback to our leadership team who then made a decision to change our name.** We involved the entire membership in the renaming process to ultimately become NICU Parent Network (NPN).



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Then

## Who Are We?

.....

Preemie Parent Alliance is a network of organizations offering support to families of premature infants. We are the only professional association for NICU Parent Leaders in the United States. PPA provides a platform for NICU Parent Leaders to come together as a collective voice representing the needs and best interests of NICU families in all facets of healthcare policy, care guidelines, advocacy, education & family support.

## Our Mission is to Champion the NICU Parent Voice

.....



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# Now

## Who Are We?

NICU PARENT NETWORK IS THE PREMIER US-BASED PROFESSIONAL ORGANIZATION OF NICU PARENT LEADERS WHO COLLECTIVELY REPRESENT THE NEEDS AND BEST INTERESTS OF NICU FAMILIES. TOGETHER, WE ENVISION A WORLD WHERE EVERY NICU FAMILY IS AN ESSENTIAL AND INTEGRAL MEMBER OF THEIR BABY'S CARE TEAM.



### AUTHENTICITY

Authenticity is the bedrock of all enduring relationships, inspires trust in who we say we are and motivates others to join our collective efforts. Therefore, we will ensure our actions & interactions in all aspects of our operations are conducted with transparency, genuineness, and honesty.



### DIVERSITY & INCLUSION

Being inclusive & diverse anchor all that we do; we respect a diversity of people & thought & provide equal access to a range of perspectives in all NPN forums, initiatives and decisions.



### SUSTAINABILITY

Long-term organizational sustainability is critical to our success. Therefore, all strategic decisions will focus on continually driving and enhancing our positive and long-term impact in the communities we serve.



### INTEGRITY

Having a culture of integrity is crucial to establish a healthy organization and culture, so we will operate with professionalism and accountability for ourselves and our member organizations.



### COLLABORATIVE

Being collaborative is an essential value within all our engagements. Therefore, we will actively work together & share relevant ideas, information & resources, both within the NPN network & with external partners, to achieve common goals and outcomes.

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**LET'S ALL TAKE A  
MOMENT TO  
BREATHE.**



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What?



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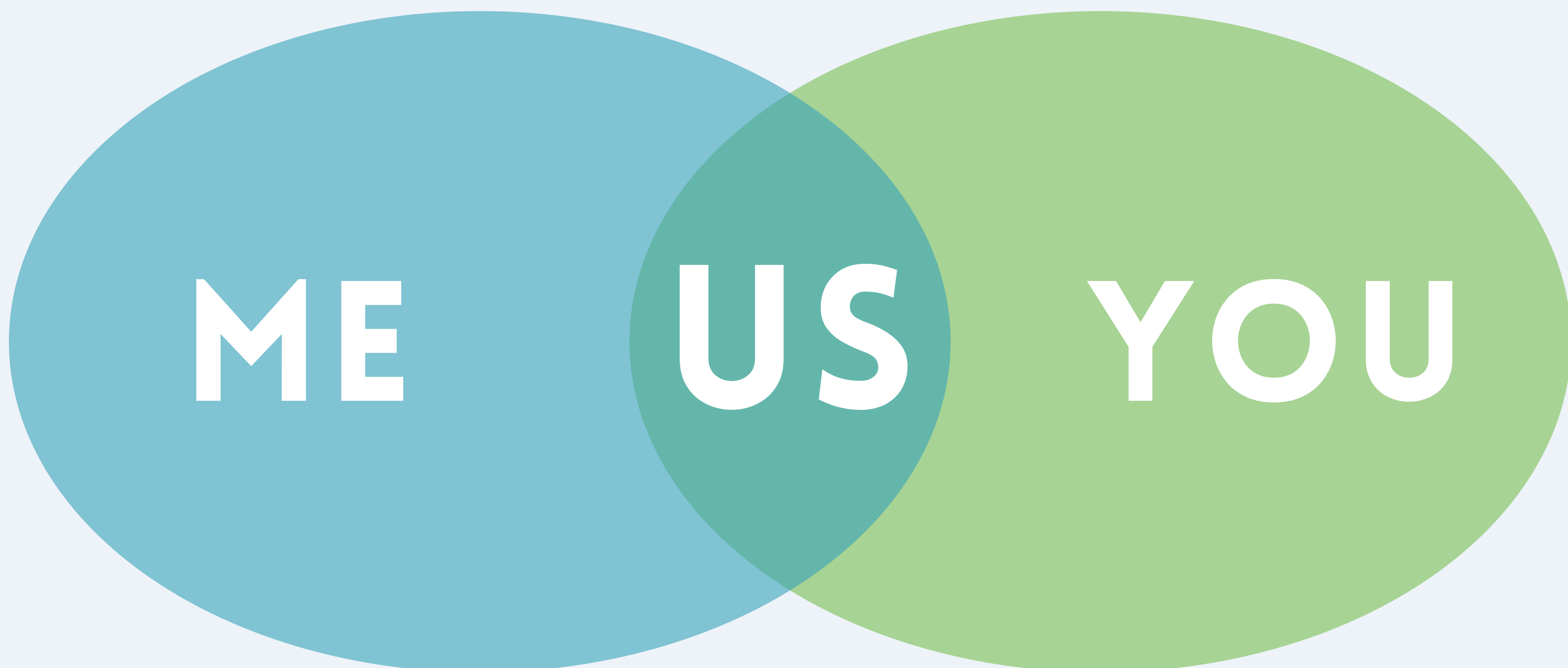
# COMMONALITY



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*Bias*

83%

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# Bias



**unconscious** *lacking awareness*

**bias** *preference or inclination  
that inhibits impartiality*



**GENDER**

**SIZE**

**ETHNICITY**

**DISABILITY**

**AGE**

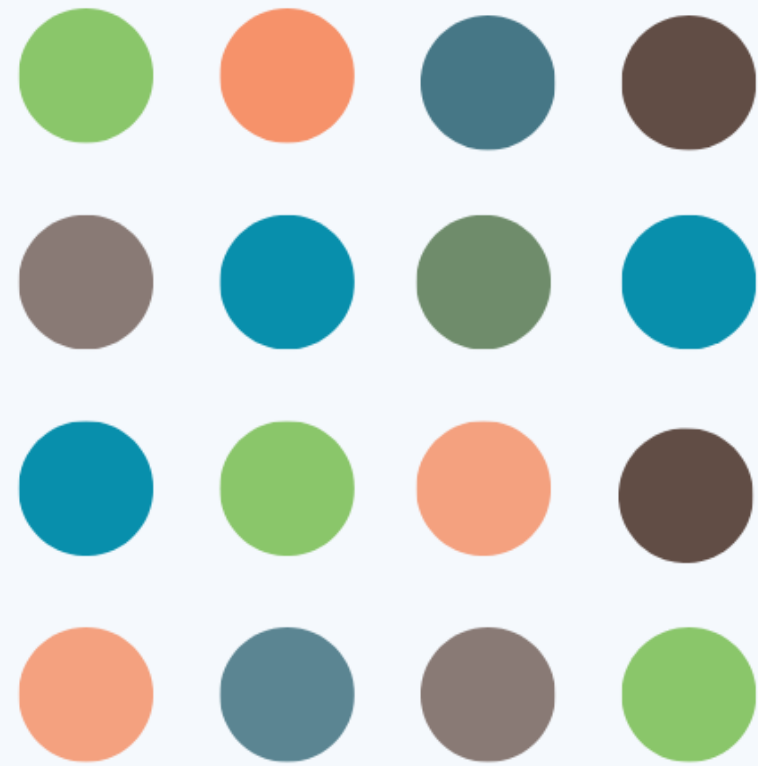


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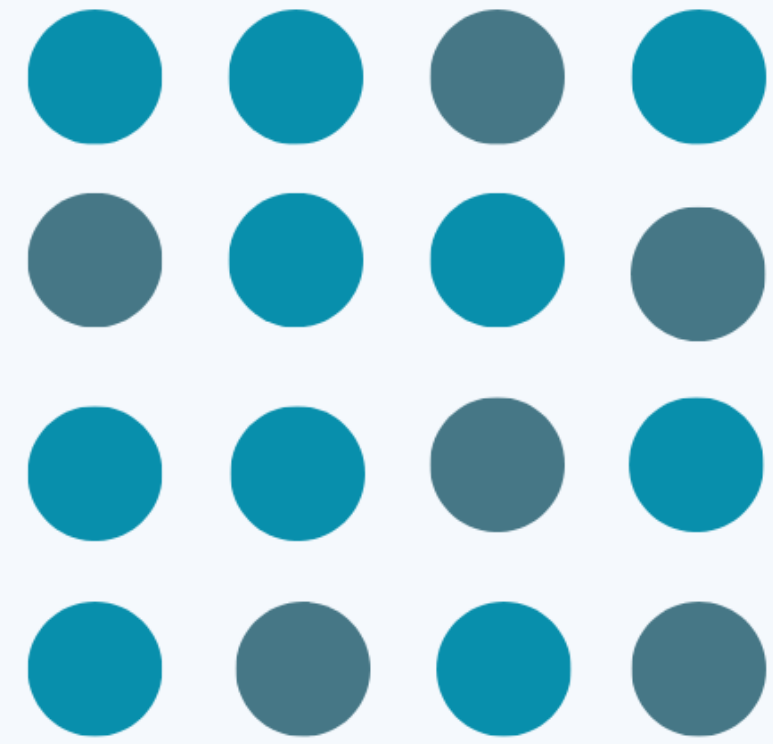
cognitive shortcuts →



One's Identity



What is Noted



What's Assumed

# cognitive shortcuts → BIAS →

- **affinity** bias



“what we do” “what we’re like”

- **confirmation** bias



selective

- **conformity** bias



“most folx are like me”

- **halo/horns** effect



motivations

- **false consensus**



“this is what we all believe”



**IN GROUP**



**OUT GROUP**



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# MY COMMUNITY

Who am I?

Who are my people?

Who am I surrounding myself with?

...How does that shape my perspective?

**ACTIVITY: My Trusted Community**

## Trusted 10

An exercise to help you look at your trusted circle and who you are surrounding yourself with.

characteristics									
name or initials	age	gender	race or ethnicity	education	sexual orientation	marital status	parenting status	disability status	

What do you see? Who are your people?

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# ANY INSIGHTS?



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# Strategies





# Identity

Who am I?

Who decides?



# IDENTITY

## The terms that define us.

Some are chosen by us.  
Some are assigned to us.  
They often predict the opportunities  
we will be offered.  
But they seldom predict  
talent or ability.



# I am...

Which are the **5** identities that are important to how you see yourself?



# People see me as...

Which are the **3** identities you think people most associate with you?



# IDENTITY

Who I am.

What I bring to my work.

These are the things that make me uniquely capable of doing this work...

ACTIVITY: Who we are. How we show up.

## IDENTITY

The terms that define us.

Which are the 5 identities that are important to how I see myself?

- \_\_\_\_\_
- \_\_\_\_\_
- \_\_\_\_\_
- \_\_\_\_\_
- \_\_\_\_\_

Which are the 3 identities I think people most associate with me?

- \_\_\_\_\_
- \_\_\_\_\_
- \_\_\_\_\_

What I bring to my work.

These are the things that make me uniquely capable of doing this work...

\_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

Thoughts?... Feelings?... Observations?

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# our IDENTITIES

They are not necessarily fixed.



- relational
- situational
- change over time
- in-group/out-group

*Privileged*

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*Marginalized  
or Stigmatized*

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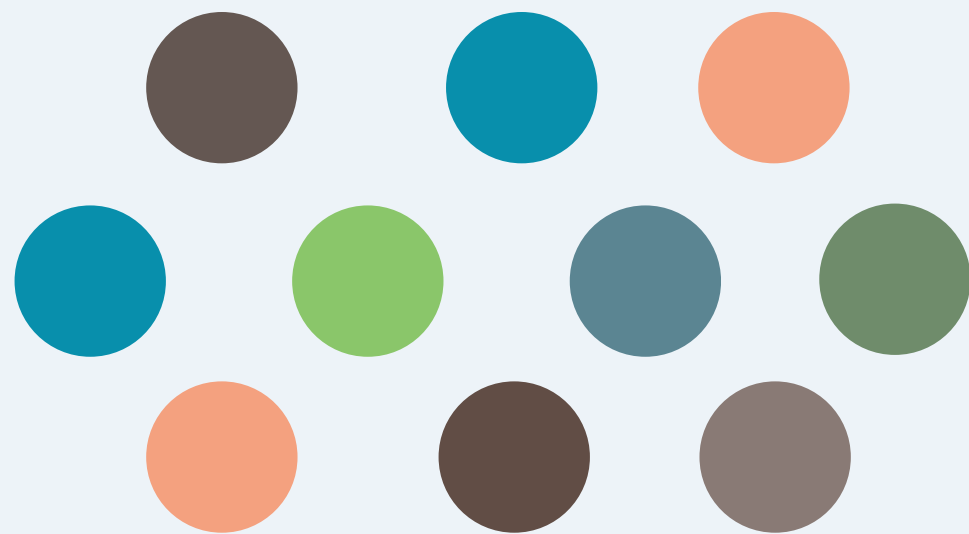
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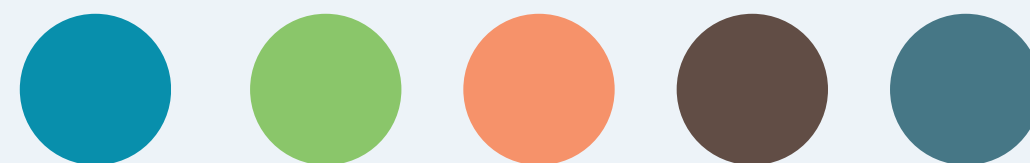
## Diversity

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All the wonderful ways in which we're different

*In diversity there is beauty and there is strength.*

Maya Angelou



## Equity

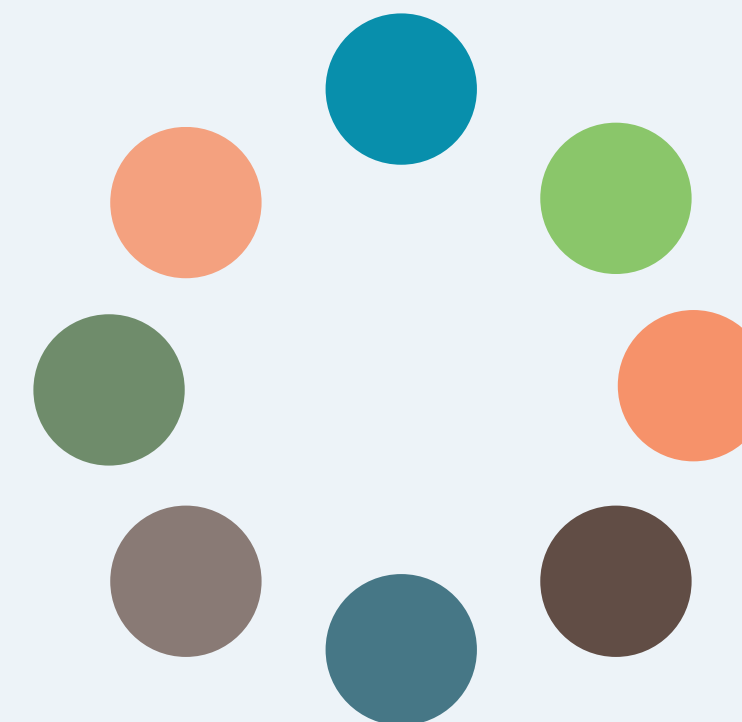
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Fair treatment, access, opportunity, and benefit for everyone.

Your identity does not predict your outcome

*Health equity is a shared responsibility.*

Michael Marmot



## Inclusion

---

A variety of people have power, a voice, and decision-making authority

*We are greater than, and greater for, the sum of us.*

Heather McGhee

# INSIGHTS?




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**The beauty of the  
world lies in the  
diversity of its people.**



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# BREAK TIME



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How?



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Diversity

Equity

Inclusion

Belonging

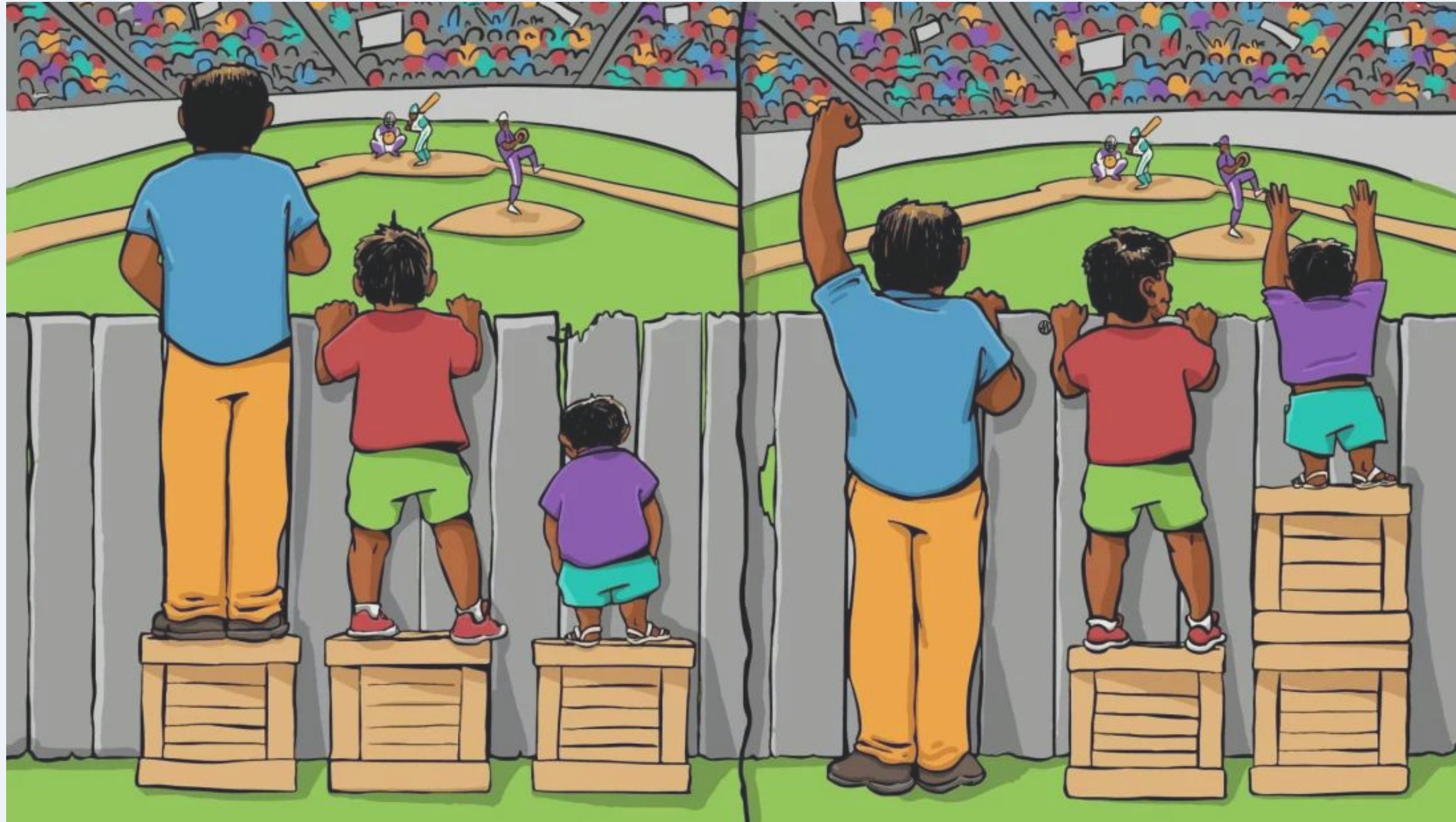
What would this look like?



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# EQUALITY

We all get the same thing.

# EQUITY

Everyone gets what they need.



Interaction Institute for Social Change | Artist: Angus Maguire 2016



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# EQUALITY & EQUITY

Look at this image.

Is there anything problematic here?



Challenging the Image on Equity and Equality

 **ACTIVITY: Looking at Images Critically**

## Illustrating Equality and Equity

Many of us have seen this graphic that is meant to illustrate the difference between equality and equity. But there are elements of this picture that many find problematic. **What do you notice?**

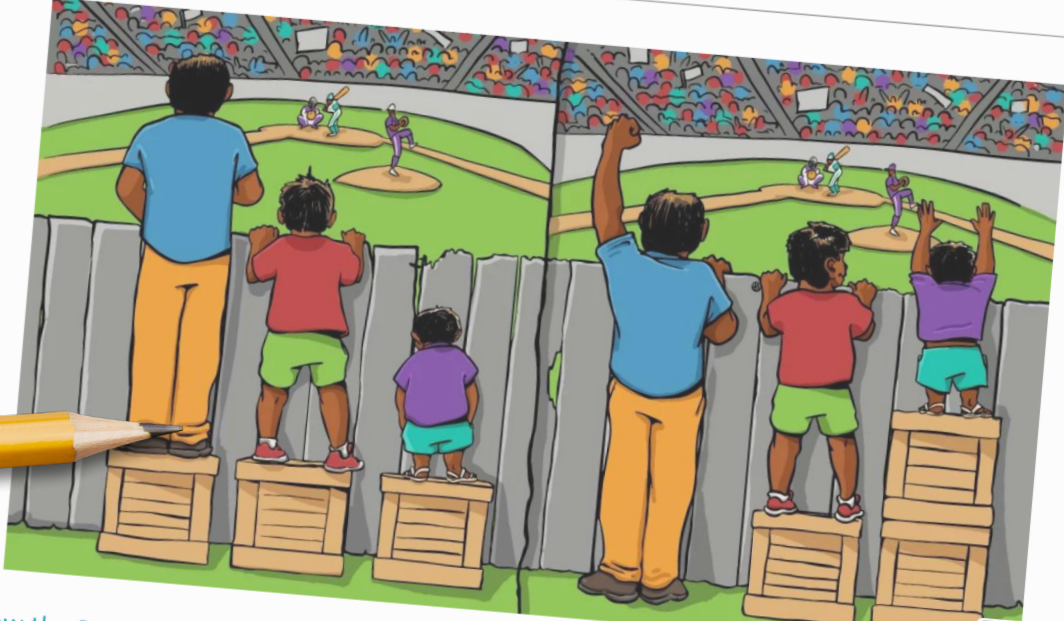
What is the setting? \_\_\_\_\_


Who is represented? \_\_\_\_\_

Why is there a fence? \_\_\_\_\_

Are they observing or participating? \_\_\_\_\_

Could this be better? \_\_\_\_\_



See how the RWJ Foundation created a new series of graphics - Visualizing Health Equity 

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## Igualdad



## Equidad



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Foundation

When it comes to expanding opportunities for health, thinking the same approach will work universally is like **expecting everyone to be able to ride the same bike.**



Visualizing Health Equity: One Size Does Not Fit All Infographic 2022

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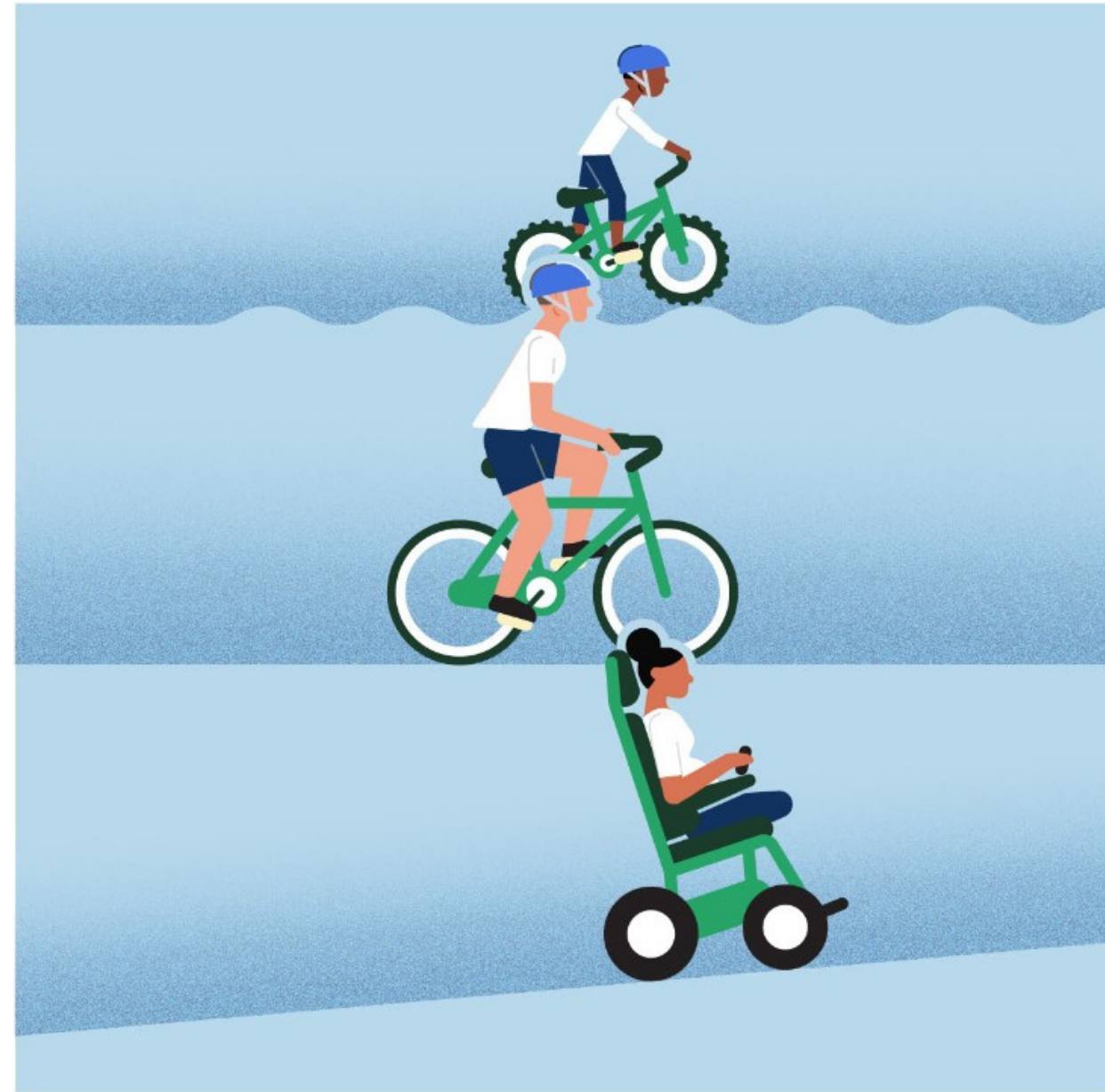
**EQUALITY:**

Everyone gets the same—regardless if it's needed or right for them.



**EQUITY:**

Everyone gets what they need—understanding the barriers, circumstances, and conditions.



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Faced with the challenge to visually convey the difference between equality and equity, we surveyed our audience and incorporated input from a range of people.

We used your insights to create a second version of our bike graphic, as well as an additional graphic.



blog: [We Used Your Insights to Update Our Graphic on Equity](#)

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**EQUALITY:**

Everyone gets the same – regardless if it's needed or right for them.



**EQUITY:**

Everyone gets what they need – understanding the barriers, circumstances, and conditions.



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The survey results led us to create an entirely new concept using a curb to visualize the issue and introducing different characteristics and their environments.

- people with lived experiences with disability
- parents of children facing accessibility challenges
- people in many fields and sectors



Crosswalk Equity Graphic



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Diversity

Equity

Inclusion

Building Teams

≠ Mötley Crüe



Motley Crew Principle



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# Motley Crew Principle

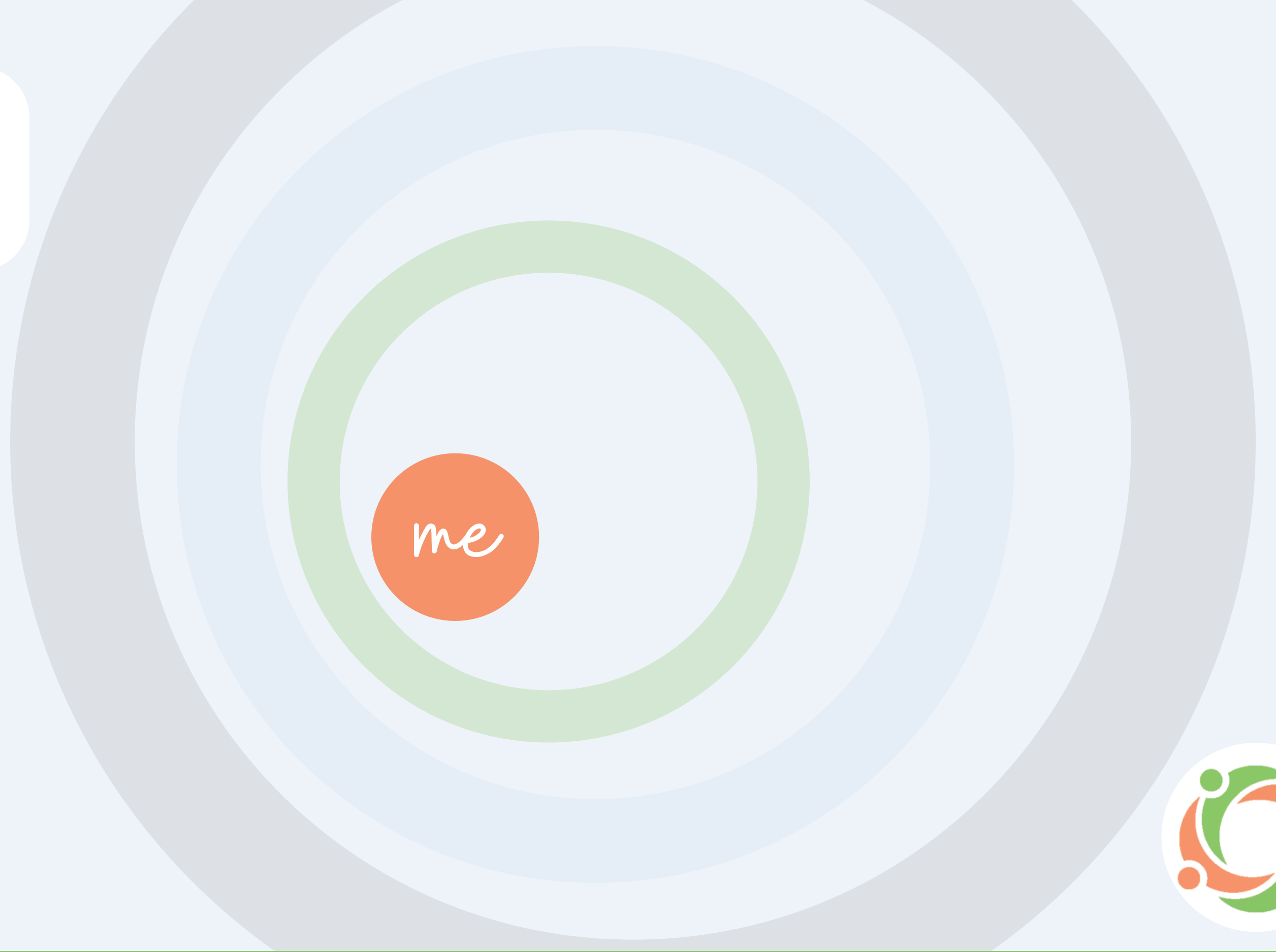
The motley crew principle tells us that **diverse contributions are best.**

A mix of **perspectives, backgrounds, and cultures** leads to more innovative ideas.

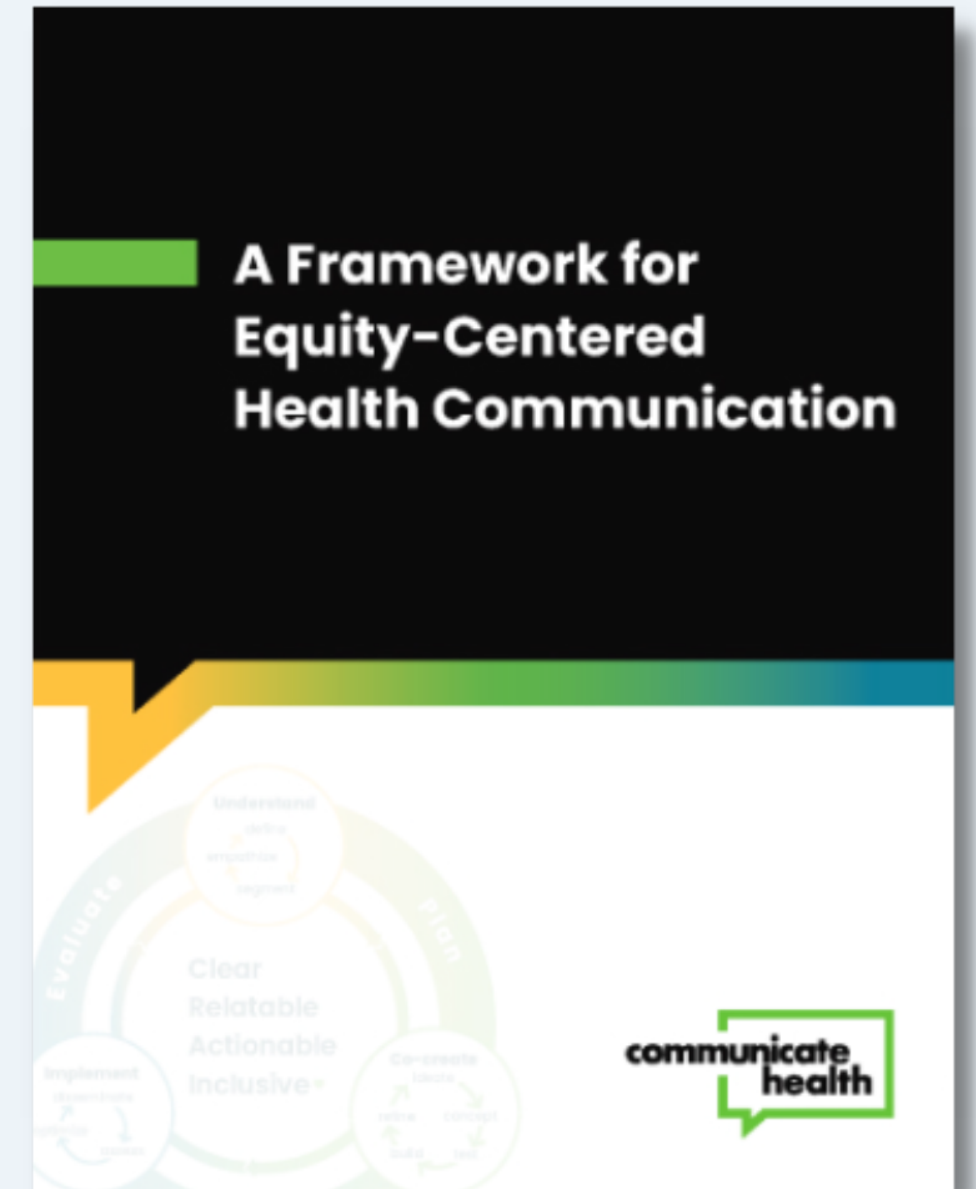
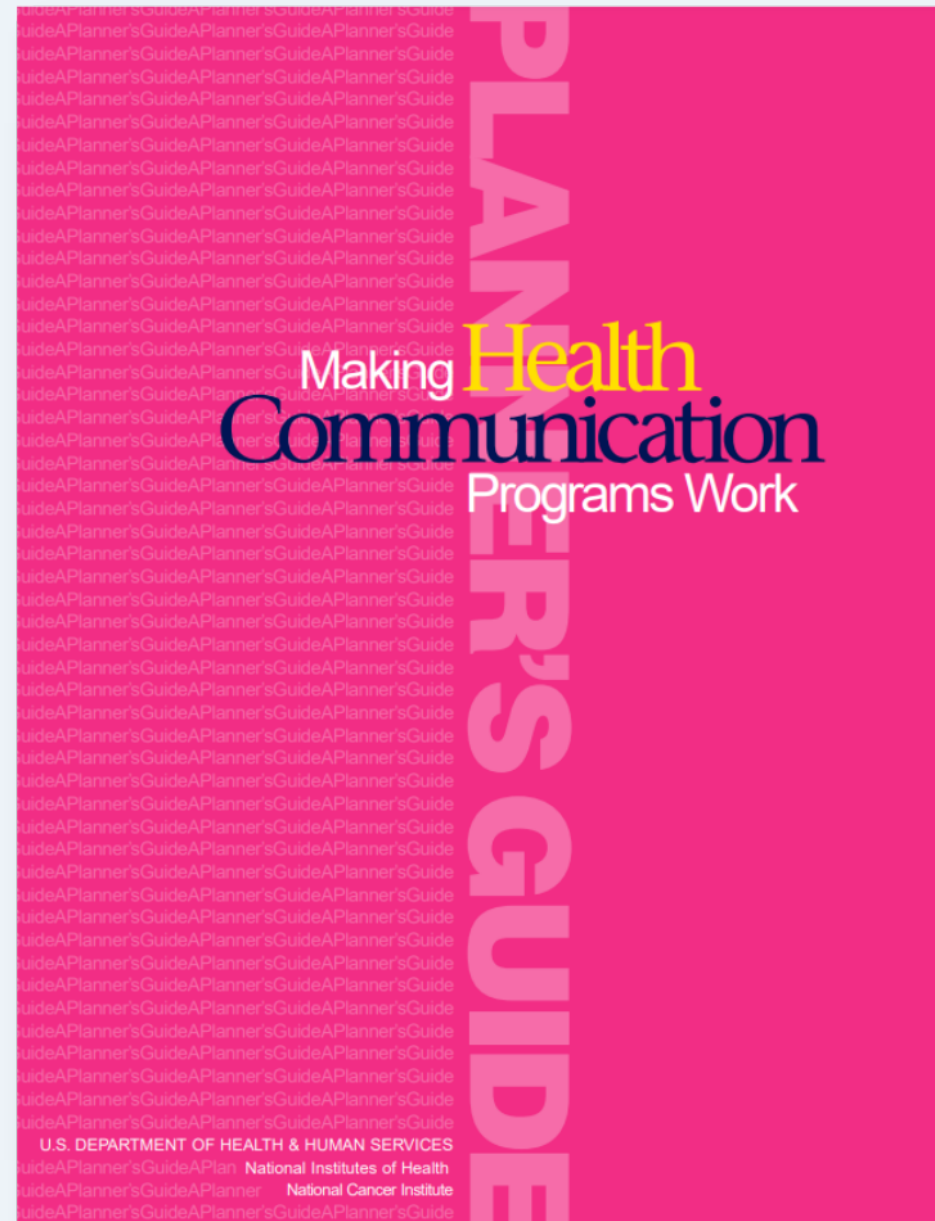


# Expand

- self-reliance
- scarcity
- affinity
- proximity
- conformity
- confirmation



# HEALTH LITERACY



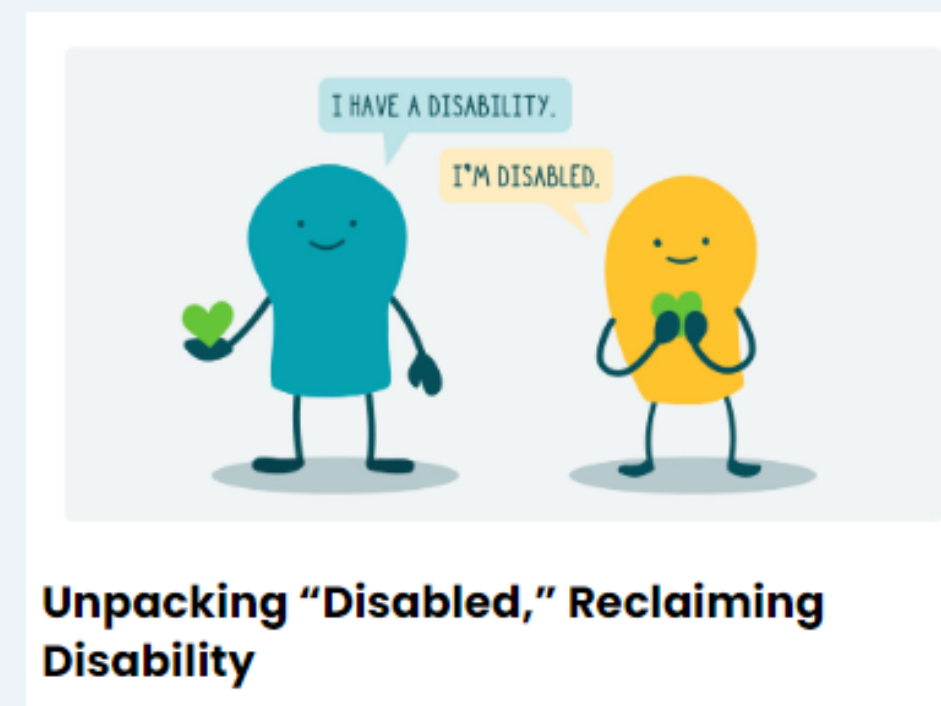
Courageous Communications: Intentionally Creating Diverse & Inclusive Spaces

[nicuparentnetwork.org](http://nicuparentnetwork.org)

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# HEALTH LITERACY

Please, stop saying that it's about a third grade reading level...



**Frequently Asked Question: How Can We Make Sure Language Is Inclusive and Clear?**

**Unpacking "Disabled," Reclaiming Disability**



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# DO YOU HAVE RESOURCES TO SHARE?



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# LANGUAGE

**BREAST  
MILK**

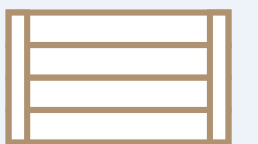
*mother-baby  
unit*

**KENTUCKY**  
**wic**  
Women, Infants, & Children

**maternal-infant  
health**

**Mother's Own Milk  
"MOM"**

*Erika's soapbox...*



*Case Study:* **BREASTFEEDING AWARENESS MONTH**

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# REPRESENTATION

## Breastfeeding Awareness Month

*Why?*



UNIVERSAL



SPECIFIC

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# BREASTFEEDING AWARENESS MONTH

NO MATTER HOW YOU DO IT...

- nursing
- pumping
- hand expressing
- breastfeeding
- chestfeeding
- body feeding
- on your own
- with support
- with the help of a donor
- for one day
- or one year
- or maybe longer

Especially when you make the choice that is **BEST FOR YOU AND YOUR BABY**

[nationalperinatal.org/feeding-our-babies](http://nationalperinatal.org/feeding-our-babies)

# BREASTFEEDING AWARENESS MONTH

#BestMilk

NO MATTER HOW YOU DO IT...



And especially when you make the choice that is **BEST FOR YOU AND YOUR BABY**

[nationalperinatal.org/feeding-our-babies](http://nationalperinatal.org/feeding-our-babies)



# BREASTFEEDING AWARENESS MONTH

INDIGENOUS MILK MEDICINE WEEK  
AUGUST 8 - 14

[indigenoustmilkmedicinecollective.org](http://indigenoustmilkmedicinecollective.org)



BREASTFEEDING IS FOOD SOVEREIGNTY



download **FREE RESOURCES**

[nationalperinatal.org/feeding-our-babies](http://nationalperinatal.org/feeding-our-babies)

# BREASTFEEDING AWARENESS MONTH

BLACK BREASTFEEDING WEEK  
August 25 - 31



WE OUTSIDE! CELEBRATING CONNECTION & OUR COMMUNITIES

download **FREE RESOURCES**

[nationalperinatal.org/feeding-our-babies](http://nationalperinatal.org/feeding-our-babies)

# BREASTFEEDING AWARENESS MONTH

Human Milk is the Best Milk



EVERYONE WHO FEEDS + NURTURES BABIES

Human Milk is Made for Babies



[nationalperinatal.org/feeding-our-babies](http://nationalperinatal.org/feeding-our-babies)

# BREASTFEEDING AWARENESS MONTH

ASIAN + PACIFIC ISLANDER BREASTFEEDING WEEK  
August 15 - 21



TELLING OUR OWN STORIES  
ELEVATING OUR VOICES

#AANHPI BREASTFEEDING WEEK

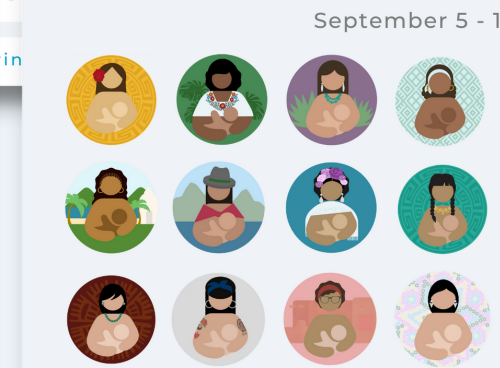
download **FREE RESOURCES**

[nationalperinatal.org/feeding-our-babies](http://nationalperinatal.org/feeding-our-babies)



# BREASTFEEDING AWARENESS MONTH

SEMANA DE LA LACTANCIA LATINA  
September 5 - 11



#LATINA/X BREASTFEEDING WEEK #MESDELA LACTANCIA #LACTANCIA

LATINA/X BREASTFEEDING WEEK

download **FREE RESOURCES**

[nationalperinatal.org/feeding-our-babies](http://nationalperinatal.org/feeding-our-babies)



National Perinatal Association - Breastfeeding Awareness



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# REPRESENTATION



## The Educated Birth

**“Representation isn't just nice, it's a necessary part of a safe and equitable health system.”**

### Bodyfeeding Positions

**BRIEFLY EXPLAINED**

**LAIID-BACK**  
A semi-reclined position bringing baby tummy to tummy with you as you're leaning back, with their head resting on your breast or chest to back. It can be especially helpful for nursing a premature newborn, or a baby that's still learning to latch.

**UPRIGHT**  
Baby faces out and cradles your body, sitting upright while they latch. Offers a lot of support to your babies - it's easier as they grow and learn to sit on their own. This can also help with baby's digestion.

**TANDEM**  
Feeding two babies at once (for an older child and a baby) can involve using a variety of positions - variations of cradle, cross cradle, clutch, and laid-back are common.

**BODYFEEDING TAKES LOTS OF ENERGY + TIME TO LEARN TOGETHER, TOO**  
The process of making milk uses a lot of energy as well as important nutrients from the way to make the best quality milk possible. Because of this, it's important to stay hydrated, eat well, and rest as much as possible. While the inner workings of milk production may seem magical, it's a lot of work. If you feel you can't stay on the outside. Be kind and patient with yourself. When you have questions or need a little extra support, we're here to help.

Source: The Educated Birth. Illustrations by @TheEducatedBirth. Content © The Educated Birth. All rights reserved.

[THEEDUCATEDBIRTH.COM](http://THEEDUCATEDBIRTH.COM)

## The Pregnant Body

@TheEducatedBirth

#### Bodyfeeding Positions

**BRIEFLY EXPLAINED**

#### Bottle-feeding Positions

**BRIEFLY EXPLAINED**

#### How To Hand Express

**BRIEFLY EXPLAINED**

#### Baby's Stomach Capacity

**BRIEFLY EXPLAINED**

#### Human Milk - Formula Storage

**BRIEFLY EXPLAINED**

Storage Method	Duration
Room Temperature	Up to 4 hours
Cooler	Up to 24 hours
Refrigerator	Up to 24 hours
Freezer	Up to 6 months

#### Newborn Diapers

**BRIEFLY EXPLAINED**

#### Lactation

**VISUAL GUIDE**

#### Cesarean Incisions - Scars

**VISUAL GUIDE**

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# SHARED DECISION-MAKING PROTECTS MOTHERS + INFANTS DURING COVID-19

**KEEPING MOTHERS + INFANTS TOGETHER**  
Means balancing the risks of...  

- HORIZONTAL INFECTION
- SEPARATION AND TRAUMA

**EVIDENCE**  
We encourage families and clinicians to remain diligent in learning **up-to-date evidence**.

**PARTNERSHIP**  
What is the best for this unique dyad?  
**SHARED DECISION-MAKING**  

- S EEK PARTICIPATION
- H ELP EXPLORE OPTIONS
- A SSESS PREFERENCES
- R EACH A DECISION
- E VALUATE THE DECISION

**TRAUMA-INFORMED**  
Both parents and providers are confronting significant...  

- FEAR
- GRIEF
- UNCERTAINTY

**LONGITUDINAL DATA**  
We need to understand more about outcomes for mothers and infants exposed to COVID-19, with special attention to:  

- MENTAL HEALTH
- POSTPARTUM CARE DELIVERY

NEW DATA EMERGE DAILY. NANN AND NPA ENCOURAGE PERINATAL CARE PROVIDERS TO ENGAGE IN CANDID CONVERSATIONS WITH PREGNANT PARENTS PRIOR TO DELIVERY REGARDING RISKS, BENEFITS, LIMITATIONS, AND REALISTIC EXPECTATIONS.

Partnering for patient-centered care when it matters most.  
nann.org nationalperinatal.org

## SHARED DECISION-MAKING PROTECTS PARENTS + BABIES COVID-19

**KEEPING THE PARENT + INFANT DYAD TOGETHER**  
MEANS BALANCING THE RISKS OF  

- HORIZONTAL INFECTION
- SEPARATION + TRAUMA

nationalperinatal.org/NPAandNANN

## SHARED DECISION-MAKING PROTECTS MOTHERS + BABIES COVID-19

**KEEPING MOTHERS + INFANTS TOGETHER**  
MEANS BALANCING THE RISKS OF  

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- SEPARATION + TRAUMA

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## SHARED DECISION-MAKING PROTECTS MOTHERS + BABIES COVID-19

**CARING FOR MOTHERS + INFANTS**  

- S eek participation
- H elp explore options
- A ssess preferences
- R each a decision
- E valuate the decision

**REQUIRES PARTNERSHIP**

nationalperinatal.org/NPAandNANN

## SHARED DECISION-MAKING PROTECTS PARENTS + BABIES COVID-19

**INFORMED PROVIDERS**  

- S eek participation
- H elp explore options
- A ssess preferences
- R each a decision
- E valuate the decision

**CARE DELIVERY REQUIRES PARTNERSHIP**

nationalperinatal.org/NPAandNANN



# PARENTS ARE ESSENTIAL CAREGIVERS

DURING COVID-19 ... AND BEYOND

**FAMILY-CENTERED CARE**  
*Advocates that families be respected as essential members of the care team.*

- We believe parents and providers are allies in care
- We recognize and respect families' priorities, values, cultures, and beliefs.
- We encourage shared-decision making and partnership in care planning.

**THE PARENT-INFANT DYAD**  
*Parental involvement in the early days and months of life supports:*

- healthy cognitive development.
- secure attachment.
- self-regulation, stability, and resiliency.

**FAMILY PRESENCE**  
*Family presence during infant hospitalization promotes:*

- parental attachment.
- parental well-being.
- continuity of care.

We affirm the rights of parents to provide essential care for their infant during hospitalization, given the life-long importance of parent-infant attachment.

**SUPPORTING PARENTS AS ESSENTIAL CAREGIVERS**  
*Parental caregiving during hospitalization is essential care. We encourage providers to value parental presence in the following ways:*

- Promote policies and practices that prioritize parental presence and caregiving.
- Invite parent participation and input when revising policies that may limit parental presence.
- Set clear expectations. Openly and honestly communicate with families about shared responsibilities that are part of being an "essential caregiver."








- [awhonn.org](http://awhonn.org)
- [nann.org](http://nann.org)
- [nationalperinatal.org](http://nationalperinatal.org)

## PARENTS are ESSENTIAL CAREGIVERS

COVID-19











[nationalperinatal.org/parents\\_are\\_essential](http://nationalperinatal.org/parents_are_essential)

## PARENTS are ESSENTIAL CAREGIVERS

COVID-19



When parents meet the expectations of "essential caregivers" to strictly adhere to local health directive measures they should be provided unrestricted access to their hospitalized infant.

[nationalperinatal.org/parents\\_are\\_essential](http://nationalperinatal.org/parents_are_essential)



Why?



## NICU Standard 4: Signage and Art

Signage and art at the entrance and throughout the NICU shall reflect the diversity of the community served and shall convey to families that they are welcomed and supported as essential to the care of their infants. This information shall be provided to families immediately after entering the NICU in languages and/or symbols understandable to the diversity of communities served.

**Interpretation:** Signage and art at the entrance to the NICU create powerful first impressions. They reinforce the importance of families to care, care planning, and decision-making for their infants. Families should not be labeled as “visitors” and hence inconsequential to care and outcomes.

Signage should convey that parents define their family and how they wish for them to be involved in care. Parents should determine who can best support them through their NICU journey.

Signage should consistently reflect actual policy and practice and encourage family participation in care, care-planning, decision-making, and key care processes such as rounds and nurse change of shift report.

Temporary signage, such as cold and flu season signs, should also use the language of partnership and not power – “During cold and flu season we will work together with families to keep babies safe.”

Signage and art at the entrance and throughout the NICU facilitate ongoing connections with communities when they are familiar to the diversity of families served. They promote hope and confidence when messages and art feature families caring for their premature infants.

[←Previous](#) [Next→](#)

← *just one word*

We **ALL** make mistakes.




*When you do...*

- Listen
- Acknowledge the harm
- Ask questions
- Make adjustments



# ACCESSIBILITY

## Designing for Accessibility Helps Everyone

- [Creating Accessible Content for Everyone](#) 
- [Why Designing for Accessibility Helps Everyone](#) 
- [Universal design, trauma-informed care, and accessibility applied](#) 



# ACCESSIBILITY



## National Research Center for Parents with Disabilities

Parents Empowering Parents  
Padres Empoderando a Padres



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# ACCESSIBILITY

[www.accessiblepublishing.ca](http://www.accessiblepublishing.ca)



## The Importance of Image Descriptions

We have developed the following list of points which explains the importance of including accurate image descriptions.

- Accessible images can teach and empower
- Accessible images reach more people
- Accessible design benefits everyone



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# ACCESSIBILITY

**Image descriptions** describe the content of graphics or photos for people who use screen readers so they **don't miss out.**



# ACCESSIBILITY



Image description: Infographic with an illustration of a White-breasted Nuthatch on each and the following words. It's not enough to just think you're being inclusive. You have to be intentionally inclusive.



Specific guidance for instagram from [accessibleinfluence.com](https://www.accessibleinfluence.com)




# ACCESSIBILITY

## Write an image description.

- consider your audience
- general to the specific - overview, details
- provide context
- be clear and concise
- be objective


\* Don't forget the hashtag. [#CamelCase](#)



 ACTIVITY: Importance of Image Descriptions

### Write an Image Description

"An image description conveys the same or equivalent information that a sighted reader would get when they look at a picture, to someone with a print disability such as those who are blind or visually impaired."



\_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

"If you are new to describing images, you may feel overwhelmed and unsure where to begin. This is perfectly all right. Writing great image descriptions takes practice. As you continue to do more you will get better and better at it so be kind to yourself as you learn."

**A Note to Describers:**

"We have found that people who spend time crafting descriptions become better communicators. It is a wonderfully reflective process that allows you to explore whether the image is conveying what you want it to say. If you have trouble interpreting the meaning of the image, it may indicate that others could run into the same challenge. Therefore, thinking about image descriptions leads to a better idea of what images are important to include, what images may need to be changed, and how to improve on the narrative either through the surrounding text or within the image description."

[www.accessiblepublishing.ca/a-guide-to-image-description](http://www.accessiblepublishing.ca/a-guide-to-image-description)

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# ACCESSIBILITY User Experience UX

The image displays seven accessibility posters, each with a 'Do...' and 'Don't...' column. The posters are:

- Designing for users who are deaf or hard of hearing:** Do... write in plain language, use subtitles or provide transcripts for videos, use a linear, logical layout, break up content with sub-headings, images and videos, let users ask for their preferred communication support when booking appointments. Don't... use complicated words or figures of speech, put content in audio or video only, make complex layouts and menus, make users read long blocks of content, make telephone the only means of contact for users.
- Designing for users with anxiety:** Do... give users enough time to complete an action. Don't... rush users or set impractical time limits, leave users confused about next steps or timeframes, leave users uncertain about the consequences of their actions, make support or help hard to access, leave users questioning what answers they gave.
- Designing for users on the autistic spectrum:** Do... use simple colours. Don't... use bright contrasting colours.
- Designing for users with dyslexia:** Do... use images and diagrams to support text. Don't... use large blocks of heavy text.
- Designing for those who have experienced trauma through domestic or intimate partner violence:** Do... design with mobile and touchscreen in mind (e.g. use click-to-call phone numbers), progressively disclose information, make sure safety alerts and info on getting help is unmissable, be inclusive of all people, use quotes and/or images from real people (if safe to do). Don't... assume your visitors are on a desktop or laptop computer, overwhelm with too many options, bury safety alerts and info on getting help on a cluttered web page, assume all survivors identify the same way, use triggering images that depict violence or uninformative stock photos.
- Designing for users with low vision:** Do... use good colour contrasts and a readable font size, publish all information on web pages, use a combination of colour, shapes and text, follow a linear, logical layout, put buttons and notifications in context. Don't... use low colour contrasts and small font size, bury information in downloads, only use colour to convey meaning, spread content all over a page, separate actions from their context.
- Designing for users with physical or motor disabilities:** Do... make large clickable actions, give form fields space, design for keyboard or speech only use, design with mobile and touchscreen in mind, provide shortcuts. Don't... demand precision, bunch interactions together, make dynamic content that requires a lot of mouse movement, have short time out windows, tire users with lots of typing and scrolling, Address.
- Designing for users of screen readers:** Do... describe images and provide transcripts for video, follow a linear logical layout, structure content using HTML5, build for keyboard use only, write descriptive links and headings. Don't... only show information in an image or video, spread content all over a page, rely on text size and placement for structure, force mouse or screen use, write uninformative links and headings.



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# TRANSLATIONS

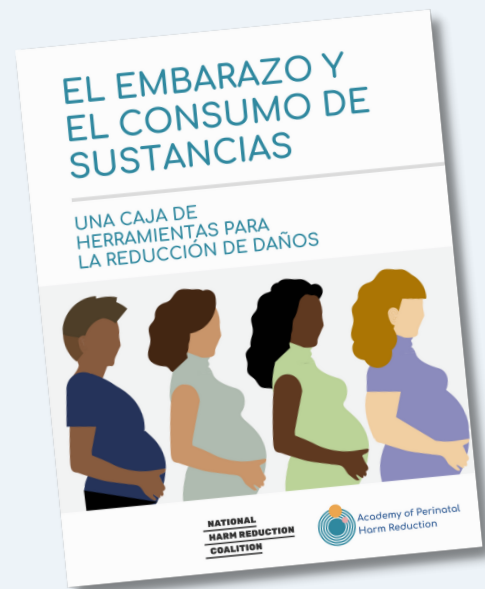
## Case Studies: NATIONAL PERINATAL ASSOCIATION

- linguistic structure - grammatical gender
- symbols - illustrating abstract concepts
- volunteers versus paid, certified translators



## ACADEMY OF PERINATAL HARM REDUCTION

- cross-cultural communication
- writing for different systems of care
- using the language of the community



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The Composition of  
**HUMAN MILK**

200+ components

Made for Babies

- 90% water
- fats (lipids, fatty acids)
- carbohydrates (lactose, oligosaccharides)
- proteins (casein, whey, lactoferrin)
- vitamins minerals
- hormones
- antibodies
- stem cells
- enzymes

..... Human Milk is Living Tissue

National Perinatal Association  
Educate. Advocate. Integrate.  
nationalperinatal.org/feeding-our-babies

The Composition of  
**BREAST MILK**

200+ components

Babies

- 90% water
- fats (lipids, fatty acids)
- carbohydrates (lactose, oligosaccharides)
- proteins (casein, whey, lactoferrin)
- vitamins minerals
- hormones
- antibodies
- stem cells
- enzymes

..... Breast Milk is Living Tissue

National Perinatal Association  
Educate. Advocate. Integrate.  
nationalperinatal.org/feeding-our-babies

La composición de la  
**LECHE MATERNA**

200+ componentes

La leche materna está hecha para bebés.

- 90% agua
- grasas (lípidos, ácidos grasos)
- carbohidratos (lactosa, oligosacáridos)
- proteínas (caseína, suero, lactoferrina)
- vitaminas minerales
- hormonas
- anticuerpos
- células madre
- enzimas

..... La leche materna es tejido vivo.

National Perinatal Association  
Educate. Advocate. Integrate.  
nationalperinatal.org/feeding-our-babies

la composition du  
**LAIT MATERNEL**

200+ composants

Le lait maternel est fait pour les bébés.

- 90% eau
- lipides (lipides, acides gras)
- glucides (lactose, oligosaccharides)
- protéines (caséine, petit lait, lactoferrine)
- vitamines minérales
- hormones
- anticorps
- cellules souches
- enzymes

..... Le lait maternel est un liquide vivant.

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National Perinatal Association - Breastfeeding Awareness



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Department of Health

NATIONAL HARM REDUCTION COALITION

PREGNANCY AND SUBSTANCE USE A HARM REDUCTION TOOLKIT

EL EMBARAZO Y EL CONSUMO DE SUSTANCIAS UNA CAJA DE HERRAMIENTAS PARA LA REDUCCIÓN DE DAÑOS

Principles of Perinatal Harm Reduction / Principios de reducción de daños en la atención perinatal

Urine Drug Testing / PRUEBA DE DETECCIÓN DE DROGAS EN ORINA

SOBREDOSIS DE OPIOIDES Y EMBARAZO / OPIOID OVERDOSE + PREGNANCY



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under revision

# NICU PARENT'S Bill of Rights

## NICU BABY'S Bill of Rights

- 1-My parents have the right to see me 24 hours and receive information about my care.
- 2-In order to best care for me, my parents need to be involved in my medical decisions.
- 3-Bonding with me is important and should be encouraged whenever possible.
- 4-Help me participate in my care as much as possible.
- 5-Feeding me should be done in a way that is safe and whichever is best for me to produce milk.
- 6-If I, or my siblings, are multiples (twins, triplets, etc.), we should be acknowledged as such.
- 7-Although I may be fragile, I am a person. Enlist the help of the parents and family.
- 8-Encourage my parents to be a component of my care, including long-term plans.
- 9-My parents should be encouraged to be involved in my care and encouraged to be part of my care.
- 10-My parents should be encouraged to support my care and to be part of my care.

- 1- THE RIGHT TO ADVOCACY**  
My parents know me well. They are my voice and my best advocates. They need to be knowledgeable about my progress, medical records, prognosis, so they celebrate my achievements and support me when things get challenging.
- 2- THE RIGHT TO MY PARENTS' CARE**  
In order to meet my unique needs, my parents need to learn about my developmental needs. Be patient with them and teach them well. Make sure hospital policies and protocols, including visiting hours and rounding, are as inclusive as possible.
- 3- THE RIGHT TO BOND WITH MY FAMILY**  
Bonding is crucial for my sleep and neuroprotection. Encourage my parents to practice skin-to-skin contact as soon as and as often as possible and to read, sing and talk to me each time they are with me.
- 4- THE RIGHT TO NEUROPROTECTIVE CARE**  
Protect me from things that startle, stress, or overwhelm me and my brain, and support things that calm me. Ensure I get as much sleep as possible. My brain is developing for the first time and faster than it ever will again. The way I am cared for today will help my brain when I grow up. Connect me with my parents for the best opportunities to help my brain develop.
- 5- THE RIGHT TO BE NOURISHED**  
Encourage my parents to feed me at the breast or by bottle, whichever way works for us both. Also, let my parents know that donor milk may be an option for me.
- 6- THE RIGHT TO PERSONHOOD**  
Address me by my name when possible, communicate with me before touching me, and if I or one of my siblings pass away while in the NICU, continue referring to us as multiples (twins/triplets/quads, and more). It is important to acknowledge our lives.
- 7- THE RIGHT TO CONFIDENT AND COMPETENT CARE GIVING**  
The NICU may be a traumatic place for my parents. Ensure that they receive tender loving care, information, education, and as many resources as possible to help educate them about my unique needs, development, diagnoses, and more.
- 8- THE RIGHT TO FAMILY-CENTERED CARE**  
Help me feel part of my own family. Teach my parents, grandparents and siblings how to read my cues, how to care for me, and how to meet my needs. Encourage them to participate in or perform my daily care activities, such as bathing and diaper changes.
- 9- THE RIGHT TO HEALTHY AND SUPPORTED PARENTS**  
My parents may be experiencing a range of new and challenging emotions. Be patient, listen to them, and lend your support. Share information with my parents about resources such as peer-to-peer support programs, support groups and counseling, which can help reduce PMAD, PPD, PTSD, anxiety and depression, and more.

Unité de Soins Intensifs Néonataux (USIN)  
**Charte des Droits de l'Enfant**

1- LE DROIT À LA DÉFENSE  
Mes parents me connaissent bien. Ils ont eu mes et me m'ont défendu. Ils doivent être au courant de mon progrès, de mes données médicales et de mon pronostic, afin de célébrer mes réalisations et de me soutenir lorsque les choses deviennent difficiles.

2- LE DROIT À L'ATTENTION DE MES PARENTS  
Pour répondre à mes besoins uniques, mes parents ont besoin de connaître mes besoins de développement. Sois patient avec eux et apprends-leur bien. Assure-toi que les protocoles et procédures de l'hôpital, y compris les heures de visite et les rondes, sont le plus inclusifs possible.

3- LE DROIT AUX LIENS AVEC MA FAMILLE  
L'établissement de liens est crucial pour mon sommeil et ma neuroprotection. Encouragez mes parents à pratiquer le contact peau à peau le plus tôt et le plus souvent possible et à lire, à chanter et à parler à chaque fois qu'ils me rendent visite.

4- LE DROIT AUX SOINS NEURO-PROTECTEURS  
Protégez-moi des choses qui me font stresser, m'excitent ou m'effraient, ainsi que mes frères et sœurs. Favorisez les choses qui me calment. Veillez à ce que je dorme le plus possible. Mon cerveau se développe pour la première fois et plus vite qu'il ne le fera jamais. La façon dont je suis soigné aujourd'hui aidera mon cerveau quand j'en serai grand. Mon cerveau est en développement.

5- LE DROIT À ÊTRE NOURRI  
Encouragez mes parents à allaiter au sein ou à utiliser le lait maternel, si possible, et à utiliser le lait maternel si possible.

6- LE DROIT D'ÊTRE UNE PERSONNE  
Adressez-moi par mon nom lorsque c'est possible, communiquez avec moi avant de me toucher et, si l'un de mes frères et sœurs passe pendant que je suis en soins intensifs, continuez de nous appeler par nos surnoms (jumeaux/triplets/quadruplés, et plus). Il est important de reconnaître nos vies.

7- LE DROIT À DES SOINS CONFIANTS ET À L'ATTENTION DE MES PARENTS  
L'USIN peut être un endroit traumatisant pour mes parents. Assurez-vous qu'ils reçoivent des soins doux et empathiques, de l'information, de l'éducation et des ressources afin de les aider à mieux comprendre mon développement.

8- LE DROIT À DES SOINS CENTRÉS SUR LA FAMILLE  
Aidez-moi à me sentir partie de ma famille. Enseignez à mes parents, grands-parents et frères et sœurs comment lire mes indices, comment s'occuper de moi et comment répondre à mes besoins. Il est important de reconnaître nos vies.

9- LE DROIT À DES PARENTS EN BONNE SANTÉ  
Mes parents peuvent vivre avec une variété d'émotions nouvelles et difficiles. Soyez patient, écoutez-les et donnez leur votre soutien. Partagez l'information avec mes parents sur les ressources telles que les programmes de soutien aux parents, les groupes de soutien et les conseils, qui peuvent aider à réduire les PMAD, le PPD, le PTSD, l'anxiété et la dépression, et plus.

10- LE DROIT À L'INCLUSION ET À L'APPARTENANCE  
Protégez la diversité de ma famille et de ma vie, y compris ma religion, ma race et ma culture. Assurez-vous que mes frères et sœurs et moi sommes acceptés et soutenus en USIN, et respectés et valorisés en toutes les formes de participation et de communication.

**NPN NICU PARENT NETWORK**  
Visitez [www.nicuparentnetwork.org](http://www.nicuparentnetwork.org) pour identifier les programmes de soutien familial de l'USIN à l'échelle nationale, étatique et locale.



Unidad de Cuidados Intensivos Neonatales (UCIN)  
**Carta de Derechos del Bebé**

1- EL DERECHO A DEFENSA  
Mis padres me conocen bien. Ellos son mi voz y mi mejor defensor. Necesitan saber sobre mi progreso, historial médico y diagnósticos, para que puedan celebrar mis logros y apoyarme cuando las cosas están complicadas.

2- EL DERECHO AL CUIDADO DE MIS PADRES  
Para cumplir con mis necesidades únicas, mis padres deben conocer sobre mis necesidades de desarrollo. Sé paciente con ellos y enséñales. Asegúrate de que tanto las políticas como los protocolos del hospital, incluyendo horas de visita y las rondas, sean lo más inclusivos posible.

3- EL DERECHO A LA CERCANÍA CON MI FAMILIA  
La relación con mi familia es crucial para mi sueño y mi neuroprotección. Anima a mis padres a que practiquen el contacto piel a piel tan pronto como sea posible y a leer, cantar y hablar conmigo cada vez que vengan a verme.

4- EL DERECHO A LOS CUIDADOS NEUROPROTECTIVOS  
Protégeme de las cosas que me estresan, excitan o abrumen a mí y a mi cerebro. Fomenta las cosas que me calman. Asegúrate de dormir lo más posible. Mi cerebro se está desarrollando por primera vez y más rápido que nunca. La forma en que me cuidan hoy ayudará a mi cerebro cuando sea mayor. Conéctame con mis padres para obtener las mejores oportunidades para ayudar a que mi cerebro se desarrolle.

5- EL DERECHO A LA ALIMENTACIÓN  
Alimenta a mis padres a que me alimenten con el pecho o con lactancia, de manera que mejor funcione para los dos. Además, hazles saber a mis padres que el leche de donante puede ser una opción para mí.

6- EL DERECHO A SER PERSONA  
Dirígeme o saludame por mi nombre cuando sea posible, comunícame conmigo antes de tocarme, y si yo o uno de mis hermanos fallece mientras estamos en la UCIN, continúa refiriéndose a nosotros como gemelos / trillizos / cuádruplos, y más. Es importante reconocer todos los vidas.

7- EL DERECHO A UNA ATENCIÓN CONFÍADA Y COMPETENTE  
La UCIN puede ser un lugar traumático para mis padres. Asegúrate que reciban atención, información, educación y la mayor cantidad de recursos posible para ayudar a educarlos sobre mis necesidades únicas, desarrollo, diagnósticos y más.

8- EL DERECHO A LA ATENCIÓN CENTRADA EN LA FAMILIA  
Ayúdame a sentir que soy parte de mi familia. Enseña a mis padres, abuelos y hermanos cómo leer mis señales, cómo calmarme y cómo satisfacer mis necesidades. Anima a participar o realizar sus actividades de cuidado diario, como bañarse y cambiar pañales.

9- EL DERECHO A LA SALUD Y AL SER APOYADOS  
Mis padres pueden estar viviendo una variedad de emociones nuevas y desafiantes. Ten paciencia, escúchales y dales tu apoyo. Comparte información con mis padres sobre recursos tales como programas de apoyo entre padres, grupos de apoyo y asesoramiento, que pueden ayudar a reducir el trastorno de estrés post-traumático, la ansiedad y la depresión, y más.

10- EL DERECHO A LA INCLUSIÓN Y PERTENENCIA  
Celebra mi diversidad y la de mi familia, incluyendo nuestra religión, raza y cultura. Asegúrate que mis padres, abuelos y hermanos se sientan aceptados y bienvenidos en la UCIN, respetados y valorados en todas las formas de participación y comunicación.

**NPN NICU PARENT NETWORK**  
Visita [www.nicuparentnetwork.org](http://www.nicuparentnetwork.org) para identificar los programas de apoyo familiar de la UCIN a nivel nacional, estatal y local.



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## NICU BABY'S Bill of Rights

### 1- THE RIGHT TO ADVOCACY

My parents know me well. They are my voice and my best advocates. They need to be knowledgeable about my progress, medical records, prognosis, so they celebrate my achievements and support me when things get challenging.

### 2- THE RIGHT TO MY PARENTS' CARE

In order to meet my unique needs, my parents need to learn about my developmental needs. Be patient with them and teach them well. Make sure hospital policies and protocols, including visiting hours and rounding, are as inclusive as possible.

### 3- THE RIGHT TO BOND WITH MY FAMILY

Bonding is crucial for my sleep and neuroprotection. Encourage my parents to practice skin-to-skin contact as soon as and as often as possible and to read, sing and talk to me each time they are with me.

### 4- THE RIGHT TO NEUROPROTECTIVE CARE

Protect me from things that startle, stress, or overwhelm me and my brain, and support things that calm me. Ensure I get as much sleep as possible. My brain is developing for the first time and faster than it ever will again. The way I am cared for today will help my brain when I grow up. Connect me with my parents for the best opportunities to help my brain develop.

### 5- THE RIGHT TO BE NOURISHED

Encourage my parents to feed me at the breast or by bottle, whichever way works for us both. Also, let my parents know that donor milk may be an option for me.

### 6- THE RIGHT TO PERSONHOOD

Address me by my name when possible, communicate with me before touching me, and if I or one of my siblings pass away while in the NICU, continue referring to us as multiples (twin/triplets/quads, and more). It is important to acknowledge our lives.

### 7- THE RIGHT TO CONFIDENT AND COMPETENT CARE GIVING

The NICU may be a traumatic place for my parents. Ensure that they receive tender loving care, information, education, and as many resources as possible to help educate them about my unique needs, development, diagnoses, and more.

### 8- THE RIGHT TO FAMILY-CENTERED CARE

Help me feel part of my own family. Teach my parents, grandparents and siblings how to read my cues, how to care for me, and how to meet my needs. Encourage them to participate in or perform my daily care activities, such as bathing and diaper changes.

### 9- THE RIGHT TO HEALTHY AND SUPPORTED PARENTS

My parents may be experiencing a range of new and challenging emotions. Be patient, listen to them, and lend your support. Share information with my parents about resources such as peer-to-peer support programs, support groups and counseling, which can help reduce PMAD, PPD, PTSD, anxiety and depression, and more.

### 10- THE RIGHT TO INCLUSION AND BELONGING

Celebrate my family's diversity and mine, including our religion, race and culture. Ensure that my parents, grandparents and siblings feel accepted and welcomed in the NICU, and respected and valued in all forms of engagement and communication.

Presented by:



NICU PARENT NETWORK

NICU Parent Network

Visit [www.nicuparentnetwork.org](http://www.nicuparentnetwork.org) to identify national, state, and local NICU family support programs.

The language is good.  
We made minor changes. But...  
How do we choose the images to use?

## PHOTOGRAPHY

- stock photography - limited, not specific
- our families - privacy, permission

## ILLUSTRATIONS

- many of the same limitations
- time, talent, cost





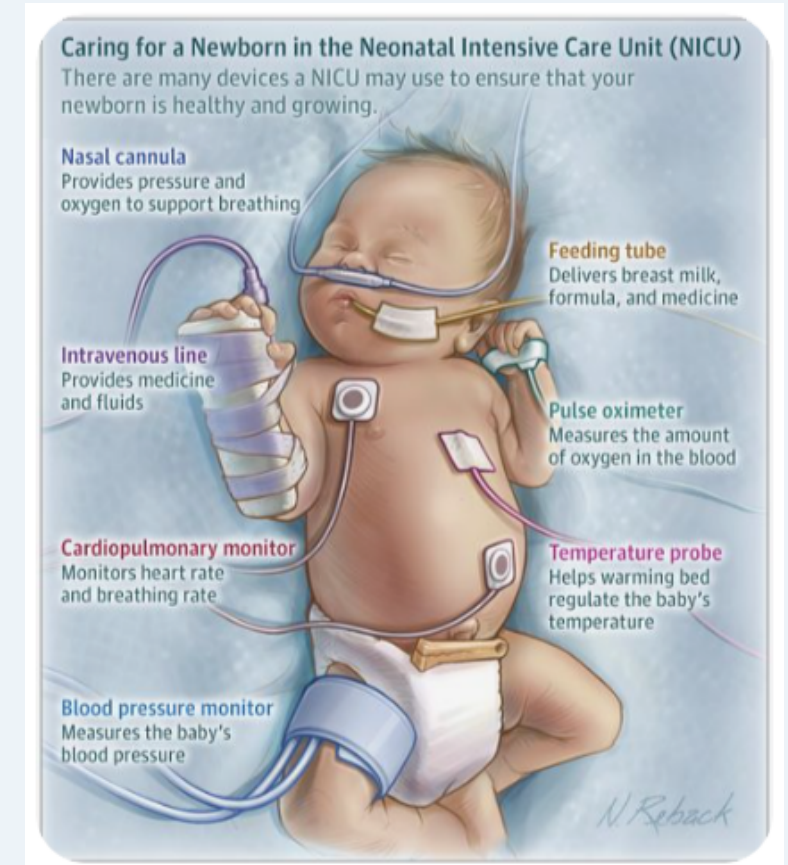
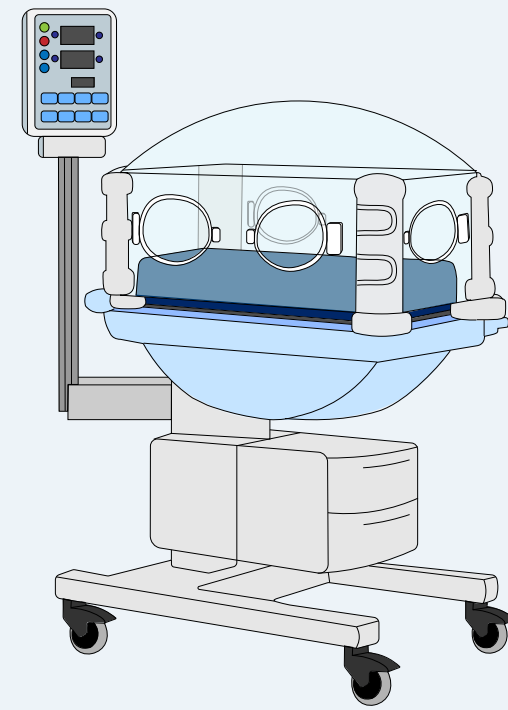
# Stock Photography Has a Diversity Problem



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[nicuparentnetwork.org](http://nicuparentnetwork.org)

2023



# NICU

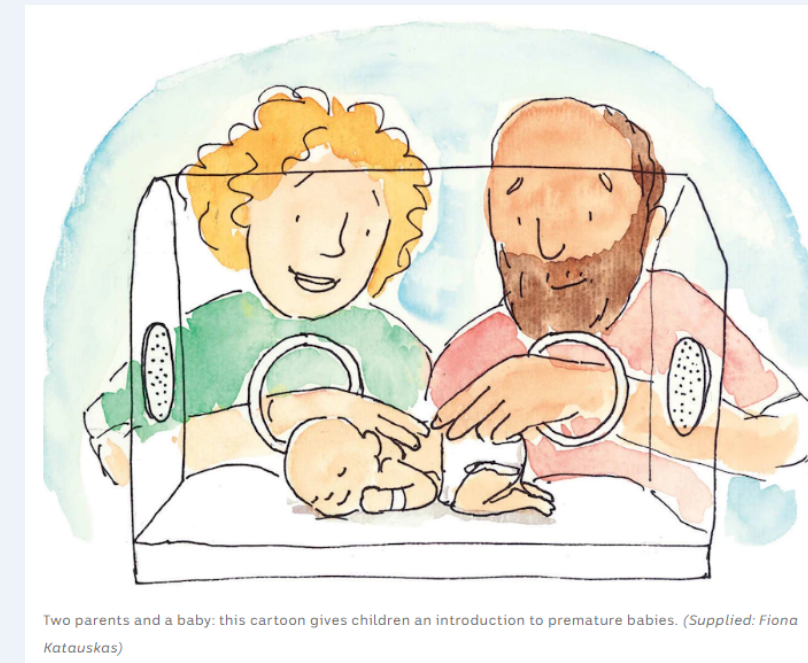
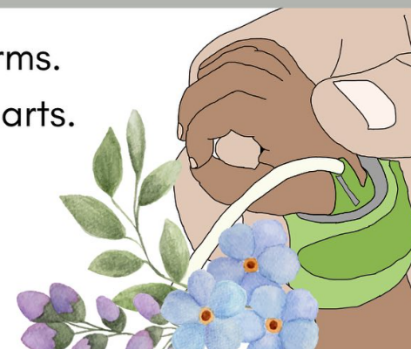
## REMEMBRANCE DAY

SEPTEMBER 26

[www.nicuawareness.org](http://www.nicuawareness.org)



A moment in our arms.  
A lifetime in our hearts.



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**Initiative Planning: Serving Our Community**

WHAT ARE WE DOING?	WHY ARE WE DOING IT?
WHO IS OUR AUDIENCE?	WHO ARE OUR PARTNERS AND ALLIES?
WHAT INFORMATION DO WE NEED TO GATHER?	"SUCCESS IS..." "FAILURE MEANS..."

**Initiative Planning: Scope of Project**

WHAT ARE WE DOING?	WHAT NEEDS TO BE DONE?	WHO IS RESPONSIBLE?	INITIAL
	TASKS - "BREAK IT DOWN"		
WHAT IS THE PURPOSE?		"SUCCESS IS..."	

**Project Planning: Step-by-Step**  
Every project can be broken down into a series of tasks. Groups can work together more productively if everyone knows what their roles are and what they're responsible for.

GOAL OR TASK	DUE	ACTIONS	RESOURCES NEEDED	WHO IS RESPONSIBLE?	INITIAL

**Project Planning: Roles and Responsibilities**  
Team efforts are often more successful than individual ones. And collaboration almost always leads to better results. When team members know their strengths - and can rely on each other for support - projects flow!

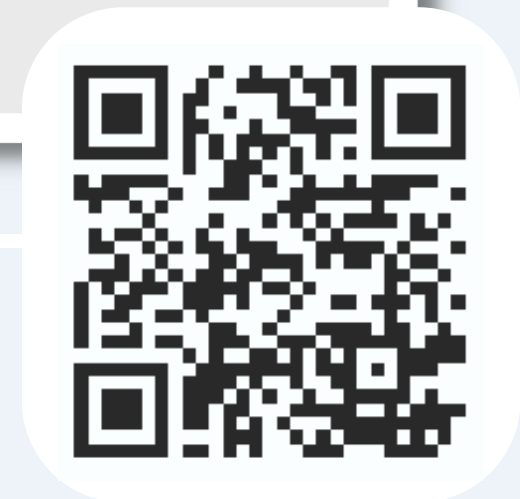
NAME	ROLE	TALENTS + STRENGTHS	AVAILABLE RESOURCES	WHO CAN HELP IF I NEED IT?

**Guiding Principles → Emerging Themes**

WHAT ARE WE DOING?	WE BELIEVE
WHY ARE WE DOING IT?	WE REJECT
WHY US?	

**FREE RESOURCES**

[www.nationalperinatal.org/npn](http://www.nationalperinatal.org/npn)



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[nicuparentnetwork.org](http://nicuparentnetwork.org)

2023

[www.nationalperinatal.org/npn](http://www.nationalperinatal.org/npn)



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