NeoQIC Family Engagement Quality Improvement Collaborative Webinar

September 15, 2020
Day 1: 1-3 pm

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Neonatal Quality Improvement Collaborative of Massachusetts

Welcome, Introductions, and Roll Call

Meg Parker, MD, MPH
Neonatologist at Boston Medical Center
Associate Chair of the Neonatal Quality Improvement Collaborative of Massachusetts
Improvement Advisor from the Institute for Healthcare Improvement

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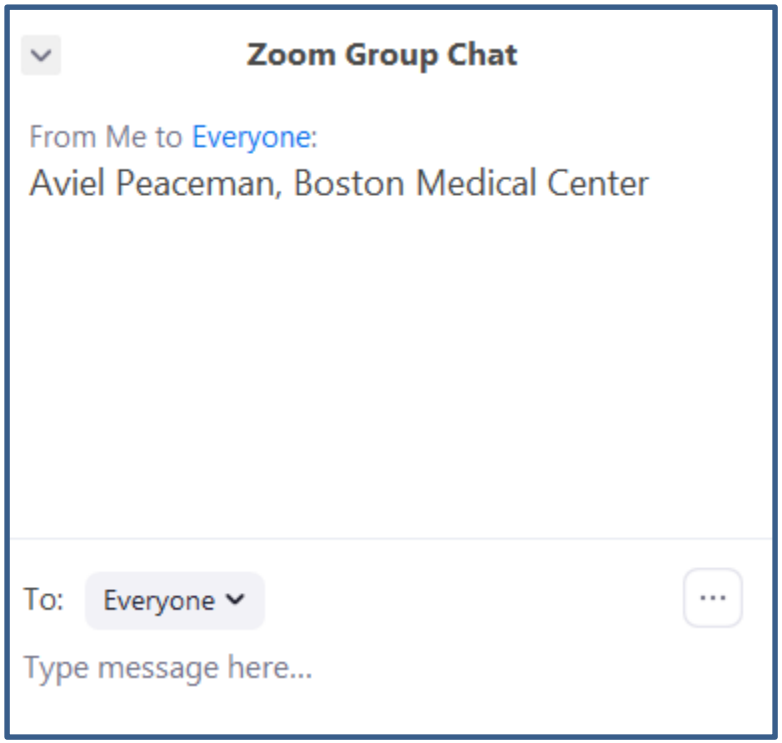
Welcome!

Please chat your name and hospital into the chat box



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Follow along and share your learnings today!

#NeoQIC2020

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Agenda- Day 1

Time	Topic
1:00	Welcome, Introductions, and Roll Call
1:15	Parent Testimonial
1:30	Importance of Quality Improvement in Family Engagement
2:15	Hospital Spotlight: South Shore Hospital
2:35	Importance of Communication with Non-English Proficient Families in the NICU
2:55	Wrap Up Day 1

Participating Level 2 and 3 NICUs in Massachusetts

- Baystate Medical Center
- Beth Israel Deaconess Medical Center
- Beverly Hospital
- BID – Plymouth
- Boston Children's Hospital
- Boston Medical Center
- Brigham and Women's Hospital
- Emerson Hospital
- Holy Family Hospital
- Lawrence Hospital
- Lowell General Hospital
- Massachusetts General Hospital
- Melrose Wakefield Hospital
- Metrowest Medical Center
- Mt. Auburn Hospital
- Newton Wellesley Hospital
- North Shore Medical Center
- Signature Healthcare Brockton Hospital
- South Shore Hospital
- Southcoast - Charlton Memorial
- Southcoast- St. Luke's
- St. Elizabeth's Hospital
- Tufts Medical Center
- UMass Memorial
- Winchester Hospital

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Key Driver Diagram- Family Engagement

Family Engagement QIC Key Driver Diagram

Aim Statement	Primary Drivers	Secondary Drivers	Potential Change Concepts
By December 2022, hospitals will improve family engagement in NICUs by: 1. *Reduce disparities in key drivers by race/ethnicity, primary language, and distance travelled*	Inadequate communication between NICU staff and families; among NICU providers *Measure: 1) Parental presence on daily rounds; 2) Timing of first family meeting; 3) Parent report of being informed consistently*	Language barrier between providers and parents	1) Increase use of interpreter services often and early
		Lack of timely and frequent family updates	1) Standardize timing and content of first family meeting after admission
		Inadequate family presence (during rounds, for infant cares)	1) Reduce parking cost; 2) Provide public transportation vouchers; 3) Minimize restriction of sibling visitation; 4) On site childcare for siblings; 5) Overnight accommodations for families; 6) Provide meals as needed
		Inconsistency in understanding of infant care plans among providers	1) Improve communication among medical consultants and primary team; 2) improve communication among primary team and nurses
	Inadequate services and social supports for families *Measure: 1) Date of first social worker contact after admission; 2) Mental health screening performed in the NICU; 3) Parental report of social and financial needs being met*	Current social services not comprehensive to address all needs	1) Social determinants screening tool; 2) establish referral service
		Social workers bandwidth; timely availability	1) Utilize parent peer support groups
		Inadequate family support in primary language	1) Increase use of interpreter services often and early
		Inadequate mental health support	1) Introduce universal screening for parental depression/anxiety; 2) Provide mental health support during NICU hospitalization
	Family engagement in Hands-On NICU care *Measure: Skin to skin and breastfeeding continuation (through day 7, 28, and discharge)*	Inadequate family presence	1) Reduce parking cost; 2) Provide public transportation vouchers; 3) Minimize restriction of sibling visitation; 4) On site childcare for siblings; 5) Overnight accommodations for families; 6) Provide meals as needed
		Families and NICU staff have unclear expectations about parental role in the NICU; lack of parental empowerment	1) Educate family on all aspects of care they can participate in; 2) Development of peer-support groups; 3) Standardize family participation in infant's care (FICare)
		Language barriers	1) Increase use of interpreter services often and early
		Mother's own milk (MOM) protocols, policies, and supports	1) Introduce MOM education and support during prenatal period; 2) Early pumping initiation; 3) Early and frequent skin to skin; 4) Address lactation issues by phone/telehealth
	Family participation in discharge planning *Measure: 1) Timing of initiation and completion of discharge teaching for families; 2) parental report of discharge readiness; safe sleep adherence post-discharge;*	Lack of shared decision making in discharge planning	1) Educate family on all aspects of care they can participate in; 2) Development of peer-support groups; 3) Standardize family participation in infant's care (FICare)
		Language barrier	1) Increase use of interpreter services often and early
		Inadequate family presence	1) Reduce parking cost; 2) Provide public transportation vouchers; 3) Minimize restriction of sibling visitation; 4) On site childcare for siblings; 5) Overnight accommodations for families; 6) Provide meals as needed
		Compliance with safe sleep practices in NICU	1) Standardize infant sleep practices and environment for all NICU infants

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Aim Statement

By December 2022, hospitals will improve family engagement in NICUs by:

1. *Reduce disparities in key drivers by race/ethnicity, primary language, and distance travelled*

Key Drivers

1. Inadequate communication regarding infant medical care between NICU staff and families

2. Inadequate services and social supports for families

3. Family engagement in Hands-On NICU care

4. Family participation in discharge planning

Which driver are you most interested in working on first?

1- Inadequate communication regarding infant medical care between NICU staff and families

2- Inadequate services and social supports for families

3- Family engagement in hands-on NICU care

4- Family participation in discharge planning

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Project Timeline

	2020				2021				2022			
	Q1	Q2	Q3	Q4	Q1	Q2	Q3	Q4	Q1	Q2	Q3	Q4
Develop Data Metrics/Key Driver Diagram	X											
Pilot Data Metrics		X	→									
Data Use Agreements/IRBs	X	X	X →									
Form multi-disciplinary hospital teams	X	→	→									
Webinars	X	X	X	X	X	X	X	X	X	X	X	X
In-person/ virtual meetings	X		X		X		X		X		X	
Data collection and reporting				X	X	X	X	X	X	X	X	X
Interventions as PDSA cycles			X	X	X	X	X	X	X	X	X	X

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Is your multidisciplinary team set up yet?

- Yes
- Not yet
- We're working on it

Is your multidisciplinary team set up yet?

Yes

Not yet

We're working on it

Is your multidisciplinary team set up yet?

Yes

Not yet

We're working on it

Any Questions?

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Parent Testimonial

Shauna Conway

NICU Parent

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Parent Testimonial

- Hello, my name is Shauna Conway and these are my sons, Benjamin and Charlie.
- Benjamin was born in 2013 at 27 weeks and 4 days. He was in the NICU for 89 days.
- Charlie was born in 2016 at 31 weeks and 4 days. He was in the NICU for 79 days.

Importance of Quality Improvement in Family Engagement

Lelis Vernon

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Lelis Vernon

Lelis Vernon

Vermont Oxford Network

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Division of Neonatal and Developmental Medicine

pcori

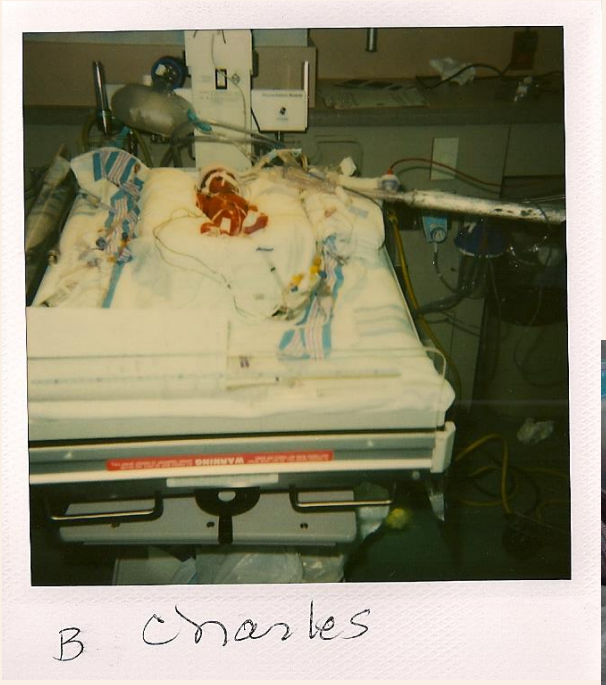
ACP
American College of Physicians
Leading Internal Medicine, Improving Lives

American Academy of Pediatrics
DEDICATED TO THE HEALTH OF ALL CHILDREN®

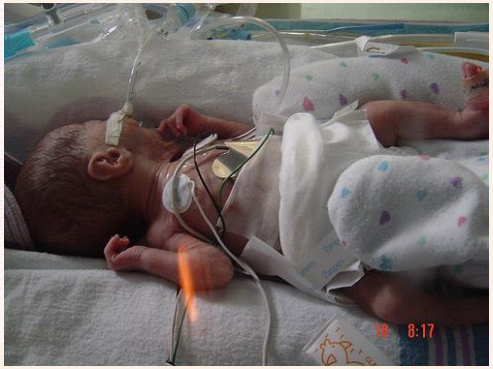
NNPQC
National Network of Perinatal Quality Collaboratives

FPQC

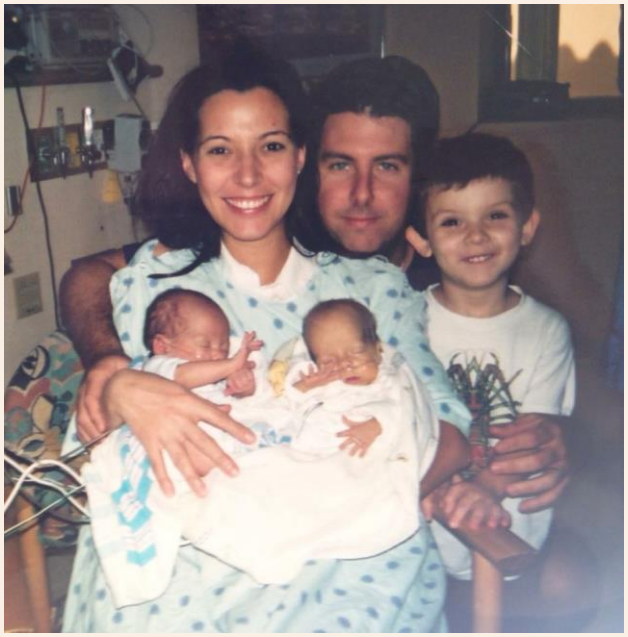
NICU days as a mother of 2 micropreemies…



Bobby



Charlie (post-ostomy)



First family photo
(Febr. 2004)

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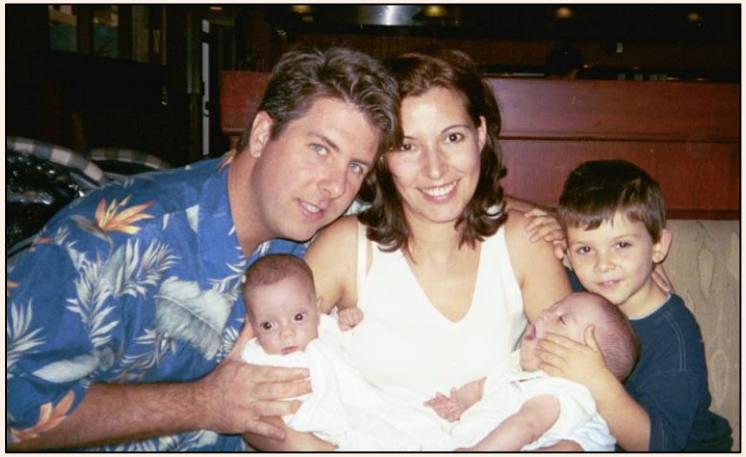
First Mother's Day (2004)



New Years (2019)

Our gifted Jazz musicians!

They are driving . . .

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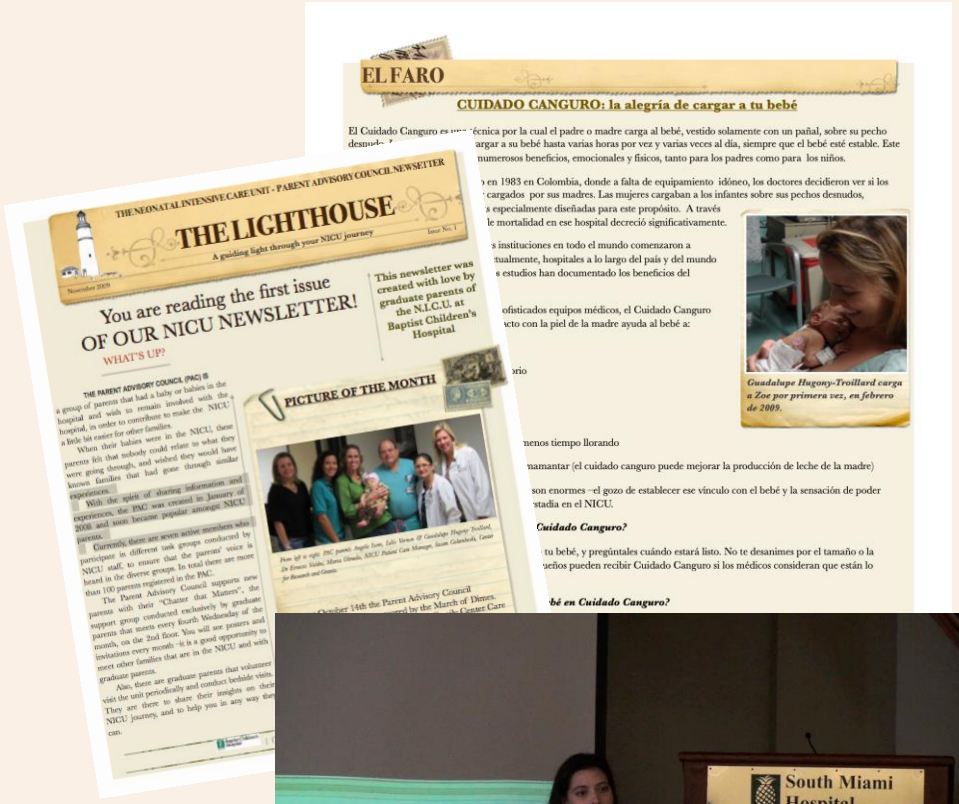


EL FARO

CUIDADO CANGURO: la alegría de cargar a tu bebé

THE LIGHTHOUSE

You are reading the first issue OF OUR NICU NEWSLETTER!

WHAT'S UP?

PICTURE OF THE MONTH

"Mi Regalo"

Soy un extraño para ti ahora,
pero déjame caminar a tu lado .
Porque he estado adonde tu estas y adonde
estar por ir,
No tengo respuestas, Te ofrezco a cambio mi
mano, mi corazón y mi oído atento, mi
tiempo y mi experiencia…. Para que un día
tu puedas decirle a otro:
Soy un extraño para ti ahora,
pero déjame caminar a tu lado .
Porque he estado adonde tu estas y adonde
estar por ir,
No tengo respuestas, Te ofrezco a cambio mi
mano, mi corazón y mi oído atento, mi
tiempo y mi experiencia….

N.I.C.U Parent Advisory Council Representantes del Hospital: Jennifer Couceyro, Marcie Applegate y Ann Marie Anderson

Contactenos!
nicu.pac@gmail.com

Para información general sobre Baptist Children's Hospital visite
www.baptisthealth.net

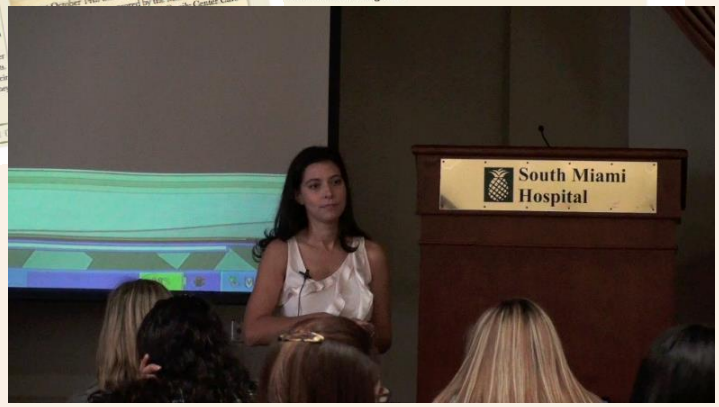
Nuestro Telefono
(786) 596-6977

Baptist Children's Hospital

Unidad de Terapia Intensiva de Neonatología

Consejo de Padres

Parent Advisory Council (P.A.C)



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EL FARO
"Mi Regalo"
Soy un extraño para ti ahora,
pero déjame caminar a tu lado .
Porque he estado adonde tu estas y adonde
Baptist Children's Hospital
Unidad de Terapia Intensiva
de Neonatología
NICU FAMILY LOUNGE
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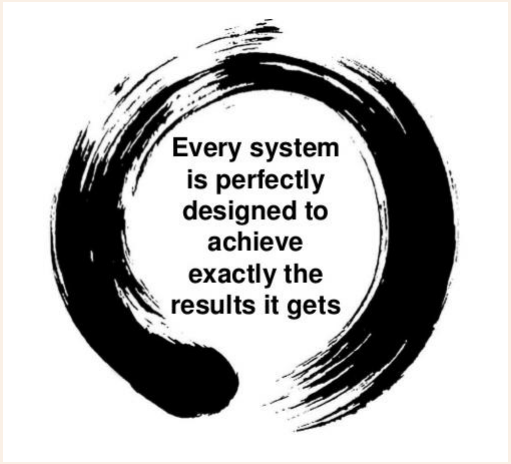
Moving from one side of the isolette to the other

- Families as drivers of change
- Families as QI partners, cycle creators
- Families addressing gaps in care and imperative needs families have.
- Qualitative real-time feedback

Why do you need to engage with families?

Representation

Change!



"#Nothing about me without me"

Advocacy

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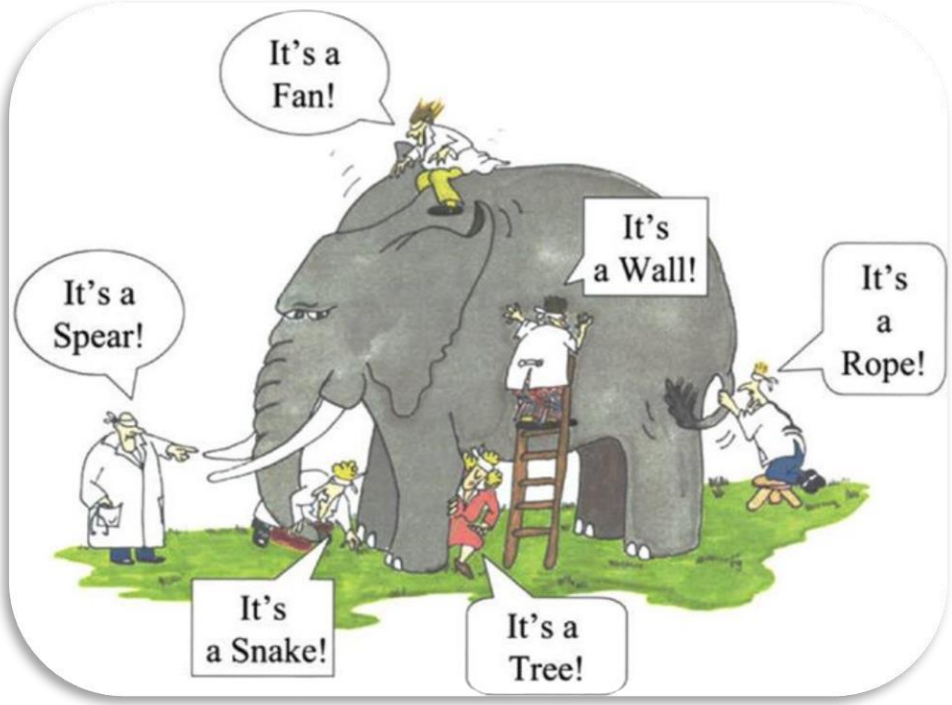
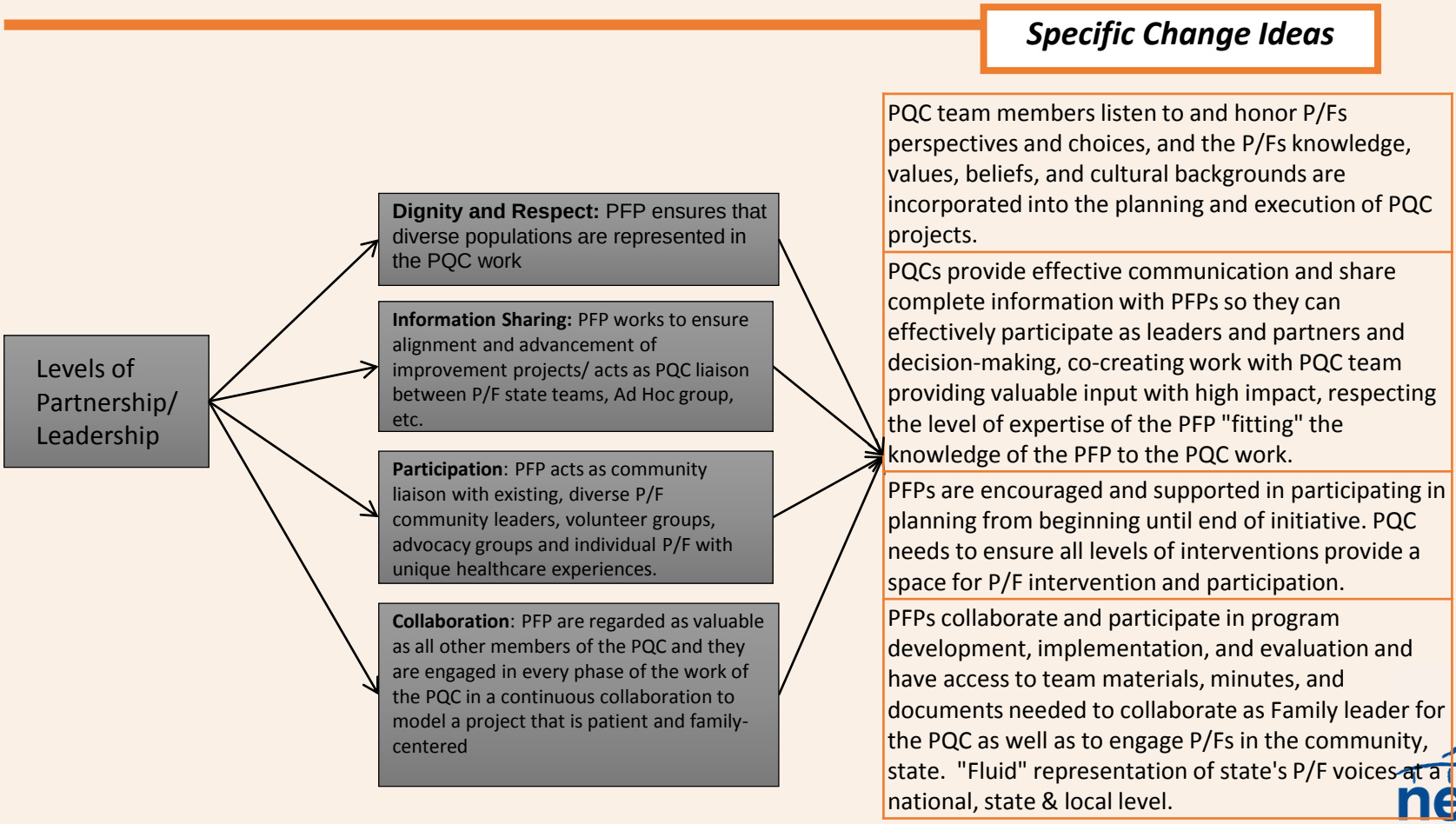
… and why are WE interested in partnering with you?



The parable of
The Blind Men and an Elephant

…because we are not treated as elephants!

How to engage with families at a PQC level?



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Racial / Ethnic Disparities in care: NICU families as partners in research

Stanford MEDICINE | the ProfitLab at CPQCC
Division of Neonatal and Developmental Medicine

The Project

- NIH-funded study to develop a disparity dashboard for NICUs
- CPQCC: turning data into action (quality dashboard)
- Disparities in outcomes
- Causes of disparity in access and care delivery:
  - Vulnerable infants more likely to receive care at poor quality hospital (Morales 2005, Howell 2008)
  - Vulnerable infants suboptimal care within hospital (Cricco-Lizza 2006, Collaco 2011, Claydon 2007)
- No routine comprehensive assessment of disparities in NICU quality --> lack of systematic efforts to remedy this problem

Process

- Survey participating hospitals during 2018's VON plenary presentation
- 324 participants (providers and parents) submitted accounts of a perceived racial/ethnic disparity in care via an electronic survey
- Stories analyzed using thematic coding and Dedoose
- Focus on the challenges faced by vulnerable families

Objectives

- Identify critical components of family centered care (FCC) in the NICU in partnership with families
- Develop measures to evaluate NICU performance on FCC according to the guidelines of the National Quality Forum

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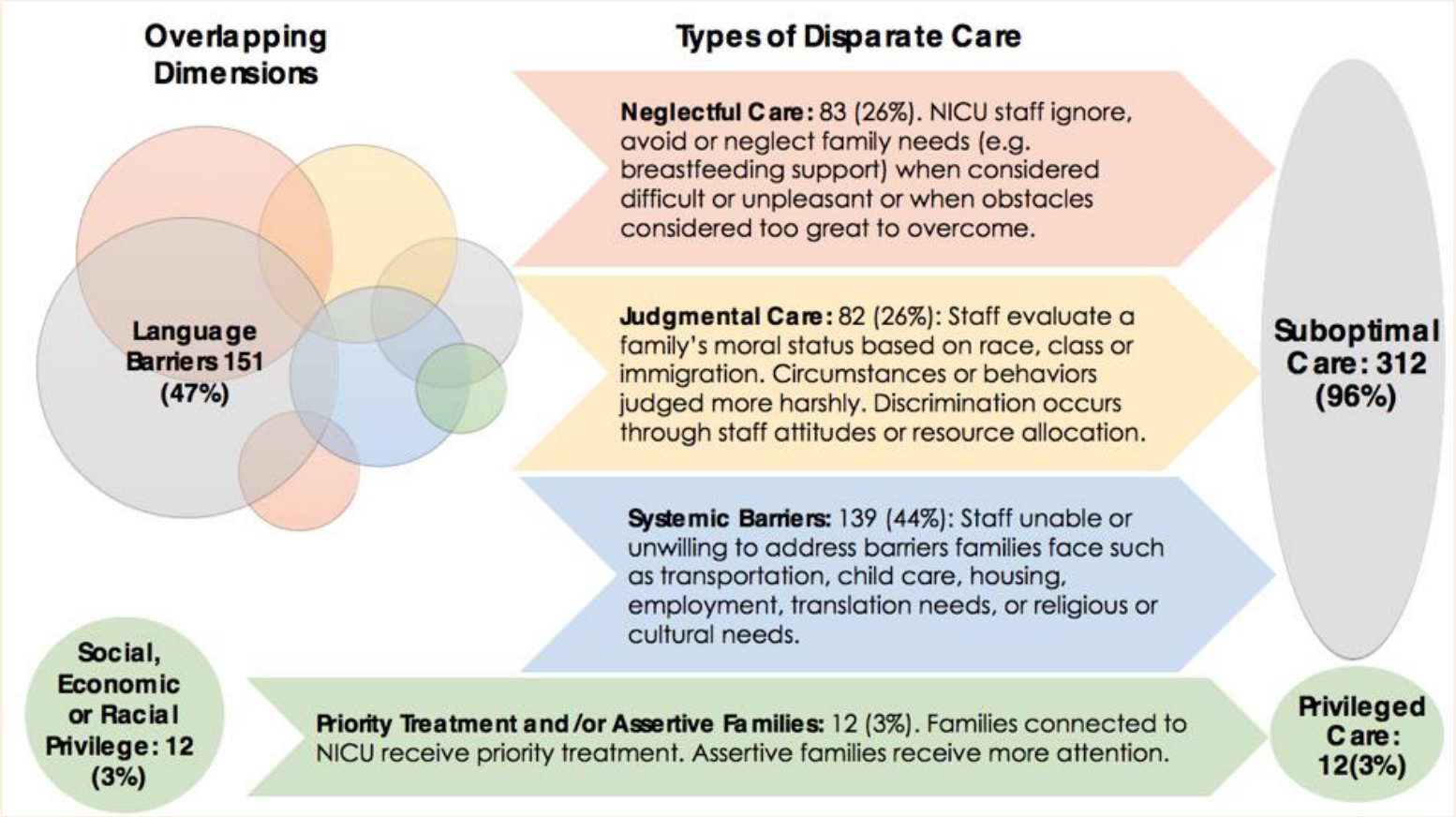
Overlapping Dimensions
Types of Disparate Care
Language Barriers 151 (47%)
Neglectful Care: 83 (26%). NICU staff ignore, avoid or neglect family needs (e.g. breastfeeding support) when considered difficult or unpleasant or when obstacles considered too great to overcome.
Judgmental Care: 82 (26%): Staff evaluate a family's moral status based on race, class or immigration. Circumstances or behaviors judged more harshly. Discrimination occurs through staff attitudes or resource allocation.
Systemic Barriers: 139 (44%): Staff unable or unwilling to address barriers families face such as transportation, child care, housing, employment, translation needs, or religious or cultural needs.
Suboptimal Care: 312 (96%)
Social, Economic or Racial Privilege: 12 (3%)
Priority Treatment and /or Assertive Families: 12 (3%). Families connected to NICU receive priority treatment. Assertive families receive more attention.
Privileged Care: 12(3%)

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Families in Action

- ✓ Conducted in-person group interviews with graduate NICU families
- ✓ Phone interviews with Latino families, in Spanish, transcribed and translated conversations
- ✓ Discussed measures selection through a modified Delphi method (twice!)*

- ✓ Reshaping the concept of "Family"
- ✓ Peers offer "therapeutical" support
- ✓ Needs of families are not reflected in current practices, goals and priorities of NICUs

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Our Publications!

Research Article

Former NICU Families Describe Gaps in Family-Centered Care

Krista Sigurdson[1], Jochen Profit[1], Ravi Dhurjati[1], Christine Morton[1], Melissa Scala[1], Lelis Vernon[2], Ashley Randolph[3], Jessica T. Phan[4], and Linda S. Franck[5]

Qualitative Health Research
1–15

DOI: 10.1177/1049732320912897
journals.sagepub.com/home/qhr
SAGE

Abstract

Care and outcomes of infants admitted to neonatal intensive care vary and differences in family-centered care may contribute. The objective of this study was to understand families' experiences of neonatal care within a framework of family-centered care. We conducted focus groups and interviews with 18 family members whose infants were cared for in California neonatal intensive care units (NICUs) using a grounded theory approach and centering the accounts of families of color and/or of low socioeconomic status. Families identified the following challenges that indicated a gap in mutual trust and power sharing: conflict with or lack of knowledge about social work; staff judgment of, or unwillingness to address barriers to family presence at bedside; need for nurse continuity and meaningful relationship with nurses and inconsistent access to translation services. These unmet needs for partnership in care or support were particularly experienced by parents of color or of low socioeconomic status.

Keywords

family-centered care; neonatal care; quality-of-care; grounded theory; patient-and-family engaged research; California; qualitative

A growing body of literature documents parents' critical role in promoting the health outcomes of low birthweight and preterm infants and a variety of models have been promoted toward that end (Franck & O'Brien, 2019). Historically, families were not permitted in the neonatal intensive care unit (NICU) or were only permitted on a limited schedule as "visitors" (White et al., 2013). Family-centered care, as an approach to NICU care, recognizes the strengths and needs of a patient's family and their important role in promoting recovery from illness and long-term health outcomes (Franck & O'Brien, 2019).

The origins of family-centered care can be traced back to British children's hospitals in the 1950s when nurses began to involve parents in the care of their hospitalized children (Jolley & Shields, 2009). The approach came to influence care in the United States over the 1980s, as families gradually came to be seen as active care partners of their children (Brewer et al., 1989). Family-centered care, consisting of interrelated principles and practices that recognize the central importance of family members in an individual's health and well-being, has since been widely applied across the lifespan and in various health care settings (Davidson et al., 2017; Johnson, 2000). It is now understood under the larger umbrella concept of "patient- and family-centered care" in that the principles of working *with* patients and families (rather than doing "to" or "for" them) can be applied to any care setting (Institute for Patient- and Family-Centered Care, 2020). For the purposes of this project involving parents of former NICU patients, we use the term "family-centered care" throughout.

Models of care that explicitly involve families are now considered best practice in the NICU and the implementation of family-centered care promotes mutual respect and shared decision-making between clinicians and families, ensuring timely and quality psychosocial supports and hospital resources that facilitate family well-being and involvement (Committee on Hospital Care and Institute for Patient- and Family-Centered Care, 2012; Franck & O'Brien, 2019). Family-centered care also includes direct care delivered by families to their infants,

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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[1,2,3] · Christine Morton[4] · Briana Mitchell[1,2] · Jochen Profit[1,2]

Received: 18 July 2017 / Revised: 29 December 2017 / Accepted: 3 January 2018

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 (324) were from a sample of RNs ($n = 114$, 35%), MDs ($n = 109$, 34%), NNPs ($n = 55$, 17%), RN other ($n = 4$, 1%), clinical 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%) race; 41 (13%) SES; 28 (8%) drug use; 18 (5%) immigration status or nationality; 16 (4%) sexual orientation or family status; 14 (4%) gender; 10 (3%) 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 care.

Introduction

Quality-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 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 factors such as social support networks 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. However, little is known regarding the interactional and systemic factors that contribute to disparities in care delivery. The

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

✉ Krista Sigurdson
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2 California Perinatal Quality Care Collaborative, Palo Alto, CA, USA
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4 California Maternal Quality Care Collaborative, Palo Alto, CA, USA

Published online: 05 April 2018

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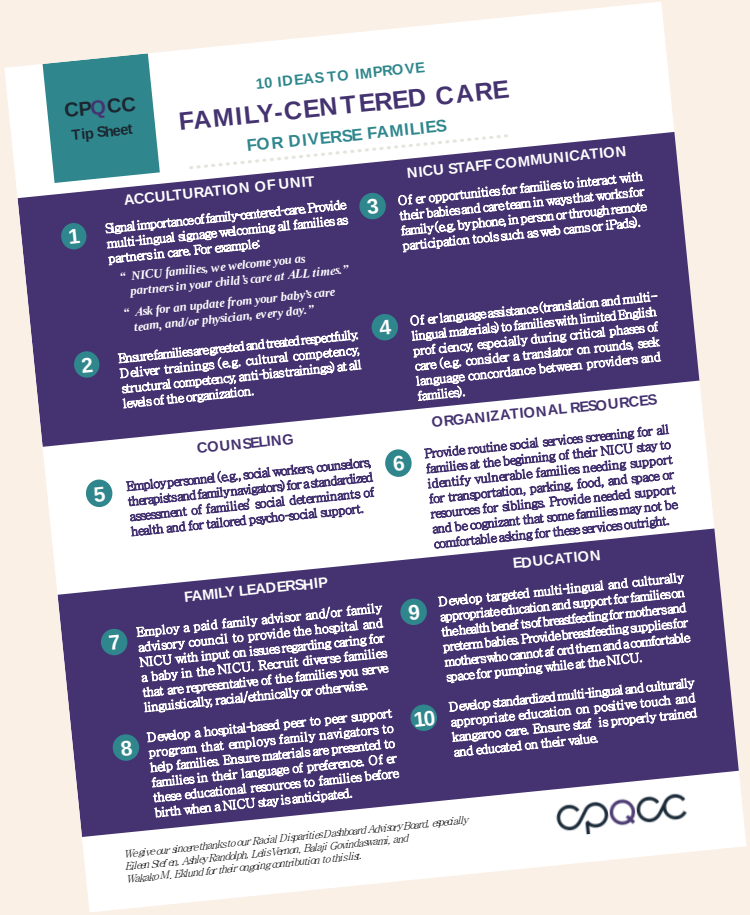
Creating Tools to Address Disparities



CPQCC Tip Sheet

10 IDEAS TO IMPROVE

FAMILY-CENTERED CARE

FOR DIVERSE FAMILIES

ACCULTURATION OF UNIT

1. Signal importance of family-centered care. Provide multi-lingual signage welcoming all families as partners in care. For example:
   - *"NICU families, we welcome you as partners in your child's care at ALL times."*
   - *"Ask for an update from your baby's care team, and/or physician, every day."*
2. Ensure families are greeted and treated respectfully. Deliver trainings (e.g. cultural competency, structural competency, anti-bias trainings) at all levels of the organization.

NICU STAFF COMMUNICATION

3. Offer opportunities for families to interact with their babies and care team in ways that works for family (e.g. by phone, in person or through remote participation tools such as web cams or iPads).
4. Offer language assistance (translation and multi-lingual materials) to families with limited English proficiency, especially during critical phases of care (e.g. consider a translator on rounds, seek language concordance between providers and families).

COUNSELING

5. Employ personnel (e.g., social workers, counselors, therapists and family navigators) for a standardized assessment of families' social determinants of health and for tailored psycho-social support.

ORGANIZATIONAL RESOURCES

6. Provide routine social services screening for all families at the beginning of their NICU stay to identify vulnerable families needing support for transportation, parking, food, and space or resources for siblings. Provide needed support and be cognizant that some families may not be comfortable asking for these services outright.

FAMILY LEADERSHIP

7. Employ a paid family advisor and/or family advisory council to provide the hospital and NICU with input on issues regarding caring for a baby in the NICU. Recruit diverse families that are representative of the families you serve linguistically, racial/ethnically or otherwise.
8. Develop a hospital-based peer to peer support program that employs family navigators to help families. Ensure materials are presented to families in their language of preference. Offer these educational resources to families before birth when a NICU stay is anticipated.

EDUCATION

9. Develop targeted multi-lingual and culturally appropriate education and support for families on the health benefits of breastfeeding for mothers and preterm babies. Provide breastfeeding supplies for mothers who cannot afford them and a comfortable space for pumping while at the NICU.
10. Develop standardized multi-lingual and culturally appropriate education on positive touch and kangaroo care. Ensure staff is properly trained and educated on their value.

We give our sincere thanks to our Racial Disparities Dashboard Advisory Board, especially Eileen Stefen, Ashley Randolph, Lelis Vernon, Balaji Govindaswami, and Wakako M. Eklund for their ongoing contribution to this list.

cpqcc

- Concrete ideas, with examples!
- These tips were born out of research, (not just observational assessments)
- Diverse families co-authored them
- These tips are expandable and adaptable

Next Steps:

- Re-launch!
- Video presentation!
- Potential expansion of themes
-

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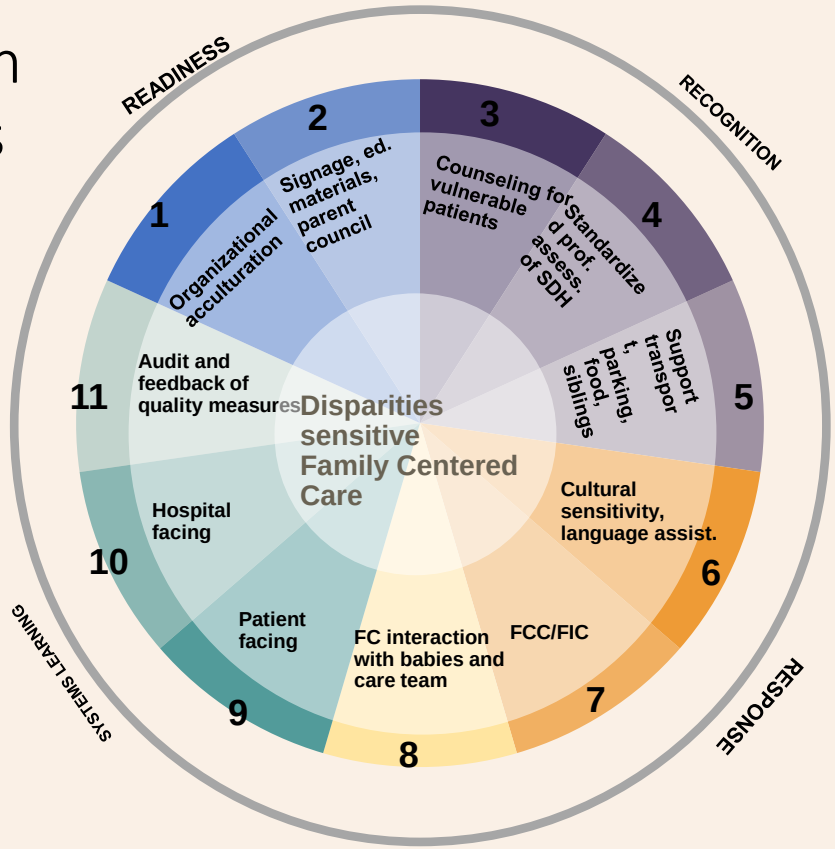
Action ideas



How can we address disparities in NICU care?

- CHANGING THE CULTURE OF CARE DELIVERY IN THE NICU
- CREATING A DISAPRITIES SENSITIVE FCC NICU

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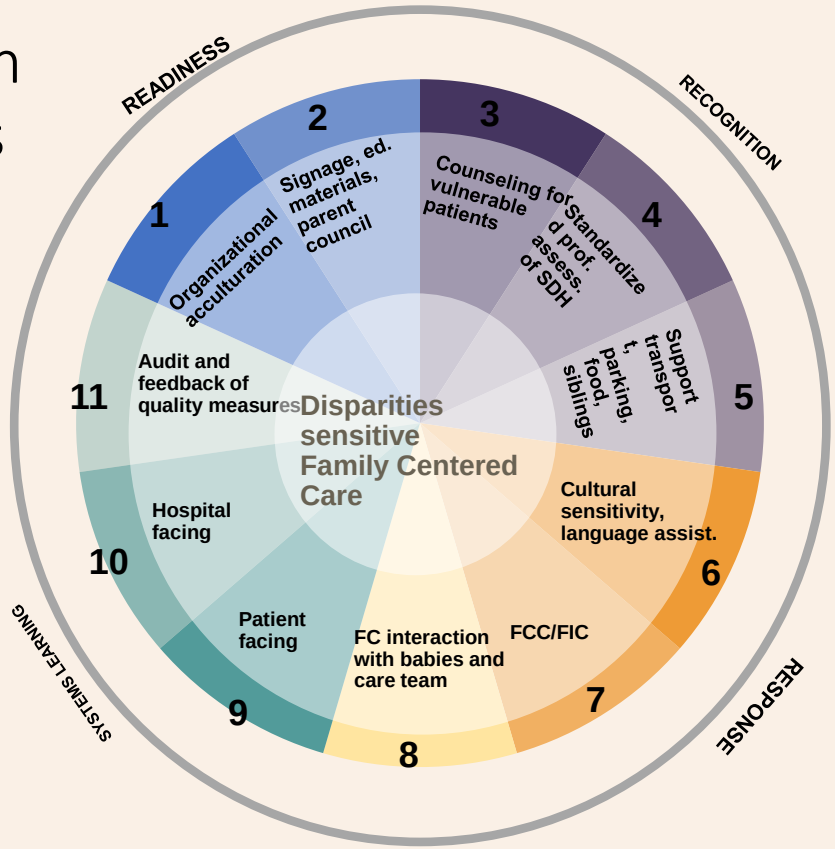
Action ideas



Organizational acculturation to address the diverse population the hospital serves

Signage, Identification (security check) and education materials, *"In this NICU, you are welcomed as a partner in your child's care at ALL times."*

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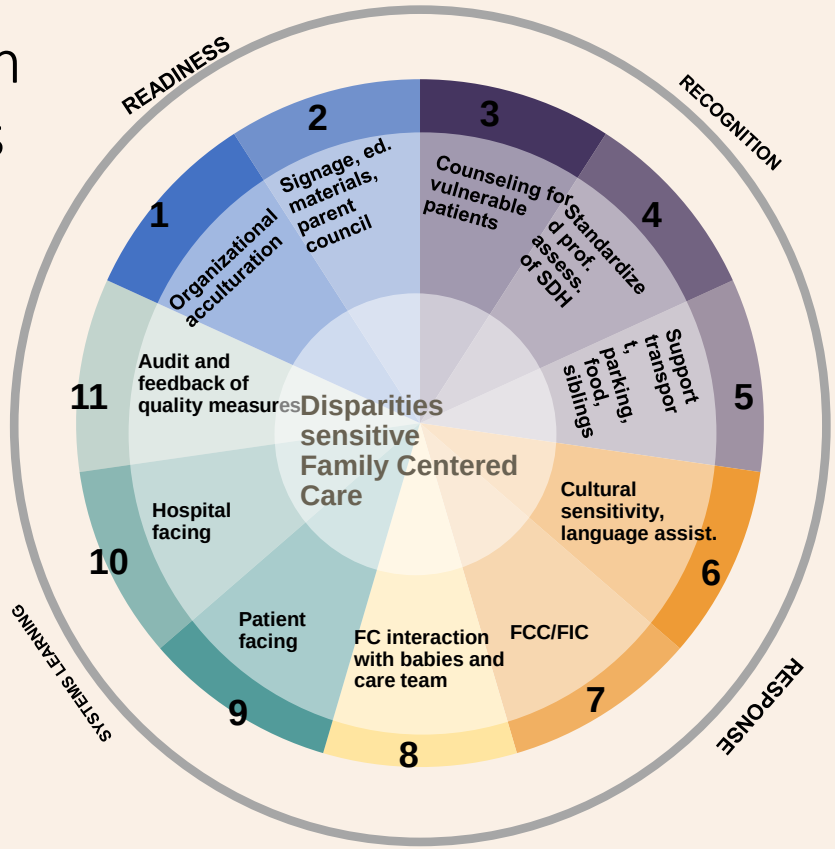
Action ideas



Counseling available to address vulnerable patients' needs

Professional and standardized assessment of SDH and psycho-social support

Support for transportation, parking, food, and siblings

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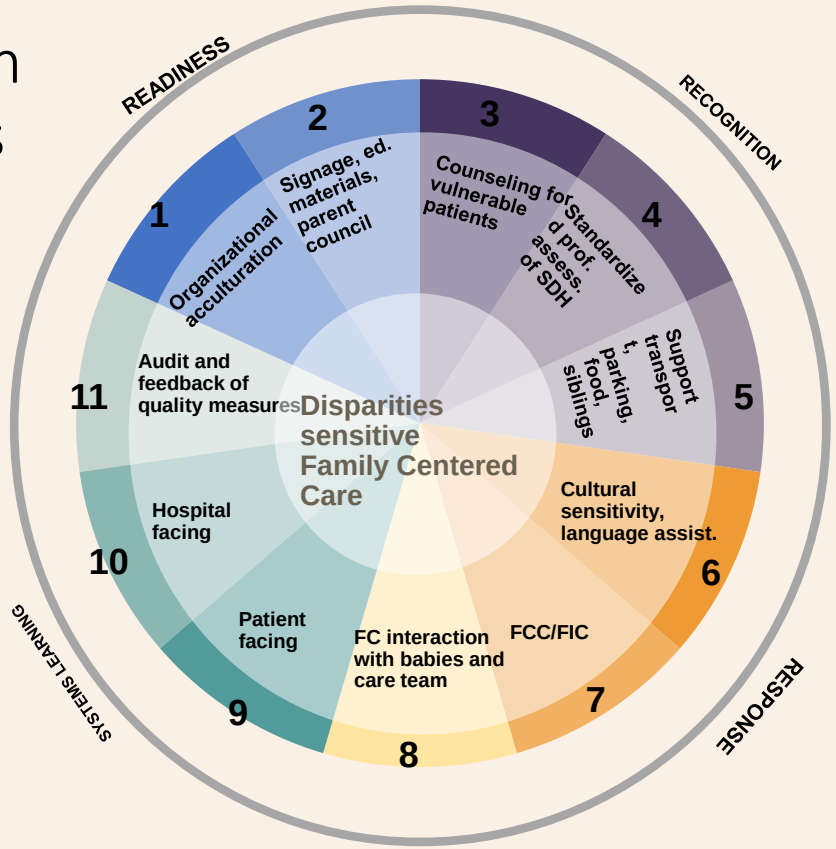
Action ideas



FCC or Family Integrated Care

- **Targeted standardized breastfeeding/skin-to-skin education**
- **Language concordance**

Cultural sensitivity, language assistance, structural competency, anti-bias training

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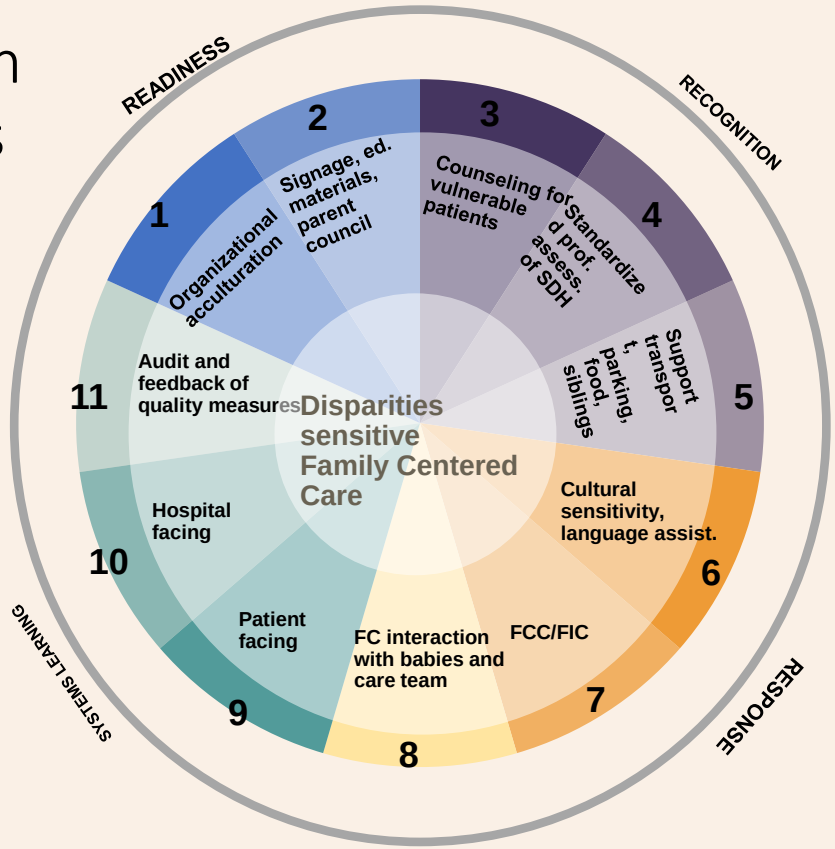
Action ideas



Patient Facing: Peer-to-Peer Support Program

Hospital Facing: Family Advisor and/or Family Advisory Council

Audit and feedback of quality measures by race/ethnicity/language

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Measuring FCC
Why, how, who and what what will it impact?

FAMILY PRESENCE IN THE NICU

- Frequency families present or not present at the bedside

PARTICIPATION IN HANDS-ON CARE

- Days to kangaroo care
- Frequency of Kangaroo care
- Days to Kangaroo by two family members

SUPPORT FOR BREASTFEEDING

- availability
- Time to first lactation consult
- **Time to priming with oral colostrum**

NEEDS ASSESSMENT

- NICU social worker availability
- Time to social worker contact
- Delayed social worker encounter
- Frequency of social worker contact

COMMUNICATING WITH FAMILIES

- Frequency of updates to families by MD/NNP/RN
- Frequency of updates to families with limited English proficiency by MD/NNP/RN
- Provision of interpreter services
- **Family Advisory Council**

COLLABORATING WITH FAMILIES

- Availability of paid family advocate

CARE COORDINATION

- Post-discharge care coordination
- **Continuity of care by RN**
- **Continuity of care by MD**

Stanford MEDICINE

california perinatal quality care collaborative CPQCC

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The FPQC, our Family Initiative and my role as Family Leader

”We are never the same after we go through a NICU experience”

Universal need
Very Frequent
Frequent

- Need for Orientation meeting/call
- Need a road Map once admitted
- Orientation to NICU admission can be done upon admission (when unforeseeable) by a nurse, or video for moms in L&D, or app and brochure, make sure dads get it

- Unexpected admission to NICU
- Not knowing anybody with a previous NICU experience
- No valid source of information other than RNs and MDs
- Dad is first contact person, gatekeeper of information
- Dads are information holders
- Dads are in “fight or flight” mode
- Dads are great assets if given a role, place and time
- Counseling is crucial and non-existent
- Families don’t know which activities they can be included in
- Open Bay exposes families to see a lot
- Mothers needs privacy in open bay setting to pump
- Open bay settings can be loud
- Open bay allow for interaction with other families
- Private rooms offer privacy, pumping, S2S
- Staff has false sense of dads security
- A lot of information at once
- Importance of calling baby by name
- Open bay unit enables friendship with neighboring families
- Unable to see baby for a # of days after delivery
- Primary nurse is crucial to develop trust
- Learning happened outside the NICU
- Lactations gives mom a sense of purpose
- Family presence as support network
- Volunteer work group was crucial support
- Peer-to-peer provides support other than medical
- Felt embarrassed to ask questions
- S2S gives first “feeling as a parent”
- Cameras are great to see baby
- Cameras
- Nurses are biggest obstacle for S2S
- NICU is mother-centered, dadas left aside
- Staff needs to make sure dads are understand
- Birth defects get neglected

- There should be standard way to communicate with families
- Inconsistency of information between RNs and MDs

- Chaplain as support person
- Nurses get to know baby better than family
- Primary nursing much preferred
- Trust building with RNs
- MDs and RNs are not on the same page as to S2S
- There needs to be a=more training for RNs for S2S
- Nurses have an agenda, families feel left aside
- RNs can act as liaisons for families
- Visiting hours are a challenge
- Staff should offer specific activities for family participation

Units should have consistency of practices throughout the year (S2S/May)

- Surveys do not reflect the families challenges or areas of improvements
- Family room for families is a plus
- Rotation of nurses causes stress, uncertainty, lack if trust
- Recliners a plus for S2S

- CPR classes should be mandatory
- Unprepared for d/c
- Felt like thrown to the wolves
- D/c was abrupt
- Rooming in needs to be accompanied by medical training
- Family felt baby/ies was/ere unprepared
- Overwhelmed with appointments
- Respite care much needed for birth defects population
- Post partum goes untreated
- Didn’t know what to do with baby
- Need for case manager
- It takes time to feel comfortable at home, feel like a parent
- Life after NICU as important (or even more important) than NICU itself

Antenatal → Admission → Discharge

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Health Literacy

Antenatal consult

- Need for Orientation meeting/call
- Need a road Map once admitted
- Orientation to NICU admission can be done upon admission (when unforeseeable) by a nurse, or video for moms in L&D, or app and brochure, make sure dads get it

(During NICU stay)

- Families turn to internet for information
- Medical cards as information source
- Rounding can be challenging with schedule conflicts
- Multiple ways of receiving information
- Information needs to be given (repeated) at different times

D/C Readiness

- CPR classes should be mandatory
- Unprepared for d/c
- Felt like thrown to the wolves
- D/c was abrupt
- Rooming in needs to be accompanied by medical training
- Family felt baby/ies was/ere unprepared
- Overwhelmed with appointments
- Respite care much needed for birth defects population
- Didn't know what to do with baby
- Need for case manager

Dads

- First person of contact
- Dads are first information holder for moms and family
- Dads is not properly updated at admission
- Dads participation would be great help for moms in NICU
- Dads have NICU baby + spouse + NICU emotional toll + jobs + household
- Dads are in "flight or flight" mode
- Dads receive a lot of information at once
- NICU is mother-centered, dads feel left aside

Communicating with Families

- Use of technology to put enable families to participate in virtual round/care conferences
- Cameras give feeling of "being there" (less stress)
- Keep an eye on practices
- Birth defects get neglected (overall poor inclusion in information sharing)
- There should be standard way to communicate with families (*)
- Inconsistency of information between RNs and MDs delivered to families
- Surveys do not reflect the families' needs and/or areas of improvements
- Specialists should be included in roundings
- Proper FC language must be used to communicate health updates to family

NICU Design

- Open bay unit enables friendship with neighboring families
- Private rooms offer privacy, pumping, S2S
- Open Bay exposes families to "see a lot"
- Mothers needs privacy in open bay setting to pump
- Open bay settings can be loud (&"chaotic")
- Open bay allows for interaction with other families
- Visiting hours are a challenge
- Family room for families (siblings, conferences etc) is a plus

Primary Nursing

- Preferred nursing care
- Trust building with RNs
- Confidence building for families
- RNs as family liaisons
- Rotation of nurses causes stress, uncertainty, lack of trust

Lactation

- Gives mom a sense of purpose
- Proper equipment and space needs to be provided
- Proper, timely education needed for moms (especially vulnerable populations) (*)
- Improve communication about MOM shortage for baby

SWs / Counseling / Support

- Family presence as support network
- Volunteer work group was crucial support
- Peer-to-peer provides support other than medical
- Chaplain as support person
- Post partum goes untreated
- Dads need support just as much
- It takes time to feel comfortable at home, feel like a parent
- Life after NICU as important (or even more important) than NICU itself

S2S

- "First time I felt as a parent"
- Units should have consistency of practices throughout the year (S2S/May)
- RNs are biggest obstacle
- RNs competency as barrier
- Recliners a plus for S2S
- Time to first hold varies (*)

My 2 cents

- Adaptability is key
- Mentorship is also key
- Bringing families up to speed is very important so project's goals are observed and survey responses are not skewed
- Do not be afraid to look for diverse families!
- Provide different venues for families to communicate with PQC, to continue being engaged, and to contribute when able and available
- Looks for p/f strengths, build on them (professional/experiential)
- Ask the same question to all p/f partners, their perspectives vary!
- Timelines are relevant for the veracity of testimony: unit variability of culture of care
- Don't be afraid to "loop back" and look for new answers to existing questions

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Thank you!

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LelisBVernon

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Chat Box Question

In the chat box: Share one practical takeaway from Lelis' talk that you think you can use in your NICU

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Importance of Communication with Non-English Proficient Families in the NICU

Gaby Cordova Ramos, MD
Neonatologist
Boston Medical Center

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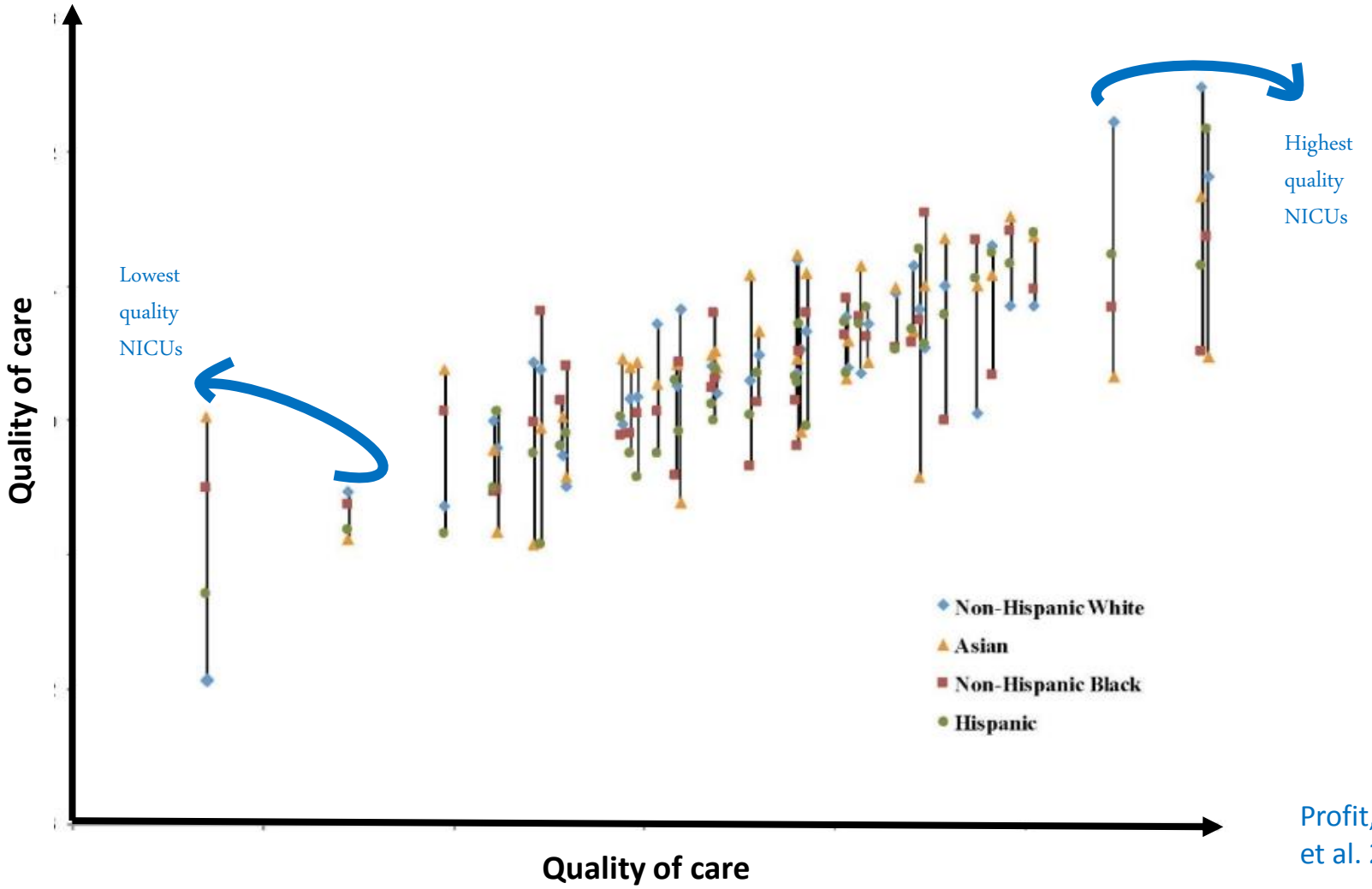
Neonatal Quality Improvement Collaborative of Massachusetts

Language-based inequity in the NICU: we can do better

Gaby Cordova

Sept 2020


Caribbean Sea
Nicaragua
Costa Rica
Panama
Caracas
Venezuela
Bogota
Calio
Colombia
Guyana
French Guiana
Suriname
STATE OF RORAIMA
STATE OF AMAPA
Quito
Ecuador
STATE OF AMAZONAS
STATE OF PARA
STATE OF MARANHÃO
STATE OF CEARÁ
STATE OF PIAUÍ
STATE OF PARAÍBA
Brazil
STATE OF ACRE
STATE OF ALAGOAS
Peru
Lima District
STATE OF RONDÔNIA
STATE OF TOCANTINS
STATE OF MATO GROSSO
STATE OF BAHIA
STATE OF GOIÁS
Bolivia
STATE OF MINAS GERAIS
STATE OF MATO GROSSO DO SUL
STATE OF SÃO PAULO
STATE OF RIO DE JANEIRO
Paraguay
Asunción
STATE OF PARANÁ
Chile
STATE OF RIO GRANDE DO SUL
Córdoba
Uruguay
Santiago
Buenos Aires
Argentina
Montevideo
Google



Profit, Zupancic et al. 2013


DO YOU SPEAK ENGLISH?

71 million (21.5 %) people speak a language other than English at home

25.7 million (9%) people speak English less than “very well”

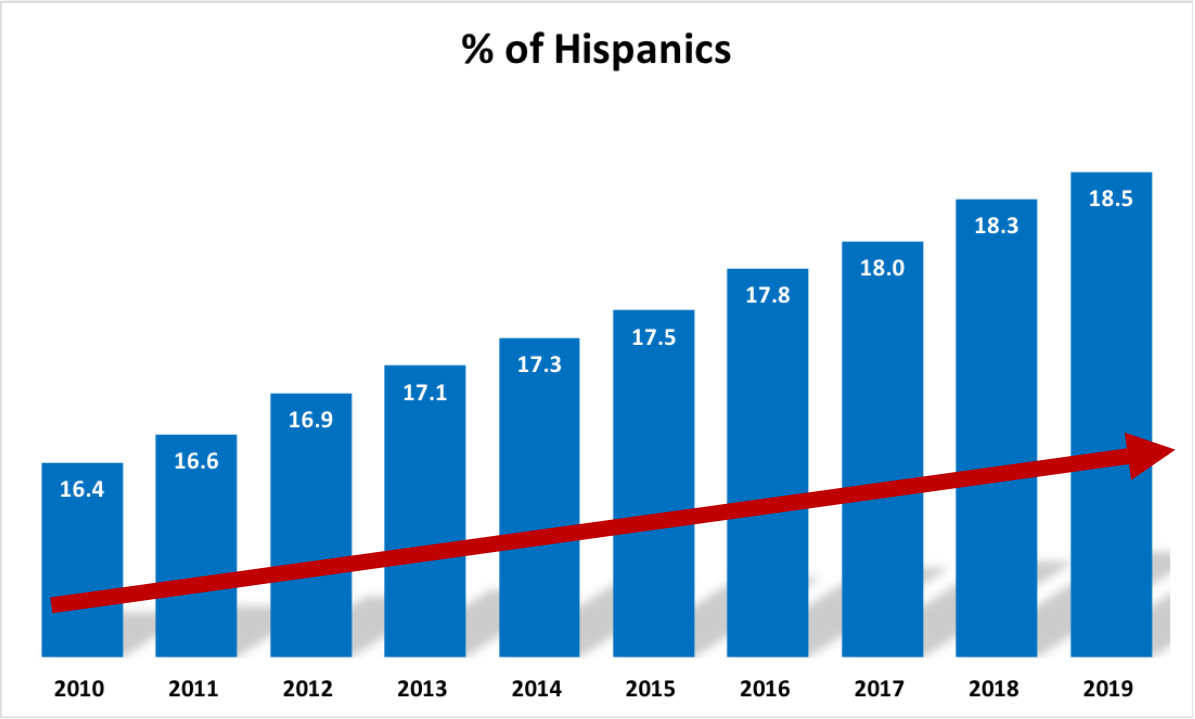
Limited English Proficiency

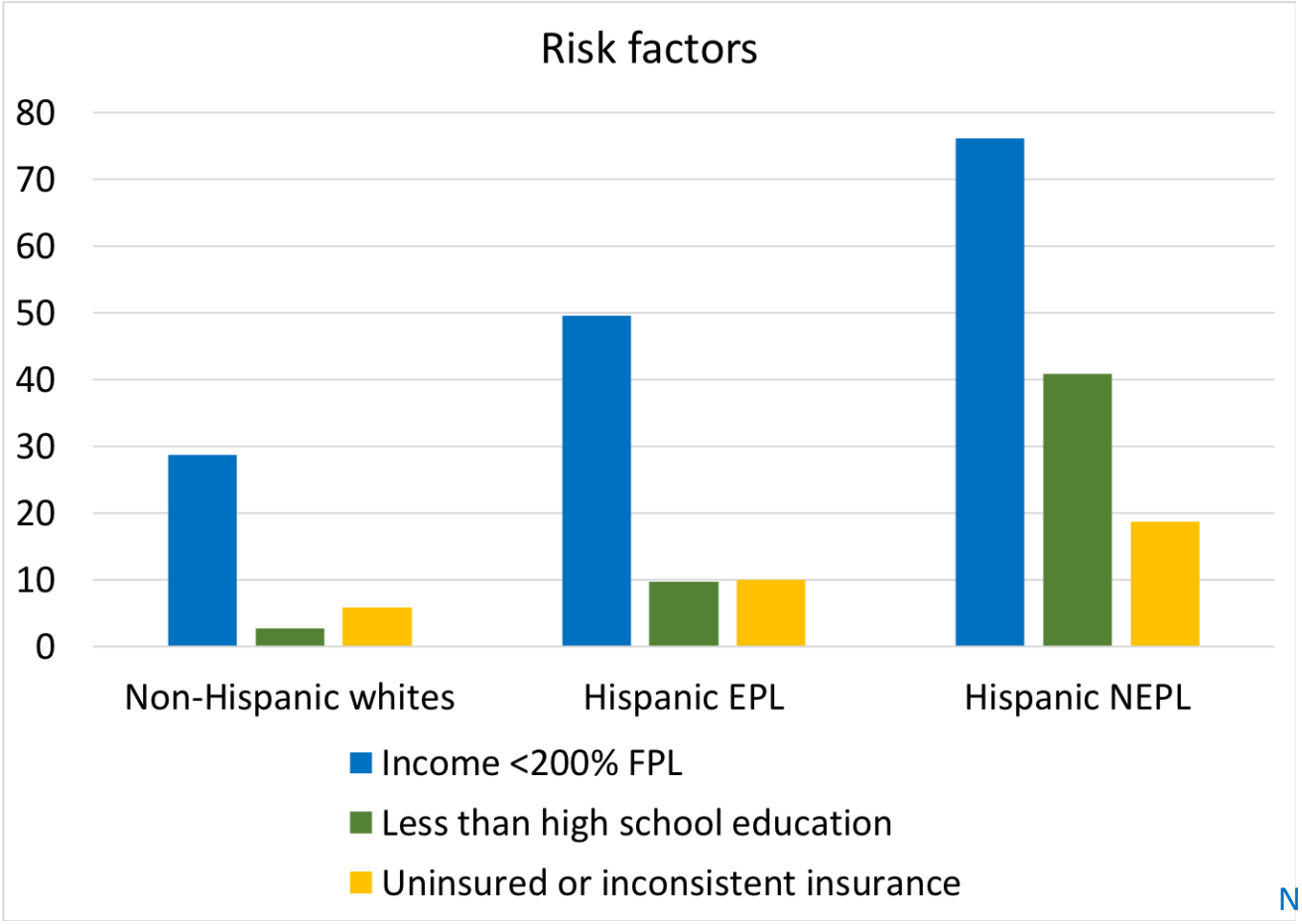
1 in 10 US adults of childbearing age have LEP

US Census Bureau. American Community Survey 2018

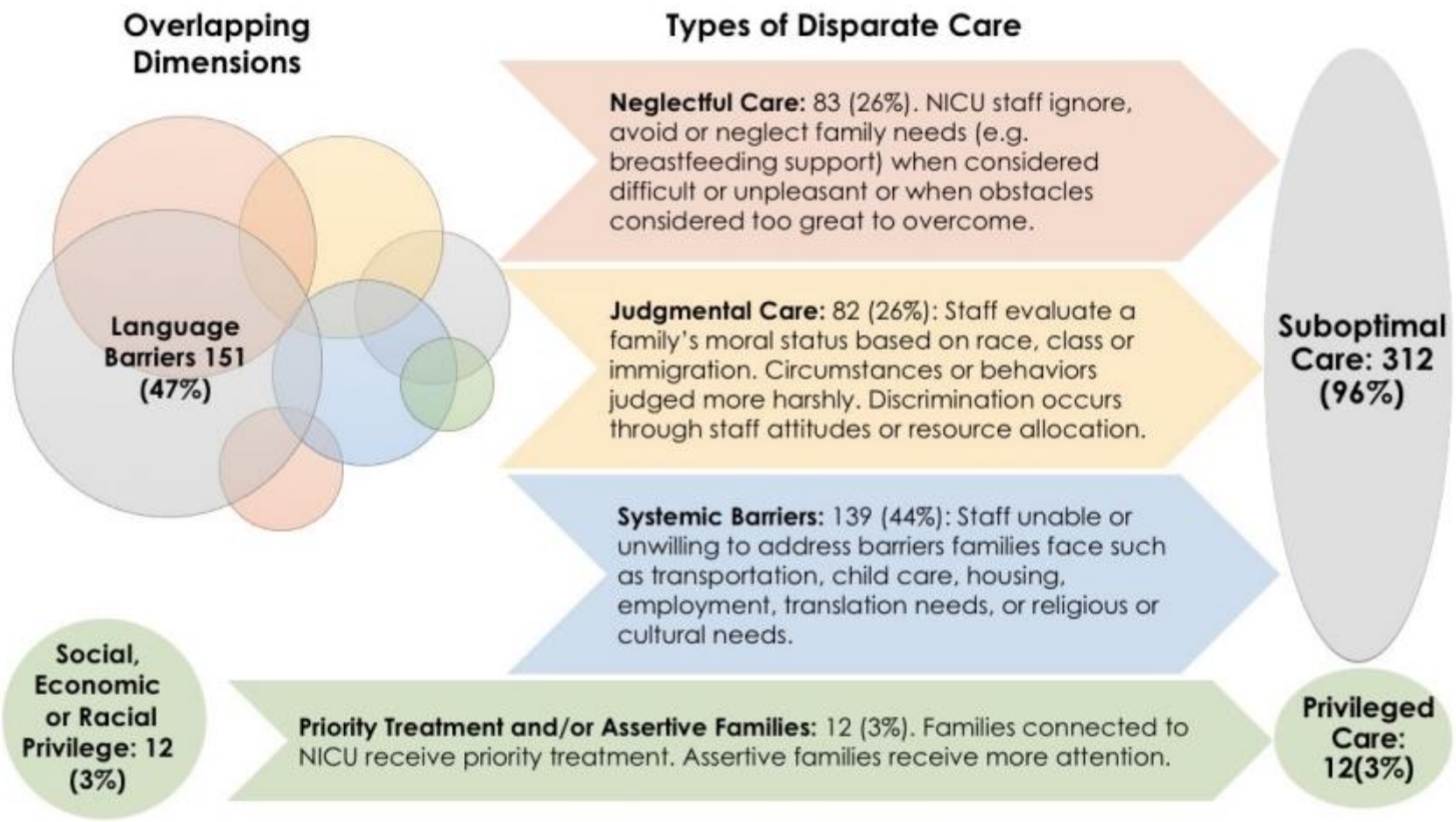
US Hispanic population growth

65% of the LEP population speaks Spanish

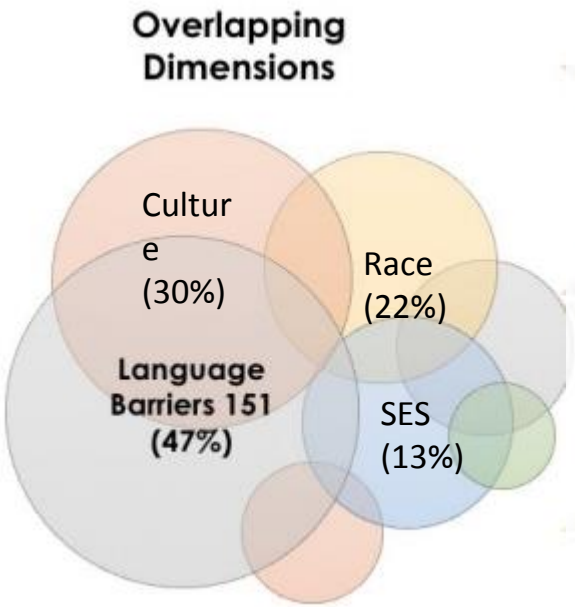




NSCH 2016-2018



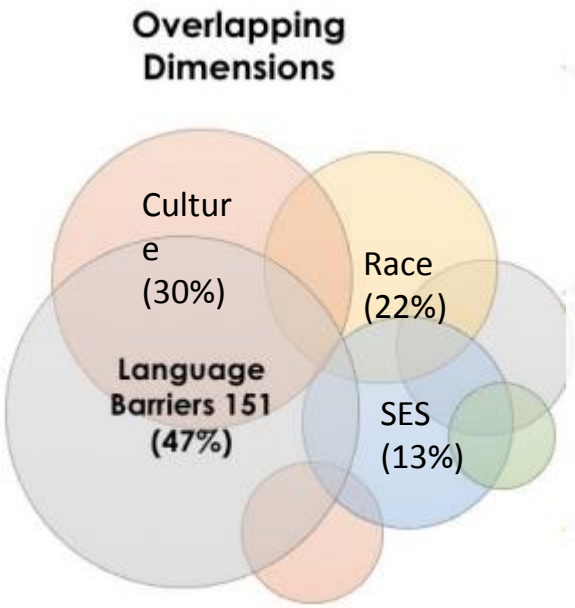
Sigurdson et al. 2018



Dimensions of difference in accounts of disparities

Family factors that render families vulnerable to suboptimal care

Sigurdson et al. 2018

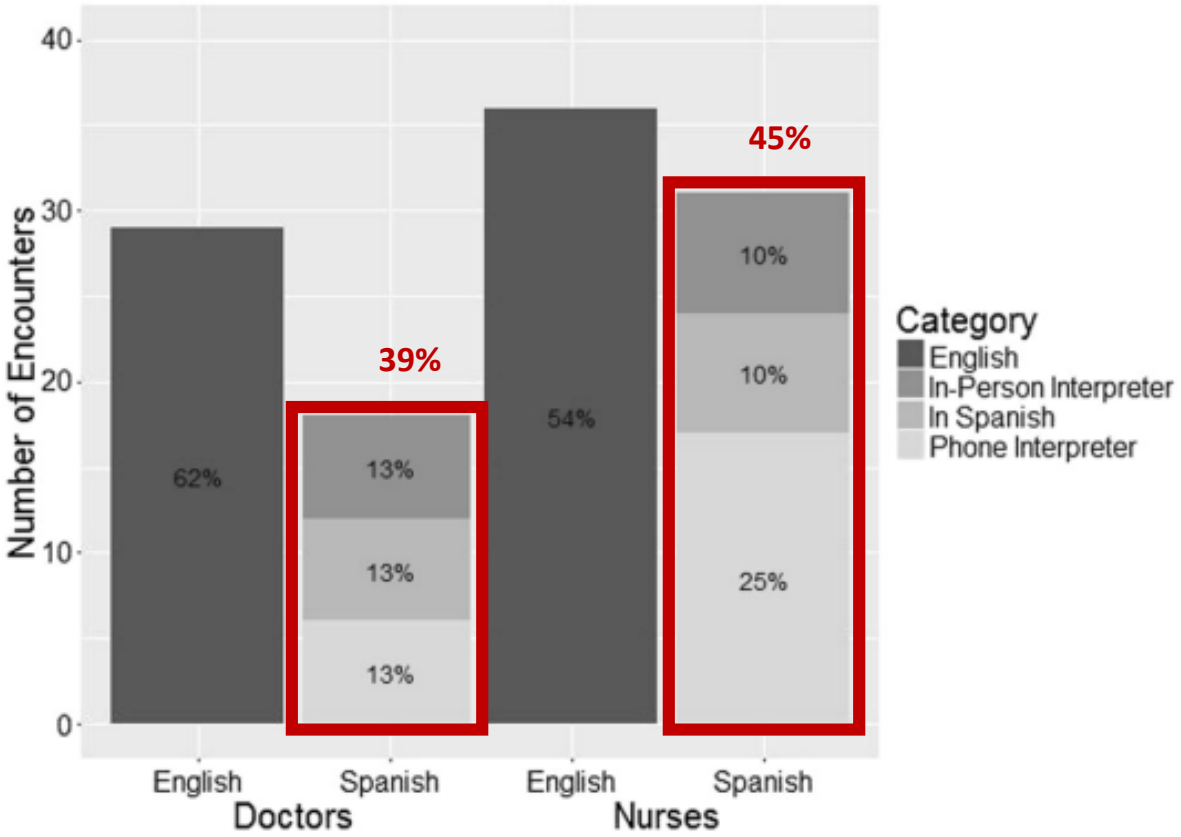


Language barriers may worsen each type of disparate care

Families who do not speak English may experience feelings of **isolation, delayed or missed opportunities** to be involved in their infant's care (skin to skin, breastfeeding, learning about their infant) and **less social and emotional support**.

Sigurdson et al. 2018

Spanish speaking parents are 4 times more likely to **incorrectly identify their infant's diagnosis** than English speaking parents

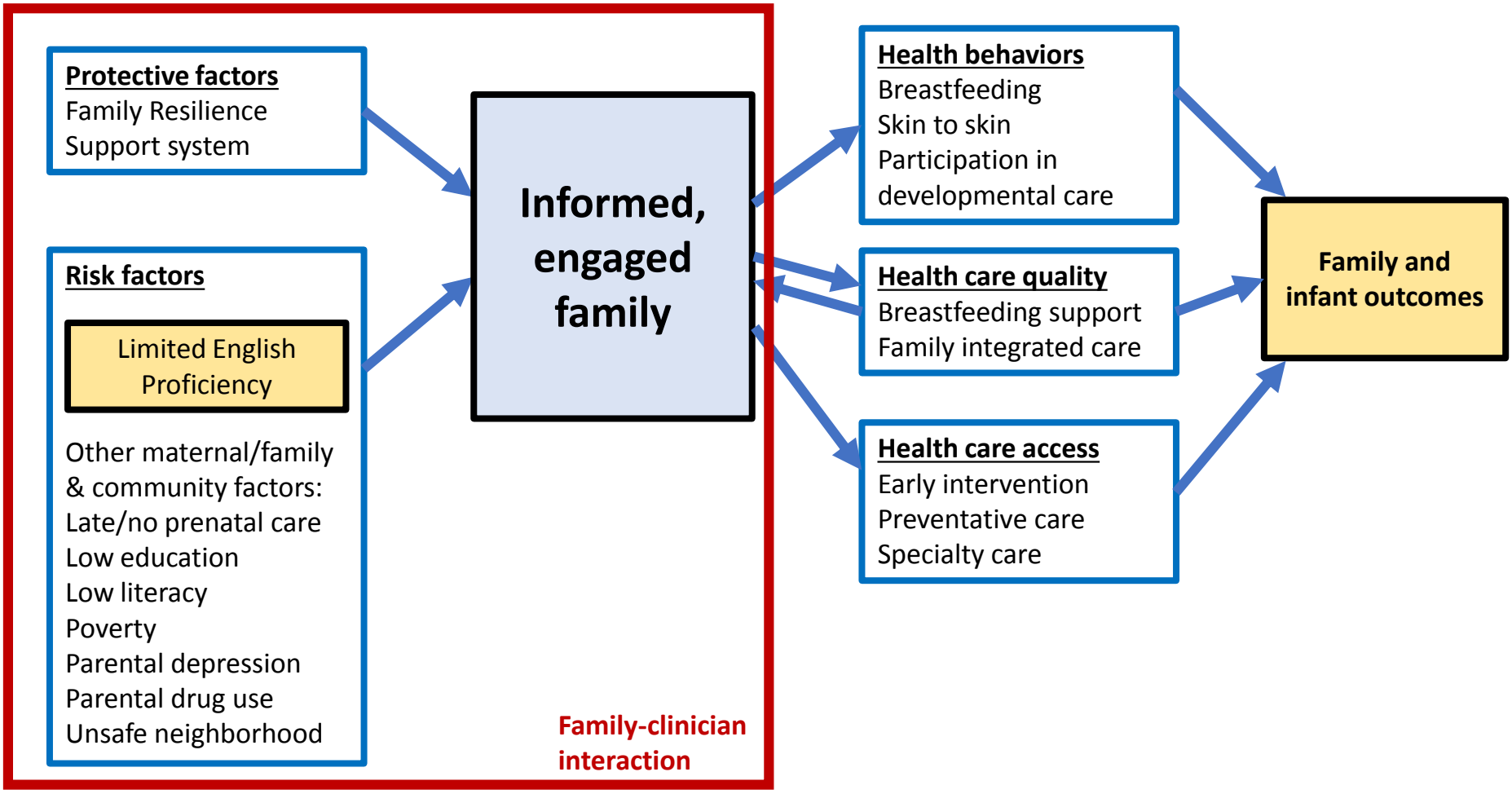


Palau et al. 2019

What would have improved your baby's hospitalization?

Circumvention of standard interpretation	"I can more or less understand what the nurses are saying in English but I can not respond." "It is good to know there are in-person interpreters available if I am still confused."
Inadequacy of phone interpreters	"We had one phone interpreter that didn't know Spanish well that we had difficulty understanding." "I was trying to explain myself and the interpreter kept telling me to use short phrases."
Basic facts regarding care not communicated	"If I had been told earlier that I could stay overnight with my baby, I could have been here for all feedings and maybe we would be home."
Written materials offered in English	"They gave us books and a welcome package but it was all in English."

Palau et al. 2019


Protective factors
Family Resilience
Support system
Risk factors
Limited English Proficiency
Other maternal/family & community factors:
Late/no prenatal care
Low education
Low literacy
Poverty
Parental depression
Parental drug use
Unsafe neighborhood
Informed, engaged family
Family-clinician interaction
Health behaviors
Breastfeeding
Skin to skin
Participation in developmental care
Health care quality
Breastfeeding support
Family integrated care
Health care access
Early intervention
Preventative care
Specialty care
Family and infant outcomes

We can do better…PSDA cycles?

- Reduce barriers to use high quality language assistance for LEP families
  1. Make language services access information available and visible: in work phones, print out in work stations
  2. Train staff to provide care to LEP families more effectively.
     - Advise against "getting by" with basic language skills.
     - "Do you have any questions?" → "What questions do you have?"
     - "I've just said a lot of things. To make sure I did a good job and explained things clearly, can you describe to me . . . ?"

Checklist: Considerations in Planning for Possible Translation and Interpretation Needs in the Clinical Setting

Planning

- ☐ Do I know what this patient needs to understand and what they need to take away from this encounter?
- ☐ Is the interpreter prepared with enough information?
- ☐ Have I planned the best way to focus on the patient?

The Patient Encounter

- ☐ Am I focused on the patient (making eye contact), not the interpreter or family member?
- ☐ Am I remembering the teach-back strategy and not depending on head nods, which often mislead?

Reflection after the Patient Encounter

- ☐ What could I do to improve the next interaction with this patient or a similar patient?
- ☐ Have I made a note in the record to include the language and interpreting preferences of this patient?

We can do better…PSDA cycles?

- Translate written materials to most common languages

Quieres Empezar?

Preguntale a tu equipo de cuidado para más información.

Los bebés deben tener un minimo de 32 semanas de edad corregida para empezar el programa.

Los padres o personal a cargo de cuidar al bebé prometen hacer lo básico

Con mi corazón te amaré
Y protegeré del estrés.
Con mi boca hablaré de lo que siento.
Con palabras suaves
Y dulces canciones cada vez que te mire
Te demostraré que mi amor es real.

Con mis dedos apuntaré a los objetos que nombro
Y los contaré en grupos para comparar.
Con mis pies te llevaré afuera para explorar
Mientras jugamos y disfrutamos del aire libre.

Con mis ojos leeré mientras te muestro el mundo
A través de imágenes brillantes e historias en libros.
Estas son formas de asegurarme
Que tu cerebro está preparado
Para éxitos donde quiera que mires.

Esta es mi promesa que hago desde el día de tu nacimiento
Que estos conceptos básicos voy a hacer fielmente.
Porque mi trabajo es ayudarte a crecer feliz e inteligente
Comenzando ahora que tu vida es nueva.
Aprenderás que tu vida es una obra de arte.
Y que tú eres el artista a cargo.
Pero antes de decidir qué hacer con tu vida
Escucha ahora
Al ritmo
De mi corazón.

LTL Learners

Lenguaje a través de escuchar (LTL) Programa de aprendizaje en BIDMC

Beth Israel Lahey Health
Beth Israel Deaconess Medical Center

Brochure to invite parents to a reading program at BIDMC

We can do better…PSDA cycles?

- Measure language data and track quality metrics by LEP vs EP

    1. Confirm and document primary language of choice in every admission
    2. When you identify a family with LEP, encourage them to request an interpreter every time they need it
    3. Avoid stigma by framing questions regarding language in the context of the team's commitment to communicate in the best possible way

What is your preferred language?

1 [__] English → If English, end questions
2 [__] [Insert language 2]
3 [__] [Insert language 3]
4 [__] [Insert language 4]
5 [__] Other

1. How well do you speak English?

1 [__] Very well
2 [__] Well
3 [__] Not well
4 [__] Not at all

2. How well do you understand English?

1 [__] Very well
2 [__] Well
3 [__] Not well
4 [__] Not at all


Together, we can create a culture of equity in which excellent care is expected for families with language barriers as it is for all families
EQUALITY
EQUITY

Thinking about your unit, how often is the quality of communication with non-English speaking families different from English proficient families?

- Most of the time
- Frequently
- Often
- Rarely
- Never

Thinking about your unit, how often is the quality of communication with non-English speaking families different from English proficient families?

Most of the time

Frequently

Often

Rarely

Never

Thinking about your unit, how often is the quality of communication with non-English speaking families different from English proficient families?

Most of the time
Frequently
Often
Rarely
Never

Wrap Up Day 1

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Any Questions?

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Day 2

- Thank you to all of our speakers from today!
- Tomorrow we will reconvene at 1 pm for another exciting afternoon

Agenda- Day 2

Time	Topic
1:00	Welcome, Introductions, and Roll Call
1:10	Parent Testimonial
1:25	Massachusetts Department of Public Health: Approaches to Family Engagement in MA
1:55	Regulatory Updates
2:15	Introduction to Plan-Do-Study-Act (PDSA) Cycles
2:45	Wrap Up and Next Steps

Thank you!

Questions?

See you tomorrow from 1-3 pm!

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