

Fragile Infant Forums for Implementation of IFCDC Standards: Integrating Diversity, Equity, Inclusion, and Justice into the Care of Families in the NICU: A Call to Action

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Background:

Having a baby in the neonatal intensive care unit (NICU) is a stressful situation for most parents. While there is substantial evidence of the common stressors that families in the NICU face, of note, some families may face additional stressors if they belong to historically marginalized groups (2, 3). but significant racial/ethnic disparities persist. Neonatal disparities have their origin in a complex set of factors that include systemic racism and structural disadvantages endured by minority families, but differential quality of care in the neonatal intensive care unit (NICU). The NICU experience is a complex and often chaotic period for families as they try to navigate unfamiliar medical diagnoses, separation from their infant, and the transition to parenthood in a unique environment, as well as external concerns like managing the day-to-day needs of life outside of the NICU (1). While this is in no way an exhaustive list, evidence indicates that families that are racially or ethnically minoritized, identify as LGBTQ+, have a disability, or are affected by substance use disorder or teen pregnancy often face the unjust burden of having additional stressors imposed on them due to unconscious bias, racism, and stigma from staff and/or the result of discriminatory policies. Such bias and discrimination can lead to higher rates of health disparities, including both maternal and neonatal morbidity and mortality (3,4).

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Over the last few years, more attention has been given to the needs of diverse families and the importance of implementing strategies to dismantle health inequities to improve the health outcomes of infants and their families. Moreover, enacting interventions and policies rooted in diversity, equity, inclusion, and justice have been touted as the solution to addressing one of the most complex issues in the United States (5). Diversity, Equity, Inclusion, and Justice (DEIJ) is a conceptual framework of values that promote a culture of fair treatment and full participation of all people, including babies, parents, partners, family members, providers, caregivers, staff, leaders, and executives. (See Box 1 for definitions of DEIJ concepts)

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Preparing healthcare professionals to provide care rooted in DEIJ principles begins with understanding how health disparities often present for infants and families in the NICU. Recognizing that health disparities cannot be dismantled if we do not address the roots of health inequity and making recommendations for integrating DEIJ principles into the NICU care environment is essential. We offer examples by applying the Infant and Family-Centered Developmental Care (IFCDC) Standard on Systems Thinking (6).

Health Disparities in the NICU:

Health disparities exist at the intersection of social determinants of health and oppressive expressions such as bias, stigma, racism,

and discrimination, creating multiple barriers to receiving high-quality healthcare (7,8). According to the Centers for Disease Control and Prevention (CDC), “health disparities are inequitable and are directly related to the historical and current unequal distribution of social, political, economic, and environmental resources” (9). This issue extends beyond our social context into clinical care settings; emerging evidence suggests stark variation in the quality of NICU care delivery (4, 10).

Historically marginalized communities are largely affected by these variations and more often receive suboptimal care experiences and outcomes (4, 10, 11). For example, when we consider disparities in nutrition and infant feeding in the NICU, Black infants born with very low birth weight are less likely to receive human milk feedings during their NICU stay, including mother’s own milk and pasteurized donor human milk, regardless of the mother’s intent to breastfeed (12). Furthermore, disparities in human milk feeding in the NICU extend to other minoritized groups, including those with lower socioeconomic status (13). Despite established knowledge that breastfeeding should be encouraged of mothers receiving medication for opioid use disorder and have known health benefits for infants with prenatal opioid exposure (14), mothers in this population consistently report receiving little to no support regarding breastfeeding management in the NICU, often due to substance use stigma (15,16). Given what is known of the root of structural health inequities, these findings suggest that individual, provider level, and systemic, organizational unit, and hospital level factors play a key role in reducing such disparities in quality of care.

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Application of DEIJ in the NICU Context and Recommendations:

Key principles of the *Standards, Competencies, and Best Practices for Infant and Family-Centered Developmental Care in the Intensive Care Unit* underscore the importance of multi-level approaches to address social determinants of health and quality of NICU care, maintaining a commitment to DEIJ for all infants and families (See Box 1). The Infant and Family Centered Developmental Care (IFCDC) Consensus Committee has been using systems thinking to guide the implementation of IFCDC within the Intensive Care Unit (6) to move toward a more holistic, equity-focused standard of care. Integrating the DEIJ principles into a unit and beyond discharge requires time commitment and the challenge of confronting potential bias and stigma within us and our unit policies and practices (See Box 1).

Through systems thinking, specific attention should be given to the NICU environment’s overall culture and integrating DEIJ-related concepts into the unit culture. When considering the diversity of families we encounter daily, hospital and unit-based policies

should support an inclusive NICU environment. For example, hospital policies that do not consider the needs of working parents, parents with young children, or parents with mandated classes can further impede parental involvement in the care of infants. Regarding auditing measures of patient outcomes, hospitals and units can implement the practice of disaggregating data to identify racial, ethnic, and social inequities specific to their community, leading to targeted quality improvement efforts and clinical practice changes. Including other information regarding social determinants of health, screening may further assist us in targeting specific interventions.

Moreover, the staff and environment should welcome families into the care space, treating them as essential members of the infant care team. Fostering an open environment involves creating safety for all families by using inclusive language and asking families their preferred use of language and pronouns to describe who they are and the support of those who are important to them. Staff and providers can work with families to identify infant and familial unit strengths and develop care coordination that promotes secure attachment between parents and infants.

“Including parents on family support teams can help staff and providers create respectful partnerships, creating mutual respect and value for providers’ clinical expertise and expertise found within the lived experiences of families (14).”

Including parents on family support teams can help staff and providers create respectful partnerships, creating mutual respect and value for providers’ clinical expertise and expertise found within the lived experiences of families (14). Doing so can improve equitable care practices and foster a sense of belonging for families. Modeling these practices and teaching new clinicians the value of prioritizing health disparities and health equity can empower them to implement these practices much earlier in their careers as a normalized approach to dismantling antiracism, anti-discrimination, and anti-stigma in healthcare.

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Social justice advocacy must extend beyond the walls of individual NICUs to ensure that structural and institutional racism and discrimination are dismantled. At the local level, this begins with ensuring that our discharge and follow-up programs are evaluated for policies and other factors that might serve as barriers to access to care. Advocacy for policies that support and address social determinants of health are also crucial to the well-being of

Box 1. Application of DEIJ to the IFCDC Systems Thinking Standards

DEIJ Conceptual Definition	IFCDC Systems Thinking Standard	Systems Thinking-Based Questions to Consider
<p>Diversity is characterized as the representation or composition of various social identity groups, such as race, ethnicity, ability, gender, sexual orientation, neurodiversity, and beyond in a unit, organization, or community.</p>	<p><i>Standard 1, Systems Thinking:</i> The intensive care unit shall exhibit an infrastructure of leadership, mission, and a governance framework to guide the performance of the collaborative practice of IFCDC.</p>	<ul style="list-style-type: none"> · Are the baby and the family central to the mission, values, environment, practice, and care delivery? · Who are the members of the team? · Does the culture encourage open communication, relationship-building, respect and value for all individuals, and creative thinking? What are the strategies and evaluative metrics that you use to accomplish this?
<p>Promoting equity involves providing resources according to the need to help diverse populations achieve their highest state of health and function.</p>	<p><i>Standard 3, Systems Thinking:</i> The practice of IFCDC in the intensive care unit shall be based on evidence that is ethical, safe, timely, quality-driven, efficient, equitable, and cost-effective.</p> <p><i>Standard 6, Systems Thinking:</i> The interprofessional collaborative team should provide IFCDC through the transition to home and continuing care for the baby and family to support the optimal physiologic and psychosocial health needs of the baby and family.</p>	<ul style="list-style-type: none"> · How is the team's competence related to the integration of DEIJ into IFCDC regularly evaluated, as well as the competence of the individual professional? Is performance competence evaluated at least annually? · Can you articulate a cost-to-benefit ratio to justify or identify opportunities for equitable developmental care practices and initiatives? How is this accomplished? · What strategies are used to provide a continuum of care that includes integration of the family and is based on the family's specific needs from admission to transition to home and follow-up care in the community?
<p>Creating a culture of inclusion involves building an environment that fosters affirmation, celebration, appreciation, and respect of different approaches, styles, perspectives, and experiences.</p>	<p><i>Standard 2, Systems Thinking:</i> The intensive care unit shall provide a professionally competent interprofessional collaborative practice team to support the baby, parent, and family's holistic physical, developmental, and psychosocial needs from birth through the transition of hospital discharge to home and assure continuity to follow-up care.</p>	<ul style="list-style-type: none"> · Does your team welcome the integration and interaction of all families regardless of background and beliefs? · Does your team, including parents and family, educate and train together? · How do you support families to feel confident as a nurturing caregiver of their baby, and competent decision-maker in managing current and anticipatory health requirements? Are their child-rearing practices and beliefs respected and affirmed?
<p>Justice constitutes a form of activism that advances operational success by integrating diversity, equity, and inclusion within an organizational system, inclusive of the vision, mission, values, culture, leadership, infrastructure, education, performance, measurement/analysis, improvement, and sustainment.</p>	<p><i>Standard 4, Systems Thinking:</i> The intensive care unit practice and outcomes will provide evidence demonstrating the continuous monitoring of information relative to IFCDC practice.</p> <p><i>Standard 5, Systems Thinking:</i> The interprofessional collaborative practice team shall be transparent regarding the access and use of medical equipment, devices, products, medications and vaccines, and technologies related to the IFCDC care in the inpatient setting, home, and the community.</p>	<ul style="list-style-type: none"> · Is there consistency in information and care delivery from inpatient to home and follow-up? Is this care individualized according to the parents' education, language, and capacity for understanding complex medical terminology and equipment? How is this demonstrated and evaluated? · What do the information and data tell you about the operation, infrastructure, outcome, education and training, practice performance, and improvement implementation of your institution's unit(s)? Is improvement continuous? · What articulated metrics are collected, monitored, evaluated, and compared with standardized outcomes? · Is there transparency in the dissemination of information and data?

the neighborhoods we serve. To improve the care and lives of infants and families at the state and national levels, providers must contribute to statewide quality improvement initiatives and advocate for legislation that holistically addresses issues of maternal and infant morbidity and mortality, such as the *Momnibus Act*, and more wide-spread targets like paid family leave.

Call to Action:

It is critical that the historical and current experiences that historically marginalized families have within the healthcare system not be minimized or ignored. As many families continue to experience the impact of toxic stress and gaslighting because of traumatic experiences impacting the morbidity and mortality of women and infants (11), we must move forward with the integration of DEIJ principles into the practices and policies of NICUs. We must acknowledge where we, as “experts,” fall short and take steps to educate our staff and get families to the table to help with decision-making regarding what works best for them. Honoring their lived experiences and partnering with our families is imperative to our forward movement.

“Our actions, policies, and practices have to move beyond simply the language and terminology of DEIJ and encompass the integrity and spirit of the DEIJ so that we can dismantle racist, discriminatory, and paternalistic systems of care.”

No “one size fits all approach” will cover the gamut of what is needed to improve health equity for diverse families in the NICUs; however, we hope that the application of DEIJ within the IFCDC Standards can help guide individual unit assessments to address barriers and encourage unit strengths specifically. Our actions, policies, and practices have to move beyond simply the language and terminology of DEIJ and encompass the integrity and spirit of the DEIJ so that we can dismantle racist, discriminatory, and paternalistic systems of care. This will require consistent and ongoing assessment of all our practices and include measurable outcomes of quality and improvement initiatives. The health of our babies, families, and communities depends on creating equitable and just healthcare for all. It is a basic human right.

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