In 2016, I published Once Upon A Preemie, a first-of-its-kind children’s book written to comfort parents of premature infants during their journey through the Neonatal Intensive Care Unit (NICU). During my journey, I discovered that reading to my micropreemie was the one activity as a mother that I could offer my son that helped normalize my overwhelming and traumatic NICU experience. During our nearly three-month stay in the NICU, I read to my son every day as research suggests that reading stimulates healthy brain development in preemies, and also helps to form a bond between parent and baby. Many of the bedtime stories that we read ended with a parent tucking the child into bed at home with Mommy and Daddy. That wasn’t our reality for three months. There were no books about us.

“I’m just a Mom,” I thought, “an African American Mom, and not a doctor.”

Her preemie parent contributions include consulting and blogging for fortune 500 companies on preemie parent needs from a cultural lens and reading as a tool for growth, development, and bonding. She serves on numerous advisory committees advocating for preemie babies and eliminating health disparities, including NICU Parent Network, The National Coalition on Infant Health, and March of Dimes Prematurity Prevention Collaborative.” She has presented at numerous conferences as a preemie parent, including Congressional Black Caucus Annual Legislative Conference, National Neonatal Nurses Association Conference, National Perinatal Social Workers Congressional Briefing, Preemie Parent Alliance, and National Perinatal Association Annual Conference. Jenné was featured in the Baby First Blog, Preeemie World, Heart and Soul Magazine, iHeart Radio, CBS Philly News Radio, Disruptive Women in Healthcare Blog, and Women of a New Sisterhood.

At birth, my son required life-saving medical interventions; oxygen, phototherapy lights, feeding tubes, a heart monitor, medication, vitamins, and even caffeine. Over our nearly three-month stay in the NICU, I traveled through snowstorms and blizzards, to parent and nurture my baby. I only missed three days (two due to inclement weather and one self-care day). A typical day in the NICU lasted from 7 am until midnight, with many breaks to pump breastmilk. My lactation consultant promised that my breastmilk was liquid medicine. Midway through our NICU journey, I had to return to work, unlike many of my new NICU parent friends who were Caucasian. My advocacy skills were tested daily, as his life
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depended on how well I could speak “neonatology” language, I had to be his voice and articulate his needs. This was challenging because, after all, “I’m just a Mom,” an African American Mom, and not a doctor.

“I now believe, that with trauma-informed and implicit bias training among hospital staff, the professional staff would have been better equipped to communicate and support my delicate and fragile nature.”

As a mother, my NICU journey was traumatic and filled with a sea of emotions, including fear, anxiety, helplessness, and isolation. Much of which NICU parents are facing due to the current COVID-19 pandemic. Many of my fears, concerns, and feelings of isolation were due to the NICU environment, which was not as culturally friendly and supportive, as I assumed it would be. I’m being generous by saying there was little cultural diversity; it was dismal at best. There were times when the lack of cultural sensitivity and bedside manner caused more pain than my son’s actual health status, and it made me very uncomfortable because as the end of each night, I had to trust my most prized possession with nurses and doctors who I did not always trust. Another challenge I faced as an African American preemie parent, was that although our larger hospital system had active and robust NICU parent support groups, these resources were not made available at the smaller hospital where I delivered my son. This hospital served more African American and lower-income families than the other hospitals. Many of the parents I developed a relationship with, felt as if their voice and parental role is undervalued.

During my NICU stay, I had to be his voice and articulate his needs. This was challenging even if the supports are outside of the NICU. Literacy and health literacy considerations for family-centered and culturally appropriate care in the NICU. Regardless of one’s educational level, the NICU terminology is overwhelming and confusing for a new parent entering the NICU. Literacy and health literacy considerations are also important factors for families who are limited or non-English speaking. Break the communication barriers by speaking the same language and utilizing interpreters even if everyone speaks English. I had a great deal of respect and appreciation for the NICU staff who used lay terms and avoided NICU jargon when communicating with me. In time, I began understanding the NICU language; however, that wasn’t my job as a preemie parent. Preemie parents should be made to feel as comfortable speaking and interacting with NICU staff regardless of their literacy and health literacy levels.

Partner with parents to address the cultural competency, spiritual diversity, and unconscious biases that exist in the NICU. Listen to the voices of parents with multicultural backgrounds to be more sensitive to racial, ethnic, language, income, education, transportation, and spiritual needs.  Encourage preemie parents to speak up. Staff should value their input. Allow parents to give their insights on their baby’s health status, and any gut feelings they may have about a diagnosis or new development. This is extremely important for minority parents who assume their voice and parental role is undervalued.

Overall, a good deal of our NICU experience was positive; some experiences left permanent and negative memories that, to this day, cannot be erased. As much as I tried checking my professional credentials at the door before entering the NICU, my interactions with the NICU staff begged, yelled, and warranted us to have those tough cultural sensitivity conversations. Not in a negative way, but as an opportunity for forming better communication, respect, and, most importantly, trust.

In my professional view, the NICU is a microcosm of the larger hospital system on steroids, particularly NICU’s serving low-income and racially, ethnically, and linguistically diverse populations. Health disparities impacting the NICU are also a reflection of a larger hospital ecosystem. Below are my preemie parent and professional recommendations for integrating health equity and cultural competency in the NICU:

1. Prioritize health equity and cultural competency as strategic priorities and goals. Establishing opportunities for integrating and addressing health equity in short and long terms strate-

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visiting their baby. Creating safe opportunities for parents to connect with their babies is vital bonding via smart devices or other safe technology solutions.

“This November, as we go purple in recognition of Prematurity Awareness Month, we hope that you will join us as we launch the Once Upon A Preemie Academy, a virtual health equity and cultural competency training program for preemie professionals and parents.”

This November, as we go purple in recognition of Prematurity Awareness Month, we hope that you will join us as we launch the Once Upon A Preemie Academy, a virtual health equity and cultural competency training program for preemie professionals and parents. For more information about the Once Upon A Preemie Academy and for additional health equity and cultural competency resources, please join our listserv and visit these online resources:

1. Once Upon A Preemie Academy Listserv: www.onceuponapreamie.com

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