



From Grief to Advocacy: My Inquiry into the Impact of Saul's Light Foundation on Black NICU Mothers

Exploring the intersection of personal experience and scholarly inquiry, this capstone project delves into the critical role of Saul's Light Foundation in providing multifaceted support to NICU and bereaved families, with a spotlight on its impact on the emotional well-being and community sense among Black mothers in New Orleans.

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Executive Summary

This capstone project investigates the effectiveness of Saul's Light Foundation in supporting families in the NICU, focusing on the emotional well-being and community among Black mothers in New Orleans. It highlights the need for culturally sensitive and inclusive support programs to address racial disparities in perinatal outcomes.

Area of Inquiry

The study highlights Black mothers as they navigate the complexities of the NICU and cope with infant loss. The goal of this study is to assess the effectiveness of the foundation's support programs, particularly in enhancing emotional well-being and community sense between NICU and bereaved families.

Conceptual Framework

The Health Equity Framework guides this study, focusing on individual, community, and organizational-based domains. This framework enables a multifaceted approach to understanding health equity issues, especially relevant to the foundation's work with families in the NICU

Research Questions

The study addresses how Saul's Light Foundation's support affects the emotional well-being and sense of community among Black NICU and bereaved mothers in New Orleans. The research also probes the foundation's commitment to its mission, how it ensures its offerings are culturally sensitive and accessible, and its engagement with the community to improve health outcomes for Black families.

Key Findings

The study highlights the need for tailored, inclusive support for Black mothers and their premature infants in the NICU. Key issues include racial disparities in perinatal outcomes, the importance of addressing maternal stress, empowering parents, and providing culturally

sensitive and anti-racist care. Strategies like palliative care, the COPE program, and psycho-educational intervention are emphasized for their potential to address these disparities and improve both infant and maternal well-being.

Design

The project utilized a literature review and qualitative data collection, including interviews with NICU mothers, staff, and licensed clinical social workers affiliated with Saul's Light Foundation. This approach allowed for an in-depth understanding of the organization's support model and its impact on families.

Recommendations

The project recommendations emphasize the need for more culturally sensitive care and the deepening of community engagement and partnerships, bringing more Black mothers to the planning process to enhance the effectiveness of support. These recommendations are rooted in the study's findings about the pivotal role these elements play in improving outcomes for families in the NICU.

Organization Context

Saul's Light Foundation

Saul's Light Foundation, located in New Orleans, is the partner organization linked to my capstone project. It was founded by Kimberly and Aaron Novod. The organization was born from a deeply personal experience when the founders tragically lost their son Saul after a 25-day stay in the Neonatal Intensive Care Unit (NICU). Saul's Light Foundation is on a mission to provide comprehensive support and assistance to families with infants in the NICU and those who have experienced the loss of their infants during or after their NICU journey. As the author of this capstone project, I must share my connection to this work. I also lost a son in the NICU after one month of life. As a Black woman who has experienced this loss, I want to understand how Saul's Light Foundation supports families who have experienced similar painful situations as myself.

Saul's Light Foundation is led by its founder and executive director, Kimberly Novod. She works alongside two dedicated staff members to ensure the effective delivery of support services to NICU and bereaved families. The foundation adopts a holistic approach to support, combining technical assistance, social-emotional support, education, and advocacy to cater to the needs of the premature infant and the entire family. The organization's support can be divided into two main areas: assistance for families currently going through the NICU journey and support for families who have lost their infants during or after their time in the NICU. For families with infants currently in the NICU, the organization establishes funds at hospitals such as East Jefferson General Hospital and Children's Hospital New Orleans to alleviate the financial burden. These funds cover essential needs, such as transportation, meals, and accommodations during the NICU stay. The foundation also encourages parents to read to their premature infants in the NICU by providing a library of books. They advocate on behalf of

families to ensure they receive the necessary support from social workers and medical staff during this challenging journey. For families who have lost their infants, Saul's Light Foundation provides CuddleCots as donations. CuddleCots are devices that slow the decaying process, allowing grieving families to spend more time saying goodbye to their infants after their death, providing crucial closure in the grieving process. The organization also arranges photography sessions, enabling families to take pictures with their babies to memorialize their lives. Saul's Light Foundation also repurposes wedding gowns to create angel gowns, sown by volunteers, to provide comforting burial attire for the babies. In addition, grieving mothers are connected with support groups to provide counseling and healing during this difficult process.

The stakeholders for this capstone project include the staff, mothers, and licensed clinical social workers who collaborate with Saul's Light Foundation. They play a central role in the project, as their insights and experiences are crucial in understanding the impact of support programs on the emotional well-being and sense of community among NICU and bereaved families. Mothers who have received support from Saul's Light Foundation are essential stakeholders, and their experiences and perspectives form the foundation for this study. Their feedback will provide valuable insights into the effectiveness of the organization's support programs. Licensed Clinical Social Workers collaborate with Saul's Light Foundation in supporting NICU mothers, and their input is valuable in understanding the effectiveness of the organization's advocacy efforts and support services.

This capstone project strives to gain an understanding of the effectiveness of Saul's Light Foundation's support programs on the mothers that they serve. This will be an opportunity to assess how the foundation's support impacts the emotional well-being and sense of community among NICU and bereaved mothers. This study aims to provide insights into the strengths and potential areas of improvement in their support programs. The focus is on the impact of cultural sensitivity and anti-racist care in improving perinatal outcomes and reducing

disparities. The project will also assess the importance of emotional support and community-building in the NICU context and their influence on the well-being of mothers.

Through a comprehensive literature review, qualitative data collection methods, and collaboration with Saul's Light Foundation, this capstone project's goal is to provide valuable insights into these support programs' impact on NICU and bereaved families' emotional well-being and sense of community in the New Orleans area.

Problem of Practice

In 2021, the preterm birth rate in New Orleans was 14.4%, meaning that one in seven babies was born preterm. Among the different racial and ethnic groups, the preterm birth rate was highest for Black infants, at 16.0%. This was followed by Hispanics, with a preterm birth rate of 11.7%. Whites had a preterm birth rate of 8.9%, and Asian/Pacific Islanders had a rate of 8.3% (March of Dimes, 2022). This data demonstrates the dire circumstances Black mothers in New Orleans are experiencing.

I studied the impact of Saul's Light Foundation's support on Black NICU mothers while investigating how these programs impacted their experiences during and after the NICU journey. I also strived to understand the experiences of mothers in bereavement due to the loss of a premature infant in the NICU. To provide framing to this problem, I drew research on adverse perinatal outcomes related to race and social factors that affect health outcomes. I specifically examined the impact Saul's Light Foundation's support had on meeting the social-emotional and financial needs of families. I also studied the impact of their partnerships with hospitals on NICU experiences.

To address this problem of practice, my study was guided by project questions (PQ), in Table 1, related to the emotional well-being and sense of community among Black NICU and bereaved mothers who have received services from Saul's Light Foundation.

Table 1*Project Questions for the Study*

Project Questions (PQ)	
PQ 1	How does the foundation's commitment to its mission influence the emotional well-being and sense of community among Black mothers and their infants in the NICU?
PQ 2	In what ways does the foundation ensure that its offerings are accessible, culturally sensitive, and address the unique needs of Black mothers and their infants in the NICU?
PQ 3	How does the foundation actively engage with the community, including community leaders and organizations, to address non-medical drivers of health, build trust, and improve health outcomes for Black mothers and their infants in the NICU?

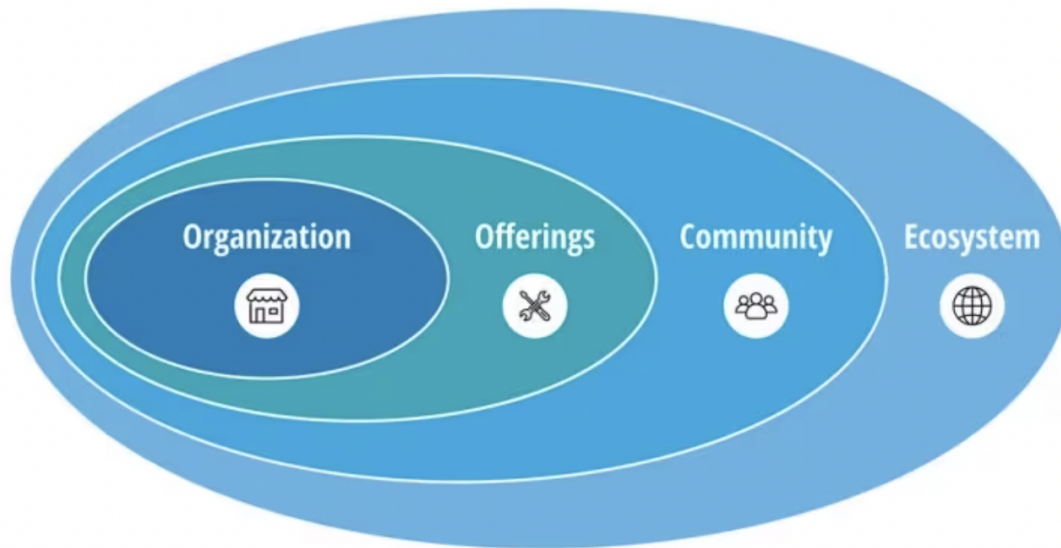
To answer these questions, I gathered qualitative data by conducting interviews with staff members who work within the organization and licensed clinical social workers who collaborate with families receiving services from Saul's Light Foundation. I also used pre-recorded interviews with mothers who had received services from Saul's Light Foundation. My goal was to engage in a comprehensive assessment of how the organization's services influence the social-emotional well-being and sense of community among Black mothers who have undergone the experience of having an infant in the NICU. The data collected from this research enabled me to identify essential components of the support model that have directly led to positive outcomes.

Conceptual Framework

The Health Equity Framework

Figure 1

Visual of the Health Equity Framework



Note: From “Activating health equity,” by K. Gebreyes, J. Perez, D. Rabinowitz, & E. Baca, 2021, Deloitte Insights. Retrieved from <https://www2.deloitte.com/us/en/insights/industry/health-care/developing-an-agenda-of-equity-in-health.html>

Health equity underpins the work that Saul’s Light Foundation aims to accomplish as they work with mothers who are experiencing the trials of the NICU in New Orleans. Gebreyes et al. (2021) describe health equity as a framework (shown in Figure 1) that emphasizes the individual, community, organizational, and ecosystem-based domains. This framework allows an entity to approach and understand issues related to health equity in a multifaceted approach. The study began with the organizational domain. When examining this domain, it was important to evaluate Saul’s Light Foundation’s commitment to its mission while examining its influence on the social-emotional health and sense of community among Black mothers and their infants

within the NICU. Qualitative interviews with the staff at Saul's Light Foundation were conducted for a thorough exploration. The interviews were an opportunity to understand and unveil how the organization strives to meet its goals and views the needs of its constituents. The collected data was analyzed and codified based on themes of mental well-being and sense of community. The themes were compared to recognize patterns and draw clear conclusions regarding the organization's commitment to its mission and health equity. This domain examined how the organization can affect personal experiences with the goal of achieving health equity.

The offerings domain was related to the experiences of Saul's Light Foundation's constituents. This domain focused on a group of Black mothers who have received services and the effectiveness of the support received. This was part of an effort to ensure that the offerings of the foundation were socially and emotionally responsive, culturally sensitive, and accessible to Black mothers who sought support from Saul's Light Foundation. Through qualitative interviews with mothers, this examination allowed insight to be gained on effectiveness, impact, and possible outcomes. Feedback and testimonials were received through one-on-one pre-recorded interviews with mothers. The qualitative data was analyzed using content analysis methods involving systematic coding and interpretation of transcripts to identify patterns, themes, and meanings. This offering stage emphasized the importance of culture, context, and how social determinants of health can shape outcomes. Using the thematic codes, the unique needs of Black mothers were evaluated in relation to the support received from Saul's Light Foundation.

The study's third and final focus was the community domain, where Saul's Light Foundation's engagement with the community was examined. The established partnerships and collaborations were evaluated to gain an understanding of how drivers of health were addressed, how trust was earned, and the impact of racial bias on maternal health. This was accomplished through interviews with licensed clinical social workers and a hospital administrator who collaborated with Saul's Light Foundation. The analysis of documents

provided by Saul's Light Foundation supported the comparison of data and the triangulation of findings. This domain focuses on the societal aspect and structure of the health equity framework. Data gathered on the partnerships and collaborations with Saul's Light Foundation allowed the identification of key themes linked to social-emotional health and trust building.

While the ecosystem domain was not a focus of this study, it is an important aspect of the health equity framework. The ecosystem domain illuminates the connection between economic, political, and environmental factors and how they have an overall impact on promoting and ensuring health equity. The ecosystem domain is an essential backdrop to the entire study that will always be present.

All four domains, organization, offerings, community, and ecosystem, make an essential contribution to the comprehensive nature of the health equity framework. This holistic framework supports a clearer understanding of the work that Saul's Light Foundation is doing with Black mothers and their premature infants in the NICU. Taking part in this study presented considerable challenges, such as ensuring that there was no bias in the interpretation of data. Incorporating the health equity framework into the study ensured a more nuanced and comprehensive understanding of what health equity looks like in reality by focusing on the work that is taking place within Saul's Light Foundation.

Literature Review

I never imagined that I would lose a child, certainly not in a NICU. This was not a reality that I ever would have fathomed. I believed that if I had education, finances, and high-quality health insurance, my maternal experience would be safe. The images from the media of infants in the NICU weighing one pound due to drug use, lack of proper healthcare and education, or irresponsibility were the stereotypes that I knew about premature birth. Nevertheless, this loss brought to light the stark realities of the systemic disparities that Black mothers face within the American healthcare system. I am a Black woman, and I now personally understand that I am a

member of a community unfairly and disproportionately affected by perinatal and neonatal mortality and morbidity.

This literature review is a reflection, a narrative, and a journey. This review aims to draw from a range of scholarly articles and concepts within the health equity framework to explore the support that Black mothers and their families receive while experiencing the hardship of having an infant in the NICU. This journey is personal to me. I lost my son, Miles, after 30 days of life in the NICU. The impact that the experience had on me was traumatic, life-altering, and eternal.

The stress that families encounter in the NICU is shocking and overwhelming. Mothers, especially, are not prepared for the depth of emotion they end up experiencing. The impact of the NICU experience on mothers needs to be addressed, understood, and sympathized with in order to change outcomes. Support for NICU mothers and their premature infants is an area that requires comprehensive exploration with a special focus on Black mothers who often experience exacerbated disparities due to socio-economic, systemic, and racial factors. Using the health equity framework to address these disparities, this literature review expands on previous works to examine further the complexities of support mechanisms in the NICU context.

The Promise of Palliative Care

Research reveals that palliative care can improve the quality of life for critically ill infants and their families. The use of palliative care as a mechanism to support families and their infants in the NICU is being explored. Incorporating palliative care is gaining traction in NICU settings as a potential strategy to alleviate parental stress. This is significant to Black mothers, who experience a disproportionate neonatal mortality and morbidity burden. In the context of the NICU, palliative care can range from pain and symptom management, emotional and psychological support, end-of-life care, and, in the worst-case scenario, bereavement support. This aligns with the health equity framework, emphasizing the need for comprehensive and accessible resources. The use of palliative care is especially beneficial to Black mothers due to

the higher levels of stress they might experience due to systemic racism in hospital settings. While palliative care is essential in reducing stress among Black mothers, it is not readily used as a strategy. More research is essential to ensure that the palliative care services that Black mothers receive are tailored and accessible to their unique needs.

An article by Gale and Brooks (2006) highlights the importance of creating and implementing palliative care programs (PCP) in NICUs. The article describes the challenges faced, from the comfort level of staff members, doctors, and families to the unpredictable death of premature infants and the strategies used to overcome obstacles. This article also sheds light on the difficulty of implementing a PCP in a NICU setting while illuminating the need for such programs. Gale and Brooks (2006) emphasize the need for continuous learning, support with grief counseling, communication, partnership and teamwork, and flexibility due to the specific needs of each situation. This is an example of a thoughtful approach to creating PCPs to support the health of the infant and the psychological needs of families.

Improving Mental Health Outcomes for Black NICU Families

Empowering parents is integral to positive outcomes in the NICU, especially when they might feel helpless and possibly lacking in control. Support programs aimed at empowering parents are key. Creating Opportunities for Parent Empowerment (COPE) is a program that demonstrates promise in having an impact on the psychological health of parents. The health equity framework requires patient-centered care, which focuses on empowering families, which is a necessary tool in supporting Black mothers as they navigate the NICU experience.

A study by Melnyck et al. (2006) focuses on improving outcomes for premature infants while improving parents' mental health outcomes. Between 2001 and 2004, the researchers conducted two randomized trials with 260 families with infants in the NICU in the Northeast of the United States. Families took part in self-administered surveys while they were in the hospital, seven days after the discharge of the infant, and at their two months corrected age.

The goal of the study was to evaluate the effectiveness of COPE, which served as an educational behavioral intervention program. The areas evaluated were parent-infant interaction, improved parent mental health outcomes, and decreased NICU stay for premature infants. Through the COPE program, parents learned educational-behavioral interventions that focused on the appearance of the infant. An intervention was provided for research-based comparison, focusing on providing parents with information regarding hospital policies and procedures.

The outcomes measured were parental stress, their beliefs about parenting, anxiety, depression, parent-infant interactions, length of time in the NICU, and the entire hospitalization experience. The results demonstrated that mothers who were participants in the COPE program reported a significantly lower level of stress while in the NICU and less anxiety and depression at the child's two-month corrected age. Blind observers were used to rate parents' interactions with their babies in the NICU. Parents who participated in the COPE program demonstrated more positive interactions with their babies than those who only received hospital policies and procedures. Infants who participated in the COPE program had shorter NICU admission lengths (31.86 versus 35.63 and shorter hospital length stays and 35.39 versus 39.19 days) than the comparison group. It is worth highlighting that while these differences are apparent, they are not highly significant. Nevertheless, the study demonstrated that the COPE program, which focuses on educational-behavioral intervention in the early days of the NICU, can lead to improved parent mental health outcomes, an enhancement in parent and infant interactions, and fewer days in the hospital for premature infants. Similar initiatives can serve as crucial tools for Black mothers in the NICU, improving their mental health and confidence in their ability to care for their infants. The Melnyk et al. (2006) article highlights that parental mental health improvement is highly linked to empowerment.

The Value of Family-Centered Care

The concept of family-centered care (FCC) and its effectiveness were examined by Weis et al. (2014). FCC was created to ensure that parents in the NICU were receiving communication bridging theory and practice while focusing on the individual. The authors of the article discuss the value of family-centered care in the NICU but highlight the need for innovative strategies to realize these principles. FCC was designed with the following mechanisms: structured dialogue, reflection, and human-centered practices. As licensed clinical social workers received more training and empowerment as they worked with families, there was an uptake in the practice of family-centered care, leading to effective and thoughtful communication.

FCC is seen as a critical strategy in NICU settings because it ensures that families are partners in the care of severely ill infants. A study by Phan, Siguerdson, and Profit (2023) examines the experiences of families and any potential barriers to the provision and receipt of FCC. The study focused on families whose incomes are below the federal poverty threshold and the need for trust and empowerment to address racial and socioeconomic disparities while receiving FCC. This study demonstrates an alignment with Roberts' (2002) study that the child welfare system and NICUs perpetuate bias and racialized dynamics that affect families of color disproportionately. Families expressed the need for consistent primary nursing, thus creating continuity of care. When there was inconsistency in the primary support, it hindered the family's ability to participate actively in the care of their infant, intensifying the inequities in family-centered care (Phan et al., 2023). This study illuminates the need for power-sharing and mutual trust (Phan et al., 2023). It recognizes the presence of racial and socioeconomic disparities as essential keys to achieving effective family-centered care. Parental involvement in the NICU can also strengthen connections among staff and families (Lundqvist et al., 2019). The

health equity framework suggests that shared decision-making and patient involvement can foster a more supportive environment for Black mothers and their infants.

Strategies for Parental Participation and Bonding

Lundquist et al. (2019) highlight the need for and importance of parental participation in the NICU. This leads to stronger bonds among staff and families, which is essential. Patient involvement promotes equity due to the involvement in shared decision-making, creating a more supporting and trusting environment for Black mothers and their infants. A study involving 240 mothers evaluated the impact of two specific interventions, auditory-tactile-visual-vestibular (ATVV) and Kangaroo Care (KC), on maternal stress and the mother-infant relationship. KC involves giving the infant skin-to-skin contact on the chest of the parent. ATVV is a multisensory intervention that involves stimulating the premature infant's auditory, tactile, visual, and vestibular senses to support their overall development. KC and ATVV are interventions that promote the development and well-being of preterm babies while in the NICU. These interventions are also noted to decrease maternal psychological stress and improve interactions between the mother and infant after discharge and during the first year of life (Holditch-David et al., 2014).

This study, comparing the long and short-term effectiveness of these interventions, found that they were more effective in the NICU setting than after discharge. The short-term effects of ATVV were associated with a more rapid decrease in depressive symptoms in the parent, and KC was also associated with lower parenting stress. While the long-term effects were difficult to place and were inconclusive, the short-term effects suggest that these strategies should be continued in the NICU and within the first year of life. Other similar studies administered to infants in the NICU have shown short-term positive benefits, but the long-term benefits were insignificant.

Mental Health & Psychosocial Support in the NICU

Black mothers in the United States experience 50% higher rates of preterm birth (PTB) than White and Hispanic mothers (Ajayi & Garney, 2023). This skewed distribution is a complicated interconnection between inequitable healthcare and institutional barriers, leading to a high rate of PTB among Black families. The focus of Ajayi and Garney's (2023) study was to gain an understanding of the mental health of Black mothers in the NICU. The findings of the study revealed a lack of mental health services for 8 out of 11 mothers interviewed in the NICU. The mothers reported not receiving mental health resources or support during their time in the NICU (Ajayi & Garney, 2023). When asked about their perception of their NICU experience, it was described as stressful, focusing on the infant's health while neglecting the mental health needs of the mothers. Stressors that created more complexity were previous trauma, breastfeeding challenges, and minimal social support. The study highlighted the need for mental health care that was culturally sensitive. Mothers voiced the necessity for care that was respectful to their cultural beliefs, needs, and practices (Ajayi & Garney, 2023). While this study presents limitations due to the small sample size limiting its relatability to broader populations, the lack of mental health services for Black mothers in the NICU environment cannot be ignored.

A study by Hall et al. (2015) emphasizes the importance of families receiving psychosocial support in the NICU. The research highlights the need for staff to be educated in enhancing this aspect of care due to the urgency of need. It is paramount that hospitals consider equipping licensed clinical social workers with the skills, knowledge, and understanding necessary to provide this level of support to families due to its return in improved family engagement and satisfaction. These findings are consistent with the Weis et al. (2013) study highlighting the need for effective communication in the NICU. The psychosocial needs of parents in the NICU are immense due to the stressors and unique challenges when an infant is

hospitalized in the NICU. When supporting the needs of mothers in particular, it is essential to consider social-emotional needs, such as coping strategies, dealing with postpartum depression, and overall trauma that can be long-lasting. There are barriers to care, and these obstacles are more prevalent with minority families and those with low socioeconomic status. Historically, mothers with premature infants have a higher prevalence of postpartum depression (Grigoriadis et al., 2018). Hall et al. (2020) suggest that social-emotional interventions, such as cognitive behavioral therapy (CBT) and trauma-focused therapy, can reduce symptoms of depression in mothers who have experienced the NICU.

More psychosocial support can be provided through coping strategies to help families navigate the range of experiences in the NICU (Hawthorne et al., 2017). While in the NICU, families must receive peer support, social-emotional counseling from a trained mental health professional, and family-centered care to thrive on a psychological level. In some cases, psychosocial needs can be met through faith, prayer, and meditative practices. Finding faith, hope, and solace in religion and spirituality cannot be ignored or downplayed due to its significant use among Black parents (Hawthorne et al., 2017). Spiritual care is considered to be an important component of palliative care. A study by Brelsford, Doheny, and Nestler (2020) stresses the importance of addressing parents' spiritual needs due to the ability to create meaning during difficult times. Meeting these spiritual needs allows families to grow in resilience while finding hope through unimaginable challenges.

Unfortunately, psychosocial support is not easily accessible to all families. The barriers to care for families of low socioeconomic status (SES) make the process of finding and receiving support difficult. The obstacles that parents of low SES experience can range from transportation issues getting back and forth from the NICU, a lack of paid parental leave, and the need to care for another child at home. These difficulties make it even more difficult for SES parents to participate in these interventions (Hawthorne et al., 2017). To alleviate these difficulties, parents should have the option to participate in telehealth therapy. Healthcare staff

also need to participate in social-emotional engagement training, allowing them to better meet the needs of SES parents (Hall et al., 2020). Considering all the needs and barriers, access to comprehensive psychosocial support must be equitable to ensure that all parents receive the support they need. More research is essential to evaluate the effectiveness of these interventions and their ability to be scaled in different types of NICU settings serving different populations with specific needs.

When Bereavement Support is Needed

In the unimaginable circumstance of the death of an infant, the importance of knowledgeable licensed clinical social workers, cultural sensitivity, and the presence of effective bereavement support staff to support families is essential. There is a pressing need to address the challenges and racial disparities experienced by Black mothers and their families when it comes to the loss of an infant. Garten et al. (2023) discuss palliative care and grief counseling as recommendations in perinatology and neonatology. They emphasize the family-centered approach. Using effective and thoughtful communication strategies, ensuring that pain management is culturally sensitive, and collaboration across support areas are essential to ensuring that Black families are receiving and experiencing equitable care throughout the perinatal loss experience. A vital aspect of comprehensive support must involve grief counselors who can understand nuances in culture and needs that are not easily expressed. A study by Hawthorne et al. (2016) examined the use of spiritual or religious coping strategies among mothers who had experienced the loss of an infant. The study examined how spiritual coping strategies were engaged in by gender, race and ethnicity, and religion around one to three months after the loss of the infant. The findings suggest that Black women were more inclined to utilize spiritual coping strategies. This highlights the need for hospitals and healthcare providers to recognize and incorporate spirituality as an available and respected coping mechanism for Black mothers and their families when they experience a perinatal loss.

The studies by Garten et al. (2023), Hawthorne et al. (2016), and Gold et al. (2017) highlight racial inequities in the practice of communication, how spiritual coping strategies are viewed, and the need for family-centered and culturally responsive palliative care and grief counseling. Addressing these disparities will ensure that healthcare providers can promote a supportive and inclusive environment for Black mothers as they traverse the painful perinatal loss journey.

Culturally Sensitive Support for Black Mothers

Recent studies suggest an urgent need to address the lack of culturally sensitive support, racial disparities in communication, and a lack of social-emotional competence in maternal healthcare providers. The need is pressing because Black mothers deserve compassionate care and protection throughout the arduous NICU journey. A study by Baughcum et al. (2017) focused on improving end-of-life care for infants in the NICU. Perspectives from parents experiencing bereavement were collected, which led to findings of essential areas for improvement. The areas identified as crucial were a need for better communication, social-emotional support, and partnered decision-making during end-of-life care in the NICU.

Houston and Walker (2022) put a spotlight on the importance of addressing the racism that mothers experience. Without addressing this bias and prejudice, improving the experiences in the NICU of Black babies, their mothers, and their families will be impossible. The article recognizes that systematic racism is prevalent in the American healthcare system. Within the NICU, this prejudice significantly impacts preterm infant morbidity and mortality rates, affecting Black infants in a significant way. Houston and Walker (2022) seek to eradicate racial disparities and discuss the need to fight the systemic silencing, exclusion, and misrepresentation of Black families, leading to many injustices. The argument from the commentary *Is This Mic On?* is that

if the experiences of Black families are centered, it can lead to the building blocks of knowledge in creating solutions steeped in antiracism (Houston and Walker, 2022).

Social Workers in the NICU

Social workers are essential to bridging the gap between healthcare staff and families in the NICU (Farley et al., 2022). According to a study in the *Journal of Palliative Medicine*, social workers are needed in family conferences due to the expertise that they offer (Farley et al. 2022). Social workers can translate complex medical information to parents, allowing them to navigate the experience, engage in conversation with empowerment, and make decisions in the best interest of their infants. The social worker can also serve as a coordinator, connecting families with resources and supportive stakeholders, enabling care coordination. A difficult aspect of the NICU is being able to manage families' expectations in an empathetic way. Social workers play a vital role in helping the family set and guide their expectations due to the sensitivity and unpredictability of outcomes for critically ill infants in the NICU. The primary role of social workers is to provide social-emotional support to families. Due to the immense need for their services, challenges lie in heavy caseloads and a high burnout rate (Farley et al., 2022). The study highlighted the necessity for hospitals to partner with social workers to support families with communication, expectations, education, and their social-emotional needs.

The Value of Peer Support

Research has found that peer support reduces anxiety, stress, and depression in parents in infants in the NICU (Fratantoni et al., 2023). Due to its positive side effects, it is recommended in the NICU as an important component of family-centered care. Data-driven evidence on the actual impact is hard to find. In response, Fratantoni et al. (2023) conducted a large randomized trial to understand the impact of peer support on outcomes after the discharge of an infant. Three hundred families were involved in the study, and all these families were due to be discharged from a Level IV NICU. The 300 families were divided into two groups; one

group received merely a care notebook, and the other group received a care notebook along with peer support for a period of 12 months.

The results of the study demonstrated that depression, anxiety, and stress significantly improved over time for all participants (Fratantoni et al., 2023). Nevertheless, the difference between the control and intervention groups was not significant. Comparably, post NICU discharge, there was no difference between the infant health outcomes between both groups in areas such as emergency room visits, hospitalization, and progression in developmental milestones. The findings from this study imply that peer study may be impactful but not beyond the point of hospital discharge. The authors of the study proposed exploring the impact of peer support groups that are introduced earlier before discharge and focusing on parents with specific and differentiated needs (Fratantoni et al., 2023).

A study by Rossman, Greene, and Meier (2023) highlights the social-emotional dynamics of mothers with infants in the NICU. The emotional burden and psychological toll on mothers is unique to the experience of the NICU. Mothers give birth to premature infants and must acclimate to motherhood in this unfamiliar setting characterized by uncertainty. The study by Rossman et al. (2023) examines the immense need for support systems that are compassionate, empathetic, and relatable beyond the conventional offerings of a professional healthcare system. A central piece to this reimagined support system for mothers is peer support provided by mothers who have experienced similar experiences in the NICU. Roseman et al. (2023) describe the role of peer support as a powerful network of aid tiered in the form of social, emotional, and informational support.

By sharing experiences with others who have experienced similar fears and anxieties, emotional resilience is cultivated. The peer support groups also help stave off isolation and provide community and belonging during a challenging period. The study also indicates the benefit of mothers with prior NICU experience serving as peers to new mothers in the NICU. This connection between the experienced and the inexperienced allows for sharing practical

advice to ensure effective coping mechanisms are used. Roseman et al. (2023) agree on the need for further research to understand which interventions need to be developed to improve and increase peer support in the NICU to ensure new mothers receive the psychological help they need.

Racism and Unconscious Bias in the NICU

A qualitative study by Witt et al. (2022) highlights Black mothers' experiences in the NICU and the racially charged incidents that they might encounter. In the study, mothers shared some of their troubling experiences with staff members related to racial bias and prejudice. They described interpersonal and institutional racism that affected the quality of care received. Witt et al. (2022) shed light on the lack of trust Black Americans feel toward the medical community due to a long history of medical abuse leading to neglect and intentional or unintentional harm. While some of these historical practices are in the past, there is still a continuation of harm. Black Americans state that there is still a culture of gaslighting in the medical profession. Houston and Walker (2022) offer the solution of partnering with community groups that provide support, advocacy groups, and peer support and empowerment from other Black families.

Based on the interviews by Witt et al. (2022) with 20 mothers 6 to 18 months after leaving a level IV NICU, the majority of mothers interviewed shared stories where they experienced racism, from interpersonal experiences to neglect to being ignored by licensed clinical social workers in decision-making. Some mothers described situations where they were described as difficult and were threatened to be reported to Child Protective Services due to their perceived behavior. Potential solutions discussed were the need for more Black representation, the option for peer support, and high-quality education and training for staff within the hospital. This research highlights the need for Black stakeholders to be involved in

designing, implementing, and analyzing support programs to ensure that respectful and effective long-term solutions are found for the well-being of Black infants and their families.

The Impact of History on Black Maternal Health Today

A book by Dána-Ain Davis, *Reproductive Injustice : Racism, Pregnancy, and Premature Birth*, illuminates the racial discrimination that Black women face frequently in the NICU. This racial disparity presents itself in the stigmatization and profiling that is endured in the healthcare system. Davis (2019) highlights a stereotype of Black women being “at risk” or “a risk” within the context of a healthcare system (107). This dual role of a Black mother creates an environment of concern and a lack of safety. The stereotypes surrounding Black mothers lead to institutional practices propagated by racial profiling. Davis (2019) discusses how Black mothers' behaviors are scrutinized, leading to them being treated as a threat. Historical precedents show a parallel between the current realities of Black women and those experienced during slavery. Davis (2019) discusses how Black women were under constant surveillance to ensure their pregnancies were not terminated through miscarriage or infanticide. This level of scrutiny in history is akin to the scrutiny and monitoring Black mothers experience in hospital settings.

A common theme in Davis' (2019) examination is the evaluation that medical professionals direct on Black mothers and their parenting abilities. These judgments, influenced by race, create a viewpoint that Black mothers cannot appropriately take care of their infants in the NICU. This lack of trust can lead to sometimes unneeded and possibly harmful interventions. A point worth addressing is the burden of blame on Black mothers for adverse health outcomes. Some campaigns that are well-meaning and focused on raising infant mortality rates in the Black community inadvertently blame Black mothers for the negative health outcomes in their babies. Another long-standing bias and stereotype is the belief that Black babies are sturdy. Davis (2019) explores a belief that Black children are strong, hardy, and more physically robust than their White counterparts. This stems from unsubstantiated claims and

theories steeped in eugenics. This perception has led to the wimpy white boy theory in the NICU. A common belief in the 21st century is that Black babies survive the NICU and White boys especially are weaker and need special care to live. I was personally told by a nurse in the NICU that my Black baby boy would survive the NICU because he was Black. It was subsequently described to me that Black babies do well in the NICU without any research or evidence to support that claim. This perception can lead to detrimental health outcomes for Black infants due to the belief in their robust health and sturdiness, thus not needing a high level of special care.

Literature suggests a multi-dimensional approach is required to thoroughly support Black mothers and their families in the NICU. This includes addressing parental stress, providing empowerment and bereavement support, promoting parental involvement, enhancing the role of caregivers, improving maternal self-efficacy, and addressing prenatal risk factors. These interventions, when delivered in a culturally sensitive, anti-racist way, have the potential to enhance the NICU experience for Black mothers and families and contribute to more equitable health outcomes. A robust, culturally sensitive, and multi-dimensional approach is needed to support Black mothers and their families in the NICU. Such an approach addresses stress, empowerment, parental involvement, caregiver roles, maternal self-efficacy, and prenatal risk factors

This personal and scholarly journey brings a magnifying glass to the importance of culturally sensitive, empathetic, and holistic care in the NICU. There is an urgent need for an approach that addresses not only the medical needs but also the emotional, psychological, and cultural needs of Black families.

Key Findings from the Literature

Based on the literature review, there are several key findings to consider. The need for tailored and inclusive support for Black mothers and their premature infants while in the NICU is

amplified through the research. Outcomes for infants have the ability to change when maternal stress is addressed; parents are empowered to advocate and are provided with the opportunity to participate in the care of their children.

A significant problem that must be addressed is the racial disparity in perinatal outcomes within the Black community in the United States of America. Compared to other racial and ethnic groups, Black mothers are experiencing higher rates of premature births, infant mortality, and many adverse outcomes. Societal factors affecting health are rampant, from access to healthcare to education level to employment, and play a crucial part in creating these racial inequalities. A history of racial discrimination in the form of bias and mistreatment continues to be a problematic issue, particularly for Black mothers and their infants.

To improve perinatal outcomes and decrease historical disparities, it is crucial to provide culturally sensitive, anti-racist care that incorporates the unique needs of Black mothers. The support Saul's Light Foundation provides to families in the NICU has the ability and potential to address these racial disparities. Palliative care, the COPE program, parental support, advocacy, and intervention, as well as maternal prenatal risk factors, were researched as part of the literature review. Palliative care is being increasingly adopted in NICU settings. The stress families experience as their infants face serious illnesses and prematurity symptoms is immensely overwhelming. Palliative care can address families' physical, social-emotional, and spiritual needs while ensuring the well-being of the infant in care.

Another strategy for parental support is a program called COPE. The COPE (Creating Opportunities for Parent Empowerment) program is targeted at providing interventions for families in NICUs by empowering them to cope with the stresses of the NICU experience. This program focuses on mental health outcomes by reducing families' stress levels during their time in the NICU and during instances of unimaginable loss. While difficult to discuss, families need support coping with their grief when an infant dies. Many NICUs across the country are lacking

in bereavement programs. Through COPE, extensive bereavement programs can be created to support mothers and families dealing with the loss of a child.

Parental participation in care is an important piece of the NICU care experience. Providing opportunities for parents to participate in the care is essential to the ultimate well-being of the child and the parents. Healthcare providers must prioritize creating inclusive spaces that foster an environment of connection between the staff, parents, and other families in the NICU. This sense of community is essential to the overall well-being of families.

When considering social, emotional, and mental health, psycho-educational intervention is essential as mothers traverse the difficulty of the NICU. In consideration of the needs of Black mothers in the NICU, psychoeducational intervention can play an important role in providing targeted support. These interventions incorporate cultural sensitivity to ensure that the support that is being received is in line with and respectful of the culture of the mothers being served. It also can address the stigma Black mothers face in healthcare while empowering them to navigate the experience with a sense of empowerment and confidence. This empowerment is necessary in helping Black mothers develop the confidence to advocate for themselves and their babies while in NICU care.

The literature provides evidence that organizations like Saul's Light Foundation have the ability to change important aspects of the NICU experience for families. The support has an impact on the social and emotional well-being of families. Melnyk et al. (2018) highlight the importance of social support and the creation of peer support through a community, leading to deeper resilience among NICU families. Meeret et al. (2019) provide a comprehensive evaluation of a bereavement program. The study found that the presence of the bereavement program led to improvements in the professional and personal lives of NICU staff who have to shoulder trauma consistently.

Data Collection

The data collection for this project involved gathering different perspectives from stakeholders associated with Saul's Light Foundation. The focus was on NICU families who have received services from the foundation, with a particular emphasis on Black mothers and their premature infants, staff members directly involved in providing support services, and licensed clinical social workers who have collaborated with the organization. Additionally, various official documents from Saul's Light Foundation were analyzed.

Data Collection Methods

I conducted interviews with two staff members from Saul's Light Foundation: Kimberly Novod, the founder and executive director, and the Director of Programs and Partnerships (anonymized). The interviews explored their perspectives on cultural sensitivity, inclusivity, and the effectiveness of the organization's offerings. I also interviewed licensed clinical social workers and a hospital administrator who collaborated with Saul's Light Foundation in the NICU context. The aim was to gather their insights on the organization's support services and the impact on families, focusing on cultural sensitivity, accessibility, and program effectiveness.

Pre-recorded interviews with 8 NICU mothers were utilized to avoid them revisiting the emotional pain of their traumatic experiences. The audio-recorded interviews were transcribed and qualitatively analyzed to gain a professional perspective on the organization's efforts to engage with the community, address nonmedical drivers of health, build trust, and improve health outcomes for Black mothers and their families in the NICU. The interviews were transcribed and qualitatively analyzed to understand the organization's commitment to its mission and impact on the emotional well-being and sense of community among Black mothers and their families in the NICU.

The analysis of documents was conducted using various sources: the 2022 annual report highlighting their accomplishments and testimonials, legislation advocated for by Saul's

Light Foundation, and articles written about the organization's achievements in the New Orleans area. Overall, these diverse data collection methods contributed to a comprehensive understanding of Saul's Light Foundation's approach to supporting Black mothers and their families in the NICU, as well as the organization's commitment to promoting health equity and community well-being.

Data Analysis

In this capstone data analysis, the goal was to explore the impact of Saul's Light Foundation on the emotional well-being and sense of community among Black mothers and their premature infants. The primary focus was to address the three project questions (PQ) listed previously in Table 1.

To answer the project question regarding the foundation's impact on emotional well-being and sense of community, a comprehensive content analysis was employed to examine documents provided by the organization. The collected program materials, reports, and testimonials were examined to identify recurring themes and patterns related to the project questions. By closely examining the qualitative data, the goal was to understand how the foundation's initiatives and support services influenced the emotional well-being of Black mothers and their premature infants in the NICU. Through thematic analysis, there was an identification of common topics, ideas, and patterns of meaning that emerged repeatedly from the documents, leading to deeper insights into the experiences of the beneficiaries. This project question also pertained to the pre-recorded interviews with mothers who received support from the foundation to learn about the impact the services had on their emotional well-being and sense of community.

The next project question pertained to the foundation's commitment to accessibility, cultural sensitivity, and addressing the unique needs of Black mothers and their premature infants in the NICU. To learn more about their dedication to responsively addressing these needs, interviews were conducted with the two main staff members of Saul's Light Foundation.

By employing open and axial coding, the qualitative data was categorized and analyzed to identify recurring themes and patterns. Through this analysis, codes were generated, and categories and sub-themes were crafted to explore commonalities and variations among participants. This approach led to a nuanced understanding of how the foundation tailors its offerings to meet the specific needs of its target community while promoting cultural sensitivity and inclusiveness.

The third project question focused on the foundation's active engagement with the community to improve health outcomes for Black mothers and premature infants in the NICU. To learn about this engagement, interviews with social workers and a hospital administrator were conducted, transcribed, and analyzed. This process of qualitative data analysis involves a systematic approach to uncovering meaningful insights from narrative data.

Document Analysis

Saul's Light Foundation is instrumental in supporting mothers through community engagement. A systematic data analysis was employed to comprehend and analyze the impact of the foundation's work. This analysis involved open coding of documents where specific terms and concepts related to community engagement, emotional well-being, cultural sensitivity, and health outcomes are investigated. The overall analysis was done through axial coding, where similar codes were grouped into larger themes. This supported the organization of the data, making it easier to organize and structure. The following words, but not limited to the terms listed in Table 2 below were coded.

Table 2*Coded Terms for Document Analysis*

Community Engagement	Emotional Well-Being	Cultural Sensitivity / Accessibility	Health Outcomes / Drivers of Health
Community	Comfort	Accessible	Mortality
Connection	Support	Availability	Morbidity
Belonging	Stress	Reach	Health Status
Inclusion	Anxiety	Barriers	Patient Satisfaction
Support group	Depression	Resources	Social Determinants
Engagement	Hope	Services	Housing
Collaboration	Fear		Food Security
Partnership			Education
Outreach			Income
			Employment

In order to do a comprehensive analysis of the documents provided by Saul's Light Foundation, I used open coding as a qualitative examination strategy. Each code represented a specific concept, idea, or theme related to community engagement efforts by Saul's Light Foundation. The qualitative data was presented through a narrative description to present recurring themes, insights, and possible patterns. This included direct quotes from transcripts and documents to illustrate what had been identified. The analysis phase presented challenges. The limited number of data sources had the possibility of affecting the depth of the categorized themes.

Nevertheless, this intricate analysis still yielded meaningful results. Therefore, consistent coding was essential to ensure the reliability of the findings. Additionally, the emotional essence of this data, due to its linkage to trauma, accentuated the need for a thoughtful and sensitive

approach. As a mother who had walked this path, I understood that my personal recollections, biases, and emotions could distort insights. Taking the time to take care of myself while recognizing my preconceptions and feelings allowed me to strive for an objective analysis.

Analysis Timeline

The data collection and analysis process took place over a span of two months in 2023, starting from the first week of July and extending through August. The process began with the collection of documents in the first week of July. This initial phase was followed by the recruitment of interviewees, which took place in the second and third weeks of July. Interviews with licensed clinical social workers were conducted in the last week of July and continued through the first three weeks of August. Parallel to this, in the first week of August, interviews with the staff at Saul's Light Foundation took place.

I collected the pre-recorded interviews in the first and second weeks of August. The entire month of August was dedicated to the analysis of all the collected data. This included reviewing and interpreting documents, interview transcripts, and pre-recorded interviews. This comprehensive and sequential approach aimed to ensure a thorough and systematic analysis of all the data collected, thereby providing robust and insightful findings.

Interview Analysis

I began with open coding to identify the themes that naturally emerged from the transcripts provided. Axial coding was then utilized to categorize similar codes into groups to find possible patterns and relationships. Through this selective coding, a central theme was found that summarizes the core of these categorized codes. Using this structured approach allowed the project questions to be answered in their entirety by using the data to develop a deeper understanding. This process involved iterating through the data numerous times to refine comprehension.

Pre-recorded Interviews with Mothers

This project question was centered upon the impact that Saul's Light Foundation's mission has on the social-emotional health and sense of community among mothers and their families while in the NICU. The data collected was based on 8 pre-recorded interviews conducted in 2023 with mothers who had recently gone through the NICU journey with different outcomes. This data was grounded in first-hand accounts from the mothers, documenting their physical, emotional, and logistical difficulties while chronicling the support they received or did not receive. Axial coding was used to organize the data, followed by broad categorization that summarized the diverse and complicated experiences of the mothers.

The data collection strategy was created to highlight the complexities of the mothers' NICU journeys. The categories that emerged were emotional responses, challenges and barriers, child's status and care, postpartum and recovery, and support and community. Through this categorization, an overall theme emerged with a focus on mothers navigating the emotional and physical challenges of having a premature child while showing resilience. This analytical approach encapsulated the range of experiences from concrete issues (transportation difficulties mentioned) to intangible matters (the emotional pain experienced) that were clear aspects of each mother's journey.

I embarked on this data journey to understand the complicated experiences of Black mothers as they navigated the NICU landscape in New Orleans. Saul's Light Foundation's mission was the main focus— to understand the organization's influence on the mothers' social-emotional well-being and sense of community and belonging. When considering the data, the highest thematic categorization with 80 occurrences was in the area of "Support and Community." This illuminates the essential role of an organization like Saul's Light Foundation and other community support infrastructures that play a role in a mother's social-emotional and psychological development. In the interview transcripts, undiluted feelings of fear, while

contrasting them with challenges such as experiencing a lack of information sharing or physical or mental health difficulties, the analysis accentuates the foundation's possible role in addressing some of these concerns.

In the interviews, mothers expressed a depth of emotion due to the distressing nature of their premature infants' existence. As one of the mothers stated, "Things went downhill very quickly...Max's heartbeat...he basically suffered major brain damage and massive organ damage..." This illustrates the intensity of the situations NICU mothers face due to the medical and emotional gravity. Another quote from a mother showed the lack of hope that permeated her experiences. "From the very start, there was not like, hey, okay, he's, you know, we'll do our best and make him go get better and grow. It was more of a like, all right, you know, get ready to say goodbye sort of thing..."

As a mother who had experienced the NICU, I was always told that the NICU was a roller coaster. It was like a journey with twists, turns, and undulating roads overcast by a tapestry of emotions, logistical hurdles, and barriers with some hope and community support interspersed. The transcript data highlights the role of Saul's Light Foundation in being an advocate for mothers and illuminates the need for community engagement and support in these high-stress medical situations where isolation, fear, and hopelessness are commonplace.

Interviews with Licensed Social Workers and a Hospital Administrator

The community domain of the health equity framework emphasizes the need for community engagement, trust, and collaboration to address the non-medical determinants that impact health outcomes. The guiding project question for the interviews with the social workers was "How does Saul's Light Foundation actively engage with the community, including community leaders and organizations, to address non-medical drivers of health, build trust, and improve health outcomes for Black mothers and their infants in the NICU?" The following data collection and analysis process seeks to answer this essential question.

Four professionals were interviewed for this project. Three were licensed clinical social workers, and one was a hospital administrator. The qualitative data collection strategy was based on detailed interview transcripts with the four professionals. The objective of the data collection was multi-tiered. The aim was to have a clear understanding of the engagement strategies used by Saul's Light Foundation. The other objectives were to assess the concrete impact of the initiatives, understand the difficulties that the foundation is struggling with, reveal the many support structures employed, and discern their collaborative efforts within the community. The themes from the transcripts illustrate how the foundation works with the community by addressing nonmedical drivers of health, nurturing trust, and striving to improve health outcomes for Black mothers and their infants in the NICU.

Interviews with Saul's Light Foundation Staff

Two Saul's Light Foundation staff members were interviewed: Kimberly Novod, the Founder and Executive Director, and an anonymous Director of Programs and Partnership. These interviews focused on how the foundation makes certain that its offerings are accessible, culturally sensitive, and tailored to the unique needs of Black mothers and their infants during and after their NICU journey. The goal was to identify first-hand accounts and insights from these two key stakeholders within the foundation. A potential challenge was the subjective nature of conducting qualitative interviews with people who are closely aligned and integrated into the organization.

The interviews demonstrated that Saul's Light Foundation is immensely influenced by the personal experiences of the mothers and families that they support. The organization employs a culturally sensitive approach that is adapted and tailored to the needs of Black mothers, their infants, and their families. The foundation strives for accessibility and equity

through continuous care during and after the NICU experience and by advocating against systemic biases.

Saul's Light Foundation strives to be community-centric, ensuring that they are rooted in the values and traditions of the diverse communities that they serve, which in turn resonates with the unique needs of the families. This engagement with families is holistic and highlights the foundation's commitment to addressing non-medical health drivers by gaining trust to enhance health outcomes for Black NICU families.

Document Analysis

Saul's Light Foundation strives to serve as an important source of support in a complex neonatal world. A qualitative analysis of several documents highlights an intricate approach to supporting mothers, their infants, and their families. The organization's work is steeped in community engagement. The documents examined were the 2022 Annual Report, House Bill 146, House Bill 650, House Bill 651, and Resolution R-19-353. Two articles about the foundation were analyzed. One was titled *Saul's Light: Finding Community and Care in the NICU* (Rosenblatt, n.d). The other article analyzed was *This Mother Turned Her Grief Into An Organization To Help Change The NICU Experience*. (Rose, 2022).

The documents examined emphasize how the organization views community engagement as essential to its mission. This engagement is evident across all the document reviews. The 2022 annual report affirms the focus on emotional well-being, accessibility, and cultural sensitivity. The articles highlight how the organization focuses on building trust and a commitment to creating connections within the community. The legislative documents demonstrate a broader goal of ensuring health equity by addressing socio-economic factors that affect health outcomes. The documents reveal the importance of collaboration and outreach to address medical and nonmedical drivers of health.

A qualitative content analysis approach was used to analyze the data. This included examining the documents to find patterns and insights relevant to the project question. Initially, specific terms and phrases were labeled through open coding based on their relevance to themes, such as community engagement, cultural sensitivity, and nonmedical drivers of health. Next, broader thematic categories were created through axial coding. The documents reveal the foundation's devotion to finding effective partners in the community.

This thematic document analysis reveals a comprehensive overview of the mission, vision, and strategy of Saul's Light Foundation. The organization adopts a multifaceted approach to improving the NICU experience. Still, it focuses on emotional well-being, cultural sensitivity, and accessibility. The focus on emotional well-being highlights the commitment to meeting the socio-emotional needs of NICU families. The foundation fosters a sense of belonging by emphasizing connection and inclusion. The focus on accessibility and cultural sensitivity demonstrates a commitment to making their services culturally relevant to diverse groups. The foundation's collaborative work with community leaders and organizations is emphasized through consistent partnerships and engagement. The attention to systemic matters such as housing and food insecurity highlights a commitment to addressing non-medical drivers of health. These efforts illustrate the foundation's goal of building trust and addressing nonmedical drivers of health with the ultimate mission of improving health outcomes for mothers and their premature infants in the NICU.

Findings

The key focus of this capstone project was to evaluate the impact of the initiatives of Saul's Light Foundation on the emotional well-being and sense of community among Black NICU mothers in the New Orleans area. The study examined different components of the foundation's work and services. The primary focus was on developing and understanding the

leverage and influence of the foundation. Unexpected findings emerged along with answers to the project questions. The outcome of the research and analysis was findings that highlight and reveal essential aspects of advocacy, emotional support, and community engagement. The significance the foundation places on the lives of mothers and their families has larger implications for the organization and the community at large.

Finding 1: Emotional Support Through the Building of Community

Emotional support plays an important part in the mental health and well-being of Black NICU mothers. The various transcripts demonstrate the importance of having someone to talk to, share experiences with, and rely upon is essential to the social-emotional well-being of the mothers. A deep sense of community is created around these shared experiences, which helps reduce feelings of isolation and creates a space for mutual understanding and support. This finding connects to the project question one related to the foundation's commitment to supporting families. The transcripts show that the foundation has been successful in making situations more bearable by creating a sense of community among Black NICU families.

The impact of offerings, engagement strategies, and connection to the work are expressed throughout the interview transcripts. A clinical social worker stated, "I think so highly of Kimberly and Saul's Light. They're one of the few organizations that I have seen do this grassroots parent component, how they engage professionals and teach professionals, and the advocacy that they do in the legislature and the community, they do that bridge so well. And I just think that's really impressive." This demonstrates the foundation's effective engagement strategies as they provide advocacy and community building. Another quote demonstrating a personal connection to the work is as stated, "I think this has just been the most meaningful and transformational work that I've done." Providing these services to mothers has a profound impact and holds a special place in the lives of the clinical social workers involved.

Finding 2: The Practice of Engaging in Advocacy to Address Systemic Challenges

This finding highlights the need for advocacy in supporting Black mothers as they traverse the challenges of the NICU. In the transcripts, there is evidence of families needing support in addressing systemic difficulties of the NICU. The support of Saul's Light Foundation allowed mothers to feel a sense of empowerment, allowing them to advocate for their needs, voice their concerns, and access the local resources they needed.

From the interviews, it is clear that the foundation is deeply aware of the interconnectedness of the family and the community in the NICU journey. One staff member said, "It's not just about the baby in the NICU. It's about the whole family. It's about their future siblings. It's about their community." This quote demonstrates a commitment to addressing the broader non-medical determinants of health that affect a family. The foundation has also taken an active stance in education and advocacy. As stated by a staff member, "We've developed a two-pronged approach. One is working with families to advocate for themselves, but two is working with hospitals and staff to check themselves." This quote reveals the important place that the foundation holds in addressing systemic biases and improving the NICU experience for mothers and their families.

Finding 3: Engaging the Community Through Holistic Support

This finding demonstrates the importance of community engagement. By involving the larger community in its mission, the foundation's work extends beyond the immediate needs of mothers and infants in the NICU. Saul's Light Foundation aims to address systemic issues that impact mothers by bolstering their relationships with community-based organizations and leaders. The organization is committed to the community, creating an environment of trust and allowing collaborative efforts to positively impact Black mothers and their families.

Project Question 3, based on actively engaging with the community to address non-medical drivers of health, build trust, and improve health outcomes, resonates with this

finding. The foundation is actively involved with the community. It demonstrates a strong focus on non-medical drivers of health, which emphasizes their holistic approach to improving health outcomes. Based on the transcripts, their initiatives have created trust and a sense of unity and support within the NICU community associated with Saul's Light Foundation.

The 2022 annual report states, "Lastly, as a grassroots organization, Saul's Light believes that partnership among hospitals and communities are the first steps to making a lasting equitable change in medicine" (Annual Report, 2022). There is a clear recognition of the importance of partnerships in improving health outcomes for NICU families and premature infants. There is also an understanding of the financial difficulties that NICU families face. An article about the foundation states, "Our work includes offering financial support to ease the burden of NICU costs, matching families with one-on-one peer support, and connecting the families to local resources" (Rosenblatt, n.d.). The foundation provides a holistic support structure by addressing the financial, physical, and social-emotional needs of families.

Unexpected Finding: Low Numbers of Black Mothers in Counseling Groups

While the core focus of the study was to have an understanding of the impact of Saul's Light Foundation's support on the emotional well-being and sense of community among Black mothers and their premature infants, a surprising finding materialized. In the interviews with social workers, it was revealed that some Black mothers demonstrated qualms when seeking out social-emotional support groups. It will be essential to further examine this drift from expected behavior.

Some factors might have an impact on this unexpected finding. There might be a perception that the support groups might not be adapted or culturally sensitive to the unique needs and challenges experienced by Black mothers. Another factor might be rooted in trust. Due to historical, unethical medical practices in the past, Black communities have demonstrated an unwillingness to participate in institutional interventions due to many instances of systemic

racism. For this reason, some Black mothers might feel solace and safety engaging in support provided within their communities. There might also be a lack of awareness of the availability and effectiveness of these support groups, which, in turn, leads to underutilization. These aspects lead to a disinclination to seeking formalized support, even if it might be beneficial.

A clinical social worker stated, "So right now I am doing the support group. Right now we didn't have any African American mothers at this time but we're hoping to have more. ... I think that's where the disconnect is because we as African-American women are taught like just keep it going, keep staying strong, and keep moving. And, oh, you don't need to go to a support group to get the help that you need." This quote demonstrates ingrained notions of self-resilience that can deter a Black mother from participating in formalized support groups.

When asked for ideas on increasing the involvement of Black mothers, a clinical social worker responded, "Have a meal available, you know, for participants. I mean, yeah... but just those incentives to come and to let them know it's okay to come and talk about how you're feeling. You know, and I guess when you're saying incentives, it's because their time is so precious, whether, and if you are having financial hardship and you're paid to do something, it alleviates that hardship, allowing you to do it, right?" This quote acknowledges the time and financial constraints that some Black mothers might be facing, making it difficult and inconvenient to participate in support groups.

Recommendations

Recommendation 1: The Need for Emotional Support Through Community

The essential need for emotional support among NICU mothers cannot be ignored. This is underscored by the stories and experiences shared in the transcripts. The narratives in the transcripts show a range of emotions, from shock and trauma due to giving birth to a premature baby, interspersed with moments of gratitude and hope. The emotional pain of navigating the

NICU is a universal experience; nevertheless, it is especially augmented for Black mothers. Therefore, a recommendation is to make mental health a priority by establishing regular mental health check-ins and tailored counseling sessions, all designed to meet the unique needs of Black mothers. This approach aligns with and propels the foundation's goal of providing support to families while making their NICU experience more manageable. The foundation can provide in-depth support by grounding support initiatives in the importance of understanding others' experiences. This ensures that these created community spaces are not simply an opportunity to share experiences but an opportunity for powerful social-emotional support for Black mothers.

Recommendation 2: Addressing Systemic Challenges Through Advocacy

Advocacy plays an essential role in navigating the unique and complex challenges experienced by Black NICU mothers. This advocacy must be strengthened through a larger community network of support. A recommendation is for Saul's Light Foundation to capitalize on and scale its impact by collaborating with more local and regional organizations. It is paramount that these partnerships are carefully curated to ensure that support is culturally responsive to the diverse needs of mothers being supported by the organization. The foundation might consider partnerships with organizations with specialized missions focused on areas such as post-partum care, mental health, and social-emotional support. The organizations should also be representative of the different groups supported by Saul's Light Foundation for cultural nuances to be understood. This will strengthen the foundation's ability to provide holistic and tailored support to mothers. A deepening and growth of partnerships will empower mothers as they traverse challenges in the NICU and help them avoid potential roadblocks and difficulties, eventually leading to high-quality and effective medical care.

Recommendation 3: Providing Support Through the Sharing of Experiences

Saul's Light Foundation actively engages in the community, which allows them to profoundly impact the immediate needs of mothers and their infants and the systemic issues

that are being experienced. Due to this immense commitment to the community that has resulted in trust and collaboration, the foundation has found a way to create a space of unity and support within the NICU community. With this in mind, a recommendation is to establish “NICU stories,” which can be a digital platform that can serve as a safe forum where mothers can share their NICU experiences in the form of videos, podcasts, and blog posts, which will be very therapeutic to mothers. As a NICU mother, I understand the need to validate and honor one’s experiences. Having a repository of shared stories can create an environment of needed healing. An initiative of this measure will grow the foundation’s ability to engage the NICU community while providing an effective support structure, creating deeper connection, empowerment, and understanding among NICU mothers.

Recommendation 4: Creating Counseling Groups That Will Attract More Black Mothers

There are considerable implications due to these unexpected findings. Outreach methods must be reassessed and adjusted to ensure Black mothers are informed of available support groups. A recommendation is for social workers and group facilitators to be trained in cultural competency to understand the unique needs of Black mothers. Another strategy to build trust is to collaborate with community leaders who are trusted figures in the community to ensure that support initiatives are utilized with a sense of trust. It will also be necessary to implement feedback mechanisms to provide insights related to why Black mothers hesitate. This will allow more effective interventions that are tailored to the mothers. Due to this unexpected finding, it is essential to have a deeper understanding of the reasoning behind the reluctance to build this gap, thus ensuring that Black mothers can receive the NICU-related social-emotional support they need and deserve.

Limitations

This study offers insights into the support available to Black mothers and their premature infants in New Orleans. Nevertheless, it is important to acknowledge the limitations. A primary limitation was having to use pre-recorded interviews and not real-time interviews with mothers. With direct interviews, there is the opportunity to ask follow-up probing questions and seek more detail. Additionally, peer mentors were not interviewed and were identified as a source of invaluable support by the mothers in the pre-recorded interviews. The unique perspectives of the peer mentors would have provided more dimension to the study's findings and recommendations.

Due to my connection to the subject matter, the matter of bias is worth exploring. There were opportunities for me to empathize and relate and the potential for bias where the pain could have clouded my perception. The emotional connection to the subject matter could have unconsciously influenced the analysis and interpretation of the qualitative data, leading to certain aspects being overlooked. The NICU journey was a lived experience, which was valuable for sympathetic insight but could also be a challenge in maintaining objectivity.

Conclusion

As a Black woman who has experienced the roller coaster of the NICU, I am aware of the challenges, feelings of hope, and overwhelming emotions this pivotal phase represents in the lives of other families. Through this study, I sought to reveal the kaleidoscope of experiences to tell the stories of Black mothers and the devoted staff at Saul's Light Foundation. The narratives of the mothers provide us with insight into the NICU journey characterized by strength, fear, and sometimes incomprehensible grief. Their stories provide us with a powerful reminder of the need for compassion, support, and cultural humility in the NICU setting. Their narratives remind us that the NICU experience is not just a place for medical treatment but also

an opportunity to comprehend and uphold the physical, emotional, and medical needs of families.

Simultaneously, the staff members of Saul's Light Foundation and the Licensed Clinical Social Workers provide a glimpse into the joys and obstacles experienced while providing this level of support to NICU families and their infants. This support team was dedicated to ensuring that Black families in the NICU received tailored care that was fully comprehensive. Their reflections highlight the importance of partnership, equity in healthcare, and tailoring support to the individual needs of mothers and their premature infants. Their insights also highlight the necessity for holistic care in hospitals, ongoing training, and resource allocation to ensure that every Black mother and their premature infant are cared for with unbiased discernment and understanding.

The NICU can be a painful path; data tells us it is an even more arduous journey for Black mothers and their premature infants. This study goes beyond the realm of numbers and theories; it is the essence of my human experience. The project was born from my pain and commitment to countless Black mothers who have walked similar paths. For this reason, this capstone project is intertwined with the story of my premature son.

Miles had a story. He was born at 25 weeks gestation and weighed one pound and six ounces at birth. My husband, Matt, and I visited him every day, sang to him, told him about his older sister, decorated his incubator, and watched him grow and struggle. Unfortunately, he died after 30 days; there were just too many symptoms of prematurity for him to overcome. I miss him every day and always question and wonder what could have been different and what was within my control. His story and mine highlight the systemic hurdles Black mothers and their premature infants face and the need for a fundamental change in how the American healthcare system engages and interacts with us. Through this capstone project, I aim to give a voice to mothers and their infants who have suffered. Our voices are collective and unyielding out of a desire for radical change in the maternal healthcare community.

In memory of Miles, this study is a testament to the power of storytelling, the need for representation, and the importance of building a world where Black mothers feel seen, heard, and understood.

Appendix I

Data Collection Instrument I

Interview with Families Who Have Received Support from Saul's Light Foundation

Welcome and Introduction

- Begin by thanking the participants for their willingness to participate in the interview.
- Explain the purpose of the interview and how their insights will contribute to improving support services for families.
- Emphasize the confidential and anonymous nature of the interview.
- Reiterate that their participation is voluntary, and they can choose to withdraw at any time.

Participant Information

- Participant Demographics
 - Record the participant's name, age, gender, and any other relevant demographic information.
- So we'd first like to start off by asking a few basic questions about your child and their NICU stay. Again, this information will be de-identified. So first, what is the name of your child or children that were in the NICU?"
- When was your child in the NICU?

We would like to hear about any specific needs and barriers you faced while you had an infant in the NICU. So our first section is going to be about the postpartum period. The postpartum period can be an incredibly hard time due to physical recovery and

adjustments to having a new baby, and there may be additional challenges with an infant being moved into the NICU and having an extended NICU stay. We would like to better understand how the postpartum period may have affected your NICU experience.

- What was the experience of being told your child needed to be transferred to the NICU and would be receiving care there?
- How long did you stay in the hospital after delivering?
- While you were still recovering in the hospital for those 24 hours were you able to go into the NICU?

In the next part of our interview, we would like to find out how different factors may have shaped your NICU experience to identify and address challenges and barriers families face in the NICU. A few aspects we will touch on are your transportation method to the hospital, support systems, health insurance coverage, any potential religious and cultural barriers you may have faced, and whether having other children at home affected your ability to visit the NICU. The first question

- After you were discharged from the hospital, what aspects of having a child in the NICU were difficult for you?
- What were some of the biggest challenges to visiting the NICU and spending time there?
 - Was finding child care a barrier to visiting the NICU if you had children at home?
- What was your support system like?
- How often were you able to visit the NICU?
 - How far away from the hospital did you live?
 - Did this distance affect your ability at all to get to the NICU or to spend time there?

- Were you able to get safely to and from the hospital every time?
- And were there ways in which access to reliable transportation, like driving time, gas, access to a car, or public transportation, made your, limited your ability to visit the NICU or made it difficult for you?
- Did you have reliable, stable, and safe housing throughout the time your children were in the NICU?
- And did you have health insurance during your NICU stays?
 - What was your experience with your health insurance?
- During your NICU experiences, did you face any cultural or religious barriers?
- Did you have any negative experiences in the hospital or difficulty navigating the hospital system other than maybe the shuffle and the long distance to the NICU?
- Were there any difficulties or challenges when you were about to be discharged, like worrying about having supplies, infant supplies, or anything at home?
- Did you face any other challenges when caring for your infant at home?
 - And are there any other needs, barriers, or challenges that you face that I did not address?
 - *We would like to hear how your experience was working with us. Our mission at Solve Light is to support as many families as we can with infants in the NICU and to improve how we serve families. We welcome any feedback.*
- How did you feel working with Solve Light or any other community nonprofit organizations?
- What were some of the resources that we were able to provide you with that made the biggest impact?
- Do you have any ideas on what more Saul's Light Foundation can do to provide for families?

- Did working with Saul's Light Foundation help with education on your infant, help alleviate mental and emotional stress, and help with the transition home and into the community?
- Did you have a Saul's Light peer mentor?
- Do you remember seeing a little library on the shelves at Children's?
 - What was your experience with the little library?
 - Do you have any thoughts or feedback on the reading program?
 - What do you feel is the main difference between the types of support you receive from the hospital and the types of support you receive from Saul's Light?
- Do you feel that the support from Saul's Light bridged any gaps in care?

Final Thoughts and Additional Information

Provide an opportunity for the individual to share any additional thoughts, experiences, or recommendations that have not been covered in the previous questions.

- Appreciation and Consent Confirmation
- Express gratitude for their participation and valuable insights.
- Reiterate the confidentiality and anonymity of their responses
- Confirm their consent for the use of their interview data in the study.

Data Collection Instrument II

Interview with Staff Members at Saul's Light Foundation

Introduction:

Begin by thanking the staff member for their willingness to participate in the interview.

Briefly explain the purpose of the interview, which is to gain insights into their role in supporting Black families in the NICU context.

- Reiterate the confidentiality and anonymity of the interview.
- Emphasize that their participation is voluntary, and they can choose to withdraw at any time.

Participant Information

- Participant Demographics
- Record the staff member's name, position, years of experience at Saul's Light Foundation, and any other relevant demographic information.

Opening Reflections

- Ask the staff member to reflect on their overall experience working at Saul's Light Foundation and their role in supporting Black families in the NICU.
- Encourage them to share their thoughts, emotions, and key moments that stand out to them.

Main Interview Questions:

- Can you describe your role at Saul's Light Foundation and how it relates to supporting Black families in the NICU?
- What are your primary responsibilities and tasks in providing support to families?
- Can you share any examples of specific ways you have supported families in the past?

- What are some of the challenges you encounter in supporting Black families in the NICU?
 - How do you address these challenges? Can you provide examples of strategies or approaches you have found effective?
- How do you collaborate with other staff members at Saul's Light Foundation to provide comprehensive support to families?
- Can you describe any collaborative initiatives or projects that have been successful in meeting the needs of Black families?
- How does Saul's Light Foundation ensure cultural sensitivity and inclusiveness in their support programs for Black families?
- Can you provide examples of initiatives or practices that promote cultural understanding and meet the unique needs of these families?
- In your opinion, what impact does the support provided by Saul's Light Foundation have on Black families in the NICU?
- How do you measure the success or effectiveness of your support programs?
- What aspects of your work bring you the most satisfaction in supporting these families?
- Based on your experience, what recommendations or suggestions would you give to Saul's Light Foundation to enhance their support services for Black families?
- Are there any areas where you believe additional resources or training would be beneficial for staff members in supporting these families?

Final Thoughts and Additional Information

- Provide an opportunity for the staff member to share any additional thoughts, experiences, or recommendations that have not been covered in the previous questions.

Closing

- Appreciation and Consent Confirmation
- Express gratitude for their participation and valuable insights.
- Reiterate the confidentiality and anonymity of their responses.
- Confirm their consent for the use of their interview data in the study.

Data Collection Instrument III

Interview with Licensed Clinical Social Workers Collaborating with Saul's Light Foundation

Introduction

Begin by thanking the licensed clinical social worker for their willingness to participate in the interview. Briefly explain the purpose of the interview, which is to gain insights into their collaboration with Saul's Light Foundation in supporting Black families in the NICU context.

- Reiterate the confidentiality and anonymity of the interview.
- Emphasize that their participation is voluntary, and they can choose to withdraw at any time.
- Participant Demographics
 - Record the licensed clinical social worker's name, position, years of experience, and any other relevant demographic information.

Opening Reflections

Ask the licensed clinical social worker to reflect on their experience collaborating with Saul's Light Foundation and their role in supporting Black families in the NICU.

Encourage them to share their thoughts, emotions, and key moments that stand out to them.

Main Interview Questions

- How did your collaboration with Saul's Light Foundation come about? Can you describe the nature and extent of your collaboration?
- What role do you play in supporting Black families in the NICU through this collaboration?

- Can you share any examples of specific ways you have collaborated with Saul's Light Foundation to provide support to families?
- What are some of the challenges you encounter in supporting Black families in the NICU through this collaboration?
- How do you address these challenges?
 - Can you provide examples of strategies or approaches that have been effective in supporting these families?
- How would you describe the working relationship between your healthcare team and Saul's Light Foundation?
- Can you share any examples of successful initiatives or projects that have been achieved through this partnership?
- How do you ensure effective communication and coordination between your team and the foundation?
- In your opinion, what impact does the collaboration with Saul's Light Foundation have on the well-being of Black families in the NICU?
 - Can you provide examples of specific instances where the collaboration has made a positive difference for these families?
- How do you ensure cultural sensitivity and inclusiveness in your collaborative efforts with Saul's Light Foundation?
- Can you share any initiatives or practices that have been implemented to address the unique needs of Black families in the NICU?
- Based on your experience, what recommendations or suggestions would you give to further enhance the collaboration between licensed clinical social workers and Saul's Light Foundation in supporting Black families?
- Are there any areas where additional resources or training would be beneficial for licensed clinical social workers to better support Black families?

Final Thoughts and Additional Information

Provide an opportunity for the licensed clinical social worker to share any additional thoughts, experiences, or recommendations that have not been covered in the previous questions.

Closing

- Appreciation and Consent Confirmation
- Express gratitude for their participation and valuable insights.
- Reiterate the confidentiality and anonymity of their responses
- Confirm their consent for the use of their interview data in the study.

Appendix II

Data Collection and Analysis Status Report Data Visualizations

Thematic Categories and Number of Occurrences from Interviews with Mothers

Thematic Category	Description	Occurrences
Emotional Responses	In the transcripts, the mothers mentioned a range of emotions. The data shows a gamut of feelings from emotional pain usually due to the shock of having a premature infant who needs intensive care to feelings of longing and isolation due to being apart from their vulnerable infant. The emotions also veer towards gratitude and hopefulness. These feelings occur during times of positive feedback from a doctor or simple interactions such as being able to carry their infant.	176
Challenges and Barriers	The main logistical challenges experienced by some of the mothers in the recordings are financial difficulties and transportation issues. Their stress is exacerbated by a lack of clarity in information and not being able to understand the medical terminologies. These challenges and their commonality stress the importance of logistical support and clear communication in NICU settings.	175
Child's Status and Care	A central piece of each mother's concern was the health status of her premature infant. This care is sometimes coupled with the daily care of another child at home. The mothers in the transcripts consistently discussed their profound worries about their child and their well-being coupled with a reflection on the quality of care being received. Due to these prevalent concerns, there must be transparent communication about the health of the child and the treatment plan.	101

Postpartum & Recovery	The postpartum phase was mentioned briefly. Maneuvering through the roller coaster of the NICU while experiencing such a pivotal phase of recovery is indicative of the resilience of the mothers and the importance of support systems.	10
Support & Community	The unswerving commitment from Saul's Light Foundation, the peer mothers group, and the community is highly apparent. This type and level of support offers emotional support, closes gaps in understanding, and creates a sense of community thus demonstrating the foundation's indispensability in the NICU journey.	80

Thematic Categories and Number of Occurrences from Interviews with Saul's Light Foundation Staff

Thematic Category	Description	Occurrences
Personal Connection Driving Commitment	The personal experience and identities of the staff are rudder for the passion and commitment to Saul's Light Foundation. As a Black woman and NICU mother who lost a child, the founder provides a unique perspective steeped in empathy and awareness leading to a personal mission. The presence and power of these connections amplify this deep commitment to serving Black families while making sure that services reflect their distinctive needs.	23
Continuity of Care and Support	Providing comprehensive support to families during the NICU stay and beyond is the main emphasis of the foundation's approach. There is a clear recognition that difficulties can persist post the NICU stay. The foundation aims to ensure lasting relationships are fostered thus making an emphasis on the essential need for continuous care and support throughout a families' journey.	47
Systemic Challenges and Advocacy	The foundation takes an active stance by advocating for Black families as they experience systemic biases and challenges in the NICU. Saul's Light Foundation raises awareness by empowering families with knowledge in order to eliminate these systemic barriers.	5

<p>Cultural Sensitivity and Community-Centric Approach</p>	<p>The foundation aims to have a deep understanding of the cultural context of the families that receive their services. They make concerted efforts to respect their values, traditions, and the experiences of the community. Being able to acknowledge this cultural bond allows the foundation to provide tailored services that are culturally sensitive to the needs of Black families.</p>	<p>2</p>
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Thematic Categories and Number of Occurrences from Interviews with Licensed Clinical Social Workers and Hospital Staff

Thematic Category	Description	Occurrences
Proactive Community Engagement	This demonstrates Saul's Light Foundation and its devotion to creating true connections, cultivation of collaborations and for nurturing active feedback channels.	27
Tangible Positive Outcomes	The reflection of the authentic impact of the foundation's initiatives, and the transformational changes that were stimulated for Black mothers, their infants in the NICU, and their families.	10
Navigating Complex Challenges	The theme addresses the challenges that are experienced in the NICU environment. It spotlights the foundation's commitment to reducing and ameliorating them.	9
Holistic Support Systems	This theme was the most dominant. It highlights the all encompassing approach and encompasses medical, practical, and emotional support.	120
Collaboration & Collective Effort	An emphasis is put on the essential need for partnerships and collaboration. This theme casts light on the foundation's belief in action as the action of a collective to achieve the greatest impact.	22

Thematic Categories and Number of Occurrences from the Document Analysis

Thematic Category	Description	Occurrences
Emotional Well-being & Sense of Community	There is an essential focus on the emotional well-being of families receiving services from Saul's Light Foundation. Terms like "comfort", "support", and "hope" frequently appear. This signifies that the foundation is making large efforts to provide emotional and psychological support to families. By focusing on this, there is a clear understanding of the immense emotional difficulties being faced by NICU families. This also highlights the foundation's commitment to addressing the socio-emotional and physical needs of NICU families.	9
Community-Related Terms	A strategy of Saul's Light Foundation is to be ingrained within the community surrounding it. Terms such as, "community, connection, belonging" demonstrate a strong desire to create a sense of community among NICU families. This approach is essential in ensuring that families feel included, supported and cared for during their NICU journey.	9
Accessibility	Terms such as, "accessible, available, and resources" reveal that accessibility is an essential theme within the foundation. The foundation is committed to ensuring that irrespective of their background, all NICU families are able to access the resources and services that they need and deserve. There is a focus on breaking down barriers in order to be readily available to those in need.	10
Cultural Sensitivity	The foundation's mission is built on essential components such as cultural sensitivity and diversity. Terms such as, " culture, sensitivity, and diversity" highlight the foundation's respect for diversity, and their focus on being culturally aware and accommodating. This approach ensures that care and	6

	support are tailored to the unique needs of families of different backgrounds who receive their services.	
Community Engagement & Health Outcomes	It is important to Saul's Light Foundation that the community and other stakeholders are actively engaged. Terms such as, "engagement, collaboration, and partnership" demonstrate outreach efforts that are thoughtful and proactive. The collaboration with community leaders indicates a focus on improving health outcomes and making sustainable and positive changes.	6
Nonmedical Drivers of Health	The foundation is aware of and recognizes the impact of nonmedical drivers of health on health outcomes. These drivers, such as housing, food security, and education, are addressed by Saul's Light Foundation with a holistic view of health. This vision is steeped in the belief that interventions are not solely medical but that they should be extended to address systemic and socio-economic needs and challenges.	3

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