

Enhanced Doula Support to Improve Pregnancy Outcomes Among African American Women With Disabilities

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ABSTRACT

Aim: This article is a meta-analysis of studies examining the influence of doula support on birth outcomes among African American women with disabilities. While an estimated 11% of women in their childbearing years are impacted by some type of disability, mothers with disabilities are faced with risks during pregnancy. When risks in addition to maternal disability are present, mothers may encounter extra barriers that impede receipt of effective care. **Method:** A meta-analysis of studies revealed women with disabilities are at risk for poor birth outcomes. Specifically, women of color living in poverty-stricken areas are at a greater risk for adverse birth outcomes. **Results:** As a result of adverse experiences related to birth, mothers may experience levels of traumatic stress. To advocate for better pregnancy and birth outcomes, the intervention of doula support is emphasized. **Conclusion:** There is a widely recognized need to promote better pregnancy outcomes among African American women to address disproportionate birth outcomes. Strategies to enhance doula support among African American women with disabilities are offered. Implications include future research surrounding the development of a training program for doulas specific to disability, trauma-informed care, and maternal mental health.

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INTRODUCTION

This article is a meta-analysis of studies examining the influence of doula support on birth outcomes among African American women with disabilities. Authors included the term “enhanced” to provide readers with a clear understanding of the idea to develop training components specific to disability,

trauma-informed care, and maternal mental health in addition to an already existing doula training curriculum. An in-depth summary and outline of the intersection of birth outcomes, doula role/function, enhanced doula training support, maternal mental health, and maternity care transformation is provided. Implications for childbirth educators, doulas,

counseling professionals, nurses, certified nurse midwives, and other allied health professionals are provided.

Pregnancy and childbirth pose numerous risks for mothers. Those risks partnered with a disability has the potential to create more challenges for women (Reblando, 2018). An interest from the federal government has surfaced encouraging researchers to further address the lack of available literature surrounding health-care disparities among persons with disabilities (Akobirshoev et al., 2017). Behavioral differences have been identified among mothers during pregnancy without disabilities. A few identified challenges include but, are not limited to, (a) an overstimulating environment, (b) feelings of isolation, (c) lack of information, and (d) anxiety during communication and scheduling (Reblando, 2018). There is an estimated 11% of women in their childbearing years that are impacted by some type of disability (Byrnes & Hickey, 2016). In comparison to women without disabilities, recent studies have stated pregnant women with disabilities are at a higher risk to experience adverse health and poorer birth outcomes (Horner-Johnson et al., 2019). To provide clarity, the term disability is operationalized according to the definition provided by the Americans with Disabilities Act (1990) which states a person with a disability is as an individual who: (a) has a physical or mental impairment that substantially limits at least one major life activity, or (b) has a record of such an impairment, or (c) is regarded as having such an impairment. There is a widely recognized need to promote better pregnancy outcomes among African American women to address birth outcome inequities (Thomas et al., 2017).

An effective intervention to promote positive birth experiences and outcomes is doula support. However, little is known about the use of doula support among African American women diagnosed with disabilities. According to Stokes and Scott's (2003) project titled "The Initiative on Triple Jeopardy: African American Women with Disabilities," the status of "double jeopardy" from being a minority with a disability quickly deviates to a "triple jeopardy" status with the addition of gender. Recommendations captured from the triple jeopardy project's participants include, the intentional development and linkage with community support groups tailored for women with disabilities, and the incorporation of cultural sensitivity training for service providers. It is essential for service providers to actively listen to African American women with disabilities in

The challenges and stigma persons with disabilities encounter partnered with factors of pregnancy, potential trauma, and race (e.g., African American) have the possibility to effect healthcare outcomes.

efforts to effectively address concerns (Stokes & Scott, 2003). The research revealed that it is essential to progress beyond the task-specific routine of service provision to the development of a meaningful relationship between the client and service provider that displays an active and consistent interest in the client (Stokes & Scott, 2003).

Mitra et al. (2016) highlighted the historical fact that motherhood and disability have been viewed as two separate concerns. Specific to women with physical disabilities, there is no known systematic efforts to develop policies or procedures specific to ensuring the needs of mothers with disabilities are met (Mitra et al., 2016). Recommendations and reported experiences from participants within earlier works of Mitra et al. (2016) indicated that women independently search for resources and information that provide insight on potential pregnancy impact or depend on other women in similar situations for guidance and support. It can be assumed that this period of inquiry may be scary, perceived as traumatic and further impact mother's abilities to effectively progress into the role of motherhood. While it is not generalized that all pregnant women with disabilities experience trauma, when present, trauma can significantly impact an individual's health, behaviors, relationships, work, school, and other aspects of life. It is crucial for behavioral health, health care, and other allied health and community support providers to gain the knowledge and skills needed to promote healing, recovery, and wellness. The following section provides a general overview of birth outcomes among African American women and their counterparts within various local communities.

BIRTH OUTCOMES

Women of color in the United States residing in high-poverty areas are at greater risk of experiencing poor birth outcomes (Thomas et al., 2017). The challenges and stigma persons with disabilities encounter partnered with factors of pregnancy, potential trauma, and race (e.g., African American) have the possibility to effect health-care outcomes. The disproportionate birth outcome rates are suggested because of preexisting conditions (Braveman et al., 2011), and poverty and experiences of racism (Latendresse,

2009; Rosenthal & Lobel, 2011). African American women hold higher records for preterm birth and low birth weight (Bell, 2012). Contributions to the disparities are debatable, and according to Bell (2012) include limited access to care, lower rates of private insurance, and single parenthood status. Research conducted by Howell et al. (2016) further confirmed that hospitals which services are rendered to majority African Americans are at higher risk for maternal morbidity over hospitals that serve white counterparts.

In addition to maternal morbidity, The Maternal and Child Health Services Title V Block Grant report identified that in North Carolina, the African American infant mortality rate was 13.4 compared to the 5.0 rate of their White counterparts. The document also identified that African American families are over twice as likely to face poverty over White families. According to the 2017 North Carolina Infant Mortality Report, African Americans rated highest among infant deaths, totaling 361 in 2017. Specific to the author's local context and communities of interest, the following counties had the highest infant death ratings: Mecklenburg, NC-41, Guilford, NC-34, Cumberland, NC-33, Wake, NC-31, Forsyth, NC-25, Pit, NC-13, and Durham, NC-12 (NC Department of Health & Human Services State Center for Health Statistics, 2018). Of those infant's deaths, 47 were due to maternal factors/complications of pregnancy and labor and birth (NC Department of Health & Human Services State Center for Health Statistics, 2017). These ratings indicate the need to address preventative methods to reduce such complications. To help mitigate the disproportionate rates of inequities in birth outcomes, doula support for the African American mothers may serve as a change agent to help reduce these occurrences. Moreover, women with disabilities are considered a vulnerable population to experience health-care deficiencies contingent on the setting and type of disability (Devkota et al., 2018). Increased access to doula support may yield improved birth outcomes among African American women, especially those living in poverty (Thomas et al., 2017). To further identify the impact of doula support on birth outcomes, Thomas et al. (2017) suggested the need for additional research surrounding doula support

among populations with identified chronic diseases, poverty, violence, and instances of structural racism. The following two sections provide an overview of doula supports and the trauma-informed care framework as a potential source of support to improve birth outcomes.

DOULA SUPPORT

Doula Role and Function

Forty percent or more women are uninformed of the benefits of doula support (Wint et al., 2019). Doulas are childbirth experts that provide emotional, physical, and psychoeducational support to mothers during the prenatal and postpartum period without medical, technical, or pharmacological interventions (DONA International, 2014). It is suggested that doula support has the potential to interrupt adverse experiences with the health-care system that may result from institutional bias (Wint et al., 2019). Doula support may also assist African American women to better navigate a health-care system where acts of discrimination are typically present (Wint et al., 2019). While the benefits of doula support are great, the cost of services are often an extensive barrier. Due to the extensive cost, many associate support from doulas as a privilege for wealthy Caucasians. As this point remains, African American mothers specifically, low income, continue to express interest in the receipt of doula support (Wint et al., 2019).

Parallel with the core tenets of rehabilitation counseling, doula care consists of empowering women to become self-advocates, maintain decision-making abilities, remain efficacious, autonomous, and engage in positive goal setting (Thomas et al., 2017). Given the benefits of doula support, women of color and those identified as low income, underutilize doula support services (Kozhimanil et al., 2014). Many pregnant women have no knowledge of available doula services, or experience barriers related to the cost of doula services (Thomas et al., 2017). Thus, bringing awareness to doula support in local underrepresented communities is essential. Some communities are acknowledging the need for increased access to doula support. The By My Side Support program was introduced by the New York City Department of Health and Mental Hygiene's Healthy Start Brooklyn in 2010. The program offers free doula support services to women who meet the Women, Infants, and Children Nutrition Program (WIC) requirements (Thomas et al., 2017). Hospitals are typically

It is suggested that doula support has the potential to interrupt adverse experiences with the healthcare system that may result from institutional bias.

the birthing location for most mothers and understanding the intersection of doula support within the hospital environment (e.g., nurses, doctors, and certified nurse midwives) is essential as well. Thomas and colleagues (2017) emphasized the need for further research on the impact of doulas on hospital practice. In addition to the impact on hospital practices, given the various areas of support mothers may require especially with those with a disability, an enhanced trauma-informed, disability-specific, and maternal mental health component to doula support may assist current efforts to improve birth outcomes.

ENHANCED DOULA SUPPORT

Trauma-Informed Care

Furthering the agenda to promote positive birth outcomes in African American mothers with a diagnosed disability, an area for future research may consist of exploring birth outcomes following the implementation of a trauma-informed approach to doula support. Trauma may take on various forms, and in some cases is an inevitable acquaintance within human existence (Kazlauskas, 2017). As a result of adverse experiences related to birth, mothers may experience levels of traumatic stress. These reports of parental concerns make sense from the point of view of lived traumatic experiences and trauma-related events. How an individual perceives the event is the determining factor of if the experience is traumatic or not (Simkin & Hull, 2011). The term trauma may have several interpretations. According to the Substance Abuse and Mental Health Services Administration (SAMHSA, 2014), trauma is caused by experiences that instigate physical and psychological stress reactions. Trauma may result from a single event, multiple events, or a set of circumstances that are emotionally or physically harmful, negatively impacting an individual's physical, social, emotional, or spiritual well-being (SAMHSA, 2014). Trauma impedes an individual's ability to cope, generating feelings of fear, vulnerability, and emotional weakness (SAMHSA, 2014). Trauma can significantly impact an individual's health, behaviors, relationships, work, school, and other aspects of life. It is crucial for behavioral health, health care, and other allied health and community support providers to gain the knowledge and skills needed to promote healing, recovery, and wellness.

A trauma-informed approach emphasizes the importance of accepting the whole person and displaying respect for their context of living life

To combat birth outcome inequities, the Healthy Start Brooklyn initiative targeted African American and Latino communities with a history of resource deprivation and implemented free doula support services.

(Harris & Fallot, 2001), all of which are essential in supporting persons with disabilities. Six essential aims of a trauma-informed approach consist of (a) safety, (b) trustworthiness and transparency, (c) peer support, (d) collaboration and mutuality, (e) empowerment, voice, and choice, and (f) cultural, historical, and gender issues (SAMHSA, 2014). Instead of operating from a deficit approach, which views the person with a disability as broken or dysfunctional and relinquishes the power to the expert to "fix" the situation, a trauma-informed approach values a strengths-based approach (Harris & Fallot, 2001). The strengths-based approach avoids defining individuals with disabilities by their issues, and highlights aptitudes and abilities (Harris & Fallot, 2001). Doulas can integrate a strengths-based approach within their style of service delivery. Implementation of the strengths-based approach can further stimulate skill development, sense of well-being, competence, and enhanced self-efficacy (Harris & Fallot, 2001).

The major support that doulas provide to mothers, partnered with the previously stated tenets, lead authors to believe in a powerful approach to doula support, and an overall improvement of health-care outcomes for pregnant mothers with disabilities. No matter the amount or level of training individuals acquire within the human services field, receiving introductory trauma information has many benefits (Harris & Fallot, 2001). Gaining a brief introduction to trauma dynamics can allow individuals to develop increased sensitivity and avoid retraumatizing the person seeking services (Harris & Fallot, 2001). A trauma-informed mindset shifts from "what's wrong?" to "what happened?" (Sweeney et al., 2018). Doulas operating from a trauma-informed perspective shift the traditional way of understanding behavioral responses that appear maladaptive, to the understanding that those responses are potentially indicative reactions of experienced trauma (Jones, 2017). An essential role for the trauma-informed doula is to understand how forms of abuse (e.g., emotional, sexual, physical) can have a major impact on individuals (Jones, 2017). It is the goal to avoid undue stress and retraumatization during the time of providing support (Jones, 2017).

Doula support should not be restricted as a privileged service only certain individuals, for example those of a higher socioeconomic status, can receive

Trauma-informed doula support is nonjudgmental and understands individuals have histories that influence choices and modes of operating in the best way known regarding self and the child (Jones, 2017).

It is crucial for behavioral health, health care, and other allied health and community support providers to gain the knowledge and skills needed to promote healing, recovery, and wellness. When considering maternal perception of birth experiences, it is critical to understand the possibility for the development of certain trauma and stress-related disorders, for example, post-traumatic stress disorder (PTSD; Simkin & Hull, 2011). When the perception of trauma surrounding pregnancy or childbirth and even postpartum is identified, mothers may experience a variety of emotions and reactions. Mothers can experience flashbacks or recurrent intrusive recollections of the event, fear of reoccurrence, negative cognitions such as diminished interest and distorted blame, panic attacks, aggression, and the avoidance of specific individuals or locations (American Psychiatric Association, 2013) as a result of perceived traumatic birth experiences. In efforts to discuss the importance of overall wellness during pregnancy, childbirth, and the postpartum, the succeeding section provides an overview of maternal mental health.

Maternal Mental Health

Due to the impact on maternal and child health, maternal mental health research has become a priority and public health issue (Satyanarayana et al., 2011). According to the Perinatal Mental Health Alliance for Women of Color (PMHA-WOC; n.d.), it is estimated that one out of five women will experience a perinatal mood and anxiety disorder during or following childbirth. It has been established that various psychiatric disorders are likely during pregnancy, while depression is estimated as the most common disorder (Satyanarayana et al., 2011). PMHA-WOC highlighted that an average of 38% of new mothers are impacted by perinatal emotional difficulties such as depression and anxiety. Specifically, women of color are impacted at twice the rate of white women. Surprisingly, 60% of women of color are without access to resources or support

for perinatal emotional difficulties. Additionally, the PMHA-WOC explained the high percentage is a result of insurance coverage, stigma, barriers to services, and inadequate culturally applicable services. A mother's postpartum mental health may cause reflection on perceived birth experiences whether positive or negative. In instances of perceived traumatic birth experiences, the manifestation of immediate or future symptoms of depression, acute stress disorder, or PTSD may occur (Anderson & Cacola, 2016). In efforts to prevent traumatic birth experiences from developing into PTSD, doula support is recommended as a strategy (Simkin, & Hull, 2011). Limited programs and literature exist that address the significance of consistent emotional, physical, social supports and overall maternal mental health for women of color, especially low income. Access to resources such as doula support may increase positive birth outcomes, and overall continuity of maternal care.

Access to Doula Support

The cost of doula support can often fall outside of low income and underrepresented women's financial abilities. Other barriers include limited information regarding services, availability of services, and cost of doula support (Thomas et al., 2017). The benefits to the receipt of doula support are acknowledged, while stable funding is a consistent barrier that impedes access (Strauss et al., 2016). To reach more underserved populations Strauss and colleagues (2016) offered recommendations for expanding doula coverage among private and public insurances. Recommendations consist of: (a) a mandate from Congress designating doula support as a mandatory covered benefit, (b) the development of clear reimbursement procedures for doula supports, (c) amending state Medicaid plans with respect to the revision of the preventative services rule, 42 CFR 440.130(c) and new and existing Delivery System Reform Incentive Payment waiver programs, (d) identifying if consistent labor support by a trained doula is within The U.S. Preventative Services Task Force, and if doula support is within the Task Force's scope, determine if trained doula services are considered a component of recommended preventative care, (e) inclusion of doula supports by Managed Care Organizations along with other payment and delivery systems, and (f) passage of legislation deeming mandatory coverage doula supports within private insurances. While increasing, but few, states are moving forward with efforts to bring awareness

and change to birth inequities faced by women of color. Minnesota and Oregon are two states with passed legislature that allow for Medicaid coverage for doula assistance (Kozhimannil et al., 2014). To combat birth outcome inequities, the Healthy Start Brooklyn initiative targeted African American and Latino communities with a history of resource deprivation and implemented free doula support services. In 2010, The New York City Department of Health and Mental Hygiene's Healthy Start Brooklyn developed the By My Side Support Program to further address birth inequities (Thomas et al., 2017). Program participants receive free doula supports if they meet the income eligibility for the WIC program (Thomas et al., 2017). The development of grant-funded programs and volunteer doula supports like Healthy Start have been created to combat disparities (Thomas et al., 2017). Advocating for the same caliber of coverage as Oregon, Minnesota, and efforts by New York, may create stronger networks of support for the incorporation of doula coverage in a variety of states. To recommend for the receipt of such support among African American women living in poverty, it would be ideal for future research agendas to replicate programs like the By My Side Birth Support Program to continue efforts of decreasing birth outcome inequities. Implementing no cost doula supports in underserved high-poverty communities of color may be the key to reducing birth inequities (Thomas et al., 2017). In addition to addressing the financial burden that often serves as a barrier to the access of doula support, the following section reflects on additional approaches aimed to support transformation in maternity health care.

MATERNITY CARE TRANSFORMATION

Centering Model of Pregnancy

An approach health-care providers can take to address the significance of emotional, physical, and overall mental health for childbearing women is the centering model. Centering consists of group prenatal care and childbirth education (Liu et al., 2017). Centering focuses on the three areas of (a) health-care delivery, (b) health education, and (c) peer support (Liu et al., 2017). Within the model, women are assigned groups according to gestational age. Each specific group meets consistently over the duration of their pregnancies (Liu et al., 2017). Grounded in self-efficacy theory, women are empowered to become active participants in their care with the intention to experience positive pregnancy outcomes (Liu et

al., 2017). Participants discuss topics related to early pregnancy, infant care, and formal and informal group sharing within centering's curriculum (Liu et al., 2017). Feelings of control and empowerment are greater because of centering (Liu et al., 2017).

With the shift of focus in maternal, newborn, and child health, the World Health Organization (WHO) outlined a high-quality vision for mothers expanding from pregnancy to postnatal (Oladapo et al., 2018). In 2018, WHO released new recommendations highlighting the significance of positive childbirth experiences (WHO, 2018). The new recommendations move beyond preventative measures of maternal morbidity and death to a person-centered philosophy to enhance the overall health and well-being of both mother and baby (Oladapo et al., 2018). The following table provides a few guiding principles from the WHO (2018) recommendations (Table 1).

In addition to the efforts outlined by Oladapo and colleagues (2018), the National Partnership for Women and Families unveiled a future plan further known as "the blueprint" to strengthen and add value to maternity care within the United States (Kennedy et al., 2018). The blueprint's primary focus is on systematic and transformational change to accomplish optimal health outcomes for women, children, and their families using resources (Kennedy et al., 2018). While a traditional blueprint is a template to build a structure, the fundamental purpose of the blueprint referenced by Kennedy and colleagues (2018) is to modify maternity care in the United States. Taking an architectural view, the blueprint consists of (a) firmness, which is the ability to maintain its physical integrity for survival, (b) commodity, referring to the functionality or practicality of the structure, and (c) delight, which denotes the effect of the structure on individuals who utilize it. When applying the same principles to maternity care the focus is on (a) achieving improved maternal health outcomes (functionality), (b) cost-effectiveness (survival), and (c) satisfaction (delight) (Kennedy et al., 2018). As a result of inequities in maternal health-care outcomes among African American, Native American, and those of low income, it is the belief that a lack of attention exists on the implementation of the architectural principles within maternity care (Kennedy et al., 2018). The blueprint is centered on six fundamental strategies aimed at high-value maternity supports. Reflecting the architectural principles, Kennedy, and colleagues (2018) outline strategies as indicated in the chart below (Table 2)

TABLE 1

Guiding Principles for Intrapartum Care

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- Labor and childbirth should be individualized and woman-centered.
 - No intervention should be implemented without a clear medical indication.
 - Only interventions that serve an immediate purpose and have been proven to be beneficial should be promoted.
 - A clear objective that a positive childbirth experience for the woman, the newborn, and her family should always be at the forefront of labor and childbirth care.
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TABLE 2

Six Blueprint Strategies for Achieving High-Value Maternity Care

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- Improve maternity care through innovative care delivery and payment systems and quality improvement initiatives.
 - Advance performance measurement for high-value maternity care.
 - Meaningfully engage all childbearing women and families.
 - Transition to interprofessional education that supports team-based care for maternity care professionals.
 - Foster an optimal maternity care workforce composition and distribution.
 - Conduct priority research to advance the science of physiologic childbearing and its impact on maternal and child health outcomes.
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The overarching goal of the blueprint is to create a maternity care system that addresses quality, safety, and costs of maternity services rendered. Coverage of the maternal health crisis in the media has influenced a major sense of awareness of necessary maternity care improvements (Kennedy et al., 2018). The awareness has extended to the development of maternal health bills currently underway within congress (Kennedy et al., 2018).

CONCLUSION AND FUTURE AREAS OF RESEARCH

Doula support should not be restricted as a privileged service only certain individuals, for example, those of a higher socioeconomic status can receive (Wint et al., 2019). The integration of doula services that entail providing physical, informational, and emotional support during pregnancy and childbirth has been known to enhance birth and postpartum outcomes (Wint et al., 2019). Doula support agencies within the local communities often work to diminish gaps by offering free or reduced services (Wint et al., 2019). Gruber and colleagues (2013) further confirmed that doulas empower individuals to experience and achieve the best birth outcomes as possible. This creates a significant opportunity for collaboration between childbirth educators, doulas, professional counselors, nurse midwives, and nurses given the emphasis placed on individuals reaching their maximum potential. Doula support can bridge the gap prior to, during, and after childbirth (Gruber et al., 2013). Hospital openness and intentional

inclusion of doula support may also help reduce disparities (Gruber et al., 2013). As mothers adjust to not only new experiences of motherhood, but also motherhood with a disability, doula support has the capability to enhance mother's self-efficacy pertaining to autonomy and capacity to influence her own pregnancy outcomes and experience (Gruber et al., 2013). Counselors, childbirth educators, nurses, nurse midwives, and other allied health-care professionals who assume a stance of maternal empowerment provide an essential element of psychological and emotional support to mothers. Given this fact, and the services doulas provide, doula support is assumed to also offer a solid sense of empowerment. Taking this stance informs maternal ability to confirm consent and remain an active participant within the birthing process, thus positively enhancing the childbirth experience, even in instances of adverse childbirth experiences (Nilsson et al., 2013).

To support efforts to improve birth outcomes among African American women, areas of future research include developing a specialized training for doulas with an emphasis in trauma-informed care, mental health, and disability as an effective element of doula training. To confront stigma surrounding women with disabilities, it is important for disability content and training to be included in educational settings, and available for professionals currently supporting women during pregnancy (Tarasoff, 2015). Collaborative efforts between researchers, women with disabilities, and disability scholars to increase exposure to disability-specific training may increase awareness and understanding

of the lived experiences, moving beyond the medical model, among women with disabilities (Tarasoff, 2015). Other areas of research should include low-income African American mothers, as limited studies exist that have examined doulas' experiences working specifically with that population (Wint et al., 2019). An additional area worthy of further research is the motivation of women of color, specifically African American women entering the doula profession. Critical to the motivation of African American women entering the doula profession is the lack of research on the race concordance of doulas and their clients (Wint et al., 2019). Additionally, investigating the birth outcomes among doulas of the same/different race and mothers is an additional noteworthy area in need of further research. To address necessary systemic modifications, Hardeman and Kozhimannil's (2016) research identified the need for an increase in the health-care system's ability to operate and respond effectively to a rapidly growing diverse population. A lack in the diversity of health-care providers has been noted as an influencer of health disparities among African American childbearing women. Working to move the agenda of transforming maternity health care, continued research surrounding the Centering Model of Pregnancy and strategies of the blueprint's impact on positive birth outcomes among African American women is a noteworthy research topic. Advocacy efforts designed to reach legislature striving for maternity care improvements, the agenda of the blueprint, and consistent assessment and systemic evaluation may influence a shift in a positive direction for childbearing women, their children, and families.

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