

The VOICES/VOCES Initiative

Moving Forward Through Women's Voices to Address Pregnancy and Birth Inequities in South Carolina

TECHNICAL REPORT
JUNE 2021

RESEARCH PERIOD: January 2020 – June 2021

Deborah L Billings, PhD Alyssa Robillard, PhD Chloe Rodriguez Ramos, MPH Ana Lòpez-De Fede, PhD Kathy Mayfield-Smith, MBA, MA



This report was prepared under a contract with the South Carolina Department of Health and Human Services (SCDHHS) and partially funded by the SC March of Dimes. The analytical summary, views, and opinions are solely those of the authors and do not necessarily state or reflect those of the SCDHHS or the SC March of Dimes.

© 2021 University of South Carolina – USC Institute for Families in Society. All rights reserved.

Full Project Name

Pregnancy and Birth Inequities in the Context of the COVID-19 Pandemic Voices of Women throughout South Carolina Who Rely on Medicaid/Emergency Medicaid for their Pregnancy-Related Care; Voices of Health Care and Social Service Leaders throughout South Carolina

Authors

The Moving Forward through Women's Voices to Address Pregnancy and Birth Inequities in South Carolina report was developed under contract with the South Carolina Department of Health & Human Services (SCDHHS) by the following Institute for Families in Society staff:

Deborah L Billings, PhD, Alyssa Robillard, PhD, Chloe Rodriguez Ramos, MPH Ana Lòpez-De Fede, PhD, Research Professor and Associate Director Kathy Mayfield-Smith, MBA, MA

For more information, please contact:

Ana Lòpez-De Fede, PhD
Institute for Families in Society
University of South Carolina
1600 Hampton Street, Suite 507
Columbia, SC 29208
adefede@mailbox.sc.edu
(803) 777-2098

Acknowledgements

We wish to acknowledge the valuable contributions made by the women who participated in these interviews shared their stories. We also acknowledge the health care and social service professionals and community leaders who shared their perspectives and insights to help us all better understand the pregnancy and postpartum experiences of women who use Medicaid. Lastly, we appreciate the support of the IFS Administrative Support staff and Data Science & Visualization team throughout this project as well as graphic design from 3RGDesignWorks for this report.

Suggested Citation

Billings, DL., Robillard, A., Rodriguez Ramos, C., Lòpez-De Fede, A., Mayfield-Smith, K. (2021). The VOICES/VOCES Initiative: Moving Forward Through Women's Voices to Address Pregnancy and Birth Inequities in South Carolina. Columbia, SC: University of South Carolina Institute for Families in Society.

Preface

As we finalize this report, we acknowledge the long-standing commitment by the South Carolina Department of Health and Human Services (SCDHHS) to the health and well-being of families throughout the state. Interviews conducted for this project with pregnant and postpartum women, as well as health, social service, and community leaders, highlighted the importance of ensuring coverage to one-year postpartum as one way to reduce pregnancy- and birth-related morbidity and mortality and address a range of needs experienced by parents during their child's first year of life.

Introduction

Healthy Connections, South Carolina's Medicaid program, supports people by covering some or all the costs of medical and health care. In 2019, Medicaid covered approximately 26% of South Carolinians with either full, limited, or partial benefits, making this program a significant contributor to the health and well-being of over one million people in our state.¹

This report summarizes the approaches used and main findings of the VOICES/VOCES initiative, carried out by a qualitative research team at the Institute for Families in Society (IFS). The summary presented here serves as the foundation for more detailed analyses that will be presented in a variety of formats throughout 2021 (See Next Steps).

In 2019, SCDHHS Medicaid paid for 61% of all deliveries, including:

73% for women residing in rural areas75% for women identifying as Hispanic84% for women identifying as Black93% for women under age 20.

Source:

schealthviz.sc.edu/Data/Sites/1/media/downloads/ SCBOI_DeliveriesandBirths-CY2019.pdf

Significance of VOICES/VOCES to South Carolina Healthy Connections

Pregnant women, mothers, newborns, and infants comprise an important sector of Medicaid beneficiaries. ² To address the needs of these populations, the South Carolina Department of Health and Human Services (SCDHHS) has taken a lead role in coordinating the South Carolina Birth Outcomes Initiative (SCBOI) over the last decade. The SCBOI brings together the insights and resources of over 100 multi-sector stakeholders to strategize and implement interventions that improve health outcomes for women and babies.

¹ https://storymaps.arcgis.com/stories/691f93b9a82e4fb4a64c336460974653

² Healthy Connections provides coverage to pregnant women and this coverage continues for the mother for 60 days after the baby's birth; the infant is covered up to age one when enrolled separately for extended coverage, otherwise the baby is automatically covered by Medicaid for the first 60 days after birth with the mother's Medicaid coverage. Eligibility include being pregnant, a South Carolina resident, US citizen or Lawful Permanent Resident, and have a social security number or verify an application for one (https://www.scdhhs.gov/eligibility-groups/pregnant-women-and-infants; https://www.scdhhs.gov/FAQs#_Presumptive). Pregnant women are eligible at 199% of FPL (https://aspe.hhs.gov/2021-poverty-guidelines

Since SCBOI's inception, IFS has led the Data Working Group, whose analyses of Medicaid-related quantitative data have been used to shape priorities and next steps in addressing the needs of communities of opportunity. But who are the people represented by the numbers, percentages, and trends documented over time? Who are the Medicaid clients/consumers/beneficiaries? What are their experiences and insights? And how can those experiences and insights be used to inform Medicaid policies and practices moving forward? The VOICES/VOCES initiative aimed to answer those questions and bring women's voices directly into the discussion of Medicaid priorities, strategies, and decision making.

By conducting in-depth interviews with women (consumers), the VOICES/VOCES team documented the experiences, perspectives, and proposals for action expressed by women throughout South Carolina who depend on Medicaid/emergency Medicaid for their pregnancy, birthing, and postnatal care. The team also interviewed key stakeholders throughout the state. Their combined stories and insights bring deeper understanding of the data and trends mapped by IFS over time, especially in relation to the racial and ethnic-based disparities and inequities in maternal health and birth outcomes that exist and persist. Importantly, the interviews also yield concrete ideas and recommendations for actions that can be taken to address disparities and inequities, making South Carolina a healthier place for all.

In October 2019, South Carolina became part of the Alliance for Innovation on Maternal Health (AIM), designed to significantly reduce severe maternal mortality and morbidity. Considering women's lived experiences and actively incorporating their insights into programming and policy will be key to making advances through the AIM bundles, including the "Supporting AIM Patient Safety Bundles" especially:

- Reduction of Peripartum Racial and Ethnic Disparities
- Postpartum Basics: From Birth to Postpartum Visit
- Postpartum Basics: From Maternity to Well-Woman Care
- Maternal Mental Health: Perinatal Depression and Anxiety
- Support After a Severe Maternal Event

Overall, our goal is that VOICES/VOCES can support SC Healthy Connections to elevate the voices of women served by Medicaid for pregnancy, birthing, and postpartum care so that they are included in Medicaid-related discussions and decisions moving forward in South Carolina.

VOICES/VOCES provides Healthy Connections with important opportunities to learn directly from women who are consumers of Medicaid. This is one critical step toward including, more fully, the perspectives, experiences, and recommendations of consumers in the decision-making processes that define policies and programs.

³ Communities of Opportunity (CoO) are underserved communities that have the potential to be strong, vibrant spaces of opportunity, built on foundations of equity and inclusiveness. Health care, focused on prevention and whole person well-being, is one core component to holistic approaches to creating impact in CoOs.

COVID-19: An unexpected and significant dynamic in VOICES/VOCES

Discussions about the importance of documenting the voices of Medicaid beneficiaries/ consumers began in 2019, prior to the pandemic. We launched the initiative in early 2020, with plans in place to train a small team of Community Health Workers (CHWs) to conduct face-to-face interviews with women throughout the state. Due to COVID-19, our plan was significantly revised so that all interviews were conducted only by phone by our three-person research team.

Additionally, women's pregnancy, birthing, and postpartum experiences were affected by the pandemic in multiple ways, including the impact of new policies and procedures put into place by health systems throughout the state.

In this report, we acknowledge the important impact of COVID-19 on the delivery of pregnancy-related health care and on women's experiences of that care. At the same time, we aim to highlight findings and recommendations that are relevant to maternal-child health in a post-pandemic setting, in which equity is central.

"COVID-19 has unveiled long-standing inequities; ...equity-focused solutions must be at the forefront". SCIMPH/DHEC Data Brief

"Well, I get frustrated first when people talk about getting back to normal. The reality is we don't want to get back to normal, if we really were being honest with ourselves. We need to take advantage of this situation to create a new normal."

- Interview with Dr. Rick Foster, VOICES/VOCES

VOICES/VOCES: Fostering Consumer-Driven Participation in Addressing Disparities and Inequities in Maternal and Birth Outcomes in South Carolina



Health disparities: differences in the relative health status of population groups defined by characteristics such as race, ethnicity, gender, economic status, geographic location, and immigration status.

Health inequities: systematic differences in health that are unnecessary, unfair, and unjust and can be reduced with effective policies and programs.

Adapted from:

https://www.ifs-mpr.maps.arcgis.com/apps/MapSeries/index.html?appid=62df61343f4e432698523d15726098b7 https://www.who.int/news-room/facts-in-pictures/detail/health-inequities-and-their-causes Stark and disturbing disparities in birth outcomes exist in South Carolina. A higher proportion of babies born to Black/African American women (14.6%) are born preterm or low birth weight (15.0%) compared to 9.5% and 7% respectively of babies born to white women. ^{4, 5} Recent data also show that 2.2% of babies born to women during the last quarter of 2015 to the 1st quarter of 2019, who use Medicaid are born at very low birthweight compared to only 0.4% of babies born to women with private insurance. ⁶ A higher proportion of African Americans reside in "High Need Areas" relative to the rest of the state. ⁷

We utilized a framework that encompasses both the social and structural determinants of health and health inequities to design the VOICES/VOCES initiative and to guide its analysis and presentation. Crear-Perry and colleagues (2021) expanded the important "social determinants of health" approach to include structure determinants to explain more deeply and explicitly the root causes of maternal health and birth outcome inequities in the United States. ⁸

Structural determinants and root causes include social and cultural norms, racism and discrimination, and policies, institutions, and practices that define how the social determinants of health are distributed. This network of factors works together to produce inequities in maternal health and birth outcomes for women, especially Black and Latina women. This framework highlights that while health care access and quality are key determinants of health, economic, social, and contextual factors are equally and sometimes more important. Listening to the voices of people accessing health care is one of the best ways to understand that array of determinants.

VOICES/VOCES illuminates the social and structural determinants for women in South Carolina whose pregnancy-related care is covered by Medicaid, how women experience these determinants, and what Medicaid's role can be to address inequities caused by determinants.

The IFS VOICES/VOCES Study Team

The study team, comprised of five (5) professionals, is diverse in terms of race, ethnicity, language fluency, origin, and professional experience (Table 1). This was important, given that all women we interviewed identified as either African American, Bi-racial, or Hispanic/Latina, with Hispanic/Latina participants feeling more comfortable speaking Spanish rather than English. ⁹ All team members identify as women, using she/her pronouns.

⁴ Institute for Families in Society. "Newborn Outcomes." https://boi.ifsreports.com/statewide/newbornoutcomes.html. Accessed March 1, 2020.

⁵ Institute for Families in Society. "South Carolina Deliveries and Births 2018." https://www.schealthviz.sc.edu/Data/Sites/1/media/downloads/2018deliv_birthsfactsheet.pdf. Accessed March 3, 2020.

⁶ Institute for Families in Society. "Newborn Outcomes." https://boi.ifsreports.com/statewide/newbornoutcomes.html. Accessed March 1, 2020.

⁷ IFS created an additive index that identifies "High Need Areas" as those with high property and violence crime rates, shortages of healthcare professionals (primary care, dental, mental health), racial isolation, persistent poverty (adult and child), food deserts, low educational attainment, and low income. Source: https://ifs-mpr.maps.arcgis.com/apps/MapSeries/index.html?appid=62df61343f4e42698523d15726098b7

⁸ Crear-Perry, J., Correa-de-Araujo, R., Lewis Johnson, T., McLemore, M. R., Neilson, E., & Wallace, M. (2021). Social and structural determinants of health inequities in maternal health. *Journal of Women's Health*, 30(2), 230-235.

⁹ Spanish was not the primary language spoken by one participant (Guatemalan) but we conducted the interview in Spanish given that no one on the team spoke her indigenous language (K'iche').

TABLE 1. IFS VOICES/VOCES STUDY TEAM

Race/ ethnicity of VOICES/VOCES team		Research roles	Training and experience
African American	1	Conduct interviews/analysis/report writing	Public health/ qualitative researcher (PhD)
White	3	Coordinate study/ Conduct interviews in English and Spanish/analysis/report writing (1) Fidelity check interview transcriptions vs recording (1)	Public health/Sociology/ qualitative researcher (PhD) Biology and neuroscience (BS)
		Transform interviews into a script for a theater piece (1)	Theater, Actor (MFA)
Latina	1	Conduct interviews in English and Spanish/analysis/report writing	Public health (MPH)

Each team member is IRB CITI-certified through the University of South Carolina. Team members conducting interviews completed individual and group training on trauma-informed data collection and engaged in mutual and self-care throughout the data collection and analysis processes. As a team, we examined paradigms of reproductive justice, obstetric violence, and human rights for their relevance in this work.

VOICES/VOCES creates an opportunity to hear the narratives of consumers from them directly. Although we as researchers made efforts to minimize or eliminate perceived power hierarchies, we recognize that they may have still existed. Reflexivity was a regular practice during our weekly discussions to understand how we as a team contextualized our relationship with participants, and how that context informed our findings.

Methods

The IFS team used qualitative methods and approaches, namely semi-structured interviews, verbatim transcription, and narrative analysis to better understand the pregnancy, birthing and postpartum experiences of women whose pregnancy-related care is covered through Medicaid/emergency Medicaid in South Carolina. In so doing, we documented their narratives of care within the broader context of their multi-dimensional lives. Narrative analysis relies heavily on understanding context—social, cultural, economic, and political—and asks, "What does this narrative or story reveal about the person and world from which [the story] came? How can this narrative be interpreted so that it provides an understanding of and illuminate the life and culture that created it?" As such, this approach offered rich insights through detailed narratives highlighting determinants of health associated with maternal health and birth outcomes.

¹⁰ Patton, M.Q. (2002). Qualitative Research & Evaluation Methods, 3rd Edition. Sage Publications: Thousand Oaks, CA. (p. 115)

Participation was voluntary and confidential. The study protocol was approved by the University of South Carolina's Institutional Review Board. 11

Participant Recruitment

In January 2020, the VOICES/VOCES team convened a workgroup consisting of members of the SCBOI with specific interest in addressing pregnancy and birth inequities. Partners included representatives from multiple agencies and organizations, including the SC Department of Health and Human Services (SCDHHS), University of SC Family Medicine Center, the SC Hospital Association (SCHA), March of Dimes, Indie Grits Labs, University of SC Center for Community Health Alignment, the SC Office of Rural Health/Family Solutions of the Low Country, and the SC Community Health Worker Association. The aim was to develop a participatory mechanism through which SCBOI members, in many cases also participants in the Birth Equity BOI Workgroup, could discuss issues relevant to the focus areas of VOICES/VOCES. When SCBOI stopped meeting in person in March 2020 because of COVID-19, this workgroup met once online.

The study team maintained a database of all participants in a secure OneDrive space linked with the University of South Carolina. Only three members of the study team had access to the complete information on participants, including demographic characteristics and contact information needed to send thank you letters and a \$50 gift card acknowledging women's/consumer's participation. This information was kept separate from all sound files and transcripts, identified by a filename that indicated the initials of the interviewer, initials of the participant, and interview date. After each interview, participants received a personalized letter sent to them via mail, which includes a \$50 Visa gift card.

Pregnant and Postpartum Women (Consumers)

Recognizing the important roles played by workgroup member organizations in supporting women to navigate resources and systems, the IFS Study team asked workgroup members to assist with recruiting women to the study by presenting the opportunity to potential participants. Over time, organizations outside of the original workgroup were included. In this way, trust and confidence in the importance and ethics of the study were built through organizations located in different parts of the state (Table 2). Recruiting participants through these organizations helped the study team to build on existing trust and develop meaningful rapport. Additionally, the study team could be responsive to women's needs that might arise during interviews and refer participants back to the organization for follow-up, per the participant's consent.

TABLE 2. ORGANIZATIONS SUPPORTING CONSUMER PARTICIPANT RECRUITMENT

Organization	Location
Family Solutions	Orangeburg
<u>BirthMatters</u>	Spartanburg
PASOs	Columbia
Power in Changing	Columbia
MUSC Women's Reproductive Behavioral Health Division	Charleston

¹¹ Pregnancy and Birth Inequities in the Context of the COVID-19 Pandemic (Pro00100005); Voices of Women Using Medicaid/Emergency Medicaid during COVID-19 Pandemic (Pro00100013).



IFS designed a recruitment flyer in English and Spanish that was subsequently distributed to organizations helping with recruitment. The flyers also were posted on <u>SC HealthViz, under the SCBOI tab.</u>

English: https://www.schealthviz.sc.edu/Data/Sites/1/media/VOICES-Wom-Eng.pdf
Spanish: https://www.schealthviz.sc.edu/Data/Sites/1/media/VOICES-Muj-Esp.pdf

An individual from each partnering organization served as a liaison to the project to identify eligible participants and notify them of the study. To be eligible to participate, women had to be: (1) 18 years of age or older; (2) either pregnant or up to 1 year postpartum and (3) using or used Medicaid/emergency Medicaid to cover the costs of pregnancy, labor, and delivery, and/or postpartum care. With participants' permission, contact information was forwarded to the study team for follow-up. Some participants contacted the study team directly through a toll-free number advertised on the flyers. The digital toll-free system (Grasshopper) facilitated communication directly, or via voicemail and/or text, between participants and the study team.

A member of the study team contacted potential participants via phone or text to schedule an interview. We used a screening tool to verify participant eligibility and sent text messages to remind participants of the scheduled interview, per their consent. Informed consent was accomplished using a detailed letter of invitation (in English or Spanish) that was sent by email, text, or postal mail. Prior to initiating the interview, each interviewer obtained consent from the participant once again.

Risks to consumer participants were minimal but included the possibility of emotional discomfort/trauma based on past pregnancy, birthing, and postpartum experiences.

Health care, social service, and community leaders (Providers)

The study team used purposive sampling that included experts and leaders in maternal health care, social services, and community leaders. Most participants came from the SCBOI workgroup organizations defined above. Some participants referred the study team to other providers whose work is relevant to this study.



Flyer for Health Care and Social Service Leaders

English: https://www.schealthviz.sc.edu/Data/Sites/1/media/VOICES-MedComm-Eng.pdf
Spanish: https://www.schealthviz.sc.edu/Data/Sites/1/media/VOICES-MedCom-Esp.pdf

Flyer for Community Health Workers

English: https://www.schealthviz.sc.edu/Data/Sites/1/media/VOICES-Community-CHW-Esp.pdf
Spanish: https://www.schealthviz.sc.edu/Data/Sites/1/media/VOCES-Community-CHW-Esp.pdf

A member of the study team contacted potential participants via email or phone to schedule an interview. We sought individuals who were health care and social service leaders and stakeholders throughout South Carolina who provided care to pregnant, birthing, and/or postpartum women who use Medicaid to cover the costs of their care—including Ob/GYN, Pediatric, and Family Medicine providers, community organization leaders, and Community Health Workers. Informed consent was accomplished using a detailed letter of invitation that was sent by email in advance of the interview. Receipt of the letter and participation in the interview indicated consent to participate. All providers that we interviewed agreed to have their name and position included in reports, papers, or other forms of dissemination.

Interviews Conducted and Transcribed

The study team designed and used a semi-structured interview guide with an informal conversational interview style to gather narratives related to pregnancy, birthing, and postpartum experiences from consumers and to gather insights and recommendations from providers and leaders. Interviewers reviewed the letter of invitation with participants immediately prior to conducting the interview. Following informed consent, a trained member of the study team conducted the interview. Interviews lasted from 60 to 90 minutes on average. Each consumer participant received a \$50 gift card as compensation for their time.

English and Spanish-language sound files were exported to an external transcription service, Verbalink (Ubiqus), via a secure website; Verbalink (Ubiqus) returned transcriptions and sound files via this same secure website. ¹² One team member, who did not conduct interviews, fidelity-checked all sound files in English against finalized transcripts and made minor corrections. The two study team members fluent in Spanish divided the Spanish language interviews to fidelity check them. All sound files and accompanying transcripts were re-uploaded to interview-specific folders in OneDrive, accessible only by the study team.

Pregnant and Postpartum Women (Consumers)

We defined a sampling framework that aimed to promote diversity in participant inclusion. This initial framework stratified participants according to race/ethnicity, prenatal care type (CenteringPregnancy vs. traditional one-on-one) ¹³, pregnancy status, and stigmatizing conditions (e.g., HIV, housing status, and substance use). The COVID-19 pandemic adversely impacted our data collection plan, resulting in a final sample of women participants (N=30) with a somewhat narrower range of participants and smaller number than originally envisioned (Table 3).

Table 3. VOICES/VOCES Women/Consumer Participants (N=30)

Descriptor	N
Race/Ethnicity (self-defined)	
Black/African American	22
Latina/Hispanic	7
Bi-racial	1
Age (mean)	
Black/African American/Bi-racial	28 years (n=22)
Latina/Hispanic	37 years (n=7)
Bi-racial	25 years (n=1)
Number of pregnancies, with current (mean)	
Black/African American	3
Latina/Hispanic	4
Bi-racial	1

 $\frac{https://www.ubiqus.io/?gclid=Cj0KCQjw5PGFBhC2ARlsAlFIMNdL9lrRw8DOMajlE9DLP3JuPq5pJ2c24lmevLmv6MZfQFhQvpWYaZMapoXEALw_wcB$

 $^{^{\}rm 12}$ Verbalink is now known as Ubiqus on Demand:

¹³ CenteringPregnancy groups were put on hold throughout South Carolina precisely at the time when the team was engaged in participant recruitment. Thus, we were unable to conduct interviews with women participating in group prenatal care. For a detailed analysis, see Heberlein, E., Halls, O. (2021) The Impact of COVID-19 on South Carolina's CenteringPregnancy Practices. Georgia Health Policy Center. In production.

2		
3		
1		
23		
7		
4		
1		
2		
Pregnancy status at time of Interview		
16		
14		
28		
2*		
Intimate partner violence during current pregnancy		
2*		
Substance use during current pregnancy		
2		

^{*} In both cases, women experienced unstable housing while escaping intimate partner violence.

Participants lived in 10 of the 46 counties throughout South Carolina; four of the ten counties are defined as "high need areas" (Table 4).

TABLE 4. WOMEN'S PARTICIPATION BY COUNTY (N=30)

County	N (%)
Spartanburg	4 (13.3%)
Charleston	2 (6.7%)
Richland	8 (26.7%)
Orangeburg	9 (30%)*#
Barnwell	1 (3.3%)#
Hampton	1 (3.3%)*#
Lexington	2 (6.7%)
Beaufort	1 (3.3%)
York	1 (3.3%)
Darlington	1 (3.3%)*#
Total	30 (100%)



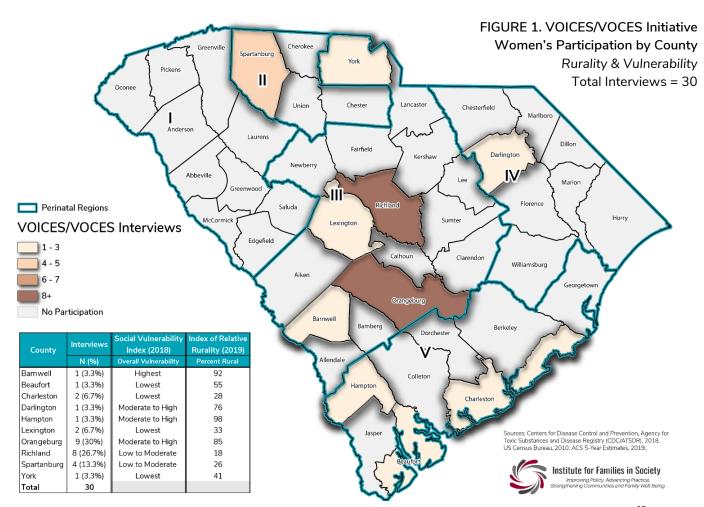
NOTES:

- * Indicates a county that is in the Top 2 Quartiles of the CDC Social Vulnerability Index (SVI), 2018. Source: storymaps.arcgis.com/stories/691f93b9a82e4fb4a64c336460974653
- # Indicates a county that encompasses "High Need Areas" (additive scores of 7-8; 9-11).

Source: ifs-mpr.maps.arcgis.com/apps/MapSeries/index.html?appid=62df61343f4e432698523d15726098b7 15

¹⁴ The mean number of children does not include the current pregnancy, if the woman interviewed is pregnant.

¹⁵ High Needs Areas were identified by creating an additive index that includes high property and violent crime rates, shortages of healthcare professionals (primary care, dental, and mental health), racial isolation, persistent poverty (adult and child), food deserts, low educational attainment, and low income. For more detail, see https://ifs-mpr.maps.arcgis.com/apps/MapSeries/index.html? appid=62df61343f4e432698523d15726098b7



Map developed by Institute for Families in Society (IFS) - Data Science & Visualization Team. Created August 2021. 16



Social Vulnerability Index (SVI) - Centers for Disease Control and Prevention, Agency for Toxic Substances and Disease Registry (CDC/ATSDR), 2018.

The SVI provides specific socially and spatially relevant information to help public health officials and local planners better prepare communities to respond to emergency events such as severe weather, floods, disease outbreaks, or chemical exposure. During the COVID-19 global pandemic, this information can be used in the US to help frame discussions around communities in need. For this map, the overall county summary ranking variable (RPL_THEMES) was used; vulnerability categories were assigned based on 4-Class Natural Breaks and identified as – Highest Vulnerability, Moderate to High Vulnerability, Low to Moderate Vulnerability, and Lowest Vulnerability.

Index of Relative Rurality (IRR) - University of South Carolina (UofSC) Institute for Families IHPR, February 2021.

The Index of Relative Rurality (IRR) is a continuous, relative index that combines frequently used census figures with other measures of rurality to create index values that adhere to a 0 - 100 continuous scale, with 0 being the most urban and 100 being the most rural. The IRR values are based on 2019 County IRR values.

 $^{^{16}}$ For more detailed information about demographics and births in perinatal regions, please see Appendix 1.

The study team conducted all interviews via phone and recorded them using Google Voice and/or LiveScribe. Two Spanish-speaking members of the team conducted interviews in Spanish with participants who indicated this language preference (N=7). All other interviews were conducted in English (N=23).

Health care, social service, and community leaders (Providers)

The VOICES/VOCES team interviewed health care and social service leaders and providers throughout South Carolina to better understand the experiences of pregnant and postpartum women who use Medicaid to cover their pregnancy-related care. Their perspectives were based on expertise in health care and social service from medical care and community-based practice.

The VOICES/VOCES team conducted twenty-three (23) interviews with a total of 33 participants (Table 5). Most (28) of the participants preferred to speak English, while two preferred Spanish. The study team conducted and recorded all interviews using Zoom.

TABLE 5. LEADER PARTICIPANT INTERVIEWS

Participant/Participant Organization	SC Location	# People interviewed
South Carolina Hospital Association	Columbia	1
University of SC School of Medicine	Columbia	1
Alliance for a Healthier SC	Columbia	1
Family Solutions	Orangeburg	1
Center for Community Health Alignment	Columbia	1
SC Community Health Worker Association	Columbia	1
Prisma Health-Midlands	Columbia	1
South Carolina Office of Rural Health	Lexington	1
PASOs Statewide	Columbia	2
PASOs Greenville	Greenville	1
PASOs Spartanburg/ CHW Reproductive Health	Spartanburg	3
PASOs Beaufort/Jaspar	Beaufort	1
PASOs Richland	Columbia	1
Good Samaritan Clinic	Columbia	1
Outreach specialist, Midlands Healthy Start, Prisma Health, Midlands	Columbia	1
BirthMatters	Spartanburg	3
MUSC Women's Reproductive Behavioral Health Division	Charleston	10
Independent Doula	Columbia	1
Independent Pediatrician	Columbia	1
TOTAL		33

Narrative Analysis

Narrative analysis, a method used to interpret texts that are storied in nature, ¹⁷ was used to examine data gathered from participants. Analysis of all transcripts was completed by three members of the study team. The study team met weekly to engage in iterative data discussions prior to and throughout analysis to assess emergent themes.

We used two approaches. For consumer interviews, we focused on narrative content emphasizing the themes that emerged as most salient in terms women's telling of their pregnancy, birthing, and postpartum experiences. We used a hybrid approach to coding, using both a priori codes (developed through deductive analysis) as well as emergent codes (an inductive approach) during the analysis process. High intercoder agreement was found using a sample of five consumer interviews. These codes then were used to code the remaining interviews, divided evenly among three members of the study team. ¹⁸

For provider interviews, we pulled out two major themes for purposes of this report: understanding of inequity and recommendations. Additional analysis is needed to extract the rich insights expressed by providers.

We used NVivo qualitative software to store, manage and analyze all the interviews. This software was installed on IFS laptop computers and is the only hard drive space where transcripts are housed. Upon completion of this study, all hard drives will be wiped clean to ensure confidentiality.

When all coding was completed and reviewed, one team member exported the content of each code into a Word file that could be easily read and discussed by the whole team, including one member who did not have access to NVivo but who needs access to the data to create the theater script.

Results Highlights

The VOICES/VOCES project has yielded a wealth of information and insights (See Appendix 2 for a full list of codes/themes that emerged from the interviews). For purposes of this initial report, we want to highlight the following five (5) areas to provide a sense of the depth of information that emerged from the interviews.

- Inequitable treatment
- Awareness of inequities
- Respectful, culturally appropriate care
- · Access to resources
- Mental health concerns and access

This section will be followed by a series of recommendations, offered by women (consumers) and providers as ways to adjust Healthy Connections to be more effective and help to push forward toward meeting the needs of South Carolina's most vulnerable populations.

Discussion about addressing disparities and reaching equity is at the forefront of approaches to pregnancy, maternal, and child health. To make advances, it is first critical to understand women's life experiences of inequity.

¹⁷ Patton, M.Q. (2002). Qualitative Research & Evaluation Methods, 3rd Edition. Sage Publications: Thousand Oaks, CA. (p. 115)

 $^{^{\}rm 18}$ See Appendix 1 for the Codebook that the study team developed.

Inequitable Treatment

Many VOICES/VOCES consumer participants felt they had been discriminated against based on one or more personal characteristics, such as race, status as a "Medicaid patient," or some combination of other characteristics. Several described instances where providers in clinical settings made incorrect and egregious assumptions about them, e.g., that they already had several children, that their child's father was uninvolved, or that they required multiple tests for sexually transmitted infections over the course of their pregnancy. These assumptions can result in lapses in care when patients leave clinics where they feel they are not being treated fairly:

"I felt so judged and like belittled and like a statistic that I just stopped going to my appointment, and I just ended up giving birth...But that wasn't good, because that could've possibly been a DSS case."

Several women who expressed concern wondered if they were being treated differently because their care was paid for by Medicaid. Race was also noted by some as a source for differential treatment. One participant described her experience with a doctor who ignored her pain, saying "You're good. You can handle it." For her, this brought to mind stereotypes of Black women being expected to "tolerate more pain" and was a harbinger for other ignored concerns and the eventual loss of her baby.

Other women noted differences they believed to be based on their race, describing situations where they felt discouraged about asking questions because of what they saw as noticeable differences in the way providers interacted with Black and White patients. An example of the differential responses during labor and delivery were noted by a Black participant who said,

"My brother's fiancé is a white woman. We gave birth around the same time in the same hospital with totally different experiences."

Homelessness, and the stigma associated with it, was a tremendous source of inequitable treatment for one participant who described harrowing experiences associated with homelessness, her pregnancy, labor and postpartum care.

Another source of differential treatment was based on COVID, or rather illness suspected by providers to be COVID. One participant had a urinary tract infection that was suspected to be COVID. Testing, which was difficult for her to access, had to be done five times over the course of her pregnancy for her to receive prenatal care.

"I just had, like, a urinary tract infection, a small urinary tract infection, and you know they can cause you to feel bad or whatever. But I had a headache, so they was like, "Oh well, you can't come to your appointment 'til you get tested for COVID'. And to come to find out, they wrote down that I had COVID symptoms when I just had a headache."

Also related to COVID were concerns raised by participants about provider responses, particularly the fear exhibited by some providers that severely reduced interaction. Participants experienced this fear as a dismissal of their health, especially during a time of heightened fear on their parts as well.

"...definitely during COVID, they treat you like you have full-blown AIDS, or like you're just disgusting or like they scared of you, when you scared, too."

Awareness of Inequity

Many women were aware of, and in some cases quite knowledgeable about, inequities in maternal health and birth outcomes. This was made clear by both women and leader participants. The consequences of this awareness were discussed in terms of the impact on care and care-seeking, as well as on mental health and well-being.

Awareness of inequity was described as part and parcel of the pregnancy experience for Black and Latina women, especially during the COVID pandemic when these concerns were exacerbated. From a provider perspective, patients were averse to virtual visits not only because of limited access to internet, but also because of "a general fear and mistrust of being Black and pregnant or being Latina and pregnant."

For Latina patients, the language barrier, and the reliance on interpreters available only by phone, not inperson, also limited virtual access. One provider stated:

"A lot of my patients know about the maternal mortality rate being higher in Black women. They are in these mommy blogs. They're online. They're reading their own information. They have their support group. And so it's not really a secret anymore that Black women are treated differently in labor and so they were scared. 'If I don't hear my baby's heartbeat every four weeks and every two weeks and you don't see me face-to-face...If I had complaints that were gonna be ignored before COVID-19, I'm guaranteed...I know I'm not gonna get any type of care if I'm not physically in the office."

For some consumers, this awareness resulted in them being proactive and vocal about their care. One VOICES participant who was homeless had to challenge stigma held by providers about homelessness and substance use. Another participant indicated that her awareness of inequities meant that trusting her providers became even more important—so important that she switched doctors 3 times to find one she trusted. Her ability to change providers with her Medicaid plan and her awareness that she could do so were two important factors in her experience.

"I trusted him a lot. And that meant a lot to me, to be able to trust him. Because let's just be honest, we already don't have the best mortality rate and stuff when it comes to being pregnant and giving birth. I guess that's why...I kind of did a little overkill in research before I got pregnant. So when I get an inkling of a feeling that a doctor didn't personally care about me, that's why I was so quick to switch and I don't want to talk about it. Because I need you to love me like my family loves me or at least pretend you do. Or make me feel secure in that I feel like you at least want to do your job to protect me and my child. And that's how I feel about my third doctor."

Mistakes, oversights, and overt discrimination in patient care were viewed through this lens. For one participant who indicated that she experienced negligence over the course of her pregnancy, a serious and life-threatening complication during her labor brought this awareness sharply into view:

"This is it. I'm not going to wake up. Because I'm so scared and all the negligence that had happened to me prior to me even being in the delivery room. Now I'm in this delivery room—well, now I'm in the OR, now I'm getting operated on. I'm thinking, 'I'm done, this is my time. This is my time. I'm done."

This participant was well aware of the disparities in maternal mortality—quoting the statistics during the interview. The opportunity to discuss the experience—to "say it out loud" gave her solace, but also allowed her to state her need for counseling because of it.

"...actually, I'm getting ready to sign up to go back to my old counselor...So, I'm getting ready to go back to her because I have PTSD from this experience... I was holding that for so long, not wanting to put too much on it, not wanting people to feel sorry for me, not wanting to be like, "Oh, let me tell you what happened to me," type of thing. But the reality of it is that it really kind of messed me up a little bit. I am traumatized and that is my truth. I am traumatized. I am scared."

Not only did inequities in maternal health and birth outcomes impact women, so did inequities around COVID and other "social inequities" related to police killings of unarmed Black people in the country. One participant described the impact of the COVID pandemic affecting medical care. She went on to say:

"...then the social pandemic hit of the killing of Breonna Taylor and George Floyd and Ahmaud. And that stressed me out seeing it all over social media. I was so bad that my blood pressure was almost in the 200s. It was so high. I was so stressed out every night because I would look and it was like a new case was coming or somebody just opened up an old case."

This was especially disconcerting to her because she was "having a little Black boy" and she was "married to a Black man." She was worried about their current and future safety.

Respectful, culturally appropriate care

Language and access to care was a major challenge faced by Spanish-speaking consumers, who stated that the process of enrolling in (emergency) Medicaid was long and complicated. The roles played by Community Health Workers (CHWs) who work at the statewide organization, PASOs, were invaluable to supporting women and families and helping them enroll and find peace of mind that the costs of some of the services they would receive would be covered. CHWs helped women to fill out the Medicaid forms and to get help from the Medicaid offices, where there is a dearth of Spanish-speaking employees.

One CHW noted:

"Yo en mi experiencia he tenido mucha gente que me ha pedido rellenar aplicaciones hasta en español mismo, porque muchas veces dicen, "No queremos ayudar a personas que ya les mandan una aplicación en español." Y en mi experiencia de ayudar a las personas en estos seguros es de que ni siquiera en español a veces las personas entienden los términos que usan en esas aplicaciones."

"In my experience, I have had many people ask me to fill applications in Spanish, because many times they say, "We don't want to help people, just send them an application in Spanish." And in my experience of helping people with these insurance plans- people don't even understand the terms used on the applications, even if they're in Spanish."

The reflections from another CHW:

"Mi recomendación más importante es que haya una persona físicamente en las oficinas de Medicaid que hable español, una o dos personas. No creo que sea tan alto el volumen para – pero sí van muchas personas diariamente. Y dejan de ir a las oficinas porque no hay quién las atienda en español. Para mí eso es muy importante. Que toda la información que tenemos nosotros acceso, porque la imprimimos directamente de la página, pero nosotros lo buscamos, buscamos en español. Pero en las oficinas no hay información en español."

"My most important recommendation is that there be a person physically present in Medicaid offices who speaks Spanish, one or two people. I don't think the volume is that high for—but a lot of people do go daily. And they stop going to the offices because there is no one to attend to them in Spanish. That's very important to me. We have all the information, because we print it directly from the website, but it's us who look for it [the information], we look for it in Spanish. But in the [Medicaid] offices there is no information in Spanish."

Access to Resources

Narratives highlighted the importance of social determinants of health in maternal health and birth outcomes, and emphasized the point that care is connected to so many different aspects of women's lives. Many described the need for "rest" and "no stress" during their pregnancy for it to be healthy. From participants' perspectives, social support was an important resource and hailed from multiple sources, including community organizations (such as Family Solutions, Birth Matters, and PASOS), sometimes coworkers, but especially family and friends. Partners and family members were a significant source of social support for most participants. Doulas and community health workers also offered tremendous support when available—facilitating access to education, other resources (like supplies for baby and links to WIC), and access to care.

"I have a doula through BirthMatters....She would come and talk to me. She got me a counselor that I could talk to, also. And she would help me get things for my baby."

Many participants living in Orangeburg expressed the intention of seeking care with doctors in Columbia because they expected better care than their previous experiences closer to home. For some of these participants, transportation was an important factor in being able to access care farther from home. Although transportation was not a problem for all participants, it was for some, and resulted in missed appointments or strenuous effort on the part of women to keep their appointments.

"Transportation was definitely an issue...I don't have a car. Yeah, I missed a couple of doctor's appointments. I had to reschedule a lot. But, you know, I kept everything up to date, but I missed a couple of them due to not having transportation or not having the money to pay for a cab to get there and back. I've even had to walk to the doctor and walk home one day."

Another important factor affecting prenatal care dealt with a policy instituted in at least one clinic that was a deterrent to prenatal care.

"I didn't want to go back to [clinic name] but at the time, I didn't want to prolong me going to the doctor 'cause when I found out, it took a minute for me to get an appointment. So once I got the appointment, when I got there, I had my son with me and they were like, "No children." I was like, "What? Since when?" They were like, "Well, we changed our policy, no children allowed." I was like, "Oh my gosh" And I was by myself so I just had to miss out on that 'cause they didn't want to make no exceptions of me bringing him so that was kinda a waste of my time."

As expected, COVID impacted the ability for participants to get needed supplies, both because of reduced finances, due to job loss, and because of reduced capacity (e.g., concerns about getting a breast pump in time because of postal mail delays). Prenatal and post-partum appointments were difficult to schedule for some because of COVID concerns and clinic policies, and follow-up services (e.g., for baby with suspected developmental delays) were also difficult to access.

"...COVID is, honestly, just really messing stuff up because I still haven't even been able to get to my appointments to get back on seizure medications so I can get cleared to go back to work."

Narratives suggested the need for a better safety net for complicated, high-risk pregnancies that involve issues like homelessness, domestic violence, substance use, and serious illness.

Mental health concerns and access

The Surgeon General's Call to Action to Improve Maternal Health ¹⁹ highlights that mental health conditions are common complications during pregnancy and in the postpartum period and may contribute to poor maternal and infant outcomes. COVID exacerbated the experiences of poor mental health for many women.

"It was – honestly, when this whole COVID thing just came, I was scared. Honestly. It scared me, because I was on social media seeing how it was affecting pregnant women and I didn't even leave my house. I was scared."

"I was even scared to go to my doctor's appointment. I'm like, "What if I go and I contract it from a doctor, from my nurses, you know?" I didn't even want to go to the grocery story. I was sending my husband out."

Worry, at multiple levels, was also a common theme throughout many of the interviews.

"I was worried about miscarrying again. I was worried about what kind of mom I was going to be. I was worried about stuff going wrong and not getting the correct attention. Or people wasn't paying me attention in the beginning. So it was like the whole pregnancy I felt like I had to worry. Then to find out that you're high-risk, and that's just a worry even more. It was just a lot. That was the most emotional nine months ever."

Health service leaders with experience offering mental health services expressed frustration and concern regarding the lack of Medicaid coverage during prenatal and postpartum periods.

"Some folks that have Medicaid, they have a particular family planning Medicaid, and that doesn't cover mental health services. And so, that actually – we see that come up quite a bit, and we don't have a great place for these women to get services."

"And so, it's even another layer of sort of frustration and inconvenience that we've got this program that's ingrained in our OBGYN field, but then we can't help a significant minority of their Medicaid patients because they don't cover any type of mental health services whatsoever."

¹⁹ https://www.hhs.gov/sites/default/files/call-to-action-maternal-health.pdf

Normalizing mental health is mentioned as one important step toward recognizing its importance in the lives of women and their families and communities. However, even with recognition, significant barriers to mental health care during prenatal and postpartum periods remain.

"I think one of the things that we try to do is just normalize maternal mental health, right? So, every time we're talking about ...this is among the most common complications of pregnancy, and we want providers talking this way, we want women talking this way. So, that's one thing that we try to do is around breaking down barriers. But, you know, the access and availability are where we see a lot of the health inequities. So, you know, availability, if you're living in an area where you don't have a reproductive psychiatrist, you know, you're not gonna get to that level of care. And then, just, you know, access has everything to do with can you take time off from your work or your family obligations? Do you have transportation? At this point, do you have connection to internet, do you have a device? Like, there's so many layers of things where you could see the inequities start happening more and more."

RECOMMENDATIONS



Listen to women/consumers and incorporate their insights into strategies moving forward.

The most often stated recommendation offered by women in VOICES/VOCES was to listen to them, particularly in reference to health care encounters. How Healthy Connections can foster listening to women on all levels- from provider-patient interactions to policymaking- will be an important consideration to tackle.

"I understand that you're the medical professional. But when I'm telling you, just please listen. Like, maybe it's something that I'm feeling that you can't see in my chart, just listen to me." (Woman/Consumer)

"I do feel like black women can get left at the wayside. I just think that that's so unfair. I feel like if I'm telling you that I feel like something's wrong or something is off, don't just kind of brush me off, even if you have heard it 1,000 times before.

This is my – that was my first experience as a woman being pregnant and it was totally ruined by other people and how they kind of treated me." (Woman/Consumer)

According to one family physician, education on how to truly connect with patients is lacking in medical schools. The importance of listening to and elevating women's voices during their pregnancy-related experiences is paramount to addressing inequities.

"If you want to give really good care, you have to go deeper. You have to meet your patients where they are, and you have to let them teach you. They are the experts on their own bodies. They have lived this experience their entire lives. We are the experts in medicine, but a woman is an expert in her own body. And so allowing it to be a mutual learning relationship is the key to giving the best care you can possibly give." (Leader)



Engage community-care resources trusted by women in strategies for improving access to SC Healthy Connections.

Community-based and community-connected organizations contribute to women's pregnancy, birthing, and postpartum experiences in multiple ways, especially in helping them to navigate systems and access

resources. The organizations that participated in VOICES/VOCES are **trusted** by community members and serve as important spaces where women and families can find information, ask questions, and know that they will be treated with dignity and respect.

Specifically, organizations included in VOICES/VOCES helped women to enroll in Medicaid, understand what is included in and excluded from coverage, as well as how long coverage would last. For women with limited English proficiency, one organization (PASOs) was especially important given the lack of Spanish-language resources about Medicaid and the dearth of Spanish-fluent staff in Medicaid offices.

"We have models that work let's learn from those models and let's replicate them or at least take the most important components from those models and scale them up and implement them in other communities. You know, if something works, use it elsewhere; let's not reinvent the wheel." (Leader)

"We have data that shows us that we have gaps, and we've seen programs that actually can make a difference. And I would argue that we've still lacked the will and the execution to put those into places where they're needed the most." (Leader)



Invest in interventions that bridge the gap between community and health care.

Community Health Workers (CHWs)

Community Health Workers are frontline public health workers who are **trusted** members of communities or have a close understanding of the community served. CHWs serve as links between health and social services and the community and help community members access the services they need. They improve the quality and cultural competence of service delivery and build capacity by increasing health knowledge and self-sufficiency. ²⁰

VOICES/VOCES found that CHWs working in community organizations (e.g., PASOs and Family Solutions) who possess deep knowledge of Medicaid and health services were invaluable resources for women during pregnancy and postpartum. For example, without CHWs helping women to apply for emergency Medicaid before entering the hospital, many women would have found themselves facing large hospital bills. Medicaid and hospitals both save time and resources when women apply before entering labor and delivery. CHWs are critical for this to happen. Postpartum, CHWs also helped several women to navigate resources for their growing families.

Doula Care

Doulas provide extensive social, emotional, and educational support to women and parents during the critical months of pregnancy, birth, and the first twelve months of parenting. They provide individually tailored, culturally congruent care and advocacy for pregnant and postpartum women through information, education, and physical, social, and emotional support. They also serve as critical **trusted** liaisons helping pregnant women and parents to navigate systems and access resources, including health care, for parents and babies. In the past several years, organizations such as the March of Dimes have supported increased access to doula care as one important tool to help improve birth outcomes and reduce elevated rates of maternal morbidity and mortality among African American women. ²¹

²⁰ https://www.apha.org/apha-communities/member-sections/community-health-workers

²¹ March of Dimes Position Statement: Doulas and Birth Outcomes. https://www.marchofdimes.org/materials/Doulas%20and%20birth%20outcomes%20position%20statement%20final%20January%20 30%20PM.pdf

Increasing access requires increasing investment in two ways:

- 1. Covering doula care through all insurance programs, including Medicaid
- 2. Scaling up organizations such as South Carolina's BirthMatters, based in Spartanburg and accredited by HealthConnect One. ²²

"And I think [that] while we're reimagining policies, we have to reimagine what it looks like to work with doulas alongside the physicians and midwives alongside the physicians and what low-risk birth looks like and what the people are really asking for and be able to really modernize the way we're thinking about giving women or birthing people their birth experience." (ARKCA-Leader)



Increase access through telehealth, especially for rural areas.

Prior to the COVID-19 pandemic, progress in implementing innovations was sometimes blocked or very slow, especially in relation to improving rural and/or maternal child health. The crises presented by COVID-19, especially stay-at-home orders, fast-tracked implementing and scaling up telehealth access. Changes were implemented in days for something that had been advocated for several years.

"We have been asking for virtual visits for the last five years at least because that's how long I've been here. And it was always one electronic medical record issue after another, one barrier after another, and somehow in 48 hours of COVID-19 we went from no virtual visits to 100 percent virtual visits. And so now we're asking well, what else have we needed but we haven't been able to get and why not?" (ARKCA-Leader)



Ensure Medicaid information and language access.

Ensure that Medicaid information, including emergency Medicaid, is readily available through print and webbased media in the predominant languages spoken throughout South Carolina. Ensure that Medicaid enrollment and support processes, including staff in offices and on phone lines, are offered in those same languages.

"Mi recomendación más importante es que haya una persona físicamente en las oficinas de Medicaid que hable español, una o dos personas...sí van muchas personas diariamente. Y dejan de ir a las oficinas porque no hay quién las atienda en español...en las oficinas no hay información en español." (DBLH-Leader)

"My most important recommendation is that there be a person physically present in the Medicaid offices who speaks Spanish, one or two people... a lot of people go daily. And they stop going to the offices because there is no one to attend to them in Spanish... in the offices there is no information in Spanish." (DBLH-Leader)



Conduct outreach with information about Medicaid.

Women often expressed confusion about Medicaid coverage, what it includes and for how long (women/mother vs. newborn). This was especially true of women using emergency Medicaid. Modes of outreach suggested included via a phone app, online, and written materials in different languages.



Increase access to prenatal and postpartum mental health services.

²² HealthConnect One is the national leader in advancing equitable, community-based, peer-to-peer support for pregnancy, birth, breastfeeding, and early parenting. https://www.healthconnectone.org/

Increasing awareness of the importance of mental health services during both the prenatal and postpartum periods highlights the need for coverage. This need was exacerbated by the isolation and limitations placed on individuals, families, and communities since the start of the COVID-19 pandemic. The impact of COVID-19 continues to be experienced by populations most severely affected, namely the same populations eligible for Medicaid coverage.

NEXT STEPS FOR VOICES/VOCES

The VOICES/VOCES initiative will support practitioners, policymakers, and researchers in understanding some of the core issues that must be addressed to improve the pregnancy, birthing, and postpartum experiences of all women in South Carolina, especially those most affected by inequities. The interviews conducted by the VOICES/VOCES team are rich and detailed and need to be leveraged and applied in a variety of ways.

• Share findings with:

- SCBOI partners, especially those working closely with women who use Medicaid/ emergency Medicaid as a main payment source for their pregnancy-related care and who reside in high need areas in South Carolina
- Study participants (consumers and providers)
- A wide range of audiences committed to addressing inequities by directly incorporating
 Medicaid beneficiaries into discussions and strategizing

• Share findings by:

- Complementing SC HealthViz's statistical and spatial data about SC Medicaid enrollment, health care plan performance, and access to care with experiences and recommendations expressed directly by Medicaid consumers ²³
- Creating infographics and a bulletin series focused on specific core topics that can be easily accessed and used by policymakers and practitioners, including health professions students
- Presenting at conferences where participants can learn from and enhance the findings; SCBOI
 Summit, American Public Health Association (APHA), South Carolina Public Health Association
- o Publishing at least two papers in peer-reviewed journals
- o Creating a theater piece based on interviews, which will be performed in South Carolina and recorded for ongoing dissemination and use as material to generate reflection and discussions.

Additional messages and materials will be developed in response to the needs articulated by the SCBOI Vision Team and SC Healthy Connections leadership.

²³ SC HealthViz is South Carolina's eHealth interactive resource and is a project of the SC Department of Health and Human Services developed under contract with the University of South Carolina's Institute for Families in Society, Division of Policy and Research on Medicaid and Medicare. https://www.schealthviz.sc.edu/about

APPENDIX 1

Ratio of Births to Women of Childbearing Age (WOCBA) by Race/Ethnicity Across South Carolina Perinatal Regions

Region	Ratio Births	Ratio of Births by Maternal Race to All WOCBA*				Ratio of Births by Maternal Ethnicity to All WOCBA*		
	to WOCBA	Black	White	Other	Unknown	Hispanic	Non- Hispanic	Unknown
	Per 100 WOCBA					Р	er 100 WO	СВА
I	29.8	6.1	22.9	0.8	0.0	3.3	26.5	0.0
II	31.3	7.9	22.6	0.9	0.0	2.5	28.7	0.0
III	28.4	10.8	16.5	1.0	0.0	1.9	26.4	0.0
IV	29.6	11.3	17.6	0.8	0.0	2.0	27.6	0.0
V	30.6	8.8	20.9	0.9	0.1	3.6	27.0	0.0
Total	29.6	9.1	19.5	0.9	0.0	2.7	26.9	0.0

^{*} Caveat – these ratios are not indicative of how many times an <u>individual</u> woman gave birth; they indicate how many births there were to women overall in each category during the time period.

- Using 5yr Estimates (2015-2019) from Department of Health and Environmental Control South Carolina Community Assessment Network (DHEC SCAN) data, Region III had the largest share of births to all mothers (III = 32.8%, N = 93,815) and Region II the smallest (II = 8.9%, N = 25,587).
- More women in Perinatal Regions II (31.3) and V (30.6) gave birth than in the other Regions
- All Regions were slightly above the state average (N = 29.6).

Table Example:

In Perinatal Region I, there were 29.8 births per 100 WOCBA; of those births 6.1, were to Black women, 22.9 to white women, 0.8 to women of another race, and <1 births to women of an unknown race. Regarding maternal ethnicity, of the 29.8 births, 3.3 births were to Hispanic women, 26.5 to non-Hispanic women, and <1 births to women of an unknown ethnicity.

Analysis developed by Institute for Families in Society (IFS) - Data Science & Visualization Team. Created August 2021

APPENDIX 2

VOICES/VOCES CODES (in alphabetical order)

Abortion or Miscarriage	Any mention of abortion or miscarriage.
Access to Resources	Any reference to having or not having access to resources as well as any reference to someone/something helping you access resources or placing barrier to resources.
After bringing baby home (longer term postpartum)	Any time after leaving the hospital (woman)- even if the baby is in the NICU-any reference to having or not having access to resources as wel as any reference to someone/something helping you access resources or placing barrier to resources
Immediate Postpartum (in hospital)	During immediate postpartum, while still in the hospital, any reference to having or not having access to resources as well as any reference to someone/something helping you access resources or placing barrier to resources
Labor & Delivery	During L&D period, any reference to having or not having access to resources as well as any reference to someone/something helping you access resources or placing barrier to resources
Prenatal	During prenatal care, any reference to having or not having access to resources as well as any reference to someone/something helping you access resources or placing barrier to resources
Awareness of Inequity	Whatever cues that woman is aware of inequity
Birth control	Any reference to birth control.
Birth Plan	Any reference to a woman's desires regarding her birthing experience
Centering Care	Any reference to Centering program.
Challenges in Women's Lives	References made by participants about difficult situations or challenges in their lives; what we as coders also define as "challenges".
Domestic Violence	Any reference to domestic or intimate partner violence
Homelessness or Housing Issues	Any reference to experiences of homelessness or having difficulties with finding or maintaining housing
Communication with or from Providers	Reference to how communication flows (or doesn't) with health care providers/ any reference to one-way messaging from providers
After bringing home baby (longer term postpartum)	Any time after leaving the hospital (woman)- even if the baby is in the NICU, any reference to how communication flows (or doesn't) with health care providers/ any reference to one-way messaging from providers
Immediate Postpartum (in hospital)	During immediate postpartum, while still in the hospital, reference to how communication flows (or doesn't) with health care providers/ any reference to one-way messaging from providers
Labor & Delivery	During L&D, any reference to how communication flows (or doesn't) with health care providers/ any reference to one-way messaging from providers

Prenatal	During prenatal care, any reference to how communication flows (or doesn't) with health care providers/ any reference to one-way messaging from providers
Concern, Worry, Anxiety	Any reference made to concern, worry, and/or anxiety, including reference to causes of concern, worry, anxiety
COVID Policies	Any reference to COVID policies in health care
Doulas	Reference made to doulas, doula care
Examples of Patient Education	Women's descriptions of the patient education they received during their pregnancy, labor and delivery, postpartum (immediate or at home). Information aimed at helping the woman understand and make informed decisions.
Healthcare Provider Responses	Actions by healthcare providers related to women's care
Impact of COVID	Any reference made to the IMPACT of COVID on women's lives
Not related to pregnancy	References made to the impact of COVID NOT related to pregnancy
Related to pregnancy	References made to the impact of COVID related to pregnancy
Income OR Financial Support OR Lack of	Any reference made to the financial support or income that women have (or not)
Inequitable Treatment	Any mention of feeling like woman was treated differently from others and/or woman's explanations of differential/inequitable treatment (in relation to other people)
Medicaid	Any reference to Medicaid.
Mental Health	Any reference to mental health.
After bringing home baby (longer term postpartum)	
Narratives of Labor Experiences	Participants describe their experiences going into and during labor, regardless of where the experience took place
Positive Experiences	Participants describe their positive experiences going into and during labor, regardless of where the experience took place
Narratives of Obstetric Violence	Examples of obstetric disrespect and violence (as a continuum from disrespect to violence; abuse, coercion, and disrespect); the mistreatment and violence against women experienced during facility-based childbirth and in other reproductive health services; See examples: https://eipmh.com/un-obstetric-violence-is-a-human-rights-violation/]
After bringing baby home (longer term postpartum)	Obstetric violence narratives after baby is brought home
Abuse	Obstetric violence narratives after baby is brought home: reference to examples of mental or physical or sexual abuse or neglect
Coercion	Obstetric violence narratives after baby is brought home: reference to examples of coercion- health care providers in relation to postpartum

Disrespect	Obstetric violence narratives after baby is brought home: reference to examples of disrespect by health care providers in relation to postpartum
Immediate Postpartum (in hospital)	Obstetric violence narratives after baby is born but woman is still in the hospital
Abuse	Obstetric violence narratives after baby is born but woman is still in the hospital: reference to examples of mental, physical, sexual abuse, neglect - health care providers in relation to postpartum
Coercion	Obstetric violence narratives after baby is born but woman is still in the hospital: reference to examples of coercion- health care providers in relation to postpartum
Disrespect	Obstetric violence narratives after baby is brought home: reference to examples of disrespect by health care providers in relation to postpartum
Labor & Delivery	Obstetric violence narratives during labor and delivery
Abuse	Obstetric violence narratives during labor and delivery: reference to examples of mental, physical, sexual abuse, neglect by health care providers
Coercion	Obstetric violence narratives during labor and delivery: reference to examples of coercion by health care providers
Disrespect	Obstetric violence narratives during labor and delivery: reference to examples of disrespect by health care providers
Prenatal	Obstetric violence narratives during prenatal care
Abuse	Obstetric violence narratives during prenatal care: reference to examples of mental, physical, sexual abuse, neglect by health care providers
Coercion	Obstetric violence narratives during prenatal care: reference to examples of coercion by health care providers
Disrespect	Obstetric violence narratives during prenatal care: reference to examples of disrespect by health care providers
Narratives of Women Taking Action for their Well-being (and their baby's)	Any example of women speaking out, speaking up, taking stance, making decisions, taking action that show they are advocating for themselves or their babies.
Perceptions of Healthcare	Statements and reflections by women about healthcare received, including by self and others; example: "the midwife really listened to me" or "]. This includes anything offered by lactation specialists.
Immediate Postpartum (in hospital)	
Labor & Delivery	
Prenatal	
Perceptions of Services	Perceptions other than healthcare [statements and reflections by women about services received, including by self and others, e.g.,

	Medicaid office— "it was very difficult to enroll in Medicaid"]. This includes social worker services located within hospital settings.
After bringing home baby (longer term postpartum)	
Immediate Postpartum (in hospital)	
Labor & Delivery	
Prenatal	
Physical illness during pregnancy (major) OR High Risk	Reference made to any illness or conditions experienced during pregnancy that were severe and put the woman's health and life or the viability of her pregnancy at risk. This excludes mental health. Mental health should be coded under node "mental health".
Pre-existing physical health conditions	Health conditions (physical) that existed prior to the pregnancy that may affect the pregnancy experience. This excludes mental health. Mental health should be coded under node "mental health".
Reactions to News of Pregnancy	Surprise, disappointment, excitement from woman, partner, family, others
Recommendations	Recommendations made by the women in relation to how to improve care, Medicaid, services
Social support including personal and organizational (and lack of)	Perception and actuality that one is cared for and has assistance
After bringing baby home (longer term postpartum)	During this phase
Friends & Family	Social support offered (or withheld) by friends and family
Organizational	Social support offered (or withheld) by organizations (community, religious, service NOT health service)
Social Media	Social support garnered through social media
Labor & Delivery	During this phase
Family & Friends	Social support offered (or withheld) by friends and family
Organizational	Social support offered (or withheld) by organizations (community, religious, service NOT health service)
Social Media	Social support garnered through social media
Prenatal	During this phase
Family & Friends	Social support offered (or withheld) by friends and family
Organizational	Social support offered (or withheld) by organizations (community, religious, service NOT health service)
Social Media	Social support garnered through social media
Spirituality or Faith	Any mention of faith, spirituality, God, higher power, higher beliefs, or faith institutions

Immediate Postpartum (in hospital)	During this phase
Friends & Family	Social support offered (or withheld) by friends and family
Organizational	Social support offered (or withheld) by organizations (community, religious, service NOT health service)
Social Media	Social support garnered through social media
Transportation	Any reference to transportation

