



Pathways to Wellness

Health Needs of Black Women After Incarceration

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Justice Institute

Letter from the Executive Director

We know, without question, that incarceration has serious negative consequences for the health and wellness of the people who have been confined. Chronic diseases, co-occurring conditions, and exposure to trauma are prevalent within this group—especially among Black women who face persistent health inequities, inside and outside of prison.

Despite that, we know very little about the health needs and health-seeking behaviors of Black women who have experienced incarceration. What are formerly incarcerated Black women's primary health concerns? Where do physical health, mental health, and wellbeing rank compared to other issues and concerns they must address after release? How do Black women's medical experiences during confinement impact their health care decisions once they are home in the community? These are critical questions we must answer if we are to better meet the health needs of formerly incarcerated Black women and to mitigate, and ultimately eliminate, the deep health inequities Black women face. These are the questions we sought to answer in the Pathways to Wellness Study.

Like all of our work at the National Black Women's Justice Institute, this study was inspired by innovation from within the community. While evaluating the California Wellness Foundation's Women of Color Health Initiatives, I was struck by one grantee's efforts to support the health and wellness of the formerly incarcerated women it served, most of whom were Black. To meet the needs of an increasing number of women with



Dr. Sydney McKinney

chronic medical conditions, the organization created a new staff position to ensure women could easily access treatment and medication.

Medical care coordination for formerly incarcerated people, particularly connecting them to primary care providers, is a growing issue. However, there is not yet a gender-responsive and intersectional framework to guide these programs, despite well-documented differences in the health needs and medical care utilization of directly-impacted women compared to directly-impacted men. The findings from this study are an important initial step toward developing a culturally-affirming, trauma-informed, and gender-sensitive medical care coordination framework.

We are grateful for the candor, vulnerability, and trust of the women who participated in this study. They courageously shared their stories with us. Regrettably, most of their experiences were negative and, in many instances, worsened existing health conditions or caused additional emotional and physical harm. But we also heard stories of “soul” care, healing, collective advocacy, and hope. In this report, we share their stories and our findings with the intention that you will join us in our work to enhance and increase the availability of gender-responsive reentry services that advance the health, wellness, safety, and healing of formerly incarcerated Black women and girls.

A handwritten signature in white ink, appearing to read 'Sy McKinney', with a stylized, flowing script.

Dr. Sydney McKinney
Executive Director, National Black Women's Justice Institute

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We are tremendously thankful to our esteemed council of advisors for their guidance, expertise, and support for the research study and reviewing this report: Susan Burton of A New Way of Life; Dr. Marilyn Jones of Because Black Is Still Beautiful; June Lee of Root and Rebound; and Jessica Nowlan, former executive director at the Young Women's Freedom Center.

We are deeply grateful to the women with lived experience of incarceration in California for sharing and trusting us with their stories.

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Executive Summary

In the United States, Black women have long experienced disparities in health and healthcare that continue to persist today. Black women generally have shorter life expectancies, higher maternal mortality rates, and higher prevalence of health conditions such as heart disease, stroke, obesity, diabetes, anemia, and stress compared to non-Hispanic white and Latinx women.

Not only do Black women tend to experience worse health outcomes compared to non-Hispanic white and Latinx women, but they are also disproportionately incarcerated. In California, Black women are imprisoned at more than five times the rate of white women. Incarceration has been shown to be a social determinant of health and an underlying cause of the persistent inequities in overall health, reproductive health, and mental health outcomes experienced by formerly incarcerated Black women.

Despite the important nexus of race, gender, health, and incarceration, few studies explore how they interact to shape the reentry experiences of formerly incarcerated women and their health, especially the experiences of Black women who are disproportionately represented within this population. This report aims to begin to fill this gap.

The National Black Women's Justice Institute interviewed 21 formerly incarcerated Black women in California about a number of topics, including their healthcare needs, how they access healthcare services, and the barriers they face in trying to access care.

Throughout this study, women reported that stigma about their incarceration history or past history of drug use prevented them from seeking help for pain and discomfort. Decisions that the women in the study made to “push through” pain and not “complain” illustrate how the behaviors and coping strategies of the “Strong Black Woman” stereotype and incarceration history interact to directly impact whether and how Black women access healthcare after release.

Summary of Findings

Incarceration negatively impacts health and exacerbates already existing health needs of Black women. Many Black women enter incarceration with existing trauma and health and mental health issues. Incarceration does little to address these issues, and often, it compounds the problems. The impact of this is that when women leave incarceration, their health is often worse than when they entered.

- **Treatment delays and lack of follow-up:** Formerly incarcerated Black women reported that when they were incarcerated, they experienced long waiting periods to be seen by healthcare providers, ranging from weeks to months. Even when women did see a healthcare provider and received a diagnosis, lack of follow-up by providers meant that women's health conditions worsened.
- **Dismissal of claims or not taking claims seriously:** When Black women were finally able to see a healthcare provider, they reported that many of those providers did not take their health concerns seriously or dismissed them entirely.
- **Misdiagnoses:** Several Black women in the study shared personal stories and witness accounts of improper medical care from providers' misdiagnoses, which ranged from benign issues like being given an inaccurate eyeglass prescription to fatal consequences.
- **High cost of healthcare in confinement:** The high cost of copays for people who are incarcerated significantly limits people's ability to access care while in confinement. In California people in prison earn, on average, \$0.08 to \$0.95 per hour for their work. For someone earning \$0.08 an hour, a \$5 copayment requires more than 7 days of work. A minimum wage worker in California would have to pay more than \$600 for a single doctor's visit if they were charged at the same rate of incarcerated people.

High priority health concerns included reproductive health needs, mental health needs & maintaining sobriety, obesity & weight gain, and certain chronic conditions. The critical health concerns of Black women, once released from incarceration, broadly focused on being more proactive about addressing and improving their physical health, including the importance of eating healthy and getting more exercise.

- **Reproductive health:** One-third of Black women in the study reported reproductive health issues during confinement, including pelvic pain, symptomatic uterine fibroids, and heavy menstrual bleeding.
- **Mental health needs and maintaining sobriety:** About two-thirds of women in the study reported a mental illness, substance use disorder, or both, which they directly connected to traumatic experiences before incarceration and the exacerbating effect of the carceral environment itself.

- **Obesity and weight gain:** More than half of the women in the study said that weight gain was among their high-priority health concerns, both during incarceration and after release. Weight gain during incarceration is a problem that disproportionately affects women in prison compared to men, especially those with comorbid diseases.
- **Chronic health conditions:** More than 75% of the women in the study reported having a chronic condition. The top health concerns that women prioritized included chronic conditions such as hypertension, diabetes, and high cholesterol. Nearly a quarter of the women in the study were at least 50 years old at the time of their latest release from confinement, and because of their age, they were especially concerned about chronic conditions.

Accessing healthcare after incarceration is difficult. The Black women in this study want to take preventative measures to address and improve their health and wellness. However, accessing healthcare after incarceration remains challenging for formerly incarcerated Black women.

- **Distrust of the healthcare system:** For some formerly incarcerated Black women, the treatment they received from healthcare providers in confinement—including inadequate and “one-size-fits-all” treatment, dismissal of claims, lack of follow-up, and misdiagnoses—engendered deep distrust in the healthcare system once released and prevented women from seeking help later to meet their health and wellness needs.
- **Complexity of insurance systems:** Although health insurance coverage is strongly associated with reduced rearrest rates among women, there is limited education and pre-release planning to facilitate women’s ability to access healthcare after leaving confinement. Formerly incarcerated Black women with Medi-Cal (California’s Medicaid program) experienced limited health coverage, especially relative to private insurance. For many formerly incarcerated Black women in the study, there was an overwhelming consensus that there is a need for updated, accurate, and accessible information as it pertains to navigating the healthcare system.
- **Geographic location affected Black women’s access to health care:** Inequities in access to quality health services, healthy food, and opportunities vary by geographic location. Therefore, the location where women were released or paroled to played a role in their ability to access health care—from the quality and availability of healthcare providers to access to fresh food.

Women develop their own strategies to address health needs after incarceration. In spite of women’s distrust of healthcare providers due to negative past experiences and the challenges of navigating the complexity of various insurance systems, many of the women in this study developed their own strategies to access healthcare that supported their own health and wellness goals.

- **Connect with supportive organizations:** Black women reported that community-based organizations—such as A New Way of Life, the Transitions Clinic Network, and Root and Rebound—were gateways to healthcare and mental health services.
- **Self-advocacy as self-care:** Many of the formerly incarcerated women in this study reported that self-care and self-love were critical strategies in accessing the type of care that they needed to support their own health and wellness goals. Self-care included advocating for themselves in various healthcare settings, going to church for supportive community and fellowship, setting boundaries in relationships, developing positive coping skills, and practicing kindness with themselves.
- **Advocate for others:** Giving back and paying it forward to other system-impacted people through advocacy and direct services was a central theme in participants’ healing. More than half of the formerly incarcerated Black women in the study work or volunteer in direct services and/or advocacy roles that leverage their lived experience to help others, such as working with people who are homeless, in recovery, and survivors of domestic violence.

Desires for health and wellness: Most women in the study said that, for them to be holistically healthy and well, they needed access to wraparound support services, including peer support, safe affordable housing, accessible information, and diverse, competent, and compassionate providers.

Implications for stakeholders

The study’s findings indicate the need for stakeholders who interact with incarcerated and formerly incarcerated Black women—whether based in a carceral facility or in the community—to listen to Black women when they express their pain and concerns, reject pathologizing, address implicit bias, and see Black women with incarceration experience as the full human beings they are.

The desires of the women in the study for peer support and help navigating healthcare systems indicate promise for community health worker roles to support Black women, especially those with chronic health conditions, in navigating the healthcare system to ensure they can access the treatment and medication they need to be well and thrive.

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Introduction

In the United States, Black women have long experienced disparities in health and healthcare that continue to persist today. Black women generally have shorter life expectancies, higher rates of maternal mortality, and higher prevalence of health conditions such as heart disease, hypertension, stroke, obesity, diabetes, anemia, and stress compared to non-Hispanic white and Latinx women.¹ Structural and interpersonal oppression drive these health disparities. For example, Black women have higher unemployment and poverty rates than the U.S. average for women, which limits their access to health-promoting resources and opportunities such as medical care. Black women also live in neighborhoods that are more racially segregated, and disadvantages like lower property values compared to white counterparts are concentrated.² These economic disadvantages and racial segregation due to chronic disinvestment and housing discrimination also lead to poorer health, partly by increasing exposure to health-harming conditions.

Not only do Black women tend to experience worse health outcomes compared to non-Hispanic white and Latinx women, they are also disproportionately incarcerated. More than 173,000 women and girls are incarcerated in the United States, and nearly 2.5 million women and girls are released from prisons and jails annually.³ In California, an estimated 189,066 women are released from state prisons and local jails.⁴ Inside those prisons and jails, Black women in particular are overrepresented across the country and in California specifically. In California, Black women make up nearly 26% of the state's female incarcerated population but only about 6% of the state's residents.⁵ Moreover, Black women in California are imprisoned at more than five times the rate of white women.⁶ And ultimately this has a disproportionate impact on Black women's health.

Incarceration has been shown to be a social determinant of health and an underlying cause of the persistent inequities in overall health. People released from carceral facilities have difficulty addressing health issues, as few prison systems release individuals with the medications they need, health insurance, or primary care referrals.⁷ Poor access to primary care and health insurance lead to higher rates of emergency department use and death among recently released individuals compared with the general population.⁸ These health outcomes are pronounced for formerly incarcerated Black women, especially in regards to reproductive health and mental health outcomes.⁹ For example, incarcerated Black women experience more sexually transmitted infections, HIV/AIDS, and post-traumatic stress than other formerly incarcerated women or women who have not been incarcerated.¹⁰ The health outcomes of incarcerated Black



women are also disproportionately impacted by substance use,¹¹ which is often associated with trauma exposure.¹²

Despite the important nexus of race, gender, health, and incarceration, there is very little research examining the health of Black women with incarceration experience. Although some research does examine how women navigate the reentry process and the factors that impact women's reentry experiences generally, few studies employ an intersectional framework to explore how race, gender, ethnicity, sexuality, age, and geographic location interact to shape the reentry experiences of formerly incarcerated women and their health, especially the experiences of Black women who are disproportionately represented within this population.¹³ This report provides critical findings from the Pathways to Wellness study that will help the field begin to better understand and meet the health needs of formerly incarcerated Black women.

The Pathways to Wellness study was a qualitative research study that aimed to learn directly from Black women about their confinement and reentry experience in California to 1) increase knowledge about and improve health outcomes of formerly incarcerated women, 2) expand the landscape of available services, and 3) facilitate access to healthcare. Although our findings are not generalizable, our analysis offers a roadmap for mitigating and interrupting the harmful effects of the interplay of racial bias, gender discrimination, and incarceration history on formerly incarcerated Black women's health and wellness.

Methodology

The National Black Women’s Justice Institute uses a Black Feminist Framework for research and evaluation. Our Black Feminist Framework aims to enhance the design and overall practices of research and evaluation involving Black women and girls through a commitment to the principles of intersectionality, a focus on strengths, cultural affirmation, dialogue and self-definition, reflexivity, and community care:

- Employing an intersectional analysis means that we are attentive to how systems and institutions create conditions of risk and harm, considering the impacts of institutional and individual-level forms of oppression and discrimination.
- A focus on strengths rejects unidimensional views and stereotypes that present Black women as problems to be fixed.
- Cultural affirmation in research requires that directly impacted Black women are centered and uplifted throughout a project—from development to implementation to analysis.
- Dialogue and self-definition create space throughout the research process for women to speak for themselves, define issues of critical importance, name their own experiences, and make decisions about their lives.
- Reflexivity requires researchers to engage in ongoing self-reflection of how personal assumptions, one’s own lived experience, and research training impact the research.
- Community care ensures that the research advances wellbeing, goals, and priorities of directly impacted Black women.

We sought to design the research study in a way that affirms the inherent value of formerly incarcerated Black women. To that end, we convened an advisory committee of formerly incarcerated women who are leading California-based organizations that provide reentry services and advocacy work. These experts helped steer the development of our research questions and worked with us to create our interview protocol. This helped us ensure that our interview questions were culturally affirming and strength-focused (i.e., did not reproduce harmful stereotypes or focus on deficits). Recognizing experience as expertise, our initial conversations with this group of experts created space for dialogue to define issues of critical importance.

These organizations also agreed to assist with study participant recruitment. They shared flyers with eligible clients and facilitated connections with other organizations

in the state. To be included in the study, participants were required to (1) be at least 18 years of age; (2) identify as a Black woman; (3) have a history of incarceration, defined as spending at least six months in a California prison or jail as an adult;¹⁴ (4) not be currently incarcerated within a carceral facility;¹⁵ (5) be able to speak English; and (6) live within the state of California. Women interested in participating contacted NBWJI research staff to learn more about the study, verify eligibility, and schedule an interview.

Between January and May 2022, NBWJI research staff conducted 21 semi-structured interviews with formerly incarcerated women in California using Zoom. Interviews were conducted in a conversational way that sought to understand formerly incarcerated Black women's health concerns, how they prioritize their wellness needs, how they access healthcare, and identify barriers to care. Interviews also explored their self-care practices, healing journeys, and what they desire from the systems that they have to navigate for their wellness. Lastly, interviews created space for women in the study to dream, discuss their ambitions, and growth. Interviews ranged from 45 minutes to 105 minutes in duration; the average interview duration was 75 minutes.

At the end of the interview, the research team debriefed with women in the study to check in about how they were feeling and how they found the interview process. Women who participated in the study chose their own pseudonyms, which are used to identify women throughout this report wherever quotes appear. Women in the study received a \$75 gift card for their participation. Additionally, after the interview, the research team mailed each woman we spoke with a “wellness package” that included various items to support women in practicing self-care.¹⁶

Interviews were transcribed, anonymized, and systematically coded and analyzed for emergent themes and concepts using NVivo, a qualitative data analysis software. Two team members collaborated to create an initial codebook based on the interview guide and a review of all transcripts. We also created memos to not only document decisions around coding, but as a means to reflect on our insights and assumptions.

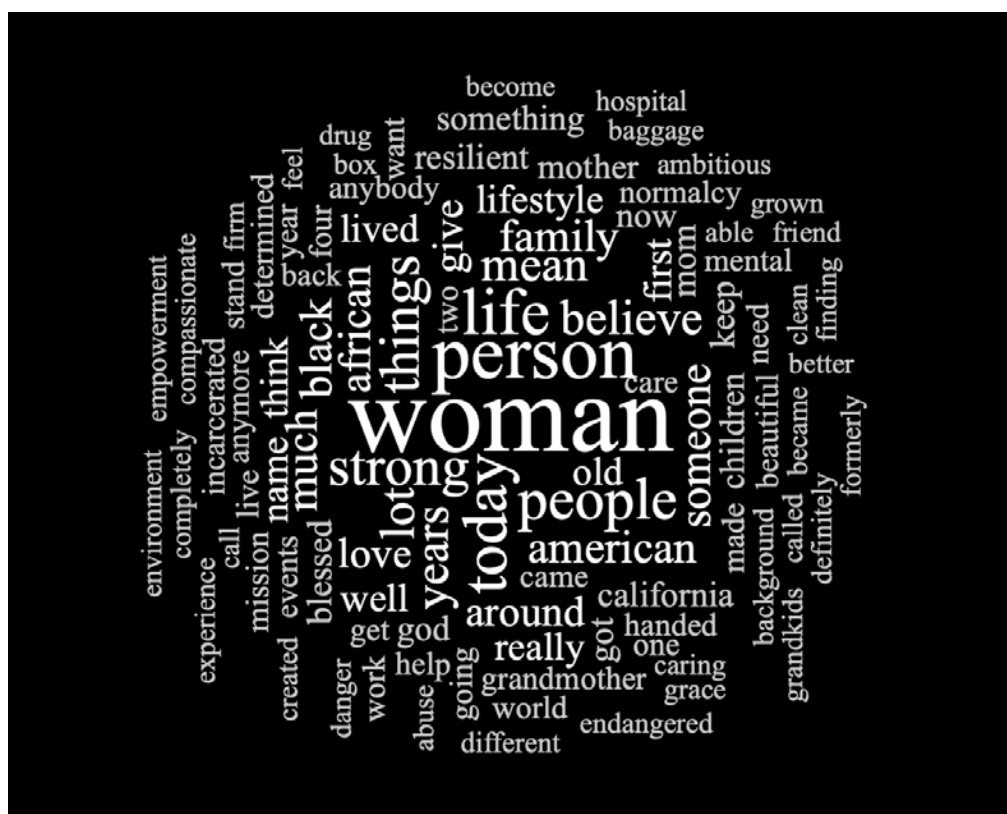
About the Women in This Study

The study sample included 21 Black women, ranging in age from 33 to 65 years old, with an average age of 50 years. Women in the study were located across six counties in the state of California, including Los Angeles (n=8), San Francisco (n=7), Fresno



(n=2), Riverside (n=2), Alameda (n=1), and Orange (n=1). Twenty-four percent (n = 5) self-identified as lesbian, gay, or bisexual. More than 70% (n = 15) of the women in the study were mothers: four are mothers of minor children, another four are grandmothers, and one is a great-grandmother. Nearly half (n = 10) of the women in the study were single, 14.3% (n=3) were married, and 2 (9.5%) were in a domestic partnership. The remaining 29% were divorced, separated, or widowed. More than 75% of the women in the study reported having some form of post-secondary education (i.e., some college, an associate's degree, a bachelor's degree, or a graduate degree). Sixty-six percent of participants were employed full-time, 24% were unemployed, and nearly 10% were employed part-time at the time of the interview. It is important to note that these employment and education statistics do not reflect a typical or generalizable profile of formerly incarcerated Black women, which is likely due to selection bias, given NBWJI's recruitment strategy. Additionally, given that our research sample includes women who have been in the community for a long time, it is expected that employment and education statistics would reflect greater attainment than if the sample was limited solely to recently released women.

The incarceration experiences of the women in the study varied widely in terms of age of entry into the carceral system, frequency of arrest, nature of charges, sentencing, and time served. Five women (24%) reported involvement in the juvenile legal system. All women in this study had multiple jail stays, and most women reported a combination of several short-term stays in county jail and at least one prison stay. Some women in the study reported having been arrested and booked up to 60 times over the course of their lives. The total time served among the women in the study ranged



from one year to more than 36 years. Eight women (38%) were serving life sentences or indeterminate sentences up to life in prison, informally referred to as “lifers.” The average total amount of time women in the study were incarcerated over the course of their lives was about 16 years. The average amount of time since the women in the study had been incarcerated was about 7 years, although that time period for all women ranged from 23 years to just three weeks at the time of the interviews.

Most women in the study were convicted of crimes against persons (n = 13; 62%), property offenses (24%), drug offenses (19%), and other offenses such as prostitution, pimping, and pandering (19%). Despite the varying types of offenses, like most women with incarceration histories, the offenses of the women in this study were often the result of their trauma, addiction, poverty, or mental illness being criminalized. Most women's pathways to incarceration history were the result of the criminalization of poverty, substance use, and domestic abuse.

When asked to describe who they are, women in the study were clear in their inherent value and their resolution to continue to evolve beyond stigmatized labels that society has assigned to them. Women chose to define themselves with characteristics including strong, resilient, ambitious, compassionate, nurturing, empathetic, determined, optimistic, and spiritual, among other descriptors.

About the Women in the Study

Employment of women in the study



Counties where women live



Mothers

70%

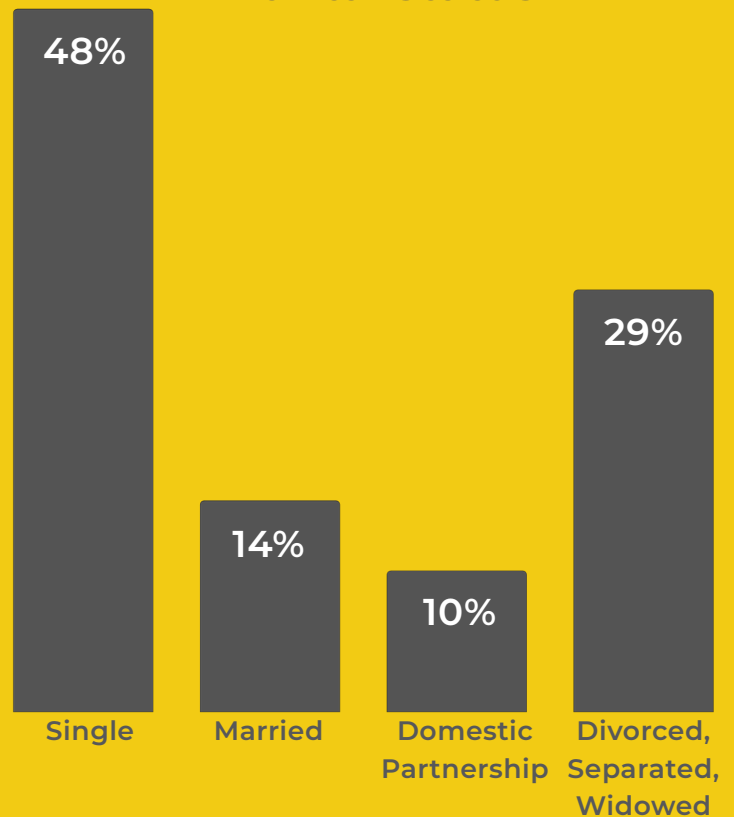
Self-identified as lesbian, gay, or bisexual

24%

Post-secondary education

75%

Marital status





Findings

This study set out to learn directly from Black women about their health and wellness after release from incarceration and how they are meeting their health needs during reentry. Specifically, we sought to answer the following research questions: 1) What health needs or concerns do formerly incarcerated Black women prioritize? 2) How do formerly incarcerated Black women gain access to healthcare services? 3) What are formerly incarcerated Black women's barriers to accessing healthcare? 4) How are formerly incarcerated Black women's sense of dignity and self-worth impacted by the healthcare system? 5) What do formerly incarcerated Black women need and desire from the healthcare system? In the process, we also learned much about the health and wellness needs of Black women and what they experienced *while* they were incarcerated.

The health needs and institutional barriers that Black women experienced while incarcerated often had a strong influence on whether and how women sought and accessed resources and services to support their health and wellness after release. Given this, our findings include themes that emerged during our interviews with participants about their health and wellness needs *both during and after* incarceration.

The negative impacts of incarceration on Black women's health needs

Research has long demonstrated the lasting negative impacts of incarceration on health. It increases the prevalence of chronic health conditions, such as hypertension, diabetes, arthritis, and asthma, and most adults are released from incarceration with more chronic medical problems than they had before they were incarcerated.¹⁷ It also decreases life expectancy: Each year in prison takes two years off of life expectancy.¹⁸

The Black women who participated in this study were no exception. Many Black women enter incarceration with existing trauma and health and mental health issues. Incarceration does little to address these issues, and often, it compounds the problems. The impact of this is that when women leave incarceration, their health is often worse than when they entered. The women in this study reported various health concerns and reported on a variety of barriers to accessing healthcare to address their concerns while incarcerated. These barriers include treatment delays and lack of follow-up, prison healthcare providers dismissing their health claims or not taking their claims seriously, misdiagnoses, and the cost of care during confinement.¹⁹

“When you’re incarcerated, you don’t receive the most adequate and sufficient amount of medical attention that you would have had you been out here in society. First of all, the staff there, half of them are not compassionate towards inmates at the time of giving treatment, and their concept or perception is that inmates have the tendency to always try to manipulate or get over on the system. And so, in all actuality, a lot of times the medical staff has the tendency to push you off and try to deter you from seeking any type of medical treatment or service. So when you do finally receive some type of treatment or service, it’s at a point where the illness or whatever sickness you may be having has gone on for so long untreated that it’s progressed and it’s become more severe than what it actually started out to be. And so that’s just one of the many examples of how the medical system inside the prison system neglects providing adequate services, and medical treatment to women.” —Rocky

Treatment delays and lack of follow-up

Recent research documenting long wait times to receive health care while incarcerated illustrates another systemic barrier to addressing health needs during incarceration. Delayed treatment for health issues during confinement has been shown to be common and a contributing factor in poor health outcomes.²⁰

The formerly incarcerated Black women we spoke with reported that when they were incarcerated, they experienced long waiting periods to be seen by healthcare providers, ranging from weeks to months. Some of the health concerns women mentioned that went untreated for long periods included a broken wrist, back pain, migraines, and vaginal discharge. These long wait times were often driven by chronic understaffing of healthcare providers, population level (i.e., how many people were incarcerated in a facility at any given time), and the many significant health needs of incarcerated women. For example, one woman, Mariah,²¹ reported complaining about chronic shoulder pain, which despite numerous visits to the in-prison doctor, never improved. When she was finally able to see an outside specialist, that doctor ordered an MRI, which finally indicated that Mariah had a torn rotator cuff with four degenerated discs in her neck that “they could have caught if they would have done it a long time ago.” She ultimately required neck surgery, leaving two plates and eight screws in her neck, which was entirely preventable.

Even when women did see a healthcare provider and received a diagnosis, lack of follow-up by providers meant that women’s health conditions worsened. For example, one woman in the study, Baby Cakes, was diagnosed with degenerative disc disease in prison, but she never received any follow-up after the diagnosis. Her condition has

since progressed over the years. The sentiment among both women in the study and previous research is that, as Tracey said, “you have to be dying for a doctor to see you.”

Women in the study also felt that racial discrimination affected timely access to medical treatment during confinement. For example, one woman spoke about a sort of experiment that she and other Black women did inside prison wherein they and their non-Black roommates would put in a request for healthcare with the same problem. The non-Black roommates would always get access to see healthcare providers first. They did this over a period of time with the same results.

Dismissal of claims or not taking claims seriously

When women were finally able to see a healthcare provider, they reported that many of those providers did not take their health concerns seriously or dismissed them entirely. The women we spoke with reported that healthcare providers would say, due to many incarcerated Black women’s history of substance use disorders, that women were just seeking drugs. These findings echo the plethora of past research showing that the pain and health claims of Black patients, especially Black women, are more likely to be dismissed.²²

Several women (n = 5) in the study were ultimately forced to file administrative grievances to get their claims taken seriously and receive proper medical care.²³ For example, one woman in the study was denied access to a special floss she needed for her dental bridges. Another filed an appeal form after having an ear infection for more than a month with so much inflammation that she couldn’t hear out of the ear. Medical staff dismissed it as an insect bite, despite her insistence to the contrary. Another woman reported “some female problems” that developed during confinement and that her concerns weren’t taken seriously. Both women filed appeals and also solicited outside help from family members to lobby the prison on their behalf to get what they needed.

Misdiagnoses

Women in the study (n = 5) shared personal stories and witness accounts of improper medical care from providers’ misdiagnoses, which ranged from benign issues like being given an inaccurate eyeglass prescription to fatal consequences. Mariah shared, “One of my roommates in the adult facility, she kept going to the doctor. They kept telling her she had hemorrhoids. They had to rush her out on emergency to a hospital, come to find out she had colon cancer, and she didn’t even live another two weeks. They don’t pay attention, they don’t listen to us, and they don’t care.”

Women we interviewed engaged in mutual aid to deal with the consequences of improper and inadequate medical care in carceral facilities. Mutual aid is a cooperative

practice of people meeting each other's needs with the shared understanding that current systems have failed to do so. For example, Baby Cakes shared a story of how she and other women in the prison took care of her friend who had all her lymph nodes removed for a condition she did not actually have. Baby Cakes shared, "She refused to be housed in the treatment center because she thought they were going to kill her... I had the officers move her in the room with me, and me and one of my other room-mates nursed this woman back to health. If it hadn't been for us, she probably would have died in there."

"It's a lot of different things that happen in there, like women being diagnosed with things then they come out here and have a physical and get all this blood work done and find out they never even had these things." —Baby Cakes

High cost of healthcare in confinement

Contributing to incarceration's negative impact on health is the extraordinarily high cost of accessing medical care in confinement. Most people who are incarcerated—like most people in the United States—must pay co-pays to access healthcare.²⁴ In carceral facilities across the United States, co-pays for health services are meant to partially reimburse the states and counties for the high cost of medical care for the people they hold in confinement.²⁵

Given the high risk for both chronic and infectious diseases among incarcerated people, it is even more critical that they receive access to the healthcare that they need.²⁶ Yet the high cost of copays for people who are incarcerated significantly limits people's ability to access care while in confinement. According to a 2010 study, in about 70% of United States prisons, incarcerated people are charged a fee of between \$2 and \$10 for each request for healthcare, and this has been shown to reduce access to healthcare and lead to poor health outcomes.²⁷ This may not seem like much, but for people in prisons, this is often more than a week's pay: For example, in California people in prison earn, on average, \$0.08 to \$0.95 per hour for their work.²⁸ For someone earning \$0.08 an hour, a \$5 copayment requires more than 7 days of work. A minimum wage worker in California would have to pay more than \$600 for a single doctor's visit if they were charged at the same rate of incarcerated people.²⁹

Research has demonstrated that copayment requirements directly affect the health of incarcerated people. This is especially true for older women, who may have multiple medical concerns but who delay seeking necessary treatment because of the financial burden.³⁰ Three women in the study discussed copayments as particularly burdensome for them during incarceration. The high cost of copays forces incarcerated people to make difficult choices between seeking care, buying basic necessities, or maintaining communication with their families. As one woman in the study explained, women often had limited funds, yet copays would be automatically deducted from women's commissary accounts without regard for their other competing needs.

"It even became a point where they started having you fill out a copay, charging you \$5 to see a doctor. And if you don't have \$5, you're indigent; they'll hold on to the copay for 30 days before they just say it's null and void. So if you get any money in your account from your family—let's say [a family member] sends you \$10. [The prison is] going to take \$5 out of that \$10 for your copay. So you have to learn how to personally navigate your money in prison for numerous things, and that's one of them." —Angel

California recently took steps to address this financial barrier to care with the move to eliminate copayment charges for medical and dental services in carceral facilities.³¹ The California Department of Corrections and Rehabilitation and California Correctional Health Care Services announced this policy change in state prisons effective March 1, 2019, citing misalignment with patient care.³² Several months later, the governor signed Assembly Bill 45 into law, which also eliminated copays and medical equipment charges in county jails.³³

High priority health concerns

"When I was inside, I said, 'if I ever get out there, one of the things I would do in my first 30 days is go see a doctor. So I went and got on G.R. [General Relief]³⁴ and CalFresh and got my Medi-Cal. Then, I went to the nearest clinic around the program where I was at. So I navigated that myself because I wanted to know what was going on with my body because I didn't trust the doctors inside. And the clinic ran all kinds of tests on things that I wanted to know about.'" —Gina

Consistent with previous research, many women in the study stated that prior to incarceration, they did not have a primary care physician and, instead, only sought medical care in severe situations in an emergency department. Previous research indicates that health issues are among the lowest priorities for individuals returning from

prison.³⁵ Women in the study, especially those with children, would often deprioritize their own health needs to ensure their children's needs were met or to meet some other immediate non-health needs.

However, as women in the study aged, they acknowledged the importance of preventative healthcare. For the women in the study, their critical health concerns, once released from incarceration, broadly focused on being more proactive about addressing and improving their physical health, including the importance of eating healthy and getting more exercise. After release, many sought out primary care providers and specialists such as OB/GYNs to monitor health indicators such as blood pressure, blood sugar, and cholesterol; stay up to date on pap smears and mammograms; and keep up with regular check-ups.

Reproductive health

Reproductive health care includes but is not limited to services related to pap smears, pregnancy, childbirth, abortion, contraception, diagnosis and treatment of issues related to one's menstrual cycle, and diagnosis and treatment of issues such as yeast infections, urinary tract infections, and sexually transmitted diseases.

One-third (n = 7) of women in the study reported reproductive health issues during confinement, such as heavy menstrual bleeding (which led to iron deficiency anemia for at least one woman we interviewed) and pelvic pain. Symptomatic uterine fibroids were the most reported reproductive health issue (n = 4); polyps, cysts, and an unknown ovarian issue (n = 3) were also reported. Black women are significantly more likely than women of other races to develop uterine fibroids, especially if they have high blood pressure.³⁶ Of the five women in the study who reported having high blood pressure, 40% (n = 2) had fibroids and another 40% had an ovarian issue.

It's common for healthcare providers to advise women who have uterine fibroids with mild symptoms to leave them untreated. However, when fibroids do become problematic, as was the case for the women in this study, there are several options for managing and treating them, ranging from hormonal medications to a hysterectomy (a surgical procedure to remove the uterus). Lifestyle changes, which include maintaining a healthy weight and eating healthy foods, may help prevent fibroids but are often not possible because of the limitations of the carceral environment. Hysterectomies, which are the most invasive and highest-risk procedure in fibroid treatment, were often the only treatment option offered, according to the women in this study. The tendency of prison healthcare providers to resort to hysterectomies as a first option deterred some women from seeking care entirely in confinement.

I feel like the prison that I was in, they damaged a lot of women. And even though they say you should get regular exams, a lot of people don't go get them for that reason—they hear the stories, and we know they're true. It's a lot of "ok, we think we should do a hysterectomy." Why do you need to do a hysterectomy on a 25-year-old? You don't need to do that. There are other options, and you guys need to find them. So it makes you not want to go to them to get those things done because you don't know what they're going to do, really. And a lot of women found out later that they had a lot of serious reproductive problems as a result of seeing those gynecologists in the prison. —Mariah

Prenatal care was another reproductive health need for some of the women we spoke with. Two women in the study gave birth while imprisoned, and they reported vastly different experiences of prenatal care. One woman, Dai, who was pregnant and gave birth in prison, had a positive experience in which her needs were promptly met, especially after she was transferred to a facility with an OB/GYN on site to monitor the pregnancy. Dai was permitted entry into a mother-infant prison program. California's mother-infant prison program, Community Prisoner Mother Program (CPMP) "provides an opportunity for pregnant individuals and mothers with one or more children, six years of age or younger, the opportunity to be housed with their children in a supervised facility away from the prison setting."³⁷ The eligibility criteria for this program are narrow, however, and Dai reported that if she wasn't permitted into the program, then her mother would have had to come get her child within a certain window of time or child welfare services would get involved.

Dai reported that her time in CPMP was a mostly positive experience that allowed her to bond and spend time with her newborn. However, she was still reminded at various points that her incarcerated status restricted her full ability to parent. For example, when her newborn got sick and had to be put on a breathing machine, she requested to stay overnight with him by his crib, and "that was when it really kicked in that I was reminded that I was an inmate because I had to really advocate for myself to be there with him."

Although Dai's experience was positive, we also heard reports of pregnant women not getting necessary prenatal care in confinement. In addition to subpar prenatal care, another participant, Nella, recalled being handcuffed to the bed while giving birth. She shared, "They didn't talk to me like a mother that was giving birth...being in prison, I was viewed not as a person, but as a number."

An estimated 3% of women entering federal prisons and 4% of women entering state prisons are pregnant at intake.³⁸ Yet there is no oversight entity that ensures adherence to the established standards of care for incarcerated pregnant people in the Unit-

ed States. A recent study compared a sample of prisons' and jails' reported physical restraint policies to state legislation and found that pregnancy policies and services in facilities vary; in addition, compliance inconsistencies with anti-shackling legislation exist.³⁹ The prenatal and pregnancy experiences of the women in the current study alone reflect the inconsistencies between policy and practice.

Mental health needs and maintaining sobriety

Research has long demonstrated the significant number of people who need mental health services in incarceration settings. Among people incarcerated in state prisons, 43% have had a history of a mental health problem.⁴⁰ This is approximately double the rate of mental illness in the overall adult population in the United States.⁴¹ And incarceration exacerbates these mental health concerns.⁴²

For women specifically, many enter confinement with traumatic experiences that impact their mental health. Research has found that histories of physical or sexual abuse and intimate partner violence are factors that impact health among incarcerated Black women.⁴³ The carceral environment itself can exacerbate the impact of these experiences on individuals' mental health. In addition, adverse childhood experiences, intimate partner violence, child custody loss, police violence, and the death of loved ones were some of the major types of trauma that women in this study had experienced prior to incarceration that have had lasting impacts on their mental health.

Substance use is a well-documented coping strategy for people with serious mental illness and past trauma. Among people involved in the criminal legal system, women are more likely than men to use drugs, to use more serious drugs, and to use them more frequently.⁴⁴ In turn, women tend to be incarcerated for drug-related offenses more often, compared to men—25% of women incarcerated in state prisons have been convicted of drug offenses compared to 12% of men.⁴⁵ Women who use drugs are also more likely to have co-occurring mental health disorders than men are, particularly mood disorders (such as major depression or bipolar disorder), social phobia, post-traumatic stress disorders, and eating disorders.⁴⁶ These mental health disorders, along with anxiety disorders, were also prevalent among the women in this study who reported having a formal diagnosis.

Acknowledging the stigma that behavioral health diagnoses carry, we did not directly ask the women in this study if they had ever been diagnosed with a mental illness or substance use disorder; rather, our interviews were structured to assess histories of mental illness and substance use by asking about previous and current health concerns, histories of help-seeking and other encounters with behavioral health professionals, and whether there were any mental or emotional challenges that they hadn't

sought professional attention for and why. About 67% (n = 14) of participants reported a behavioral health issue. Specifically, 33% (n = 7) indicated a history of substance use disorder with no mental illness, 10% (n = 2) indicated a history of mental illness with no substance use disorder, and 24% (n = 5) indicated co-occurring substance use disorder and mental illness.

Accessing mental health services

Despite the overwhelming need, most of the women in the study received little professional mental health support while they were incarcerated. There was a general consensus among women in the study that mental health providers in the prison setting prioritized prescribing medication over providing therapy. For many, their experience was limited to the required standard evaluation that is administered at intake and for parole hearings.

One woman we interviewed described the risk assessments for violence that are used in parole consideration hearings for indeterminately sentenced people: “When getting board prepped, we do have to see a psychologist that does an evaluation and then like a battery of tests on us [which ask questions like]: have you ever killed the cat? Have you ever been brutal to an animal? Were you a fighter in school? Have you ever hit an elderly person? You know, it was just things to see if I was violent, if I’ve been violent all my life, or was I violent just for this one point in time and then became violent? It’s like a risk assessment to see if I would do well in society if I was released.” Although this assessment is conducted by a mental health professional, its purpose is not to support the women’s mental health but rather to inform a clinician’s “expert opinion” on one’s risk for future violence to the parole board.⁴⁷

After leaving incarceration, however, the number of women accessing mental health care changed dramatically. Most of the women in the study reported having seen a mental health professional—whether voluntary or required—at some point after being released. Several women in the study voluntarily participated in parole outpatient clinics and reported positive experiences. Some women were required to receive mental health services as a condition of parole or family reunification. In the mandated cases, the women might not have sought it out voluntarily, but once they started to go, they saw the value of mental health services and continued to access those services even beyond the required period. Karina, for example, shared:

“One of the requirements to get custody of my children was counseling. And once I did begin counseling, I felt like I needed it at that point.... It was helping me in many areas to sit with someone and just let it all out and have someone that’s not judging me and really listening to me. Yeah, it was required and then I continued.”

Some women in the study expressed concerns about being diagnosed or “labeled” if they started receiving mental health services. In Latifah’s case, if she wanted to continue seeing a provider in the parole outpatient clinic (POC), she learned that a diagnosis was going to be required.⁴⁸ She shared, “I found POC to be a refuge until I learned after four weeks, in order for them to continue seeing me, they had to diagnose me as having an adjustment disorder or something like that. And I said, ‘No, absolutely not. I already have enough labels on me’... So in order to get some type of help where I can talk and have an outlet, I had to have a label or be put in a box. And so I had to make the decision of continued help or being stifled, and I wasn’t happy with that.”

Women in the study also discussed the fear of being misdiagnosed and the potential negative impact of mental health diagnoses and other labels on other important reentry goals such as reuniting with children. Nella, for example, shared:

“Any little thing a person writes on paper can hinder what I’m trying to accomplish, you know? And so I do want mental health support but to a certain extent. I’d rather see a clinician or a therapist versus a psychologist who diagnoses people and prescribes medication... And I don’t want someone to feel like I’m not mentally stable to raise my child or to get my other two kids back in my life is something I have experience with. You can tell them one thing and they blow it all the way out of proportion, and then they start diagnosing you with A, B, C, and D and all. I’m always leery of that.”

Overall, all of the women in the study indicated that mental and emotional health was important to them. Many had made commitments to focus on healing and growing from the trauma they experienced.

“Therapy really does help me to be able to see life through a different lens and to forgive people, to forgive myself and to pace myself and understand like, this is a marathon and you have to do the steps. You can’t just jump in and say ‘I’m healed.’ That’s not how it works. I’m probably gonna be healing until the day that I die.” —Dai

The women we spoke with sought (or are seeking) mental health and medical care providers who they can trust, who are attentive, and who seek to understand their reentry journeys. Women who reported positive provider experiences cited providers who demonstrated themselves to be trustworthy, listened without judgment, were transparent, and who respected their boundaries.

Maintaining sobriety

In addition to prioritizing mental health, many women also prioritized maintaining their sobriety as part of their health and wellness needs once released from incarceration. More than half of the women we interviewed (n = 12) reported a history of substance abuse or misuse, and 24% explicitly named maintaining sobriety as a primary reentry priority.

Two women participated in substance use treatment programs while in confinement and were required to make an exit plan, which helped identify their reentry priorities. Women who were involved in treatment programming both during confinement and after their release found the continuity of care effective in maintaining sobriety.

Once released from incarceration, women reported that 12-step program interventions and mutual support programs (such as Alcoholics Anonymous, Narcotics Anonymous, and Cocaine Anonymous) that connect individuals with a sponsor and peer support were helpful in maintaining their sobriety. Several participants were released from confinement to residential treatment programs, and sometimes sober living homes thereafter, to support their sobriety.⁴⁹ While sober living homes seek to provide safe housing and supportive structured living conditions for people exiting drug rehabilitation programs, the women's narratives indicate that sober living alone is not enough to fully address their multifaceted and competing reentry needs.

One woman in the study, Karina, shared the difference in her experience in sober living compared to the comprehensive services and support she received through A New Way of Life Reentry Project that addressed her as a whole person.⁵⁰ She shared:

When I was in treatment and sober living, I was just working on me. It was just about being clean. It was just about the 12 steps. It was just about meetings. Once I got to A New Way of Life, my journey began as far as becoming the woman I used to be before I was incarcerated and addicted. It was regaining my being and being a productive person in society. So, in sober living and treatment, you don't have a community there. It's just basically about being sober. So once I got to A New Way of Life, that's when my journey started. Being on the streets and then incarcerated, you lose a lot of tools, as far as cooking, grocery shopping, being a woman... you lose that. But at A New Way of Life, I was able to really put the work that I was doing in sober living and treatment, the tools I got there, [I] was able to combine them with the tools at A New Way of Life. And that's when my journey began.

Women Aging in Prison

Trends in law enforcement, sentencing, and reentry policy over the years have led to a growing, aging prison population. Today, older adults represent the fastest-growing demographic in the U.S. prison system.⁷⁹ Incarceration itself—and the conditions that individuals must tolerate, including poor diet, lack of medical care, and chronic stress—tends to accelerate the aging process.⁸⁰ The effects of accelerated aging among incarcerated people are evident in their earlier onset of age-related health needs and higher rates of chronic conditions and mental illness compared to the general population.⁸¹ This is especially true for women.⁸²

Women are a significant and much-neglected subset of the growing population of older incarcerated adults. The increasing number of women serving long prison sentences—including unprecedented numbers of women serving life sentences—means more women are aging in prison.⁸³ Black women incarcerated in California are especially likely to grow old in prison, as one in four women serving a life sentence in the state is Black.⁸⁴ Incarcerated women tend to seek medical care in prison at higher rates than men due to more serious health problems.⁸⁵ Older incarcerated women are also more likely to report difficulty with activities of daily living specific to life in prison compared with men, such as hearing orders from the staff, dropping to the floor for alarms, and getting to the dining hall for meals.⁸⁶

More women aging in prison also means that many women begin menopause while incarcerated. About 62% of the women who were interviewed began perimenopause or menopause while incarcerated or shortly after their last release.⁸⁷ According to a longitudinal study of midlife women in the community, Black women reach menopause 8.5 months earlier than white women and have worse symptoms, such as hot flashes, depression, and sleep disturbances. Yet Black women are less likely to receive hormone therapy or medical and mental health services.⁸⁸

For incarcerated women, institutional barriers make access to treatment for menopause symptoms even less likely. For example, most carceral environments are not conducive to common lifestyle interventions to alleviate menopausal symptoms (e.g., layered clothing, cool drinks, frequent showers). Previous research also suggests that women are

Women Aging in Prison cont.

often punished for actions taken to mitigate symptoms (e.g., rolling up sleeves, not wearing undergarments while sleeping).⁸⁹ Taken together, menopause and other health issues specific to aging women are not adequately addressed by carceral healthcare systems. As women grow older in prison, it creates more demand for healthcare to address the specific needs women have related to chronic conditions, reproductive health, any potential cognitive impairment, and physical disabilities that occur due to aging.

When imagining the “perfect place” for formerly incarcerated Black women to receive health and wellness care, one of the study participants, Latifah, said that if she had the resources, she would design a center that “has geriatrics because most of us are aging. We don’t know about menopause. When we went to prison, we were younger, and so we come out premenopausal. We have all these things that we don’t know anything about.” This sentiment speaks to how important age is as a factor in reentry, as it can pose additional health-related needs and challenges for reentering Black women. Most incarcerated women will eventually be released—many of whom will need support addressing their age-related health needs and concerns during reentry after serving long sentences. Reentry planning and medical care coordination for older formerly incarcerated women is a necessary intervention to smooth the transition back to the community and ensure older women receive proper medical and mental health care.

Karina was fighting to get custody of her children upon release when her probation officer sent her a referral to the Community Reentry Center at DOORS,⁵¹ which partners with A New Way of Life to provide family reunification services. Karina was able to take the parenting and anger management classes that were required in her case plan, got a lawyer to go with her to court with her children, get a job, get overnight visits with her children, and eventually successfully close her case with child protective services with wraparound support from A New Way of Life.

Obesity and weight gain

Obesity can have serious health, psychological, and economic consequences, particularly for low-income people of color.⁵² Individuals who are overweight or obese are at higher risk of developing conditions such as high blood pressure, type 2 diabetes, coronary heart disease, stroke, or mental health problems such as depression, relative to non-obese peers.⁵³

Research suggests that the prison environment itself—from limited freedom of movement to limited low-sodium options and fresh produce—contributes to weight gain and obesity, exacerbates chronic conditions, and makes it difficult for individuals to maintain or improve their health. Weight gain during incarceration is a problem that disproportionately affects women in prison compared to men, especially those with comorbid diseases such as high blood pressure, high cholesterol, and diabetes.⁵⁴ Previous research suggests that gender differences in weight gain and obesity may be explained, at least in part, by the opportunities that men have for work release and recreational and physical activities compared to incarcerated women.⁵⁵

More than half of the women in the study (n = 12) stated that weight gain was among their high-priority health concerns, both during incarceration and after release. A majority of those women self-reported at least one other chronic condition, including high cholesterol (n = 3), high blood pressure (n = 2), pre/diabetes (n = 2), asthma (n = 1), and gastritis (n = 1). Women with these comorbid conditions attribute it to a combination of unhealthy eating habits, movement restrictions of residential treatment programs, family history, and various stressors such as sexual harassment at work. Reflecting on her top health concerns, one woman in the study, Julia, said, “I’m trying to get some of this weight down. It’s kind of hard when you’re in a [residential treatment] program because you can’t really go anywhere, and you just eat up everything.”⁵⁶

Many of the women in the study made commitments to better self-care once released from incarceration, including eating healthier food, portion control, and regular exercise.

Chronic health conditions

Research consistently shows that incarcerated and formerly incarcerated people report high and disproportionate incidences of chronic conditions, such as hypertension, diabetes, and high cholesterol.⁵⁷ Many of the same characteristics of the prison environment itself that contribute to weight gain and obesity—from limited freedom of movement to limited healthy food options—also contribute to and exacerbate these chronic conditions and make it difficult for individuals to maintain or improve their health.

Our findings were consistent with this research. More than 75% (n = 16) of the women interviewed reported having a chronic condition. This was reflected in the top health concerns that women prioritized, which included chronic conditions such as hypertension, diabetes, and high cholesterol. Five (24%) of the women in the study were at least 50 years old at the time of their latest release from confinement, and because of their age, they were especially concerned about chronic conditions.

Barriers to accessing healthcare after incarceration

Formerly incarcerated Black women deserve holistic health and wellness—physical, mental, emotional, and spiritual. The Black women in this study want to take preventative measures to address and improve their health and wellness. However, accessing healthcare after incarceration remains challenging for formerly incarcerated Black women. The primary barriers include 1) the distrust women have of the healthcare system, which often began or was exacerbated by their healthcare experiences while incarcerated and which continued once they were released, and 2) the complexity of navigating insurance systems and inadequate information regarding services and resources that might be available to them.

Distrust of the healthcare system

The formerly incarcerated women we spoke with cited distrust of the healthcare system as a meaningful barrier to accessing healthcare after release from incarceration. For some women, treatment by healthcare providers in confinement engendered distrust and prevented them from seeking help later to meet their health and wellness needs. For others, the distrust came from past experiences with healthcare providers outside of incarceration and the stigma and discrimination they experienced based on their history of incarceration.

Women in the study described healthcare providers dismissing their concerns, and they attribute this dismissal to healthcare providers' discrimination based on the women's incarceration history: Because many formerly incarcerated Black women have a past history of substance use disorders, women in the study believed that health care providers often dismissed their healthcare claims as drug-seeking behavior. This stigma led some women to decide to not complain about pain or discomfort, a coping mechanism that reflects the "Strong Black Woman" (SBW) stereotype, a race-gender schema that prescribes expectations for Black women to demonstrate incredible strength, resilience, and care for others.⁵⁸ Women who endorse the schema overcome obstacles with limited resources, cope with stress on their own, and provide support with no expectation of reciprocity.⁵⁹

While some may find the SBW schema to be positive or admirable, it has been linked to adverse mental and physical health outcomes. Decisions that the women in the study made to "push through" pain and not "complain" illustrate how the behaviors and coping strategies of the SBW schema and incarceration history interact to directly impact whether and how women accessed healthcare after release. Women in the study expressed that when healthcare providers made assumptions about them based on their stigmatized identities as "criminal," Black, and woman, they were further marginalized and unwilling to subject themselves to potentially unfair treatment. In some ways, the SBW schema can be projected onto Black women by healthcare providers when they view Black women as able to endure more than most. This perception aligns with well-documented research on racial bias in pain perception and treatment recommendations.⁶⁰ One of the members of the advisory committee for this study shared:

"[Health care providers] don't think we have as much pain. They don't think we tell the truth as much. And if you're honest about your health or your past drug history, that's it. So now I don't [disclose my history with drugs] anymore because it doesn't matter if it was 20 years ago. If you share that information, they're going to think you're lying; it doesn't matter."

The actual and anticipated discrimination Black women with histories of incarceration face can increase their vulnerability to chronic illness, ultimately impacting their long-term health and impeding efforts to live their fullest healthiest lives. Gabrielle, for example, discussed the stigma she feels because she is Black, has a criminal record, and speaks her mind. She shared:

"I wish it was a way that people would be able to get to know me before you just judge me... You look at me as a criminal instead of a survivor, or because I am a darker shade and I talk with my hands. This is me. Don't be frightened by that."

The distrust of the healthcare system extends into the mental healthcare system as well. Many women in the study had no history of accessing professional mental health support prior to incarceration due to distrust and cultural stigma. Several women were hesitant and distrustful of mental health professionals. Overall in the general population, racial and ethnic minorities have less access to mental health services than whites, and when they receive care, it is more likely to be of poorer quality.⁶¹ When mental health services are available, Black women may not engage in those services because of social stigma, misgivings about the efficacy of treatment, and distrust of providers.⁶² This is due to, at least in part, the lack of cultural competence and affirmation that exists across most mental health providers: only 4% of psychologists in the United States are Black.⁶³

Women in the study cited general distrust of the mental healthcare system, much of which was based on past experiences of being vulnerable with mental health professionals, often in connection to other systems of the state, and their honesty being “held against” them. One woman shared that she was taken from her mom after she had spoken with a mental health professional, who was a mandatory reporter.⁶⁴ Dai, who works with an organization that connects clients to therapists, explained how mandatory reporters’ relationships with child protective services (CPS) could be a barrier for women to open up.

“A lot of our women have trusted certain systems at a time and they didn’t understand that those systems are not working for you. For example, CPS. CPS is working for the child, right? Like most of those workers, they want to see their family back together and they will work on that. But for the most part, they’re documenting everything because their job is to work for the child. And so when I trust you and you tell me to open up and I open up, but you use it as a weapon against me, then I don’t want to open up anymore. And so now I’m going to look at you and all the rest of the therapists the same way because you all start off with the same little note: ‘I am a mandated reporter,’ so it really does cause people to shut down from healing, which is why [clients] would rather process with me or process with someone that they know than they would a therapist or somebody like that.”

The impact of discrimination due to incarceration on health and mental health that the women in this study discussed echoes similar findings from past research. A previous study of men and women who had been released from prison within the prior six months concluded that participants who reported discrimination due to a criminal record were more likely to report fair or poor health.⁶⁵ Another study measured formerly incarcerated men’s self-reported criminal record discrimination by healthcare workers

and their utilization of healthcare services, and it suggested that discrimination based on a criminal record may negatively impact healthcare access and utilization.⁶⁶

Complexity of insurance systems

Federal regulations terminate Medicaid coverage for people incarcerated in a prison or jail for more than 30 days. As a result, individuals released from carceral facilities may experience a gap in health insurance coverage unless they enroll in Medicaid within the appropriate time period while still incarcerated. The experiences of women in the study indicate that pre-release planning to facilitate women's ability to access healthcare after incarceration is inconsistent at best. While most women in the study reported having to figure out their release plans on their own, two women in the study reported having access to Parole Planning prior to their release to create a personalized case plan with a list of goals and resources meant to enable successful reentry.⁶⁷ However, both women expressed that the plan and resources were not personalized at all, but that parole planners did offer support in signing up for medical insurance, along with food stamps and other government-based assistance as they approached their release date.

However, for many people, once released from incarceration, they do not understand the full scope of medical, dental, and vision insurance, the difference between HMOs and PPOs, or how copays and deductibles work:

We're uneducated when it comes down to learning how to navigate your insurance policies and navigate the insurance company, figuring out which company is the best company for you... We need to be educated. Incarcerated women need to be educated on how to navigate their insurance companies when they get these jobs. [Understanding], your insurance coverage package you're covered for, you know, 'OK, I'm only covered for \$2,000 and my surgery cost \$6,000, so I'm going to be \$4,000 out of my pocket.' – Angel

Without an understanding of how insurance works, what it covers and what it doesn't, individuals are limited in their ability to make well-informed decisions about their healthcare and to access the health services they need. This is critical because health insurance coverage is also strongly associated with reduced rearrest rates among women.⁶⁸

Among the women in this study, upon release from incarceration, all of the women were able to enroll in Medi-Cal (California's Medicaid program).⁶⁹ Research has found that women with Medicaid coverage were more likely to receive primary health care in the year after release compared to those without coverage.⁷⁰ Despite this, the women in the study who received government-based insurance were often limited in the ser-

vices that the plan covered and the providers they were able to access. This also contributed to the perceived notion among women in the study that Medi-Cal approved providers are not as good as out-of-network providers. Some women believed they would have received better quality medical care if they had private, employer-sponsored insurance.

Medi-Cal does the best that it can, but it's not like Aetna or Kaiser. In order for you to have access to Aetna and Kaiser, you are working and you're paying for your insurance, which gives you a better quality of healthcare. So I believe that is another barrier. —Carrie

Once women achieved the goal of employment and were either able to enroll in employer-sponsored insurance or surpassed the income threshold for public, state-sponsored insurance (i.e., Medi-Cal), they were often satisfied with their care, having access to more established or “seasoned” providers. For example, one woman we interviewed discussed how when she had Medi-Cal and was looking for a therapist, all of the people she worked with were interns. She said, “I could tell that they were practicing on me. And so [with Medi-Cal], you're getting all these people who barely know what they're doing serving you in your mental health needs compared to Blue Shield, Blue Cross. I might have to pay a \$30 or \$40 fee, but I'm getting somebody who's been in this for 20 years seasoned, who can sit across from me comfortably and help me process something, which is what I know that I need now.”

At the time of our interviews, more than half of the women in the study had access to private insurance through their employers, suggesting how important employment is for reducing recidivism not just because of the job, but also for the access to healthcare. However, formerly incarcerated Black women generally have the greatest difficulty securing full-time employment compared to other formerly incarcerated people.⁷¹ Therefore, although employment is a critical gateway to comprehensive health insurance, it is a gateway few incarcerated women are able to access because of their difficulty securing full-time employment offering health benefits.

Despite having insurance, however, many formerly incarcerated women still found themselves left with unexpected or unaffordable out-of-pocket costs when receiving healthcare.⁷² It's difficult for people who have never been incarcerated to navigate healthcare; it's even more difficult for people who have been incarcerated. Updated, accurate, and accessible information is necessary all around.

Geographic location affected Black women's access to health care

Inequities in access to quality health services, healthy food, and opportunities vary by geographic location. Therefore, the location where women were released or paroled to played a role in their ability to access health care—from the quality and availability of healthcare providers to access to fresh food. Some counties were known by women in the study to have more resources than others. For example, San Francisco County, Alameda County, and Los Angeles County were noted as having relatively more resources.

Strategies to address health needs after incarceration

In spite of women's distrust of healthcare providers due to negative past experiences and the challenges of navigating the complexity of various insurance systems, many of the women in this study did ultimately develop their own strategies to access health-care that supported their own health and wellness goals.

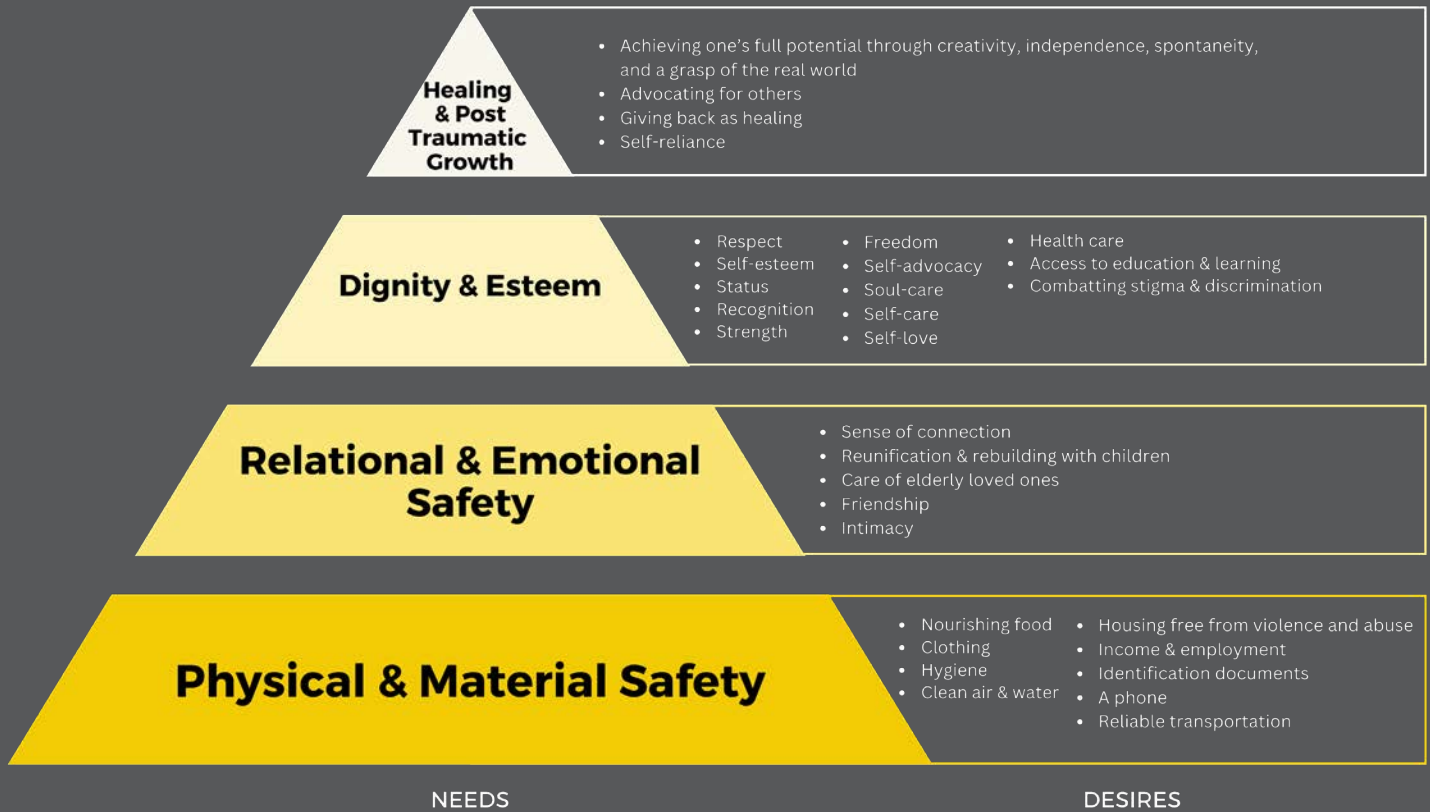
Connect with supportive organizations

For many women in the study, connecting with supportive organizations after they were released from incarceration was critical to accessing various resources and services to support their health. Community-based organizations—for example, A New Way of Life, the Arming Minorities Against Addiction & Disease (AMAAD) Institute, Root and Rebound, and Transitions Clinic—were cited as gateways to accessing medical and mental health services, either through providers on staff or through strong referral networks that facilitate women getting all their wellness needs met.⁷³

One woman discussed how she went to Root and Rebound as a client to get her record clean and, as a result of the intake process, she was introduced to her first therapist. Today, as an employee, she said: “All of our clients, we connect them to therapy. We make sure that their insurance covers it because Medi-Cal only covers certain things. And also, we prepare them in group, and let them know, ‘this is what therapy is. It’s you processing through something, somebody giving you feedback, somebody helping you with tools, coping skills’ because we got to get past that trust barrier. But once we’re passed that, then they understand.”

Women in the study spoke of a combination of self-initiative, word-of-mouth, and organizational referrals that helped them ultimately connect to various organizations and access healthcare services. For example, after being directed by her parole offi-

Prioritizing Needs & Desires After Incarceration



cer to enroll in Medi-Cal, one woman in the study learned about Southeast Health Center's Transitions Clinic from a mentor who worked there as a community health worker. Transitions Clinic provides chronically ill individuals who have been recently released from prison with medical care and coordinated social services.⁷⁴ Another woman in the study, Nella, was connected to needed services through word-of-mouth referrals. She learned about the AMAAD Institute from another incarcerated woman and was then able to seek assistance from the parole planner in prison to make arrangements for a spot there. At the AMAAD Institute, Nella was able to get free therapy, along with rental and food assistance. Nella spoke about how women returning to the community from confinement need more information about available services and resources beyond word-of-mouth, sharing:

"Lucky for me, I knew about these services and even these services that I utilized are like the bare minimum. I'm pretty sure it's so many more out there that exist. Like I told you about the AMAAD program, one of the ladies at the program told me about that. Like all the services that I have been utilizing since I've been home, they have not been from the people who supposed to tell you. It's been the people that's in the same situation I'm in. I mean, like, "hey I heard about this." "Did you hear about this?" or "Check this out." You know what I mean? So you need infor-

mation, because if you don't know, you don't know. How can you utilize something you don't know exists?"

To get the emotional and mental health support they need, women in the study reported connecting with various types of organizations and groups. When asked about who their “people” are, women named a range of collectives and organizations, including pastors, church circles/spiritual community, and support group meetings such as Alcoholics Anonymous and Narcotics Anonymous. Women in the study reported seeking and appreciating sources of support that are empathetic and non-judgmental but also willing to hold them accountable. One woman described having a supportive community as having a “board of directors” for herself—people whom she can talk to who will tell the truth and not judge, and who want to build each other up.

Other women in the study who were very early in their reentry journeys had not yet established a strong supportive community but were in the process of building relationships with others through connecting with organizations. For women who were in treatment programs while incarcerated (n=2), they were required to make a plan to identify their reentry priorities and ensure their substance use treatment continued outside of confinement. Regardless of whether they were in a treatment program during incarceration or not, most women in the study who reported a history of substance use had connected with support groups to support their sobriety after release.

Self-advocacy as self-care

Many of the formerly incarcerated women in this study commonly reported that self-care and self-love were critical strategies in accessing the type of care that they needed to support their own health and wellness goals. Self-care included advocating for themselves in various healthcare settings. For example, Shawney, who has a history of addiction, explained her history to her pain management doctor and made it clear that “there are just certain things [she] won’t take” to prevent any triggers. Other women discussed the importance of being communicative with all of their providers and being unafraid to ask questions or get a second opinion. Latifah shared a story about advocating for herself about the payment for a lab service that her doctor did not make clear was not a covered service. Her self-advocacy resulted in the charges being waived.

Although speaking up for themselves has been helpful in improving the quality of care for many of the women in the study, doing so can be burdensome and challenging. Dr. Marilyn Jones, a member of the advisory committee for this study, shared:

“One of the main problems with healthcare is our communication style. People don’t like it when we do or say something for ourselves. If we have something

going on that's not feeling right... you shouldn't have to code-switch in a crisis. People don't like the way we talk... It's not that we don't have agency, but when we do have agency, it's not met well.” —Dr. Marilyn Jones

The formerly incarcerated women in the study also reported other self-care activities that supported their mental health and provided sources of strength and resilience, including “self-love,” going to church for supportive community and fellowship (e.g., Sunday school, prayer partners), prayer, and reading the Bible. According to the women in the study, self-love included

- **setting boundaries in relationships**, for example learning how to say “no,” not tolerating abuse of any kind, adjusting expectations of others, and focusing on what they can control themselves, practicing celibacy;
- **developing positive coping skills**, for example, reading or meditating instead of eating out of boredom; and
- **practicing kindness with themselves**, for example, “My self-care [is] knowing that it’s going to get better...having compassion for myself and reminding myself that I made a mistake, but I have the option and the choice to fix it. And I’m going to do that.”

What I’ve been doing is taking inventory daily of who I am because I know that was just something from being broken. And today I’m whole and I am a powerful woman. I have my boundaries. I cut off when I need to cut off and now let in what I need to let in. God is the source. He’s my source so he gives me everything I need as I still continue to take daily inventory when I lay down and when I get up. I set aspirations and I set goals and I set intentions for my day. And that’s what helps me to navigate. —Blessed

Advocating for others as healing

Giving back and paying it forward to other people impacted by the criminal legal system through advocacy and direct services was a central theme in women’s healing. More than half of the women in the study work or volunteer in direct services and/or advocacy organizations that serve marginalized populations. One formerly incarcerated woman who now works as a health and wellness coordinator shared:

“I think the healing part for me is giving back. I actually care about [the clients]. I want to see them succeed. This is a transitional facility. They come from the recovery detox to here to learn how to live out there. I guess I’ve just done it and at this point, I’m successful. I feel like I’m being a role model for them.” —Angel

Desires for health and wellness

When asked what formerly incarcerated Black women would need to be holistically healthy and well after release from confinement, most women's responses included the need for wraparound support services, safe affordable housing, accessible information, and diverse, competent, and compassionate providers.

Holistic support services

When asked to dream up the perfect place or resource(s) to support formerly incarcerated Black women's wellness, women in this study imagined health clinics and healthy living centers specifically for system-impacted women where they could address their healthcare needs holistically in the same physical location. They want comprehensive housing support with strong referral and partnership networks with access to healthy food, childcare, support groups, nature, mentorship, and legal support. The Sisterhood Alliance for Freedom and Equality (SAFE) Housing Network is an exemplary model of comprehensive reentry support.⁷⁵

Accessible information

Formerly incarcerated Black women want more information about the wraparound services that are available to them to support their reentry. They also want user-friendly information regarding insurance policies and premiums.

Supportive community with peer support and mentorship

Women value environments with others who have similar backgrounds and experiences for mentorship and guidance, and people who express care and concern.

Diverse, competent, and compassionate providers

Formerly incarcerated Black women want providers who are compassionate and trustworthy. They want providers to see them as full human beings and not only for their previous incarceration. They want healthcare providers who treat them with dignity, listen empathetically, and are non-judgmental. They also want more Black providers and providers of color who understand their experience or at least show genuine interest in understanding. See "What Black Women Want from Health Providers" for a summary of these themes.

What Black Women Want from Healthcare Providers

Theme	What Women Reported
Longevity	"I've had good experiences with mental health services because I've been dealing with the same people for quite a long period of time." —Julia
Attentiveness	"She was my gynecologist... I thought she was an excellent doctor to even recognize something that I didn't about my emotionality. She used to see the torment that I was having from my ex-husband... 'You sure you're okay? You don't look like yourself today.'" —Blessed
Demonstrating care by going above and beyond	<p>"When she found that I had been incarcerated, she had resources for housing and things like that for me to apply for to try and assist me in that area. She was really good... She wanted me to speak more about being incarcerated because she was genuinely interested in hearing..." —Gina</p> <p>"I felt comfortable because she went to great lengths to order certain tests and I just feel like she really cared about my well-being. She showed a genuine interest in my health." —Gina</p> <p>"What I like about the young doctors is that they overly prepare. So, you might go for a headache and they're going to get you a CAT scan. We're going to get you the answer... I will say that the newer doctors that I've seen, they're upbeat, they're passionate, they're excited. And I love the fact that they do not mind billing insurance like, 'we're going to do everything to figure it out.'" —Dai</p>
Responsiveness	"If I send the message, even if she can't get back to me, she'll make sure to have someone respond to my message to call me back." —Grace
Taking time to educate	<p>"...I have an amazing doctor. She knows my experience and she actually educates me about what I don't know. I'll give you an example, and I don't know if this is simply her job or if it's just her personality... But she was telling me about the vaccine for shingles. I didn't know they had the vaccine for shingles. And she encouraged me. She offered it to me. She told me the benefits of getting it." —Latifah</p> <p>"I love the fact that [the younger doctors] educate. They take the time to educate me on whatever it is. If I have questions, they don't get frustrated. They actually like it. They welcome it. So, I've had some good experiences in that sense." —Dai</p>
Respecting boundaries	"I have a really big thing with boundaries when I'm dealing with someone of authority. So with that being said, I think on our second meeting, Miss [redacted] had said something and it was harmless, but it was something to the extent of 'hey girl,' or something like that. So when I expressed to her that that made me uncomfortable, 'I'm not your friend, you're not mine. I'm here for therapy. I feel more comfortable if you can keep it professional,' she was so receptive to that. She didn't get offended, she didn't get an attitude. She didn't act differently. She corrected it and it didn't happen again. Then there were times when we would talk and even if she felt like maybe she kind of crossed the line, she would say, 'hey, are you ok with this? Are you comfortable with this?' So that just kind of made me feel like she was actually here to help me. It wasn't about her, it was about me and that helped our relationship to the point where I could kind of drop those boundaries a little bit, so that helped a lot. It made it easy for me to talk to her." —Nella

Study Implications and Conclusion

The purpose of the Pathways to Wellness study was to learn directly from Black women about their health and wellness during confinement and through their reentry experience in California to

- 1) increase knowledge about and improve health outcomes of formerly incarcerated Black women,
- 2) expand the landscape of available services, and
- 3) facilitate healthcare access.

Study findings from interviews with formerly incarcerated Black women have important implications for carceral and community-based healthcare professionals, correctional staff and administrators, policymakers, and community-based reentry service providers.

Women in the study detailed experiences of inadequate and neglectful care, which they described as resulting from racial and gender bias, stigma related to drug use and being “criminal,” and the perception that Black women don’t feel pain. These biases and stigmas resulted in treatment delays, a lack of follow-up, and misdiagnoses during confinement, which worsened health outcomes. Due to the influence that medical, mental health, and dental care during confinement has on the care that Black women seek and receive in the community after being released from incarceration, changes to correctional care are critical.

Women in the study perceived the healthcare providers in prison as low-quality, some even referring to them as “reject doctors.” This aligns with investigations and court records in California and other states showing patterns of prisons hiring healthcare providers with disciplinary records and histories of incompetence. The quality of healthcare in carceral facilities can be improved by ensuring that all providers are in good standing with local licensing boards, incentivizing the employment of health professionals who are genuinely interested in serving incarcerated women, and enacting policy changes that require a consistent standard of healthcare for incarcerated women with provisions requiring trauma-informed care.

Ultimately, though, trauma-informed care—an approach guided by the principles of safety, trustworthiness, choice, collaboration, and cultural responsiveness—is antithetical to the traumatizing nature of the carceral environment itself. Black women

with incarceration experience, most of whom are survivors, need trauma-informed, community-based approaches to healthcare to effectively address their needs and honor their experiences.

Culturally affirming approaches, such as the Araminta Approach, call for service providers and key stakeholders in the criminal legal field to be attuned to the complexities of being a Black woman with a history of incarceration in order to create much-needed change. Additionally, anti-racism and implicit bias training curricula should be incorporated into medical school education, continuing education requirements, and professional development for healthcare professionals who interact with incarcerated and formerly incarcerated Black women.

Another prevalent theme in the experiences of the women in the study was the desire for community and wraparound support. The Sisterhood Alliance for Freedom and Equality (SAFE) Housing Network is an exemplary model of comprehensive reentry support that leverages the leadership of formerly incarcerated women.⁷⁶ Support for family reunification must be built into reentry programs supporting Black women, including legal support for formerly incarcerated parents to fight for custody of their children, parenting education, and child-friendly housing. Policymakers can support wraparound services by enacting legislation that authorizes implementation grants to community-based nonprofits to operate one-stop reentry centers, such as the One Stop Shop Community Reentry Program Act.

The desires of the women in the study for peer support and help navigating healthcare systems indicate promise for community health worker roles to support Black women, especially those with chronic health conditions, in navigating the healthcare system to ensure they can access the treatment and medication they need to be well and thrive. Community health workers are trusted members of a particular community to facilitate access to services and to improve the quality and cultural competence of service delivery.⁷⁷

Models like the Transitions Clinic Network utilize community health workers with lived experience of incarceration as a central component in supporting people who are returning from incarceration; the community health workers serve as liaisons to navigate health and social services. The shared history between community health workers and reentering individuals helps build a trusting and engaging relationship, which improves health and reentry outcomes.⁷⁸ Similarly, peer support specialists who have relevant lived experience (of incarceration, mental illness, substance use, etc.) can provide valuable support and guidance to Black women as they begin their reentry journeys.

The experiences of the women in the Pathways to Wellness study highlight the inadequacies and impacts of carceral care on Black women’s health outcomes, the barriers Black women face and the strategies they use to meet their wellness needs after release, and their overall desires for health and wellness. The study’s findings indicate the need for stakeholders who interact with incarcerated and formerly incarcerated Black women—whether based in a carceral facility or in the community—to listen to Black women when they express their pain and concerns, reject pathologizing, address implicit bias, and see Black women with incarceration experience as the full human beings they are.

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We aim to dismantle the racist and patriarchal U.S. criminal-legal system and build, in its place, pathways to opportunity and healing.

We envision a society that respects, values, and honors the humanity of Black women and girls, takes accountability for the harm it has inflicted, and recognizes that **real justice is healing**.



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