STAND UP TO STIGMA

How We Reject Fear and Shame

PERNESSA C. SEELE
CEO and Founder of The Balm in Gilead, Inc.

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—Rev. Dr. Otis Moss Jr., international pastor, theologian, speaker, author, and activist

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PERNESSA C. SEELE

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This book is dedicated to *three little boys* who are growing into GREAT MEN. Each of them have moved me far away from my comfort zone in areas of stigma, fear, and shame. As I continuously watch them STAND UP to Stigma every day within their young lives, I am becoming a better human being.

I Love You Dearly!

Desmond Maurice Dease
(13 years old)

Richard Milton Smith, Jr.
(27 years old)

Darius James Dease
(41 years old)

I wish to thank Rev. Dr. Renita J. Weems for her "Just a Sister Way" love and support, which always flows freely and tells you just how it is — straight up; and to Dr. Marsha A. Martin for her friendship and lifelong commitment and dedication to end the AIDS pandemic on planet Earth. I have been truly blessed by many great individuals over the years, who answered the call to give their time and energy to The Balm In Gilead Inc. Each of them, past and present, in their own unique way, have been the wind beneath my wings and a healing balm of courage and strength.

God Is.

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Blessed are they that hunger and thirst for righteousness,
for they shall be filled.

The Gospel of Matthew 5:6

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PREFACE

Lionel and I became dear friends in the early 1980s. I met this extraordinary, world-renown baritone through a New York City artistic magazine in which he was featured. I had just been given permission to establish the Cultural Arts Institute (CAI) within the Brooklyn Truth Center. This was a dream that I shared with my pastor at the time, The Reverend Don Nedd, who allowed me to use the space of the well-over fifteen thousand square foot church building. Over a short period of time, the CAI became a hallmark for music and dance classes, with a slate of acclaimed professional instructors. Within a few months of Lionel becoming the piano instructor, the pastor invited him to be the director of music for the Brooklyn Truth Center. With both of us living in Manhattan, we looked forward to our journey together to Brooklyn on Sunday mornings.

Over time it became very noticeable that Lionel was not well, and his condition, which he would not speak about, was worsening. All of us, including the pastor, other members, and I, became concerned about his obvious "silent" illness.

Lionel did not show up for choir rehearsal one Thursday night, and we all knew something was very wrong. A few choir members quickly decided to drive up to Harlem to Lionel's apartment to see about him. They found him slumped over in his chair. Deceased.

The pastor fully supported Lionel's mom, who arrived from Texas having just lost another son several months earlier. I also visited with his mom while she was attending to the business of her deceased son. There was never any mention of Lionel's illness or what became of his body. There was no funeral or memorial service in NYC that I knew of. Our church, however, did recognize his transition and spoke of his greatness. I can still hear my friend singing, "I Surrender All." Lionel's voice captured the writer's soul when penning that song.

Perhaps two weeks after Lionel's death, the CAI's violin teacher, another world-renown artist who lived in Harlem, called me to inquire about the cause of Lionel's death. I remained clueless.

"GRID! I bet Lionel had GRID."

I had never heard that word and remained clueless to what it meant. Gay-related immune deficiency (GRID) would become a word I would learn much about in the years to come. I will never forget the next statement Jerry made. It would be the last time we spoke. "If I got that, I would kill myself." A few weeks later, Jerry found out he had GRID, now known as AIDS, and committed suicide.

In 1989, working at Harlem Hospital, I became tormented by the lack of family and spiritual support for people who were, at that time, dying of AIDS. These were the dark days of AIDS. I was and remain baffled about the absence of compassion for people who suffer from AIDS or any disease or devastating situation in life. The results of my good intentions and neophyte understanding about HIV and AIDS was the creation of the Harlem Week of Prayer

for the Healing of AIDS, which gave birth to The Balm In Gilead, now an international nongovernment organization working to strengthen the capacity of faith communities in the United States and around the globe to become a beacon of light in areas of health promotion and disease prevention — and to serve all of God's people with compassion and knowledge, not with hatred and ignorance.

This book is not about HIV and stigma. It is about the inherited social disease of stigma that continues to infect each of us in some way and is passed on continuously from one generation to the next.

I am a child of stigma, shame, and fear. I grew up a colored child with congressional rulings that mandated that I drink from most often dirty, "Colored Only" water fountains. "White Only" signs stated with cruel punishment that I could not try on any shoes or clothes in the department stores in Charleston, South Carolina. I could not walk the shores of Folly or Myrtle Beaches. In fact, I was allowed only on the colored Atlantic Beach, passing all the "white only" beaches along the 116-mile drive. My mom had to pack a big lunch for the almost three-hour drive in both directions because colored people could not eat in any of the restaurants along the way. (There were no interstate highways.) During the long ride to the beach, once a year, the bus made at least two stops near the woods so that we could relieve our bodily functions behind a tree. Coloreds were not allowed in bathrooms.

I was also an obese child. "Fatty" and "Porky Pig" were my nicknames growing up. My father was an alcoholic. I grew up living with shame and fear. Fear of the next bully,

my father included, who would attack me by hitting me or calling me names or taking my personal power away just by laughing at me. Oh, and by the way, I was adopted, which really wasn't a bad thing, until I found out that everyone knew about it except me.

I have spent most of my adult years working to heal myself of my inner shame and the impact of stigma on my life. I wish I could say I am all healed. But I am not. It is a lifelong process. Throughout my career in public health and as a spiritual being who stands strong in the awesomeness of God and His omnipotent glory, I have witnessed first-hand the erroneous, messy, filth of stigma in public health and in religious communities around the world. The messy filth of stigma is certainly strong and horrific among many of my beloved Christians of all races, who often seem to hate people just as much as they love Jesus. The same can be said about many of my dear colleagues in public health. Their great intentions to save humanity from sickness and disease are equalized by their inherited, institutional, and personal biases that judge one's character, tolerance for pain, and worthiness to live by the color of a person's skin, zip code, or socioeconomic status.

Stigma is a burdensome and heavy word. It carries the weight of negative and often unfair beliefs that we hold about each other. Perhaps most tragically, stigma locks people into stereotyped boxes and denies us all the right to be our authentic and whole selves. We all have the tendency to sit on our high thrones and look low as we proclaim how progressive we've become. However, the reality is that we

both perpetuate and experience the burden of stigma in our public and private lives every day.

Yet another generation of children are being taught to hate other human beings for one reason or another. When does it stop? Stigma-like bombs are intended for the destruction of lives and territories. For many of us, we have had enough. However, without purging our own realities of hate — why we hate and how we hate — we will continue to pass on to our children and their children's children the world's greatest social disease: stigma. They, too, will grow up and live out their lives in shame and fear or as unconscious bigots.

For those who agree, we must stand up to persons and institutions that choose to kill and destroy human beings on any level. We must stand up to stigma everywhere! Each of us who believes in goodness and righteousness must work to eliminate stigmas about people who are different from us. We must stand up to laws and policies that discriminate against all people. Two institutions, in my opinion, that have the greatest influence to change how we think and live together as human beings are religious and public-health institutions. Religious and public-health discrimination policies must be acknowledged and eliminated if peace and righteousness will one day inherit the earth. Stigma and discrimination, resulting in shame and fear, are powerful war tactics that play out in schoolyards, grocery stores, places of worship, Congress, and within every home, every day. Institutions are made up of people. Each of us has a responsibility to be consciously clear about each decision

that is made. Is it a decision of discrimination and bias or one of peace and righteousness?

This book is about examining who we have become and why. I believe we all can stand up to stigma and change representations in our places of worship, public-health institutions, and media; we can get rid of laws and policies targeting stigmatized groups and set an example for future generations, starting with our very own children and grandchildren.

Today, with factual knowledge and my own spiritual understanding, I am a practicing Christian, and I have great respect for all of God's people who make up the diverse mosaic of religious and spiritual paths, and I am a strong advocate for public health and science.

INTRODUCTION

Before launching into this work, I would like you to consider three terms. Although each term can be seen as a single, simple word, each one also carries a vast amount of meaning. What's more, these three terms are dramatically affecting our world today, and if we are to truly progress as human beings, we need to acknowledge, address, and radically alter the path they describe.

The first term I want you to consider is *civilization,* which is "the condition that exists when people have developed effective ways of organizing a society and care about art, science, etc."[1] Although the history of humanity goes back tens of thousands of years, it is only relatively recent by the historical clock that human beings have been dubbed *civilized.* Precise definitions have fluctuated over the years, but the majority agrees that being civilized refers to human societies having a high level of development in technological and cultural arenas. This is opposed to the state of being "primitive" or "belonging to or characteristic of an early stage of development."[2]

Within the context of the word *civilization* is the state of being civilized, or to be "polite, reasonable and respectful."[3] Civilized societies are cooperative by definition. It is commonly accepted by authorities that civilized humans (civilizations) first appeared around 7000–8000 BC. We are now

well on our way into the twenty-first century AD. It stands to reason that if we have had nine to ten thousand years to practice and explore being civilized, then we should, today, be at a very advanced state of politeness, reasonability, and respectfulness. Unfortunately, that is not the case. In actuality, it appears that we as a civilization are regressing to a more primitive and reactionary mindset — reverting back to a period of "Dark Ages."

Take as an example the next word, *stereotype,* which is "to believe unfairly that all people or things with a particular characteristic are the same."[4] The term is more acutely defined in psychological circles as "a fixed, over generalized belief about a particular group or class of people."[5] Of course, not all stereotypes are intended to be hurtful and many are considered positive, like seeing obese people as "jolly," considering judges to be "sober," or believing that blonds "have more fun." However, it is far more common for people to focus on negative stereotypes such as Native Americans being "savage," people from Poland (Polacks) being "dimwitted," or persons living with HIV being "extremely contagious."

Stereotyping originated from a very advantageous form of behavior when civilized humanity was young. For example, judging that all cultural tribes that wore green facial paint were vicious and warlike served to prompt us to act quickly (based on previous experience of our own or those in our circle) when someone or something similar appeared to us. However, the tree of humanity, I believe, has experienced tremendous growth from its original civilized roots. Our world has exploded in technological, educational,

scientific, and medical advances that cater to our civilized lifestyles. As a result of such advancements in modern civilization, we no longer have to fear such things as insufficient means of storing food, monthlong journeys on foot or horseback, or living in caves or flimsy structures. The problem is that in the midst of such advancements, the social aspect of our civilization is, at best, stagnant and, at worst, declining.

Tiya A. Miles, an American historian and professor at the University of Michigan, expounds, "Stereotypes are so powerful and resilient that they operate beyond the individual psyche to shape cultural currents and societal structures. Certain images have long operated in American culture as containers for a host of ideas that distort and belittle groups of people in ways that have material consequences."[6] Although great advances have been made over past centuries, decades, and years, stereotypical judgments about those we see or meet have become fixed in our consciousness, even if we choose not to act upon them. Stereotyping has branched into what we today call prejudice — "an unfair feeling or dislike for a person or group because of race, sex, religion, etc." — and discrimination — "the practice of unfairly treating a person or group of people differently."[7] In today's society, people are constantly favored or disfavored based on a variety of unfair judgments, many qualities of which were not chosen by them (for example, sex, ethnicity, age).

Stereotyping, prejudice, and discrimination no longer serve us as they might have many thousands of years ago. Such behaviors are now disadvantageous and work to drive

divisions between social structures that are rapidly transforming into larger, united circles through globalization. As we are witnessing, these divisions are not helpful but harmful to the advancement of civilization because of unjust, untrue, and outright ignorant assumptions that are made by individuals about other people. Stereotypes, prejudices, and discriminations, therefore, serve only to disrupt the flow of social growth specifically and cause a breakdown in the stability of civilization in general. Thankfully, a growing number of people are coming to an understanding about the harmful effects of stereotyping and are moving away from such unfounded prejudices and discriminations when making individual assessments.

This brings me to the third term, which is a lesser known and acknowledged phenomenon that is taking place, although it has greater potential to threaten our civilization than stereotyping, prejudice, or discrimination. This final word is "stigma," and although related to the others, it tends to define civilization or society as a whole compared with the more individualistic form of stereotyping. Stigma is defined as "a set of negative and often unfair beliefs that a society or group of people have about something."[8] Stigmatization is broader in its effects than stereotyping because larger numbers of people adhere to negative and unfair beliefs. A few examples of stigma that continue to permeate our humanity are those that mark all people living in the mountains (hillbillies) as poor, white, ignorant, barefoot, and living in shacks; all whites as dominating and prejudiced; all Muslims as terrorists; all blacks as poor and lazy; or all Hispanics as associated with gangs that start riots and

destroy entire neighborhoods. In all likelihood, these long-standing trends of stigma are at a critical point of destroying our entire nation and way of life.

Stigma, as we all know, can involve a deliberate attempt to mark the intended victim with a feeling of lower status or shame. One might encounter a prejudiced person and never know his inner thoughts if he keeps them to himself. However, one who "stigmatizes" intends to brand the other — either by words or deeds — thereby adding to its hurtfulness as a phenomenon.

To our shame as human beings, we are witnessing the negative results of our ever-festering stigmas, which are rising to an uncomfortable and dangerous regularity throughout the world. We are witnessing it in the United States, which is considered to be one of the most civilized nations on earth. We are witnessing it in Europe, which has centuries of experience more than the United States in civilizing its peoples. We are witnessing it in Russia, China, Australia, and practically every other country. Various groups, cultures, religions, media outlets, and even governments are busy fanning the flames of stigma, which have risen to feverish and destructive levels of assault on nations of people. Perhaps what we are witnessing is the result of our ignoring the stronghold of stigma that has festered for generations against individuals and groups of people. Perhaps it is due to the rapidity of globalization, merging together peoples from various religious, ethnic, linguistic, or other backgrounds. Regardless, these are not excusable reasons. However, if we are to progress as civilized human beings, we must quell the rise of stigma by actively addressing the

issues, educating the masses, and coming together as one kind . . . humans.

This book addresses the ever-present and perpetual sting of stigma, how stereotypes develop, the processes and effects of stigma, the levels of intervention that are needed, the need and process to change cultural thinking regarding this subject, and practical ways that stigma can be managed to create a healthier and more fulfilling environment for all.

CHAPTER 1

The Venom of Stigma

Stigma is a simple, two-syllable word. Yet because of an array of sociological factors, for many people it creates powerful impressions and emotions that always conjure up a variety of uncomfortable and even hurtful feelings. Many people may not be familiar with the term *stigma,* while others may refer to it only on a casual basis. Still others believe that the very injustices that the word represents have long been removed, or at least drastically reduced, in our "civilized" culture. However, is that really the case? No! It is not! For too many people in our society, we wear the impact of stigma like flaky, dry skin. The continuous application of lotion to cover up the unappealing, flaky, dry cells is a perpetual, daily exercise that almost never eliminates the problem. The human skin is our largest organ. It consists of three layers and is made up of mesodermal tissues that adapt to the internal and external environmental conditions of our bodies to protect our inner muscles, skeleton, and other organs. Our top layer of skin, often dry, flaky, and wrinkled, depending on our age, is called the stratum corneum. Its primary function is to protect us from the environmental conditions of the earth — or society, community, or family in the case of stigma.

Everyone experiences stigma at some point in their lives. Being the recipient of stigma is painful, regardless of the situation. However, becoming stigmatized because one brings a peanut butter and jelly sandwich to elementary school every day cannot begin to compare with the daily encounters of stigma experienced by millions of people as the result of culture and inherent systems of mass hatred of fellow human beings — systems that have been bred into existence through intergenerational words, thoughts, actions, and policies.

During these early years of the twenty-first century, we are witnessing the severe impact of ingrained hatred of populations in a civilized society. Among many persons presently living on planet Earth, there is a longing for the continuation of stigma and fear through legislative polices that will reconstruct or keep systems in place that render people fearful, hateful, and helpless for many generations to come. At the same time, there is hope and protest among others who want to dismantle stigma and hate of every kind and on every level, resulting in the birth of the next generation of human beings living in peace among themselves and within themselves.

Stigma is a devastating social disease in our world. The coherent progression of hate, fear, and shame for centuries has widely spread this infectious, debilitating social disease. Stigma kills millions of human beings of all ages, races, and creeds every day.

As with all diseases, it is important to first find the root cause. Is the disease caused by a bacteria, virus, or parasite? How is it transmitted — perhaps like malaria, a virus

carried to human beings by female mosquitoes of the genus *Anopheles*? Or is stigma transmitted between two human beings when they encounter each other's body fluids — such as blood — when one person's blood is infected with the virus? This would suggest the continuous transmission of the virus and the disease, as is the case of the human immunodeficiency virus (HIV) that causes AIDS.

The first step in understanding the terms that define and affect society and all human beings that make up our world is to go to the roots of those terms. If you trace the root meaning of the volatile word *stigma,* you will find that it originates from the Greek language and culture. In the world of the ancient Greeks, those who were considered "lesser than" — such as criminals, traitors, the mentally ill, and slaves — received a mark (stigma) that was burned, cut, or branded into their skin. This visible mark announced that these human beings were blemished, defective, or otherwise outcast and should therefore be shunned and avoided by the general public.

Initially I called this chapter "The Sting of Stigma." However, a sting is usually considered a quick, sharp pain that oftentimes contains poison. There are so many over-the-counter antibiotics for a mere sting that I felt the word misrepresented the extreme violence and lasting effects of stigma on individuals, populations, and the communities to which they belong. On the other hand, *venom* conjures up in my mind the most terrifying predators in the world — snakes and scorpions. I personally have an extreme aversion to snakes (all kinds) and scorpions, viewing them with a hatred so strong and an almost toxic anger that I

just have a desire to kill them. I know these animals don't deserve to be judged so harshly, but their cultural baggage is hard to avoid. The effects of stigma in our world, both historic and present, are the result of conscious poisoning with an undeniable desire to kill the mind, body, and spirit of another human being.

It is well documented that in the United States, there is a longstanding history of stigmatizing people who are deemed different. The Pilgrims who arrived in 1620 were escaping governmental and religious persecution. Ironically, the Puritans who followed in 1630 identified religious lawbreakers with bright letters that were worn on their clothing or by letters burned into their chests, including A for adultery, D for drunkenness, and B for blasphemy.[1] These Reformed Protestants sought to "purify" anything and anyone that did not meet their definition of the world as they saw it through their scriptural interpretation of the Bible. Criminals, "savage" Native Americans, African slaves, migrants, women, and others who were deemed offenders of ordinances and laws or who were simply different were often branded, disfigured, or otherwise marked in some fashion for identification, punishment, and lifelong shaming.[2]

We in the United States no longer impose the barbaric practice of physical disfiguration or marking as a means to identify certain categories of people, but we must grapple with the reality that almost four hundred years after the arrival of the Pilgrims, the interwoven fabric of stigma and its impact are on full display. The long-lasting protocol of applying stigmas to people or groups that we think deviate

from what is normal remains an effective, behavioral intervention. The marks may no longer be physical brands, but the damage is most definitely etched into the psyche, which can often manifest in physical illness or death. History is filled with examples of past atrocities of stigmatism that not only stained our country but set the foundation for the sustained culture of stigma, hate, and fear in which we are all continuing to live.

Stigma against Native Americans

The effects of the US genocide on Native Americans are not readily talked about within the borders of the United States or on the world stage. The scope of the history, values, and contributions of Native people that is taught in American classrooms is extremely limited, at best. To give even the smallest sense of the stigma placed on "first peoples," consider how easy it is to complete this sentence: "The only good Indian is a . . . " Atrocities committed against Native Americans by European settlers and the established United States government have been extreme. A few of us might argue that the extremes continue. It is estimated that more than ten million Native Americans occupied the territory now known as the United States when European explorers first arrived. However, by 1930, the US census counted 332,000 Native Americans and 334,000 in 1940.[3] The sheer numbers involved in this decimation can be considered as nothing less than a real attempt at genocide, yet the US government remains silent, by and large, while chastising other nations for similar acts.

As the people of the young United States spread west across the continent, Native Americans were increasingly found to be occupying land that was considered valuable for farming, mining, logging, traveling, and the like. Native American tribes were systematically eliminated by force through starvation (destruction of crops and depletion of wildlife), exposure (causing members to flee during harsh weather), poisoning of food and water sources, disease (trading disease-infested items), and the outright slaughter of entire encampments (men, women, children, and elderly). More than five hundred treaties were made between the US government and Native Americans, but the majority of those (if not all) were changed, broken, or nullified when the interests of the government and/or corporations required it.[4] Many of these "Indian treaties" are still in existence and enforced today, although they are greatly reduced in their effectiveness.

Today, according to the 2010 US census, there are only 2.5 million Native Americans (inclusive of American Indians and Alaskan Natives), with about one million living on reservations.[5] Most Native Americans living on reservations do so in extreme poverty and squalor. The mental and physical health of reservation Natives are far worse than that of the general American public. Tuberculosis is 600 percent higher, diabetes is 189 percent higher, alcoholism is 510 percent higher, and suicide is 62 percent higher, and of Native Americans over twelve years of age, one out of ten becomes a victim of a violent crime every year.[6] Although conditions have been slowly improving over recent years, many Native Americans, especially the younger generations, are

choosing to leave their tribal communities to pursue higher education and a better life in mainstream society. However, they have to continuously overcome hurdles of discrimination from peers, schools, housing authorities, health-care providers, businesses, and other segments of our society that still consider them to be lesser beings.

The reality is that mainstream society continues to be disrespectful and intolerant of Native people. The present fight of the Standing Rock Sioux Tribe, which began in 2016 against the Dakota Access Pipeline, is evidence of the continual disrespect of culture, land ownership, and tribal traditions that Native people still endure.[7] The Standing Rock Sioux Tribe, once a part of the Great Sioux Nation, is fighting to stop the construction of a pipeline that would, when linked with other pipelines, carry 470,000 barrels of oil per day from western North Dakota to Illinois.[8] After the pipeline was deemed too risky to be constructed near Bismarck, the capital of North Dakota, because of the possibilities of contaminating the water supply, it was rerouted to run parallel to the Standing Rock Sioux reservation, under Lake Oahe and the Missouri River, which borders the reservation.[9] The Standing Rock Sioux Tribe, like the people of Bismarck, is concerned about the possibilities of major environmental disasters, such as oil spills and water contamination, as well as the cultural threats that are being cast upon them. According to Standing Rock chairman Dave Archambault II, in his address to the Human Rights Council of the United Nations in Geneva, this action is yet another US violation of an existing Indian treaty.[10] It's noteworthy that the Obama administration halted both the Dakota Access

Pipeline and the Keystone XL Pipeline, citing safety and America's commitment to fighting climate change.[11] The Keystone XL Pipeline is a $7 billion project of TransCanada, which is constructing this oil vessel from Alberta, Canada, to Nebraska. It will at some time in the future connect with an already existing oil pipeline that runs from Oklahoma to the Gulf Coast.[12] Within five days of taking office, newly elected President Donald Trump — who boldly called Massachusetts Senator Elizabeth Warren "Pocahontas," without hesitating to disrespect her Native American ancestry, the direct family descendants of Amonute (known to us as Pocahontas), and all Native people — signed an executive order reauthorizing the completion of both the Dakota Access Pipeline and the Keystone XL pipeline along with the removal of thousands of protestors who were camped near Lake Oahe.[13]

Images of Native people as savage and unworthy of land as well as of life are being witnessed every day in our twenty-first century mainstream society. When we think of Native people, we most likely bring forth images of red-skinned men in enormous headdress costumes or savages riding on horses killing white men, women, and children. *New York Times* reporter Jack Healy, in an article published September 13, 2016, provides a glimpse of the present-day cultural divide and racial attitudes toward Native people regarding the pipeline. In the midst of only peaceful protests and demonstrations, Bruce Strinden, the commissioner of Morton County, North Dakota, and also a part-time rancher, shared in an interview the unwarranted

historical fears and attitudes of surrounding white residents. He stated, "These ranchers, it's their livelihood. If somebody would come and set fire to their hay reserves and come and cut their fences and cause their livestock to get loose, that causes real problems."[14] On the other side, Jana Gipp, a member of the Standing Rock Sioux Tribe, who was also interviewed, stated that most people "don't know that we're hard workers. We don't all drink. We have jobs. We have to support our families."[15]

Stigma against African Americans

There are many historians, scholars, and individuals who try to deny the truth, but the lasting and present-day stigma of racism in America is the direct effect of the US holocaust of Native Americans and the American slave trade, which was used in the colonies between 1607 and 1776 and then flourished for almost another one hundred years. African men, women, and children were sold, bought, and bred for the purpose of the machine of slavery, which was essential to the economic empire of the South. From the early 1700s to the Civil War, enslaved people outnumbered free whites in places like South Carolina. Slave ownership meant an individual was legal property and could be separated from family members at the will of his or her master. During slavery, black people were "marked" for ownership, and offenses such as disobedience, insubordination, running away, poor work, and others were normally met with fierce reprisals, including, but not limited to, whipping, cutting off body

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