Every Cook Can Govern

At Friendship And Kay Street



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Cynthia Hamilton

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t took me a long time to decide to write this book. It wasn't t took me a long time to decide to write this book. It must until Mom beat the blood clot, and we got the upper hand on the autoimmune skin disease that I decided to write. In large part, the book is a tribute to my mother. It was she and my father who were selfless to the end. I never reached that stage. So this is a tribute to Mom and Dad.

It is also an acknowledgment of my caregivers who were not direct beneficiaries of the civil rights movement like I had been. They remind me of the cost to the black community when so many of us left. There were serious costs—the population diminished. There was a place for developers to move in; drugs and crime could develop with no internal checks. These women (my health aids) were left behind and tried to maintain values and standards on their own, without husbands and supportive communities.

The final objective of this book is to talk once again about what we must do to rebuild our communities. My years of disability resulted in my house becoming my community. Unlike other jobs where communities develop from within, the university prevents the collaboration and sharing so necessary for community. I guess that's why I've spent my whole life trying to recreate community or looking for conditions that would

facilitate it. After all, what happens to an activist on disability? All I could think of is Langston Hughes's poem "A Dream Deferred"—"does it wither and die?"

I fought disability (with my mother's help) until 2007 fighting every step of the way. Doctors said, "You'll need to rest in the middle of the day . . . You may lose your voice . . . You won't be able to write . . . Just make an X . . . Sell your house, leave your job . . ." If it hadn't been for those years of activism, I wouldn't have made it. I had learned we struggle one day at a time, from one generation to the next.¹ Even my mother insisted "You cannot stop, you'll want to die . . ."

Those years of activism taught me everything I needed to know about searching for alternatives. In the environmental battles, we had to search for solutions to air, water, and soil solutions as we looked for ways to cure them (which contamination had caused), alternatives in health care, medicine, cooking/food, as well as politics. Sharing and collaboration was learned and practiced at the Garvey Institute in East Lansing, Michigan, while work, study, and practice with C. L. R. James² in Washington, DC, Mom and Dad taught me everything I needed to know about living a life with meaning and faith. They were both Southerners from New Orleans who loved themselves and "their people" but hated Jim Crow. My mother and her mother were feminists before there was a movement; my father and his father were Garveyite populists.³ It's no accident that I

¹ Kimathi Mohammed, Organization and Spontaneity: The Theory of the Vanguard Party and Its Application to the Black Movement in the US Today (1973, 2013).

² C. L. R. James, *Notes on Dialectics (1938)*. *This is the book we worked with for six months.*

³ Marcus Garvey, came from Jamaica, he lead the largest mass movement of African Americans. The ideology of the movement embraced both black nationalism and Pan Africanism.

found my politics with a Trinidadian socialist, C. L. R. James, whom I worked for in the years between undergrad and graduate school.

My family support is the reason I was able to survive the MS. That support allowed me to do all the things I thought were important at the time I choose. My parents supported my political choices even when they didn't understand them. They trusted me to carry on as they had instructed, and I think I did. The MS was a heartbreaker for my father, and the disability I'm sure accelerated my mother's dementia. I will always feel responsible and remorseful.



INTRODUCTION

am black, and I have MS (multiple sclerosis). I am a baby boomer. My parents married after my dad returned from WWII, and I was born in 1950. I am old enough to remember everything—the civil rights movement, Vietnam, strong families, stable communities, schools we were proud of, all the changes that legislation produced, and inner-city riots. I am the product of a black high school, a black community, and a black church. It never occurred to me that I should doubt who I was or where I came from. I knew I was black, and I had to work hard, harder than white people. But I never doubted myself or what was around me because we were black. Then I went to college in 1967, and everything was different.

I guess I've spent my entire adult life trying to return to aspects of those days (particularly stable communities), and finally, I built my own community, and it was perfect for all the things I had hoped for. The only problem was that Mom and I were sick—Mom, too sick to know, and me, too sick to do anything. Furthermore, our society is too sick to care. But I will still end this book by proposing what might make a difference.

This book is part autobiography, part tribute, part polemics. I need to tell the story of how I survived MS—faith, love,

commitment, and politics. At the same time, I'm telling Mom's story of survival—the worst of the twentieth century (Jim Crow), civil rights, urban riots, black power, white universities, watching your children grow up with things you don't understand but giving them attitudes and beliefs that have sustained you.

In the end, this is a story of six black women, very different but very much the same, and how they help each other and all those around them.

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HISTORICAL BACKGROUND

don't excuse the Greeks for slavery or for excluding women from political participation. But I understand C. L. R. James's enthusiasm when he wrote *Every Cook Can Govern*⁴ for the rotation of council seats on an equal basis—everyone had a turn. It was their system of sortation—selection by lot—that captured James. Precisely because such a system would be emphatically opposed in the modern era by everyone (north, south, east, and west). (I worked for C. L. R. James when I was twenty.) Issues of policy (domestic and foreign) and issues of administration of the state are all the special expertise of bureaucrats and politicians. For the Greeks, equality and democracy were used interchangeably.⁵

That's how I run my house. And that's my approach to medicine. Poor women take care of everyone—old and young, male and female. They don't have to be told what to do; they do it. Even young daughters and grandchildren want to help and do (even though they may sometimes charge).

⁴ C. L. R. James, *Every Cook Can Govern: A Study of Democracy in Ancient Greece (1938), correspondence.*

⁵ Kent Worcester, C. L. R. James: A Political Biography (State University of New York, Albany, 1996).

Western medicine (like Western politics) requires that you leave it to the experts—doctors and pharmaceutical companies. My politics gave me the strength to resist the approach of Western medicine, and my faith allowed me to stand even when I couldn't physically. My faith directed me to search for comfortable solutions for Mom even though she is ninety-six and doesn't talk any more.

What we learn from all this is that everyone who wants to can make a contribution. We must be prepared to accept it, regardless of source. I have always been inclined to favor too much democracy—of course, if things get out of hand, I will resort to dictatorship with a smile.

I've always believed all people can do, accomplish, learn, and produce equally if given the chance in a supportive environment. So the "proof of the pudding" is that Mom could no longer be in charge of my house after Dad's death. She really didn't want to be here. But that gets ahead of the story.

How I Came To Love/Appreciate Community

I was born in New Orleans as were my parents. The decision to leave New Orleans was major, it meant leaving a community, people, places, a history and meaning all of which would have to be recreated. Mom and Dad did that for my brother and myself. They moved to a new place and made it like an old place. They found a church home. They found music instructors, piano for me, saxophone for my brother. And then we had to look outside to see if there were things we could adopt. No one would believe it today but learned ballet at South Park, Spanish dance at Roosevelt Park, and Tap dance from a park where Locke High School is today. Black people were rejected by and excluded from the larger society so they had to create their own. And they did, you could learn anything in your community—how to read, how to speak, how to sing, how to cook, how to sew. This is the reason the Civil Rights Movement was successful.

Mom was a Girl Scout leader. W(e had a troop at Miramonte Elementary School, Troop 2482. We participated in parades, dance festivals, went camping (Dad went with us), had Christmas parties, went to Disneyland, roller skating, ice skating. The Church (Neighborhood Community Church) had an active Sunday School because mothers wanted to do everything they could. There were Easter plays, Christmas plays, lots of music every spring with the June Rose Festival, and the summer picnic. Black people did these things by themselves, for themselves.

This was the key to the Civil Rights Movement, people doing for themselves while challenging laws which isolated them. Our yearly summer vacations driving from LA to New Orleans demonstrated how this was done. We took a trip a year from 1958 to 1965, before and after the Civil Rights Bill. I remember my father pre paring—leaning over maps on the kitchen table to determine where we could stop and how long it would take to get from one point to another. My father was very brave to travel with a five year old, and an eight year old, and a wife who looked white until you saw her kids. Those trips were quite an experience. I'll never forget one moment.

School was a very important experience in black communities; you learned who you were for real, class and race were no longer abstractions. Location was very important outside the south. I was in High School after the Watts riots and I went to a black school in South Central LA so "nerds" had to "represent", like athletes you had to win to make everyone proud and it didn't matter what it was, a speech contest, a beauty contest a debate or a football game. When the Civil Rights Bill passed in 1964 there was a new option presented itself, white colleges opened up to black students.

The Community We'll Always Remember⁶ 1966 Volkswagen Terry A. Hayes

I really don't know how many people I was able to fit into my red-with-white-stripes 1966 Volkswagen Beetle (1300). All I know is that there was always a group from Jordan that always piled in. Since it's been almost fifty years, the names of my passengers are foggy, but I remember a Chinese girl (whose family owned a grocery on Willowbrook near 103rd Street) and a bunch of guys I either played chess with or who were in the Jordan High School band. That's right; the Chinese girl was also a cheerleader. We went everywhere together in that car. A year before I had been relegated to riding the "red bus" or Atkinson Transportation Company to school. This was the only bus line that served Greater Watts in the time before SCRTD. The red bus was always late, and on the ride to school (Imperial to Central to 103rd), the seats were always wet because the bus was hosed down for cleaning (the seats only started to dry out just at the end of our journey). Oftentimes, those of us in the "neighborhood" (that's what our turf was called as opposed to the "bricks," i.e., Nickerson Gardens public housing on the other side of Central Avenue) just walked the three miles or so to Jordan. We arrived with no water stains and a lot dryer.

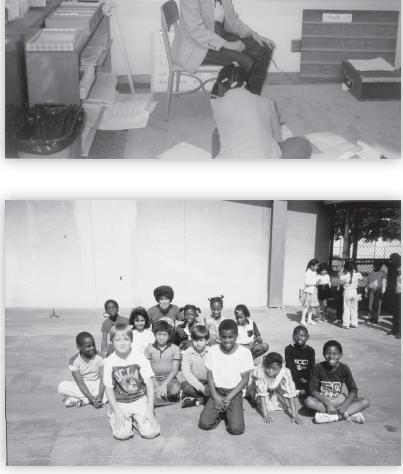
Now that I had a car, my whole life changed. Mobility opened me up to see all the nooks and crannies of Watts. I saw more nooks than most because I used the car to take deliveries for my dad's pharmacy. I knew the layout of every housing project

⁶ Terry Hayes, CEO, Hayes & Associates, old friend.

(Nickerson, Jordan Downs, Imperial Courts, Avalon Gardens). I went to old eastside neighborhoods where blacks had lived for generations east and west of Hooper (hupah as we called it). Although tinged by the unrest of 1965, Central Avenue was still the center of the Los Angeles black community. I used this artery countless times to spin off to homes, boardinghouses, backhouses, rest homes, and stores to deliver drugs and sundries. I wasn't dangerous. I did not feel unsafe. It was where I lived and played. Part of it was Watts, and the other parts had no name (the term "South Central" had not yet been born). It encompassed homes of friends and relatives and, for my dad, customers.

In 1966, I couldn't see it from my perch inside my speeding beetle. Probably, nobody could see it, but our community was changing. It's clear now that, after the unrest, our community and its institutions collectively crossed over some juncture, and we were on a different path.







My freshman year was exciting. It was a new experience on my own, and now I/we had to confront Vietnam/war, racism, and organizing for change on our own. The civil rights movement seemed far away, but the Panthers were near-in Oakland. My first quarter (a new system), I volunteered to be on a panel to discuss a play by LeRoi Jones (the Dutchman)⁷ for a school-wide audience—no one threw anything, so I guess it was all right. The next quarter, I joined the committee to develop plans for a black studies program. Everything was going so fast, and then in 1968, M. L. King was killed. I thought I would die, but now, I had to rethink everything (school, career, life), but the biggest thing was deciding if I should stay in this country. If they didn't want King, why would they want me? The next year, I did leave the country. I went to Tanzania with Crossroads Africa. I became a very different person. My politics were now very global; my understanding of problems, very universal. The Afro-Americans that I met were all people who had consciously left the United States. Some, like Robert Williams⁸, had to leave (Williams had been head of the NAACP in Monroe, North Carolina; he and his wife left to avoid prosecution for kidnapping). I met members of the Mozambique People's Liberation Army. I met people who explained to me that politics is very hard and very serious. My life had changed.

I asked my group leader in Tanzania questions which he could not answer—like why were we building another elementary school in Moshi after the president of Tanzania had warned that there had to be an equal number of elementary and secondary schools to maintain employment and civil peace. He didn't have an answer. I didn't want to be part of a problem, so I left the group (that's how I met Robert Williams and his wife and members of MPLA). Going home from Tanzania, one of the executive

⁷ Last play that Jones did before he changed his name to Amiri Baraka in 1964.

⁸ Robert Williams, Negroes with Guns (African American Life Series, 1998, 1962).

administrators of Crossroads confronted me about leaving the group. I would meet him again years later when he was an executive with the Ford Foundation and I was a graduate student looking for foundation support for school. He remembered me. Oh well, I learned that you pay a price for your actions.

When I got back to school, I decided to stay in the United States because of the needs I had seen in Africa. C. L. R. James, author of *Black Jacobins*,⁹ came to speak at Stanford. It was a significant encounter. Another important stage in my life began. I graduated early from Stanford and decided I would not go to law school; instead I went to Cornell University in New York for their new graduate program in Africana studies. But I would leave the graduate program at Cornell to work independently with James. While working for James in Washington, DC, I met people I would work with politically for the rest of my life.¹⁰

I decided to try graduate school one more time in 1972. I went to Boston University because Howard Zinn was in the Political Science Department. Before going to Boston, he taught at Spelman College in Atlanta. He was an advisor to members of SNCC (Student Nonviolent Coordinating Committee) who had been responsible for the sit-in movement, the youth wing of the civil rights movement. That was the closest I could get to the civil rights movement. I met a minister who had come to BU because King went there. We were both in a seminar with Zinn (I remember my presentation on Rousseau), and he encouraged me to apply for a job at Simmons College where they were trying to set up a black studies program. I got the job with the Government Department. I taught there for ten years. I worked full-time while I completed my dissertation.

⁹ C. L. R. James, *The Black Jacobins: Toussaint L'Ouverture and the San Domingo Revolution (1938).*

¹⁰ Kimathi Mohammed and the Marcus Garvey Institute.

It was an interesting period. My politics were now internal. I took a leave of absence from the job to work at a factory to understand what happens to workers' thought process when they are on the assembly line. I was the guinea pig, and I could barely keep my eyes open after 6:00 p.m. I started at 8:00 a.m. in the morning with thirty minutes for lunch, and I clocked out at 4:30 p.m. I worked the end of the line. I lifted a platform of speakers and stacked them along with another worker. It was actually an easy position. I had other positions higher up on the line, but I wasn't fast enough. The company made stereo speakers.

Organizing inside of a factory is extremely difficult. My dissertation topic was "Organization and Dominance: The Case of Industrial Organization in the United States, 1890-1918." It was a theoretical discussion of the similarity in organization inside and outside the factory.

I did some housing organizing, and that drew me into the issue of community redevelopment. America had decided, since cities had to be rebuilt after the urban riots, they would rebuild to exclude black people. All my research and writing since the 1970s has been on neighborhood restructuring.

Greater Roxbury Neighborhood Authority (GRNA)¹¹

My friend Bob Terrell and I had been reading Andre Gunder Frank's¹² theory of dependency and development and felt that the theory was perfect for describing the black community, so we decided to test our ideas about development, and we ran for positions on the Board of Directors of the Greater Roxbury

¹¹ Robert Terrell, Executive Director, Boston Fair Housing, old friend.

¹² Andre Gunder Frank, *The Development of Underdevelopment, Monthly Review Press, 1966.*

Neighborhood Authority, and we won. It was an interesting experience. Some people agreed with us that all the community's assets were spent outside the community and there was nothing that was produced and consumed locally. We had great ideas about trying to have someone invest in a plant-producing, prefabricated housing material that could have been consumed locally and sold outside. It would also have been great for jobs. But remember Boston is the city where white construction workers organized against black workers bendcause they weren't unionized.

These were not the types of development projects that were being proposed. Instead, fast food developments were proposed. We even thought a new grocery for Roxbury would have been useful; it may have even been useful for local farmers. Some of these ideas can still be useful today.

The dissertation process doesn't begin until after the qualifying exams. While I was studying, I sat in on a black/ African literature class. Politics was my first love, but literature was my second, particularly negritude literature developed by black writers from French colonies. And I met the man who would become my husband. I was xeroxing an old article on James (he worked at the copy shop—Copy Cop). I had put it on copy paper—no one knows what that is today. As he began to lecture me, he noticed the books I was carrying and asked if I'd be interested in going to a poetry reading. Everything was uphill after that. We courted for three years even when he went to Montreal for his master's degree in comparative literature. The high school girls couldn't believe that the man who brought flowers every week was my boyfriend. But within months after we married, our marriage was over. I returned to Boston, finished my degree, and was denied tenure at Simmons. My grandmother died, and I left Boston trying to get as close to home as possible.

I took a job as director of black studies at the University of New Mexico in Albuquerque. That didn't last long (though I have a dear student from those days who is quite accomplished¹³). I quit with the intention of leaving the university forever. I returned to Los Angeles and got a job with the lobbyist for the long-term care industry. I am sure my fear and distrust of nursing homes started then. After many sleepless nights, I got a job with Pacifica Radio. I loved it—maybe this was my calling. I did news and public affairs (morning news). I took the job to rediscover LA and successfully built an audience that actually read the books I recommended. The bookstores actually asked me to give them advance notice when I reviewed a book so they could have it on hand.

The most exciting thing that happened while I worked in radio was my trip to Grenada. Maurice Bishop had just come to power, and it looked like Grenada would become the first black socialist country in the Americas. I couldn't wait. I would actually send stories from the island—just like a real foreign correspondent. I was there for two weeks. Within two months, the United States invaded the island, and Maurice Bishop was killed. Another dream gone.¹⁴

I finally decided to return to teaching at the university. I went directly to the college most students from my high school had gone to, California State College, LA, in the middle of the barrio/ Chicano neighborhood in East LA.

¹³ Stephan Haymes, *Race, Culture, and the City, a Pedagogy for Black Urban Struggle, State University of New York Press, 1995.*

¹⁴ Cynthia Hamilton, "US Foreign Policy and Grenada," *Race and Class* 26, no. 2 (1984).

California State University (Cal State)

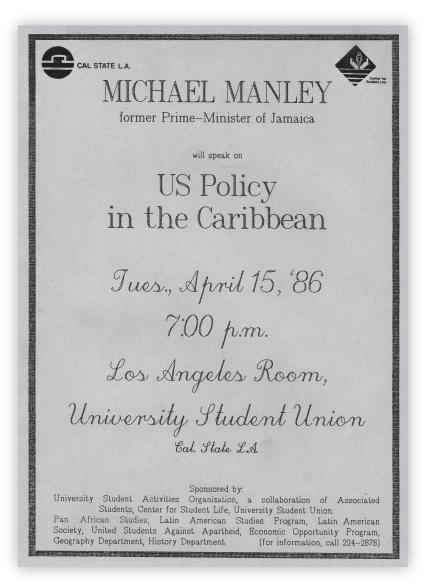
All students at Cal State worked, either before classes or after. We were a working-class school for sure. What was so wonderful about that is it put a very different kind of pressure on classes. They had to immediately show their relevance. I'm speaking from my own experience as a black academic in political science and black studies.

This was particularly the case when I started teaching urban politics. I worked with one of the state senators¹⁵ for about a year. We organized a visit by Rev. Jesse Jackson after he ran for president of the United States. This was an incredible event for a state college. The campus TV station broadcasted live closed circuit all over campus so you didn't have to be in the same room with him to be part of the event. We were in the student union. There were people everywhere. Students brought their children, their siblings, their parents. It was wonderful.

Then there was the visit of former Prime Minister Michael Manley of Jamaica. This was years after the fight with the IMF that cost him his job.

Cal State was an incredible experience, demonstrating what is possible but also making it clear there would be a response; this was after all President Ronald Reagan's state.

¹⁵ State Senator wanted students from a state college to have greater access; we worked with her and her assistant Lois Hale for a year.



DEPARTMENT OF PAN AFRICAN STUDIES

GUEST SPEAKERS

Winter Quarter, 1986

January 16	Senator Frank Barrows (Connecticut) "The Need for a New Black Agenda"
January 30	Councilman Richard Alatorre "L.A.'s City Council and Minority Representation"
February 6	Dr. Lou Simpson (Psychiatrist) Councilman Daniel Tabor (Inglewood City Council) "Public Opinion, Polls and Voter Trends"
February 13	Ms. Marilyn Hudson (Past President CRA) Mr. Charles Lewis (Minority Architects) "Growth and Development problems and proposals"
February 20	Reverend Jesse Jackson (Presidential Contender 1985) "The State of Black America"
February 27	Senator Diane Watson Mr. John Dyer (Executive Director, Metro Rail Project) "Transportation Projects: Implications for Development"

All lectures are on Thursday from 6:00 to 8:00 p.m.

University Times

ol. 107 No. 23

California State University, Los Angeles

lesse Jackson to speak at CSLA



Wednesday, February 19, 1986

Rev. Jesse Jackson

CSLA reacts favorably to address evaluate his speech style and content. In so doing, 1 though he was an excellent prease. It discusses was good. It also had prease the start of the start of the intervention of the start of the start continued by Hale. "I dentified with his comment on today's youth being materially observed," with the start of the start of the start Mischael Jackson and Prince." Valanda Jahonon, graduate sociology student, said Jackson's speech impired her to control today's fusion.

Philippine aid should cease says Jackson

By COURTNEY GABLE STAFF WRITER

The United States should suspend all aid to the Philippines, according to the Rev. Jesse Jackson. Jackson's statements came at a press conference he held prior to his Gal State LA. speech on 'The Challenge of Chalding the Faculty's the Challenge of the state of the the theory of the chalding the Faculty's the theory of the conference of the state of the state mast atop all did to the Philippines or ac-equir responsibility for the hyproducts of its continued support of a corrupt govern-ment.

continued support of a corrupt govern-ment. Repairing News emphasisment of the second second

ire," he added. Jackson commented that as a nation we leed to face the future boldy. Jackson encouraged everyone to take oting action to enact change. He also sug-cated writing letters and filing lawsuits at

<section-header><section-header><section-header><section-header><text><text><text><text><text><text><text><text><text><text><text><text><text><text><text><text><text><text><text><text><text><text><text> student, aid Jackson's speech inspired her, to confront today's issues. "The issues he spoke of made me avare of the situations in the world," whe said. "I thougt about what changes I could make to better the world." Grover Peary, recent graduate of San Francisco State University, said, "I hopp people will embrace his theme of the moral authority and preservation of the family and continue to foster those beliefs." EXII



Reverend Jesse Jackson Speaks to Capacity Crowd at Cal State L.A.

One of the largest crowds ever to gather at California State University, Los Angeles, with the exception of the University's annual Commencement exercises, filled the University-Student Union to apacity Feb. 20 to hear 1984 Presidential Andidate Rev. Lesse Lesken speak

andidate Rev. Jesse Jackson speak. And speak he did, to the filled-toapacity Los Angeles Room and via video monitors to the overflow crowd of students, faculty, staff and others.

Sharing the podium with Jackson was Blshop H. H. Brookings, who has crown Jackson since the 1950s; as well State Senator Diane Watson, one of the University's most well-known alumni; Dr. Sidney Ribeau, acting chair of the Department of Pan-African Studies; Associated Students President Robert Morgan (who himself gave a brief, albeit vousing, speech); and University President James Rosser.

Despite a bad case of the flu, all agreed kson was dynamic, whether or not one agreed with his views.

His topic, "The State of Black America: A New Challenge for American Party Politics," was actually misleading; his subject matter — a challenge to rebuild the world, national and nuclear families — was iniversal.

"Each person must pull his own weight," Jackson exhorted the crowd, "If you are not a registered voter, then you are uctually an Afrikaaner. If you are not registered to vote, then you are a supporter of (former Filipino president Ferdinand) Marcos.

"There is a trend toward oppression, oward insensitivity in society. We are acing a headwind and must struggle to urn back the clock," Jackson said.

People, Americans especially, are not s sensitive to the threat of oppression in ociety, said Jackson, because of selfteception. "I believe we are obliged to ead the signs of history," he said.

Jackson compared the situation in

South Africa to the situation in Southcentral Los Angeles with stunning effect.

"There are trends," he said, "of a growing income gap between the haves and the have-nots, between Blacks and the rest of society. This is the same trend in South Africa as it is in South-Central Los Angeles. For instance, only 40 percent of the general population make 68 percent of the total income in America. This is the widest income gap since 1947."

Jackson blasted the Reagan administration's budget cuts, saying health care reductions are directly responsible for the recent rise in infant mortality. "There is a closed-door policy in Washington today," he said. "Reagan and (South African Prime



Minister Pieter) Botha are spiritual twins," he continued. "Botha is the Fourth Reich."

Jackson then took aim at how talented, young Black student-athletes have, in general, been taken advantage of by the colleges which they attend.

"There is a new face on old forms of oppression," he inveighed. "Black students are used as the new gladiators. We have gone from cottonballs to basketballs."

The solution, according to Jackson? Monies raised as revenue from college games featuring gifted young Black studen athletes should be placed in a foundation for their education.

What can people do to fight the rising tide of oppression?

According to Jackson, it will be a battle, but well worth the cost. "We can surrender or we can coalesce and fight bac against injustice," he said. "Morale and morals drop when you surrender. We mut then, be sober, sane and sensitive. People in freedom lose their way, just like the children of Iscal lost their way after they had departed from Egypt. That's why Moses had to go to the Mount and receive a higher law, a moral law. And even if we are free, nobody has earned the right to do less than the best.

"A disciplined, informed, sober mind is the most powerful thing in the world," Jackson continued, calling drug and alcohol abuse and sexual promiscuity "moral wrongs" which are weakening today's youth.

"We must," Jackson concluded, "have integrity and resolve to build the family." Jackson's appearance was part of a

packors appearance was part of a speaker's program sponsored by the Department of Pan-African Studies, with the assistance of the Associated Students, the Center for Student Life, University-Student Union, Educational Opportunity Program and Black Leadership Conference. I absolutely loved Cal State, and the students loved me. It was in teaching my class on urban politics that my most successful community organizing began.

The city had found a solution to the problem of trash. The landfills were disappearing/used up. Santa Monica Bay was next, so the city contracted with Waste Management to build a solid waste incinerator (LANCER)¹⁶ in South Central LA.

Urban Restructuring and the Birth of MS

The struggle against LANCER had remarkable consequences precisely because of the way it was sold to the white Westside. We had to combine our discussion of environmental issues and redevelopment/restructuring issues. It was wonderful for me because now I had a real issue to tie theoretical discussions to. My radio work (I continued to volunteer at Pacifica) was perfect because I could focus on issues too cumbersome to explore in a meeting. The *LA Weekly* newspaper sponsored a daylong dialogue on community development at UCLA.¹⁷ Now faculty and students from across the city were brought into the struggle against LANCER. We defeated the project, but our organization was defeated internally.

In the middle of the battle, I went to Boston to attend a meeting designed to organize black academics nationally. I fell face down in Harvard Square. It was the summer of 1989. The only people who rushed to my assistance were two street kids who would have been asked "What are you doing in the Square?" They were very nice and very helpful, asking "Lady, are you all

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¹⁶ Cynthia Hamilton, "Concerned Citizens of South Central Los Angeles," in Unequal Protection Environmental Justice and Communities of Color (1994, Sierra Club, San Francisco).

right, you have to do be careful." I was so embarrassed. I hurried to make my Roxbury connection. When I got back to Sister Janie's house, she insisted that we go to Beth Israel Hospital after I told her what happened. We went to emergency, and they very quickly told me it was MS. They had not taken my blood pressure, temperature, nothing. I still had a bad case of 1960's conspiracy theory phobia, so all I wanted to do is get out of the hospital and back to LA. When I did get back, I went to a hospital in Long Beach. The doctor took one look at me and said, "Black people don't get MS." My conspiracy theory was the only thing I had to make sense of this. I had been at the center of the battle with the multinational corporation (Waste Management) over the waste incinerator, LANCER. If it went up, it would be the first solid waste incinerator to be built in a residential community. We had to stop it.

Thus began my personal relation with alternative medicine. First, acupuncture,¹⁸ then a chiropractor and homeopathy. I changed my diet. I hadn't smoked since I moved back to LA; the smog was too bad. There were several other problems that had to be explored, menopause being first. I tried everything including taking all the mercury from my mouth by having fillings removed.

All the alternative practitioners were wonderful. They were all traditionally trained but had come to alternatives looking for better health.

The battle lasted five years and ended with Major Tom Bradley speaking out against the incinerator. The project was over along with Major Bradley's political career. My career could

¹⁸ Joseph Aquah, Osher Center of Integrative Medicine, University of San Francisco. I have relied on Joseph since I went to him for headaches in 1984.

have ended too if I had not been protected by my angels. I ended my battle and my stay in LA on a panel with Condoleezza Rice discussing "The Environment and National Security." It was an effort to humiliate the Left—it failed.¹⁹

The Left in LA

I'm very proud of the little accomplishment we have done because it proves something different is possible. The black and white Left came together. That was facilitated by the concentration on development. Three tools were key for organizing—Pacifica Radio, the *LA Weekly* newspaper, and the Labor Community Strategy Center. All but the LCSC were destroyed internally (like concerned citizens). The *LA Weekly* was sold about six months after sponsoring the daylong session on community economic development that brought together black and white, activists and academics. Pacifica lost the director of the news department, and the other member of the news team went to Nicaragua. A Hispanic major was elected as LCSC turned its attention to organizing the Hispanic community. The LCSC is still around, still doing good work.

This is very significant because the gangs were out of control, along with the LAPD who conducted a roundup of anyone with a red or blue bandana, and they were booked in the Coliseum.²⁰ If that had happened in Central America there would have been major protests.

Many of us thought the gangs were being used to move older residents from established communities and drive property

¹⁹ Cynthia Hamilton, "Coping with Industrial Exploitation," Z Papers (January - March 1994). <u>http://www.cmhamilton.com</u>

²⁰ See Mike Davis, *City of Quartz, Vintage, 1990.*

values down, making it easier for developers to move it. That was on the Westside—on the Eastside streets were being sealed off making it impossible to get in or out except one way—that meant ambulances and fire trucks were blocked as well.

Schools were being closed for lack of attendance. At the same time houses were being threatened with demolition for school expansion.

If the Left had been able to organize, our futures would be very different. Instead we have lost a generation and our confidence.

Moving to Rhode Island

I had moved to Rhode Island with no intension of turning back. Everything that I loved didn't love me back—my political organizations, my city, my school, my employer, my new boyfriend. So here I was at the beginning where it all began.

I went to grad school in Boston, and now after fighting a major multinational corporation in LA, here I was starting over in RI. They had recruited me for the job and offered it very quickly. I asked if they were being sued (I had twenty years experience working at universities; my first job was in Boston in 1973).

As I prepared to leave LA, the movers were to come in the morning. It was 2:30 a.m., and everyone was inside, labeling boxes. I had gone on the porch to wrap some Makonde sculpture that has always been with me. I looked right and stepped left; I fell off the porch, down a flight of stairs . . .

I broke my tibia and my knee. I was lying on the ground hugging my leg. My mom was crying hysterically, and the paramedics wanted to straighten my leg. I refused; they assumed I was drunk. Then we had an argument about hospitals. They wanted to take me to M. L. King Hospital; again, I refused. There had been too many shoot-outs at the hospital. My mother suggested Southgate—a Catholic hospital. She got in the front seat of the ambulance; she knew the way.

Now, I must reschedule everything. Fortunately, I can still get to school before classes start. I'm starting on crutches with a cast up to my hip.

That's the beginning. Three months later my cast was off, and I was on my way to have my license switched from California to RI. I fell—nothing serious, I assumed; my wrist just hurts. So I got to the DMV and took the test. My wrist really hurts; I couldn't stand it. So I detoured to the orthopedist's office to have him take a look. He was really concerned. The wrist was broken. He sets it after I promise to see a neurologist. The next day, I saw the neurologist, and he didn't hesitate to make a prognosis. "I'm pretty sure it's MS." He scheduled the MRI.

And so the ordeal began. I continued to teach (fortunately, I had done it so long I could go on with my eyes closed). I had several additional accidents. I broke my left wrist after breaking the right one, broke a rib, broke a toe, and broke my front teeth. But I couldn't stop teaching; I didn't want to stop. It got harder, and I got more determined.

The hardest battles were ahead; the war continued. I never stopped driving. At the beginning of the semester, when I agreed to team teach introduction to Afro-American studies at Providence College, I had a car accident, not going to Providence, but going to my house from URI. It was a strange accident—no other cars or people involved. I hit a patch of salt in a curve and went over an embankment. I ripped out the bottom of my car, broke both ankles, my leg, and once again, my tibia and knee (same leg). This time, the leg and knee got put back together with metal pins. This time the doctor who performed the surgery came by to see me to advise that I leave my job, sell my house, and go on disability. My mother and father came in from LA and helped me say no.

I never complained about the accident (I never had any pain) because I thought it was a sign from God. I had purchased a ticket to go to Guatemala to see a "healer". My girlfriend's cousin from Belize who ran track in the Olympics said he and his friends saw this woman regularly for their legs and whatever she did worked. I was desperate; I'd try anything. But I knew it was wrong. So I prayed and asked God to make the decision for me. The next day, I had an accident. There was no blood, no broken glass. I knew this was his answer. I'd be able to turn in my ticket with no problem. Donald did it for me.



Mom

Mom took over the house, her forte; she didn't want help. Donald and Mark will give Mom the only she want.

Donald was my girlfriend's son. He moved to RI for a new job at an electronics company. He graduated from Morehouse in Atlanta. He needed a place to stay, and he moved in, but I told him early to keep looking. RI is not the place for a young black man. Mark will be like a brother/angel for me. I met him through the sisters across the street. They sent him to cut the hedges. I discovered Mark has all kinds of skills; he paints, does plumbing, lays flooring—anything you need done to a house, he can do. He and Donald were about the same age, and they became friends.

Initially, everything was fine. Mom was amazing. She did everything; she was my nurse, my therapist, my counselor. She cooked and enjoyed going to the market. She will even be my driver. I was not thinking; Mom was eighty years old when she came, and even though she and the sisters across the street were like girls in their twenties (going to church functions, talking, and laughing—this is OK), Mom and Dad have not been apart in fifty years.

Mom became the fourth sister; that's what Helen (Mrs. Keys's daughter) called her before she died of breast cancer. Helen and I were the same age. We both used holistic medicine. We were friends. Mom and I had moved to the perfect place. I had impressed Mrs. Keys when I spoke because I knew about the National Council of Negro Women (1918). Mrs. Keys had two sisters (they lived next door). They grew up in Newport, so they were one of the oldest families around. Mrs. Keys was considered Newport's black historian. I became friends with the other sisters' children. It was the neighborhood we hadn't had for twenty-five

years. I was able to give Mom two birthday parties, her eightieth and ninetieth.

Mom and Dad both came to South Kingstown when I initially moved to Rhode Island. They both hated the place. It was a house on a hill, far from the street with a golf course/ driving range at the end of the block. When I locked myself out, I remember ambling down the two levels of the driveway to the street to ask for help only to have men pass me by or stop and say they didn't have time. Finally, a woman picking up her children gave me a ride to school. The women who lived in South Kingstown were so alone and afraid. One came to the house begging me to have dinner. The time passed quickly then.

The first year, Mom had a bad experience with blood pressure medicine. Her doctor in LA had given her too large a dose. Her symptoms were very confusing. My brother thought it was a cold and kept giving her Alka-Seltzer Plus, and she kept getting weaker. He was returning to California in the morning, so we had to get to the hospital quickly. The diagnosis was prompt. They put her on potassium intravenously. Lumas left to catch his plane. Mom and I would leave the hospital later with instructions: "No more blood pressure pills."

I knew I must find another place to live. Mom was watching squirrels eat the seed in the bird feeder. I kept teaching, and I kept falling. I even went to Switzerland on crutches.

One Sunday after I returned, I was *awakened by* angels (there's a knock at my front door, but no one walks up that driveway) to the smell of diesel. There's smoke and fire in my basement, and Kingstown only had a volunteer fire department. They put the fire out; that's when I knew I must move. Finally, after two winters, the pipes on my second floor burst. No damage to my papers and books; I had moved everything to school.

Soon, we moved to the "house that God sent"; that's what the minister's wife called 100 Kay Street because it wasn't on any of the lists of properties she prepared to encourage me to move. The last thing I remember about the house in South Kingstown is a wasp walking across the empty floor. One chapter of the RI saga was over; chapter 2 started well. Mom loved the house. But I started with a broken rib—this wasn't going to be easy. I was on my way to an event at the multicultural center when it was located in one of the frat houses confiscated after a drug bust that got the fraternity ejected off campus. They wanted to give the house to AAF, but I reminded everyone that I was from LA where you learn never to pick up anything drug dealers leave behind.

Providence College was starting a black studies program, and I agreed to offer the first course jointly with a faculty member from the campus. And that February, I had *the* car accident returning to Newport to pick up Donald and Mark. They were to return to school with me to see a film we were showing for Black History Month. I hit a patch of sand in a curve, ripped out the bottom of my car, broke both ankles, and shattered my left knee. When I got to the emergency room, Mel (Representative Melvoid Benson) and several others were waiting (I had called Joan from the ambulance, and she gathered people). We called my mother, and the doctor operated the next day.



CHAPTER 1

Mom

The Oldest Takes the Lead in the Days Before Dementia

he was an absolutely beautiful woman, but I'm not sure she thought so because her mother and her cousin, who she grew up with, were especially beautiful. My grandmother, her mother, was adventurous, always willing to try something new—leaving the father of her child, living in the French Quarter, telling fortunes (after all New Orleans was Marie Laveau's²¹ town).

She boarded the seamen from the West Indies because they had no problems spending their money while in port; she had moonshine parties, fish fries, and I suppose there was the occasional white man. But I have a feeling Mom put an end to all this after her grandmother's death when she went to live with her mother, and she went to work. Then Grandmother/Mother

²¹ Marie Laveau (1794-1881) was a practitioner of voodoo renowned in New Orleans. She married a Haitian who immigrated after the revolution in 1804.

settled in with a skilled working man (that didn't last, but this is not Josephine's story). Even though Evelyn's grandmother, Mrs. Beana, objected to her daughter's fast life, it was Mrs. Beana's affairs with Mr. Frank that produced three lovely daughters but no support. There was little time for education with all this excitement, even though Josephine could read and write. For her daughter, the emphasis was employment, and soon it was clear that she'd have to leave New Orleans. Evelyn did leave. She checked out New York, Washington, DC, St. Louis, and LA. Mom went back to New Orleans after she traveled to LA to see if she could convince her mother to move with her, and behold, she ran into Lumas again after seventeen years. She met him first when she was fourteen. He was older, and he was nineteen. Now, things were different. He had been to war, so returning to the "Jim Crow" South wasn't an option. This time, they did what they couldn't do seventeen years earlier; they got married and left New Orleans.

It wasn't a happy or easy departure; they had a car accident on the way to California and had to travel the last leg separately. But once in LA, they did all the things they could only dream about in New Orleans. They got a house, and Lumas got a job at the post office (which had eluded him in New Orleans). Evelyn became the community activist she always wanted to be. She opened a day care center and was active in PTA and at church. She organized a Girl Scout troop and enrolled her daughter in ballet and piano classes and her son in saxophone class and the swim team—things they could only dream about in the South. And that was only the beginning. Later, her daughter would go to Stanford and her son to UCLA. What more could there be?

Cynthia went off to college shortly after the Civil Rights Act; black students were being recruited by white universities. She went to Stanford and became a political activist, which she would be for the rest of her life. Evelyn and Lumas never objected to their daughter's politics, but when M. L. King was assassinated, Cynthia was very depressed. She didn't leave school; she left the country. She went to East Africa, and another stage of her activism developed. Conditions in Africa sent Cynthia back to school where she met C. L. R. James, West Indian activist and scholar, who came to speak at Stanford. She decided to do more work studying this independent Marxist, and when the graduate program objected, she left to go to work for him independently. In Washington, DC, she met other activists of similar persuasion through C. L. R.

Everywhere Cynthia went, Evelyn was not far behind. She came to Stanford and then to Boston; she would visit New Mexico and later Rhode Island. Lumas and Evelyn helped Cynthia move into her first house in Kingstown. After the doctor diagnosed the MS, they came back. Her dad took her to Westerly for the MRI. He was devastated when the doctors said the MS was hereditary; he never got over that.

The first medicine Cynthia took for MS left her nearly unconscious, no speech or movement. When she tried to find out what happened, the pharmaceutical company refused to speak to her. The doctor said she must have done something wrong. She called her old acupuncturist in California and stopped taking Betaseron.

Evelyn came back when Cynthia started taking Copaxone (initially, they said she won the lottery). In the early days, we had to fill the syringes with medicine before administering the injection. Both Evelyn and Cynthia were nervous about giving the injection. They would alternate. Cynthia did the leg and the stomach; Evelyn did the arm and the hip.

The irony of the MS was that Cynthia and Evelyn got to know each other all over again. They had not lived together since Cynthia was seventeen graduating from high school. Evelyn would see what kind of teacher Cynthia was. The first ten years, Evelyn took care of Cynthia; the next ten would be Cynthia trying to care for Evelyn.

We would move from Kingstown to Newport. Cynthia had the car accident. Mom would do everything—drive, be my nurse, therapist, and housekeeper. Sister Mary Gabriel, an old friend that once lived with us and who is now a nun, got special permission from her Mother Superior so Mom could retire.

Dad

Dad retired a few years before I moved to Rhode Island. It was a real relief for him. Mom, on the other hand, saw work as fun. She hadn't worked outside the home until I went to college, so it was an outlet of sorts. She got a job as a teachers' aid the first year they used the position in California (1968), and she worked with kindergarten; she loved it. Even after thirty years later when she retired to take care of me, she still loved it. That's why I never was upset by the hallucinations; she was seeing children. But I think it was the loss of Dad and the children that pushed her over the edge.

Dad was very supportive of Mom leaving to be with me after the accident. He had been to Rhode Island and compared Kingstown and Newport, and after the accident, he would rotate the driving with Mom and staying at school with me. Dad was being treated for prostate cancer, so he'd only stay for short periods of time and return to LA.

In 2002, Mom and I went back to LA for the summer. We went to church the weekend before we were scheduled to leave, and as we were getting out of the car, Dad had a stroke. He helped me into the wheelchair, and he collapsed. All I remember was saying, "God, you can't have him yet," and when he died in Rhode Island in 2004, I reminded myself that he had given me two years.

Dad regained consciousness almost immediately after the stroke at church. They transferred him to Kaiser in West LA. Everything seemed to be going well so we went home to rest. The next day, we returned to find my father spread-eagled and tied to his bed. I was crazy with anger, and I confronted the nurses (all Pilipino), why had they done that to my dad, one of the kindest men I've ever known. They said, "It's because he pulls his catheter out." I couldn't believe it.

The next day, I called the hospital administrator and told him to transfer my father or prepare to go to court. The next day, they transferred him to a rehabilitation facility in Carson. I will never recover from seeing my father tied to the bed.

My father would return to Newport with Mom and me.



CHAPTER 2

Kristen and Her Sister

knew it was a fall. She didn't yell or cry. There was silence. My heart stopped. I didn't breathe. Then she cried, "God have mercy." Mom had fallen down the stairs to the basement. It was a Saturday evening; Mom had cooked chili. She had been carrying two plates, one for me and one for a "friend" (a hallucination).

I breathed again and grabbed the Healthwatch button, pressed madly, pushed the books out of the wheelchair, moved into it, and slowly made my way down the hall, yelling, "Mom, I'm coming." It was the scariest moment of my life. I reached the stairs. Mom was scooting down the next flight. The phone rings. We don't have cordless phones; I must go back down the hall. It's Mom's friend from across the street; she had a key, and Healthwatch had called her to get in. I told her Mom had fallen. She said, "We'll be right there." I went back down the hall; when I got there, Bessie and Sarah had arrived with the paramedics. They ripped open the legs of Mom's pants, no blood. They picked Mom up to carry her to the ambulance. They told me they can't take me. I asked Bessie to go with her, and I will go in the wheelchair. Sarah stayed with me. I got dressed, and we walked to the hospital.

It all happened so fast, but there was no injury—nothing broken, no scars, not even a bruise; God was with us. We stayed in the hospital a day. I had called Lumas; he's on his way.

Everyone's conclusion was that Mom and I cannot be alone. The social worker from the hospital said she'll find people. That's how Kirsten and her sister started working for me. Her sister had to stop when she adopted her great-nephew. Kristen was with me a long time, but we had to find someone who could cook.

Finding Someone Who Can Cook

Anna

I must admit that when it was finally time to find outside assistance for the house I was nervous. It was not just the cooking I was concerned about. I needed women who would be strong and unafraid.

The hardest days were behind me, I thought. Mom had disappeared and fallen down the stairs; all we had to do is keep her in the house. I still had MS, but I continued to believe in angels. But I needed someone to be "me" at my house when I wasn't there—Anna was the person.

Though she would say all the time, "If it hadn't been for MS, we would never have met"—that was supposed to be a slur, a comment about how we were from different worlds—but our differences were really a reflection of the different consequence of East Coast/West Coast racism. The East Coast had a large white working class, so there was no place for an accomplished black working class. All blacks had to be forced into an underclass; drugs and alcohol helped. Some women could escape with appearance and good choices. But the families of all the women who worked for me demonstrated the racism and its consequences. Only the sons who left the city have escaped prison.

The white working class must have room for upward mobility without competition (presently, that's not the case, and white women can be blamed for being childless or having children from black men).

Years ago (after WWII), the West Coast was different. Fewer blacks, a newer infrastructure, and cities that wanted to grow—these things made all the difference. But even though Anna and I were the same age, she made me revisit all of Mom's old stories.

Every story Anna told had an equivalent from Mom's (Evelyn's) batch from almost a century ago. From her brother, Alley Boy, who walked his way to Alaska, to her oldest sister whose white father denied her, to Anna's son who could have been my grandmother's brother except my grandmother's brother was shot by the police.

Anna did everything to keep her family together, from big Sunday dinners (hence, the cooking skill) to taking in her sister's children after she died and her husband went to jail. Anna had done everything except go to school. Although she is very smart, she would say she wasn't interested, but it was in her eyes. If someone had taken care of that when she was young. Of course, Mom's problem was her ears, but we could blame Jim Crow.

After Anna met some of my students (from LA and RI), she gave me the finest compliment ever when she said, "Maybe if I had had a teacher like you, things would have been different." She didn't mean it to be a compliment, necessarily. It's just the way working class people think: "The proof of the pudding is in the eating." But the other comment, "If it weren't for MS, we would never have met," was meant as a slur. Though it was not true. I went to the *Garden Party*, a play directed by Raffini in which Shane performed. I really wanted to bring the play to URI. It was a wonderful teaching tool. Set in a turn-of-the-century salon. It's like being part of the Harlem Renaissance. Shane was also a student at URI. It was Anna's cousin who was also a student there who told me about Anna.

Anna worked for me when I was still teaching, the years between Dad's death and my departure. She worked alone, and I was losing my strength. Anna lost a kidney during that period, and I had an accident on the ride van, which injured my back severely. I hadn't been able to transfer since then.

The routine got harder for Anna. She was working alone, doing everything. I was now going on disability and becoming a real pain as I prepared for "my death." That was the way I viewed Anna brought her niece whom she had raised after her sister's death. Other things were happening in Anna's life. Her youngest son had been arrested and was on his way to federal prison.

Dorothy was a wonderful addition; Mom loved her, and she had a two-year-old daughter whom she would bring with her.

Dorothy

We all laughed about Mom liking Dorothy the best because she was the youngest; the reality is that women with young children are perfect with dementia patients. They are kind and patient. They don't raise their voice, and they are gentle. We had quite a combination. Anna had all boys. Debbie had two and two, and Dorothy's oldest was a girl. Five years later, she had Aden. But her first child was born dead, and she almost died, bleeding to death. Racism is a terrible thing because it shapes ideas and behavior. For the first pregnancy, Dorothy went in the hospital with her sister; she was hemorrhaging. She was told to wait. When she collapsed, it was too late; the baby suffocated, and then the doctors had to work to save Dorothy.

It's amazing that Dorothy has remained so kind throughout her life but so too have her brothers and sister. She and her sister and her sister's children have lived together since they left Anna's house. They just moved apart this year after Dorothy's baby boy was born. I still couldn't get over how she gushes over the baby. She said, "Sometimes I can't believe he's really mine."

And then there's Mom and the baby. When Anna brought the baby over (Mom was now ninety-six), the blisters were all dry, and Mom had no pain. Mom held the baby and didn't want to give him up. Mom ran a day care center out of our home for about five years before she organized a Girl Scout troop. I still can't get over the similarities. Dorothy had her daughter's fiveyear-old birthday party at a hotel with a pool so the kids could swim. Her daughter was a real helper who wants to be a doctor. When she's old enough to understand what happened to her first brother, she'll really want to be a doctor.

All the women who work here have children, but they're all grown except for Dorothy's two. They all have grandchildren. Anna wants to open a day care center; she already takes care of two. I can't sing the praises of these women enough.



CHAPTER 3

The Men of Kay Street

Lumas

y brother walked into my father's shoes with ease. When my dad had a mild stroke days before Mom and I were scheduled to leave LA and return to RI, Lumas²² was on a shot in Mexico. We had left a message on his phone. He called back, and Mom was in tears; the next day, he was home.

Dad was taking Mom and me to church. We pulled into the driveway between the pastor's house and the church. Dad helped me into the wheelchair, pushed it around the car, and collapsed. The deacons and the minister were all right there. They caught him, put someone's coat under his head, and called 9-1-1. I immediately said, "You can't have him yet." It just came out of my mouth. No one was with me, but God heard me. By the time I got to the hospital, Daddy was recognizing people and using names. Now, we had to change hospitals. We were in downtown LA; they'd have to transfer Dad to Kaiser in West LA.

²² Lumas is a makeup artist in Hollywood.

Even with all the moving around, Dad was fine. We didn't mind leaving him to go home. But when we got to the hospital, my father was spread-eagled and tied to the bedposts. I thought I would die. The nurses kept saying, "He pulls the catheter out." I couldn't believe it.

I called the hospital advocate and told him if his nurses couldn't handle my father without a catheter, transfer him out of the hospital, or prepare for a lawsuit. The next day, they transferred my father to a nursing home. But we still weren't satisfied. Dad would come back to RI with Mom and me and be fine and happy for over a year.

Lumas came to see us every Christmas, and he would cook and take inventory to see what we needed. Every Thanksgiving, he'd send a turkey. He could only come to see us once a year because he worked as a makeup artist, and Hollywood has its own rules—it comes first, and those who fail to understand pay dearly. Lumas did not work for two years after leaving Mexico when my dad had the stroke. There was a time when Hollywood's rules were being considered for all workers.

Mark

Mark was my Newport brother (I'd call him my angel privately). I met him through the sisters across the street who sent him to cut my hedges. But he has been there for me ever since. It's really difficult for me to explain why Mark is so important to me, but I think it's the fear that comes with disability. I've lived alone since 1970 and never discussed fear with anyone. Even in Kingstown, which was scary, I hadn't felt fear, but now the disability was real, and yes, I was afraid, not all the time, but it was good to know I had a number I could always call. Poor Mark probably thought it was about the tasks of housekeeping. It was interesting when I brought Mark to school with me, there were the disapproving voices. But it was Mark who helped me put up the Makonde sculpture exhibit in the library at school—the exhibit that the disapproving voices failed to come and see. Mark was the person who spoke to the therapists after the car accident.

I could never have managed the house or anything else without Mark. Whatever I was considering—whether it was a special exhibit of the Makonde sculpture at the library at URI or painting my house—Mark was there for me. He had been there from the beginning. I hope he feels the same about me. After all, I stayed on him about getting a job outside of Newport; I believe he could. But then he wanted me to get rid of my South Providence crowd. Oh well . . .

Apollo

My first exercise coach was a chance development. Apollo was the son of one of my health aides. He had a twin sister whose name was Venus. One day, when he was still in high school, he visited with his mother. He looked in the room we call the exercise room—I had accumulated several pieces of exercise equipment that my mom and I tried to use. I had a treadmill, an exercise bike, a trimmer, a Pilates bench, an air catcher, and small cycles. Apollo was impressed. He was a fitness fanatic and had several of his friends in training. So of course, he wanted to know if I was using the equipment. I told him I didn't have a spotter, and he offered to work with me. And he did, for several years after he graduated from high school. The results were so impressive that my brother joined a gym in LA—he stopped; I didn't.

Now that I was on disability, I had nothing but time. I worked out three days a week. I tried to get Apollo to go to junior college to train as a physical therapist assistant. He would have been wonderful; he is so patient and so strong. MS is so stubborn. You can never tell if you're doing the right thing and/or if it matters. You just have to keep working and believing.

That's a perfect place to introduce my new exercise coach.

Shane

Shane is Dorothy's youngest brother. He was eight when he lost his mom to death and his father to the criminal justice system. Anna stepped up to care for him and his sisters. Shane is very talented. He has a beautiful voice, so it's not surprising that he was drawn to entertainment early. He was very popular, so it's not surprising that he had three children before he went to school at URI. That's a lot of pressure for a young man alone in the world. But God works in mysterious ways. Shane dropped out of school but found religion and the old civil rights movement. He has reclaimed his children. He has enrolled in online theology training, and God has sent him to me. I don't know if it's for him or me, but I know Shane takes evangelism very seriously, and I know my organizing wasn't finished. I guess we'll see.



CHAPTER 4

Another Autoimmune Disease²³

n the day before Mom's ninety-fifth birthday, her feet were very swollen. Because we had plans for the following day, I thought we better go to emergency and make sure everything was OK. So Debbie and I and her grandchildren with Mom in one of my wheelchairs started the march to the hospital. Mom thought there was something wrong with me. When we got to the hospital, the nurse who checked Mom in was funny. Mom's blood pressure was so high that she said there must be something wrong with her instruments. They rushed us to an exam room-Mom still thought it was about me. We took her clothes off, and the doctor joined us and sent Mom for a cardiogram; he thought it was a clot. The technician confirmed and said the doctor will explain. We're admitted to the hospital. I stayed with Mom. Debbie and the girls left; Anna will be in the next day. Mom is given a blood thinner and put on an IV. Mom responded right away. We stayed in the hospital two days and came home to the hardest assignment ever-we had to give Mom a shot in her stomach every night (Lovenox, a blood thinner). Even though it was working, it was like killing Mom

²³ MS is an autoimmune disease.

slowly. After three months, I begged the doctor to take her off the injection. I had read somewhere that we could try it. He did.

My insurance sent a nurse to do a home visit. She remembered me from years earlier. After the car accident, she was still in school. My MS was fine, but she suggested that I put Mom on hospice care so she could see a nurse regularly. The hospice team was very nice—the nurses, CNAs, social worker, and the doctor. We really didn't think about the care that women provide.

Mom stopped talking shortly before we started hospice. Though Mom was still cognizant, she explained to me, "I can't really say what I mean." And I used to think MS was the worst disease anyone could have; now I knew different.

I never considered letting any of my health aides go-Team Kay Street-so we all worked together. There was activity that started at 9:00 a.m. every morning, but after about six months, Mom began to develop blisters between her legs and she stopped walking. Mom was a good sport—no crying. We all had a theory about what was wrong, but nothing worked-new diapers, patches, ointments. So when Anna said it's just like Job in the Bible, I immediately called the ministers. But then Mom started to bleed, and I was desperate. I went to my general practitioner who was familiar with autoimmune disease. She said, "It sounds like bullous pemphigoid, take her to a dermatologist."24 I went the next day. She was correct. Our months of searching were over. Now we had to heal. The treatment for this autoimmune skin disease was steroids. I wasn't thrilled; my godmother took prednisone, and there were lots of side effects. My acupuncturist was my next call. We had to find an herb to protect her kidneys. Meanwhile, the blisters continued; Mom's fingers and arms swelled. Team Kay Street began to panic and doubt itself. Anna

²⁴ Thank you Dr. Boyle (Middletown, Rhode Island)

said she couldn't do it anymore and maybe Mom needed to be in the hospital or a nursing home. We parted ways after almost ten years. Mom wasn't going anywhere. Kirsten was having a slow relapse, and this time I couldn't take any chances. Team Kay Street was down to two.

Then there was Apollo's disappearance. It could have been the National Guard, his new girlfriend, or his family. But I needed the exercise. Team Kay Street down to three.

Shane (Dorothy's brother) joined us, initially because he needed a job (he wasn't sure he could do it), then I think he began to like it. Shane was a new Christian evangelist. He is absolutely committed to the philosophy of nonviolence. And I think he'd like to be part of my recovery.

Elaine and Silvia

Elaine joined Team Kay Street to help Dorothy. She was Dorothy's daughter's grandmother. It was absolutely amazing to look at the countless number of ways black women have mothered black children. In this house, there are three grandmothers who have cared for grandchildren and still are. I was happy to welcome another grandmother and grandchildren. In another life, Mom would have loved it. In another time, the children would have been kinder. I had to explain dementia-the disease-which made me confront it rather than hide from it or deny it. I am still angry that my own disability was part of Mom's problem. If I hadn't lost my voice, I would have been able to sing-nursery rhymes would have been fun and reminded Mom of her days working with kindergarten. We may have been able to keep Mom talking longer. If it weren't for the tremors, we would have been able to play hand games. If I had been able to walk, we could have walked together. We could have gone grocery shopping.

But we did have good times together before 2013 when Mom lost her ability to speak. Mom is a very social person, so the loss of speech was major. Mom understood that something was wrong when she said to me, "I can't say what I mean so you can understand me." We never stopped talking to Mom or playing music. Elaine would even dance, and Mom would smile.

I owe many thanks to Silvia (who was the only trained CAN) and Elaine; they brought Mom through the hard moments. Elaine and her granddaughters pushed the wheelchair to the hospital when Mom had the clot. The sisters were with me in the many visits to the dermatologist. The period that was the worst, no one knew what "it" was; the nurses would place bandages and pull skin off accidentally. Mom was bleeding, but her hands begin to swell. She got tears in her eyes—she was afraid.

This was a difficult time for the group; doubt replaced the confidence of the grandmothers. Anna was the first to say "We can't do this. Mom needs to be in the hospital." The nurse said, "They won't admit her with this. She'll have to go to a nursing home." The divisions began. I had never questioned the team's ability, but training was winning the day. I knew there had to be an explanation for Mom's condition. Silvia said we can do it. I made an appointment to go to the hospital's womb center, but simultaneously, I had to see my general practitioner,²⁵ who had knowledge of autoimmune diseases. When I cried to her, she said, "See a dermatologist and tell him to check bullous pemphigoid."26 We were on our way back, sort of. Mom did have this autoimmune skin disease, but the treatment was steroidsspecifically, prednisone. I called my acupuncturist in California. He told me to get an herb, Astra Essence, and take that along with the steroid to protect her immune system. We use that today.

²⁵ Dr. Michelle Boyle, Middletown

²⁶ Ibid.

Hospice Care

A nurse who came to check on me referred me to hospice for Mom; it was after the blood clot and shortly after Silvia started working. The nurse assured me that it was only to make sure Mom saw a nurse on a regular basis. It would be better than seeing the doctor. We were referred to Visiting Nurses Services of Newport and Bristol Counties. They have been absolutely wonderful. Nurses and CNAs come several times a week. The women are so kind and considerate, jobs only women could do. It's a service paid for by Medicare, and it's wonderful particularly for people, the elderly, who are alone. There are people who want to stay in their home but need some assistance. Nursing homes require that you sign your home over to them; your social security goes to them.

There had been several negative reports on nursing homes. The cost is very high, and workers are denied basic benefits.²⁷ Like pharmaceutical companies, nursing homes are more concerned with investors than patients or workers.

Visiting Nurses is wonderful, but I think it's very hard on the workers. The women travel to different locations daily. The houses are all different, and the patients are all different. The nurses and CANs do an incredible job. But we don't reward or promote these jobs. The society could, but we must deemphasize doctors, hospitals, and nursing homes.

²⁷ Joe Sexton, Workers Win \$2 Million Settlement from Assisted Living Giant, http://www.nationofchange.org/39929.



CHAPTER 5

Alternatives

Medicine

lzheimer's/dementia has been compared to a tsunami that will hit the United States in less than a decade affecting one in three families. But there are ways to prepare. Baby boomers are now caring for their parents, but the disease promises to hit them harder. The alternatives that I will outline for medical care and housing are just the start.

The assumption is that we must choose one form of medicine or another-either Western medicine or "alternatives" (acupuncture, herbs, homeopathy, and chiropractics). Rarely do we think a collaboration might be the best solution. The Journal of the American Medical Association in a recent article suggests that we use the term "complementary" rather than alternative.²⁸ There is at least one medical school that's trying.²⁹ But I think Americans must think more seriously about health care, which

²⁸ JAMA, "Perspectives on Complementary and Alternative Medicine Research" 310, no. 7 (August 21, 2013).

²⁹ Oster Center, UCSF.

is very difficult because we're looking through a cover created by insurance companies and pharmaceutical industries.

Collaboration can look like this: my mother's autoimmune skin disease had to be treated with steroids. My acupuncturist (who knew my mother is ninety-six) told us about an herb to protect her kidneys while we experimented to find the right dose of steroids. One of the hospice nurses was excited to tell other patients on steroids—anything to protect the kidneys.

I have lived with MS since 1993, and I found a doctor who respects the fight. So when I asked him if I could try a pharmaceutical drug (Ampyra) for walking (I'm in a wheelchair), he said yes. The drug has been wonderful for my cognitive state. This is a Western drug, but we found it is good for something it does not advertise.

This doctor did not require that I give up my alternatives/ complementary practices to see him.³⁰ So I have been able to find a solution to my speech problem (oral chelation). He never required that I give up herbs that worked for other things (Jade helps to maintain my sight; Citricidal helps my immune system).

All this requires work on the part of the patient, but that's what makes it an alternative. I would not be so well informed if I had not started looking for alternatives when I was politically active.

Home Care

Generally, home care is too expensive for the ordinary pocketbook. We are directed to agencies or "experts" or directed

³⁰ I can't thank Dr. Martin, the nurses, and therapists at the MS center at Sturdy Memorial Hospital enough for their openness to alternatives.

to nursing homes. I'd like to suggest that we use very different measurements for evaluating expertise, one which will allow us to consider new people for the jobs.

There were five women who worked at 100 Kay Street. Two were sisters, an aunt and her niece. All had children and grandchildren. One was a CNA who had worked at the hospital and several nursing homes, but she had lost her license; one of the sisters had not renewed her CNA license. To lose your license meant only that you hadn't renewed it.

All these women, I hired independently. I didn't hire them all at the same time. Their needs and our needs (my mom's and mine) were both considered. Each brought something special to the job. It was easy to rotate schedules if some needed time or a fill-in for a day or longer. The house really became everyone's house; Mom was everyone's Mom.

When Mom's dementia got more serious, the youngest and the trained CNAs were the best.

Because the issues of seniors, health care, dementia, and Alzheimer's are very popular topics. MS has been good for one thing; it has allowed Mom and I to spend our last days together, each of us keeping the other out of a nursing home. Mom came to tolerate holistic practices, and I learned a lot about dementia. If it weren't for some of my MS infirmities, I think I could have been more helpful with Mom's disease. I know she and Dad were both devastated by the loss of my ability to walk and my ability to talk, so if I had been able to do either, it would have been helpful—to be able to sing with her would have been fun and helpful. I thought children were the answer, but children were not what they used to be. That's when I began to think about housing alternatives. The bungalow alternative allows for all the necessary alternatives to coexist, and it helps to solve a pressing economic issue—jobs and housing.

Housing

It Takes a Village

If we are truly going to talk about solutions to the housing crisis (homelessness and foreclosures), it will be necessary to begin with a critique of what we currently have—single family, privately owned, detached housing. I'd like to propose a return to bungalow courts of the early twentieth century. They were a response to the need for housing for the working poor who could have the amenities of home without the cost and maintenance that came with a single-family residence on its own lot. The bungalow was normally a one-story home that lead to a common garden. The courts could include a common laundry and/or clubhouse and were the makings of its own community.

The court . . . was both an expedient way to minimize the value of city land, and an attempt to entice urban residents with a sense of community all too often lacking in fast growing cities of the early twentieth century. Even a narrow fifty-foot lot could be made to accommodate two rows of small cottages, facing inward on a lawn or driveway. In this way, a builder might fit four or more small units in a space, which otherwise would be occupied by one, slightly larger house. On higher-priced city land, such crowding might be the only way for a developer to guarantee a return on his investment. Bungalow courts offered a cheap alternative to the anonymity of apartment living; they represented the opportunity for a patch of lawn and a shelter from the street, all at a cost well below that required for a full home.³¹

Historically, courts were identified as a solution for some social issues. For example, in 1913, *Ladies Home Journal* identified courts as a solution for single women needing "safe, reliable housing."

Bungalow courts have been proposed as low-income housing . . . for GIs and for GIs' homeless families . . . In addition, bungalow courts function as microcommunities for groups such as elderly women and the ion, bungalow courts function as micro-communities for groups such as elderly women and the disabled, and as housing for workers of all income brackets.³²

This is a perfect arrangement for mothers with young children, for assisted living, for seniors, for the handicapped, or for those who just like to think outside.

What's truly different about this housing is that it may also be a place to work.

There are two theoretical issues that we must critique before we can begin the discussion of alternative housing. We must go back and identify how we function; most would quickly identify the individual as the basic unit. But in spite of the theoretical emphasis on the individual, we function as units or groups in society. Race, gender, and class are meaningful conceptions in law and policy. Similarly, the city, the neighborhood, the community, the town, even the apartment building, gives meaning to the

³¹ Karana Hattersley-Drayton, "Historic Architecture Survey Report for the Bungalow Court Project, Fresno, California", page 15 <u>www.fresno/gov/dept</u>

³² op. cit., page 20.

individual, to who we are. But despite this, capitalism views the individual as primary.

The second theoretical issue that we must confront is the idea of exchange value. Exchange value is primary in any discussion because it refers to the money associated with the item in a capitalist system, and thereby determining value. The housing crisis in the United States demonstrated the real difference between use value and exchange value and what parties were associated with either.

The housing crisis demonstrated dramatically how mortgages/ exchange value had outdistanced the individual's ability to pay and had nothing to do with the value of these houses to the people who lived in them. Sharing cost is something that the cohousing movement has pioneered, but we must go one step further. For a real discussion of alternative housing to begin, we must recognize the changing structure of families and work that may leave children alone and adults overwhelmed.

The single-family house in the suburbs was a post-WWII craze. Its popularity was assured by the GI Bill, which made government assistance/loans available for vets and made home purchases possible for returning vets. The suburbs were supposed to be a step up from the noisy, polluted, industrial city of work. Shopping malls would follow buyers to the suburbs, and highway construction connected everything but women who were more isolated than ever in their detached, kitchen-centered, single-family houses. Gender had become the dominant means for defining roles and work in the home.

Today the family is significantly different. Not only are there more female-headed households, but most women work. It is necessary to look closely at all the tasks and roles that a family needs to be functional. In our alternative housing, many of these tasks can be performed by nonfamily members in exchange for housing or for cost.

I think Anna may have had something similar in mind when she moved to the cul-de-sac with Shana and Dorothy (her nieces she raised after her sister, their mother, died) and their children. They can make use of their large family. They have created alternative housing out of necessity. In courts, everyone lives separately, but sharing is built into the formula. At Anna's, the one car is passed around. My idea was that someone could create a job by driving those without a car of their own. Anna cooks on all special occasions—in the courts model, there is a common cooking and eating area, and a job could be created for the cook (though everyone has to clean).









Conclusion

I end this exposé as I began with concern for community that made us whole and we could always depend on. The idea is not new; there have been many times in the past when community was seen as a solution to problems. Today, we have a variety of problems that may be a result of the collapse of community. The world is getting smaller, and we are moving farther apart. There will always be those who have and do fine alone. I'm not talking to them. It's the rest of us. We vary in age, race, abilities, and needs. We must learn to come together again, using and depending on each other mutually.



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ABOUT THE AUTHOR

ynthia Hamilton, Ph. D. is retired Professor Emeritus, University of Rhode Island where she was chair of African and African American Studies. She fancies herself a scholar/activist even though she has had multiple sclerosis for twenty years. She has had her Ph. D. for thirty years and has taught at several universities from California to Massachusetts. She studied and worked with C.L.R. James in the 1970's, was a community organizer in the 1980's, diagnosed with MS in the 1990's. Her mother moved from California to Rhode Island to give her the last active years of her academic life. Her mother now has dementia and does not walk. They live together in Newport, Rhode Island, still working for change in their personal lives and the lives of others.