



“You need to Press On”

Lillie Johnson as a Pragmatic Public Intellectual

KAREN FLYNN

INTRODUCTION

caribbean women in canada have a history of challenging gender, racial, sexual, and other forms of oppression.¹ The occlusion of Black women from a range of institutional sites where power is located and knowledge is produced and validated is hardly surprising given the general omission, or “absented presence”² of the Black³ experience from Canada’s historical and mainstream narrative. Consequently, Caribbean women have had to carve out other spaces in civil society such as churches and community organizations to creatively respond to discrimination and exclusion from the larger Canadian society. Together with their Black Canadian sisters, Caribbean women have participated in, and established organizations that included, but were not limited to, the West Indian Federation (WIF), Universal Negro Improvement Association (UNIA), Canadian Negro Women’s Association (CANEWA), and the Congress of Black women of Canada (CBWC).⁴ Indeed, the lack of economic, social, and political currency coupled with gender discrimination has not deterred Caribbean women from individually and collectively engaging in a range of activities specific to their communities, activities that are integrally connected to Canada’s nation-building project.

As critical participants in public sphere politics, Caribbean women continue to recognize the significance of a social uplift mission and its relevance to the broader Black Canadian community. The activism of Jamaican-born Lillie Johnson, founder of the Sickle Cell Association of Ontario (SCAO), is exemplary. For more than three decades, Johnson has provided counseling

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and support to individuals with sickle cell disease (SCD) and their families. She has engaged in advocacy efforts with the Ontario government, health administration officials, medical personnel, and educational institutions.

Using the life history approach,⁵ primary sources, and heeding the directives of scholars such as Joy James, Erica Lawson, and Edward Said in particular, I maintain that if we reconfigure and expand the definition of the public intellectual to include ordinary people, then Johnson’s untiring and endless intervention and advocacy efforts with the SCAO mark her as a public intellectual. While I utilize Said’s criteria of the intellectual throughout this paper, I am mindful of the examples of intellectuals he references, which suggests that a ninety-two-year-old Jamaican Canadian might not be whom he had in mind. Taking this into consideration, coupled with the various modes of Johnson’s activism, I surmise that she is a pragmatic public intellectual based on her uncanny ability to engage with a broad constituency while demonstrating an investment in the disenfranchised. Johnson does not work in isolation, but is a visible, action-oriented individual diligently striving to advance a social justice mandate while remaining true to certain principles. I insist, however, that appreciating Johnson’s role as a pragmatic public intellectual requires paying attention to her middle-class Jamaican upbringing, training as a teacher, migrant nurse, and midwife, and the concomitant experiences that inform and shape her outlook. The aforementioned dynamics have positioned Johnson uniquely to articulate and create awareness around SCD mostly within Black communities and in Ontario, despite her age, gender, and race.

DEFINING THE PUBLIC INTELLECTUAL?

Do public intellectuals exist presently, or are they relics of another time?⁶ An equally significant question, for the purposes of this paper, is what roles do public intellectuals who are nonacademics play in our society? Trying to delineate who constitutes an intellectual—whether public, traditional, popular, organic, or otherwise—remains a contested endeavor for several reasons. First, the problem rests with the definition of the term *intellectual*; whether influenced by Antonio Gramsci or Karl Marx, Edward Said maintains that an intellectual is perceived as someone who ought to be listened to, or is the leader of a faction.⁷ They are bequeathed, Said notes, “with a faculty for representing, embodying, articulating a message, a view, an attitude, philosophy or opinion to, as well as for, a public.”⁸ But, even as scholars such as bell hooks and Cornell West acknowledge that public intellectuals can be nonacademics, the tendency is to focus on academics or politically conscious celebrities.⁹ It appears that not only are academics the ones who are most likely to be considered public intellectuals, they also remain the group largely responsible for determining the criteria. And, similar to public intellectuals such as West and hooks, the

1 cadre of people usually touted as intellectuals, broadly conceived, whether
 2 preachers, musicians, or artists are usually in the public domain and have
 3 access to institutional sites or other cultural apparatuses where knowledge is
 4 disseminated and legitimized.

5 In many ways, public intellectuals tend to reinforce the racial, gendered, and
 6 classed hierarchy of Western society as reflected in the *Prospect Magazine* (UK)
 7 and *Foreign Policy's* (US) top one hundred most important public intellectuals
 8 who are currently alive and active in public life.¹⁰ White men, mostly from
 9 the Global North, dominated the list, and, unsurprisingly, women of African
 10 descent were excluded. The list did include Kenya-born Florence Wambugu,
 11 a plant pathologist. Yet, there are nameless men and women across Africa
 12 and the diaspora who are indispensable to the struggle for social transforma-
 13 tion, but whose contributions remain in obscurity. A relevant example is the
 14 Jamaica Seven, a group of domestic workers who faced deportation for alleg-
 15 edly lying about their dependent children in order to work in Canada. In her
 16 analyses of these women, Erica Lawson notes that they “position themselves as
 17 public intellectuals using an experiential standpoint to critique social relations
 18 embedded in power differences.”¹¹ The act of publicly fighting to challenge
 19 unfair immigration policies culminating in some changes to the status of
 20 temporary workers is Lawson’s rationale for designating the Jamaica Seven as
 21 public intellectuals.

22 Lewis Gordon’s distinction between public and popular intellectuals is also
 23 worth taking into account when exploring Johnson’s ascendance in the public
 24 eye. He posits that popular intellectuals are often renowned and admired,
 25 “while the public intellectual is only public as a result of their mandate which
 26 addresses issues that have an impact on the communities in which they live and
 27 conditions these intellectuals’ roles in such communities.”¹² Gordon’s definition
 28 of the public intellectual is certainly applicable to Johnson. Similar to the
 29 Jamaica Seven, Johnson’s advocacy and ongoing efforts on behalf of vulnerable
 30 sickle cell patients can be read as a critique of larger societal inequalities in
 31 Canadian society. In prioritizing and privileging the voices of those considered
 32 “the least of these,”¹³ Johnson offers a template to humanize and democratize
 33 Canada’s health care system, a template intricately connected to how and where
 34 she was raised.

36 GROWING UP IN JAMAICA

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 38 Johnson’s biography, as it relates to her socialization in Jamaica, provides a
 39 lens through which to understand not only the career she would ultimately
 40 choose, but also the principles and values that led her to speak with, and on
 41 behalf of, sickle cell/anemia patients and their families. Johnson was born in
 42 1922 in Guys Hill in the parish of St. Ann into a deeply religious, middle-class

family; born after three boys, she was the first girl of nine children. In addition to weekly church attendance and participating in its concomitant rituals, Johnson’s father coordinated church socials and other activities; he was also a catechist, officiating wedding ceremonies. Referring to her father, Johnson pointed out, “He was very busy and community-minded. He was committed to students and their parents.”¹⁴ Johnson’s mother and siblings were also active in the church. As a young woman, Johnson directed the choir and planned concerts for special occasions, and on Sundays she and her mother alternated playing the organ. The church foregrounded two overlapping principles that Johnson’s parents modeled for their children. The biblical admonitions were to “love thy neighbor as thyself”¹⁵ and, unlike Cain in relation to his brother Abel, accept being each other’s keeper.¹⁶ These dictums of extending love and caring for others regardless of reciprocity coupled with a commitment to community would serve as a roadmap throughout Johnson’s life. In practice, these values translated into an emphasis on the collective versus the individual desperately needed in colonial Jamaica where colorism and class privileges were imbricated in all aspects of social and institutional life.

Despite their own minimal education and the difficulty of accessing quality education for the majority of the island’s inhabitants, Johnson’s parents emphasized the importance of a good education to their children. A generation removed from slavery, Johnson’s parents gained social mobility “through teaching in elementary schools,”¹⁷ and thus their children, according to Bridget Brereton, “if they entered certain secondary [high] schools...might be able to enter middle-class occupations that brought with them a rise in social status.”¹⁸ Johnson and her siblings fell into this category, as they were formally educated in some of Jamaica’s exclusive high and secondary schools. As a young girl, Johnson attended the prestigious Wolmers Girls School, which, as historian Ula Y. Taylor underscored in her discussion of Wolmers alumna Amy Garvey, represented the “essence of elite education.”¹⁹ Notwithstanding Wolmers’s status, Johnson, who is dark-skinned, spoke candidly about the colorism displayed toward students of darker hues: “Some were nice and others were not. Some teachers were very prejudiced. In Jamaica at the time, the majority of teachers were white, and some were brown-skinned and there was a lot of favoritism.” Johnson insisted, however, that her goal was “to get that certificate,”²⁰ constructing her young self as independent, determined, and courageous, which was further reflected in her decision to migrate and pursue training as a nurse.

MIGRATION, TRAINING, AND WORKING IN THE UNITED KINGDOM

While patriarchal ideologies and the socialization of girls and women as nurturers were mediating factors in how choices were made about careers,

1 Johnson insisted that she had always wanted to be a nurse. Her father, however,
 2 objected, emphasizing, “Nurses have too much of a hard time.” He sent Johnson
 3 to teachers college instead. Upon graduation, Johnson taught for seven years,
 4 and while she admitted, “I was very good at what I did,”²¹ she still yearned to
 5 be a nurse. At the age of twenty-six, immediately following her mother’s death,
 6 Johnson applied to a hospital in Scotland; and in 1950, much to her father’s
 7 disappointment, she left her family and friends to fulfill her dream of becoming
 8 a nurse. Johnson is unique in that although the majority of Caribbean people
 9 migrated to England following World War II, she chose Scotland. Having
 10 made a promise to herself, Johnson refused to renege on that promise, pointing
 11 out that “if I want to go to the end of the world and nobody’s going with me,
 12 I’m still going.” She further added: “It’s not that I don’t need companion-
 13 ship—it is that I have one life to live and I’m going to get on with it.”²² This
 14 attitude would serve Johnson well.

15 The migration of Caribbean people to the United Kingdom (UK), espe-
 16 cially Britain, following World War II, was met with mixed reactions and,
 17 in some cases, downright hostility. Caribbean migrants quickly learned
 18 that their status as British subjects rarely translated into equal access and
 19 opportunities. While there is ample research on Caribbean migrants in
 20 England, less has been written about Scotland.²³ Johnson’s recollection,
 21 however, suggests that racism and discrimination was hardly a phenom-
 22 enon particular to the British. In addition to dealing with the transition
 23 associated with migration, during and after her midwifery/nurse training
 24 in Scotland and later England, Johnson experienced the insidious effects of
 25 gendered racism. Johnson tells the story of how during midwifery training
 26 she was not assigned any duties each night, but that “the night duty charge
 27 nurse would tell me off proper that I wasn’t doing anything.” Eventually,
 28 Johnson’s colleagues discovered that she was being chastised by the night
 29 duty nurse and reported her to the matron. She opted to return to Jamaica,
 30 but was encouraged to stay and complete her training. There were times
 31 when Johnson’s expertise as a nurse-midwife was questioned by residents and
 32 physicians. And, on occasion, patients, based on her skin color, would request
 33 “another midwife.” Despite these impediments, upon her graduation the
 34 Oxfordshire County Council hired Johnson as the first Black domiciliary,
 35 a nurse-midwife who visited patients at home. Johnson proclaimed, “I did
 36 such an excellent job. I loved it!”²⁴ She had not only entered an arena that
 37 had traditionally been the purview of white women, but as a nurse-midwife
 38 with her own district, she trained resident doctors who were mostly male.
 39 Even as Johnson worked with physicians, pupil midwives, nurses, and other
 40 health care practitioners, her attention was often directed toward the most
 41 vulnerable, the newborns and their mothers. After spending eight years in
 42 the UK, Johnson worked as a staff nurse both at the University College of

the West Indies (UCWI) in Jamaica and Beth Hospital (New Jersey) before migrating to Canada in 1960, where she hoped to continue to her career as a nurse-midwife.

MAKING CANADA HOME

Upon their arrival in Canada, British-trained Caribbean migrant nurses (including midwives) were shocked to learn that the bodies responsible for nursing in Canada had difficulties adjudicating their foreign credentials. In order to obtain Registered Nurse status in Canada, the nurses had to upgrade because the “British system” (on which Caribbean nursing education and licensing was based) defined obstetrical and pediatric training as separate qualifications not included in the regular RN stream. Thus, they lacked the crucial component necessary for Canadian licensure. Equally significant, in Johnson’s case in particular, was the prohibition against midwifery practice.²⁵ Difficulties with the accreditation process and disappointment with the physician/nurse hierarchy in hospitals led Johnson to enroll in the University of Toronto in 1964, where she obtained a Diploma in Public Health Nursing. As opposed to being confined to the hospital, Johnson preferred to work in the community, “working with new mothers [families] and young children,”²⁶ where due to more flexibility and autonomy she could make a difference. It was during this period (the 1960s and 1970s) that Johnson visited many patients with SCD, a life-threatening condition characterized by severe, unpredictable painful episodes and complications that can limit daily activities and cause disability.²⁷

Unfortunately, knowledge about sickle cell and its genetic and hereditary configuration was largely unknown, a reality that, Johnson recognized, had profound implications, including the threat of death.²⁸ In an interview with Canadian Television (CTV), Johnson explained how, during the 1970s, “[t]he doctors did not know these infants were being born with sickle cell...they were not testing if the gene was there...these children got very, very sick and we lost a lot of babies.”²⁹ It was these factors in conjunction with her encounters with sickle cell patients that led to the birth of the Sickle Cell Association of Ontario (SCAO) in 1981. Together, Johnson and five other committed individuals conducted the organization’s work from their respective homes where the first task was to educate a largely uninformed population about sickle cell.

There were several issues facing Johnson during the initial stages of the SCAO’s inception. Sickle cell was not exactly included in the medical research agenda on hereditary and genetic diseases, nor was it part of public discourse and consciousness during the 1970s and 1980s. In addition to being largely mysterious, there was barely any institutional support for patients with SCD.

1 Whether neglected by the medical profession or the state, sickle cell patients
2 suffered from a lack of material and medical attention. That the sickle cell
3 population consisted disproportionately of newcomers from Caribbean who
4 were unaccustomed to Canadian culture further compounded the issue.
5 This influx of immigrants³⁰ needed an advocate. Johnson emerged as the
6 individual who not only foregrounded the complexity of SCD, but also acted
7 as a liaison on behalf of patients to people and institutions that were unfam-
8 ilar with sickle cell as well as with the cultural values of people who were
9 not white and Canadian. Indeed, as Said intimates, “the intellectual always
10 has a choice either to side with the weaker, the less well-represented, the
11 forgotten or ignored.”³¹ In order to facilitate the SCAO’s mandate, Johnson
12 drew on already existing resources, which included a summer course she took
13 on genetics in the early 1970s that helped her to understand the etiology
14 of SCD. She also developed and sought out alternative methods especially
15 in her interactions with SCD patients. What remains evident and relevant
16 to this day is that Johnson is a pragmatic public intellectual who refuses
17 to remain detached from the marginalized and voiceless. Indeed, Johnson’s
18 sphere of influence extended beyond the realm of sickle cell to include other
19 marginalized groups.

20 In addition to sickle cell advocacy, Johnson engaged in a range of commu-
21 nity-oriented activities, while working for remuneration. She initiated peer
22 counseling support for women of color working in administrative positions;
23 as a board member of the YWCA of Toronto and Richmond Hill (a suburb
24 outside of Toronto), she organized support groups for domestic workers who
25 immigrated to Canada as part of the state-sponsored domestic program.³² From
26 1974–1981, Johnson served as a nursing consultant for the Ontario Ministry
27 of Health and eventually became the first Black woman director of nursing
28 for the Leeds, Grenville, and Lanark District Health Unit, where she worked
29 from 1982–1988. During this time, she advocated for improved living conditions
30 for Caribbean farm workers residing in the area. Besides her work as a public
31 health nurse with the Victorian Order of Nurses (VON), Johnson was also a
32 masters teacher at Humber College’s Health Services Division during the early
33 1970s. She taught basic and postgraduate nursing courses in maternal and child
34 health. Whether in her capacity as a public health nurse, administrator, or
35 volunteer, there is a practical component to how Johnson manages the various
36 dimensions of her activism. As a pragmatic public intellectual, Johnson is not
37 only an educator; she is also a counselor, supporter, and promoter. In the latter
38 category, Johnson develops programs aimed to address not only the needs of
39 SCD patients, but also to educate the larger society. Thus, in the initial stages
40 of the SCAO, Johnson expended much of her energy, educating, counseling,
41 and providing support to patients and families. Of course, Johnson prioritized
42 those affected by SCD.

WORKING WITH SCD PATIENTS

Globally, there is a wealth of research documenting SCD’s impact on patients’ ability to function daily.³³ In more than three decades spent educating patients with SCD, Johnson has developed an array of methodologies. Johnson makes it patently clear that her responsibility is not to exacerbate what is already a difficult and painful situation. She is cognizant that SCD “carries a huge psychosocial burden, impairing physical, psychological, social and occupational well-being as well as levels of independence.”³⁴ Sympathetic to the emotional and psychological distress that accompanies sickle cell, Johnson tailors her educational programs to address the needs of patients and their family members. Here, she explains a typical first meeting:

I don’t just tell people. I find out what people know, and I enlarge on it. I ask, “Do you know how you get sickle cell?” Most people will say it’s a black disease. I will explain it to them. I have charts and use them to explain the genetics of the disease. For example, if both parents are carriers, then there are one in four chances that the child may have sickle cell disease. Lots of people still believe that you catch sickle cell, or it’s cancer, HIV, or sexually transmitted.³⁵

For Johnson, the first step is to dispel myths around SCD, such as the idea that it is inherently specific to Blacks, by helping patients understand the biological aspects of the disease. Of course, people’s relationship to SCD, whether as patients or carriers of the trait, are mitigated by social, cultural, economic, and political factors as well as by race, gender, and class. Johnson is fully aware that people are not just biological but are also social and cultural beings, which also influences their relationship to the disease.

Being a member of the Caribbean community does not preclude Johnson from explicitly acknowledging the gendered dimensions of how the disease is viewed by men. For Johnson, the task is to persuade Caribbean men that they have an important role to play in both sickle cell prevention and management. “Men have a difficult time going to the doctors, or they don’t believe what you are saying. We have to work with them for them to understand that the quality of life for the child is important, not just the number of children you produce,”³⁶ Johnson states. In her capacity as pragmatic public intellectual articulating “a view or a message,” Johnson seeks to develop creative approaches to address the ongoing reluctance of some men to seek medical attention while also urging an examination of long-held cultural acceptance regarding Caribbean manhood and masculinity as it relates to producing children.

Johnson’s philosophy regarding sickle cell is that the more educated patients are about the disease, the better informed they will be to make lifestyle

1 decisions that would enable them to live more productive lives. Johnson sees
 2 sickle patients as active agents who ought to have a stake in their own well-
 3 being and survival. It has been more than three decades since the founding
 4 of SCAO, and Johnson's commitment, especially to young people with sickle
 5 cell, remains consistent. A 2012 press release announcing Bill 105, the Sickle
 6 Cell and Thalassemia Care Ontario Act,³⁷ reflects this. Included in the press
 7 release was the following statement by Johnson: "The next challenge for young
 8 people with sickle cell is for them to be more independent and self-sufficient.
 9 To say 'I do' and 'I can' make a contribution to the country of Canada."³⁸
 10 Johnson consistently worries about the mindset of sickle cell patients. "They
 11 tend to have "low self-esteem" and a "poor me attitude," she points out.
 12 Thus, a critical component of Johnson's counseling session is empowering
 13 patients. She reminds them that having SCD no longer has to translate into
 14 a death sentence and provides examples of others living healthy, enjoyable,
 15 and productive lives.

16 To that end, Johnson and the SCAO have identified a target group with
 17 which they are currently working. "They are the eighteen to thirty-plus group.
 18 We don't want them constantly in and out of the hospital; we are focusing on
 19 alternative forms of managing sickle cell, not just obeying the doctors' orders.
 20 We stress that part of the treatment is [their] responsibility. We encourage
 21 them to get counseling."³⁹ Additionally, Johnson underscores the significance
 22 of the day-to-day in the life of sickle cell patient, offering practical solutions.
 23 She tells patients that "they have to drink lots of fluids especially water, know
 24 what you can do, don't push yourself; don't overdo it." Being able to manage
 25 stress, Johnson continues, "is important in a crisis. Anything can cause stress:
 26 going to school and taking exams." And, Johnson reminds them, "Any of you
 27 can be a doctor, lawyer, or anything; it's only that it will take a longer time."⁴⁰
 28 Even when sickle cell patients themselves are disheartened, depressed, and
 29 ready to capitulate due to the burden of the disease, Johnson sees their value
 30 and potential. Clearly, Johnson pays attention to the constellation of patients'
 31 needs beyond pain management and hospital visits. As a pragmatic public
 32 intellectual, she has consciously chosen to be on the side of the defenseless,
 33 less well-represented, often forgotten, and disregarded.

35 WORKING WITH MEDICAL INSTITUTIONS AND THE STATE

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 37 Johnson and the SCAO's advocacy and awareness work extends to critical insti-
 38 tutions such as the state, medicine, and the educational system, among others.
 39 The aim is to include every qualified professional with whom a sickle cell
 40 patient may come in contact. Regardless of how much counseling and aware-
 41 ness efforts Johnson and the SCAO do, the cooperation of the aforementioned
 42 institutions is necessary for sickle patients to actualize their full potential and

contribute to the development of Canadian society. This requires, according to Johnson, the implementation of comprehensive care, which she outlines:

We are looking at a multidisciplinary program, in which there are not only qualified doctors and nurses, but we are looking too at psychiatrists, social workers, and teachers, because these kids spend a lot of time in school. They lose a lot of time and they need follow-up because our mission is to try and keep them as well as possible so that they can gain as much from their school program and be active members of society.⁴¹

In a public policy press release for Bill 165, another sickle cell anemia–related initiative, Johnson further elaborates on an additional component of comprehensive care, whereby, “Individuals are encouraged, supported to live life at their maximum, and assisted to be positive, courageous, independent and self-sufficient.”⁴² In her appeals to legislative and other institutional bodies, Johnson never loses sight that she is representing a group of individuals who in general lack the resources or a platform to speak on their own behalf.

By virtue of, or as an extension of, the advocacy work she is involved in, Johnson produces and disseminates new knowledge, which challenges the status quo. Over time, it became increasingly clear to Johnson that despite the advantages of socialized medicine, Ontario’s health care system requires modification; of special concern is the medical model of care. Often physician-centered, the medical model reduces SCD to its etiological component without much attention to the patients’ overall well-being. It is also not designed to allow patients with SCD to have input into their treatment. Johnson’s objection to the medical model as it currently operates in Ontario is not exactly novel. Upon migration, Johnson discovered the monopoly physicians had around childbirth, an area she strongly believes is women’s domain. Consequently, she opted to work in the community as opposed to in the hospital, refusing to be a “glorified handmaiden for the physicians.”⁴³ A multidisciplinary team then not only attends to the intricacies of SCD but also decenters the physician, allowing for a diversity of voices and perspectives, with an emphasis on individuals with SCD and their families. Johnson’s Jamaican upbringing, largely rooted in a sense of working together communally coupled with the reality that nurses were more prominent than physicians in her district, allowed her to name and further identify the limitations of Canada’s medical system.⁴⁴

While Johnson’s mandate is to educate a broad audience, it bears repeating that she continuously positions the patient at the center of the discourse. This practice is especially significant given how physicians are often viewed as the ultimate purveyors of scientific knowledge and the guardians of biomedicine. In relation to sickle cell, Johnson challenges physicians’ epistemological dominance and practice. Indeed, as a pragmatic public intellectual, she is not only

1 articulating a view or message on behalf of SCD patients, but understands
 2 how medicine could delegitimize the struggle around sickle cell awareness.
 3 While Johnson might not have recognized herself as a pragmatic public intel-
 4 lectual until she read this paper, it is clear from the aforementioned interview
 5 with CTV that she is unafraid to challenge and contest hegemonic discourses.
 6 Even with the recognition that the state and other established institutions
 7 are critical to the SCAO's mandate, Johnson is unbowed in pinpointing their
 8 shortcomings while simultaneously making audible the silent voice of SCD
 9 patients.

10 Johnson's presentation to the "Standing Committee on Social Policy—
 11 October 27, 2008—Bill 97, Increasing Access to Qualified Health
 12 Professional Ontarians," corresponds once again with Said's image and role
 13 of the public intellectual. He notes that she is "a representative figure that
 14 matters—someone who visibly represents a standpoint of some kind, and
 15 someone who makes articulate representations to his or her public despite
 16 all sorts of barriers."⁴⁵ Drawing on almost three decades of activism,
 17 Johnson underscores the advantages of a multidisciplinary program that
 18 would involve a specialized group of personnel in hospitals, health care, and
 19 community centers:

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 21 After twenty-seven years, what we've discovered is that one of the most
 22 important things is access to the different health care [centers] like hospitals
 23 and others especially where adults are looked after. We need specialized
 24 people, like hematologists, doctors, and geneticists, who will be following up
 25 with [patients with SCD].⁴⁶
 26

27 Three years earlier, Johnson's advocacy and educational work as it relates
 28 to sickle cell's hereditary configuration finally paid off when the Ontario's
 29 Ministry of Health and Long-Term Care included sickle cell disease on the list
 30 of twenty-eight genetic diseases for newborn screening (NBS). This victory was
 31 possible because Johnson and her supporters worked assiduously to convince
 32 government policymakers and health practitioners that being able to identify
 33 infants who might be at risk for SCD is critical to their overall mandate. While
 34 Johnson concedes that the provincial victory is laudable, a closer examination
 35 of her presentation implies that NBS is far from an antidote:

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 37 At that end of it, you have the newborn screening; that is, early identification.
 38 At the other end of it, we need to be following up with the people or families
 39 with traits. So we have, then, that group, plus those in high schools and
 40 different carriers, because since this is an incurable disease, we need to be
 41 looking at different aspects where we can reduce the number of people being
 42 born with sickle cell disease; that is, we have to find the traits, the carriers.⁴⁷

Essentially, NBS has to dovetail with other initiatives, such as locating carriers, and ongoing interaction with those who have the trait.

Johnson is equally ever mindful of the economic, social, and demographic shifts occurring in Ontario, which has important consequences for those with SCD: “We have French; we have different people from different parts of Africa, the Caribbean, Somalia and different people who speak different languages. So there also is a problem with how we can get our educational programs out there,”⁴⁸ she explains. At the heart of Johnson’s petition to the state is a deep concern for those with and affected by SCD, and even though she does not mention this, a critique of Canada’s multicultural policies.⁴⁹ By calling attention to questions of language and newcomer status, Johnson is, in fact, speaking on behalf of a constituent, as she did in the 1980s, whose contact with regimes of power in Ontario is almost nonexistent.

In addition to making visible the language barriers and the issues new migrants with SCD face, Johnson also includes those patients who reside in the suburbs outside of the Greater Toronto Area (GTA); these cities have seen an increase in population over the last two decades. Johnson articulates the following:

Outside of Toronto, when you go to Brampton, Mississauga, and the different areas, there are no specialists in the different hospitals who can attend to sickle cell patients, and we feel that this could be addressed at this level, that we do have more trained people specifically. I know you can’t do it for every hospital, but I see that there is a problem when they are turned away and not able to get—especially those who have just been discharged from Sick Children’s Hospital. At eighteen years, there is absolutely no care. Most of the physicians are not too up to date with the care of young adult sickle cell patients.⁵⁰

Instead of merely stating the problem, Johnson offered a realistic resolution in the form of community centers housed with specialized medical/nursing personnel. Given the distance and proximity of Brampton to Toronto, for example, traveling would undeniably exacerbate the situation for a patient in crisis.

To grasp fully the significance of specialized centers, Johnson offers the following illustration, which can be interpreted as way to help members of Parliament (MP’s) understand how a crisis unfolds in the life of a sickle cell patient. By giving a name in place of using the ubiquitous Patient X, Johnson humanizes the discussion:

This is just a suggestion, from how I see it. Let’s say that John is eighteen years old, so John is not able to access care. He gets in a crisis and he goes to a hospital. He sees new people he has never seen before. For anyone

1 who has studied sickle cell and the complications, it is not very good when
 2 you are in a crisis. They must know how to treat you immediately. So my
 3 suggestion would be—and it's easy; we don't have to get into a whole lot of
 4 money—we could have different centers. On a Wednesday afternoon, John
 5 could go to “B” because they know that that afternoon a trained hemato-
 6 logist or a physician would be there, and this is somebody that they would
 7 be seeing each time. In other words, we are saying that we could select
 8 different areas and we could say that a half day would be the day when
 9 sickle cell and thalassemia patients would be seen. In other words, we could
 10 share services.⁵¹

11
 12 As Canada continues to restructure its health care system as a response to
 13 globalization, specialty centers might actually benefit the province financially
 14 if practitioners who know and understand SCD care for patients. Specialty
 15 centers will reduce or eliminate the time spent in hospitals as well as the use of
 16 unnecessary resources to determine a diagnosis by medical personnel unfamiliar
 17 with SCD.

18 Johnson opted to also include other red blood disorders, such as thalassemia
 19 in the presentation, as there are sickle cell patients who might have both
 20 genetic disorders:

21
 22 We usually talk about sickle cell, but sickle cell is not the only disorder. This is
 23 a red blood cell disorder, and at this point in time we should be emphasizing
 24 thalassemia and the other disorders, because they are all red blood cells. What
 25 we find now is that many of the individuals out there have sickle cell thalas-
 26 semia and different disorders like sickle cell C, D, E, and whatever. So we
 27 would like to approach this as the hemoglobinopathies—that is, all of them
 28 under one heading. We have to include all of them.⁵²

29
 30 Adding other blood disorders under the rubric of “hemoglobinopathies” could
 31 be viewed as yet another strategy on Johnson's part. A more inclusionary and
 32 expansive approach could increase funding opportunities as well as create a
 33 broader support base, especially among health care professionals.

34 Given Johnson's own subjectivity as a nurse-midwife, coupled with an
 35 extensive work trajectory in the UK, Canada, Jamaica, and the United States, it
 36 makes sense why nurses have unique roles to play in caring for those with SCD.
 37 “I firmly believe that looking at treatment, the role of the nurse, especially in
 38 Ontario is important, they play such a great role. They should know about
 39 sickle cell before patients come in with a crisis”⁵³ As the largest group of health
 40 care workers in Ontario and possibly the first point of contact for sickle cell
 41 patients, nurses have to be knowledgeable in order to effectively ascertain the
 42 symptoms of the disease and possibly act as mediators between patients and

physicians. At the legislative hearing, Johnson expressed her concerns with nursing schools and, by extension, students:

I have been trying to get to the schools of nursing to say that hemoglobinopathy should be taught in a more specific way. Right now, I'm mentoring students, so I do know that they know very little or nothing about sickle cell. The only thing they know is to tell you that it's a black people's disease.⁵⁴

In a recent conversation, Johnson mentioned that she continued to work hard with nursing schools to get them to accept a curriculum where they teach about sickle cell. She was happy to report that Humber College School of Nursing (where she taught in the 1970s) has agreed to include sickle cell as part of the nursing curriculum.

As she cautiously highlights the constraints of the Canadian health care system in relation to SCD, Johnson is as a consequence holding the government accountable to its citizens. Instead of merely underscoring problems with the system, Johnson offered concrete recommendations. As an older Black woman (she was eighty-eight years old at the time) speaking to the legislature, Johnson serves a symbolic role, testifying not only to sickle cell harm, but giving “the experience a public identity”⁵⁵

That Johnson repeatedly takes issue with the assumption that sickle cell is a Black people's disease is worthy of some commentary. While she admits that sickle cell disproportionately impacts people of African descent and those from the continent, Johnson quickly clarifies that the inherited blood disorder also affects people of South Asian, Mediterranean, and South American heritage. This demographic expansion could be seen as an interventionist approach to avoid further pathologizing Black patients, a group that by virtue of their skin color is already subject to racist stereotypes. Johnson's reaction is most likely connected to the tendency on the part of physicians to view patients in crisis who seek assistance in emergency rooms as “drug addicts” because they require medication such as morphine, which “remains the drug of choice to achieve a prompt analgesia in patients with SCD.”⁵⁶ Patients with SCD not only have to cope with life-altering consequences of the blood disorder but also have to contend with physicians' and other health practitioners' racism.

Cuts in social spending, which affect state-sponsored support such as welfare, an important resource for sickle cell patients, means that Johnson and the SCAO are compelled to be creative and develop new approaches in response to the changing political, economic, and social climate. To that end, Johnson and the SCAO have partnered with a number of organizations such as the Black Health Alliance (BHA) with the intent that collaboratively they can play a pivotal role in engendering ongoing changes relating to sickle cell

1 education and awareness. Even though the SCAO has formed alliances with
 2 the BHA, Johnson points out, “We don’t want to just form partnerships with
 3 only Black groups because then we would be going against our commitment.”⁵⁷
 4 Forging partnerships with nonblack organizations could mean new funding
 5 opportunities and greater visibility for the SCAO. The partnership with the
 6 BHA has resulted in one of Johnson’s recommendations coming to fruition:
 7 the development of a specialty center.

8 Following an announcement in 2005 from then-minister of health and long-
 9 term care George Smitherman that the government planned to increase satellite
 10 Community Health Centers across the province to improve primary health care
 11 and strengthen communities, the BHA saw this as a perfect opportunity to
 12 lobby for such a venue.⁵⁸ The spring of 2012 saw the creation and opening of
 13 TAIBU Community Health Center (TAIBU CHC) in Malvern (Scarborough)
 14 to serve the disproportionately Black population in that city.⁵⁹ Another of
 15 Johnson’s visions materialized when the SCAO and TAIBU CHC, working in
 16 partnership with Scarborough Hospital, established an “effective and efficient”
 17 emergency department protocol for sickle cell patients.⁶⁰ Despite these laudable
 18 victories, Johnson insists that there is still more work to be done.

19 The journey to educate and effectuate sickle cell awareness at the commu-
 20 nity and governmental level has not always been smooth. Johnson and the
 21 SCAO have faced and continue to face obstacles such as maintaining the
 22 organization’s legitimacy and relevance in a climate when neoliberal policies
 23 as a response to globalization are becoming the norm. Then, there is the
 24 ongoing issue of finding and maintaining committed volunteers. Funding
 25 remains a major concern, which is further compounded by the fact that
 26 SCAO is a nonprofit organization focused on a disease of which the general
 27 population remains oblivious—unlike heart disease or diabetes. “How do
 28 we survive without money?” Johnson asks, and then responds: “We were
 29 committed; we would not have been around for twenty-eight years. It has
 30 been a real up and down thing.”⁶¹ Johnson has also met her share of cynics
 31 who have questioned her and SCAO’s effectiveness. She explains, “People
 32 will say, ‘Well, nobody knows about you, what you have done?’ And I will
 33 reply with all sincerity and honesty that we done a lot of things. For anybody
 34 to have lasted that long, [we] must have been doing something right.”⁶² To
 35 be sure, as Johnson emphasizes, meeting the needs and advocating on behalf
 36 of, the sickle cell population has to have meaning beyond the need to be
 37 personally recognized and rewarded.

38 Indeed, Johnson has appeared on and been featured in a number of main-
 39 stream and community media; what remains striking is her continued passion
 40 and message of hope for those living with SCD.⁶³ Still, her lifelong dedica-
 41 tion to educating those with SCD and their families, health practitioners,
 42

policymakers, educators, and government about the symptoms and implications of the hereditary disorder has not gone unnoticed. Johnson has been the recipient of numerous awards and certificates of recognition, including the 2009 Public Health Champion Award by Toronto’s Board of Health, and a Distinguished Alumnus Award from The Lawrence Bloomberg Faculty of Nursing at the University of Toronto.

Perhaps the most prestigious has been the Order of Ontario (2011), which validates Johnson’s role as a pragmatic public intellectual at the provincial level. The Order of Ontario—the province’s loftiest official honor—was created in 1986, and recognizes the highest level of individual excellence and achievement in any field. Members of the public make nominations.⁶⁴ Former provincial minister and president of the Project for the Advancement of Childhood Education (PACE) Mary Anne Chambers, who nominated Johnson for the honor, had this to say:

I cannot think of a more deserving individual for the Order of Ontario....Her lifetime of service to others makes her an exceptionally deserving candidate for the honor. The results that she has achieved speak to the legitimacy of her mission and serve to illustrate that ordinary but special people can achieve extraordinary things. She has already made so many lives better and even more will benefit from her legacy.⁶⁵

Chambers further added:

She became a trailblazer in her own right as a Black woman, but more importantly as a nurse who applied a wide worldview in her approach to her work. Ontario’s families and the field of public health are beneficiaries of Miss Johnson’s dedication, knowledge, professionalism and fearlessness.⁶⁶

To be sure Johnson’s training as a nurse-midwife, public health nurse, educator, and administrator provided her with the tools to articulate and create public awareness around sickle cell.

Her activism, however, did not occur in a vacuum or by mere coincidence. Growing up in a deeply religious family that emphasized two principles influences Johnson’s public engagement: “We are our brother’s keeper” and “Love thy neighbor as thy self.” Elaborating on the question of, “Who is thy neighbor?,” Johnson responded: “Everybody, not only the person next door, but all people. That is not an easy thing, but that is what we strive for. To love people and not be judgmental and just because people are poor does not mean you can’t talk to them and treat them like human beings.” She continues, “I come from a family that believes in teaching, and a family that believes in

1 community. We believe that every person has a purpose here. We believe in
 2 giving, for in giving you get.” Indeed, biblical and pragmatic wisdom dispensed
 3 by Johnson’s parents deeply inspired her activism.⁶⁷

5 CONCLUSION

6
 7 In elucidating the rationale for why Black feminist Anna J. Cooper is a public
 8 intellectual, Carolyn M. Cusick asks: “What else is the mission of the public
 9 intellectual than to advance human knowledge and freedom, to give back and
 10 better the world—or at least some piece of it?”⁶⁸ Cusick could have easily been
 11 referring to Johnson, albeit in another time and place. Influenced by her Jamaican
 12 upbringing in a family that took seriously Jesus’s admonition “to care for the least
 13 of these,” Johnson connects with those who face the debilitating effects of SCD.
 14 She values their experiences and, at the political level, she constructs solutions
 15 to alleviate some of their burdens. Indeed, as a pragmatic public intellectual,
 16 Johnson consistently engages ideas about the meaning, purpose, and value of life
 17 in a manner that is accessible not just to sickle cell patients but to the general
 18 public, health care professionals, and government officials.

19 As with many Caribbean migrant women who have made Canada home,
 20 Johnson has faced her share of gendered racism. While nurses generally have
 21 difficulties discussing racism in a gendered occupation within which caring is
 22 foundational to its ethos, Johnson refuses to promote the notion of racism-free
 23 nursing, which would also support the erroneous myth in relation to the larger
 24 Canadian society. Despite the hurdles, Johnson repeatedly harkens back to
 25 her knowledge and expertise: “You need to press on, it was a fight, but if you
 26 know your job, you can stand up to any challenge.”⁶⁹ At the age of ninety-two,
 27 Johnson has no desire to slow down. She often makes the daily trek from her
 28 home in Scarborough to the SCAO’s office in Toronto, and despite some recent
 29 health setbacks, she still participates in seminars, conferences, any initiative
 30 associated with sickle cell. Johnson has a number of plans, which include going
 31 to back to school, writing a survival guide for sickle cell patients, and writing
 32 her memoirs. When asked about her age, she advises: “Don’t let your age slow
 33 you down; if your body and mind tell you that you can do it, you’ll do it.”
 34 Indeed, Johnson has made Ontario, and by extension Canada, a better place
 35 though her relentless struggle to advance human knowledge and the delivery
 36 of healthcare.

38 ACKNOWLEDGMENT

39
 40 Special thanks to the following: Felix Gemaine, Assata Zerai, Ruby
 41 Mendenhall, and Merle Bowen, members of the American Association for the
 42 History of Nursing (AAHN), and Lillie Johnson, who continues to inspire me.

NOTES

1. See for example, Vijay Agnew, *Resisting Discrimination: Women from Asia, Africa, and the Caribbean and the Women’s Movement in Canada* (Toronto: University of Toronto Press, 1996); Dionne Brand, *No Burden to Carry: Narratives of Black Working Women in Ontario, 1920s–1950s* (Toronto: Women’s Press, 1991); Karen Flynn, *Moving Beyond Borders: A History of Black Canadian and Caribbean Women in the Diaspora* (Toronto: University of Toronto Press, 2011); Erica Lawson, “The Gendered Working Lives of Seven Jamaican Women in Canada: A Story about ‘Here’ and ‘There’ in a Transnational Economy,” *Feminist Formations* 25, no. 1 (2013): 138–56.
2. Rinaldo Walcott, *Black Like Who? Writing Black Canada* (Toronto: Insomniac Press), 97.
3. I’m using Black as a political category to include people who have been in Canada since the seventeenth century and more recent newcomers from the Caribbean, Latin and South America, and the African continent.
4. Amoaba Gooden, “Community Organizing by African Caribbean People in Toronto,” *Journal of Black Studies* 38, no. 3 (2008): 413–26.
5. The life history approach, according to Atkinson, is “the story a person chooses to tell about the life he or she has lived, told as completely and honestly as possible, what is remembered of it, and what the teller wants others to know of it, usually as a result of guided interview by another.” Johnson was provided a draft of the article, where she made the appropriate changes, an indication that she accepts my argument that she is a pragmatic public intellectual. See R. Atkinson, *The Life Story Interview* (Thousand Oaks, CA: Sage, 1998), 8.
6. The genesis of the term *public intellectual* emerged in the Dreyfus Affair. C. Wright Mills is credited with using the term *public intellectuals*. See C. Wright Mills, *The Causes of World War Three* (New York: Ballantine Books, 1960). Russell Jacoby is said to have popularized “public intellectual.” See Russell Jacoby, *The Last Intellectuals: American Culture in the Age of Academe* (New York: Basic, 1987).
7. Edward W. Said, “The Public Role of Writers and Intellectuals,” in *The Public Intellectual*, ed. Helen Small (Oxford: Blackwell Publishing, 2002), 20.
8. Edward W. Said, *Representations of the Intellectual: The 1993 Reith Lectures* (New York: Random House 1996), 11.
9. In their discussions regarding the Black intellectual, hooks and West focused on the role of academics; the latter Black women, and the former men. West, however, mentioned that the church and the Black musical tradition are sites for the development of organic intellectuals. See Cornel West and bell hooks, *Breaking Bread: Insurgent Black Intellectual Life* (Boston: South End Press, 1991); See also, “Posner’s Prejudice: Citation Counts of Black Public Intellectuals.” The author’s critique was leveled at Judge Richard Posner who included in his book a total of twenty-six Blacks (five Black women and twenty-one Black men) from a list

- of 546 intellectuals. "Posner's Prejudice: Citation Counts of Black Public Intellectuals," *The Journal of Blacks in Higher Education* 37 (2002): 21–22. See Richard Posner, *Public Intellectuals: A Study of the Decline* (Cambridge: Harvard University Press, 2001). Whether chosen by critics or Posner, the majority of the public intellectuals were academics, men, and mostly white. In the Canadian context, a similar discussion bemoaning the death of the public intellectual is reflected by Alex Good's question, "What has become of the Canadian public intellectual?" See Alex Good, "Woe is Us," *Toronto Star*, April 8, 2007. Similarly, Michael Ignatieff, who was included in the 2008 *Foreign Policy* list and is widely acknowledged as one of Canada's most prominent public intellectuals has written on the topic. See Michael Ignatieff, "The Decline and fall of the Public Intellectual," *Queen's Quarterly* 104, no. 3 (1997): 395–403. While Mark Kingwell (another of Canada's public intellectuals) acknowledges how problematic defining the intellectual can be, he included in his list the same white men and women: Marshall McLuhan, Northrop Frye, Margaret Atwood, among others who have traditionally been cited in national conversations. See Mark Kingwell, "What Are Intellectuals for? A Modest Proposal in Dialogue Form," *Queen's Quarterly* 118, no. 1 (2011): 44–63. Black Cultural Studies scholar and critic Renaldo Walcott and novelist Dionne Brand are sometimes cited as public intellectuals. See George Elliot Clark's critique of Walcott, Brand, and others in "Treason of the Black Intellectuals?" <http://canadian-writers.athabascau.ca/english/writers/geclarke/treason.php>, Accessed August 7, 2013.
10. http://www.foreignpolicy.com/articles/2008/05/14/top_100_public_intellectuals. Accessed June 26, 2011.
 11. Erica Lawson, "Black Women as Public Intellectuals: The Case of the Jamaica Seven," presentation at the *Black Women as Public Intellectuals: Past, Present and Future Symposium*, University of Alabama, Tuscaloosa, October 7, 2010.
 12. Lewis Gordon, "Foreword," in *Transcending the Talented Tenth: Black American Intellectuals*, by Joy Ann James (New York: Routledge, 1997), xiv.
 13. Matthew 25:45 (KJV).
 14. Lillie Johnson, interview by author. Tape recording. Scarborough, Ontario, August 9, 1999.
 15. Matthew 22:39 (KJV).
 16. Genesis 4:9 (KJV).
 17. Bridget Brereton, "Society and Culture in the Caribbean: The British and French West Indies, 1870–1980," in *The Modern Caribbean: A Regional Overview*, ed. Franklin W. Knight and Colin A. Palmer (Chapel Hill: University of North Carolina Press, 1989), 90.
 18. Ibid.
 19. Ula Y. Taylor, *The Veiled Garvey: The Life and Times of Amy Jacques Garvey* (Chapel Hill: University of North Carolina Press, 2002), 12.
 20. Johnson, interview.

21. Ibid. 1
22. Ibid. 2
23. While the article deals with an earlier period, the authors validate the presence of Caribbean people in Scotland. See Anne Dunlop and Robert Miles, “Recovering the History of Asian Migration to Scotland,” *Immigrants & Minorities* 9, 2 (1990): 145–67. 3
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24. Johnson interview. 7
25. Karen Flynn, “Experience and Identity: Black Immigrant Nurses to Canada, 1950–1980,” in *Sisters or Strangers: Immigrant, Ethnic, and Racialized Women in Canadian History*, ed. Marlene Epp, Franca Iacovetta, and Frances Swyripa (Toronto: University of Toronto Press, 2004), 381–98. 8
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26. “A Challenging Beginning,” *The Pulse*, University of Toronto (2012), 28. 12
27. See the SCAO’s Web site: <http://scao.org.frostyserver.com/AboutSickleCell.aspx>. 13
28. At this point, there are no available statistics on the number of people who have died from sickle cell. 14
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29. <http://toronto.ctvnews.ca/sickle-cell-disease-activist-honoured-by-ontario-1.601811#ixzz2LsoJqEtX>. Accessed June 7, 2011. 16
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30. Census data give a sense of the number of immigrants from the Caribbean overall; the number of Caribbean immigrants who arrived in Canada during 1967 was 5,641, and in 1971 it was 10,843. By 1981, Ontario alone boasted more than 130,000 residents from the Caribbean including Guyana—many, but not all, were of African descent. Census of Canada, 1971, Immigration, “Arrivals by Country of Last Permanent Residence”; Census of Canada, Population (Catalogue 93-930, Vol.2 Provincial Series), Table 8, “Population Born Outside Canada by Sex, showing selected Countries.” 18
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31. Said, *Representations of the Intellectual*, 11. 26
32. Dawn P. Williams, *Who Is Who in Black Canada: Black Excellence and Success in Canada*, Vol. 2 (Toronto: D. P. and Associates, 2006), 197–98. 27
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33. See for example, H. Caird, P. Camic, and V. Thomas, “The Lives of Adults over 30 Living with Sickle Cell Disorder,” *British Journal of Health Psychology* 16 (2011): 542–58; P. Cole, “Black Women and Sickle Cell Disease: Implications for Mental Health Disparities Research,” *Californian Journal of Health Promotion* 5 (2007): 24–39; Moji Anderson and Monika Asnani, “You Just Have to Live with It”: Coping with Sickle Cell Disease in Jamaica,” *Qualitative Health Research* 23, no. 5 (2013): 655–64. Accessed August 7, 2013. 29
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34. V. Thomas and L. Taylor, “The Psychosocial Experience of People with Sickle Cell Disease and Its Impact on Quality of Life,” *British Journal of Psychology* (2002): 345. 36
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35. Johnson, phone interview. 39
36. Ibid. 40
37. Private Members Bills rarely become law. 41
38. http://sicklecellanemia.ca/pdf/bill_105_press_release.pdf. Accessed June 7, 2011. 42

- 1 39. Johnson, phone interview.
 2 40. Ibid.
 3 41. Ibid.
 4 42. [http://www.sicklecellontario.org/public-policy/ontario-bill-165/bill-165-press-](http://www.sicklecellontario.org/public-policy/ontario-bill-165/bill-165-press-release)
 5 [release.](http://www.sicklecellontario.org/public-policy/ontario-bill-165/bill-165-press-release)
 6 43. Johnson interview.
 7 44. Caribbean people in Canada often draw on their Caribbean experience to address
 8 Canadian realities. See Greg Wiggan and Jean T. Walrond, eds., *Following the*
 9 *Northern Star: Caribbean Identities and Education in North American Schools* (New
 10 York: Nova Publishers, 2013).
 11 45. Said, *Representations of the Intellectual*, 12.
 12 46. Phone interview with Lillie Johnson, August 2009.
 13 47. [http://www.ontla.on.ca/committee-proceedings/transcripts/files_html/27-](http://www.ontla.on.ca/committee-proceedings/transcripts/files_html/27-OCT-2008_SP014.htm)
 14 [OCT-2008_SP014.htm](http://www.ontla.on.ca/committee-proceedings/transcripts/files_html/27-OCT-2008_SP014.htm). Accessed June 7, 2011.
 15 48. Ibid.
 16 49. Canada's official multiculturalism policy continues to be a protracted debate,
 17 which has been renewed in the forty years since its inception. Renaldo Walcott in
 18 his critique of the policy notes that it "textually inscribes those who not French
 19 or English Canadians, and yet at the same time it works to textually render a
 20 continued understanding of those people as from elsewhere and thus as tangential
 21 to the nation-state." See, *Black Like Who*, 77. See also Yvonne Brown, "Ghosts in
 22 the Canadian Multicultural Machine: A Tale of the Absent Presence of Black
 23 People," *Journal of Black Studies* 38, no. 3 (2008): 375–87. Lloyd Wong and Vic
 24 Satzewich offer a different perspective on the debate. They note that as a result
 25 of immigrants' involvement in transnational practices, this "can be viewed as chal-
 26 lenging forms of multiculturalism that are bounded by the state." See *Transnational*
 27 *Identities and Practices in Canada* (Vancouver: UBC Press, 2006), 1. For a more
 28 recent discussion, see, Ho Hon Leung, "Canadian Multiculturalism in the 21st
 29 Century: Emerging Challenges and Debates," *Canadian Ethnic Studies* 43/44, no.
 30 3-1 (2011/2012): 19–33.
 31 50. [http://www.ontla.on.ca/committee-proceedings/transcripts/files_html/27-](http://www.ontla.on.ca/committee-proceedings/transcripts/files_html/27-OCT-2008_SP014.htm)
 32 [OCT-2008_SP014.htm](http://www.ontla.on.ca/committee-proceedings/transcripts/files_html/27-OCT-2008_SP014.htm). Accessed June 7, 2011.
 33 51. Ibid.
 34 52. Ibid.
 35 53. Johnson, phone interview.
 36 54. [http://www.ontla.on.ca/committee-proceedings/transcripts/files_html/27-](http://www.ontla.on.ca/committee-proceedings/transcripts/files_html/27-OCT-2008_SP014.htm)
 37 [OCT-2008_SP014.htm](http://www.ontla.on.ca/committee-proceedings/transcripts/files_html/27-OCT-2008_SP014.htm). Accessed June 7, 2011.
 38 55. Said, "The Public Role of Writers and Intellectuals," 25.
 39 56. Pasquale Niscola et al., "Pain Syndromes in Sickle Cell Disease: An Update,"
 40 *American Academy of Pain Medicine* 10, no. 3 (2009), 474.
 41 57. Johnson, phone interview.
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58. <http://sharenews.com/malvern-health-centre-providing-prompt-care-for-sickle-cell-sufferers/>. Accessed, April 15, 2013. 1
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59. Ibid. 3
60. <http://sharenews.com/institutions-need-to-develop-protocol-for-sickle-cell-disease/#sthash.a8hNBJYH.dpuf>. Accessed June 7, 2011. 4
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61. Johnson, phone interview. 6
62. Ibid. 7
63. See the following: <http://archive.sharenews.com/local-news/2011/12/02/lillie-johnson-honoured-work-nursing>; <http://sharenews.com/archives/20110202two-stalwarts-named-order-ontario/>; <http://www.theafronews.ca/2011/02/24/5828/>; <http://toronto.ctvnews.ca/sickle-cell-disease-activist-honoured-by-ontario-1.601811>; <http://bloomberg.nursing.utoronto.ca/news/bloomberg-celebrates-first-book-on-black-canadian-nurse-pioneers>; <http://cusointernational.org/life-changing-stories/lille-johnson-%E2%80%93-home-where-volunteer>; <http://news.ontario.ca/mci/en/2011/01/29-appointees-named-to-ontarios-highest-honour-1.html>; <http://humberetc.com/2013/04/12/sickle-cell-blood-disease-seminar-tells-nursing-students-of-invisible-pain/> <http://thecaribbeancamera.com/?p=1425>. Accessed April 15, 2013. 8
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64. <http://www.citizenship.gov.on.ca/english/citizenship/honours/orderofontario.shtml>. Accessed April 15, 2014. 19
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65. <http://sharenews.com/archives/20110202two-stalwarts-named-order-ontario/>. Accessed, April 15, 2014. 21
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66. Ibid. 23
67. See for example, Carol B. Duncan, *This Spot of Ground: Spiritual Baptists in Toronto* (Waterloo: Wilfred Laurier Press, 2008); Dorothy Shadd Shreve, *The AfriCanadian Church: A Stabilizer* (Grand Rapids: Paideia Books, 1983); Yvonne Bobb-Smith, “We Get Troo...’: Caribbean Canadian Women’s Spirituality as a Strategy of Resistance,” in *Theorizing Empowerment: Canadian Perspectives on Black Feminist Thought*, ed. Notisha Massaquoi and Njoki Nathani Wane (Toronto: Inanana Publications, 2007), 55–71 ; Evelyn Brooks Higginbotham, *Righteous Discontent: The Women’s Movement in the Black Baptist Church, 1880–1920* (Cambridge: Harvard University Press, 1993); Jacquelyn Grant, *White Women’s Christ and Black Women’s Jesus: Feminist Christology and Womanist Response* (Atlanta: Scholars Press, 1989). 24
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68. Carolyn M. Cusick, “Anna Julia Cooper, Worth, and Public Intellectual,” *Philosophia Africana* 12, no. 1 (2009): 21. 35
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69. “A Challenging Beginning,” *The Pulse*, 28. 37
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