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Rivers of Blood and Babylon:
An ethnography of social suffering and resilience among Caribbean service users in London

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Abstract

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By Kwame Matsimela Petiri Phillips

Suman Fernando (2003) argues, “racial injustices and cultural oppression are felt most acutely” by Black and ethnic minority service users in the field of psychiatry. Research on the mental health services in the UK consistently find that Black and ethnic minorities are more often diagnosed as schizophrenic, more often compulsorily detained under the Mental Health Act, more often given high doses of medication, and more often dissatisfied with statutory services. The dissertation asks how the current treatment provided under the mental health system in London, England re-traumatizes Caribbean service users. To investigate this question, I gathered ethnographic data - through official interviews, conversations, participant observation and visual material - from more than 40 adult service users and 26 health professionals. The qualitative, ethnographic research uses both visual and textual presentations of data in its approach and resulted in the production of four ethnographic films exploring themes of identity, community, resilience, voice and civil disorder.

The dissertation puts forward that for the Caribbean population in the mental health system, there is a pervasive problem of social suffering, both as a result of mental illness and of coming into contact with the mental health system, such that coming into contact with the institution of the National Health Service itself can be considered a risk factor for furthered suffering. I further propose that the psychiatric philosophy of containment held by the mental health services, linked with a societal culture of fear and stigma, and a history of political failure to implement, follow through on and maintain progressive components within healthcare policy, must be addressed and improved if any meaningful change for the better is to be effected. The research highlights continued tension in the relationship between service users and the medical establishment, with a general sense of resentment to the amount and administering of medication, the power afforded to medical staff, and the dominance of Eurocentric academic and medical classification at the expense of their own models and theories of illness.

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Rivers of Blood and Babylon

Kwame Phillips

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Chapter One: Introduction

Prologue: The Lucky Ones

When I think I was 10 and I think my brother was 8, and after I think we were both summoned to our parents' room to sit on their bed to 'have a talk,' my brother and I were told that we would be moving back to the Caribbean. Now my brother and I were born in London, but I am almost certain that my parents said we were moving 'back.' My father was born in Trinidad and my mother in Jamaica, and in their liberal, forward thinking manner, they gave us an option of choosing which we would prefer after a six month trial period in both. I imagine that for many children, being uprooted from everything you know to move to a different country would be at the very least disconcerting. But in my 10-year-old brain, I concluded that something new would be better than London. London for me was my school and my school for me was the place I went to where I felt most uncomfortable and where at 10 everything seemed like a slow descent into a nightmare vision of grey skies, heavy coats, drugs and sinisterness. I didn't want to become one of the boys sitting on the wall outside of the school smoking, but I also didn't want to become one of the boys beat up by the boys sitting on the wall outside of the school smoking.

In my class, it was I, Ricky, Harrison and Rakesh. Everyone else was white. Not that anything is wrong with white people. Some of my best friends were white. Nevertheless, there was definitely something about being one amongst only four students of colour in a middle school class. Something like being out of place. We were various kinds of dark and first generation British. We weren't really friends, but I got the sense that we all understood that we were in the same boat. We tried to fit in; we tried not to seem too different. I felt mildly popular. I was one of the smart kids, but wasn't a nerd. I was one of the athletes, but wasn't a star. I did well at being all things to all people. I had a

BMX and couldn't ride it. I tried to balance not sticking out as different with a level of exceptionalism that would make me appealing. It made me tired. It took a lot of effort to share my packed lunch because the other students hadn't seen West Indian food before and wanted to try it. It took a lot of effort to gently persuade my best friend Simon over the course of a few days to stop referring to me as 'colored.' It took a lot of effort just to be. And when I was amongst my parents and their friends and my grandparents and their friends, they all seemed so happy. They laughed and joked in West Indian tongues that I was vaguely familiar with and did West Indian things in a West Indian way. It seemed like everyone in all of South London knew each other. It didn't seem like so much of an effort for them. To be. They already were. Just in a new place. I didn't even know what I was. Except that I knew that I wasn't English and I knew that something new would be better than London. And so we moved 'back Home.' And when I returned to London many years after, the West Indians my brother and I left behind called us 'the lucky ones.'

Introduction

This dissertation examines the historical role of mental health diagnosis, migration, social exclusion and racial stigma in exacerbating social suffering, and the subsequent creation of resilient service user communities, as can be seen in Caribbean mental health advocacy and support centres. It draws upon ethnographic interviews and observations with Black Caribbean mental healthcare service users, as well as healthcare professionals, including advocates, doctors, academics and community workers, observations at advocacy agencies, centres, hospital wards and communities, and photographic and video data produced by and with service users, to provide a contextual overview of the culture of resilience as it relates to these Caribbean service users. It also examines the manner by which service users impose order on life events, and make

sense of and create continuity between past, present and imagined worlds to further create a space of resilience within which they are able to survive in the face of adverse health and social conditions. The study explores how narratives of illness draw upon culturally shared images and connections between individual and society and that by combining image-and-sequence-based with word-and-sentence-based anthropological data, subjects are able to relate, meaningfully represent, act out ideas and show concepts that do not fit easily into words.

My project seeks to investigate the context of the lives of Caribbean service users in the mental health system, not solely issues connected to experiences of being Caribbean, being an immigrant, and being a patient, but the ways in which social suffering and mental health problems interplay, how the meaning-making generated from all these experiences are used as a means of resilience, often despite the conflicting effects that experiences as a mental health patient have to resilience, and the ongoing negotiation that this group has with pharmaceutical medicine and psychiatric practice. A critical aspect of this investigation is learning from the service users themselves, though to thoroughly investigate this context, it is also important to speak to mental healthcare professionals and researchers, and to observe the agencies, institutions and environs that the service users interact with. Despite the benefits they would provide, the voices and values of service users are strikingly absent in most quantitative research (Alexander, et al. 2009). But at the forefront of the project is the direct experiential voice of the service user, as it is only this perspective that can truly inform public health strategies that hope to be patient-centered. In addition, not only is this voice critical, but it is often marginalized as an influence on policy, or absent completely. This dissertation is led by the voices and values of those who have experienced and there is unique value in trying to 'know' in the way that these subjects 'know' (Spradley 1979). This does not mean that these voices will not be critically examined, rather they will be analyzed not only for "substantive information" (what is said) and "construction of meaning" (how it was said), but also "the ways the 'what' and 'how' are interrelated and what

circumstances condition the meaning-making process” (Holstein and Gubrium 1995).

In considering this ‘voice,’ it must be recognized that culture is embodied and in many ways, mental illness is an embodied presentation, so it is essential that visual representation is present in this anthropological work (Ruby 2000). Visual anthropology is not simply anthropology of the visual, but an anthropology of the relationship between the visual and culture and society at large, and not simply the use of visual methods in research and representation, but also the methodological practice of combining visual with other media in the production and representation of anthropological knowledge. The decision to utilize visual anthropological methods aligns with the arguments of anthropologist Sarah Pink who states, “perhaps some problems we face when we write linear texts with words as our only tool can be resolved by thinking of anthropology and its representations as not solely verbal but also visual and not simply linear but multi linear” (Pink 2006). Visual methods then are a valuable means of confronting key anthropological questions, and combined with textual presentation of data can effectively “represent sensory experience theoretically and ethnographically” (Pink 2006).

Research Question

Aims and Objectives

The main research question for this project is as such: how does the current treatment provided under the mental health system in London, England re-traumatize Caribbean service users? It is important to note that I explicitly ask ‘how’ and not ‘whether’ because as the project shows, there is general agreement that Caribbean service users suffer negative consequences within mental health services, so much so that the Bennett inquiry concluded that mental health services in the UK are “institutionally racist” (BMH UK 2011) and the British government has made efforts to address the problem through initiatives such as the Delivering Race Equality in Mental

Healthcare programme. It is widely accepted that there is a problem; the question is the nature of the problem. The aim of the project then is to investigate the experiences of these Caribbean service users and the relationship between social suffering and mental health treatment practices. This main question and aim necessitates a number of objectives: to describe the experiences and report the stories of a representative sampling of Caribbean service users in the mental health system in London; to seek to understand the impact of migration and transnationalism on these experiences, especially so as it relates to issues of identity and belonging; to seek to understand how media and institutional power, such as the treatment systems and interventions associated with the National Health Service and beyond are influential on the culture of treatment; to seek to understand how the culture of mental health intervention often clashes with the culture of health for service users and how policy and political economy struggles to accommodate a stated objective of person-centered treatment; to seek to understand the ways in which social suffering and mental health problems interplay; and to describe the culture of resilience that has formed largely outside of the statutory mental health locations, in places like Caribbean day centers and the ongoing negotiation between community cultural values and values that are prescribed by pharmaceutical medicine, psychiatric practice, the NHS and the law.

Summary of argument

Over the course of the data collection and having spoken to service users and members of support and health services, research and the greater community, I put forward that for the Caribbean population in the mental health system, there is a pervasive problem of social suffering, both as a result of mental illness and of coming into contact with the mental health system, such that I propose that coming into contact with the institution of the National Health Service itself can be considered a risk factor for furthered suffering for Caribbean service users with diagnosed mental

health problems. This argument draws from Kleinman's definition of social suffering as being of three types – structurally violent, where suffering is driven by structural processes that constrain agency; interpersonally experienced, such as illness experience; and caused or intensified by bureaucratic indifference and action (Kleinman, et al. 1996; Kleinman 2009a). Using this definition, the research of scholars such as Nazroo (1997), Bhui et al., (2002) and Fernando (2003) are given added force, where they find that Black and ethnic minorities are more often diagnosed as schizophrenic, more often compulsorily detained under the Mental Health Act, more often given high doses of medication, and more often dissatisfied with statutory services, such that Fernando argues that “racial injustices and cultural oppression are felt most acutely” by Black and ethnic minority service users in the field of psychiatry.

I further propose that the psychiatric philosophy of containment held by the mental health services, linked with a societal culture of fear and stigma, and a history of political failure to implement, follow through on and maintain progressive components within healthcare policy must be addressed and improved if any meaningful change for the better is to be effected. This premise is supported by Francis (1993) who argues for the connection between racialized social suffering and the role of mental health treatment and policy, stating that contemporary race relations theory and practice, at its worst, allows for the authorization of state agencies to act in concert as a circuit of control, to protect the social order, from problematically defined (by race and illness) ‘dangerous’ individuals. I propose that this is linked to a history of continual negative portrayals across media forms which appears to have negatively impacted not only perceptions and self-perceptions, but also has negatively impacted the culture of treatment and policy making for the Caribbean population. The imagery of black Caribbeans in the UK has often been accused of having been “emptied of history” and bodies of the subjects are ‘racialized,’ denying the subjects historical agency and psychological complexity (Rony 1996). For service users, this racialized stereotyping is made ever more problematic by what Gilman (1988) argues is a societal

need to define itself as sane and thus necessarily create a separation between the sane and the ‘insane,’ where at its extreme, this separation requires physical confinement and clear recognition and visual localization of who is ‘mad.’ The mad and the dangerous then converge in the body of the black Caribbean service user. The research highlights continued tension in the relationship between the service users and the medical establishment, with a general sense of resentment to the amount and administering of medication, the power afforded to medical staff, and the dominance of Eurocentric academic and medical classification at the expense of their own models and theories of illness.

The data collected highlighted arguments that across generations, Caribbean persons in Britain have either struggled to maintain a connection to their Caribbean heritage or attempted and struggled to connect with a British identity. This engages the concept of transnationalism, which challenges more traditional conceptions of the permanent rupture and uprootedness of migration, and instead allows for what is apparent for the Caribbean process where migrants develop and maintain multiple familial, economic, social, organizational, religious and political relations that span borders (Glick Schiller, et al. 1992). This finding is supported by theories that for the individual in the Diaspora, “a Caribbean identity usually implies a crisis of belonging” (McGill 2005). Older generations often retain a strong connection, both real and ‘imagined’ to the Caribbean, but similarly have struggled to find a sense of ‘home’ in the British environment. Hall (1992) argues, the Caribbean diaspora, while retaining these strong links with their places of origin and their traditions, must reckon with the new cultures they inhabit.

For service users, this crisis of belonging transcends being an issue of national identity, and is part of an ongoing tension that I argue results in a ‘two-ness’ that is not only based on trying to reconcile Caribbeanness with Britishness, but also with competing models of illness and the consequent impact on health outcomes. In arguing for this duality of tension, Lacan (1949) and

Bourdieu's (1977) concept of 'misrecognition' and Du Bois' (1903) concept of 'double consciousness' are particularly relevant as theoretical tools, because of their articulation of the individual conflicted and split by psycho-social divisions, because of issues of self-image and race, and that individual's reconciliation of these divisions. Extending the concept of double consciousness to matters of mental illness, this project asserts that one way in which the service users of the Caribbean diaspora tackle this issue of belonging is by nurturing a sense of resilience that is often grounded in fostering a Caribbean identity within the London environment, specifically with Caribbean mental health day centers.

In the face of marginalization and exclusion in the British society, based on both ethnicity and illness, social suffering for service users results in a problematic conception of home and a sense of voicelessness. This voicelessness is both actual and metaphorical. In actual terms, service users' perspectives have been found to be largely ignored in policy-making decisions.

Metaphorically, as Morris (1996) asserts, "suffering is voiceless in the metaphorical sense that silence becomes a sign of something ultimately unknowable [and] encompasses an irreducible nonverbal dimension that we cannot know-not at least in any normal mode of knowing-because it happens in a realm beyond language." Central aspects of the created resilient space are the formation of a sense of community and belonging and the fostering of the service user voice.

Additionally, a central aspect of the methodology of the research are participatory visual methods that create opportunities to hear service user voices and bring their experiences into the policy-making process (Lorenz and Kolb 2009). Caribbean mental health day centers serve as resilient communal spaces, where service users are able to affirm an identity outside of the excluded spaces reserved for them as the ill or the foreign, often clashing with existing, overwhelmingly negative images and notions of 'Caribbeanness,' 'blackness' and mental illness.

Methodology*Research Design*

The location of the study and data collection was in London, England. The primary sites of participant recruitment for subject interviews was community-based support centers where I first made contact with the staff so that they could direct subjects towards the study and be aware of my presence and could intervene if necessary. I also placed flyers in various agencies so that subjects were able to contact me directly if interested. I was unable to attain permission to interview subjects on hospital wards, but instead made partnership agreements with mental health organizations that mental health service users frequented outside of the hospital, namely the Fanon Resource Centre (both in Merton and Lambeth), the Oremi Centre, Family Health Isis, the MELLOW group (which is connected to a number of other service users groups) and Social Action for Health. At these organizations I was able to learn about the services offered to service users and the environments in which they interact with each other and access treatment and care. I also engaged in participant observation by frequently attending drop in services at these agencies, most frequently at Family Health Isis where I assumed a volunteer role in the Hearing Voices Group and the Men's Group. Family Health Isis proved to be a fruitful source of research data, such that it became a sort of case study for how a Caribbean mental health day center operates and is beneficial to Caribbean service users, and as such a section of this dissertation is dedicated to an ethnography of that agency. I also attended a number of service users forums and meetings concentrating on care and treatment, attending student training sessions, conducted and participated in focus groups, and socialized at other events with service users.

As the project expanded to broader questions on the experience of Caribbean services users in the mental health system, the culture of mental health intervention, the culture of resilience, and the severe and pervasive problem of persistent negative contact with the mental health system, it

remained important to not only speak to subjects in the Caribbean community who had come into contact with the mental health system, but also to mental healthcare service professionals, including advocates, doctors, academics and social workers, observations at advocacy agencies, centres, hospital wards and communities to provide a contextual overview of the culture of mental health intervention as it relates to these Caribbean service users. Vulnerable populations such as children, pregnant women, illegal immigrants and prisoners were not included.

For a period of time, it was difficult to obtain interviews from service users. One health professional remarked that service users have “consultation fatigue” and were tired of having their opinion sought by various researchers, but never being followed up on. This forced a change in strategy to favouring group discussions for service users, resulting in the Social Action for Health forum and multiple discussion meetings with The Men’s Group and The Hearing Voices Group at Family Health Isis. In addition, this made the use of visual data critical because for some service users, while they were uncomfortable with being interviewed, they were comfortable with being filmed, especially using the collaborative methods of this project where a measure of control was afforded to the subjects. From this, I was able to gather ethnographic data - through official interviews, conversations, participant observation and visual material - from more than 40 adult service users and 26 health professionals (including academics, community development workers, agency directors and psychiatrists). This number for the service users is an approximation because of the fluctuating numbers of attendees at the agencies. For instance, The Men’s Group had a core attendance of about 12-15 service users and staff, but this number could go up to 25 on any given night.

The qualitative, ethnographic research uses both visual and textual presentations of data in its approach, aimed to elicit meaning and understanding from the situations, actions, interpretation and explanations of subjects. The data in the dissertation is presented in a number of forms.

Firstly, interviews are presented with minimal interruption and without analysis in order to preserve the emphasis on the subject's voice. Service user interviews are presented in longer transcripts, while the interviews with healthcare professionals are presented in shorter selections, divided by professional field – academics, community workers, directors of agencies and staff from within the National Health Service - with a range of voices being highlighted within each field. In interviews and conversations, the emphasis was on getting the subject's voice, understanding the impact of migration and transnationalism, reflecting issues of identity, community and nationhood, understanding the nature of their social suffering, and exploring the manner in which resilience was realized. Interviews were open-ended and were usually done at the offices or agencies that the service users attended or the professionals worked.

Secondly, in order to collapse the traditional dichotomy between visual records produced by investigators, and visual documents produced by those under study, a collaborative photographic representative method was used (Banks 1995). This methodology sought to make visual representations (studying the subjects by producing images), examine pre-existing visual representations (studying traditional images of mental illness and the Caribbean population in the UK), and to collaborate with subjects in the production of visual representations, in situations where subjects were reluctant or unable to be involved in the photographic process, and were able to instruct me about what photographs they would want me to take on their behalf. Included with photographs taken of the subjects are photographs taken by the subjects themselves, photographs from the Notting Hill Carnival of 2013, the premier Caribbean cultural event in London and photographs of Caribbean people and cultural representations in the London area. These images are put together to form a photographic chapter that provides insight into the environment in which the service users inhabit and to reveal the community and aspects of resilience that service users demonstrate.

Thirdly, I asked subjects to participate in the the production of an ethnographic documentary. The original intent was to produce a single long form documentary, but I found that mixing the manner in which filming was conducted was more comfortable for the service users and eventually the innovation of a series of shorter films allowed for more distinct ideas to be presented over a number of pieces. Four films were produced, three of which focus on the Men's Group at Family Health Isis - *The Circle*, *Studio Isis* and *A Friendly Game of Dominoes*, exploring themes of identity, community, resilience and voice. The fourth film, *Masquerade*, juxtaposes the 2013 Notting Hill carnival with the history of civil disorder and social suffering relating to the African Caribbean population in the UK.

Context

The phenomenological approaches used in this methodology emphasize getting service user life stories and experiences directly from the subjects' voices. These approaches include gathering 'deep' information and perceptions through inductive, qualitative methods such as interviews, discussions and participant observation, video and photography, and representing it from the perspective of the service users (Lester 1999). These voices are used for understanding the impact of migration and transnationalism, reflecting issues of identity, community and nationhood, understanding negative experiences in the mental health system through social suffering, understanding the means by which resilience is created and maintained, and understanding the role of media and institutional power. The subject 'voice' is more than just what is and how it is said, but is also a phenomenological perspective represented through visual means. Subject accounts based on ethnographic observation and interviews are often discounted on the basis of inconsistency (Kloos 1988) or for "inheriting misconceptions from cultural insiders" (Marano 1982). But as Marvin Harris states "no one expects to achieve absolute operational purity" (Harris 1976). Phenomenological approaches are "powerful for understanding subjective experience,

gaining insights into people's motivations and actions, and cutting through the clutter of taken-for-granted assumptions and conventional wisdom" (Lester 1999). Public health strategies looking to correct a lack of progress in improving mental health outcomes for Caribbean service users are now promoting a patient-centered emphasis. This movement necessitates a subject perspective, especially since health policy has long been criticised for ignoring this perspective. The challenge of this project is to ensure that this perspective is appropriately examined and analyzed and provided a context within which it can be verified.

The choice to receive these accounts as narratives is based on narrative being one of the fundamental ways in which humans organize their understandings of the world (Cortazzi in Atkinson 2001) and "the primary scheme by means of which human experience is rendered meaningful" (Polkinghorne 1988). For a project concerned with subject experience and subject voice, it is fitting that a narrative approach is adopted since narratives share the meaning of experience. In narratives, the subject gives their own interpretations and explanations, and is able to evaluate the meaning of events and wider relevant contexts (Cortazzi in Atkinson 2001). Narrative is also concerned with the representation of voice, that is, the sharing of the subjective experience and the publicizing aspect of voice to give "higher public profiles to human qualities, often to reveal crucial, but probably generally unappreciated, personal and professional qualities" and to "portray the insiders' view of what a particular experience is 'really' like" (Cortazzi in Atkinson 2001). Even though the narrative approach posits that reality is "situational and fluid," this does not mean that there is nothing 'real' that can be abstracted from the narratives, just that there is no single true underlying perspective (Silverman and Gubrium 1994; Holstein and Gubrium 1995). Such an approach ensures that the knowledge that can be learned from the subjects is in their own voice, and any themes found in the narratives are true to the 'realities' of subjects and do not impose the researcher's own categories on the 'reality' (Hammersley & Atkinson 1983, Thomas 1993, Mackenzie 1994, Baker 1997).

The Afiya Trust states that real progress in public health strategies can only occur when it is “based on a moral and political commitment to social justice and human rights for racialized groups (with) a firm acknowledgement of the interconnectedness of people’s material and social circumstances, including everyday experiences of discrimination, racism and social exclusion (and) the multidimensional contexts of individuals’ and communities’ everyday lives” (Afiya Trust 2010). The ethnographic interview process was one means of proceeding with the project, but in order to present the richest representation and fullest appreciation of the experiences of the subjects, and to contest prevailing theories, it was important to go further. This meant collecting the narratives of these persons, not only in words, but also in images. Giving the control of the camera over to the subjects, they not only could speak their stories, but also show them. By placing cameras in the hands of the subjects themselves, the images produced were bridges of communication into unfamiliar, unforeseen environments and their inner worlds (Ruesch and Kees 1972). The images transcended a use as mere visual captures of ‘reality’ and instead challenged subjects, provided nuances, triggered memories, led to new perspectives and explanations, bridged psychological and physical realities, and allowed the combination of visual and verbal language (Hurworth 2003). The subject’s camera and the decisions they made about what they shot, were valuable ways of granting them power to present who they are, what is meaningful for them and what their relationship to the space around them is, in a way that the written word and the spoken question could not ascertain by itself (Banks 2001; Beloff 1985; Heider 1976; Hockings 1988; Rose 2001; Worth 1981). In this way the camera was a means to accessing a ‘voice.’

It should go without saying that the camera was not a means of having the visual play a simple complementary role to written anthropology or a technique of supplementary documentation (Barbash and Taylor 1996; MacDougall 2006). Rather than have this function where “visual approaches are placed in the service of textual preoccupations” (Grimshaw and Ravetz 2005), a

true and genuine visual anthropology is one that is instead a process of inquiry in which knowledge is not prior but emerges and takes distinctive shape “through the very grain of the filmmaking” (MacDougall 1998). As Pink (2006) argues, what is required is “to explore further how writing and video might combine to represent sensory experience theoretically and ethnographically.” Visual anthropology is not simply anthropology of the visual, but an anthropology of the relationship between the visual and culture and society at large, and not simply the use of visual methods in research and representation, but also the methodological practice of combining visual with other media in the production and representation of anthropological knowledge, without a reduction of the visual to merely being an illustrative counterpart for anthropological text.

The visual methodology used in this project aligns itself with the tradition of participatory visual research, particularly photovoice, a method often used in public health and community development, where “any form of visual art through which individuals can communicate their perspective to others” is used as the data to better understand individuals and communities (Baird 2009). Lorenz and Kolb (2009) discuss the photovoice research process as one where participants take photographs and discuss them in order to understand positive and negative aspects of a situation, community, problem or illness and carry out outreach activities for education or advocacy purposes. Such methodological processes are being increasingly used in social science and public health research and are often used in case study research, ethnographies and the investigation of the illness experience of patients (Lorenz and Kolb 2009). Recently photovoice has yielded projects such as Dr. Michael Yonas’ Visual Voices programs where participants created paintings and drawings to share their perceptions of community safety and violence, combining their individual art projects into public exhibits. Wang et al. (1996) asked women in rural China to photograph issues of importance to them, so their views could be incorporated into a major rural development project. Lykes (2001) used participant-generated drawings and

photographs to address rural poverty and the effects of civil war on community life in rural Guatemala. Putting cameras in the hands of service users shifts the power differential between researcher and subject and provides a tool for participants to teach researchers and policy makers. In this way, participatory visual methods help to avoid passive forms of representation that may reinforce existing power hierarchies and social inequality, and thus contribute further to social suffering. The data resulting from such methods, in challenging traditional methodologies, may lead to “new future visions, unanticipated strategies, and policies that improve the lives and health of individuals and their communities” (Lorenz and Kolb 2009).

Lorenz and Kolb (2009) argue that in prompting a more direct understanding of subjects, their life experiences, and their perceptions, than can be done by data collected and controlled solely by the researcher, visual methods challenge the assumption that the experiential knowledge of lay people is “invariably limited,” compared to so-called experts. They argue that professional understandings of illness and disease are inevitably limited and as such need to be placed in a context that includes lay peoples understandings of health systems and practices. Participatory visual methods, including those used in this project, are a means to generating understanding of “the wider context and develop a shared body of knowledge that, ideally, integrates the knowledge of social scientists and the daily life knowledge of research participants about their health and communities” (Lorenz and Kolb 2009). This is especially critical for persons whose economic status, age, gender, race or health status makes them significantly vulnerable or marginalized in society, and whose voices are often not heard in policy-making efforts. Participatory visual methods create opportunities to hear these voices and bring their experiences into the policy-making process, fostering increased understanding and awareness of health and health-care challenges facing individuals and communities (Lorenz and Kolb 2009).

The philosophy behind photovoice work, of having subjects produce visual work that prompts research and produces knowledge is part of an older movement in the social sciences, including anthropology, of not only viewing visual data as a means of communicating intangible aspects of culture that often remain invisible in textual presentations, but a larger paradigm shift towards having research subjects produce the visual data. This begun in the shared and subject-empowered ethnography advocated by filmmakers such as Jean Rouch, where “those in front of the camera shared the power with the director” and the reflexive work advocated by the evolving practices of MacDougall (Ruby 2000). Another early example is the seminal collaborative study conducted in the 1960s by Sol Worth, John Adair and Richard Chalfen with a group of Navajo students. In this work they taught the Navajo students to make documentary films, creating a film series known as the *Navajo Film Themselves* for which Navajos created films to show their understanding of the world and the place of their people and culture.

Another such movement has been the indigenous media movement, considered to be “work produced by indigenous peoples, sometimes called the ‘Fourth World,’ whose societies have been dominated by encompassing states, such as the United States, Canada and Australia” but is distinguished from the national and independent cinemas of non-Western developing nations in Asia, Latin America and Africa (Ginsburg 1991). The aim of indigenous media is to creatively address the needs of marginalized indigenous groups and often transcends just technological work, but is connected to activist work focused on education, career training, policy debates, and economic assistance. Video efforts have generally been small-scale and small-budget and most often restricted to local contexts, but there have been some production companies such as the Inuit company, *Igloolik Isuma Productions* in Canada and the *Warlpiri Media Association* in Australia, and there have been acclaimed indigenous works, such as Tracey Moffat’s ‘Nice Coloured Girls,’ a film that confronts Australia’s colonial history and tackles the issue of race and gender from a female, indigenous perspective.

Cooperatively produced and subject-generated films are significant because they offer the possibility of perceiving the world from the viewpoint of the subjects, who traditionally do not control “the means for imaging the world” (Ruby 1991). Subject-generated films can be used by marginalized people “to negotiate a new cultural identity” and to negotiate a position of power in the established order (Ruby 1991). The films produced for this dissertation embody this cooperative movement. For *The Circle*, I mostly engaged in a participatory and observational cinematic process (a few shots are subject-generated), where the filmmaker acknowledges entry into the world of the subjects and asks them to imprint their own culture directly upon the film. This commits to a method that “follows” the action rather than “directs” it, with an emphasis on detail and forging an intimate relationship between the camera and its subject. This method allows the filmmaker to take his or her mandate from the subjects and for knowledge to emerge, rather than imposing his or her own explanatory frameworks upon the subjects and their situations (MacDougall 1975, 2001, 2006). *A Friendly Game of Dominoes* is completely subject-generated. *Studio Isis* sits somewhere between being subject-generated and collaborative. *Masquerade* is an experimental montage film that is in many ways in conversation with experimental documentaries like Isaac Julien’s *Territories* (1984) and John Akomfrah’s *Handsworth Songs* (1985), both of which explore race and disorder in Britain, and both of which use experimentation to challenge conventional forms of representation (Russell 1999). The visual anthropological method of this project is subjective and reflexive, in line with the innovative histories of filmmakers such as Rouch and MacDougall and aligns with advocates of modern visual approaches that make “reflexivity, collaboration, new approaches to ethics and new technologies necessary themes in any ethnographic methods text and especially in visual ethnography texts” (Pink 2001; Banks 2001). Thus, it is a ‘shared anthropology’ and one where the camera is a witness to events, as they happen, so that culture is revealed, rather than used to document events that have been selected by the filmmaker to illustrate what they have pre-judged to be culturally significant. In addition, the audience is allowed to hear subjects speaking in their

own language and understand what they are saying, rather than having events interpreted for them and relayed by an authoritative Western voice (Barbash and Taylor 1996), thus representing “a definite shift in voice and authority” (Ruby 2000).

Analysis

A content and narrative-based qualitative analysis was made of the visual and textual data produced (photographs, transcripts, video). The value of these analytic methods is that they are more reflective of an individual's constructs and contextual organization of experience (Smith 1992). Content analysis was used to reduce the large body of qualitative information to a more manageable form and coded to reveal relevant themes. Coding systems were culled from existing systems developed for social science research that investigate social alienation, anger, sadness, tension, anxiety (Gottschalk 1995; Hall & Vande Castle 1966; Smith. 1992; Viney 1983), emotional expression (Pennebaker et al. 1997), generativity (McAdams & St. Aubin. 1992) and self-definition and social definition (Stewart 1992).

To complement the content analysis, the narrative analytic method allowed for a holistic approach that provided access to subjective experience and insights into conceptions of self and identity and opened up new ways of studying memory, language and thought, and socialization and culture (Smith 1992). The narrative approach is said to (a) provide meaning and coherence to, and perspective on, experience and one's social traditions (Bruner 1990); (b) construct a person's knowledge (Bruner 1986; Daiute 1995), including a person's sense of self or identity (McAdams 1993; Miller et al. 1994); (c) produce an organizing principle for human action (McAdams 1993; Sarbin 1986); (d) alter the teller's way of thinking about events, and/or sense of identity (McAdams 1993; Polkinghome 1988; Schafer 1992; Spence 1982); and (e) bring about emotional

adjustment and healing (e.g., McAdams 1993; Pennebaker et al. 1997). Thematic significance was based on the frequency of similar issues that emerge from the collected data.

Data was then organized into three ethnographic chapters: an ethnography of Family Health Isis, and then a chapter each for the service users and health professionals' interviews. Interview findings were arranged according to key issues discussed by subjects and presented under themed headings as direct quotes without interpretation or analysis. Some statements were edited for clarity and grammar where it was felt that a statement would be unclear if this was not done. The aim was to be as faithful to the actual words of the subjects as possible. Data was then analyzed and discussed in two further chapters, linking findings to existing literature, critiquing prevailing theories and providing fresh interpretations linked to the data. A final chapter giving concluding statements on the project and detailing issues and implications of the research is provided.

Constraints of methodology

There are of course limitations to the narrative methodology. Richmond (2002) in "Learners' Lives: A Narrative Analysis" highlights three such limitations: the illusion of causality, where the patterns of a learner's self identity, their culture and community and any transformations that take place over time are telescoped by the learner in the telling of his/her story; the significance of repeated patterns, where no single story should be taken as the full understanding of a phenomenon; and the possibilities and potentialities of transferability, where narratives can mutate on different tellings. Every narrative has to be viewed as a version from a particular, but crucial perspective, that can be structurally analyzed for substantive information, meaning construction and the relationship between the two (Holstein and Gubrium 1995). Each narrative can also be broken down into structural categories: an event structure, which reports happenings; a description structure, which gives background information on time, place, people and context

necessary to understand the narrative; and an evaluation structure, which presents the speaker's motivations in telling the narrative and their judgment on the events (Richmond 2002). In this way, account is taken of the function, the performance and the cultural context of narratives.

There are obvious hazards with working with a group at risk and the sensitive nature of the research. This however does not mean that there is a high likelihood of harm. One anticipates that at the very least, discussions about mental illness with subjects could result in a certain amount of stress and distress. Bearing this in mind, I was mindful to have the support of staff members in the mental health day centers that I visited and made very clear to the subjects that if at any time they felt the need to stop an interview or to withdraw completely from the project, then they were free to do so.

The use of a visual methodology provides both challenges and advantages. One must bear in mind, despite the camera being a mechanical recording device, it is not a "neutral technology" and images created are "subject to the influences of their social, cultural and historical contexts of production and consumption" (Banks 1995). The visual methods I chose were carefully considered and took into consideration subject empowerment and power dynamics and aimed to be as collaborative as is feasible. One must also bear in mind that there is a danger that the visual can be relegated to simply being supplement for the textual. This dissertation follows more in the tradition of similar works that seek to illustrate the power of both the word and the image to provide relevant anthropological knowledge. As already stated, in combining "image-and-sequence-based" with "word-and-sentence-based" anthropological data, the hope is to present the broadest possible picture of the subjects (MacDougall 1995; Mermin 1997). It is argued that the "video-and-photo method captures the stories" behind the material and lets people act out ideas or show concepts that do not fit easily into words and makes it possible to "create deeply meaningful—and visible—representations of things that are normally invisible, such as feelings, thoughts, and expectations" (Bean 2008).

As with all qualitative approaches, there concerns about sample size. For this project, this is especially so for the service user perspective where a select number of voices are used to speak more representatively for the larger Caribbean service user population. Participant observation within service user populations was conducted for about two years and I was able to speak to a number of service users both formally and informally. In general, female service users perspectives across interviews and films are underrepresented. This was mainly a consequence of day centers having more male attendees and the spaces I was allowed to observe (for instance, no men are allowed in women's group meetings). Attendees at these day centers also skewed slightly older as well, with most persons being 40 or over. Though each individual voice is not represented in the ethnographic chapter, the selected voices both fairly represent the broader concerns of the majority of persons I met and spoke to, but also fit with the findings of other researchers who have done work on this population. The difference in my research is the emphasis on having the subjects speak for themselves, both in words and through imagery.

Lastly, there is a danger of speaking about race and 'Caribbeanness' as if they are clearly defined, homogenous categories, or employing them as research categories for the sake of convenience. For the purposes of this project, these categories are given meaning because of the significance prescribed by medical outcomes and medical treatment. Caribbean persons in the United Kingdom are overrepresented in the mental health system with diagnoses of schizophrenia. Caribbean persons more frequently come into contact with the mental health system through the justice system. Outcomes such as these are real despite the messiness of what a Caribbean category is. As Frazier (2014) states, race and ethnicity while not being end points that can be addressed through medical interventions, are starting points and embodied concepts through which we can understand medical outcomes. It is as imperfect, starting points for the investigation of mental health treatment and social suffering, that they are used in this project.

Contribution to anthropology

Arthur Kleinman in 'Medical Anthropology and Mental Health: Five Questions for the Next Fifty Years' highlights that over the past fifty years the central questions for anthropology as it relates to issues of medicine and psychiatry have been questions of taxonomy, of subjective experience, of treatment systems and their interventions, of culture, of policy, of political economy, and of social theory (Kleinman 2009). The challenge going forward for anthropologists is what new can be contributed. Kleinman proposes five questions that can "advance an intellectually strong, academically robust mental health sub-discipline as well as the larger field of medical anthropology" (Kleinman 2009). Of these five questions, two are most relevant to this project: what difference there is between social suffering and mental health problems and how this difference is significant; and what is the implication for anthropological research interested in medicine of going beyond stigma to redefine in cultural terms what is at stake in the most severe psychiatric conditions.

This project contributes to the relative dearth of research of mental health issues in the Caribbean population, especially anthropological work, and goes some way to providing those involved in the care of these individuals, insight into ways by which they can better serve the community. Malinowski's "Practical Anthropology" called for anthropology to move "beyond the sterile confines of academia and enter the world," (Malinowski 1929). Similarly Chambers challenged anthropologists to "use the knowledge, skills, and perspective of their discipline to help solve human problems and facilitate change" (Chambers 1985). National health policy and the politics of medicine become ever more complex and the nuance required to positively influence the direction of treatment demands tools that recognize that policies cannot change or bring about change if we do not continue to develop our understandings of the phenomenology of illness. The phenomenological approaches of this research are a means to providing beneficial tools.

Work has not frequently engaged with the Caribbean experience as it relates to mental illness, and has not frequently engaged directly with service users (Amery 1999; Barkow 1992; Bhugra 1995; Biehl, et al. 2007; Cassel 1982; Desjarlais 1995; Csordas 1994, 2002). This dissertation corrects this by accessing more directly the voice of Caribbean subjects by having them speak for themselves. This use of a narrative method provided subjects with an opportunity to impose order on life events, and to create continuity between past, present and imagined worlds (Ochs & Capps 1996). The dissertation builds upon existing theories of narrative and collaboration and argues that narratives themselves are collaboratively performed events between teller and audience, in that they order events that are connected in a meaningful way for the purpose of a particular audience to make sense of the world and experiences in it (Hinchman and Hinchman 1997; Langellier 1989, 2001). Specifically, narratives of illness draw upon culturally shared images and connections between individual and society (Mattingly & Garro 1994; Hyden 1997), and connect the personal experiences of individuals to public issues of social structure (Williams 1984; Carricaburu & Pierret 1995; Bell 2000).

Our consciousness of the being of almost everything in the world involves vision (MacDougall 2006). This consciousness is of course also shaped by culture, and culture itself is embodied, thus it is imperative that visual representation is present in anthropological work (Ruby 2000). Despite this, it has been argued that image-based research is undervalued and under applied by the orthodox qualitative research community and that it can make a proportionately greater contribution to research (Prosser 1997). Even now, though the technology for this kind of work is readily available, more work can still be done to push the agenda of anthropology creatively by using visual media (Wright 1998). This dissertation contributes to the use of visual methodology becoming a more standard practice, so that this practice can continue to pose fundamental challenges to anthropological ways of 'speaking' and knowing (MacDougall 1998). The use of visual methods in this project builds on existing scholarship in visual anthropology and on

research that continues to push for innovative ways to investigate topics of study (Maynard 1997, Nichols 1981). In addition, as a collaborative work, the images produced in this dissertation challenge traditional iconography and semiology of images of blackness, illness and Caribbeanness, especially so in the UK context where particular images (such as Caribbean people being excessively hostile and prone to schizophrenia) of Caribbeanness and Caribbean mental illness exist (Pink 2001). This dissertation explores issues of representation of illness in traditional images and the use of both still photography and film, and an emphasis on narrative, elicits fresh exploration of existing theories. The complement of text and image-based work makes for a richer anthropological product (Asch and Chagnon 1975; Bateson and Mead 1991; Deren 1977). Further, in addressing the role of media power, this dissertation contributes to literature investigating the location of the production of meaning and ideology in the mass communication process, and how to characterize processes of agency and interpretation (Spitulnik 1993).

Current literature on migration and transnationalism offers the theory that notions of nativeness and native places have become very complex as more individuals are identified or identify themselves in reference to deterritorialized "homelands," "cultures," and "origins." What has emerged is an awareness of the global social fact that people are constantly mobile and routinely displaced, and invent homes and homelands in the absence of territorial, national bases through memories of, and claims on, places that they can or will no longer corporeally inhabit (Malkki 1992; Appadurai 1998, 1990; Said 1979, 1986; Clifford 1988; Rosaldo 1989; Hannerz 1987; Hebdige 1987). This dissertation adds to this by investigating the effects that being a migrant or a post-first generation migrant has on a notion of becoming and being an individual with a cultural identity (Hall 1990). In addition, this dissertation explores the idea that in the face of social exclusion, the Caribbean service user community has been able to create a resilient space that utilizes the transcultural experience.

In general then, the broader implications of this work are that it will provide a fresh perspective on the issue of resilience and mental health by utilizing non-traditional methods that will challenge well-established theories and open new questions and by making a commitment to allowing the voices of the subjects themselves to be paramount in both the content and the direction of the research (Edwards 1997, 2002; Maynard 1997; Nichols 1981). Through a synthesis of collaborative, narrative and visual methods the project will contribute to the movement for fresh and innovative methodology; to the movement of visual anthropology into the mainstream as a consequence of its successful application to traditional issues; to academic work that looks to combine visual and textual analyses; to the growth of ethnographic and anthropological products that not only empowers the subject but cedes a measure of control to the subject; to further nuance the discussion and theories of social suffering; to the body of literature dedicated to issues of migration, transnationalism, mental health and the Caribbean; and to semiological and iconographical literature, especially so as it relates to illness. The dissertation builds upon three major areas of anthropological research: social suffering, the anthropology of resilience and visual methodology.

Chapter Two: Literature and Background

Introduction

The main research question for this project is how the current treatment provided under the mental health system in London re-traumatizes Caribbean service users. A major outcome of answering this question was the way in which service users create resilient spaces as a response to this trauma. In order to effectively investigate the experiences of these service users it is important to contextualize the project in existing literature and theories. In organizing this chapter, it made sense to think of it as building a narrative of service users, individuals with a migrant history, perceived negatively in the British society, impacted by the occurrence and diagnosis of, and policy making for mental illness. These experiences converge to produce social suffering that many combat with a cultivated resilience that draws from that migrant history. To understand the impact of migration and transnationalism, and how it relates to issues of identity and belonging for this population, it is important to look at migration and transnationalism literature and have it be in conversation with literature on identity and culture. This then necessitates looking at how this diaspora is perceived in the British context, so literature that explores representation and the role of media, specifically as this relates to blackness and illness is required in order to understand how media and institutional power are influential. This influence extends to the culture of treatment, so as part of the objective of describing the experiences of Caribbean service users in the mental health system and understanding how policy affects treatment, it is important to look at literature and discussions surrounding these policies. This leads to analyzing theory relating to social suffering to understand the ways in which social suffering and mental health problems interplay, before lastly analyzing how the resilient responses to social suffering are discussed in literature and theory. This chapter is divided into five sections: transnationalism and identity, media and representation, policy and practice, social suffering, and resilience.

Literature*Transnationalism and Identity*

One little suitcase, one little valise... full of food... there was yams, and sweet potatoes and breadfruit, there was eggs, pumpkins. I'm walking through the airport with a suitcase filled with food. And there's sugar cane syrup... molasses. Molasses is good for the blood pressure in Britain, you know, that sort of thing ... So all that, and bush, bush tea, the bush for making bush tea.

Jasper (15 yrs.) in 1965 when he arrived to join his parents in Britain (Chamberlain 1999)

Mary Chamberlain, in her article “The Family as model and metaphor in Caribbean migration to Britain” makes meaning of the 'compressed fullness' of this suitcase, arguing that not only was it filled with food, but also the “symbols of a family and a culture, transported, transplanted and transformed across the ocean” (Chamberlain 1999). This cultural perspective in Caribbean migration to Britain has historically been absent from academic literature, with the focus being more so on economic factors and labor and capital demands. Prominent in this economically focused literature has been the Dependency and World Systems theories of Gunder Frank (1967) and Wallerstein (1979) with their focus on the exploitative economic power relationships between central wealthy states and poor, underdeveloped periphery states where resources are extracted from the periphery and flow towards the developed, industrialized world. Peach argues that the main determinant of West Indian migration to Britain was the demand for labor in the UK and that the result was the concentration of West Indians in areas being abandoned by the white population. 75% of West Indians in Great Britain lived in towns that had shown net decreases in white population (Peach 1968). Up until the early 1960s, approximately 300,000 Caribbean

migrants had made their way to the UK. Many of them were ex-servicemen who had seen war service in Britain and believed that they would have more opportunities there for improving their lives there after World War II. At the time British government and industry were claiming that the Welfare State offered full employment for all, and so thousands made the long trek to Britain 'to better themselves,' even if that meant taking on unskilled menial jobs and working grueling hours. As Barbadian poet and novelist George Lamming noted, "England [had] come to mean opportunity, horizons, success." But this journey to those horizons was a rough one, made more rough by the colour of West Indian's skin, that not only acted as "a cage which betrays the bird within it," as Lamming would say, but also was "a cage which was to keep him imprisoned in a social and economic strait jacket, denying him equal rights with the host population" (Hinds 1966). In *Journey to an Illusion*, Donald Hinds describes the migration beautifully:

They came in their light-weight suits and straw hats and felt sombreros, teeth chattering, shivering in the draughty, freezing, alien, impersonal, busy atmosphere of the railway stations - Waterloo, Victoria, Charing Cross, or anywhere else they were dumped, together with their cardboard boxes, battered suitcases, and string-tied baskets. London had seen nothing like it before and Londoners were taken aback. A certain annoyance showed on the faces of the cockney porters, waitresses, cabbies, and policemen at this sudden onslaught on their quiet preserve. London's newspaper reporters, columnists, feature writers, and photographers had a field day or, to be more accurate, many field days at Waterloo station and London airport, covering the arrival of fresh contingents of West Indians. Their papers spread front, centre and back pages with an array of pictures, heavily spiced and peppery stories. The banner headlines described West Indians 'whose calypso flamboyance could not be chilled even by the frosty air of an English winter.' Actually, those gay West Indians were cold, hungry, miserable, and frightened.

Despite newspaper optimism about this imported labor (one 1948 headline read “WELCOME HOME”), and the dire need for this labor, Caribbean people (specifically black Caribbeans) faced resistance from both government and unions who together with employers and various state agencies contrived to marginalize and stigmatize Caribbean migrants. Wiltshire in Glick-Schiller, et al. (1992) argues that given Europe’s long historical efforts to maintain racial identity and the concept of the nation bounded by clear territorial boundaries having emerged from Europe it is unsurprising that there was general resistance to immigration.

Despite the relationship of Britain to the former colonies, the reality of ‘Mother England’ was that English society was closed to migrants and assimilation was deemed undesirable. Ironically, this made it easier for migrants to retain their customs and values (Lewis in Palmer 1990). In Britain, welcomes became warnings that white, Christian culture was being polluted by “dark, alien forces” and became wailings by xenophobic nationalists that there was ‘no black in the Union Jack’ (Rex & Tomlinson in Palmer 1990). Most extreme in his denunciation right from the start of this black migration into Britain was Oswald Mosley, whose paper *Action*, cried "Blacks Invade Britain," and "Send the Coloured Immigrants Home." Similar press reports served to instill more apprehension and fear in the minds of the British people, who began to view these migrants as invaders who would disrupt their stable pattern of life and impair their standards, customs and morality (Hinds 1966).

With internal economic problems, rising racism and social rejection being a reality, this resistance began to manifest legally in the 1960s. The British Parliament passed the Commonwealth Immigrants Act in 1962, restricting the perceived heavy influx of immigrants, permitting only those with government-issued employment vouchers to settle. This type of regulation continued on in amended form with the Commonwealth Immigration Act of 1968 and the Immigration Act 1971. Some rescindments were made with the 1976 Race Relations Act, which outlawed racial

discrimination, but the absence of meaningful state monitoring systems, a shortage of resources and resolve weakened efforts to protect the immigrant population (Thompson in Palmer 1990). The result then was that immigrants were denied “real British” identification. Paradoxically when civil rights movements began to emerge and the self-identification of ‘Afro-Caribbean’ was made, this too was contested. Conservative MP Terry Dicks wrote in the *Tatler* publication in 1989, “I don’t believe in the phrase *Afro-Caribbean*. They are West Indians and that’s where they came from. If they want to go back to Africa then we can give them some ladders and they can climb up the trees if they want to” (Thompson in Palmer 1990). The result for West Indian people in Britain was a sense of both anomie and alienation, where they live “in a world of social acts taken for reality which are not of [their] own making” (Littlewood and Lipsedge 1997).

Murdoch argues in *Creolizing the Metropole* that this “explicit conflation of race and nationness projected fears and anxieties that paralleled similar exclusionary themes - grounded in theorized conflations of “belonging” and temporality that appeared at first blush to be beyond stereotyped discourses of race and place - espoused in “objective” contexts” (Murdoch 2012). Public opinion helped usher in the legal racialization of immigration initiated by the Immigration Act and Rules of 1971 and 1973, both of which restricted immigration. The Nationality Act of 1981 further and more drastically restricted and redefined the criteria for British citizenship, insisting that the subject or their parents had to be of British birth. This officially formalized the door shutting on former colonials who would no longer have the right of permanent entry into Britain. Mother England had officially abandoned its ‘children.’

Littlewood and Lipsedge (1997) highlight that membership of a group, whether that is a class, or a nation or a race, is defined by those that are excluded from it. They argue that those who are excluded are perceived as different, “an undifferentiated mass with no individual variations.” As outsiders, distinguished by biological or cultural difference, they pose a threat to the status quo

and a dangerous just by virtue of being different. The mentally ill and the non-European are both considered as outsiders and aliens, set apart as being different by virtue of deficiency of certain characteristics. They state that the paths of the mental patient and the non-European often run across and parallel, where the same theories often keep them alienated (Littlewood and Lipsedge 1997). Following this line of argument, it is evident how difficult it would be for the biologically and culturally different migrant to fit in. Once you take into consideration the social opposition and legal restrictions to their presence and the onset of mental illness for some, exclusion certainly does become alienation. But Littlewood and Lipsedge (1997) argue that this does not become less of a problem for later generations of Caribbean migrants, who are born in the United Kingdom, for who it might be thought are less on the outside of the national group by virtue of birth. They state that “official racism” in Britain actually worsened after immigrants became British rather than remaining as migrant laborers. In *Black Britain*, Chris Mullard (1973) wrote:

A black man born in Britain is a shadow of a man. A form but no identity, because you are black. You are not a West Indian, Indian, Pakistani or African, because you were born in Britain and you know little or nothing about your parents country. Even if you wished to you cannot pretend you are a black immigrant, because embedded in your being is the knowledge that you are not... in the end you have no alternative but to remain alone, insecure, without an identity of your own making. Is it possible to be black and English? Does it necessarily follow that because a man is born and educated in a particular country that he should rightfully assume the identity of the nationals of that country?

Older generations had grown up in a colonized homeland, raised in the belief that as a colony they were essentially British, arrived on British soils and faced racially motivated anger and resentment and unequal access to the benefits of citizenship. Figures such as Mullard argue that the situation was not any different for the legitimately British children of migrants, as they were

still considered essentially alien and non-British. This sentiment was most famously articulated by parliamentarian Enoch Powell in his infamous "Rivers of Blood" speech, delivered to a Conservative Association meeting in Birmingham on April 20 1968, which encouraged the re-migration of migrants, drawing upon racialized fears of ethnic and cultural difference, and was visualized in growing numbers of Commonwealth immigrants of colour. With the Race Relations Act of 1968 on the horizon, which would make it illegal to refuse housing, employment, or public services to a person on the grounds of colour, race, ethnic or national origins, Powell argued that the "legal weapons" provided by "the ignorant and the ill-informed" would allow immigrant communities "to overawe and dominate the rest," such that looking ahead, he was "filled with foreboding, like the Roman [seeing] the River Tiber foaming with much blood." He continued, "in 15 or 20 years' time the black man will have the whip hand over the white man" (Powell 1968). Powell became the symbolic figurehead of the vocal anti-immigration movement. Immigrants were pictured as invading hordes who, with their "peculiar practices and origins and predilection for crime and moral turpitude, would never be able to assimilate" (Favell 2001).

The experience of many Caribbean migrants in the UK was one characterized by discrimination, violence, financial and employment difficulties and difficulties in assimilation and coping. Shut out of being 'real British,' but surviving in the British context, what emerged was either a rejection of Britishness completely or the complex adoption and co-opting of multiple national loyalties, especially for the offspring of these migrants. Caribbean migrants, then after decades abroad, still identified strongly with their homelands and retained an "ideology of return" and believed that return migration is the natural completion of the migration cycle, as there is "no place like home" (Philpott 1973; Potter et al. 2004; De Souza in Potter et al. 2005). Eric Williams, Trinidad & Tobago's first Prime Minister would go as far as to say "there can be no Mother India... no Mother Africa... no Mother England... A nation, like an individual, can only have one Mother. The only Mother we recognize is Mother Trinidad & Tobago." Williams'

assertion is not wholly accurate. The reality is that Caribbean nations have fluid and permeable borders, and often, especially for smaller Caribbean islands, more nationals live outside than nation's borders than within it. It might be argued that the Caribbean individual in the diaspora, though looking to belong and be accepted, has no one mother or no mother at all.

Relatively particular to Caribbean migration is an idea of 'transnationalism' where it is not merely an issue of changing 'homes' from one nation to another, whether it is an exodus to the metropolis or a return to 'homeland,' but that there is a sense that migrants seek to maintain a sense of 'home' in two nations, facilitated by constant communication and economic transactions with their native countries from their new residences and by technological advances in transportation and telecommunication (Glick Schiller, et al. 1992). Transnationalism challenges a more traditional conception of the permanent rupture and uprootedness of migration that must make way for this Caribbean process by which immigrants build social fields that link together their country of origin and their country of settlement. These 'transmigrants' develop and maintain multiple familial, economic, social, organizational, religious and political relations that span borders (Glick Schiller, et al. 1992). The central premises of transnationalism are that bounded social science concepts such as society or culture limit the ability of researchers to analyze the phenomenon of transnationalism, but that the development of the transnational migrant experience, grounded in the daily lives, activities, and social relationships of migrants, is inextricably linked to the changing conditions of global capitalism, and must be analyzed within that world context. These transnational migrants live a "complex existence that forces them to confront, draw upon, and rework different identity constructs – national, ethnic and racial," and this fluidity compels a reconceptualization of the categories of nationalism and ethnicity (Glick Schiller, et al. 1992).

The reality of transnationalism is not necessarily positive. For the individual in the Diaspora, "a

Caribbean identity usually implies a crisis of belonging... uprooted from the familiarity of home, cut adrift and all alone in a new land, feeling insecure and sometimes scared,” away from a ‘natural’ environment is to be deprived of “ever again functioning completely and fitting in instinctively,” (McGill 2005; Breytenbach 1993). For later generations there is a new sense of rootlessness and identity crisis that is made more problematic by the history of British resistance to assimilation and Caribbean romanticism for a return ‘home.’ It is already the case that ethnic minorities in the UK are younger, live in larger households, and generally live on lower incomes compared to the native White population and that parental socioeconomic profiles signal bleaker life chances and opportunities for minority and immigrant youth compared with their White counterparts (Tienda in Rutter & Tienda 2005). This is compounded by a potential cultural identity crisis for second and future generation Caribbeans in the UK, who may not have the same access to community support that the first generation were forced into by British social resistance to their presence or have the same transnational connections to the Caribbean that this older generation had. Thomas-Hope points out that “as Caribbean communities overseas have become increasingly dominated in number by second and third generation born in the host country, so interest concerning them back home has diminished proportionately” (Thomas-Hope 1992). Those later generation members who move ‘back’ to the Caribbean, are not necessarily welcomed and are often treated with skepticism, jealousy and mild derision (Horst in Plaza & Henry 2006).

Media and Representation

Another interesting though unexplained element in the formation of second-hand notions about colored people among the English urban lower-middle and lower classes was, even as late as the 1930s, the threat used by mothers to naughty children: 'Now then, Johnnie, you stop being naughty or the black man will come and get you.' (Patterson 1963).

Fundamental to understanding the culture of mental healthcare within which these negative experiences are felt by African Caribbean service users, and connected to the alien position of the transmigrant, is a culture of media that produces, maintains and reinforces negative and stereotypical portrayals of race, ethnicity and illness. This has occurred over an extended period of time, in such a way that these portrayals have in an overwhelming manner been taken to be 'real,' not just at the level of the lay person, but has had political resonance and has informed policy, laws, treatment and policing. Mass media is often defined as the electronic media of radio, television, film, and music and the print media of newspapers, magazines, and popular literature. As it relates to media studies scholarship, the term 'media' is thought of in a more far-reaching sense to include and encompass communication channels, technologies, formats, genres, and products. Vidali argues that media is best defined by what it is not: face-to-face communication (Spitulnik 1993; 2000). This is interesting because of the implications it has for perceptions of minority ethnic groups in societies where the dominant cultural groups effectively control media and its production and transmission where it is possible that there is a lack of meaningful face-to-face communication between the groups. Media are key agents in the political economy of language, helping to circulate not only ways of speaking, but have implications for the production of culture, ideology, and identity (Spitulnik 2000). There are implications for how media representation of blackness and illness affect Caribbean service users and a history of negative representation in British society highlights how cultural control has impacted treatment.

- *Media and Blackness*

Rony (1996) argues that black Caribbeans bodies are racialized and denied historical agency and psychological complexity, such that imagery of Caribbean bodies has been "emptied of history." Rony states, "individuals are read as metonyms for an entire category of people, whether it be ethnic group, race, or Savage/Primitive/Third World." If unchecked, the proliferation of such

imagery might seduce the viewer into seeing them as ‘real,’ especially so in the absence of alternative, countering images. The perceptions of West Indians in the UK often evoke ideas of criminality, aggression, broken families and boorish youth. These perceptions and stereotypes are not new and in many ways exist as enduring, stale leftovers of long-held colonialist attitudes that have been failed by the textbooks in schools, the newspapers in corner shops and the programming on televisions. Many a stranger has entered the British borders, but the “visible alienness” of the ‘dark strangers’ that Sheila Patterson describes provided an intensified brand of “the usual British insularity and antipathy” (Patterson 1963). Traders, who had reached the shores of West Africa around 1550, wrote some of the earliest English descriptions of Africans. Robert Baker's poem recounts his voyages to the West African coast in 1562 and 1563:

*And entering in [a river), we see
a number of blacke soules,
Whose likeliness seem'd men to be,
but all as blacke as coles.
Their Captain comes to me
as naked as my naile,
Not having witte or honestie
to cover once his taile. (Baker 1563)*

Winthrop Jordan (1984) in *Race in Britain: Continuity and Change* argues that for the English, the concept of ‘blackness’ was already loaded with intense negative meaning, especially as opposed to ‘whiteness’ and so the description of the African complexion as ‘black’ became equally loaded. The dictionary definition of black before the sixteenth century included, “Deeply stained with dirt; soiled, dirty, foul. ... Having dark or deadly purposes, malignant; pertaining to or involving death, deadly; baneful, disastrous, sinister. . . Foul, iniquitous, atrocious, horrible,

wicked . . . Indicating disgrace, censure, liability to punishment, etc.” By the eighteenth and nineteenth centuries, the themes of savagery, heathenism and promiscuity associated with Black skin were used to justify slavery and exploitation and the biblical interpretations of black stereotypes as being a divine curse were replaced by scientific ones. Prominent Scottish philosopher David Hume wrote, “I am apt to suspect the Negroes, and in general all the other species of men... to be naturally inferior to the whites” (Hume 1753). With industrialization and industrial and commercial values becoming more significant in Britain, negative associations of black people as lazy and lacking ambition became added stereotypes (Hartmann and Husband 1974). In 1788, the Gentleman's Magazine, one of the most popular and influential periodicals of the day, provided their image of the ‘Negro’ that contained all the major facets of the prevailing perceptions of the day and had sustained from the sixteenth century:

The Negro is possessed of passions not only strong but ungovernable; a mind dauntless, warlike and unmerciful; a temper extremely irascible; a disposition indolent, selfish and deceitful; fond of joyous sociality, riotous mirth and extravagant show. He has certain portions of kindness for his favorites, and affections for his connections; but they are sparks which emit a glimmering light through the thick gloom that surrounds them, and which, in every ebullition of anger or revenge, instantly disappear. Furious in his love as in his hate; at best, a terrible husband, a harsh father and a precarious friend. A strong and unalterable affection for his countrymen and fellow passengers in particular seems to be the most amiable passion in the Negro breast.... As to all the other fine feelings of the soul, the Negro, as far as I have been able to perceive, is nearly deprived of them.

It would be untrue to state that all views held in British society of black people in the seventeenth century were ‘negative,’ but it would be also untrue to characterize the dominant ‘positive’ image of the ‘noble savage’ as being any more progressive. Here black people were thought of as having

a natural innocence akin to that of children, which of course only bolstered enduring paternalism and the theory of white superiority.

The centuries old images of blackness continued on into the 1960s. Darker skin when combined with “Negroid features” was associated with alienness, lower social status, primitiveness, savagery, violence, sexuality, general lack of control, sloth and irresponsibility, but also with athleticism, artistry, musicality, and “with an appealing and child-like simplicity which is in no way incompatible with the remainder of the image” (Patterson 1963). The historical negative portrayal of and sentiment towards black people in the United Kingdom only intensified and complexified as mass migration in the 20th century from the Caribbean occurred. This migration in the 1950s coincided with the advent of the mass installation of television sets in British households (Daniels and Gerson 1990). As early as the 1940s and 1950s, American performer Paul Robeson and Jamaican folklorist and poet Louise Bennett contributed to BBC television programmes drama and entertainment, so there was not been a complete absence of black representation in televised media. The issue has mainly been a combination of the nature of that representation alongside the relative scarcity of it. Hall (1990) argues that the depiction of black cultures in popular media in the 20th century had largely been restricted to a narrow presentation of stereotyped images - the slave, the native, the entertainer, such that these limited presentations, reinforced by a lack of alternative images, became representative for all black people. In this process of simplification and reduction, black communities were constantly framed by media texts within a narrow repertoire of meaning, fostering a situation where an audience that might not have had first-hand or meaningful experiences of those communities had no reason to challenge them, since their frame of reference would not include opposing conceptions of blackness. The narrow repertoire takes on “iconic dimensions, signifying in one constructed image, the complex of diverse and heterogeneous communities, reducing individual uniqueness to a false and essentialized black ‘other’” (Ross 1996). In addition to the relative scarcity of black

representation, there was also programmes like the BBC's *Black and White Minstrel Show*, which as the name suggests consisted of white performers singing and dancing in 'blackface' in an homage to the American stage tradition, complete with representations of black people as "cheerful, rolling-eyed simpletons" (McQueen 1998). The programme, which ran from 1958 to 1978, was according to David Milner, "the single most regular exposure of 'black' people on the television screen" during its time on screens.

Cottle (1993) similarly laments that under-representation and stereotypical characterization within entertainment media, negative problem-oriented portrayal within news forms, and a tendency to ignore structural inequalities and lived racism experienced by ethnic minorities in both news and entertainment are recurring research findings. He provides a historical perspective on the connections between misrepresentation, sensationalism and race. In Britain in the late 1950s through to the 1970s, for example, studies observed how immigrants were reported in relation to the so-called 'race riots' of 1958 (Miles 1984), public health scares (Butterworth 1967), problems of 'numbers' and tensions of 'race relations' and how this effectively concealed problems of British racism (Hartmann and Husband 1974; Hartmann et al. 1974; Critcher et al. 1977; Troyna 1981). In the 1970s and across the 1980s, studies of news, and other factuality genres, identified the ways in which a 'moral panic' orchestrated around 'mugging' (Hall et al. 1978), the portrayal of street violence (Holland 1981) and inner city disorders served to criminalize Britain's black population and ignored continuing social inequalities and growing anger at policing practices and harassment (Sumner 1982; Tumber 1982; Joshua et al. 1983; Murdock 1984; Burgess 1985; Downing 1985; Hansen and Murdock 1985; Solomos 1986, 1989; Cottle 1993a). In the 1980s and 1990s, studies charted virulent press attacks on anti-racism campaigns, the vilification of black representatives and the support given to statements of 'new racism' by prominent politicians, as well as xenophobic reportage of refugees and migrants – actively disparaging attempts to further multicultural and anti-racist agendas (Murray 1986;

Gordon and Rosenberg 1989; van Dijk 1991; McLaughlin 1999; Philo and Beattie 1999). Across the years, numerous studies have also observed the media's use of stock stereotypes of black people as 'trouble-maker', 'entertainer' and 'dependent' (Hartmann and Husband 1974; Barry 1988; Twitchin 1988; Hall 1990a). For example, *Policing the Crisis* (Hall, et al. 1978) sought to analyze how black youth had become criminalized and characterized as a new 'folk devil' by the media in the 'mugging' scare of the early 1970s. This 'moral panic', it was argued, helped pave the way for a new form of neoconservative 'authoritarian populism' that also was a response to national economic decline and growing political dissent. This is not dissimilar to or disconnected from comments made by historian David Starkey on BBC2's *Newsnight* in the aftermath of the 2011 UK Riots:

The whites have become black. A particular sort of violent destructive, nihilistic gangster culture has become the fashion and black and white boys and girls operate in this language together... This language, which is wholly false, which is this Jamaican patois that has been intruded in England, and that is why so many of us have this sense of literally of a foreign country (Newsnight 2011).

The complexity of the power dynamic of media, as it relates to representation, is that it is possible to have the good intentions of creating a positive alternative to negative stereotypes and have them both be damaging. The brute can also be the noble savage. As Malik (2002) states "it is quite possible to be adored and violated, excluded and objectified, to be treated as inclusive and Other, and for these processes to work contiguously both in a multiracial society and within representation." The problems then, are not always about stereotyping, marking and abjecting; they are also about omitting (heritage texts), excluding (public debates) and misrecognizing (Black-British youth cultures).

A report in the United States in 2011 by The Opportunity Agenda entitled "Media Representations and Impact on the Lives of Black Men and Boys" argues that the power of mass media to shape, recreate and reinforce popular ideas, attitudes and public perceptions about black males not only helps to create barriers to advancement, but also makes that position seem natural or inevitable. They draw a causal link between media and public attitudes, which has created problematic understandings and attitudes among audiences, that include general antagonism toward black males; exaggerated views of, expectations of, and tolerance for race-based socio-economic disparities; exaggerated views related to criminality and violence; lack of identification with or sympathy for black males; reduced attention to structural and other big-picture factors; and public support for punitive approaches to problems.

The report also found that these media representations also impacts on thinking of black males themselves, with scholars stating that media have a negative impact on black perceptions of self. They hypothesize that negative media stereotypes are demoralizing and reduce self-esteem and expectations, and dealing with negative expectations might also create stress and drain cognitive resources in some contexts, "leading to the lowered performance associated with 'stereotype threat'" (Opportunity Agenda 2011). Significantly there are implications on the outcomes for the stereotyped population, which, as the report states "can be negatively affected any time a black male is in a position where his fate depends on how he is perceived by others." In the report, these real-world outcomes are hypothesized to include less attention from doctors and harsher sentencing by judges. In the British context, one could easily add higher likelihood of certain diagnoses and higher incidences of police detention as it relates to mental health issues as reasonable hypotheses for outcomes of negative media stereotyping.

- *Media and Mental Health*

The work of Sander Gilman on mental illness and historical representation in media is pertinent. As McCracken, et al. (2008) highlight, Gilman's work shows that media representations of disease are inseparable from broader cultural and historical frameworks. Gilman (1988) argues that the idea itself of mental illness structures both the perception of the disease and its form and mental illness cannot be simply attributed as a product of biology in the same way that more visible physical illnesses are. Traditionally this has meant visual representations of 'madness' in a variety of forms manifested through body types, gestures and dress that are grounded in a societal need to "identify the mad absolutely." Health was equated largely with beauty and illness equated with physical ugliness. Gilman states that this need is borne from society's necessity to define itself as sane and thus necessarily create a separation between the sane and the 'insane.' This separation at its extreme requires physical confinement and localization, but at its bare minimum has resulted in a visual localization that separates what sanity looks like as opposed to madness. In order to be maximally effective, this visual localization must have immediacy, so that the mad can be recognized instantly. As Gilman says "one does not even have to wait for the insane to speak" and this instant recognizability of the constructed image of madness need not necessarily be based on the illness itself.

Gilman goes as far as to explicitly separate the definitions of illness and disease as it relates to this desire to socially construct confined classifications of health, where 'illness' refers to the overarching category of pathological physical and mental states, and 'disease' refers to the social construct of illness (Gilman 1995). This construction and the need to construct this separation between sanity and madness is so powerful that even clinicians who might "believe themselves free of such gross internal representations of difference" cannot honestly avoid them and they inextricably alter the relationship between the clinician and the client (Gilman 1988). Equating

illness with a physical look meant that cultural constructs of health and disease in the nineteenth and twentieth centuries could make a physical look itself a social disease (Gilman 1995). Illness could then be attributed to ethnicity and 'racial' features, such that Karl Paumgarten's illustration of the 'normal' Aryan in contrast with 'ugly' races such as Jews, Asians and Africans is intimately tied to articulations such as Nietzsche's that the "modern soul must overcome its Jewish aspect" (Graz 1930; Nietzsche 1887).

Efforts to tackle stigma and to better educate the public about mental illness have of course happened, increasingly so in recent years. But even with these efforts, a Guardian newspaper article in 2012 reported that in speaking to the Royal College of Psychiatrists, Labor party leader Ed Miliband said the UK needed a mental health strategy "outside as well as inside the National Health Service, tackling the culture and changing the way our society treats mental health". According to Miliband, mental health will only cease to be a problem if all people with mental health difficulties can find their place in life, with taboos lifted and everyone pulling in the same direction. What Miliband's comments point to is an ongoing negative portrayal of mental illness in media. McCracken, et al. (2008) in 'Mental Health, the media and public perceptions' investigate the effect of the media on attitudes to mental health, specifically asking whether the media shapes or reflects public perceptions. They found that mental health service users and campaigners complained that despite some trends and efforts to provide and present more positive and balanced coverage, there remained underlying negative and stereotypical reporting that portrayed sufferers of mental illness as being different and dangerous to themselves and others. They argued that the almost exclusive focus of media on high profile and extreme cases of violence and homicides by mental health users, shaped public attitudes by exaggerating risks and reinforcing rather than combatting stigma and discrimination (Thornicroft 2006). This coupled with the shift by the government to what they considered to be more risk-driven policies, like the

2007 Mental Health Act, that purported to prioritize public safety did little to curb a culture of fear of mental illness and mental illness sufferers.

A comprehensive review commissioned by Shift, appears to confirm the view that ‘negative’ media coverage may reinforce fears that mental health users pose a public risk, and ‘positive’ images might have an opposite effect (Rose et al. 2007). Concerns continue about the manner in which media often dwell on and report stories on mental health, the level to which they assert risk and the role these media stories play in reproducing and reinforcing stigma, prejudice and discrimination against people with mental health problems. This criticism is not made only of tabloid newspapers, though they were found to be the worst offenders, but ‘broadsheets’¹ were also found lacking in balanced reporting, often focusing on high profile cases in a problematic and sensational way. TV news was also found wanting and prone to sensationalist treatment of stories, one case in point being that of Anthony Joseph. One 2007 BBC headline stated of the case “Schizophrenic admits knife death,” with a sub-heading “A paranoid schizophrenic has admitted stabbing a hospitality worker to death in a row over throwing chips on a London bus” (BBC 2007).

Similarly, London (2010) in his study of stigma and mental illness, found that mental illness was frequently depicted inaccurately and unfavorably in the mass media and in a manner that perpetuated harmful misconceptions about people who were mentally ill (Gerbner et al. 1981; Steadman & Coccozza 1977; Monahan and Arnold 1996). In an analysis of prime-time television in the USA, it was found that the mentally ill were portrayed to be about ten times more violent than other television characters (Diefenbach 1997). In another study, it was found that nearly half of national press coverage linked mental illness to violence and criminality and the representation

¹ A newspaper with a large format regarded as more serious and less sensationalist than tabloids.

² By disorder I mean to imply a ‘disruption of order’ rather than ailment.

³ The Ladywell is comprised of six wards, one adult inpatient ward for the three Lewisham localities, specializing in acute cases (Powell, Clare and Wharton Ward); a fourth specializing in

and reporting by the media, of a few rare cases of homicides committed by people who were mentally ill, was shown to disproportionately exert a negative influence on public attitudes to mental illness (Ward 1997; Guimon 2001). Monahan and Arnold (1996) argue that this public perception of a strong link between mental illness and violence was important, because they impacted laws and policies, which attempted to control the behaviour of the mentally ill, which in turn determined informal responses and ways of interacting with people perceived to have mental illness. News reports about mental illness and violence provide a model for thinking about violence, its causes and solutions and the news media has the unique ability to tell people what to think and how to think about violence and mental illness; and these factors have a critical impact on public health practice and policy (Taylor and Sorenson 2002).

Policy and Practice

Francis (1993) in his essay “Psychiatric Racism and Social Police: Black People and the Psychiatric Services” argues that in the recent history of the UK, “black people are almost synonymous with the idea of madness,” although in the early development of psychiatry, when the idea of the ‘noble savage’ was dominant, black people were thought to be too primitive to experience complex mental illness. He argues that with the figure of madness being a crucial element in the historical construction of race, racism and racial difference, psychiatrists were foremost in the articulation of race along biological and cultural lines. Furthermore, the development of psychiatry occurred in parallel with European colonial expansion and domestic industrialization, with the intellectual quest to understand the nature of 'Man' providing a philosophical backdrop to the economic and political ambitions.

Francis sees a historical continuity between early scientific efforts like the anthropological movement of somatometry during the latter part of the nineteenth century which attempted to

identify and measure ascertain physical attributes to determine class or racial differences and modern practices like Intelligence Quotient (IQ), a means of measuring human mental aptitude. He argues that all such efforts are different aspects in the domain of psychometrics and can be traced back to the early science of comparative psychology and psychopathology. As such, he sees race as being inseparable from considering such science, especially so because a Western concept of rationality is the measuring stick by which modern psychiatry judges normality and pathology. Jung's words are particularly resonant to this fact, "The inferior man exercises a tremendous pull upon civilized beings who are forced to live with him, because he fascinates the inferior layer of our psyche" (Jung 1970). Here then, madness or psychic inferiority is the normal of the inferior man or primitive. As Francis states, "culture thus becomes important to psychiatric diagnosis as part of the rubric of what is normal and what is pathological" (Francis 1993).

Like Gilman, who argues for society's need to construct separation between sanity and madness, Francis argues that along with its role in defining psychological and cultural norms, psychiatry also played a crucial role in answering the political and economic need to preserve social order. Psychiatry is said to have been one response during industrialization to the problem of pauperism, indigence, vagrancy, prostitution and delinquency. The mental institution or asylum then became a major site of control, where the whole spectrum of anti-social delinquency could be detained. Scull (1980) states that during the eighteenth and nineteenth centuries 'mad' people were not treated as a separate category of 'deviants'. Instead they were grouped in with the morally disreputable, the poor, minor criminals, and the physically handicapped. As Littlewood and Lipsedge (1997) state, "the modern psychiatrist is a descendant, not of the psychoanalyst, but of the nineteenth-century mental asylum keeper."

Francis argues that contemporary race relations theory and practice, especially as it related to psychiatric practice and policy allows for the authorization of state agencies to act in concert, as a

circuit of control, using as their rationale the idea that black people are a serious threat to the social order, as a malignant pathology, for which special social police controls are needed. It is this theory that he sees as the reason for the disproportionate over-diagnosis of black people in the UK as mentally ill, especially so major psychotic illnesses where black people have been diagnosed at up to five times the rate for the rest of the British population (Cochrane 1977). The legal sanctions under the 1983 Mental Health Act, whereby individuals can be compelled to have treatment, are also exercised more often in relation to black people (Runnymede Trust 1983). He further argues that once they are admitted to a mental institution, the medical treatment accorded to those admitted has often been harassing and torturous, with rampant over-use of medication and numerous instances of physical abuse (Mercer et al. 1984). The answer from the medical profession has been to see this as a problem of culture and anthropological knowledge, where in the act of diagnosis that certain 'errors' are made in the interpretation of black behavior (Littlewood and Lipsedge 1981). This Francis argues is merely a subtle version of blaming the victim, and no different than psychiatrists such as Laubscher (1937) claiming that he could not tell the difference between irrationality and the culture of the savage, such that 'normal' modes of black cultural expression can be easily misunderstood for pathological symptoms (Tewfik and Okasha 1965).

Another of Francis' arguments is that this philosophy of psychiatry makes its way into public policy, thus giving legal authority to what he considers racist practice. As such, the medical system and the political state operate together to define pathology and to provide a framework for the referral of patients. As an example, Francis looks at the most criticized sections of the 1983 Mental Health Act, namely sections 2, 3, 4 and most notoriously section 136. Sections 2, 3 and 4 under the Act allow for, by force if necessary and with only doctors and approved social workers required to authorize execution, the compulsory detention of individuals in mental institutions in the case of emergencies for 72 hours (section 2), assessment for 28 days (section 3) and for long-

term treatment for up to 6 months (section 4). Section 136 sanctions the police to apprehend individuals found in a public place and considered to be 'a danger to themselves or others' and to take them to hospital, thus allowing the police “both to criminalize and to medicalize (Francis 1993). The concept of dangerousness is left up to the interpretation of the police, and The Act says that compulsion is necessary in cases where the individual thought to be mentally ill has become a danger to themselves or others. In practice, it is assumed that severe forms of mental breakdown, particularly those diagnosed as 'psychotic', involve a loss of the individual's ability to think and act in his or her own best interests, or in the interests of 'the public'. Thus the state will assume control of the lives of those defined as mentally ill (Francis 1993). Basaglia (1980) states, “That which psychiatry defines as sick is, in fact, that which the social set-up defines as dangerousness for its equilibrium, according to its changing requirements.” Francis argues that being black and sick then in the British context equates to being doubly dangerous.

This theory is supported by the work of Metzl, whose book *The Protest Psychosis: How Schizophrenia Became a Black Disease* focuses on Ionia State Hospital in Michigan, one of the largest and most notorious state psychiatric hospitals in the United States. Here he uncovers the trend in the 1960s in this hospital of diagnosing African Americans with schizophrenia. The book suggests that in part the sudden influx of such diagnoses could be traced to a change in wording in the second edition of the Diagnostic and Statistical Manual, which added "hostility" and "aggression" as signs of the disorder compared to the previous edition. Metzl found that before the 1960s, schizophrenia was explained as a psychological reaction to a splitting of the basic functions of personality. Official descriptors emphasized the generally calm nature of such persons, and thus it was often associated with middle-class housewives. But in 1968, in the midst of a political climate marked by profound protest and social unrest, DSM-II was published which recast the paranoid subtype of schizophrenia as a disorder of “masculinized belligerence.” The text read ‘the patient's attitude is frequently hostile and aggressive and his behavior tends to be

consistent with his delusions.’ Data in the book shows how this language was used to justify schizophrenia diagnoses in black men at Ionia in the 1960s and 1970s and how this change in language resulted in structural racism (Metzl 2010).

The issue of blackness and dangerousness is relevant in the case of David Bennett, an African Caribbean inpatient in a mental health unit, whose death in 1998 was a watershed moment for mental health services in the United Kingdom. The subsequent inquiry into his treatment and care and the report that followed, concluded, “Mental health services within the UK are institutionally racist” (BMH UK 2011). Although an extreme case (in the sense that Bennett died, not that the case is necessarily uncharacteristic), the experiences of David Bennett are considered to be largely typical of the African-Caribbean experience of mental health services. His story exemplified a history of misdiagnosis and points to the high incidence of African-Caribbean persons being diagnosed with psychotic conditions and treated using medication, often of a higher dosage.

Prior to the findings of the David Bennett Inquiry, a number of experts and researchers had highlighted the negative manner in which BME service users come into the mental health system. In ‘Pathways to Care for Patients with a First Episode of Psychosis A Comparison of Ethnic Groups’ (Cole, et al 1995), it is acknowledged that patients from ethnic minority groups, particularly African-Caribbeans, have a less desirable access into the psychiatric system than other patients, with an excess of police, civil and court compulsory admissions and a low level of GP involvement (Rwegellera 1980; Harrison et al. 1989; Moodley & Perkins 1991). Some of this excess of African-Caribbean service users may be accounted for by higher rates of psychotic illness and late intervention that may lead to involvement of emergency services (Owens et al. 1991). It was also suggested that mental illness carries more stigma in the Caribbean community, which might explain the delays in reaching services and an increased likelihood of adverse

pathways (Harrison et al. 1989). Though, mental illness and involvement with psychiatric services are generally considered to be stigmatizing, they argue that this is likely to be more pronounced in the Black community where negative perceptions of the relationship between Black people and psychiatry are widely held and reinforced by their experience of psychiatric services (Cole et al. 1995). After first contact they may be more likely to reject the notion of being mentally ill, avoid services and not comply with treatment, thereby acquiring an increased vulnerability to relapse and deteriorating health. Statistically speaking, African Caribbean men were five times more likely to be detained on locked wards and were six times more likely to be sectioned under the Mental Health Act despite having similar rates of mental ill health as other ethnic groups (Office of the Deputy Prime Minister 2004). Reports found a history of misunderstanding and discrimination regarding the use of these compulsory powers and a number of African Caribbean service users have died in care. Many also argued that culturally appropriate and acceptable behavior had been wrongly construed as symptoms of abnormality or aggression and the recourse to advocacy, tribunals and to appropriate care packages has been slow to positively impact this group (Songhai 2004).

Although the David Bennett Inquiry report brought the issues of Black and Minority Ethnic patients in mental health services to national attention, it had long been argued by community activists that the situation had become a crisis and that black service users had long suffered discrimination in mental health services, had been excessively diagnosed as 'schizophrenic', excessively 'sectioned' on wards and excessively apprehended by the police as 'mentally ill', despite having similar rates of mental ill health as other ethnic groups (BMH UK 2011). Professor Suman Fernando found that Black and ethnic minorities are more often diagnosed as schizophrenic, more often compulsorily detained under the Mental Health Act, more often admitted as 'offender patients,' more often held by police under Section 136 of the Act, more often transferred to locked wards, more often not referred for psychotherapy, more often given

high doses of medication, more often sent to psychiatrists by courts, more often faced with having unmet needs and more often dissatisfied with statutory services, while Black service users were twice as likely to disagree with their diagnosis. Fernando argues that it is in the field of psychiatry that “racial injustices and cultural oppression are felt most acutely” by BME service users and as a consequence they suffer poorer health, have reduced life expectancy and have greater problems with access to health care than the White population (Fernando 2003).

The years following the Bennett Inquiry brought about a number of initiatives and legislations to address the issue of inequality in mental health services and to alter the mental health system, often specifically as it related to Black and Minority Ethnic service users. The major outcome was the Delivering Race Equality in Mental Healthcare programme (DRE) in 2005, a five-year action plan for reducing inequalities in Black and Minority Ethnic patients' access to, experience of, and outcomes from mental health services. In 2007, a new Mental Health Act was introduced that amended the 1983 Act and in 2011, the Health and Social Care Bill would recommend radical changes in the NHS as a whole. It is important to detail what these different efforts are to demonstrate the philosophies behind the initiatives, to judge their success or lack thereof and to provide some context for the criticism they would receive from service users and campaigners.

- *The Delivering Race Equality in Mental Healthcare programme*

The DRE action plan contained specific actions based on foundational principles that there should be better and more culturally appropriate and responsive services; better engagement of services with local communities; and better use of information and evidence. The vision was that by 2010 there would be less fear and increased satisfaction of mental health services among BME communities and service users; a reduction in the rate of admission, compulsory detention and seclusion of people from BME communities to psychiatric inpatient units; fewer violent incidents

that are secondary to inadequate treatment of mental illness and the prevention of deaths in mental health services following physical intervention; more BME service users reaching self-reported states of recovery; a more balanced range of effective therapies, such as peer support services, psychotherapeutic and counseling treatments, and pharmacological interventions, that are culturally appropriate and effective; a more active role for BME communities and BME service users in the training of professionals, in the development of mental health policy, and in the planning and provision of services; and a workforce and organization capable of delivering appropriate and responsive mental health services to BME communities (DRE 2005). One of the major initiatives to spring from the DRE programme was the Count Me In census, a 5-year initiative that analyzed the results found from investigating inequalities in access and outcomes affecting in-patients from Black and minority ethnic communities and from studying how people's hospital stays are managed.

- *The Mental Health Act 2007*

The Mental Health Act of 1983 was largely concerned with the circumstances in which a person with a mental disorder could be detained for treatment for that disorder without his or her consent in order to prevent them from harming themselves or others. The Mental Health Act of 2007 was introduced to modernize mental health treatment. Firstly it applied a single definition for 'mental disorder' throughout the Act. It changed the criteria for detention so that it was no longer possible for patients to be compulsorily detained, or their detention continued, unless appropriate medical treatment and all other circumstances of the case was available to that patient. It replaced the role of the approved social worker with that of the approved mental health professional, broadening the group of practitioners who could perform professional assessments to include community psychiatric nurses, occupational therapists and psychologists. The Act introduced Supervised Community Treatment (SCT) for patients following a period of detention in hospital. SCT

allowed patients who were discharged from detention to be recalled to hospital to help avoid the ‘revolving door’ situations of patients who leave hospital, do not continue with their treatment, have their health deteriorate and then require detention. This new section provided for a Community Treatment Order (CTO) to be imposed in certain circumstances. It made it a duty to make arrangements for help to be provided by independent mental health advocates and it required that patients admitted for mental disorder under the age of 18, be accommodated in an environment that is suitable for their age and subject to their needs (Department of Health 2009).

- *The 2010 White Paper and 2012 Health and Social Care Act*

In 2010, when the government changed hands to the Conservative/Liberal Democrat coalition, they proposed extensive organizational changes, producing a White Paper, “*Equity and Excellence: liberating the NHS,*” that would radically transform the structure of the NHS and consequently the mental health system, setting out the Government’s long-term vision for the future of public health in England. The aim was “to create a ‘wellness’ service (Public Health England) and to strengthen both national and local leadership” in the strategy entitled ‘Healthy Lives, Healthy People.’ The White Paper would eventually develop into the Health and Social Care Bill of 2011 that proposed three key principles: that patients should be at the centre of the NHS; that there should be a changing of the emphasis of measurement to clinical outcomes; and an empowering of health professionals, in particular GPs. In doing so, NHS primary care trusts and Strategic Health Authorities (the liaison bodies between the Department of Health and the NHS responsible for developing plans for improving local health services) will be abolished and those powers would be transferred to several hundred clinical commissioning groups, partly run by general practitioners and that all NHS trusts will become, or be amalgamated into, foundation trusts (largely independent bodies that represent the interests of the community and of local partnership organizations as part of an effort to de-centralize public services). On 27 March 2012,

the Health and Social Care Bill gained Royal Assent to become the Health and Social Care Act (2012) and would officially alter the structure of the NHS and aim to reduce "the power of Whitehall" (Rivett 2011).

Social Suffering

The experience of illness and the risks and consequences of societal and medical forces as it affects Caribbean service users makes the concept of social suffering relevant and necessitates a broader discussion than just focusing on mental illness can provide. Kleinman defines social suffering as pain and suffering caused by social forces such as global and local economics, politics, social institutions, social relationships, and culture; the interpersonal experience of suffering and experience of chronic illness; the contribution that society and its institutions make to the causality or worsening of social and health problems; and a concept "meant to be an omnibus and to mix together social and health problems of every sort" (Kleinman 2009a). He argues that social suffering comes in three types. Firstly, structural violence, where such suffering is "structured by historically given (and often economically driven) processes and forces that conspire whether through routine, ritual or as is more commonly the case, the hard surfaces of life to constrain agency." In such cases, choices are limited by factors like racism, sexism, political violence, and poverty. Secondly, interpersonal experiences, such as illness experience. Thirdly, suffering caused or intensified by bureaucratic indifference and the unintended consequences of bureaucratic action, where it is argued that public policies and programs have created some of the worst instances of social suffering and human misery, whilst seeking to manage social suffering (Kleinman, et al. 1996; Kleinman 2009a).

Kleinman, et al. (1996) argue that the phenomenon of social suffering "results from what political, economic, and institutional power do to people, and, reciprocally, from how these forms

of power themselves influence responses to social problems.” They advocate a theoretic collapse of dichotomies such as those that “separate individual from social levels of analysis, health from social problems, representation from experience, suffering from intervention.” Kleinman makes the argument that issues of inequality and medical care cannot be separated if something like poverty is a major risk factor for a number of disorders and because there are health disparities across class, ethnicity, gender and age, this means that “suffering and inequality is at the heart of global health policy.” In his plenary session “Five Questions on the Future” at the 2009 Society for Medical Anthropology Conference, Kleinman argues that social suffering often exists alongside mental illness, and the impact of social suffering and mental illness should be understood together because “social suffering extends far beyond the pathological” and “normality, as well as disease, embodies social suffering” (Kleinman 2009b). What follows below is an exploration of literature that investigates connections between mental illness and numerous risk factors and social dynamics.

When applied, the concept of social suffering is relevant to the relationship between migration and mental illness, where studies have shown that migration itself can be considered a risk factor for mental illness. Cantor-Graae, et al. (2003) in "Migration as a risk factor for schizophrenia: a Danish population-based cohort study," Zolkowska, et al in "Increased rates of psychosis among immigrants to Sweden: is migration a risk factor for psychosis?" and Coid, et al. (2008) in “Raised Incidence Rates of All Psychoses Among Migrant Groups: Findings From the East London First Episode Psychosis Study” all support the argument of mental illness rates increasing for migrants groups. Zolkowska, et al. highlight increased risk for admission for schizophrenia-like psychoses for immigrants to Sweden compared to native-born individuals with a similar tendency for schizophrenia-like psychoses. Cantor-Graae, et al. (2003) found that foreign birth and foreign background (i.e. second-generation immigrant status) were risk factors for the development of schizophrenia for Danish residents by their fifteenth birthday. This risk extended

to people with a Danish background who had a history of foreign residence prior to their fifteenth birthday. Based on the methodology, the study was unable to precisely identify the ethnicity of the foreign-born individuals but still felt that the results have implications for the debate about the excessively high rates of schizophrenia found in people of African-Caribbean origin in the UK, by adding a focus on migration.

Coid, et al. (2008) in their East London study found that incidence of both affective and non-affective psychoses was higher for black and minority ethnic subgroups compared with white British individuals. Notably, of these subgroups, only black Caribbean second-generation individuals were found to have a significantly greater risk compared with their first-generation counterparts. For the black Caribbean group, they argue that the magnitude of this risk was significantly greater in the second generation principally because first-generation black Caribbean immigrants have now largely passed through the main period of risk of psychoses. They further argue that although the magnitude of risk for the second-generation black Caribbean group was higher than for its first-generation counterparts, the cumulative effect of factors that serve to increase the risk of psychoses in Black minority ethnic groups is probably similar across generations, although the exact specification of these factors will probably differ. For example, the pressures faced by first-generation black Caribbean immigrants in the 1950s and 1960s were very different from those faced by their second-generation counterparts in the 1990s and beyond. This meshes with the results of the 2003 study by McKenzie, et al. (1995) that reflect findings from the general population where the rate of suicide in younger people of Caribbean origin is climbing while older people of Caribbean origin remain at lower risk than their White British peers (Soni-Raleigh 1996). An association between biological risk factors and the rates of psychosis in African-Caribbean persons in the UK has not been supported, however, racism was frequently brought up as an issue by patients (Sharpley, et al. 2001). A study on the connection between racial discrimination and mental illness performed by Chakraborty and McKenzie (2002)

revealed that racism (real and perceived), in its many forms might be important to risk. This is supported by evidence from the Fourth National Survey of (UK) Ethnic Minorities, which showed that from a nationally representative sample of 5196 persons of Caribbean, African, and Asian origin, those who had experienced verbal abuse were three times more likely to be suffering from depression or psychosis. In addition, those who had experienced a racist attack were nearly three times more likely to suffer from depression and five times more likely to suffer from psychosis. Those who said their employers were racist were 1.6 times more likely to suffer from a psychosis (Fourth National Survey of Ethnic Minorities 1997). As such then, though ethnicity seems to be the stronger correlate for the rising rates of suicidal behavior amongst Caribbean young people, racism might affect individual experiences, where continued oppression might operate as a persistent stressor and an overtly racist act as an acute stressor that is superimposed upon this chronic stress (Bhugra & Cochrane 2001).

Conversely, Hickling (1996) highlights in “Psychopathology of white mentally ill immigrants to Jamaica” that the opposite does not seem to occur, at least for when white immigrants migrate to former colonies. In this study, white immigrants did not develop schizophrenia at a higher rate than Jamaican controls matched for age, gender and social class. This differs from most other studies that show patterns of mental illness in migrant populations around the world where migrants develop schizophrenia at an increased rate compared with the native population. He argues that the political/economic situation which exists in black postcolonial countries like Jamaica provides a protective social environment for white immigrants, which buffers them from the etiological conditions that engender schizophrenia in immigrants to other countries with predominantly white populations.

Studies in the US, replicated in the UK found that ethnic minority groups were more likely to suffer from mental illness when they were a smaller proportion of the population in an area

(Laveist 1996; Halpern 1993; Boydell, et al. 2001). The Boydell, et al. (2001) study found that the incidence of psychosis was twice as high for persons from ethnic minority groups in London wards whom lived in areas where they were a low proportion of the area, compared with those living in areas with high ethnic minority population densities. McKenzie, et al. (1995) cites work done by Neeleman that shows a relationship between the density of people of Caribbean origin in an area and their rates of suicide and suicide attempts (Neeleman & Wessely 1999; Neeleman et al. 2001). Older people of Caribbean origin are found to be more likely to stay living within their community. The loss of support of the community or the higher exposure/loss of protection from discrimination faced by younger people of Caribbean origin who move away from their communities and into more diverse occupational and residential areas could be important.

Bhugra relates this issue of ethnic density to ethnic identity and the role it plays in the individual's self-esteem and its affect on the social causes and courses of psychiatric disorders. He argues that there are yet undetermined consequences of the new pluralist context of multicultural societies for individuals' psychological well-being, but that the globalization process with its "multiple belongings, multi-ethnic communities, long-distance networks and flexible identities" divides as much as it unites, and the causes of division are identical to those promoting global uniformity (Bibeau 1997, Bauman 1998, Bhugra 2004). Integral to this globalization is "progressive spatial segregation, separation and exclusion" and that this when combined with a sense of alienation, can be seen as "a cumulative way of increasing the stress of vulnerable individuals" (Bhugra 2004). Among African-Caribbeans, both the scattering of the population, and altered cultural and social identity and low self-esteem may contribute to high rates, low and delayed recognition and poor outcomes. In addition, African-Caribbean males are more likely to have been separated for longer than 4 years from their fathers and thus patterns of secure attachment and lower self-satisfaction and achievement may also play a role (Bhugra 2001).

McKenzie et al. (1995) also hypothesize decreased migratory coping skills as a risk factor, where it is proposed that older persons of Caribbean origin who decided to migrate to the UK may be better equipped to cope with the pressures of being a minority in the UK than their children are. This is agreed upon by Gunnel and Lewis in 'Studying suicide from the life course perspective: implications for prevention' who state that "the issue of migration and the disparity between the experiences of those who have moved and the children of those migrants seems to be a significant factor" (Gunnel 2005). There are also generational factors to consider, with evidence from the US finding that second and subsequent generations minority groups seem to approximate better to the suicide rates of the host population (US Department of Health and Human Services 2001). They hypothesize that the same might be found in the UK. They also make mention of community factors, hypothesizing that older persons of Caribbean origin are more likely to stay living within their community and as such, younger persons might be faced with a loss of support from their community of origin or higher exposure and loss of protection from discrimination.

With regard to conclusions as to why migrants of African heritage, especially African-Caribbeans seem to be more susceptible to mental illness, Hickling and Hutchinson (1999) in "Roast breadfruit psychosis: disturbed racial identification in African-Caribbeans" argue that one component that contributes to mental illness in the African-Caribbean population is an attempt to rationalize their identity, complicated by an overwhelming desire for acceptance by European society, that results in shame of one's indigenous culture with an exaggerated rejection. The experience of social difficulties because of racism or experiencing abuse because of an inability to succeed on European terms can exacerbate this to psychosis. This phenomenon they call 'Roast breadfruit psychosis,' named as such for the Caribbean dish, where the breadfruit's green skin, when roasted, becomes charcoal-black, while the inner flesh is white in color. The appearance then lends itself to the description of Black people who think themselves White, that is, dark on the outside, white on the inside. They further argue that that the psychiatric problems of this

population are grounded in their social experience in Britain and is characterized by increased dissatisfaction and illness in the second generation which also might suggest a lack of access to protective factors that have worked for their former generations or indeed the indigenous White community, such as a sense of community or belonging. They conclude then that what might distinguish the environment in Britain from that of the Caribbean for these individuals, is a sense of cultural control of the environment where In the Caribbean context, Caribbean people have been able to culturally validate themselves in modes of expression ranging from religion to music, which to a large extent has protected them from the “psychic challenges of their history.” This is similar to Littlewood and Lipsedge’s (1997) argument that prejudice is not just experienced by the immigrant, but becomes a part of their self-image, where even successes are measured within stereotypes.

In his response to Hickling and Hutchinson, McKenzie (1999) argues that racism is an attractive explanation for the increased rates of psychotic illness in African-Caribbeans in the UK and that although there is little doubt that racism is an important stress producing factor, it remains to be explained why this phenomenon would only be seen in one ethnic minority group in the UK and that detailed study and documentation is needed if such an illness category is to be entertained. Oyeboode (1999) takes his criticism of Hickling and Hutchinson further, arguing that like Fanon (1952), who argued that the Black Caribbean historical experience of slavery and colonialism produced a particular kind of psychopathology and vulnerability to racial identity confusion, Hickling and Hutchinson's fallaciously accept race as a meaningful category (Oyeboode 1999). He argues that the idea of a 'roast bread fruit syndrome' has yet to describe in clear terms what attempting to alter one's skin color, based on an overwhelming desire for acceptance, accompanied by feelings of shame of one's indigenous culture, rejection of one's indigenous language and manners and would mean in practice for Black people. Oyeboode (1999) asks if this is shorthand for saying that “a Black person who happens to value highly the art of Shakespeare

or Beethoven is thinking himself as White” and if the indigenous culture of a second generation African-Caribbean person is English or Caribbean if this person normally resides in Birmingham and has never visited the Caribbean. He also asks if White people tanning is also a marker of pathology or is it only a marker of pathology in Black people.

Selten and Cantor-Graae (2005) in "Social defeat: risk factor for schizophrenia?" offer another explanation for the susceptibility of migrants to mental illness, namely ‘social defeat.’ They argue that migrants and city residents are exposed to high levels of social competition, which if becomes social defeat (defined as an embodied “subordinate position or as ‘outsider status’” brought about by continual losing in this ‘social competition’) might be a risk factor for mental illness. This losing is then also complicated by experiences such as discrimination and economic hardship. They state: “ethnic disadvantage... might make it more difficult for migrants to create a life plan, insofar as role models and community institutions may be lacking. Thus, the stress of making decisions concerning adult life, perhaps in combination with weaknesses in executive functioning, might contribute to the development of schizophrenia.” This concept they derive from experiments on rats where they found, which they argue that if extended to humans, “chronic exposure to social defeat may lead to sensitization of the mesolimbic dopamine system and/or overactivity of this system, and thus further the development of psychosis,” which then might be exacerbated by the use of dopamine-enhancing drugs (such as cannabis). Their analysis shows that this risk was greater for migrants from developing countries than for those from developed countries, and then also greater for the second generation than for the first. They expected a bigger increase in the second generation because outsider status would be “even more humiliating for individuals who feel entitled to the status conferred by their birthright.” This risk is reduced when minority ethnic groups comprise a greater proportion of the local population, interpreted as a protection caused by the social support they are able to access (Boydell et al. 2001).

Research heavily supports the finding that black service users of Caribbean heritage are over-represented among those receiving psychiatric treatment in the UK (Lloyd 1998; Nazroo 1997; Bhui et al. 2002), with disproportionate numbers appearing in treatment statistics for psychosis and schizophrenia (Harrison, et al. 1989; Henderson, Thornicroft and Glover 1998). In contrast, in primary care, Black Caribbeans are less likely than the general population to report psychiatric morbidity and to receive formal diagnoses or treatment for common mental disorders such as depression (Edge and Roberts 2005). The ‘over-diagnosis’ of psychoses and apparent ‘under-diagnosis’ of less acute disorders might not be an accurate reflection of the prevalence of these conditions among Black Caribbeans. Shaw, Creed, Tomenson, Riste, and Cruickshank (1999) reported little difference in the prevalence of depressive symptoms between African Caribbeans and White Europeans, while the Fourth National Survey of Ethnic Minorities reported significantly higher levels of clinical depression among Black Caribbeans than among their White British counterparts (Berthoud & Nazroo 1997; Nazroo 1997). This discrepancy in diagnoses of illnesses such as depression raises the possibility of factors that influence diagnosis or count against symptom recognition and Black Caribbean’s willingness and/or ability to consult with depressive symptoms. Influences within the consultation and diagnostic processes, such as subtle language differences, which reduce the likelihood of Black Caribbeans receiving formal diagnoses may also be associated (Shaw et al. 1999; Paykel & Priest 1992). The juxtaposition of disproportionate numbers of Black Caribbeans at the coercive end of psychiatry and their ‘under-representation’ in primary care raises questions about how psychiatric practice, racism, or racial stereotyping contribute to the appearance of Black Caribbeans within certain psychiatric categories and their absence from others (Spector 2001). There is also a lack of knowledge about, and possibly a lack of respect for, the lay views of Black Caribbeans on issues that might affect their willingness to consult with mental health problems such as differing concepts of mental health and perceptions of primary care management (Edge and Roberts 2005).

Resilience

For Caribbean service users, the experience of social suffering encompasses the discrimination that resulted from migration, the social component of race and identity where blackness and danger are conflated, the medical component of their experiences of illness and the power disparity where much of the service users' lives are dictated by the immediate decisions of doctors, police and judges and the indirect decisions of policymakers and politicians. The findings of this project will show that for service users, there is an ongoing tension in their relationship with the medical establishment, where they must look at themselves through the eyes of the medical establishment and be measured by medical standards they often believe do not take their own models of health into consideration.

Service users' perception of self are often at odds with the representation of who they are, and it is this representation that tends to hold more authority. As Gilman argues, historically the preoccupation with health and disease and the tendency to order the world by demarking selfhood and otherness is borne out of the fear of our own physical vulnerability, and has been represented in images of beauty and ugliness, with health being associated with the "beautiful body," and illness associated with the perversion of that beauty (Gilman 1985; 1988). To escape the anxiety of the loss of self-control that is caused by disease and illness, the fear is projected onto the creation of representations of disease as an 'other,' in ugly, maligned forms. This becomes further complicated when infused with the political implications brought about by "race" as a social and medical category. This conflation of the otherness of illness and the otherness of blackness makes for a powerful negating force, where belonging to either category is alienating, but belonging to both is almost utterly exclusionary. Stigmatization can be viewed as a deep-seated unconscious need to construct 'us and them' schemes, in which fragile self-identity is reinforced through the pathologization of outsiders, such as persons with mental illness (Gilman 1982).

This fragility within the Caribbean service user, where self-identity tussles with negative representation from outside the self invokes the psychoanalytic concept of ‘misrecognition,’ popularized primarily by Lacan and continued by Bourdieu. Lacan developed the concept of misrecognition in his analysis of the mirror stage, in which children develop an idealized self-image through a confrontation with their image in a mirror, where first, this self-image is idealized and fictional; and, second, its success depends on the presence of another - in this case, the misrecognized reflective Other in the mirror. As we grow and develop, this dynamic persists and our sense of self depends on the image that is reflected to us in our engagements with concrete others as a defensive operation of the ego “against one’s “discordance with [one’s] reality” (Lacan 1949; Schiff 2009).

In Bourdieu’s articulation of misrecognition, he observes that social actors tend to hide the workings of power and the conflicts and inequalities that they create, a process that he calls “misrecognition” akin to Marxian ideas of ‘false consciousness’ (Gaventa 2003). Bourdieu extends the concept into the cultural arena, arguing that created social differences and unequal structures become taken-for-granted assumptions because the power behind creating this inequality is concealed (Navarro 2006). Consequences of inequality then can then be misrecognized as inherent cultural capital (competencies, skills, qualifications) in individuals and groups rather than contingent on structural inequity. Extended further to the relevance of this project, in situations where the individual lacks social capital and agency over their own self-image, the reflection in the mirror becomes the outside perception, and the conflict becomes an attempt to resolve what that reflection shows and what one perceives of self. In situations where the individual lacks cultural capital, this can be misrecognized as being innate. The unemployed then become naturally lazy. The ill become ugly. The criminalized become dangerous. The Other becomes pathological.

As it relates to a context for the intersection between diagnosis and identity, two arguments emerged from my research, both of which suggest a maladaptation of persons of Caribbean heritage in the British environment. Firstly, persons such as David Pinder, the director of the Fanon Resource Centre, have argued a social maladaptation. He argues that the inherent nature of the black Caribbean community runs counter to a Western model of independence, thus juxtaposing collectivist and individualist models of culture. When Caribbean people, separated from “the hub and the safety net” of community, living in relative isolation from each other, and possibly receiving distorted views of Caribbeanness and Blackness, adopt this individualist model, problems may arise. This is said to be especially so for young people, where negative behavior and identity issues and confusion about whether they are British, Caribbean or a combination of both may arise. Secondly, there have been arguments for psychological maladaptation. For example, in instances of dysmorphia, where pathological attempts to rationalize identity, complicated by an overwhelming desire for acceptance by European society, have resulted in shame of one's indigenous culture with an exaggerated rejection of blackness, which in extreme form has meant skin bleaching and even skin painting.

These two instances of what might be considered maladaptation, one social, one psychological can be viewed as exemplifying W.E.B. Du Bois' concepts of ‘double consciousness’ and the ‘veil.’ Du Bois argument relates to the concept of misrecognition, but goes beyond the psychoanalytic to intimately connect the issues of representation and self-identity to race, society and history. In *The Souls of Black Folk*, DuBois' most famous work, he introduces these two intertwined concepts that describe Black experience in America. He writes:

[I]t dawned upon me with a certain suddenness that I was different from the others; or like, mayhap, in heart and life and longing, but shut out from their world by a vast veil... the Negro is born with a veil, and gifted with second-sight in this American world,—a world

which yields him no true self-consciousness, but only lets him see himself through the revelation of the other world. This sense of always looking at one's self through the eyes of others, of measuring one's soul by the tape of a world that looks on in amused contempt and pity. One ever feels his two-ness, an American, a Negro; two souls, two thoughts, two unreconciled strivings; two warring ideals in one dark body, whose dogged strength alone keeps it from being torn asunder (DuBois 1903).

For DuBois, the concept of the veil has a number of metaphorical implications. Firstly, the veil can literally be the darker black skin that operates as a physical distinguisher from whiteness. Secondly, the veil suggests a lack of clarity and access, both to seeing the 'truth' of black selves, but also an inability to see the black self outside of what dominant society describes and prescribes for the self. Double consciousness then is the sensation of the struggle to unify one's identity in a society that historically represses and devalues and forces individuals into a conflict of how they perceive themselves against how they might be perceived by the external, but more powerful world, where the internalization of anti-black sentiment can shape the black experience.

There are then a number of apparent dualities, at this macro level: blackness versus whiteness, Us versus Them, a black citizen versus a 'true' citizen. It is at the individual level that double consciousness is relevant for Du Bois, where this duality, this two-ness, is an awareness of being "an American and an African-American," and the largely unconscious, almost instinctive movement between these two identities. The concept of the veil and double consciousness can be transposed to the British context, where similarly there has been tension about who gets to claim Britishness and the perpetual othering of blackness and foreignness in British society. The question of community and identity and its constant transformation in transnational contexts, especially when considering mental illness, "results in a specific and distinct doubling of identity

and community” (Murdoch 2012). As Hall argues, the Caribbean diaspora, while retaining strong links with their places of origin and their traditions, either by birth or by familial heritage, must reckon with the new cultures they inhabit, that they must belong to whether they accept it or are accepted. Their cultural identities, by retention and in many ways because of being excluded from mainstream avenues of social capital, “bear upon them the traces of the particular cultures, traditions, languages and histories by which they were shaped” (Hall 1992). They are a product of several interconnecting histories and cultures, and inhabitants of several spaces, while potentially not belonging to any particular ‘home.’

I mean to distinguish what I characterize as the double consciousness performance of this service user population from ‘code switching,’ which in linguistics is the phenomenon where a speaker alternates between two or more languages, or language varieties, depending on their context, often as a means of navigating different cultural spaces. Even in its broadest application, where one might code switch between different aspects of one’s identity, code switching doesn’t imply the disorder² that double consciousness inherently implies in its irreconcilability. Double consciousness also better fits with Littlewood and Lipsedge’s position that even in redefinition of self, categories of definition are most often located in dominant models. I also mean to distinguish my use of double consciousness from that of Gilroy in *The Black Atlantic: Modernity and Double Consciousness* (1992) where he proposes understanding blackness in Europe in relation to European modernity, where the black identity in the West is an ongoing process of travel and exchange across the Atlantic Ocean. The ‘Black Atlantic’ then is a physical and metaphorical space of transnational cultural construction and hybridity that “transcend[s] both the structures of the nation state and the constraints of ethnicity and national particularity,” that recognizes a non-absolutist understanding of Diaspora for one that acknowledges the “doubleness that results from this unique position — in an expanded West but not completely of it —[as

² By disorder I mean to imply a ‘disruption of order’ rather than ailment.

being] a definitive characteristic of the intellectual history of the black Atlantic.” This articulation of double consciousness is intricately linked to a reconsideration of history.

In both the articulations of misrecognition and double consciousness, Lacan and DuBois propose a sense that the individual continually attempts to reconcile internal conflict. The post-colonial experience for Caribbean people has been one of rooted exile, in the UK. For mental health service users they are, in essence, exiles in exile. And while the general diaspora are said to have “learn to inhabit at least two identities, to speak two cultural languages, to translate and negotiate between them,” for the exiles in exile that are the Caribbean service users, with mental illness and treatment also a consideration, the reconciliation has even more at stake. This project proposes that the creation of a resilient space, specifically in Caribbean mental health day centers, is the reconciliatory response to double consciousness. Here they have created a space of resilience, where “dogged strength” can be fostered, where diagnosis, age and status lose meaning, and a ‘psychotic patient’ who has difficulty in mobility and speech can be the dominoes partner of a PhD candidate who is in the space to be a participant observer.

Psychodynamic theories of ego resiliency build from Freud's concept of ego strength that emphasized the capacity of the ego to accept reality and utilize adaptive defenses and Adler's concept that health can also be seen in one's ability to build social ties by sharing interests with others and striving for usefulness (Block and Block 1980). Ego resiliency is described as a “measure of a capacity for flexible adaptation to both internal and external stressors, and resourceful negotiation of change” and “a mediating resource that creates mediating conditions that buffer the impact of stress” (Klohn, et al. 1996; Tusaie and Dyer 2005). Richardson (2002) articulates this inquiry of theories of resilience as having come in three waves. The first wave was characterized by the identification of resilient qualities through phenomenological identification of developmental assets and protective factors. The second wave described resilience as a

disruptive and reintegrative process for accessing resilient qualities. The third wave exemplified the postmodern and multidisciplinary view of resilience as a force that drives a person to grow through adversity and disruptions (Richardson 2002). Resilience has come to mean different things to different theorists, running the gamut from a process, to an outcome, to a dynamic steady state in the face of adversity, to a defiance of risk/vulnerability (Almedom and Glandon 2007). This third wave has seen a paradigm shift from models that focus on vulnerability and deficiency to models that instead focus on triumphs and positive mental health (Van Breda 2001).

Luthar, et al. (2000) in their critical evaluation of resilience literature argue that the theoretical and research literature on resilience reflects little consensus about definitions, with substantial variations in operationalization and measurement of key constructs. In addition, discrepancies also exist in conceptualizations of resilience as a personal trait (stemming from theories of ego resiliency) versus a dynamic process with researchers using the term interchangeably to refer to each of these (Luthar, et al. 2000). As a personal trait, resilience can be defined in terms of the “presence of protective factors (personal, social, familial, and institutional safety nets)” that enable individuals to resist life stress (Kaplan et al. 1996, p. 158), where an individual’s resilience at any moment is calculated by the ratio between the presence of protective factors and the presence of adverse life circumstances. R.L. Jarrett in “Resilience among low-income African American youth: An ethnographic perspective (1997)” highlights the work of Rutter (1987) and Garmezy and Rutter (1983) as being important in early formulations of resilience, where it is conceptualized as the individual's “ability to positively respond to stressful situations.” As a dynamic process, resilience refers to encompassing positive adaptation within the context of significant adversity. Implicit within this notion are two critical conditions: exposure to significant threat or severe adversity; and the achievement of positive adaptation despite major assaults on the developmental process (Garmezy 1990; Luthar & Zigler 1991; Masten, Best, & Garmezy 1990; Rutter 1990; Werner & Smith 1982, 1992). Friborg, et al (2009) outline two

different understandings of resilience: the more limited understanding where resilience is “the direct opposite of a poor mental-health outcome,” and an expanded understanding where resilience is “more than just the absence of pathology” and instead “may foster psychological growth, [develop] new competencies or a new outlook on life.” As such, resilience is characterized as adaptability rather than as stability, and might be seen as a “process of bouncing back from harm rather than immunity from harm (Garmezy 1993; Adger 2000; Klein, Nicholls, & Thomalla 2003; Layne et al. 2007).

The current wave of resilience theory not only moves away from models of vulnerability and deficiency to those of positive mental health, and models of static hardiness to those of dynamic adaptability, but also to models of individual hardiness to models of resilience that stress an interplay between the individual and the broader environment (Rutter 1993; Egeland, et al. 1993). Further, the interactions among risk and protective factors at an intrapersonal and environmental level are integral to the definition of resilience (Tusaie and Dyer 2005). Environmental factors that influence resilience include perceived social support and a sense of connectedness (Rutter 1987; Werner 1993, Masten 1994). Tusaie and Dyer (2005) argue that reactions to stress can no longer be seen as isolated events eliciting a response, but rather must consider “a dynamic interaction of patterns of coping responses, personality characteristics, social support, and genetically determined biological reactivity” including a historical perspective that encourages the recognition of the “not only the immediate context, but the larger contexts of age cohort, family history, social class, nation/culture, history, and gender” (Lerner 1995).

Van Breda (2001) argues that resilience theory has, historically, considered the community as a risk factor, where community factors such as poverty, crime, political instability and discrimination have been identified as community stressors. As resilience theory has evolved, increasing attention has been given to the community as a source of protective factors, with

support systems such as the extended family, religious communities and the local community being cited (Van Breda 2001). Sonn and Fisher (1998) go a step further, introducing the idea of more than just the community being a support for individual resilience, but the community itself being a site for resilience. They introduce the term ‘community competence,’ arguing that while communities that are exposed to oppression and discrimination are often seen as becoming dysfunctional, many in fact become stronger or resilient as a result of the adversity, developing the capacity and resourcefulness to cope positively with hardship and foster individuals who derive “values, norms, stories, myths, and a sense of historical community” (Sonn and Fisher 1998). As such, these oppressed cultures maintain a sense of cultural identity by continuing to “practice and hold to the primary culture when they are in other settings,” such as church groups, cultural groups and families, rather than succumbing to oppression or complete assimilation. These adaptive mechanisms that characterize resilience in these diasporic communities are thought to owe much to religion, where worship has played a significant role in the Black community (Taylor, Chatters & Levin 2003). Studies have shown that religious attendance is associated with increased levels of subjective well-being and lower psychological distress and mental illness in general (Ellison, Boardman, Williams, & Jackson 2001) and in the Black community (Ellison 1995). Outside of religion, in general, racial socialization and group identification that “instill meaning, purpose, pride, and commitment to the goal of self-development” are features found to be relevant to understanding the mental health resilience in the black populations (Fischer & Shaw 1999; Branscombe, Schmitt, & Harvey 1999). So while on the surface, communities appear to show signs of capitulation and assimilation, but at a deeper level they manage to protect core community narrative and identities by acquiring “skills, competencies, and behaviors that are functional in the dominant group context; thus, they become bicultural”. Groups may develop processes and mechanisms that ensure the survival of valued cultural identities and the positive development of group members (Sonn and Fisher 1998).

A similar theory is presented by Littlewood and Lipsedge (1997). They argue that while the Caribbean migrant came from home countries where they were educated from textbooks written in England, sat exams from the Oxford and Cambridge Examination Boards, lived in towns named for English places and people, when they arrived in Britain, “the historical cultural navel of West Indian society,” they were met with the sentiment that Britain had “never faced a greater danger.” In response to this rebuff they argue that first generation migrants reaffirmed their rejected Britishness through a rearticulation, through a Caribbean lens, of British ideals. Littlewood and Lipsedge state that this can be seen in the Pentecostal direction of Caribbean religiosity. Campt (2012) argues that through fashion, presented often in photographic portraiture, Caribbean migrants expressed their articulation of British ‘gentlemanliness,’ that was “much more than the mimicry of an English style copied in an attempt to be assimilated,” but instead referenced “forms of British subjecthood through which these individuals signify a sense of belonging both in migration and ‘at home.’” Style and fashion became more than just a “superficial means of cultural engagement,” but was a “visual and tangible affirmation of their existence, or who they were, and of their cultural and social relevance in their new ‘home’” (Campt 2012).

Littlewood and Lipsedge (1997) state that the response of second generation Caribbeans was the establishment of a more hybrid identity, which drew from both the Caribbean culture and the lived experience in Britain, in a process called ‘ethnic redefinition.’ Ethnic definition is defined as “a reassertion of the values of a disadvantaged or stigmatized group [that] contains not only a reasserted identity but an explanation of the original stigmatization.” They argue that this reassertion, because it is a redefinition against the assumptions of white society, is in large part still defined by the stereotypes disseminated by this white society, accepting the validity of the stereotypes and giving it positive value or “playing rather uneasily with it.” In this way they state that ethnic redefinition may provide a secure identity in the face of continual invalidation, but it is

still an identity conceived from the perspective of the dominant culture, such that the identity of the Black British is primarily that of blackness. This is not dissimilar to the shamans documented by Taussig (1987), who in the face of British colonial suppression fused existed cultural practices with a redefined identity that was adopted and adapted from British stereotypes. Taussig states that the shaman harnessed the "mystery" and "wildness" projected onto him by the British in his practice, thus "folding the underworld of the conquering society into the culture of the conquered [like] a chamber of mirrors reflecting each stream's perception of the other" (Taussig 1987).

Tracey Reynolds (2004), in her work on Caribbean families finds that young Caribbean people, unlike their parents often struggle with creating identity for themselves as they bridge between older generations and current UK society. As a result, new hybridized means of identification can be recognized, such as ethnic classifications (Indo-Guyanese-British), cultural events (Miss Jamaica UK) and language (the development of youth slang based on adaptations of Jamaican patois and regional UK slang). These act as a means of asserting identity and creating community, but also may be evidence of a larger problem of lacking social support. Reynolds cites Putnam, Coleman and Bourdieu's work on family, community and social relationships (that is, social capital) and how they impact upon shared objectives and access to group benefits, as being relevant to the discussion of identity and community for young Caribbean people (Reynolds 2004).

In many ways, resilience behavior is an extension of the peer support model promoted by Estroff (1982), where persons with serious mental illness would mutually support each other. The peer support model grew out of the context of self-help groups such as Recovery Inc. and Schizophrenics Anonymous, and is rooted in the belief that interpersonal relationships and a shared sense of community lay the foundation for the process of healing (Davidson et al. 1999). Solomon (2004) defines peer support as "social emotional support, frequently coupled with

instrumental support, that is mutually offered or provided by persons having a mental health condition to others sharing a similar mental health condition to bring about a desired social or personal change,” by persons who have been harmed by or are dissatisfied with the mental health system and have sought an alternative to traditional psychiatric interventions. Peer support groups foster alternative conceptualizations of the meaning of recovery that may be more about recovering from mental health treatment than mental illness (Crossley 2002, 2004; MacNeil and Mead 2005; Mead, et al. 2001).

Resilience behavior is also related to the therapeutic community model. Adame and Leitner (2008) reference therapeutic communities where alternative residential treatment settings for mental illness have been created outside of traditional hospital or psychiatric institutional settings that have been criticized for the “depersonalization and decontextualization of people’s struggles and for fostering dependency on the mental health system”(Chamberlin 1978; Cohen 2005; Fisher 2003; Mead and Copeland 2000; Unzicker 1989). Their argument is that the medical model renders the person helpless to contribute to their own recovery process by designating the diagnosis and treatment of such disturbances strictly within the domain of the psychiatrist’s expertise and control. Mosher and Burti (1994) argue that the medical model takes a “guilty-until-proven-innocent approach” toward treatment, where extreme states of consciousness are labeled as sick, and wellness is construed as the lack of such experiences. Clinician–researchers such as Mosher and Burti 1994; Perry 1999; Podvoll 2003) have written extensively on the success of respite home programs designed for acute psychological crises where similarly to the peer support model where the relationship itself is the catalyst for healing, “residential alternative facilities are themselves the treatment,” where these transitional facilities provide an environment accepting of people’s experiences (Mosher and Burti 1994). The resilient space of places like the Caribbean mental health day centers provide both peer support and alternative facilities.

Chapter Three: Family Health Isis

Prologue

*Meet me at the bank of the beautiful river,
Meet me at the bank of the beautiful river,
And your journey has end...*

*Right over there...
Right over there...*

*It's green and gold, it's the rainbow.
It's green and gold, it's the rainbow.
It's green and gold, it's the rainbow.
It's green and gold, it's the rainbow.*

The rainbow...

“Red, Gold, Green” – Burning Spear (1975)

Introduction

As previously mentioned, Family Health Isis was the organization where I spent the most time engaging in participant observation, filming with and learning from service users and staff. Isis has an important place in this dissertation because of the apparent effectiveness and benefits of their therapeutic approach for Caribbean service users, so it is crucial to have a detailed understanding of how Isis, as an exemplar of a Caribbean mental health center, is organized and how it functions on a day-to-day basis, as well as some historical information on its origins and

development as an institution. This chapter presents an ethnography of Family Health Isis, that covers Isis in their original home in Catford, London where they had been housed for over 20 years, its significance to its members, the trepidation and implications of being forced to move, and Isis in their new home in Lee, London.

Family Health Isis

Family Health Isis (FHI or affectionately known simply as 'Isis') is a community organization based in the London Borough of Lewisham. It was set up in 1987 by a group of mental health professionals, services users and community workers and was initially launched as the Black Mental Health Group to provide a service to African and African-Caribbean people who may have experienced some form of mental health distress. Isis takes its name from the Ancient Egyptian Goddess Aset (Isis), symbolizing an organizational philosophy of using a pan-African holistic approach to solving contemporary social problems, based on self-reliance and self-determination, reclaiming and promoting the central role the family plays in African and African Caribbean societies.

Isis is one of the oldest African and African-Caribbean mental health organizations in the UK and has demonstrated effectiveness in providing culturally relevant services for black people with mental health problems. They cite the evidence of the need for their services as being increases in referrals over time from both the statutory and voluntary sectors; ongoing positive feedback from the local community and from consultations; ongoing research, evaluations and statistical analysis based on members and samples taken from the various programmes run both within the center and the wider community. Isis' aims are to support service users to be heard in the way that they wish to be heard; to work with service users to be involved in their own care and treatment, to direct and guide service users to make better use of mental health services; and to represent

service users to promote quality in mental health services.

Organizational Structure

Isis has a staff team comprised of full-time, part-time and voluntary workers, as well as social and community work students who are on placement, a mix that provides a broad environment of care for those who come into the center. In operation, this mix feels relatively non-hierarchical. Often I wasn't sure who was a service user, who was a visitor, who was a volunteer and who was staff. It was a space of egalitarianism - an alternative space of friendly familiarity. You were just as likely to see the director dancing with a service user at a function or a senior staff member helping out in the kitchen as you would any other staff member. For the most part everyone is referred to by their first names or a pet name, although on a few occasions I have heard service users call staff members Aunty or Uncle. After introducing myself to the service users during their Social Gathering meeting and telling them that I was a doctoral student, my pet name became "Doctor" from there on out, which was confusing when first meeting service users who would hear others refer to me as 'Doctor' and then ask me for medical advice. This level of familiarity between staff and service users did not undermine a sense of respect, but it did promote an environment of togetherness and greater equality than I found on hospital wards where roles and status were clearly defined and reinforced.

The center was originally built with joint funding from health and social services, and had two sites, the day center in Catford with 11 staff and an assertive outreach team of six in Deptford, both in South London. Currently, the staff organization is made up of a main director, Estella Weston, a marketing and fundraising director, Paul Clarke, an executive board of members, a team of staff members that includes counselors, advocates, community workers and chefs. The organization also has a number of volunteers from the community and former service users, and

students who are training to be community workers, social workers and community psychiatric nurses. A lot of emphasis is put on taking on students because it is felt that it is important that more practice professionals take the opportunity to work with Black people outside the psychiatric setting. Weston states that in this community setting, there is less opportunity for workers to fall into the usual expectation and responses to Black people based on their diagnosis (Christie 2001). An added benefit of having students is that they are budget friendly.

Isis is a registered charity and funding is secured from a variety of sources including the London Borough of Lewisham and South London and Maudsley Mental Health Trust (SLaM). As a well-respected local resource, Isis has a long history of partnership working with National Health Service (NHS) mental health services in Lewisham. The partnership approach between Isis and NHS services is said to have been beneficial for both parties. Isis fills gaps in NHS services, and acts as a valuable, critical partner to NHS services, and in return much of Isis funding comes from the NHS. Isis staff is involved in the induction process for new NHS mental health staff, and have also been involved in the recruitment process for NHS staff. Their ability to work collaboratively with statutory and independent agencies creates greater choice and flexibility in service provision to the African and Caribbean community (Christie 2001). During my time at Isis, there were two training social work staff members who assumed important roles in the Women's Group, the Social Gathering sessions and other day-to-day activities.

Since its establishment, Isis has grown from a relatively small organization to a quite sizable one, at least in terms of responsibilities. This has increased the call on staff time to attend meetings with funders and planners with these external expectations and demands from funders often exerting added strains on already pressurized agendas. The issue of funding is crucial for non-statutory organizations such as Isis, and often there is the sense that "the funders [are] calling the tune and the voluntary organizations are having to dance to the beat of an unfamiliar and

undesired rhythm” (Christie 2001).

Activities and Services

Isis is open for business support hours from Monday to Thursday from 10.00am to 6.00pm, and on Fridays from 10.00am to 4.00pm. Fridays are usually reserved for internal staff meetings and bookkeeping, but is closed to service users. Most recently, having moved from Catford to Lee, the centre is open for general drop-in services from Monday to Thursday, from 11am until 4pm, with different group events happening up until 9pm on most nights. Women’s Group is held on Mondays from 12pm until 2pm. The Art Therapy workshop is held on Tuesdays from 2 until 4pm. The Social Gathering group meets on Wednesday afternoons and the Ubuntu Young People’s Group from 6 to 8pm. The Hearing Voices Group and the Men’s Group are usually held on Thursday evenings from 2pm to 4pm and 6pm to 9pm respectively. Counseling is available throughout the week via appointment.

Isis’ services include individual support to both relatives and friends of people with mental health problems and to people experiencing mental distress and group activities that include exercise, the women’s group, the men’s group, as well as music, sewing, arts and crafts and creative writing workshops. The longest established group at Isis is the Social Gathering group, a forum for all members to get together and socialize. Speakers and workshop facilitators are regularly invited speakers, as well as quiz hosting, dance classes and other culturally related activities and events. Culturally related events include events such as how to cook Caribbean meals for yourself, Black history month activities and how to take care of your health needs using natural means. Other group activities include an annual Christmas celebration, outings, in-center birthday celebrations and information to local events.

In addition the center provides advocacy, accompanying people to appointments, hearings, case conferences, compiling letters, completing application forms, drafting complaints and generally ensuring members views are heard and understood as a form of self-empowerment.

Also provided is a flexible and client-focused support service carer and family liaison, offering practical support to families experiencing mental health difficulties, advice and information about benefits, housing, employment, the Mental Health Act and general information about race and mental health issues. Isis also offers training and awareness by facilitating workshops and giving presentations at conferences and seminars designed to raise public awareness of the issues of most importance in the mental health field as they affect African and African-Caribbean people.

An open day is held every month to facilitate information exchanges. There is both an assertive outreach team acting as an interface between members and other agencies in a culturally sensitive way and an 'in-reach' support team facilitating hospital admission for those requiring it and providing support to in-patients to lessen trauma. Isis provides a counseling service, which is available to anyone from the local African and African-Caribbean community and is one of the longest running black services in London, operating on a sliding scale related to income.

Additional Services

Isis operates the Oji Black African/Caribbean Drop-in Centre, a project targeting the needs of the Black African/Caribbean community living with mental health in the London Borough of Greenwich. Isis was commissioned by the borough to provide this service, which similarly provides a social environment that is safe and welcoming for service users, and a range of information on welfare benefits, housing, employment training, and rights and responsibilities under the Mental Health Act. Oji has a staff team that comprises of two full-time Community Development Workers, voluntary workers, as well as social and community work students who are on placement with Family Health Isis. Oji is open on Mondays from 11am to 4pm.

Oji operates out of a rented space in the Trinity Methodist Church Youth and Community Centre in Woolwich, London. The space has a gym area, a kitchen, a main social area and a games room with a pool table and a ping-pong table. My brother lived close by to the space, so I spent a lot of time at Oji as well, again assuming a volunteer role, helping with meetings, lunches and helping initiate a program of monthly outings to local places of interest. During my time volunteering, we visited the National Maritime Museum to see their slavery exhibit and had a picnic and cinema trip. The small Oji membership (usually about 12 persons) was mainly of African heritage, which I assume was linked to a smaller Caribbean population in the borough of Greenwich compared to Lewisham, and a higher African immigrant population in Greenwich. Despite this, Oji retained a lot of the Caribbean identity that Isis has, demonstrated mostly in the staff where 3 of the 4 main staff members were of Caribbean descent, with the main staff in charge, Abraham, being African. Occasionally the lunch served had an African inspired meal, but for the most part it felt very much like an offshoot of the Isis spirit, in a different environment, with less domino playing and quieter, more gospel oriented music.

Isis also runs the 'Bun and Cheese' group, established in 2010 for African and Caribbean service users and meets fortnightly at the Bracton Centre. The Bracton Centre is a medium secure unit comprising of 6 wards for service users who require specialist mental health services for forensic or challenging behaviour. The group provides a space for the Black African and Caribbean residents to discuss issues of importance to them and share a meal.

Family Health Isis, in conjunction with the voluntary organization Ubuntu Social Living Networks, also runs the Ubuntu Youth Project on Wednesday evenings. Ubuntu is inspired by the challenges of discrimination and inequality facing young people of African/African-Caribbean heritage, and the concept that they 'can do great things'. Ubuntu means "I am because we are," which is the motto for the group. Two community activists facilitate the group. Sixteen-year-old

Ishmael, a member of the Ubuntu programme said, “Ubuntu has given me the confidence to stand up for myself and speak freely to the community. It has also given me the power to overcome struggle and stress, which has enabled me to become a loving and understanding young Black male of the community” (FHI 2011).

Referrals

Isis provides an inclusive service that takes self-referrals, referrals from relatives, friends and referrals from voluntary, independent and statutory agencies. Services are officially offered to persons of African/African Caribbean descent living or working in the London Borough of Lewisham, between the ages of 18 and 65, though there are members who are older than 65. The ages of members was quite varied but seemed to skew slightly older than 35 just from sight. Younger members did use the services, and especially would turn up for specific groups, but those that hung out the most at the centre seemed to be older. Oji accepts referrals from all statutory and voluntary mental health providers within the London Borough of Greenwich, and also accept self-referrals and referrals from family and friends. Ubuntu programmes are open to any young person who believes they can benefit from them, and whose parent or carer are committed to being involved in the programme.

The role of Isis in the lives of service users

Isis is committed to the provision and development of more appropriate mental health services for African and African-Caribbean individuals and families. Isis’ ethos is developed from the following accepted “facts”: that there is an over representation of black people in psychiatric hospitals; that there is a much higher rate of diagnosis of schizophrenia amongst African and African-Caribbean people; that there is a disproportionately high rate of schizophrenia in African and African Caribbean communities as compared to the rates of schizophrenia in their native

countries; that black people are more likely than white people to enter a psychiatric hospital formally; and that black people are likely to experience the most basic of treatments once they have gained access to mental health services (Isis 2008).

My introduction to Isis was in their role as advocates for African and African-Caribbean service users on hospital wards in the Lewisham area. I first began working with Isis as a volunteer in 2002. One of my main duties was to accompany Cordwell Thomas, then a senior advocate, on ‘in-reach’ advocate visits to the Ladywell Unit, an inpatient mental health unit at the local Lewisham Hospital³. At least once a week, we would navigate the wards, following up with service users on existing cases or introducing ourselves to potential new clients, informing them of their rights as patients, asking them if they had any concerns or needs. Isis’ Advocacy team, comprised of an Assistant Director and four team members, helps service users to gain a better understanding of their current situation and acquire greater information to help decision-making and make better use of existing services, and provides support in treatment and care packages, reviews and case conferences, courts, tribunals and formalizing of complaints.

What I found valuable while working as an advocate, was the role Isis played in bridging the separation between the life of the service user as an in-patient and the the life they had temporarily left behind on the outside, where often children, relationships, jobs and housing were significantly impacted. Even though Lewisham was just outside, inside the wards felt like a separate world. In this world you needed permission to leave, all the dinnerware was plastic and all the food was reminiscent of everything that was hateworthy about cafeteria-style school

³ The Ladywell is comprised of six wards, one adult inpatient ward for the three Lewisham localities, specializing in acute cases (Powell, Clare and Wharton Ward); a fourth specializing in general assessment and treatment (Triage Ward); a fifth, a psychiatric intensive care unit (Johnston Unit) within which a separate, designated place of safety, a ‘136 Suite’ has been established for those persons brought to hospital by the police under Section 136 of the Mental Health Act; and sixth, the Hayworth Ward that provides inpatient assessment, treatment and care for people aged over 65 with acute mental illness or under 65 for people who have dementia.

lunches. Inside, the world smelled like standard issue disinfectant mixed with the smell of inescapable, noxious despondency that wafted from the never-empty, designated smoking room. Being in long term care, service users were concerned about how their children were or the state of their homes or if we could convince the staff to let them have unescorted community leave. They frequently spoke of wanting a health care professional who they believed understood them and could provide the kind of care that they felt would be of benefit to them. Though I can't remember exactly what she said, I distinctly remember a service user saying something in Jamaican patois, that I knew could possibly be misinterpreted as symptomatic of mental illness. Her expression caused the consultant psychiatrist to ferociously start scribbling notes and caused me to interject with my interpretation of what she meant and why he should be careful with his interpretation of her words. Working on the wards, I got the overwhelming sense that once service users had entered the mental health system, the direction of their life's course was no longer in their hands. Their life stories were now reduced to the contents of their patients' notes, and who they were was now dictated by diagnosis and who they could be was dictated by medicine.

Once on the outside, service users often were not ready to reintegrate into their communities in a constructive way. Linked to this advocate/'in-reach' approach, was the assertive outreach team (AOT) that supports members to become more knowledgeable and empowered in managing their health issues outside of the mental health system, as well as helping them to be more active members of their local community. Acting as an interface between service users and the statutory sector, assertive outreach, like the advocacy team, provides support on issues including welfare rights, housing benefit issues, medical and other concerns that members might identify as being currently unmanageable, such as managing their budgets, sustaining accommodation, maintaining personal relationships and enhancing their life skills. The AOT is a pro-active and positive service, aimed at complementing existing services by offering culturally sensitive services within

the local environment. Isis' Assertive Outreach Team works in collaboration with local agencies with those members perceived to be 'hard to engage'. This service was a forerunner for now borough-wide outreach services.

Isis also has a counseling department with a team consisting of one full-time counselor and a dedicated back-up team of volunteers and student counselors. Sessions at Isis can be weekly, bi-weekly, or monthly depending upon individual need. Counselors often participate in the Social Gathering meetings to encourage service users to seek counseling should they need it, introducing its benefits and advantages to a group that is most often only recommended medication by statutory services. Persons using the counseling services often represented a hidden population amongst Isis members. In the old Isis building, the rooms used for counseling were on the upper floors and persons using the service didn't necessarily spend any significant period of time in the main area socializing with other members.

In 2001, The Black Spaces Project set out to discover how a number of Black voluntary organizations filled the gaps left by the mainstream mental health system, which was found to leave Black service users feeling that their needs were not being met. These gaps included a lack of culturally sensitive care, a lack of equal access to alternatives to medication, a lack of practical support in life matters outside of illness, a general sense of dissatisfaction in the treatment they were receiving from statutory bodies. The project found that many Black organizations were stretched to the limit, working with few resources while having to provide a range of services. Isis was one of the seven organizations selected as a model to be studied from which other organizations and the wider mental health care system could learn.

Of Isis specifically, the project received positive feedback from service users that the Isis building was "very clean with lots of information on the walls;" that there were "also lots of Black pictures

and posters with poetry on the walls;” that disabled accessibility was good; that there was a shower room with a washing machine and dryer that members could use; and that there were rooms for counseling (Christie 2001). This speaks to the value of positive culture representation and information for service users, to the requirement of practical amenities like access to laundry facilities and the necessity of accessing counseling services. One female member of Isis stated, “Being here helps me to be comfortable with myself. I don’t have to worry about what other people think of me by coming to a Black group. I enjoy the Black bit, I am not keen on the association with mental health.” In addition, one Isis staff member stated, “What makes our service relevant to Black people is that we speak the same language, we understand what’s happening in people’s homes and what’s happening on the streets and we communicate from the same or very similar standpoints.” The Isis logo itself invokes the cultural commitment of the organization, utilizing the Pan-African colors of red, gold and green, originally inspired by the flag of Ethiopia (as well as other African nation flags) and adopted by Pan-Africanist ideological movements like the Rastafarian movement.

The Isis space

The old Isis office in Catford was a large, but old building, owned by the council, situated in the heart of the town. To the right of the building was the local post office, then a busy betting shop, then a local corner shop. To the left was a fast food eatery, then another corner shop, then a local pub. Across the road was the library where you would often find service users checking their email or browsing the Internet. Computers had been promised to Isis by a supporter, but had yet to be donated during my time there. Not far down the road was Lewisham Hospital, where many of the service users had been treated. There was nothing obvious on the front door to suggest that a mental health centre was inside. A busy bus stop was right outside, and often locals would peek through the blinded windows to see what was going on inside. On a few occasions, the curiosity

got the best of some and they pressed the buzzer to be let in, just to ask what was going on inside. The Isis space was separated into three stories. On the uppermost floor were the staff offices and a few smaller private rooms used for one-to-one sessions with service users. On the middle floor were a couple of larger rooms that were used for larger meetings such as the Hearing Voices Group and Art group. The bottom floor was the main space of activity. At the front of the space was a reception desk that was rarely manned and a seating area, that allowed newcomers to visit without necessarily going too much further inside and allowed old members to hang out in a slightly quieter space. Attached was a kitchen space, where tea and drinks were offered and a traditional Caribbean lunch was sold at a cheap price. Further inside was the main communal space, which served for multiple purposes. At lunch it was a dining room. At any time it wasn't being used for a specific function, it was the room where loud dominoes, not so loud chess, loud music on a service user donated stereo, loud conversation and quiet reading were done. Walls were covered in service user art, event announcements, posters of historical events and black leaders. It was a well-worn space, but was much more like a comfortable pair of old slippers than a damaged pair of shoes. The group had likely grown too large for the space, but it was most definitely their space. The private environment separated by a private door from the very public exterior made it feel like an escape of sorts. The loud south London community outside was replaced by a loud connected community inside.

For the Black Spaces Project, Isis staff talked about the restrictions of the building, where the physical separation between the staff team and members was not ideal and raised safety issues. Though it allowed some staff to get on with their paper work more easily, it required more staff to be on hand downstairs for security reasons. With that said, at no time did I ever feel unsafe. Related to this, there were 'Ground Rules' for Isis members posted on several walls. The rules stated that all members should respect the rights and feelings of others and be aware that their behavior could affect others; any member who deliberately abuses or damages the facilities of

FHI can be charged for the damage and suspended/expelled from the group; any member who causes unreasonable distress to others can, in the first instance, be cautioned and then if persistent suspended/expelled; any member who fights or abuses any member of staff or FHI can in the first instance be cautioned and then if persistent expelled; any member who brings the reputation of FHI into disrepute can have their membership reviewed; under no circumstances can alcohol or illegal substances be allowed on the premises; a member can be banned by a decision of one FHI staff member and the decision to re-admit the member will be made by the Review Panel; the length of any member's suspension shall be decided by the Review Panel; and smoking is not permitted on the premises and must be done in the designated smoking area outside. I never once saw any members actually reading the rules, but I also only once, over the year or more that I was at Isis, saw a member break the rules (he was found with alcohol or illegal substances on the premises and asked to leave).

In the two years or so that I spent at Isis, I frequently attended drop in services to just hang out, talk to service users and staff informally and play dominoes. Eventually I assumed a volunteer role in the Hearing Voices Group and the Men's Group. Actually, it is more accurate to say that the role was assumed of me because I was so frequently present, and over time certain responsibilities were handed off to me. I often initiated the start of the Men's Group and the Hearing Voices group, arranging the room and bringing the meetings to order. Often other staff members would ask me what the topic for the Men's Group discussion was going to be.

The Hearing Voices Group was open to any Isis members, but focused on being a space for person who suffered from hearing voices to speak about their experiences, though you did not have to hear voices to be in the group. The group, usually of about 10, sat in a tight circle and members would introduce themselves and state how their week was. A tray of fruit was passed around while people spoke and a table was set up for tea and juice that people usually made for

themselves at the beginning of the meeting. After introductions, the meeting would proceed from a prearranged topic or a larger conversation would jump off from an individual comment. Often a prearranged topic would get derailed by a spontaneous conversation. The size of the group, the intimacy of the room and the privacy of exchanges that were a characteristic of the Hearing Voices Group gave individuals a sense of freedom to tell stories of themselves. One senior member of the group spoke of an experience of arriving in England as a young woman to reunite with her family, standing at the train station trying to figure out how to get to her destination. Believing she was getting on the correct train, over the loudspeaker she heard the train announcer loudly repeat, "mind the doors." In a panic, she jumped back off the train and frantically started screaming, "I don't want to go to Minor Doors, I want to go to London!" Another member kept a journal of elaborate dreams she had that were, from her perspective, prophetic in nature. She would often bring the journal to the meetings and read her latest dream from it. Many times the dreams would relate to a topic or another member's experiences that had been discussed in a prior meeting. Before being a member of the group she stated she had felt uncomfortable about sharing the dreams and her belief that they had prophetic powers with others, but she now harbored ambitions of publishing the journal in some form.

The Men's Group at Isis is a weekly gathering, held on Thursday evenings. It is exclusive to the male members and any female members that may be around when the gathering is scheduled to start are asked to leave. The Men's Group had a core attendance of about 12-15 service users and staff, but this number could go up to 25 on any given night, usually with a range of ages from mid-20s as high as early 70s. The membership was almost exclusively persons of Caribbean heritage, but there was at least one regular attendee of African heritage. Usually the men play dominoes, watch television, read or generally socialize for a free period while 2-3 staff members begin preparing a meal. The meal is sold to the members for a minimal cost and is usually West Indian food with a meat and a vegetarian option. After a while, the men form a seated circle,

which is a space for discussions and debates, unless the decision has been made to view a documentary or film that often relates to black or African history, current affairs or health. The discussions are usually unplanned, but often a theme is decided ahead of time. A carved wooden cane is held to control the floor and each member is required to, at the very least, greet the room, say their name and briefly speak about how their week has been. Depending on what is said, discussions may branch off from this. When the meal has been cooked, the circle breaks up and members eat communally. On certain occasions, such as birthdays, a dessert is also offered. While I was present, one member was taking a cooking class and so he would bring in the baked desserts that he had been practicing. During my fieldwork I assumed a volunteer role with the Men's Group, often initiating the start of the Men's Group, arranging the seats into the circle and bringing the meetings to order. Occasionally I set the agenda for the discussion.

During my time at Isis, sadly two members passed away. Fitzroy Jordan passed away suddenly in July 2013 and Leah Raeburn passed away in August of the same year. I was familiar with Leah and she would often come around to speak to one of the leaders of the Women's Group, Sharon, with whom she was close. Sharon told me that she had had a small disagreement with Leah and had called her, received no response, and assumed that it was as a consequence of the quarrel. Having not heard from her for a few days, she had a sense that something was wrong and eventually went to her apartment and found her dead. Leah, an epileptic, had been dead for 3 days. A celebration⁴ was held for Leah's "life and journey to the Ancestors," to which many Isis members attended. Later that year, a fundraising event was held at Isis to raise money for a trust fund for Leah's young son.

Despite black mental health spaces being open to all black persons, the vast majority that I visited had a Pan-African focus that was filtered through a Caribbean perspective. This is most likely a

⁴ Some photographs from this remembrance for Leah can be found in the photographic chapter.

result of a longer history of Caribbean persons being in the UK and being involved in working in mental healthcare and healthcare in general. It would be quite easy to mistake this Pan-Africanism for Rastafarianism, but I found the majority of service users to be Christian, even though there were quite a few Rastafarians. The Pan-Africanism was focused on pride in self, recognition of culture and promotion of historical learning and didn't have a particular religious bent to it at all, despite some shared language and iconography with Rastafarianism. Some agencies like Fanon, made efforts to reflect a more diverse perspective, but this was related to having a more diverse membership and because funders had required that they have a more diverse focus. Isis was very much Caribbean focused, though there were a significant number of members of African heritage. Despite this Caribbean focus, I got no sense from the African members that they were uncomfortable, and often they would adopt Caribbean language terms or relate Caribbean foods to foods they were familiar with from their own heritage.

Almost every Caribbean-specific mental health day center I visited, Isis included, had certain things in common: local dialects being spoken, including by the staff; music being played, often very loudly; dominoes being played, also often very loudly, Caribbean food being cooked if there was a kitchen on site and the presence of local Black newspapers like *The Voice*. The illness behavior seen in the hospital setting was replaced by much more vibrant behavior that wasn't dictated by illness at all. It was a space that very obviously people drew strength from. It was a space away from London's unnaturalness, as many described it. It was a space where service users had a voice, often a very loud one. This is in stark contrast to the environment in the wards on hospitals. More than anything the contrast is that these Caribbean-specific centers feel alive and hospital wards feel sterile. Locked doors in the wards that you have to buzz to get into feel like they are locking people in. Locked doors in the centers almost feel like entrances to a different world. For a Caribbean person, entering that world, there are familiar smells and sounds and faces. The familiarity of the hospital setting is quite different and not pleasant. For some it is

‘hell;’ for all it is definitely not ‘home.’ It is a space that service users have no control over, whereas, as Malcolm Phillips describes of the Oremi Centre, service users helped design it. They wanted to see pictures of themselves on the walls rather than posters. They fought for café services for the center, believing it to be crucial for Caribbean community services. The service users describe the center as feeling like a “home”, a “sanctuary.” Non-Caribbean visitors described it as “not like a hostel.”

The Move

Isis, amidst some controversy, uncertainty and trepidation, has since moved to a shared building in Lee after the building they had occupied for more than 20 years was sold. There was a long period where rumors had spread among the service users that Isis would either close or move and that there was nowhere to move to. These rumors dominated more than a few service user meetings. One session of the Hearing Voices group was dedicated to allowing members to speak about the fears they had related to what was then the rumored move. The Isis staff, led by director Estella Weston, held a forum to ease some of these fears and address the rumors, admitting that they had a deadline to move out of their current building but had yet to confirm a new residence. This news did little to ease fears, but service users seemed appreciative to have been given new information and to feel involved in the process. From the conversations I had with staff members, I got the sense that the sale of the building was related to budget cuts by funders and was out of their control. They had been promised a new building, but the process had fallen through a couple of times, leaving them in a somewhat precarious position.

When a new building was eventually found, it had to be shared with an art group and did not have sufficient private rooms to continue some of the advisory services that Isis provides. One staff member told me that counseling services had to now be done offsite at a local library. The new

space was also did not have sufficient separate rooms for different functions, so activities like the Men's Group and the Women's Group were interrupted. Gym sessions were no longer accessible and hospital liaison work was made more difficult because the commute was now a few miles by vehicle rather than a simple walk down the road. Also, in the making the move, the centre had to close completely for a few weeks. I was informed by a staff member that in that time, with there being no place for regular day centre visitors to go to, a number of the service users fell ill.

The new Lee space was much different, much less lived in, but Isis has made the effort to make it their own again. The building is now situated in the middle of a neighbourhood, which initially seems to have caused some anxiety for their new residential neighbors. There is a nearby park where service users and staff often walk. The local corner shop is further away, as is the local betting shop. The outside is no longer as loud, with the dominating noise now being from Isis. It is a less closed in space, though you still have to buzz to get in. There are large windows into which you can look and see the main socializing area. The front door is more clearly marked that it is a mental health centre, but there are far less curious passers by. The Isis space is now separated into two stories. On the second floor are the staff offices and a private room, as well as the offices of the Art group that they share the space with. The bottom floor is still the main space of activity. The reception desk is now a space to itself, and used as a business office, reducing some of the separation between staff and members that the old space in Catford had. Down the corridor are accessible bathrooms and an exit to the back of the building where members smoke. Across from the reception space is the main social space, which has an attached kitchen where tea and drinks are still offered and a traditional Caribbean lunch is still sold at a cheap price. Further inside is a smaller communal space that is almost exclusively used for domino playing. This room leads to the back also. Dominoes are still loud, chess is still not so loud, and music and conversation are still loud and vibrant. The walls are once again covered in service user art, event announcements, posters of historical events and black leaders. It no longer feels like a

comfortable pair of old slippers, and instead feels like the shoes you were made to wear with your uniform for school. They are yours, but not really your style, but you will make them work for you.

Chapter Four: The Service Users

Prologue

He is despised and rejected of men; a man of sorrows, and acquainted with grief: and we hid as it were our faces from him; he was despised, and we esteemed him not. Surely he hath borne our griefs, and carried our sorrows: yet we did esteem him stricken, smitten of God, and afflicted. But he was wounded for our transgressions, he was bruised for our iniquities: the chastisement of our peace was upon him; and with his stripes we are healed. All we like sheep have gone astray; we have turned every one to his own way; and the LORD hath laid on him the iniquity of us all. He was oppressed, and he was afflicted, yet he opened not his mouth: he is brought as a lamb to the slaughter, and as a sheep before her shearers is dumb, so he openeth not his mouth. He was taken from prison and from judgment: and who shall declare his generation? For he was cut off out of the land of the living: for the transgression of my people was he stricken.

Isaiah 53:3-8; Standard King James Bible

A note on quotations⁵

In both this and the following chapter, in transcribing the interviews and conversations I had with subjects, I adhered closely to exact words spoken. On occasion I corrected for grammar or altered sentence structure to make the writing more readable. In some cases, where words were spoken in

⁵ In making this declaration, I must give credit to Tanya Luhrmann from whom I borrowed the idea after seeing it in her book *When God Talks Back: Understanding the American Evangelical Relationship with God* (2012).

patois⁶ or slang, I have chosen to write them in standard English if I felt that doing so would not lose the essence of what was being said and would instead undermine the information of the subject and the understanding of the subjects' words. In making these adjustments, I have made every effort to retain the sense of what was said by the subjects.

This is an example of the way I have altered quotations to make them more 'reader-friendly':

The original:

"I don't know how to tell my life story good, you know, but there's more to my life story than what I can tell you. I can't tell my life story very good, you know. I can't tell it very good, you know, but me will try, me will try. I will tell you what I can."

The way the quotation would appear in the chapter:

"I don't know how to tell my life story well. There's more to my life story than what I can tell you. But I'll try, I'll try. I will tell you what I can."

Introduction

The underlying intention of the interviews with service users was to allow them to tell stories of who they are and of their experiences in the mental health system. Though I followed a semi-structured interview format, the conversations I had usually flowed from a basic instruction: 'tell me about yourself.' I never explicitly asked anyone what their diagnosis had been or what they were being treated for. As much as possible I decided against asking questions that they may have found clinical. The aim here was to allow subjects the power to dictate their persona and

⁶ Jamaican Patois or Jamaican Creole is an English-lexified creole language with West African influences spoken primarily in Jamaica and the Jamaican diaspora.

personhood in a way that is sometimes missing when filtered through the medical perspective that the subject's medical records, their healthcare providers, and their diagnosis often provide, with little or no control by service users. This decision was also in the spirit of the created resilient spaces, where I found these kinds of details were rarely discussed. In general conversation, service users might discuss the effectiveness of certain medications or experiences in hospitals or other experiences that might hint at or give clues at what a diagnosis might be, but I never heard anyone say "I am a schizophrenic" or "I suffer from depression" or something similar. Further, because there was often expressed doubt about the validity or the meaningfulness of diagnoses, finding out what specific diagnosis an individual had been given likely would not have given me any significant information except the specific name of the diagnosis.

In this chapter, I present selected text from interview transcripts and for the interviews; a select number of voices are used to speak more representatively for the larger Caribbean service user population. This selection is due to space limitations and the desire to present the transcripts in as full a form as possible. Following the narrative analysis process, after analyzing the content of the interviews for common events, descriptions and themes, I have chosen interviews that are representative of general themes present in service user opinions as a whole. Despite the limitations, I have attempted to show variety, primarily in subject location, gender, and age. The selected voices include one subject from the Fanon Resource Centre, two subjects from Family Health Isis, excerpts from the Men's Group at Family Health Isis and the transcript from a focus group at Social Action for Health. Though not perfect and though each individual voice is not represented in the ethnographic chapter, the selected voices both fairly represent the broader concerns of the majority of persons I met and spoke to generally during fieldwork, and also fit with the findings of other researchers about the concerns of service users who have done work on this population. The key difference in this project is that it allows service users to speak for themselves.

This data is presented with minimal interruption and without analysis in order to preserve the emphasis on the subject's voice, allowing the voice alone, as much as possible, to demonstrate meaning elicited from their experiences. My voice is only present when its absence would make the quotations difficult to understand or if during the course of the interview a particularly interesting or useful theme emerges from my contribution. A contextual introduction will be presented for each subject, including participant-observation notes from the recruitment center for the subjects. The names of the subjects have been changed to protect their identities. The ellipsis [...] within a paragraph or between paragraphs indicates that some material has been omitted. Editorial comments are given within brackets in italics. Modified text used to replace text in a quotation to make it clearer is also given within brackets.

Noel

I interviewed 'Noel' in August 2011, at the Fanon Resource Centre in Merton, though he was a service user at the centre in Lambeth. Fanon is a mental health resource centre, a subsidiary of the Southside Partnership charity since 2005. Described specifically as a 'resource centre' rather than a 'day centre,' Fanon offers music workshops, discussion forums, advice, liaison with other services, life and work skills projects, volunteering and training projects, befriending and mentoring training and activities, hearing voices groups, tenancy sustainment projects and offering outreach services. Both centres perform similar activities but are located in very different settings. Fanon Merton is located on the ground floor of Justin Plaza; a multi-tenanted office building arranged over four floors with individual suites in Mitcham, which is on the outskirts of London, and does not have a particularly dense black population. It was the former location of Merton Oasis, which was a mental health organization dedicated to promoting mental health and well being in Black and ethnic minority elders and their carers, which Fanon took over in 2007 and launched it as Fanon Merton. It does not have the feel of a space that is conducive to mental

health support, and certainly does not have the comfort level that many Caribbean mental health support centres have. Instead it reads as office space. Despite this, the staff and members have done their best to make it their own. On the walls are examples of the recovery focus that Fanon promotes, with posters detailing tools for learning and self-reliance. On the bookshelves, Namba Roy's "Black Albino" sits beside "Introducing Sociology." The main communal space has a number of flyers and publications lying around that promote opportunities for services and events in the local area that may be of interest or benefit to the service users who come in. I visited during the period of Diwali, the Hindu festival of lights, so there were signs up celebrating the season.

By contrast, Fanon Lambeth is located close to the heart of Brixton, probably the place in London most identified with Black Caribbean people. It started as a soup kitchen on Effra Road after the Brixton Riots in 1981. Like Fanon Merton it focuses on giving service users life and work skills, including cultural competence and leadership training, as well as traditional mental health support. The centre is located in a modern multi-storied building of its own, decorated to fit the needs and philosophies of the group. The main glass doors open to a welcoming reception desk that leads down into a communal area with comfortable seating and tables for dominoes and other games. A separate table was dedicated to showcasing books; a cookbook sat beside a black history primer, the Bible sat beside the Qur'an. Walls were covered with pictures of important black figures; here Nelson Mandela was grouped with Bob Marley and Barack Obama. Also on the walls were numerous photographs of service users and staff, and artwork produced by service users. There was also a display cabinet of arts and crafts that had been produced by the women service users, above which various health and advice pamphlets stood.

Both Fanon Merton and Lambeth are primarily for African and African Caribbean men and women, but has expanded to include other ethnicities in the area they serve. This expansion was

dictated by economic constraints that forced the closure of other care centres and required Fanon to accommodate a larger service user population. In addition, this expansion was a source of frustration for 'Noel,' who was dissatisfied with the more inclusive direction that Fanon had been forced to make and believed that Caribbean service users would be better served by remaining independent from Southside Partnership and maintaining a focus strictly on Caribbean culture. He spoke negatively of his experiences in the healthcare system and of the impact of medication and the necessity for culturally competent services. Prior to the interview, I had not met 'Noel' before, so there was no immediate rapport, neither did I know anything about him or his life. Everything I learned about him happened through the interview. Ian Wint, a community development worker at Fanon Merton, recommended him to me. 'Noel' is a middle-aged man of Caribbean descent, with dreadlocks and a serious demeanor. He was admittedly slow to trust unfamiliar figures asking him questions. Despite this, he appeared to speak quite openly, though deliberately. We conducted the interview in a free room inside the centre, across the table from each other.

Noel's Interview

KWAME: You were born in Jamaica and came over here, can you tell me about when that was?

NOEL: It was in either '71 or '72 I came over. It was my parents who sent for me and brought me over here. I was 11. I spent my 12th birthday over here.

KWAME: Have you been back since?

NOEL: 2005.

KWAME: Do you have any memories about what it was like in Jamaica when you were growing up?

NOEL: Yes, I can't forget, that is what is keeping me going now. All the memories, that is what is keeping me going. [...] I've got four brothers and one sister. Two were born over here and four were born in Jamaica.

KWAME: What kind of good memories do you have?

NOEL: The togetherness and the freedom we had as young children. I came over here and it was strange. The way we were brought up we just knew what to do. It wasn't like they were beating us to know what to do, we just knew. It was like a spirit was guiding us. When I came over here it was not like that with the children. [...]

KWAME: So you've had interactions with the mental health system, how long has that been?

NOEL: This year makes 29 years from about '81, '82. I was 25. What brought me into the system was when I saw what was going on in Africa and things like that and I couldn't do anything and no one was doing anything, it depressed me. It brought me into a state where I needed someone who was willing to listen to me and there was no one to listen and so that is what brought me down. My family, they didn't know what to do, I had to try to go other places. I went to the Twelve Tribes⁷ and they said they can't help me. I went to another place in Brixton where some Rastas were, where I could 'reason⁸, ' play some drums and I was all right and felt better. [...]

I was living with my girlfriend and one night some spirits came upon me and I nearly killed her. There was a white man at the door, looking in while what was going on was taking place with me and my girl. I nearly killed her, and I couldn't live with that. For me to pull a knife on anybody, I couldn't believe that. She was 5 months pregnant and I don't know what happened, but while it was going on, the door just opened and she ran off, and in my mind was to get back to Brixton to the Twelve Tribes to just tell them what was going on. But when I went to the train station there were no trains, so the spirit that was in me said to

⁷ The Twelve Tribes of Israel are a branch or 'mansion' of the Rastafari movement, founded by Vernon Carrington in 1968. They have groups worldwide and are considered to be the most liberal and inclusive of Rastafarian groups and believe in salvation for all races.

⁸ To *reason* is to engage in communal meeting with other Rastas.

walk on the train line. I walked on the line from Bromley-by-Bow to Tower Bridge. When I reached Tower Bridge there was a train there, but the police came and took me to Brixton. I was born in a place called Fremont in Jamaica and grew up in a place called Mount Zion. I told the police I was born in Mount Zion and they took me to a doctor, the doctor admitted me to a psychiatrist and the psychiatrist said chronic schizophrenia and from then on I've been living in hell. The medication isn't working; it's what I do for myself that works. What the medications does is it takes away the good in you, that's my experience anyway, and brings out the bad, so I have to fight myself to do what is good. The first time I was in hospital, I came out and I was lost; I didn't even want to cook or wash myself. Night after night, in my bed, I kept fighting it until I made a breakthrough. For about 4 1/2 years I had been cooking just rice and sardines and going to bed until I started to cook properly and then I started to go to centres. [...]

What I find in these Afro-Caribbean centres, whenever the staff do something and the centre is running well, a lot of white students come in for information. When they give the information, the centre breaks down, and everywhere I have been that is always happening. I've been to one in my area, east London, and the same thing happened. One of the staff was a West Indian girl but she was young. We showed her what was going on because we did not like what was going on and she stood up for us. When she confronted the people above her they tried to put her in a mental hospital. We wanted a group that is for Africans. So when she started doing this stuff for us now, the white group they came in and we did not like that, because we wanted to talk about ourselves, our issues and it caused contention. The white institutes come in for information, they want to see what we do and how it runs and when they get this information they go over it and they cut the stuff and the money so that they can't really continue to do what they did for us. So in the end it breaks down and that's what I see is going on. [...]

I'm not in the Twelve Tribes now. I joined the Ethiopian World Federation⁹ because I don't like what the Twelve Tribes do. It's a black organization. I didn't like seeing my enemy because everything I went through was not caused by my people, it was caused by my enemy, so I call them my enemy.

KWAME: Who would you describe as your enemy?

NOEL: [laughter] Well you know, those not of my race, all those who don't do according to the laws of equality and justice.

KWAME: So you went into the institution when you were 25, how have things changed in the institutions, is getting better?

NOEL: It's getting worse because all these cuts are putting the institutions in a tight position.

Take Fanon, before we joined up with Southside we used to have a proper cook and when we joined up with Southside they took away our cook and we don't have a cook now. If we don't get a volunteer to cook, no food is cooked. [In the hospitals] it's worse because what has happened is that we are older than the nurses and they show no respect and most of them don't listen to what we really have to say. If we cause tension, they give us an injection that puts us out for hours. The way I see it, they just want information about us, the doctors they just want information. When they get this information, if you do something they don't like, they know how to hurt you. In the '80s, they used to give us all sorts of different medications. One of the last times, the doctor gave me a medication where if I went in the sun, my skin felt like it was burning, so I was in the hospital having a shower and bath, shower and bath, shower and bath. He came to me and I said I can't go in the sun, so I cussed him and told him I am from a hot country so he shouldn't give me that [medication] and he took me off it. That was 2001, 2002 when that happened. [...]

⁹ The Ethiopian World Federation is a not-for-profit organization formed in New York City in 1937 whose main goal is said to be “inherent in its name: Ethiopian (meaning all black, peoples), World (everywhere), federation (working together)”.

To tell you the truth I have learned a lot since I've been in the system, but most of what I have found out I've had to keep to myself or to those that are willing to help us. I'd like to see them stand up more for us as patients because some of the things that they do is not right and most of the time it is somebody that you are 10 or 20 years older than and they look at you like you're nothing. Just because they give the medication that does not mean they can't listen to us. This is supposed to be a multiracial country but in my eyes it's not, but all they want is information. They always want information. They are always having meetings upon meetings upon meetings, they just want information you give them information and they are not doing anything for you.

I think I'm normal, it's just medication that is messing me up and making me do the things the doctor says is the illness I've got. But I can't come off it. I tried to come off it but the doctor said he would keep me in hospital. It was terrible man. When I was on medication it was like there was a drill in my head. I kept banging my head against the wall to get rid of it. It was terrible, some of it I can't even explain unless I'm talking to somebody who has experienced it. Some of the words I don't even know. I can explain but not all of it because some of the things I don't even know the names or the words. Hearing voices, sometimes I even saw some disfigured white people in front of me, dancing around my bed. [...]

When someone has the right to do what they want to do with you, you never have a good relationship, you have to make that work for you to get what you want. If anything happens, you know that he is going to come down hard on you, so when you're going to confront the authorities you have to know what to say and what to do and how to act. Some are frightened to talk and some are not. But you have to know what to say to get what you want and you have to show caring, I don't know how to explain it any further, but you have

to show a caring way. It's like you have to give your heart and they have to see because if not you won't get respect. [...]

I can't come off the medication just like that because it's been 29 years. If I don't take it, the side effects they give me, I will walk around like a zombie. You are not only drowsy but you can't stay in one place, you just keep walking up and down. Sometimes even at 1 or 2 o'clock at night I used to be on the street, walking up and down, trying to get rid of the feeling. It feels like you are somewhere and you are nowhere. When you try to set your mind at ease it's like something in there is saying no. The medication is helping to get rid of that goodness that is in you. I've got to fight that every day. Every now and then I have to fight to recognize myself. [...] I'm just a normal black man. An African. Trying to survive in this time.

David

I interviewed 'David' in November 2011, at Isis' old space in Catford. I became acquainted with 'David' while working with him in the Hearing Voices Group. 'David' was one of the coordinators of the group, recently having taken over from the old coordinator, who had decided to walk away from working in mental health for a while. In many ways, he represented a changing of the guard for the group. He brought a different energy and a different perspective, not only having been a former service user, specifically one who experienced hearing voices, but also as a devout Christian. His religiosity wasn't something he overtly forced upon the group, but it was definitely something he was exploring ways of introducing into discussion. On a couple of occasions he had religion as the discussion topic for the week, which resulted in a slight splintering of the group into those who were enthusiastic about Christianity and those who were not interested in having that conversation. After this experience, he backed away from it a little and explored starting an additional group that would fill his desire to discuss faith.

When not in the Hearing Voices group, he would often be found in the social area playing chess with members. He is a tall, well-built man, with a shaved head and now in his 50s, but could easily pass for much younger. He always dressed neatly in long sleeves shirt, dress pants and dress shoes. He wasn't an imposing figure, but he did carry an air of respectability that was noticeable. He and I became good companions, and he would often seek me out to have conversations. He was keen to exchange phone numbers and remain in touch outside of Isis. As such, the interview was extremely comfortable and he was happy to contribute, seeing the project as being something worthwhile. The interview was conducted in one of the larger meeting rooms on the middle floor at Isis' old building in Catford.

David's Interview

DAVID: I am a mental health service user. I suffered ill health back in the '80s. It's a long story with me really. I remember the very first doctor who interviewed me about my health, the only thing I can remember about this gentleman is he said to me "take this little blue pill and you should be okay," and I never liked the sound of that. I don't remember what medication they put me on to begin with; I think one of the medication was called promazine¹⁰. I had an up-and-down relationship with doctors; I found it hard to accept that I was mentally ill. I spent a lot of years taking medication. When I didn't take the meds I would break down. Obviously the doctor's line is that if you take the medication the chances are you remain stable, whatever stability actually means. But looking back now I think I was green, in that I was in the infancy of mental illness and in growing ripe I had a lot of lessons to learn. I came to a conscious decision probably in the 90s, the late 90s, 2000s, that I had to have a strategy for dealing with the doctors and I needed a strategy

¹⁰ Promazine (Sparine) is an older medication used to treat schizophrenia that belongs to the phenothiazine class of antipsychotics.

because I needed to distance myself from them because I had a natural distrust, and probably still do for the services. I would do as they say. I thought the only way I was going to be free from my suffering was to take the medication that they were prescribing, because my history with mental health problems has been such a long history, from 1986 to the present day. [...]

From 2002 onwards I began to make some real positive decisions and one of those was to stop smoking. For many years because I had used marijuana as a social thing I was put on clozapine¹¹ which seemed to give me rest in my mind. I began to have a greater grasp of my situation. I also met one or two doctors who I could communicate with and who made some positive contribution which I appreciated. I continued to be stable and piece my life together. [...] I was taking it up until the last 2 months when I weaned myself off it. I managed to show my doctor that as much as this drug has done for me, I wanted to dream again for one, because when I'm on that particular drug, you don't have dreams, you sleep too heavily, you are too heavily sedated and she seemed to understand that, that was one of the reasons. The second reason, with clozapine, in the early years you started with having two weekly blood tests and then in the later years which is maybe 20 years later I was reduced to monthly blood tests, so that blood tests giving up the blood every month. Even though it's to check that everything is okay with you, at the same time there's a degree of paranoia, I don't know how to describe it, as a human being it's not something you want to be doing for that particular reason, for any reason. It's not pleasant to be poked at. [...]

I've matured, obviously. I've matured as a human being in my later years now. I was 51 the other day. This ripened understanding that I have now, is one of the tools that I use and is

¹¹ Clozapine is an atypical antipsychotic medication used in the treatment of schizophrenia, and is also sometimes used off-label for the treatment of bipolar disorder.

always there, but not up front in every conversation was my spiritual life, my love for Jesus, but more accurately love for the Bible and the fact that I have always been fascinated by its contents. I used that book in my darkest hours, that has stayed with me to this very day. Over the last 12 years I have kept a serious relationship going with a woman. So I could describe it as a fruit maturing but it's also the breaking of many chains because you as a mental health sufferer have a lot of chains to break, to come to a place where you are in control of your life and doctors don't readily want to say to you at any point, at any time, that you are okay now, now go off into society and make your way. I don't actually believe they say that to anybody. I think that's because the profession [psychiatry] is in its infancy, maybe in its teenage years and they are still experimenting and learning and they have not got the solutions obviously. It's also an industry of sorts.

Through experience I thought it necessary to have the doctor on one side of the fence and myself on the other because my freedom is not something I barter with and to be an independent person is everything to me. I won't take all the praise; I've had my wife behind me in recent years, who gives me that support that you need to live in London. She will cook a meal and keep a clean home, get your clothes washed, we share all the simple things and you need those things so that you then can look forward toward things you need to achieve. You need a foundation and I found that even when getting married in February of this year, even though our relationship is 12 years old, we got married in February in Jamaica, I did not let the doctor know I was getting married because I could not take the risk of giving them information which they would have and how their response could have had negative slants to it. I couldn't take the risk; it was too important a decision. So this is how I actually feel this relationship with doctors has been over the years - trust them but don't but not hand over fist, work with them but maintain a lot of yourself.

I can't over emphasize the need for me to have had something other than the daily routines of life. I have done courses, I have done car mechanics, I have gone to college and done a little English, all these other pastimes and hobbies and work efforts, all of those I would've thought have benefited me when I approach my doctor and have a conversation with her. I feel I needed to have the tools to communicate with her or him as the case may be on the level where I gain respect. From there I can show how with my good health and my compliance that I don't really need you that much, you must recognize now that's this fellow is a man who is in control of his life and can control his life. [...]

As a Jamaican, I don't let people tell me or try to show me that I am in any way inferior. In fact, I believe as someone of Maroon blood I am superior to other people. I know it sounds a little like something from blonde haired, blue-eyed Hitler recruits, but I think it's in us, I honestly believe this! For example, when Adolf Hitler was sat at the Olympics Games, it was Jesse Owens, a black man, who God put in his sight to show him you think you people are superior, but here is superiority and he proved it. I used to say to black brothers, maybe some of them are downstairs now, they got up this morning, washed their face, made breakfast, by the time they have gone onto the street, [thought] "I think I will pop into Isis and have a cup of tea, have my lunch and I've got to see his doctor in a couple of weeks time, I'm on my meds..." They are not taking on the fight and I think you need to for your own self-worth. [...] But it's hard to communicate that language when our culture in this present time is telling the youngsters and the young man and men right up to my age and older than me that it's drugs, it's marijuana, and it's all about your music and all about your attitude towards women, it's all about getting money to live the life of the superstars. If you can't get there imitate them. [...]

The youth are being made to feel they should compete with [each other]. First of all they

have not had that strong matriarch and patriarch [educating them]. I think they feel that, they must feel that society is not really offering to them the chances and opportunities to progress and succeed in their own right. And then I think the world is a very, very hard place and if you do not have that strong family structure and you don't have that vicar, it's a lot to deal with. I think if you compared the suicide rate in this country, if you compared with Jamaica and you were able to see and compare circumstances I think you're going to find that the rate of suicide in London amongst the black youths would be greater than it is in Jamaica. Sometimes we live as if we live in cubicles. Here you grow up on an estate, in a little flat instead of what is closer to our natural way, our nature of being, of being in a healthy environment. The English man is clever but he has created, in London anyway, a society where he himself doesn't know what he has created. He himself is stuck in traffic jams now and he doesn't really want to be stuck in traffic jams every day going into the city, but he has made this. There's a sense that money is the God, Mammon¹² rules and Mammon has the illnesses. If you do not have sufficient money, you are not going to be able to buy your way out of the society and you're still expected to, with the chains that are still on, you are still tied down having to go and see your psychiatrist and then you're going home and you are not living any life, then you are given medication which doesn't free you, it once again adds to your captivity because it's slowing you down physically and dumbing down your ability to see with clarity. [...]

I've only known one person that has actually committed suicide and I was actually in a position to help the person somehow sort through that. Through the grace of God, I was in a position to help that person on the morning that she committed suicide and I gave advice to her, I would call the ambulance, etc., but circumstances got out of hand. I thought I had

¹² *Mammon*, in the New Testament of the Bible, is material wealth or greed, most often personified as a deity, and sometimes included in the seven princes of Hell.

done enough, we thought we had done enough to help her but it turned out we hadn't. She was in an abusive relationship as well and the partner wasn't able to support her, he didn't support her in the way he should, foolish as he was. So I suppose there are circumstances around each individual who takes their life and if they are males then it's a little bit sad to think that a man doesn't have the determination to fight any situation that is negative in his life, to try and overcome it. Maybe I have old-fashioned views a little bit, but it surprises me that anybody sees that much darkness in their life to think that that person is going to make anything totally defeat them. [...]

I'm not absolutely sure how I found Isis. I think I heard over the radio somebody mention that there was a black organization in this region. I thought to myself, being a pro-black man, I wanted to know more about what Isis was actually doing. I came here to the lady in charge and made her know that I want to get somewhere, either in music or in a field, any field. I wasn't making enough progress on my own and I felt ostracized, that happens to a lot of black males in this country, and needed to make connections to try and help myself. I'm a voluntary worker here at the moment. I'm here 3 days a week and I've been coming in for the last three years. I support the other workers on the floor downstairs mainly. I was doing the men's group, I did music group for a little. I have taken on the Hearing Voices group. I just believe that through hard work and endeavor something will always come out of it, if you put your efforts and energies into it. So I'm still reading and practicing and believe in the power of prayer and I would like to somehow gain the skills to start my own group to encourage people in the religious field. I just think that I could do something. For Isis there is a need, a definite need and without having to push the Bible down people's throats as such, but to let them know the need for it as one of the books in the libraries and have a kind of a message for black youths and black men generally, black men, black women, black families. This is Family Health Isis so I am in the right place if my idea or

my product is any good and can become a popular product. It's not just for popularity, but also for effect and for nourishment for the black people in England and in London. We need inspiration, we need entrepreneurs in every field and as common as my field may seem, the use of my education is to be shared with others so we can stop the rut and the rot that is going on at the moment, we need to stop the rot. [...]

I see myself as one of the arrows of an archer and whether the arrow hits the target, which target the arrow hits at this point in time I'm not sure, but yea I think I see myself as an arrow shot from a bow. Hopefully that arrow will be fast and true because I think that as I said, 5 years from now, 10 years from now, we'll be in a position in England where there will be no turning back. We would have been here through generations from the 1960s up until what now, so we've got what two generations born in this country, and you push that boat a little further out, we are almost in mid-waters, where there is no going back.

Jamaica's just a song for people, it's just words in a song and that message from Jamaica is becoming quieter and quieter. And these youths, some of who are taking their own lives, it's not a healthy picture. 10 years from now I'm hoping that my arrow will hit the target that will put us back onto a path and not just get lost amongst the numbers.

Mary

I interviewed 'Mary' in December 2011, at Family Health Isis, after the Hearing Voices Group, in the same room that the group was held. It was also the same room that the large printer/photocopier was in, so a couple of times during the interview we were interrupted by the sound of stacks of paperwork being produced. She was an active member of the Service User Forum, the Women's Group and the Hearing Voices group. She is an extremely warm, friendly, seemingly self-assured and well-spoken person and is almost a fixture at Isis and a respected

elder. She always dressed modestly, with a head tie and dark rimmed glasses and almost always was smiling. Her most distinctive feature was maybe a thin curtain of greying facial hair, which I got the impression she left untouched after resolving her mental health problems in 2000. She was another member for whom faith was very important, and the Christianity she expressed was infused with an Afrocentrism that she would often express through flourishes to her attire. She would often read poems that she had written at Isis events. Though I knew her primarily through the Hearing Voices group, she was someone I was familiar with from my volunteer stint at Isis in 2001-02. Even at that time she felt like she had been there for a long time, but I learned from the interview that she had started coming to Isis in 2000.

Of the subjects I spoke with about the photographic element of the project, she was the most enthusiastic about giving me instructions about what photographs to take on her behalf. During the interview she spoke about how much of a religious place she thought England was at its core. The photographs that she asked that I take on her behalf were of religious symbols in London, both at London Bridge. One was of the inscription on the company arms at the Fishmonger's Hall which states "All Worship Be To God Only," and another of the inscription at the bottom of the Frieze on the Portico of Sir William Tite's Royal Exchange, which states "The Earth is the Lord and the fulness thereof." The interview itself was very much like a free conversation that she seemed to relish, so much so that I didn't really have to prompt her much. She spoke at length uninterrupted.

Mary's interview

MARY: When I was in Jamaica I heard that my parents were in England and when I heard that I said that I don't want to go there. I was only about 7 or 8 because I came here when I was 9 years and 11 months old. When they said that they were going to send for us, I was going

to school and my uncle was preparing for me to take a scholarship in Jamaica and all of a sudden I couldn't do it and I had to come to England. I said I would not go there if they paid me, I would not touch it with a barge pole, this was the last place on earth that I would want to go. But in the end I came and when I first arrived, I didn't know my mom. We were living with our granddad and uncle, so I don't know how long they were here before we came, but we came in the early '60s, '61, and they must have been here since 50-something. When I first saw my mom I said to my sister, "Don't you hear the lady say you must not do this?" She heard me and said "I'm not the lady, I'm your mother." That was the first time that I realized that she was my mom. [...]

Years go on and we did get the hatred from English children here. We had them stoning us, stoning our door, they set dogs on us, but we did not know any better, we sort of thought it was a joke. They even got my dad in trouble, they said he kicked the dog and they got the police on him. In the end we moved and went to another part of Battersea, we felt really comfortable there. We went to a church there and my brother and I joined the choir. After that we moved again to Brixton. I grew up and got married and had my children. I remember when I moved to Deptford, where I am living now, I remember having this stiffness and thinking to myself what is happening here, what have I done. I kept screaming and screaming, so what I did was I ended up playing a lot of religious music, read scriptures and putting the cross inside the house. I don't get it now, it's gone but what happened was when I had my children I began feeling my mind wasn't right. I don't know if they call it anti-natal depression or something, postnatal depression. I never knew anything about that but I felt that I was alone and I was feeling weird and not communicating well and would not leave house or anything. When I had my first two children it was six years before I had another child and because of that, well because I felt young, I thought that I should be out there doing something or working or something, but I

ended up having the third child. That is when I started to write Holy Scriptures on the cupboards and the doors. I wrote a whole lot of things and my children said to me “Mum, you are going crazy.” But it was like I was expressing something. I just wanted to know what was going on in my mind. [...] That went on from 1979 until ’84. [...]

I said I'm going to go and pick up my Bible and I looked in that, and I am on my knees and I am saying to myself there must be something in there for me to practice. I saw Psalms 143¹³ and it was telling me things that were happening to me and I felt gosh this is great. So I meditated on it all the time. [...] It's like everything opened up to me because I read that Psalms 143, I was really into it. I am reading and I am writing, and the children keep saying to me “Mum, stop writing on the cupboard.” So I said okay I am going to write it on the back of a calendar. I wrote everything down. I used to call myself Ebony April Jah-Love Lioness of Judah Greaves. It was like I was discovering myself. They thought I was over the top and not only that I think it was affecting their dad because in the end he decided that he couldn't take anymore [laughter] because I was so into the Holy Scriptures. [...] It was like it was giving me the strength to believe in myself and to know that I don't have to take anything from these people anymore, that's how I felt. [...]

¹³ Hear my prayer, O LORD, give ear to my supplications: in thy faithfulness answer me, and in thy righteousness. And enter not into judgment with thy servant: for in thy sight shall no man living be justified. For the enemy hath persecuted my soul; he hath smitten my life down to the ground; he hath made me to dwell in darkness, as those that have been long dead. Therefore is my spirit overwhelmed within me; my heart within me is desolate. I remember the days of old; I meditate on all thy works; I muse on the work of thy hands. I stretch forth my hands unto thee: my soul thirsteth after thee, as a thirsty land. Selah. Hear me speedily, O LORD; my spirit faileth: hide not thy face from me, lest I be like unto them that go down into the pit. Cause me to hear thy loving-kindness in the morning; for in thee do I trust: cause me to know the way wherein I should walk; for I lift up my soul unto thee. Deliver me, O LORD, from mine enemies: I flee unto thee to hide me. Teach me to do thy will; for thou art my God: thy Spirit is good; lead me into the land of uprightness. Quicken me, O LORD, for thy name's sake: for thy righteousness' sake bring my soul out of trouble. And of thy mercy cut off mine enemies, and destroy all them that afflict my soul: for I am thy servant.

I was still going through my mental things and I wanted to find somewhere I could come and I wanted to know if there were any black places for me to go because I was secluded, I had been kind of cut off. I thought I must get back to normal, you know, going out and enjoying and things. Oh Jesus it took a long time. I was in Catford looking around and you know the black place across the road, I just walked in there because it had to do with blackness, so I said to them do you know any black places that I can go to and he goes yeah right across the road, Isis. This was way back in probably 2000. When I came in I didn't talk to anybody, I just came in and had a look. I didn't say much, I was so quiet and then all of a sudden, after coming regular times, I heard [one of staff] say something about me. The way she spoke gave me a bit of confidence because I thought I was useless having been away so long from meeting people, talking to them and things like that. She made me feel a part of the group. There was a session here with some English people as the chair and they were talking about mental illness and drugs and stuff like that, but I said I came through my mental illness through reading the Bible and as soon as I said that everybody packed up and left [laughter]. I thought don't they want to hear that? It's funny, I went over to the town hall and there was a woman there talking about mental illness. She said that she wanted to talk to a preacher and the doctors wouldn't allow her to speak to one and I thought to myself it's as if there is something to do with the spirits in black people when they have this mental illness.

KWAME: So what would you consider the illness because with the Scriptures being the healing, the things that other people found alarming like the dedication to the Scriptures, the writing of the Scriptures, to me it sounds like that was a part of the healing process to you, but for other people they might look at that and see that as part of the illness.

MARY: Oh really? Yes! It's true. The illness part of it was I felt as if my mind couldn't concentrate properly. The fact that I had my children more or less stopped me from doing anything. [...]

In this area [Deptford] it's like the English people didn't want to know the blacks. Battersea it was more open, you were in your own little area but at least you knew that it was open. But Deptford, it's a depressing area; it makes you depressed. My sister said to move, but I said to her no because it was like I was trying to get rid of the evil in it. When I was sorting it out, I felt as if I was mentally ill, I really did. The other thing I said to myself was I didn't want to take any medication or go to a doctor because I know that if I started going to the doctor he would put me on things that would affect me. I said I have to fight this myself, that's why I didn't go anywhere near the doctor and tell them. I ended up having something else wrong with me; I had kidney problems. When I went to the doctor and told him that I wasn't feeling well, I didn't mention about the mental thing, the doctor just kept telling me to take this and take that. [...]

There is a spirit in me I feel because I remember going shopping one day and a woman said to me there is a spirit following you. I didn't question her, I wish I did because I feel something, I really feel something. [...] When my youngest one was going to primary [school], I went to the assembly and looking back at my assembly days and we had hymns and Scripture readings and things like that. When I went to my son's primary school it was 'this is what we did in class yesterday.' Not even a prayer, not even a hymn and I said to myself 'this ain't right.' When they did their Christmas thing, they don't do a thing about Jesus and Mary. I was a dinner lady at his school, so I said to myself I might have to do something to just bring a little bit of Jesus in it. So I asked if I could sing the song 'Mary's Boy Child,' just to give it that little extra Christ-ness in it. The way schools are now, they lack of spirituality. We are all spiritual beings, that's how I see it. Black people as well as everyone, but I know black people are more spiritual than the English. You know how they said that England is paved with gold, I say England is paved with gods who were booted the hell out. That's how I see it now and that's what I would say to the Prime Minister if I

had the chance, truly because this country is a very spiritual country. If you go along London Bridge, you have to look up to see the words ‘All worship be to God.’ It that has been printed there since 1890-something. You go to another place near the stock exchange: ‘The earth is the Lord's and the fullness thereof.’ You go again around near the Barbican there is another thing [that reads] ‘Honour God.’ So it's there. There is something about this country. I didn't want to come here but I began to look for things, for the reason I am here, why am I here, you know. There is something about this country and it's like the Englishman does not want to know, so I think we should take it over [*laughter*].

The Family Health Isis Men's Group

Of everyone I spoke with, the Men's Group was the most enthusiastic about engaging in the dissertation project, especially the filmic aspect, motivated by a desire to produce a documentary that both showed who they were and showed how Isis worked for them. They were always interested in talking about issues of social suffering and identity, specifically negative experiences of treatment and how black people could have better experiences in the UK in general. Even when my dissertation was not prompting conversations, discussions would often be about these topics. Much of this can be seen in the films made in collaboration with the service users. My work with the Men's Group produced three films - *The Circle*, *Studio Isis* and *A Friendly Game of Dominoes*, exploring themes of identity, community, resilience and voice. *The Circle* shows the group in action with service users and staff debating what they expect of the group, what is valuable to the group and ultimately, who should be in the group. Members are given the opportunity to exercise their voice and be heard, with the ‘stick’ a metaphorical tool of individual autonomy (despite the fact that members' often speak over each other anyway). The circle, much like the center itself, is a contained safe space where every member is allowed and required to minimally introduce themselves and say how their week has been. In having to

introduce themselves weekly, members are constantly reaffirming their identity. Sometimes this identity is fluid - one member introduces himself as 'The Joker' - but nevertheless it is affirmed. The production of the film itself involved an affirmation of communal identity, as it was the group who decided that they should be filmed, so that they the 'world' could see who they were. Articulation of what or who this 'world' was didn't happen, but the film was made to show 'Them' what Isis is about. I made a rough edit of *The Men's Group* to show to the group at one meeting, the film replacing the circle as the evening's activity. There was genuine excitement as they saw themselves on screen, and I got the sense that even by putting it on a DVD to show them, it felt official and real as a product of value in their eyes. A sizable group gathered around the television to watch the circle on screen, and they watched with enjoyment and laughter, pointing at each other, calling out to other members who may not have been in the room to watch to hurry up and come because they were on screen. They watched the rough edit three times in a row on the evening I brought it in.

Studio Isis gives the members further control over their presentation, and interestingly many treated it as if they were in the circle, giving their name and speaking about their present feelings. Rather than having to wait to see themselves on screen, there is greater immediacy, as they are able to see themselves during the recording. The contained safe space is now the laptop screen on which they can see themselves. Again, they take the opportunity to treat the filming as a broadcast, speaking out to an audience, presenting an identity and their thoughts, and for one a number of songs. Many use the medium to express the value they find in the Isis community, telling the audience what their resilience is and showing the audience what resilience looks like. No one speaks about mental illness. Instead they speak about being well or politics or being late for dinner or community.

This same sense of community is seen more simply in *A Friendly Game of Dominoes*, a short excerpt of the game that they play constantly, a game regularly played in the Caribbean, mostly by men, often accompanied by a fair amount of alcohol. The game itself is a symbol of resilience. It recalls the Caribbean and community at once and performs wellness. By this I mean, no matter how physically ill a player may seem, their dominoes playing revealed a sharpness of mind. One regular player had an abnormal movement disorder that caused him to place dominoes down in an almost twitching motion. Another player had a lethargic demeanor and spoke and moved slowly and deliberately, but was one of the better players there. Everyone played the game together regardless of these markers of illness. The transcript below is from a session between September 2011 and May 2012. The subject 'DENNIS' is a staff member at Isis and often coordinates the meetings.

The Men's Group Interview

CLIVE: It's bloody poison; it's bloody poison, man. Sometimes I feel like it's messing up my kidneys. It's not medicine because when I take the tablet it tastes bitter, bitter like poison in my mouth.

AMET: If we don't take care of ourselves, these people, I am sorry to say, but they don't really care, they just sometimes see us like experiments. I am not saying don't go to the hospital or leave your GP, I even have my own GP. The only thing I have taken, which is recent, is I took an antidepressant. It was prescribed to me and what is very scary about it is I was told by my GP, if I took *Fluoxetine*¹⁴ I can't just stop taking it. But to be honest I didn't feel any different.

LEROY: When you started taking it you became more alive.

AMET: Are you serious?

¹⁴ *Fluoxetine* (Prozac) is used to treat depression or obsessive-compulsive disorder in adults.

LEROY: Yes, before you didn't do anything, you were like static. Before when he was not taking it he was quiet, he couldn't be bothered to do anything, I had to tell him why are you sitting indoors all day, go outside. But as soon as he started taking it, he was more alive.

AMET: Depression is not a good thing. I was in denial about depression, but I probably did not know I was depressed. When you hear about depression it sounds like something people should not speak about, people will laugh at me or they will think oh this guy does not have his mojo anymore, he's no good, he's lousy.

DENNIS: That's stigma.

AMET: It's like why am I in this state or I think back and say why is it that what I give out I am getting back negativity. And every time if you are trying to do positive stuff, if someone keeps knocking it in your face, it's not an encouragement. If you are not strong mentally sometimes this is why people go to the doctor or you go to the psychiatrist. Actually I have to see a psychologist. I'm thinking if I'm going to see a psychologist what do I tell the psychologist, sometimes they don't care, they are just doing their job and sometimes they might just sit there.

DENNIS: Robotic.

AMET: And say I recommend this...

DENNIS: More tablets.

AMET: This is why I believe in herbal medicine now. We are not in our natural environment, there are so many things against us, even this weather that keep changing; it is not good for us. Even the birds have to migrate sometimes because of the weather; they are confused, so I think our bodies sometimes react like that. I'm not anti-medicine, my sister is a pharmacist, has been for years in the US, but it's a subject I do not discuss with her, not that she is part of the system but that's how it is. I'm just encouraging people to go and try something different, because for too long now these pharmaceuticals, I'm sorry, it's not really saving that much lives as I can see.

CLIVE: The tablets I was taking, I will tell you how I feel, it's poison. You see me walking? I can hardly walk properly. I can't say that I am not going to take the tablet because if I don't take the tablet, I cannot stay [in the living facility] where I am, so I have to take the tablet. [...]

MARK: The medical system is not there for you. The system is not there for you. They can't cure the common cold or influenza. The system is there to make money from you.

CLIVE: Exactly.

MARK: The doctors are in control. It's a big money industry. [...]

GEORGE: I just want to direct something to you [MARK]. It's like people today are programmed to do certain things and to use your brain correctly you have to go outside of the circle to learn something. My question is why are you the way you are, knowing so much, but not putting certain things into practice in order to better yourself. You do not have to go through life with depression or you don't have to take the medication, this is the route that you want to go.

MARK: I want to be off medication.

GEORGE: So why are you on medication now?

MARK: Because I am paranoid schizophrenic. Every time I stop the medication people tell me it is not good for you.

GEORGE: You are talking about what people tell you, what I am saying to you here now is what will happen if you don't take the medication?

MARK: I will get a relapse. Every time I stopped taking the medication I get a relapse. I get disorientated, I get paranoid feelings, the side effects I start walking around London feeling paranoid, I start seeing things, my brain opens up...

GEORGE: And then from then it's more medication.

MARK: I get put back in hospital then and they inject me with more medication.

GEORGE: So you are not going to get better. There is no way you are going to get better if you keep on the road, medication to medication, so there has to be an alternative. [...] I have been a patient. I will tell you what happened. I was overworking and I did not get to sleep and when you are not sleeping it affects the brain, right. So this is what happened, I went to the doctor, the doctor says you are a bit confused or something, you are talking gibberish, all I needed was a good night's sleep and nothing else. But what did they do? Where did they take me? To [the hospital]. When I woke up the next day I felt really good because they gave me a bed to sleep in and they put me on medication. How long did I take, maybe a couple of weeks, I go home and I am out of there. But why these things happen? I was depressed and all these things are going on, but there are the reasons behind these, why you're depressed, why you're sick, why you're sad and so on. And if you get to the root cause of these things then I am saying things can be changed. [...] I have things to do now because I am better. I'm looking at you as an individual, if I was like you and I know what you do, see the medication that you take, if you have to go private, go private and see someone that can deal with you and not just give medication upon medication. [...]

MARK: Basically what it is, we are in an unnatural environment. If you take a lion out of Africa and you put him into a zoo in London, naturally the lion will go mad. It does not have its friends, it cannot taste its own food, we are in an unnatural environment.

GEORGE: You keep saying we, we, we. But what I am saying is take you as an individual, if you want to get out of this situation, if you want to get back to normal, you can't help everybody, you have to help yourself first.

MARK: If it's me I want to go back to Africa where it's natural. I'll give you an example, I've been smoking cigarettes for years, I went to Barbados in 2008 for my aunt's wedding. As soon as I got there my throat was hurting me, I was in pain. The next day I had no relapse, I had no inclination to smoke. It's just the environment. [...]

KEVIN: Let me touch on the medication. I was in Brixton right and I saw this guy, this guy has been in Brixton always troubling people, so you know there is something wrong with him. And a white woman just came by and he punched her down on the floor and started laughing. Two plainclothes police grabbed him and arrested him and I'm saying this guy is crazy; they need to put him in prison for life. He was mentally ill; something in his head was gone. They decided to give him medication. I saw him maybe 3 or 4 years after and he was alright. He doesn't make any trouble. He might ask you if you have any money to help him out but he doesn't make any trouble. So in some cases the medication, I understand what you're saying, but in some cases the medication has its good points.

GEORGE: But was that what he needed?

KEVIN: Well it helped him.

GEORGE: It helps him, but it doesn't make him the man that he should be, does it? What they are doing is they are controlling him so that he doesn't go out and knock anybody down or kill anybody, but they are not healing him.

KEVIN: But he is not troubling you. He is not killing you.

GEORGE: That's right, but he wants more out of life, he wants to do something with himself but he can't.

KEVIN: But which would you prefer? Would you rather they say leave him, let him try and find his way and go out slapping people, stabbing your daughter, stabbing people? If they give him the medication he won't trouble anybody.

GEORGE: That's the way the system works. If you put him in the right environment, the right treatment, that person would be better. But they just give him medication after medication and he's not going to be better.

KEVIN: If you could find that right cure for everybody you would be a multimillionaire.

AMET: Believe me it's out there.

GEORGE: Listen, with the doctor and with these psychiatrists, if you get one sensible person to work amongst them, for example one of the persons you know who has a mental issue, if you take them and supervise them with the medication with an alternative medicine, that person can be better, but if you keep giving them medication after medication all it does is slow the person down and it is not making the person any better! [...] When somebody needs help you put them in a hospital and give them injection. He comes back, they ask Mr. so-and-so “are you all right?” “Yes. Not too bad.” They give him medication, two of this and two of that and he slows down like a zombie. But that's not what the man needs!

KEVIN: That's exactly right, but what I'm saying is that I prefer that man to become like that, and my daughter's safe, rather than [encountering] him on no medication.

GEORGE: Because he is not getting the right help!

KEVIN: No my friend, I believe you have to give the medication to certain people.

GEORGE: Yes, but do you know how long it takes for a man to get on the streets? To stab somebody? Do you think he just gets up one day and stabs that man? No! Things have been happening for a long time and he hasn't get the help he needed and then he went and did that.

MARK: The politicians they are the ones with mental health because they send out millions to kill millions of people, they send out bombs and bloody armies to go out and kill millions of innocent people but they are not seen as mental health. The one with mental health, the so-called mental health, goes out and kills one person and it is blown up, but look at the politicians.

ELIJAH: They're not telling us that the medication that they give us is not to cure us, they just inject us, it's not to cure us!

KEVIN: I didn't say to you that the medication is going to cure you.

AMET: You prefer that controls the person rather than he goes and murders.

KEVIN: Yes.

GEORGE: But why don't they take him to a safe environment and give the person the right treatment and let them come back out and live normal in society, rather than giving them medication all the time? We need to get the doctors here or the psychiatrists.

MARK: Sometimes the doctors don't know shit. They don't know nothing.

GEORGE: We need them here to question them.

CLIVE: I'm on medication, and when I felt like I didn't need the medication and I tried to say to the doctor I don't think I need all this medication, you know, I can live without these medications, I can't need all these medications, I can live a normal life without the medication and the doctor turned around to me and said you can't do it, you need it.

AMET: They talk you into it.

CLIVE: He didn't give me a reason why I need it. I know I am not going to kill, I don't hate anybody, I don't have a grudge against anybody and I don't think I have any enemies. I don't keep enemies, what I like to do with my life is go home and make friends, so I don't think I have any enemies. I said I don't think I need all this medication. But the doctor said no! You need this medication!

KEVIN: Listen, get your key worker and let them talk to the doctor and what they will do is give you a trial and cut it down. That's what they do. See your key worker. [...]

GEORGE: You are a student and you have the knowledge where you can go into certain things and you can do a bit of research and come up with some information, but how much change do you think you can bring to things? Because it's like you are fighting against a multi-billion corporation and if you have to go into them and do anything to change the system, remember they're getting paid, money is the main thing, not your health, they don't care about your health, it's just money.

KWAME: I hear what you're saying, my standpoint is this: if you don't do anything then nothing will change anyway, so might as well...

GEORGE: So what you can do, we appreciate it, what you can do, we are right behind you, but can you really change the way we are today? If you are a doctor and you want to open a hospital, if you want to change things, if you want your own hospital and you want to treat these people, you can help, but if you want to work within the system, it's not going to work.

KWAME: The way I think it can work, the quickest way I think it can actually happen is changing interpretations of how doctors look at you.

GEORGE: Okay, that means more understanding of proper mental health.

KWAME: But also that impacts how they diagnose you.

GEORGE: Yes.

KWAME: Because then if they have an understanding of who you are and where you come from they are not just going to throw out schizophrenia...

GEORGE: So with you helping the doctors, being in there, you can be in meetings to talk to the doctor, that will help because the way they do things is so different, so they don't really help is just medication, medication, medication, medication.

KWAME: Well it's about trying to change the culture of medication.

GEORGE: Right.

KWAME: You're not going to be able to change the entire structure of the NHS.

GEORGE: But it will help.

KWAME: But by trying to bring sense to what they're doing, trying to show them who people are...

GEORGE: You are going to educate them.

DENNIS: That's it, like that.

KWAME: So you teach me, I teach them.

The Social Action for Health focus group

Social Action for Health (SAfH) is a community development charity that works alongside marginalized people and their communities in East London, working towards justice, equality, better health and wellbeing. Prior to setting up the focus group, I had first interacted with the members of SAfH at the MELLOW Group service user barbecue, at the invitation of Sandra Griffiths, then coordinator of the MELLOW (Men Emotionally Low Looking for Other Ways) Campaign. The barbecue was held at Lee House, an employment and rehabilitation centre in East London. Service users prepared the food and played the music. I played a game of dominoes with the members. Apart from being a social gathering, the event also served as an opportunity for service users to display the garden that they had been tending. The focus group that was set up contained 8 men of ages ranging from early 30s to 60s and was also held at Lee House in November 2011 and was preceded by a sponsored lunch. The number of attendees would have been slightly higher but a couple of members felt uncomfortable speaking about their experiences and left early. Another walked in late, saw that it what was happening and walked back out again. Despite having gone to the barbecue event, I was not really familiar with any of the subjects and so the early part of the focus group was mainly me talking about what my project was and trying to get them comfortable. Two of the service users, 'Isaac' and 'Malik' were most talkative and once they became engaged, the rest of the group followed. The group were mainly in their 30s and 40s, and a few attendees didn't speak at all, but remained in the meeting and seemed to agree with what was being said. The names of the service users, as well as names they mentioned, have been withheld. Also in attendance were two project workers from the organization ('HENRY' and 'JAMES').

The SAfH interviews

ISAAC: Sometimes in the notes that they have, the care workers, they write fabrications. In my case, they wrote fabrications. In my case, I was coming down the steps and I jumped from the third step down. I was excited about going out, quite happy that day, you know, I had some bag on my back with skates in there. It was quite heavy. It wasn't that heavy, but there were other things I was thinking about and I hurt my leg. But they put [in the notes] that "he has fleeting thoughts of suicide." Now, where does that come into anything? I mean, I had an accident and they said I had fleeting thoughts of suicide. So I didn't say that, and I told them to change it. I had a review yesterday, I went there and I brought it up again. It's an Italian doctor, I requested a Caribbean doctor. They were asking "do you think it would be any different if it was a black person who was your consultant or giving your physical or mental examination?" and I gave them my answers. She didn't agree to it or understand it straight away, but before it came to a close, she said "yea, I would expect that if I was in Italy and dealing with an Italian from my area it would be probably easier for us to understand each other." [...]

My story is, I've been diagnosed with schizophrenia, I had a bad back injury and alongside that traumatic experience and not having a father, being brought up in foster homes, faced with homosexual abuse, faced with torment of being a slightly different shade of colour in the '70s and '80s, I moved to Canada and lived there for 3 years, came back and still the same kind of thing, having trouble from dark skinned brothers. You know as a black person you get the normal looks from certain white counterparts, so you know it's kind of difficult. There's a lot to talk about. My thing is I don't believe that I have been diagnosed correctly, I believe I've been misdiagnosed and if I could get a black Caribbean doctor,

someone like that who understands where my family have been... I'm here with no father, just a young man trying to get through academically and socially.

WAYNE: There is a misinterpretation, miseducation of black people that suffer from mental illness, that it's a taboo, it's never talked about, it's shoved underneath the carpet, it's misunderstood and that's why I believe we are in the situation we are in now. There needs to be better understanding. That's why I believe a lot of us are suffering from these severe traumatic experiences.

JAMES: The doctors are more interested in treating the symptoms. If they think someone is hearing voices, they want to treat that, but they are not worried about the other factors.

ISAAC: That doesn't make sense though because everyone is different. Maybe some people feel like how I feel about being misdiagnosed, some people may not. I talk to some of my friends and they say "ah, its good for you." Maybe they are confused, I don't know. Maybe they need it, maybe it is for them. But in my [case], I told them from the beginning, I don't need your medication. So now I am just sitting back like "okay, I'll just take your money"¹⁵ then, because to tell you the truth, I don't take the medication, I haven't taken it for a year now. I've done this before and I've told them that, it hasn't made any change. What I'm taking is 10mg of dopamine, I studied what it does, it blocks natural dopamine or something in your brain or something like that. I don't need that because I had a bad back injury, I've still got my bad back injury. It's not going to help what's happened. Sometimes when you're young and physical, you know, it's like "ah, am I gonna get through this?" Sometimes it's like that, but I've past that now. That may have been acute depression, you can maybe put it down to that, but that's gone, so they should have left me alone and even

¹⁵ Individuals diagnosed with a mental illness may claim certain benefits. At present, these include Disability Living Allowance, Attendance Allowance and Employment and Support Allowance. Disability Living Allowance (DLA) and Attendance Allowance (AA) are benefits for people with disabilities who need help looking after themselves or who find it difficult to walk or get around. Employment and Support Allowance (ESA) is paid to people whose ability to work is limited by mental or physical ill health or disability.

maybe helped me to go further in my life by directing to me to places where black afro-Caribbeans are and understand those kinds of traumatic things and we can share our experiences together and continue to get past those things, you know what I mean. But some people may want to stay in the mental health thing, but I didn't want to. They only inject people, inject people. They've got no second opinion doctor on a black level at all, that I've come across in my 2 years. I've not come across any of that. But the argument they give you is higher medication, put you in the hospital, so it's deep, it's deep. [...]

HENRY: What most of us don't understand, not only are we misdiagnosed, but most of us go through the system like me, through police, being sectioned you know.

ISAAC: Fear factor.

HENRY: Being nicked¹⁶ and you know, yea that's where it mostly started.

ISAAC: Fear factor and mind control.

WAYNE: And what it is too is it comes back down to bullying and intimidation by the professionals, because I can remember, it may be funny now, but when I was suffering from mental health issues, I went into the hospital ward as voluntary, you can go in where they assess, and because I saw how other mental health users on the ward were interacting I became a bit fearful and apprehensive because they were like dribbling, shaking, in zombie-like states and I said to the doctor "no I cant stay here, this assessment is taking too long." So he said to me, "either you take the medication and stay here for one month or we section you and you stay here for six months." So I said to him, "I'll take the medication" [laughter].

HENRY: We've all gone through it. The depot¹⁷.

¹⁶ Common British slang for 'arrested' or in other contexts 'stolen.'

¹⁷ Depot medication is a special preparation of the medication, which is given by injection. The medication is slowly released into the body over a number of weeks.

JAMES: Back in the day, mental health was very... it was there, but because of the stigma involved it was kept very quiet, particularly in the black community. I think the family was there to support people, so rather than take them to the system, families were supporting people going through whatever it was they were suffering.

ISAAC: I never had a dad though and my mum was the one who was mentally ill, so I was in foster homes.

JAMES: That's what I am saying, that kind of support has fallen away over the years. You end up where families were together back in the '60s and '70s, the families supporting each other as we went through the '80s and '90s, that kind of family support disappeared and I'm not sure why.

MALIK: I know why, its because in the '60s black people were rising up all around the world and unifying as one nation. So they had to destroy black people, so they introduced crack cocaine, guns, drugs, and those kinds of things. Then they decided to do single parent families and the way that they did it was they started closing all the factories down and the jobs down, so people's fathers were out of jobs, so that's how the families starting breaking up. The fathers were away and the mothers were raising the kids.

ISAAC: That's what happened to me. My dad went to Jamaica, he said he don't want to work for the white man, then he went back to Jamaica.

JAMES: Their options are only intimidation tactics. It's like you're a lamb led to the slaughter, you've got no say.

MALIK: There's nothing wrong with anybody. If you start believing what these doctors say about there being something wrong with you and you start taking the pills, you are gonna die. That's why you talk about high suicide rates. I know about 6 people who killed themselves in the last 3 months or died in the last 3 months, who have been in hospital or come out of hospital. What it is, you get overmedicated, you stop taking the medication, as soon as they

find out they overmedicate you again, they put you in the system, start working you through again, and keep on doing this cycle to you, until you conform to what they want. When you don't conform, they say you are aggressive or intimidating and they give you depots and all this stuff, and all this stuff kills us. That's what's killing us, you know, that's what it is.

When I was at university, I was studying health and medicine, I was against western medicine altogether. My mum came to my university, not saying there was nothing wrong with me, but I'm not trying to be in hospital for the rest of my life, it wasn't that kind of problem, you know, but when they took me to the hospital the doctor said to me, do you see things, can you hear things, do people interfere with your thoughts and some other rubbish. And I looked at him and I said, "Do you see things? Where? Do you hear things? Do people interfere with your thoughts?" These are all spiritual terms. If you say 'yes,' I never said yes to anything, they still gave me the medication, [but] if you say yes to these things, they are gonna give you medication to stop it. And this medication stopping it is going to kill you. That's what its about, mental health. My brother is a psychiatrist, used to be a psychiatrist. That's all it's about: white man trying to understand spirituality, trying to understand the black man or the black family. And anything they can do to destroy the black family, is what they're gonna do, because it's either you go to jail, go to the madhouse, do sports, you're on the dole or you do a minimal, low paying job. [...]

KWAME: You were saying before, when you were growing up in the '60s and '70s, you didn't see as many people that they say are unwell as it is happening now, why do you think this is?

EDWARD: It's more open now. Back when I was growing up, not saying there wasn't institutions and people that were unwell, but it wasn't talked about like now. I'm not too

sure why it wasn't talked about. If a person had mental health problems, people wouldn't know about it. You might see them around, they look ok, you never really know about it, you know, it wasn't really talked about much.

JAMES: It was taboo.

EDWARD: You know what I mean, it was like if a person had mental health problems, it was like the families used to keep it quiet, they didn't want a lot of people to know about it.

MALIK: But in other societies, if you were in Africa, I don't know about the Caribbean, but if you were in Africa or Latin America, if you had so-called mental health issues like where you could see spirits, they'd call you a shaman, you'd be raised as an elder in your tribe because you have the gift from the gods. That's all it is, certain people are blessed with the gift from the ancestors, its passed down, may skip a few generations, but its in the bloodline. And that's what they're trying to stop. When people relapse all the time, [when they] stop taking the medication and your body is trying to sort itself out, and it starts reacting, they will come to you, and say why are you not taking your medication, and they will start bullying you. So you become aggressive to defend yourself, and they say its relapse. That's it. It's white people, white people, white people, white people. White people will put a label on it. [...]

It's kill or be killed. We're dying everyday, black people are dying from gunshots, stab wounds, medication, we're dying, the whole family is dying, women in prison. You go to the hospital, you've got the old people section, you've got the mother and baby section, you've got the men's section, you've got the women's section, you've got the acute section, this is all in one hospital. I'm talking about the low secure, medium secure, the maximum secure. So what is going on?

ISAAC: Something's going on.

JAMES: Someone said to me its like a merry-go-round, its hard to get off.

HENRY: It's like a cycle.

MALIK: A vicious cycle.

KWAME: So what do you think could be done to break that cycle, because I hear from a lot of people that once you get put into the system, it's very difficult to come out of the system and live.

MALIK: There's no alternative.

JOHN: There should be holistic approaches.

WAYNE: All it is is plying you with medication instead of using other alternatives.

MALIK: And you start hearing voices after you take medication. [...]

EDWARD: When you are in the system it is very hard to get out of the system, only if they say you can come out of the system. I've been in the system for over 10 years now and it's been very hard.

ISAAC: Do you wanna get out?

EDWARD: I've wanted to get out, but its like, I think I'm well, but to anybody else if you don't want to use depots or tablets, you are not well, so you see what I'm saying? You have to take your depot and if you don't they are gonna draw you back to the ward and then they inject you one way or the other.

MALIK: And they restrain you and bully you to take your depots.

EDWARD: Any mess up right now and I'm not at the surgery every 2 weeks, they're sending police to my address and they are taking me back to the ward, then you're getting injected. I know a person, that didn't pick up his prescription, in two twos the police are at his house, he went straight back on the ward. He was up there for 6 months, just because he didn't pick up his prescription.

JAMES: And they've got more powers now with this new community treatment order thing, whereas before they could only enforce if you were in the hospital under section. Once you

are discharged, you are not under section; they didn't really have powers to force you to take medication. Now with this new community treatment order they can do this.

MALIK: They put me on depot for 3 years, I've been off it for 3 and a half months, I ain't taking no medication, I feel fantastic. I know I don't need no medication. All you need in these situations is talking therapy, that's all you need, and rest. All you get in hospital is a small amount of food, they pump you with so much medication, you're swollen up, everybody thinks, oh you're unwell, not knowing its the medication that makes you look like that, your stomach is small, you get ulcers, you get diabetes, like right now they told me I have a high chance of diabetes, high chance of stroke, high chance of heart attack, I was unhappy. I've been in the system for about 9, 10 years. It's bullshit, it's a bullshit system. Every tablet you take is from a plant, and then they give you chemicals to add with parts of the plant, to cure you. That is wrong. That's why people get swollen stomachs, swollen faces, because of these chemicals they put in, get us addicted to it. Bullshit, its rubbish, its all rubbish. That's why we are dying and they keep it hush hush. You know [name withheld], [name withheld]'s dead. You know [name withheld]? [name withheld]'s dead. [name withheld]'s apparently dead.

JAMES: Which [name withheld]?

MALIK: Big [name withheld].

ISAAC: She died?!

MALIK: That's what I heard. That's what somebody said.

JOHN: Which [name withheld] is that? Your friend?

MALIK: No, not that [name withheld], the other [name withheld] that was on the ward. He was on section 3 and he kept fighting, trying to get out. They put him in [one ward] for 10 years; they released him and put him on [another ward]. He was there, he went for a tribunal and won the tribunal and they moved him to an open ward, and from there he was stuck in there and he killed himself. I knew him for about 3 years. He was very generous,

probably about 27 years old tops. That's what's happening. People being overmedicated and what they do, what makes it worse, is they look for something to hold you with. Like me, I never had a criminal record before I went into the system. I have been to jail since I have been in the system. They're looking for an excuse. It is an excuse to study us. All they want to do is study us. We're on the ward, you've got nurses writing rubbish, writing lies upon lies upon lies upon lies about you. Once a week, you're there with the doctor for about 3 minutes.

ISAAC: And when you're with the doctor in the room, what are they? European or Asian, all suited up.

JAMES: That's a small number, there's more than that. I've been a room with about 20 of them and you don't know who's who. You don't know who's in control.

ISAAC: Can I pour my heart out? Should I wait? Should I start here or should I start there?

WAYNE: But you're in a situation where if you say too much, they give you more medication. If you say too little, they give you more medication.

EDWARD: You can't say nothing wrong because if you say something wrong, they'll say you are unwell and give you more medication.

HENRY: If you are black, you are more likely to be medicated.

MALIK: It's a trap. The fact of the matter is, all the black people that I know come through the system have 2 diagnoses, either they suffer bipolar or they suffer schizophrenia, but there's so many different disorders out there how can all the black people be bipolar or schizophrenic. Why is that?

HENRY: All you hear is acute schizophrenia, acute schizophrenia.

ISAAC: My mum was manic-depressive. I was about 10 years old, I saw them come in the house banging on the door, this was the 70s, taking her into the ambulance, and me and my younger brother, who is 6 years younger.

MALIK: My doctor, she said “oh you can come to my surgery and we can take the medication they’re giving you and give you an alternative as well, holistic¹⁸ remedy to balance it out. Why not just give us the holistic remedy and forget the psychiatric remedy? [...]

WAYNE: They are trying to give services users more alternatives, whereas back before in the ‘70s, the ‘80s, the ‘90s, there were no alternatives, it was shoot them up with drugs, leave them there and see what happens.

KWAME: Now that there seems to be more options, do they actually offer you those options?

MALIK: Ain't any options for us.

WAYNE: Your support network has to be very persistent.

HENRY: For you to access it.

WAYNE: I've been on high doses of medication where I was having severe side effects and they just kept on saying you need the medication, keep taking the medication, it will make you well. And if it wasn't for the persistence of my parents who kept saying he needs a medication review, he's having serious side effects with his medication, blurred vision, shaking, terrors, muscle spasms, putting on weight, if they weren't persistent in having my medication changed, I would still be suffering these side effects now, because I had been suffering those side effects for three years before they changed the medication.

ISAAC: When you get some of those tablets man, they make you sick!

WAYNE: These medications they mess up your liver and kidneys when you're on high dosages you turn diabetic.

MALIK: Half the people are diabetic.

HENRY: The medication causes that.

JAMES: Some of the side effects of these medications cause other conditions like diabetes and they don't care!

¹⁸ The service user used the term ‘homeopathic’ but I believe he misspoke.

EDWARD: When you get the prescription, when you get the tablets, on the back and you see the side effects, and it's a bunch of different things you can catch. Why?

WAYNE: I always read the side effects on any medication I take from the doctor or the psychiatrist. I always look, open it out and look at the side effects and you'd be surprised by the things they can cause. [...]

HENRY: We need more integration of BME¹⁹ people within the services, you know the decision-makers in the mental health services. Until there really is a mixture of BME consultants there things won't get better. You never see an African consultant, very, very rarely.

WAYNE: A lot of the times when our own black people get into positions of authority they forget us.

HENRY: I call them gatekeepers, they don't normally open it for us.

MALIK: When you do get somebody that qualifies through the system and graduates and keep on graduating, he is more and more isolated from the black community and they can't relate to the black community. Then they start looking down on the black community, thinking we are not as smart as them. My brother is a psychiatrist; you saw what he said that time about how black people are prone to mental illness. That's wrong. So that's what I am saying you get to a certain level and you don't see black people as human beings, you see us as cattle or something. Maybe it's because you haven't spoken to other black people on your level. It's easy to dismiss black people when you see them day in day out [as being unwell] and think they are all the same, you are a schizophrenic, you are a schizophrenic, you are a schizophrenic, you are bipolar, you are a schizophrenic, take this medication. At the end of the day they are getting [paid a lot], they don't care until it hits them, what they become

¹⁹ BME is a demographic category that means 'Black Minority and Ethnic' or 'Black and Ethnic Minority'.

unwell and they have to start taking medication. Then they realize “oh, what I was doing to those people was wrong.”

WAYNE: What it is too is anything that they come into contact with they must put a label on it whether it's good or it's bad, they must put a label on.

HENRY: What's still in the UK though is the issue of stereotyping the BME community, in mental health services especially. They always talk about London is multicultural or England is multicultural but it's only when elections are coming they will take that race issue and bring it up to the front, these politicians. But if you look at all those big heads you don't see one black person. You go to the conservative party conference; you will run out mate because you will stand out.

WAYNE: What it is too again, why I think people are having more mental health issues because they are being painted a picture, including now with what we have seen with the London riots, people are seeing for themselves now what the real picture is. They are seeing it now and they are saying is this what it is all about. They are seeing it for themselves, the true picture and they can't handle it. The government is saying you should do this and you should do that and they are not doing it themselves. People are seeing the broader, clearer picture of what society and what the government is now and it is blowing their brains. [...]

MALIK: What you're trying to do is good but it is bigger than you. I remember in 2002 I was watching BBC News Parliament and there were these 2 black guys [talking] about mental health, saying anybody who you think is dangerous, you should medicate them and put them back in the community and they will be half the person, that is what they were saying, said they are half the man they used to be. People are soft now because of the medication. People see them but they won't be frightened or intimidated by them. That's what it's all about. They will say he is aggressive or he is intimidating, that's what they said about me. Did they say that to you?

ISAAC: Yea, they said that to me.

MALIK: [*Pointing around the room*] Did they say that you? Did they say that to you? Did they say that to you? Did they say that to you? That's it and they medicate us. They were saying they should keep people with mental health medicated so that they are not violent. [Once you are in the mental health system] the same thing will happen to your kids and their kids and their kids and their kids. Once you've been in care or the system or mental health, you have no rights. That's why you are in mental health, because your mum was in there before. I am the first in my family so if I have kids in this country they will be in mental health.

WAYNE: Hopefully you can break the cycle. It's going to be hard, but you can break the cycle.

MALIK: Leave the country.

WAYNE: I have experienced it where I felt I would never get out of this mental health system but again it's the mindset. You have to start making preparations or a path from now. For instance I attend research and training programs to educate other people, black people to let them know there is hope and there is a way. But you have to change your mindset.

MALIK: Where is the hope though? Where is the way? If you are on medication there is no way. You are in purgatory.

WAYNE: What I am saying though is if you don't prepare, just thinking it by itself is not productive.

MALIK: But taking the medication makes you do nothing, you know. Talk to the doctor, this is what a Rasta man told me yesterday, go to the doctor and ask the doctor what's in this medication and the doctor can't tell you. Ask the doctor "do you know if you take 100 of these tablets it will kill a normal human being? You tell me to take one tablet per day, so you are slowly killing me?" You will get to 100 in the end; you will die. These medications are there to kill you.

Chapter Five: The Professionals

Prologue

KWAME: I went to the GP, I had a back pain, and he was looking at my records and said “Oh you're from the Caribbean” and “Caribbean people are very lively and they don't get depressed.” Which was interesting because it was unprompted and had nothing to do with why I was there. To me that makes me think if that is your attitude already, suppose I had come in with a mental health issue or the back pain was related to something.

*Excerpt from interview with Jan Oliver
(Director, Fanon Resource Centre Lambeth)*

“Naturally most of the race are care-free, live in the ‘here and now’ with a limited capacity to recall or profit by experiences of the past. Sadness and depression have little part in his psychological makeup.”

*W.M. Bevis, ‘Psychological traits of the Southern Negro
with observations as to some of his psychoses’,
in the American Journal of Psychiatry, Vol. 1, 1921.*

Introduction

In addition to speaking to service users directly, it was also important to speak to a cross-section of healthcare professionals and researchers from various agencies and institutions involved and invested in mental healthcare. In this chapter, I present excerpts from the transcripts of these interviews. Rather than emphasizing selected voices in greater detail, this chapter will be divided by professional field – academics, community workers, directors of agencies and staff from within the National Health Service - with a range of voices being highlighted within each field. This range of voices is not meant to privilege the professional voice over that of the service user,

and the professional voice is not meant to be seen as an ‘expert’ voice. The professional voices are auxiliary to the service user perspectives and meant to provide greater context for service user experiences in the mental health system and provide additional viewpoints from individuals who have for worked in the system and are familiar with the issues that service users are concerned with. The quotations selected highlight themes and noteworthy thoughts from these professionals, and are presented with a short biographical introduction for each that highlights the work they have done that is relevant to the Black Caribbean service user. In the interest of space, the quotations presented are examples of themes that emerged from the interviews and do not mean to represent the frequency or the prominence of particular themes. These broad themes will be analyzed in the subsequent chapter. Again, the emphasis is on the subject’s voice, and my voice is only present when necessary for comprehension or if my contribution is beneficial.

Academics

Various academics were approached for their opinions on the experiences of Caribbean service users in the mental health system. I thought it important to speak to persons who had put forward theories and worked directly on research regarding mental healthcare and the Caribbean, as well as working with the service user community.

Professor Frederick W. Hickling

Professor Frederick W. Hickling is Professor Emeritus in the Faculty of Medical Sciences in The Department of Community Health and Psychiatry at the University of the West Indies in Mona, Jamaica. In the 1990s Professor Hickling was instrumental in helping to shape policy for African Caribbean Mental Health in the UK and was elected to the role of Head of Psychiatry at

University of the West Indies from 2000 to 2006, and Professor of Psychiatry from 2006 to 2010, before his retirement.

HICKLING: There is no doubt that something happens to people when they go abroad, especially to the UK. I suspect it's the same thing that happens to all Caribbean people who go to Europe, whether it's the French or the Dutch or the English speaking. I suspect a similar thing happens to people who are going to North America, however the major difference, especially in the USA, is there is a huge pool of black people and the sociological and psychological factors, both positive and negative, are submerged, diluted and not seen so easily. With people who go to Europe, there is a huge stripping away of the psychological defenses that have been engendered in the Caribbean. A study²⁰ found that [for] geographic locations within Europe, the higher the percentage of black people in the geographic location, the lower the percentage of illness in that area. There is absolutely no doubt that when black people go to England, they end up in the mental hospitals and prisons at an enormous rate. [...] There was a paper by Coid²¹ [recognizing] that people who migrate are maybe 2-3 times more prone to developing psychosis as a result of migration. Paradoxically the study I did here in 1996 looking at white people who migrate from the UK and the US [to the Caribbean] found just the opposite, they got less psychosis. There is something happening in the UK with black people that we are not clear about, that we are not understanding.

The hypothesis that has been emerging in the last ten years is the concept of social defeat²²,

²⁰ Veling, et al. Ethnic Density of Neighborhoods and Incidence of Psychotic Disorders Among Immigrants. *Am J Psychiatry* 2008; 165:66–73

²¹ Coid, et al. Raised Incidence Rates of All Psychoses Among Migrant Groups. *Arch Gen Psychiatry* 2008; 65(11):1250-1258.

²² Selten and Cantor-Graae. Social Defeat: Risk Factor for schizophrenia. *British Journal of Psychiatry* (2005), 187, 101-102

a neurobiological term that has come out of rat laboratories. They have linked high dopaminergic rates in rats who have been in social stress environments and extrapolated those results to the results of black people in Europe and come up with the hypothesis that when black people migrate to Europe they are defeated by the civilization of white people. When I heard that first in 2005 at the World Psychiatric Conference, I nearly went ballistic. That's absolute rubbish. I think that's just the latest projection of white people to try to label what happens to black people in Europe as something that's inherently, intrinsically problematic with themselves. [...] There is certainly something that happens to black people when they go to the UK, when they migrate to white environments in their attempt to adapt to the social situation in that country. They take on the adaptive coping mechanisms of the native people and may take on an excess of this as they are subject to huge social stresses of racism and exclusion. The more black people migrate, the more they try to take on the characteristics of the country they migrate to. But at the same time, they try to hang on to the social mores of their homeland, of the Diaspora and so they develop a splitting where they are actually living two separate lives, where on the one hand they can operate in the white world and the other they operate within the black world. They take on the same language, the same social values, the same ideas, the same reference groups, but at the same time they are met with racism and that creates a high level of rage and hostility, which I think is partly responsible for this psychological response to the environment.

Professor Tom Craig

Professor Tom Craig is Professor of community and social psychiatry at the Institute of Psychiatry, King's College London. Professor Craig served as the head researcher on the Cares of Life project, an innovative service designed to encourage black people to seek help for mental health problems. The project was based in Southwark, south London and was launched by South

London and Maudsley NHS Foundation Trust (SLaM), running until the end of 2005. For the project, a team of psychology graduates was recruited as community health workers to provide a range of services, promoting the project with a double-decker Health Bus that offered simple physical health checks as well as the chance to talk about any possible emotional or psychological problems. The idea of the Cares of Life project was to break down barriers and make services more user-friendly and accessible, while extending mental health care to include practical physical health matters.

CRAIG: The Maudsley²³ and official psychiatric services are and have been, viewed with cynicism and skepticism by the local black community, not least because of the experiences of care. One of the sad realities is there are much higher rates of hospitalization and compulsory treatment for severe mental illness for people from Caribbean and African background and so the whole idea of the Maudsley is tainted in the eyes of that population.

When I started out, most mental health in this country was focused in hospitals. I would say that now most of it focuses around community sites of one kind or another. We are still a way away from the next focus, which is to take it out genuinely into real community locations, partly because we don't know how to. We don't know for sure how things work. We know for example, if you have been abused as a child and taken into care and had a rotten childhood, your risks for mental illness skyrocket. There are clearly interventions focused on better parenting and better care as a child that needs to be delivered and that is beginning to happen. In 20 or 30 years we will be doing a lot more early preventive, early intervention work. You've got things now like the early intervention services for psychosis

²³ The *Maudsley* Hospital is a British psychiatric hospital in South London and is the largest mental health training institution in the UK.

that are making a real impact on the most severely mentally ill. [Progress] is slow and recursive, it takes a step forward and then it goes back a step and its reflected in two philosophies that run in mental healthcare. One is a kind of negative philosophy that serious mental illness is a damaging, degenerative process. That's a terrible philosophy because that just generates hopelessness. The other philosophy is intervening earlier, orchestrating things in a way that is helpful and will prevent longer-term deterioration. There is now a genuine effort to increase cultural awareness and sensitivity in treatment services. I'm not saying it's very good, but it's definitely there as something that we all know we should be doing. There is a long way to go but it's definitely there in a way that before it just wasn't. It just wasn't on any part of the landscape really in the early '70s. There was no interest. [...] I think the message is clear that we need to do things differently; I think that is accepted. But there is a big investment in traditional mental health centers and the existing services, a big shift to move the ship in a different direction, which is not going to happen overnight, much as we would like it.

The thing that was valuable about what we were offering was the practical support, actually getting hands in, going into the family and doing something, as opposed to what you would get in standard therapy, which is someone would come in to talk to you and you would talk to them, but you would go back to the same practical things. There is a paradox in that when we spoke to staff, they valued the psychological more than the practical because in a sense anyone can do the practical. But we were saying that's the bit that really matters! I think a lot of therapy is hot air.

Professor Roland Littlewood

Roland Littlewood is professor of anthropology and psychiatry, director of the Medical Anthropology Centre at University College London. He is the co-author of the seminal text *Aliens and Alienists* with Maurice Lipsedge, which examines, through a series of cases studies, the links between racism, psychological ill health and inadequate treatment of ethnic minorities. In the text, they discuss the psychological legacy of colonialism and slavery, the racist bias in psychiatric and psychological theory, diagnostic bias, the role of religion in mental health or illness, the value of anthropological and psychoanalytic insights, and the development of transcultural psychiatry.

LITTLEWOOD: It's dreadful these days. I am retiring from medicine next year and am very happy to do so. Medicine has just become more and more tied up with normative thinking. To get into a psychiatric hospital now is quite a forensic issue for the more difficult or dangerous people. It's quite different from when I was a junior psychiatrist. Community care is cheaper.

[...]

The media is just about safety. The popular stereotype is that of a big, black dangerous man, we must protect our citizens against him, so take him away and lock him up.

Dr. Dawn Edge

Dr. Dawn Edge is Lecturer in Qualitative Methods within the School of Psychological Sciences and as a Frontline Adviser for the Research Design Service North West (RDS NW) at the University of Manchester. Her work is strongly committed to integrating research, policy and practice and to public service, actively engaging in working with communities to improve health and wellbeing, especially among those who are marginalized, socially excluded and experience inferior access to health and care. Her research has ranged from mental health of Black Caribbean

women in primary care to broader areas of health and social care, including interventions for schizophrenia and psychoses, perinatal mental health and child health, resilience and recovery in mental health, and spirituality.

EDGE: Dr. Elaine Arnold set up something called the Separation and Reunion Forum²⁴. A lot of Dr. Arnold's work deals with attachment theory, looking at the children of people who were left behind and then came and joined the parents, and what happened in the dynamics of those families. I brought her to our church for our women's convention and she started talking about her work and some of these people started to talk about their experiences. Their children and their grandchildren were astonished because they never talked about [their experiences]. There was a huge amount of shame around what happened to them when they came. They came with all the hopes of their families pinned on them and experienced "No Dogs, No Blacks, No Irish" signs. They left [the Caribbean] as qualified nurses and came here as nursing auxiliaries, cleaning the toilets rather than dispensing medication. They left as teachers and then were lucky if they got secretarial jobs. So there is a lot of that, but they never told people about it. Some of them actually cut off all ties with their families back home. People thought it was because they thought they were too good for the people back home. It's not that, some of them were too ashamed to admit to the families who had invested huge amounts, sometimes all their life savings to send them to the UK to make it on behalf of the family. When they got here and realized that all they could do, as a teacher, is sweep floors, they couldn't tell them.

We've stopped talking. Part of that is that [as a Caribbean person] you don't talk your business. When I was doing my mental health research, one of the things that the women

²⁴ Separation and Reunion Forum (SRF) was founded in 1999 by a group of African-Caribbean women who as children experienced broken attachments through the immigration process.

talked about was not having developed a language to talk about psychological distress. So there's no language and we don't talk our business. There's no discourse about weakness. There's no discourse about vulnerability. There isn't that tradition, so we can't talk about it and we don't know how to talk about it because we've never heard it talked about. The language that is available is actually quite Eurocentric and we don't necessarily feel like that. We don't necessarily conceptualize what we feel as something medical or pathological, but we know it's not right. So if I feel down, I feel low, I feel flat, I wouldn't say its depression, but if that's the only word to describe it, do I really want to take that to myself? Taking that label [might] actually run counter to the very concepts that I'm using to stay alive, to survive in society. So if part of what keeps me going, against all the odds, is seeing myself as a strong black woman, if I start to say I am depressed, and depression and strength are not easy bedfellows, how do I reconcile that? [...]

People [see] the Bible as a manual for living and that's what you turn to for guidance, for meaning, for hope and people would pray with scriptures during particularly difficult times. We all know the 23rd Psalms, we all know Psalms 91. On the other hand, very often what we don't recognize is the passages in the scriptures that are talking about people who are very often depressed. If you read a lot of David's Psalms including Psalms 23 or Psalms 41, 42 where he is saying "why are you cast down, o my soul?," that's what he is talking about. When you read it there's actually a lot of psychologizing type behavior in that when he is saying, "Why art thou cast down, o my soul? and why art thou disquieted within me?" and then his next bit is "hope thou in the Lord." [...] A lot of mental health professionals, if they came to a church like mine... [laughter]

KWAME: They would section²⁵ everyone?

EDGE: Everybody.

Dr. Frank Keating

Dr. Frank Keating is Senior Lecturer in the Department of Health and Social Care at Royal Holloway University of London. His research focuses on the relationships between African and Caribbean communities and mental health services, specifically on social inequalities in mental health. He was the lead researcher for a major review of services for African and Caribbean communities published by the Sainsbury Centre for Mental Health (*Breaking Circles of Fear: A review of the relationship between mental health services and African and Caribbean communities*). He subsequently served on one of the National Boards that oversaw the implementation of the Department of Health's National Programme for Delivering Race Equality in Mental Health Services and completed a literature synthesis for the NHS Service Delivery Organization to identify research priorities for patient and carer-centered mental health services.

KEATING: The more I started to think about cultural sensitivity, the more I began to think that actually it's not a very helpful concept. There is this notion that if you could tell people what particular cultures are like and help them understand the culture, then that will make them work better with BME communities. I think that we need to move away from the cultural sensitivity [paradigm] and [include] the institutional racism paradigm, but you can't blame every mental illness in the black community on institutional racism. If we accept the statistic that 1 in 4 people at any stage in their life will experience mental illness, then that should go for African-Caribbean communities as well. That's where the whole

²⁵ Being sectioned is when doctors use the powers given to them under the Mental Health Act to insist on medication or a stay in hospital for an individual, if a person's behaviour puts them or others at risk of being harmed.

thing becomes complex. I take a more a macro perspective. It's not just what goes on between the practitioner and the patient, there are other factors that impact on that relationship. [...]

When you look at how particularly black men come into the system, they are more likely to be excluded from school, they are more likely to have contact with the criminal justice system, they are more likely to have been unemployed, if we are going to address this intractable situation, then all those sectors need to start talking to each other. Teachers need to come into psychiatric wards and see what happens when people get excluded from school because they can't see those connections. [...] The problems that the African-Caribbean communities face in mental health are social, economic and also political. If one cannot understand it like that, you can't just deal with it socially, you can't just throw money at it; you also have to change politically how you think about it and how we address it. [...]

Institutional racism requires institutional reform. I've always argued if you really want to learn how to work with this community, go spend a couple of days in a black voluntary sector organization and just see the difference. In a day centre run by the local authority you get a particular feel and [in a black voluntary sector organization], you just get a different feel. There's a different relationship; there's a different set of values. There's just a different understanding of what it is they are trying to achieve. That intelligence we have in the struggling voluntary sector is not being transferred into the mainstream, where the mainstream can actually learn how to work in a way that begins to benefit this particular community. [...]

There is a search for identity, but in a way that is destructive. When I first came to England, black people talked about the Brixton riots, the Toxteth riots, they talked about

Liverpool. There was a sense of the community acting together, whereas now when a black man dies on the psychiatric ward, everyone is upset, but there's no big march. Community activism, which I think gives people a sense of identity, the younger generation in the UK probably hasn't got that. So that is something that has been eroded. There is a whole culture of 'I have to do for myself' and 'I have to fight for myself,' but if you've been excluded from school or been in contact with the criminal justice system, then the identity that you are going to find is the identity of people who are just like you. We are looking at a group of people who have no space in society, who are trying to find a space, but the space they find is destructive and may then lead to them ending up in the psychiatric system.

Community workers

Juliana Frederick, Janice Williamson and Frederica Joseph

It was also important to speak to professionals whose day-to-day jobs were to work directly with service users to get their perspective. Juliana Frederick is the Senior Community Development worker, Janice Williamson, the Community Development officer and Frederica Joseph, the Community resources and employment coordinator at the Oxleas NHS Foundation Trust. I had intended to interview Frederick alone, who I had known previously from her time working at Family Health Isis, but Williamson and Joseph happened to be in the office at Oxleas at the same time and joined in. Oxleas is the main provider of specialist mental health care in Bexley, Bromley and Greenwich. Recently, in partnership with Greenwich Council and NHS Greenwich, they coordinated a Men's Comedy Night. Frederick helped to organize the event for the Black and Minority Ethnic (BME) Mental Health Forum, designed to reach out to men in the borough and raise awareness of men's health issues. Oxleas has also been involved in the annual Happy

Soul Festival, a film and arts festival exploring and raising awareness of well-being in Black and Asian communities. Williamson also had a coordinating role at Isis Oji.

FREDERICK: Issues still remain but I think the cultures have merged a lot more. When we were younger we listened to certain music, white people listened to their certain music. There were different groups within the groups even. There was 'Reggae Heads,' there was 'Soul Heads'. The Soul Heads wore the trousers slightly too short with the white socks and the strange shoes and the Reggae Heads all kind of headed roughly towards Rastafarianism.

JOSEPH: And everyone talked like a Jamaican.

FREDERICK: And everybody was Jamaican. Nobody came from any other islands, they were all Jamaican.

WILLIAMSON: Can I just say we can't help that.

FREDERICK: Oh shut up!

JOSEPH: I'm blaming you Janice, you and your kind.

FREDERICK: There were just too many of you, that's what it was.

WILLIAMSON: [*looking at me*] And where are you from?

KWAME: I was born here, but I grew up in Jamaica.

FREDERICK: So you are one of *dem*²⁶. *Dem. Dem* over there. The rest of us had to pretend we were from there because nobody had ever heard of us. [...]

Sometimes that box that needs to be ticked for ethnicity, sometimes the staff tick it. They don't even ask you because they don't understand the relevance of asking you about it. They know it causes contention for some people, so they just look at you and tick the box or they don't and the box is left empty. Ticking that box is not enough because it doesn't

²⁶ 'Dem' is simply translated from general Caribbean dialects as 'them,' but was said with an intentional playful dismissiveness that required a Caribbean tongue for its effect. As such, I left it in its stated form. In this context, it best translates in American vernacular to a teasing usage of 'you people.'

give you a sense of what that person might need. You can tick a box that says 'black African.' Do you know how big Africa is? Do you know how many countries there are in Africa? Where I live, there is a big Nigerian population and a big Ghanaian population, how would you know that by ticking the box 'black African?' [...]

Back then [in the 1970s and 80s] there were things that we were angry about. We were angry about the lack of access to higher education. We were angry about unemployment. We were angry about poverty. We were angry about inequality. If you saw the housing and where we had to live, we were burning it down in '81, dear. We just decided we aren't doing it anymore. We burned it down. Those issues are still there but I don't think people are as conscious of them. It's like people have absorbed that that's just the way it is and you have to find another way around it, as opposed to looking at it and saying this isn't fair, this is not what we want, we want more.

JOSEPH: It was so blatant back in the days. It wasn't uncommon to walk into a store and see that little flyer on the wall saying 'no dogs, no Irish, no Wogs²⁷ or blacks.' That was a common thing. Or being spat at in the face on the streets.

FREDERICK: Or called names.

JOSEPH: They used to call you names as a child!

WILLIAMSON: It was in your face, now it's much more 'politically correct.'

FREDERICK: They think it, but they just don't say it.

WILLIAMSON: I think they do, just in a different way. I think it's all still there. [...]

FREDERICK: Even though we are talking about 30 years ago, the numbers of BME people who are subject to the Mental Health Act and who are subject to psychiatric problems, remain constant. It doesn't go down. That in itself is a statement of something.

WILLIAMSON: It remains very high.

²⁷ A derogatory slang term, from 'Golliwogg,' a 19th century blackface doll.

FREDERICK: Disproportionately so.

WILLIAMSON: And it's our younger generation that is being locked up.

FREDERICK: And by younger, they are now talking about medium secure units for under 18s.

12-20.

JOSEPH: Twelve? No way.

FREDERICK: Twelve. Belmarsh has a youth unit and they are building a specialist unit for children. Twelve. And you know that is going to be populated by children [of the BME community].

WILLIAMSON: But the Bracton²⁸, when you go in there it's just awful.

FREDERICK: It's kind of scary.

WILLIAMSON: Very. My first time there [at the Bracton] I was so upset by the time I left. It's like 90% [BME].

FREDERICK: My first medium secure was the Dennis Hill unit which is up at the Bethlem Royal²⁹. That was heartbreaking. 80%. And there was one girl there, all of them were men but one girl, she couldn't sleep. She said she didn't want to be there, she hated it there. I was so distressed. The figures haven't changed. It may be that the older generation at some point felt that they were going to get better and things might get better, but the younger ones know that once they walk into those units, this is what life is going to be like forever. Why would you put yourself through that? You're never going to have a partner. You're never going to have a life. You're never going to have children. You're never going to have a job. Why? [...]

²⁸ The Bracton Centre is a medium secure unit that provides a range of specialist forensic mental health services for people aged 18 - 65 living primarily in the boroughs of Bromley, Bexley, Greenwich and Lewisham.

²⁹ The Bethlem Royal Hospital is a hospital for the treatment of mental illness located in London and part of the South London and Maudsley NHS Foundation Trust. The word 'bedlam' is derived from an old alternative name for the hospital that it held in the 14th century.

For 25 years in Lewisham they had a walk-in service that where for 2 days a week, for a certain number of hours, anyone who felt they needed to speak to someone about a problem, could go and talk to a professional person and if there needed to be a follow-up, the crew would follow it up. Then one day someone said “that's not how we are supposed to be offering services, people are supposed to be referred, we are putting our staff at risk.” So you have got the information that this thing works, that it allows people to access mental health services directly. 25 years and they stopped it because they felt it was not good use of their worker's time. You are sat in the meeting asking them “why are you doing this?” and they tell you it is a cost cutting exercise. And you watch, give it 5 years and it will come back. You think I am joking? They will call it the early intervention service or something. [...]

The reason I stopped doing the work I was doing [in the voluntary sector] is that I started to bury people. I was going to funerals every two or three months. Some of these people were people I had been working with for 20-odd years. You just get to a point where you can't sing 'Rock of Ages' or 'Abide With Me' every whenever, it's not good for your insides. What's worse is that you know the quality of life that those people have had has been completely and utterly undermined by the fact that they have had contact with the mental health services and that 30 years ago people who were 18 were being told “there is nothing in life waiting for you and you will be coming to this day centre drinking tea and smoking cigarettes forever; goodbye, have a nice life.” Now that is changing, but for those people who have been on the medication for 35 years, their body can't take it anymore; they are going to die. These are things people don't talk about. They don't tell you that if you are on this certain medication for 15-20 years, that you life expectancy is shortened. They don't talk about how our community will be given 2 or 3 medications and we will be given the maximum or just under the maximum for ridiculously long periods of time. I don't think

they will see 50 being on medication for that length of time, but what's horrendous is you will never see a cause of death being the medication; it's always natural causes. One gentleman died on the toilet. He was constipated because of the medication. His mother opened to door to find him dead in the cubicle. [...]

People can't be honest with the services about what is going on with the people that they love because the services only know one way to respond. So if you go in and say, "I am a bit frightened of how little Johnny responds sometimes, I think he might actually put his hands on me." People aren't hearing the subtle 'you're not sure.' All the other things you said before that don't mean anything, it is that one piece that people hold onto. The Mental Health Act is supposed to be there to balance the care of the individual and the protection of society or your community or your family. That is what it is there for. But I do not believe that anyone has ever really looked at that balance properly. We should have a whole range of services available to people that they can access, because if your GP doesn't feel there is nothing wrong with little Johnny, he won't make a referral. King's College Hospital has all of the psychological services in it and one year they only had 1% of the psychological services come from the African and Caribbean communities, and [referrals to] psychological services are very much controlled by the GPs. [Across the street] the Maudsley had a walk-in 24-hour psychiatric service. When you see people walking down the road, all the black people are going that way [to the Maudsley] and all the white people are going that way [to King's]. What are you trying to say? People born in this country, raised in this country, educated in this country don't know how to talk to a psychologist? If all of the 2nd generation Caribbean people are predominantly the people locked up in the Maudsley, what are you trying to say, that culturally we are not able to talk to the people we went to school with? I don't understand it.

Ray Johnson

Ray Johnson is a Community Development Worker at the Oremi Centre, a mental health day centre offering mental health support services to African and Caribbean people in the Kensington and Chelsea area of London. He has been working in African Caribbean mental health for 20 years and has a background in anthropology.

JOHNSON: I was shocked by the high rates of black people in hospital against the wider population. I mean we are roughly about 2%³⁰ of the population, yet we could be about 80% representation in the hospitals and pretty much every black person that I know knows somebody who was in the mental health system. [...] Speaking to members, one of their concerns is that they tend to get medicated first and asked questions second, so they are in the system very fast. Alternative treatment is not offered that widely. The first port of call seems to be to contain the situation, so it's usually medicate first and once you medicated you are in the system. Then to get yourself back out of the system is quite difficult. Then if you get a young, strong, virile guy [who believes there is] nothing wrong with him, being held down because he refuses the medication seen as being for his own good and the protection of society and so on, he gets very angry, especially as some of the medication plays havoc with their virility. It causes a lot of conflict and so the cycle can start, the more they get angry, the more they get medicated. [...]

The family and extended family plays a crucial role in keeping someone safe. White people, generally their families are quite small in comparison. There is mum, dad, brother and sister, if you are lucky you might talk to a couple of cousins. But with the African-

³⁰ According to the 2011 census, Black or Black British make up 3.5% of the United Kingdom population (1.1% Caribbean, 1.8% African, 0.5% Other). In addition, Mixed White and Caribbean make up 0.8% and Mixed White and African make up 0.3% of the population.

Caribbean it extends much wider than that, and cousins and second cousins and what have you are seen as close as brothers and sisters. That really can help because there is more people to talk to, but it can also have the opposite effect because you are not expected to have those kind of thoughts, you are supposed to be able to pull yourself together and get on with it more.

Dr. Yemi Oloyede

Dr. Yemi Oloyede is a psychologist, intercultural psychotherapist, researcher, clinical supervisor and trainer, and serves as the Director of Reflective Partnership, an agency that specializes in providing reflective practice training for organizations. She had previously worked in statutory organizations, providing services for hard to reach black clients.

OLOYEDE: On this side of the river (North London), they have cut down on specific black services because they have this understanding that they want everything to be integrated. I had that fear for my own service that at some point it was going to become a ‘ghetto’ service, [where they] just dump all the difficult people in there that they cannot work with. They don't appreciate that you are doing a difficult job with them, they just say “he's black, you're black, send him over there, whatever happens to them that is their problem.” There was no appreciation of how difficult it is. Because you have the color, it is assumed you know how to deal with them, even though you might not be able to. When I was working at [my former agency], 90% of my clients were black. The white staff all had different clients but all the black clients got to me for some reason; they had a way of allocating them all to me, the most difficult ones. In some ways it was good because I was able to engage them in ways that white staff could not engage them. Well it's not that the white staff could not engage them, they were too fearful of them. [...]

OLOYEDE: I've got two boys and my boys don't really equate themselves as African boys.

LITTLEWOOD: Years ago I remember you were frightened that your boys would turn into West Indians.

OLOYEDE: It was because I was living in Hackney [laughter].

KWAME: You mentioned a little bit earlier about your kids becoming West Indian, but I was interested to know...

OLOYEDE: At the time, they were quite young then, and at the time Hackney had a very bad reputation. The schools in Hackney always used to label black boys and I was very, very concerned with them growing up in Hackney and being identified as this label that the African-Caribbean boys are very notorious. They skipped school; they behaved badly in school, so that was the general feeling in Hackney about not wanting to mix with black boys, which the majority of them were Afro-Caribbean. So when my children were growing up I was very concerned and about mates, it's not just about whether they are going to be, it was about mixing in school and the social groups. And also most of the black boys were labeled as using drugs and whatever. But a lot of that was influenced by the work I was doing at the time in Lambeth and most of the boys that were there had drug-induced psychosis and they were quite young. So I was very, very concerned to the extent that I bought them this book on drugs... So its not about them turning, it's about them mixing with different groups of people that might change them into something different that I don't like.

Caroline Morris

Caroline Morris is a mental health nurse, specializing in mental health promotion. She had previously been the Institute of Psychiatry Project Officer for the Consent for Consent initiative

that aimed to increase the number of participants in research studies. Through this position she had taken a role in the Cares of Life project.

MORRIS: [While working with the Cares of Life project] we found at the local college [in Lambeth] people were saying [of persons with mental illness], “oh well, people are violent and people are intellectually impaired, people are quite smelly,” one thing or another. There were awful discriminatory practices out there. [...] There's great importance being placed upon general education, about raising awareness rather than training because there are lots of myths and the media has portrayed all this false information. It's very basic stuff. There's nothing magical about it at all.

Directors

Estella Weston

As it became evident that the role played by culturally specific mental health organizations was a crucial aspect of the study, it became increasingly important to speak to those persons in charge of these agencies. I spoke to Estella Weston, Director at Family Health Isis that I profiled earlier. Isis is a community organization with a day centre that provides community health services to black African and African Caribbean people who live in the borough of Lewisham. I met Weston initially during my volunteer stint at Isis in 2001. She has been a member of the Isis staff since the early days of the organization and has been director for more than a decade. Aside from her commitment to providing appropriate mental health care to the black African and Caribbean community, she is also committed to providing support to students. When I initially became a volunteer, it was as part of a quest to improve my mental health work experience before applying to medical school. Having then returned to Isis for my dissertation research, she was equally

amenable to allowing me to engage with the Isis service users and staff, and to be a subject for interview herself.

WESTON: If you go to a GP and you start to say you are depressed, the majority of the black community will be sent to the secondary stage of mental health; they should be staying at the primary care and getting talking therapy. Now they have set up cognitive behavioral therapy and a lot of the primary care trusts, have taken up having counselors on sites, so some people can access counselors and they also have the system where you can talk over the phone. So they have moved forward. They have listened to what we have said years ago that some people just need talking therapy, but it is still not enough. 9 times out of 10 young people still don't trust their doctors because there is this mystery about what they can do to you if you go to the GP. Most people when you go to the doctor they don't have any time for you anyway, you are in there for 5 minutes and he is writing the prescription before you can say 'Jackanory.' [...]

You have a whole bunch of young black people growing up in the prison system. Half of them won't make it, they will either be diverted into the mental health system or they will be committing suicide. They won't live. So it's about what we do with them. You can see it's happening, but it's almost like people are saying "well just get them off the streets." The fact that a large proportion of our community is going to be incarcerated sets alarm bells off. [...] Most people, they might as well stay in prison. Don't get deferred into the mental health system because I think that's worse than anything. At least you do your prison sentence and you are released, people in the mental health system they never get out of it. It's always a noose around your neck.

[...]

A lot of the people I have worked with over the years who have taken their lives did so because they felt so isolated and felt that people didn't understand them and were detached

from society. The only way they saw was committing suicide to take them out of the hell. When we had the Assertive Outreach team, they could at least visit those people who were staying in their houses and finding it difficult to come out, so they would see another face at least once or twice a week. What they have done now in Lewisham, is they have taken away our assertive outreach teams and a lot of them have been integrated into continued care teams, so that means that there is no specialist team in the borough that is working with those hard to reach people, predominantly African and African-Caribbean. People still don't understand them, yet they set up all the structures to embrace equality. How can you have all the things that they reckon are empowering people, but in the next breath the structures that they need to get the support are not there? [...]

It is very painful to watch a lot of the people who come in here because a lot of them will say they feel suicidal because they are estranged from their families, and when they go outside of Isis, people treat them like they are not even human. We have stories where the neighbors are criminalizing people because they have mental health problems. Most of the people that come in here, it is only by the grace of God that they haven't committed suicide because they just want somebody to take them out of their misery.

They did a report on assertive outreach and we never saw it, we are still waiting for it. I think they didn't show us because we had a success rate, the man actually told us, a success rate of, I think, 80% working in a voluntary sector environment and the statutory sector didn't have a very good percentage. This is how it started, when the assertive outreach initiative came on board the Institute of Psychiatry decided they wanted to monitor a voluntary organization and we were chosen. In the end when they completed the reports, when they were supposed to publish it, they put it on hold for some reason. After 3 years doing the research, I want to see what the end result is. They gave me some little piece of

paper saying this is what they said about assertive outreach. But for me that was not good enough because how can we validate our work? We did some good work; half of the people who were hard to engage are out of the system now. I have stayed here long enough to see it. But what I am also seeing is that some of those people are going back to hospital because assertive outreach is no longer there. [...]

People are prescribing these medications, and they know what the risk factors are and they're still giving you the medication! How can that be right? All they say is 'well we've got to deal with the presenting problem,' and if that person is psychotic, let me deal with the psychotic symptoms first and maybe we will deal with the rest afterwards or one outweighs the other.

KWAME: But, how would that ever change?

WESTON: I think it would have to change at the GP level. There's gotta be a way where we can decipher the ones who do not need medication, psychotic medication. If you talk to half the people downstairs (in Isis) they never needed psychotic medication. They needed talking therapy maybe, but they never needed psychotic medication. Once they got on it, they found it very difficult to get back off of it because it's a cocktail of drugs. The side effects of this one means you have to take this one which brings on side effects and if you don't take this one, this happens. And it's just like a never-ending circle. Which one do you want? Do you want the mental health problems or the diabetes? Do you want the high blood pressure or do you want bipolar? Really you don't want any of them, but because you've been put in that position, which one is going to give you that quality of life? That's what it's down to, your quality of life. Your quality of life can be severely harmed if you are on medication... There's some horror stories I tell you.

David Pinder

David Pinder is the Project Manager at the Fanon Resource Centre Merton, as well as, acting Director of Operations and Community Development Advisor at the African Community Development Foundation. I spoke to him mainly because of his role at Fanon, but the African Community Development Foundation (ACDF) aims to improve livelihoods by building capacity for self-reliance within African Communities. It was established in the UK in 1999 and is based in the UK and Africa. As previously mentioned, Fanon is a recovery focused organization that works with Black, Asian and Minority Ethnic people living in London, with centres located in Lambeth and Merton providing a range of services including life and work skills programmes, training and volunteering initiatives, mental health support, outreach, drop in, health and well-being activities, access to talking therapies and women's services.

PINDER: We came to the end of the DRE³¹ in 2010 and they packed everything up nicely and put it on the shelf and that was it, as if racism had suddenly stopped. The structures that many people operate in are still not conducive to improve mental health. One of the key outcomes or objectives of the [DRE] policy was less fear of mental healthcare services by BME communities, and even though people may say its only a five year period, how are you going to manage something big and broad like that, that's a big piece of work involving stigma, involving the stereotype around mental health services, around people's experiences of mental health services, around diagnosis of individuals with mental health issues. They are in an alien culture, an alien country that doesn't really take into

³¹ The national Delivering Race Equality (DRE) Programme was established to improve access, outcomes and experiences for people with mental health needs. It was designed to tackle mental health inequalities for all people of Black and Minority Ethnic (BME) origin, including people of Irish or Mediterranean origin and East European migrants.

consideration an individual's cultural perspective. They think if they give them a can of Red Stripe or they serve curry on a Tuesday, that they are being culturally competent. [...] This is the kind of discourse and mindset that the mental health services are in. They are resisting becoming more culturally competent because their priorities are not about less fear of mental health services, it is about making sure that people who are perceived to be a danger to society are off the streets. So we have supervised treatment orders and community treatment orders, we have people who are put under the different sections, which for all intents and purposes is just to keep them quiet and off the streets. You have home treatment teams which means they medicate people inside their houses, so those people then, because of the anti-psychotic medication that they are on, they are unable to get the motivation or the energy to get up and go out. And that suits some of the community psychiatric nurses and the psychiatrists. [...]

We have to attend so many tribunals and mental health reviews to help people advocate for themselves because they really do not feel, even the most vocal ones, able to advocate for themselves. You are the one patient and then there is one person over there saying let me give you the medical way and then another over there saying let me give you the clinical way, and then this one saying this is the medical way. You are just so overwhelmed. The power dynamics needs to shift. You can help some people with cultural competency, but it is a power dynamic between psychiatrists, community psychiatric nurses and patients that needs to change. They might say that now the service user is allowed to express themselves but at the end of the day the psychiatrist, even when you know the medication is to your detriment, can still force you to take that medication. [...]

When people are feeling unwell and in a bad place, the default setting for most of us is our culture. That's why it is a good starting place to help somebody start rebuilding themselves,

by recognizing the role that culture has played in keeping them well up to that point. The security of culture.

Malcolm Phillips

Malcolm Phillips is a licensed psychologist and the director of the Oremi Centre, a mental health day centre located in West London providing outreach, advice and information and community development. This center offers a wide range of facilities, including a day centre, advice and information, outreach visits, community programmes, health promotion, community carer support. The center provides a space for the personal achievement and mental well-being of African and Caribbean people, and has recently expanded to specialist care for Arabic speakers. He also worked at a center in Hammersmith for young people who had attempted suicide.

PHILLIPS: Often you have [youth] out in group homes in nice country areas in the surrounds of London. When they turn 18 they consider them adults and move them out. Between 18 and 21 they have Independent Support Teams, who move them into their own flats and support them to get on with life. There is a very high rate of suicide among black kids at that stage; we get a lot of referrals from the Independent Support Teams because one of the things they do is they say, "he's black, he needs to be where his people are." One of the first referrals I had, she was black so they found her a flat in Shepherds Bush. She was terrified of black people and within months she had attempted suicide because she was confronted with her otherness, from both sides. [...]

When I first started working, a big thing in the black community was being diagnosed as

ESN³² and black kids being put out of school or being diagnosed with conduct disorder. The focus of the institutions was on black youth in schools, black boys especially. Then there was this wonderful diagnosis in the Midlands of ‘ganja psychosis.’ So then that was the focus of the institutions. Then there was a massive rise in the diagnosis of schizophrenia for black people. Then for about 5 years they got very focused on dual-diagnosis. It's back to ganja now, but now it's skunk³³ so it is a different kind of ganja that is causing the problem. [...]

The government has done very little. They made a form and added more categories; that is their idea of being inclusive. The Race Relations Amendment Act and quality impact assessments and these things are really just a tick of the box; they have no impact. In fact, the last 10 years, 15 years our government has seen far less effort to do anything for the black community. I used to chair the national network of African and Caribbean mental health services and back then in the late '90s, there were 350 organizations around Britain and 42 in London. There are probably now less than 40 around the country. They have all had their funding cut; they have disappeared. Whereas before when black people were at their worst they could go [somewhere] where they would be understood, what they have to do now is go and explain themselves in a European way, in a European setting, at a time when they are least capable of doing that. They have to try and fit in and they find that they don't fit in. So they try to cure themselves. They either self medicate, they hit the bottle or drugs, they harm themselves or they steer away from the hospital until they are picked up on the street. The government just poured a lot of money into a piece of crap called

³² The category of educationally sub-normal (ESN) was classified under the Handicapped Students and School Health Service Regulations of 1945 as “consisting of children of limited ability and children retarded by ‘other conditions’ such as irregular attendance, ill-health, lack of continuity in their education or unsatisfactory school conditions” (Warnock, 1978).

³³ Skunk refers to a subset of sativa-dominant Cannabis strains. It is popular for its skunk spray smell, hence the name ‘skunk.’

‘Delivering Race Equality’ for the last 5 years. It did nothing. It's own report said it had less than no impact. It had a negative impact. We are in a worse position. We have no substantial change. The stigma is just as bad. The fear of services is just as bad amongst BME communities. [...]

My kids will say, “I'm British, I'm English;” that was a bad word when I was growing up. But it does cause some psychological difficulties, issues of identity, and those who struggle to deal with that are the vulnerable ones.

KWAME: To play devil's advocate, for newer generations of people like your sons who regard themselves as being European, does that mean then that there is less need for culturally specific services?

PHILLIPS: That's a good point... No, it means there is more need. If my son says he is a horse, it does not mean that we need more vets; we need more doctors who will understand that he is actually a human being. Just because my son, who is a Caribbean child, thinks he is British [laughter], it doesn't mean we don't need Caribbean practitioners. We need practitioners who understand why black children think they are ugly. That wish to assimilate is an unhealthy thing. That wish to be somebody other than who we are is not a healthy wish. In Europeans that would be recognized as an illness. This would be a cultural dysmorphia. [...] At the Maudsley I worked with a particular client who painted herself white. I have worked with maybe 5 or 6 people who have painted themselves white or who will bleach their skin with actual bleach. [...]

You are weighed down by being in a culture and an atmosphere of oppression. I was born here and brought up here and ‘Home,’ the Caribbean, was a fantasy to me. When I got to my late teens I first traveled to St. Kitts where my parents are from with my 3 brothers and two of them moved back there straight out of university. I started going every year for a month and eventually it hit me, I was on the plane and burst into tears because I realized

how fundamentally different I was in St. Kitts as opposed to how I was in London. It was like I was wearing a heavy overcoat, a wet heavy overcoat all the time. So when I was dancing in the club I was wearing this. When I was with my girl, when I was in bed, when I was making love, when I was playing, when I was working... It was a recognition of all those microaggressions³⁴. One day in St. Kitts, I was walking down the street and there was just the joy of realizing if shit happens here, it's my fault. If I get stopped by the police, it's going to be a black police and it's not going to be racism, it's going to be because I messed up. It takes work in this country just to be. Wearing that coat, I could still get about my business, I could still live, but it weighs you down and you never know when it is going to trip you up, when something is going to happen and it's just too much. So it creates a vulnerability.

Jan Oliver

Jan Oliver is the director of the Fanon Resource Centre Lambeth and a non-executive director at Guys' and St. Thomas's Hospital, where she has been on the board for nearly 10 years, a unique position for a black woman to occupy within health services. The position allows her access to important policy makers and power brokers, and affords her the opportunity to see the bigger picture, while also being a front line member of staff at Fanon. Before working at Fanon, Oliver held a job in television.

OLIVER: [I] see how decisions impact at the other end. And there is a complete and total

disconnect between what is really going on and what they would like to think is happening.

[...]

³⁴ Racial microaggressions are brief and commonplace daily verbal, behavioral, or environmental indignities, whether intentional or unintentional, that communicate hostile, derogatory, or negative racial slights and insults towards people of color (Sue, et al. 2007).

SLaM (South London and Maudsley) is very focused on the recovery agenda, focusing on how you can support people back into a meaningful life. Although the medical model still dominates to a certain extent, there is a real move now in mental health to focus on helping people, be it with or without medication back into a meaningful life. It is about focusing on strengths and not weaknesses. It is about empowering people. It is about putting service users at the center of the own treatment and illness and saying how is it that we can support you to move on. We are trying to redress the balance because what has happened in the past is that the medical model has dominated to the detriment of the other parts of people's lives. But I think there is now a recognition that when you start with the person as a whole, looking at it holistically, that might be a better way of supporting the individual in their recovery than just giving them medication or locking them up. [...]

Black is a label that I have been given because that's how it's easiest to categorize me. But me myself I would say British, African, Caribbean because that's what makes me up. British first because I was born here and there is a Britishness about me that is more emphasized when I go to the Caribbean and when I go to Africa. I feel more British when I'm in those places than I do when I am here. My parents came to this country, I was born here and I didn't know much about the Caribbean until I went to discover it for myself. My parents didn't really talk about it very much. [...] I really like the fact that your parents took you back to the Caribbean to be educated because I feel that at least you have a whole experience now of who you are in terms of your identity compared to maybe me.

KWAME: I'm trying to remember how I felt at the time. I know that when they gave us the option to move back I was completely fine with it because I'm not sure I particularly enjoyed the south London experience. At the time drugs had begun to come into the school and I was 11 then, so I was aware enough that this particular environment was not going to work out for the best. So if we were going to move somewhere where I prefer the food and

there was sun, I was cool with it. But then I was also very aware that when we actually moved to Jamaica I had to pay my dues to earn my Jamaicanness. I kind of remember not speaking for a long time so that when I opened my mouth I wasn't going to sound too English. Having grown up in that environment, when I eventually came back here, I didn't really feel much of a connection. I wouldn't say that I feel British or even English, I more feel London. [...] When I hear people speak about British history, English history, I go to the British Museum, I have no connection, nothing. It doesn't do anything for me. If I go to a Caribbean Museum or an African Museum, I feel like this is my history. So even though I was born here and based on my birth certificate my history should be the Tudors and whatever, I don't have any feeling for it, there is nothing there.

OLIVER: I hear you. I hear that. The thing is if you have never been to the Caribbean, then this is your experience, this is your frame of reference, this is where you brought up, you didn't have a father in your life, I'm going to go there because people won't and I think it is really important that as a culture and as a community we really begin to look at that. So for me one of the questions is how do you learn to be a man when you live in this white dominant culture, all the images you see of success from a black perspective are footballers or rap artists or singers. You very rarely see lawyers or black doctors. You go to school where there is very little or no expectations of you whatsoever, none at all. [...] How you can develop as an individual? [...] Where does that sense of identity come from? Really, who are you? How do you then define yourself?

Matilda MacAttram

Matilda MacAttram is the founder and director of Black Mental Health UK, established in 2006 to raise awareness and address the stigma associated with mental illness. BMH UK has led various campaigns to raise awareness of the inequality of mental health treatment provided to

Black communities. MacAttram works proactively on politicizing the Church, and sits on the steering group of the BME Mental Health Network and is a member on the National Advisory Panel of the mental health charity, Mind. MacAttram is also a specialist health journalist and has written on health matters for publications including Mental Health Today, New Nation newspaper, The Voice, Community Care Magazine, Blink.org.uk and Black Britain online.

MACATTRAM: Anyone from the diaspora who happens to be in the UK will have the same experience regardless of whether they are of African origin or Caribbean origin because of the way they treat people from the diaspora. The differences are very distinct of course, the history, the culture, the language, the food, everything. When here these differences are not acknowledged in the system. Detention rates for people who come from the Caribbean and detention rates for people come from Africa, it might be slightly higher for people from the Caribbean, but the numbers are starting to even out. Even if you look at the way these groups have migrated, how they live, all the experiences are the same. They live in the same areas, they have the same outcomes at school, they have the same outcomes at all the institutions because they are perceived to be the same and are treated the same. We see the issue of mental health, not as a healthcare issue, it is human rights and social justice issue because all the indicators show that accessing certain types of care is consistently uneven for one group and whether they come from the Caribbean or they come from Africa.

NHS Professionals

Yvonne Coghill

It was also important to speak to individuals whose primary experience was working in the National Health Service (NHS) itself. I spoke to Yvonne Coghill over the telephone. She is the Senior Programme Lead at the NHS Leadership Academy and former National Programme Lead

of the Breaking Through Programme at the NHS Institute for Innovation and Improvement, a programme set up to identify, select and develop talented managers and clinicians from BME backgrounds and support them to achieve director level positions. Coghill commenced nurse training in 1977 and following qualification as a staff nurse, went on to train as a mental health nurse and health visitor, before becoming a team leader for Health Visitors, School Nurses and Community Pediatric Nurses in 1986. She has since worked in a variety of clinical leadership and general management posts in the NHS. Coghill was awarded an Order of the British Empire (OBE) for services to healthcare in the 2010 New Years honors list.

COGHILL: We're coming from a place in this country where it wasn't particularly politically correct or even interested in black and minority ethnic people. The host population aren't really interested in sharing power and aren't really interested in or understand the consequences of their behaviour. Now that's not to say that they are all racist bastards and they all hate us and want us to die, what it is is that they don't put enough thought into it because it doesn't impact on their lives. The people who are in positions of power and authority are so far removed from the Peckham estate or single parent mothers living in tower blocks, they are so, so far removed from that and do not grasp it, understand it, know it or acknowledge it even because they just do not have that experience of it. They have experience of it from the TV, from reading in the newspapers, but actually they don't really know. I am talking about politicians and MPs and so on, who actually are making policies for the whole country based on their experiences, based on what they believe. We, BME people, black people, people from ethnic minorities, are constantly pushing against this door and beating our head against this brick wall, but unless the people on the other side want to start banging on the wall too and bring the wall down, we're not going to get anywhere very fast. They have to want to work with us on this and I think the tricky thing is that they don't see the need to because what they will say to me is "well, you know

Yvonne, if I'm commissioning services for people, I am commissioning services for people not whether they are white, black, blue, pink or green, I'm commissioning people." The point they are missing is that everybody is different and you actually have to commission sensitively in order for there to be a good outcome for everybody. [...] What I try to do is to communicate with both groups of people about what needs to happen for us to bridge that gap. There have been things like reverse mentoring where you get a BME person to mentor a senior person in a high level job in the NHS, but it's not consistent. You get it in pockets, in various places, and in order to make those changes, what has to happen, and it hasn't ever happened, is that senior leaders, and that is starting with the Prime Minister, have to really want this thing to happen. They have to genuinely want a diverse community where everybody is seen as potentially talented and given equal opportunities. We need to work on those people because, whether we like it or not, they are in positions of power and authority. They are the ones who can make a difference. If my Chief Executive turns around and says I want this to happen, it will happen. Someone said to me, and excuse my language, if you grab people by the balls, it will drag their minds with them. I think if you grab people by the balls, they are more likely to be angry and aggressive and unhappy with you pulling them along that way. So what you are trying to do is pull their minds along.

KWAME: And hopefully their balls follow.

COGHILL: What legislation does is pull them by the testicles because what they say is we have to tick all the boxes. They don't really believe it, but they just do what they have to do to make sure they don't get [in trouble]. [...]

The aspiration of people like my mother, to come to this country and do their best, to get the education and the money to give us all a better life, I think the next generation began to realize that it wasn't as easy as that and it wasn't going to happen the way that their parents thought it would. I remember my mother saying the streets are paved in gold and England

is the mother country when I was younger; I remember it. Those belief systems started to break down and disappear and things were incredibly difficult for younger black people. Racism was rife in those days and black children were not doing as well in school for all sorts of reasons, but not least because teachers, who have a lot to answer for, were not as supportive to black children as they could have been. So the kids became angry, they became disillusioned, they began to say this society has nothing for us. [...]

I am Guyanese, first and foremost. People will argue with me and say no you are British, you're English, but if anybody asks, I am Guyanese. Secondly I suppose African-Caribbean. Thirdly, I would then be British.

KWAME: How would your children stack up in the same way?

COGHILL: That's a question! [*Long pause*] I think they're English. Yea, they are English children. But that changes though. With children, if they go back to the West Indies they feel more connected with it. Like yourself, if I asked you, you would say you are Jamaican.

KWAME: Right.

COGHILL: Even though you were born here.

KWAME: Yea and even though I speak with this accent [*laughter*].

COGHILL: And even though you speak with a strong English accent. You would see yourself as being Jamaican.

KWAME: Most definitely yea.

COGHILL: So I think it comes and goes. I don't know. I will have to ask them, but I think they would probably say they're English. Black English. Black British. Yea, Black British. They haven't got any other reference apart from here. But I suspect that if they went back and stayed for as long as you did or for even shorter, I think it would be even shorter. A friend of mine took her children back and they stayed a year and they came back and in one year, they were not English anymore. [...] The reason I go back to the West Indies so often is

because I feel so comfortable there. You get off the plane and you are with people like yourself. You don't have to worry. You can walk into any shop, any bar, anywhere and feel comfortable about being who you are. Whereas here, that is never quite the case. Even though I am relatively well accepted amongst the circle that I move with, there is always in the back of your mind that you are different from the host population. You are always wondering whether they are going to accept you, whether they are going to reject you and that causes additional stress. So in terms of mental health, even though they are African-Caribbeans and they are born here and brought up here and they are supposed to be English, actually England doesn't accept you. Society isn't accepting of them, they have nowhere to go, they are not West Indian but they're not British either and they are somewhere in no man's land, and when you've got nowhere to go and nowhere to turn, it's a horrible place to be. [...]

Change needs to be political; it needs to be where the power and the money are. It needs to be first and foremost with the politicians who have access to the media, because they are the other really powerful group in our society, the media. The media influence people in this country like you wouldn't believe and people don't recognize that they are being influenced. The media does more damage to our cause and diversity than any other group. They talking about immigrants in a derogatory way, they talk about Islam in a way that is inflammatory, they talk about black people being thieves and crooks and they constantly are bombarding people in this country with those images of people who are foreign and different. That could be easily be dealt with by senior politicians and other influential people by negating what they are saying and saying it quite strongly and they don't. In fact they do the opposite; they agree with it. [...] I don't know how to make them believe in diversity, because for them to do that it means acknowledging that their power base will be reduced and nobody wants that. There has to be some fundamental shift and change in

media, the newspapers, the television, our senior politicians, senior businessmen, people from the Confederation of British Industry, all of that. That's where the change needs to be. People who are in these positions of power are the same people that used to throw stones at me, and call me 'Blackie' and 'Woggy.' So therein lies our problem because their thinking, their experience of, their interactions with black people back in the '60s and early '70s were not necessarily very positive and they also believe absolutely, totally and fundamentally that they are superior. That is the real issue. If you talk to them, they won't say it to you, but if you listen to what they have to say you will hear it.

Mary Clarke

Mary Clarke spoke at “The Implications of the Proposed NHS Reforms on Health & Social Care” Conference hosted by the Nurses Association of Jamaica in the UK on 12th November 2011.

Clarke is a former NHS London Associate Chief Nurse and Lead for Equalities and current Associate Non-Executive Director for the Croydon Health Services NHS Trust. Clarke is a registered nurse by background and a qualified District Nurse and Practice Nurse. She worked in the NHS for over 35 years and was awarded an Order of the British Empire (CBE) in the Queen's New Year Honors List in January 2005 for Services to Nursing.

CLARKE: Just to give an overview of the principal context we have been working in, we have had something like about 8 or 9 different changes in the NHS architecture over the last 20 years. We have to wonder if [this] allows any time to actually embed the changes to see what difference we are going to be making and I actually don't think it does. So in the NHS every 2 or 3 years we have been through some kind of change and just as you think you are getting there it's “okay let's start all over again,” and then you start with a new management team, with a new set of directors and then a new set of policies. We are not allowing

ourselves the time to see what those outcomes might be and the benefits. So this new change [the 2012 Health and Social Care Act] that the coalition government has introduced is quite an interesting one and one of the things that I thought about when I reading about the changes was that this looks a little bit like déjà vu, where we are going back 30–35 years to bring health and social care back together it feels like we are just going round and round in a circle and not actually getting anywhere.

Sean Cross

Dr. Sean Cross is the Consultant Liaison Psychiatrist at SHIELD, a major three year project to improve services for those who present with self-harm to the A&E departments of St. Thomas' and King's College Hospitals, London. Cross completed his medical degree at the University of Edinburgh and his doctoral research degree is on-going at the Institute of Psychiatry, King's College, London. Cross has been employed full-time as an NHS consultant psychiatrist by South London and Maudsley NHS Foundation Trust since 2010. Cross also works in acute trust hospital settings, based at St Thomas' and King's College Hospitals, where his main interests include self-harm and mental health crisis management and the overlap between physical health and mental health difficulties. In 2012, Cross won Psychiatric Trainer of the Year at the Royal College of Psychiatry Awards.

KWAME: Speaking to the service user I spoke to yesterday, he is compliant with his medication, he has been for 29 years now, he told me about the discussions he has with his physician, and essentially what he is telling me is that he tells the physician what he thinks the physician wants to hear and he takes the medication, not because he thinks the medication works, but he has taken the medication for three decades because he knows if he doesn't take the medication, he is going to get put in hospital. So he doesn't believe in the

physician, he doesn't believe in the medication, but he knows that if he doesn't take the medication, the consequences are not that he will become unwell again, for him the consequences are 'I will be put in hospital.' So to him, the medication and the physician are part of the problem.

CROSS: I have no doubt at all that that is the description of many kinds of therapeutic relationships and I am sure that's not the description of many other kinds of therapeutic relationships... There's a lot of stuff there, its about service development, its about engagement, it's about the barriers between that engagement – culture, ethnicity, race, socioeconomic stuff, sociocultural determinants; these are big topics, big areas, big conversations. [...]

From Enoch Powell, to the early '80s to August 2011 (the riots) and whatever that means, but the thing that is over-lined at the top, as that arc of history charges on, the more mundane stuff is that health services, local authorities, governments, try and classify people and put people in boxes and ask people to fill out ethnicity monitoring forms. And that's an evolving situation as well because all these labels are created out of a fire of political discourse over here and then there is a second run of labels and at some point there is a shift in these labels because the context has changed. At the moment we have these ONS (Office of National Statistics) categories, either you are African-Caribbean or the ludicrously long Black-slash-Black-British-dot-African-Caribbean or you're Black-slash-Black-British-dot-African. Or Black other. And these are the main local authority classifications and that's what services talk about and that's what census talks about... Very sort of basic, interviewer ascribed ethnicity, and this is what a lot of medicine deals with. You're white, you're black, you're Asian or you're other. It's not particularly difficult. What happens in our trust is a subjective described ethnicity, where people can sort of label themselves. The problem is in a country of 60 million people, what inferences

can you draw? Is it important? In our trust, we have about 69 options, many of which are nationality based... Some of the more settled BME communities here, particularly with later generations, people will end up ticking something like not African-Caribbean, not Caribbean, not African, but Black British and then what happens is you end up having to address the meaning of that.

Chapter Six: The Photographs



Various organizations set up tables at the Happy Soul Festival, an annual celebration of Black and Minority Ethnic film and arts exploring wellbeing. This table belonged to the Time To Change campaign, a statutory initiative aiming at ending discrimination surrounding mental health.



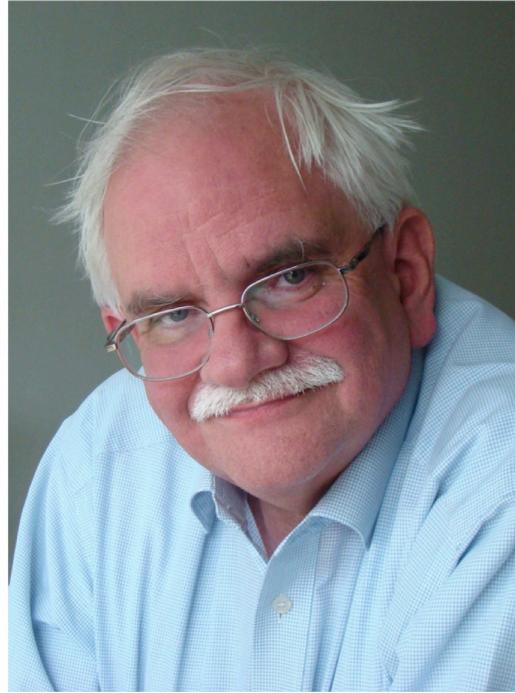
The Oremi Centre is located on the ground floor of the Trellick Tower in North Kensington, and so is located right in the heart of a residential area. The director, Malcolm Phillips, informed me that the center receives support from the neighborhood for the work that they do for the BME community.



There is an extensive library inside the Oremi Centre, made up primarily of literature dedicated to black history and issues.



Like most, if not all, of the Caribbean mental health agencies that I visited, space was always reserved for images of or created by service users. Similarly, music was also an important activity at such agencies.



Dr. Dawn Edge, Lecturer at the University of Manchester (left).

Dr. Tom Craig, Professor at the Institute of Psychiatry, King's College London (top right).

Malcolm Phillips, Director of the Oremi Centre (bottom right).



Juliana Frederick, Senior Community Development worker at the Oxleas NHS Foundation Trust (top).

Dr. Frank Keating, Senior Lecturer at Royal Holloway University of London (bottom).



The locations of the Fanon Resource Centres in Merton and Lambeth contrast from each other. Fanon Merton is located on the ground floor of the relatively old Justin Plaza, located on a busy street in Mitcham, Surrey. Fanon Lambeth is located in its own building on a relatively quieter back road in Brixton in a much newer building.

Southside Partnership Fanon FANON RESOURCE CENTRE OPENING HOURS

Monday	12:30	-	4:00 P.M.
Tuesday	10:30	-	4:00 P.M.
Wednesday	APPOINTMENTS & OUTREACH ONLY		
Thursday	10:30	-	4:00 P.M.
Friday	10:30	-	2:00 P.M. (APPOINTMENTS ONLY 2-4 PM)
Saturday & Sunday CLOSED			

Fanon Resource Centre is closed on Bank & Public Holidays

Supporting People To Lead Independent Lives

Fanon Resource Centre

Welcome to Fanon Resource Centre. While you are here we ask you to follow our House Rules. These help to make sure that everyone can enjoy the Centre and get the best possible service from us. We therefore take any breaking of the rules seriously.

Respect

Help us to keep the Centre safe and welcoming for everyone. We can show respect by treating each other with civility and courtesy, accepting personal differences, listening to what others have to say, and refraining from ridiculing, embarrassing or hurting others.

Complaints, Compliments & Comments

Despite our best efforts we do not always get it right - but we do try our best to put things right if they have gone wrong. If you are unhappy about a service, if we have not done something we promised to do, or if you think we have not treated you in the way we should, we want to know about it.

Safe From Violence or Threats

We want you to be safe. We all have the right to work and visit without fear or intimidation. We will take action to protect everyone from threats, abuse or bullying. If you need advice and support in this area, please ask.

As might be expected, rules and regulations for members' conduct are often posted in common areas. A day or half day dedicated to appointments and/or bookkeeping was also often a feature.



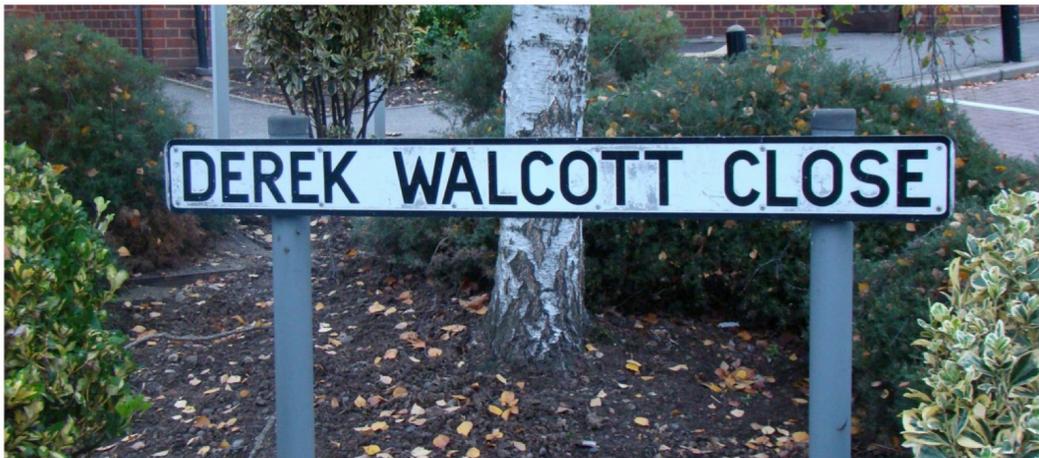
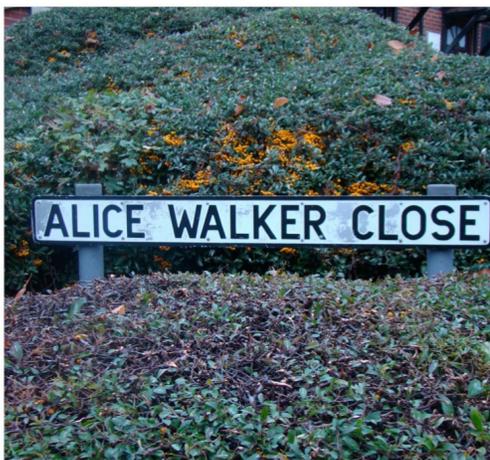
Much like the Oremi Centre, Fanon Lambeth put an emphasis on maintaining a library. At Fanon Lambeth, a main table in the common area was used to display different books on different days, usually dedicated to black and black Caribbean issues.



When on display, images of service users held no less importance than images of political leaders and popular figures. Individuals like South African leader Nelson Mandela, Jamaican reggae artist Bob Marley, and American President Barack Obama were commonly found on the walls of Caribbean agencies, such as here at Fanon Lambeth, and even Caribbean businesses.



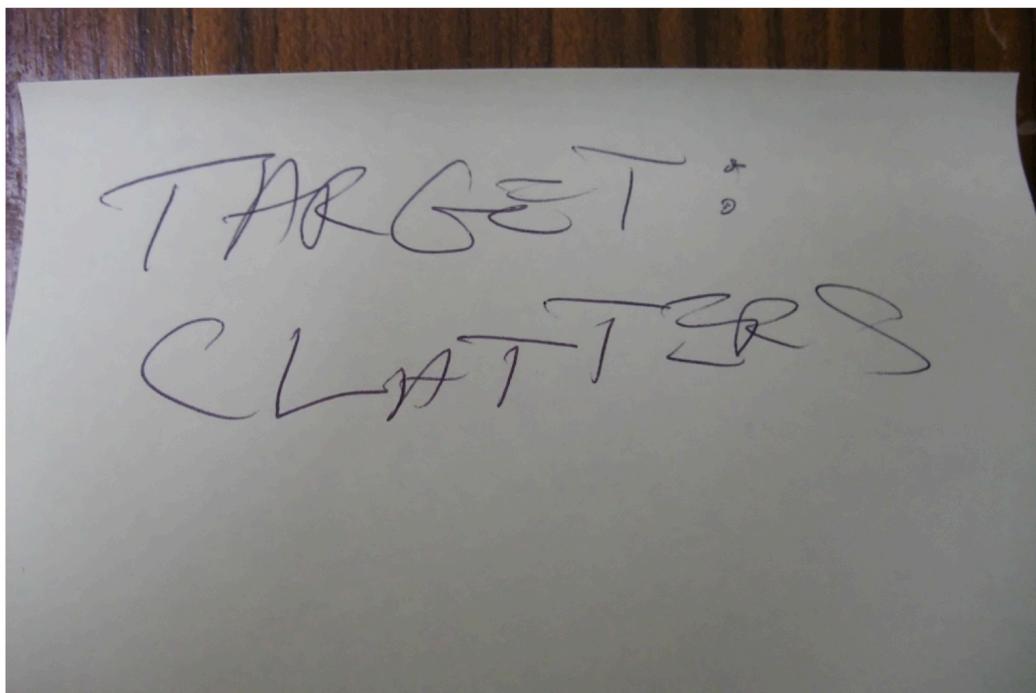
In addition to photographs, Fanon Lambeth also had a display cabinet for arts and crafts made by the female service users. I didn't find such an elaborate kind of display necessarily common in Caribbean agencies, but at the very least there was always artwork or poetry from service users on the walls.



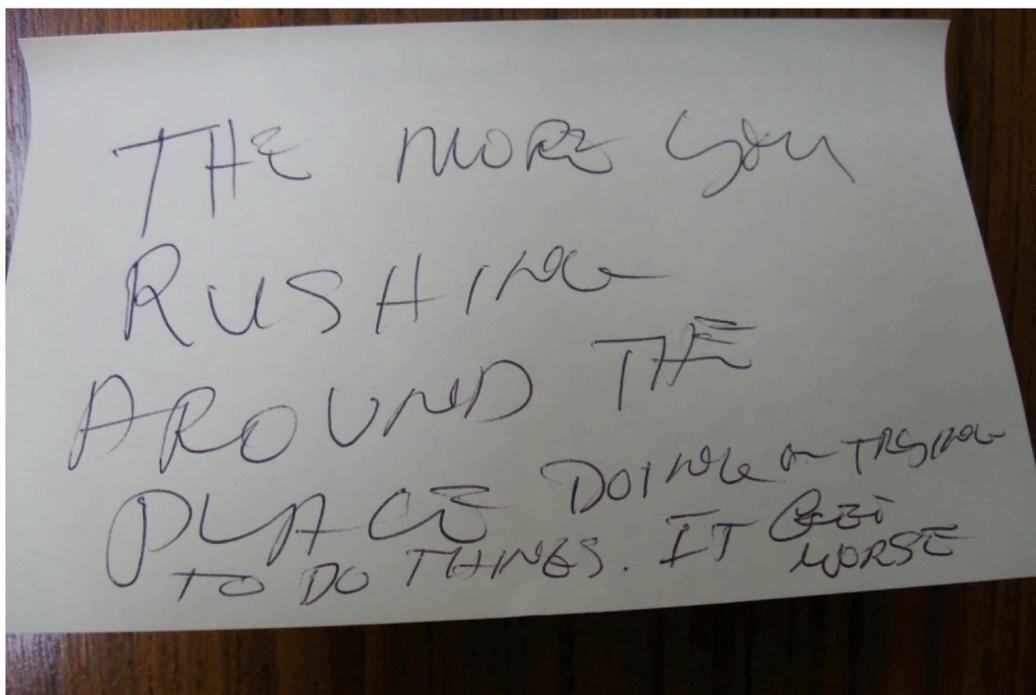
Brixton is the area of London, and of the UK as whole, most synonymous with the black Caribbean population. One newly developed section of the residential neighborhood has streets named after famous writers. Alongside Walt Whitman Close, James Joyce Walk and Pablo Neruda Close were these roads dedicated to black and Caribbean writers.



During my interview with 'Mary,' she spoke about how much of a religious place she thought England was at its core. These were photographs that she asked that I take on her behalf. At the top is the Fishmonger's Hall and at the bottom the Frieze on the Portico of Sir William Tite's Royal Exchange, both at London Bridge.



TARGET:
CLATTERS



THE MORE YOU
RUSHING
AROUND THE
PLACE DOING A THING
TO DO THINGS. IT GETS
WORSE

The following set of images was taken by the service user 'George,' an active member of the Men's Group at Family Health Isis. They are of notes that he wrote during the period that he was unwell and doesn't really have a good memory of his state of mind at the time. His description of his illness was that he was overworked at his job and had not been sleeping regularly.

STOP OR
DIE.

you must GET
SOME SLEEP
TO REPAIR THE DAMAGES DONE

STAY STILL
DONT MOVE ABOUT
DONT DO ANY
THING

TRY READING

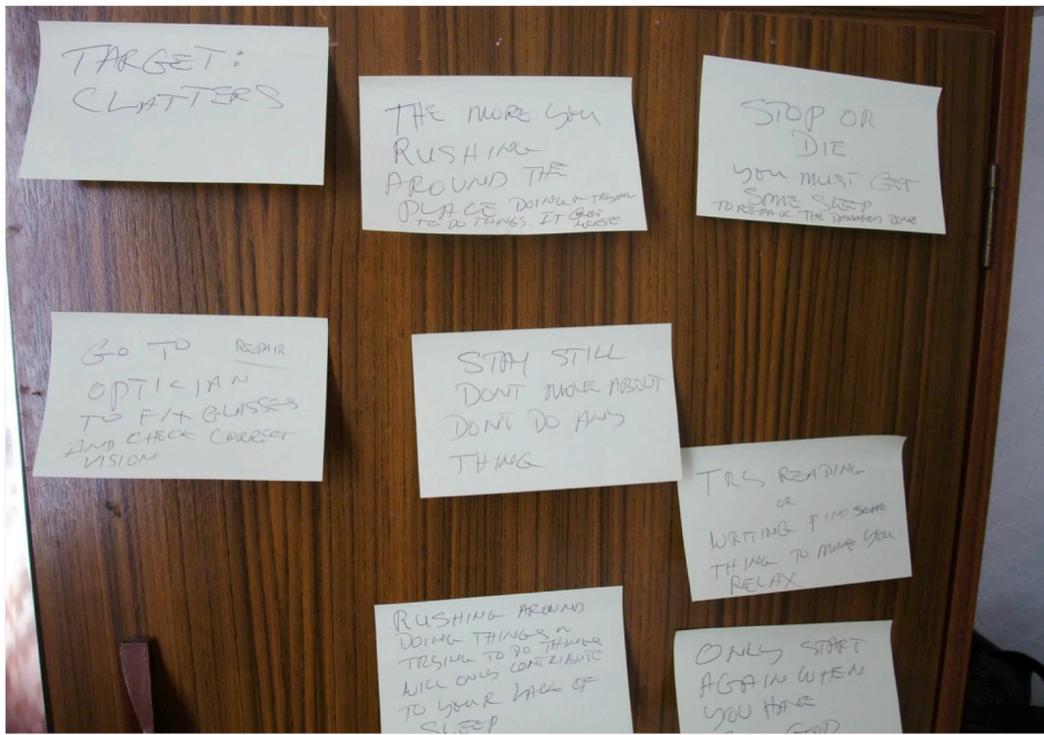
OR

WRITING FIND SOME
THING TO MAKE YOU
RELAX

ONLY START
AGAIN WHEN
YOU HAVE
SOME GOOD
SLEEP

RUSHING AROUND
DOING THINGS &
TRYING TO DO THINGS
WILL ONLY CONTRIBUTE
TO YOUR LACK OF
SLEEP

GO TO REPAIR
OPTICIAN
TO FIT GLASSES
AND CHECK CORRECT
VISION



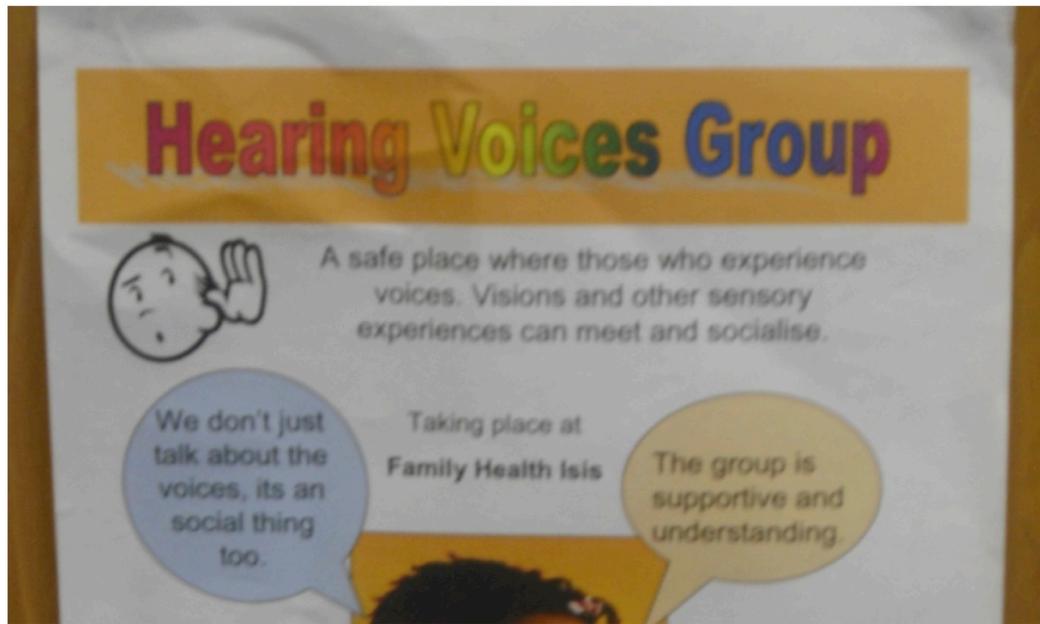
The notes he had written were posted up on a door in his home as reminders, at the time, of actions he should take, and at the present, of how unwell he had been. He also photographed the medication he was given. Zopiclone is prescribed for insomnia. Citalopram is prescribed for depression, anxiety, OCD, panic disorder, PTSD, and premenstrual dysphoric disorder.



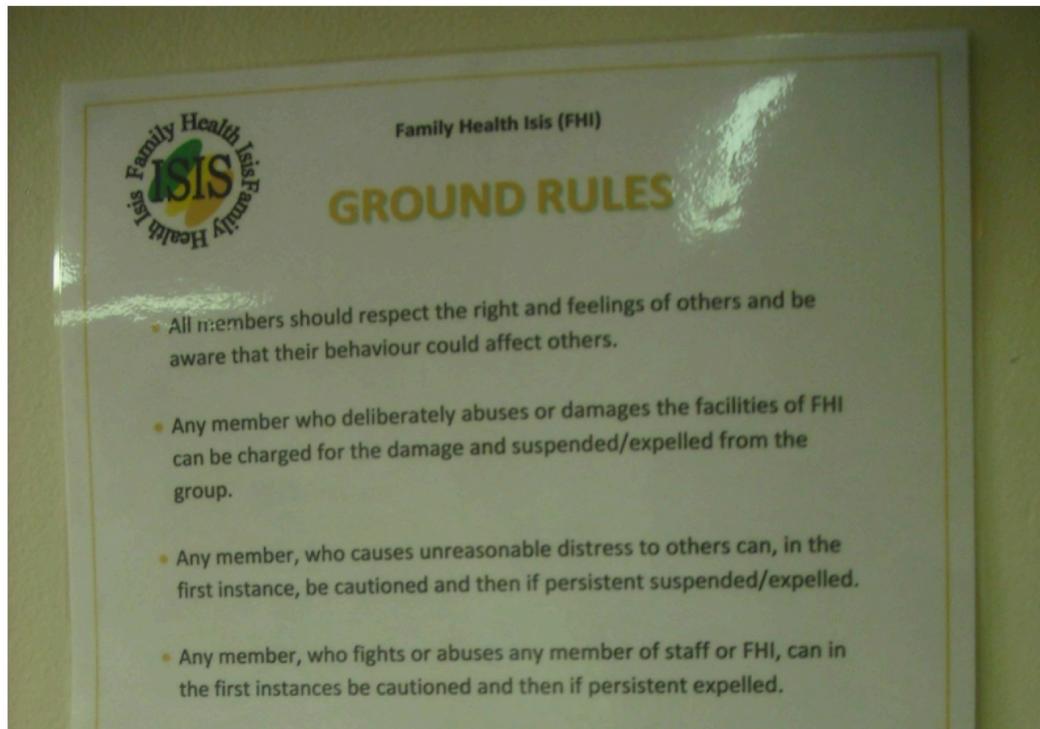
Family Health Isis members would take annual outings/trips to different places in England as a means of doing something fun, away from their normal everyday lives, together as a group. These are photos that 'George' took during one such trip. These two photographs are of three members of the Men's Group.



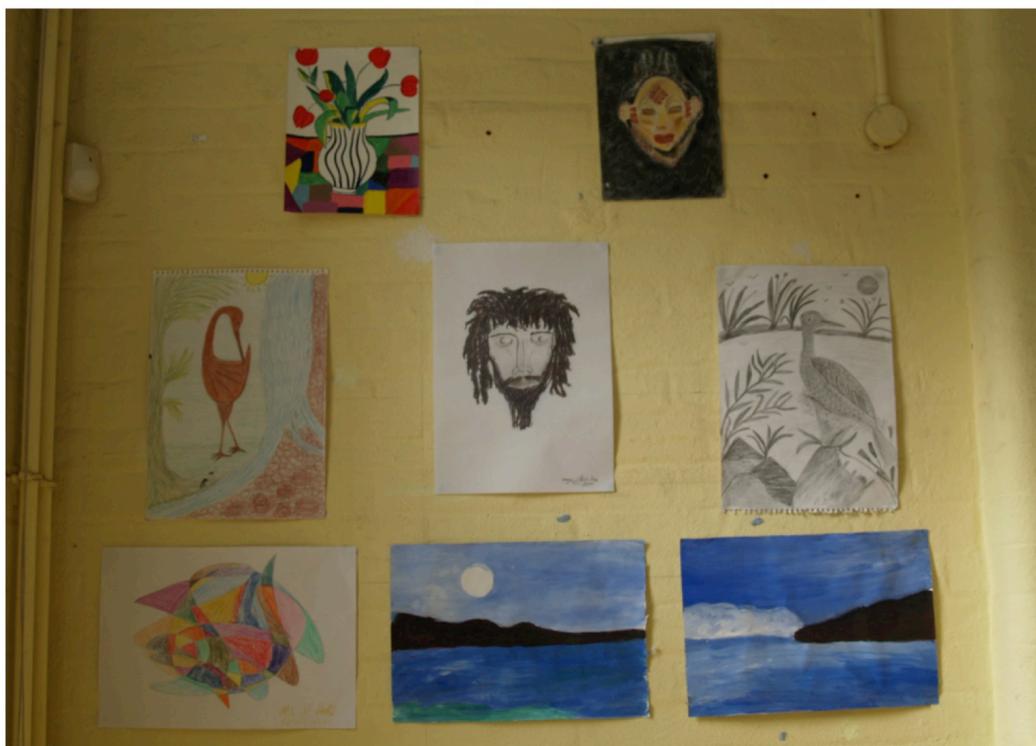
More photos from the beach trip taken by 'George.'



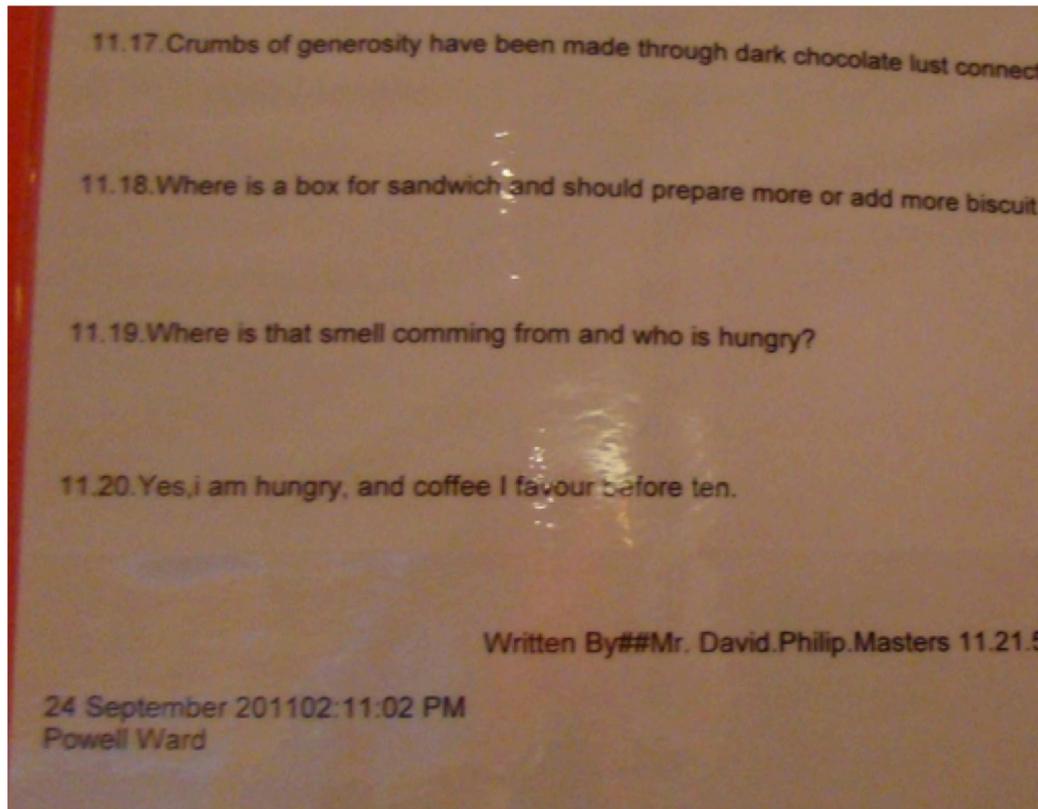
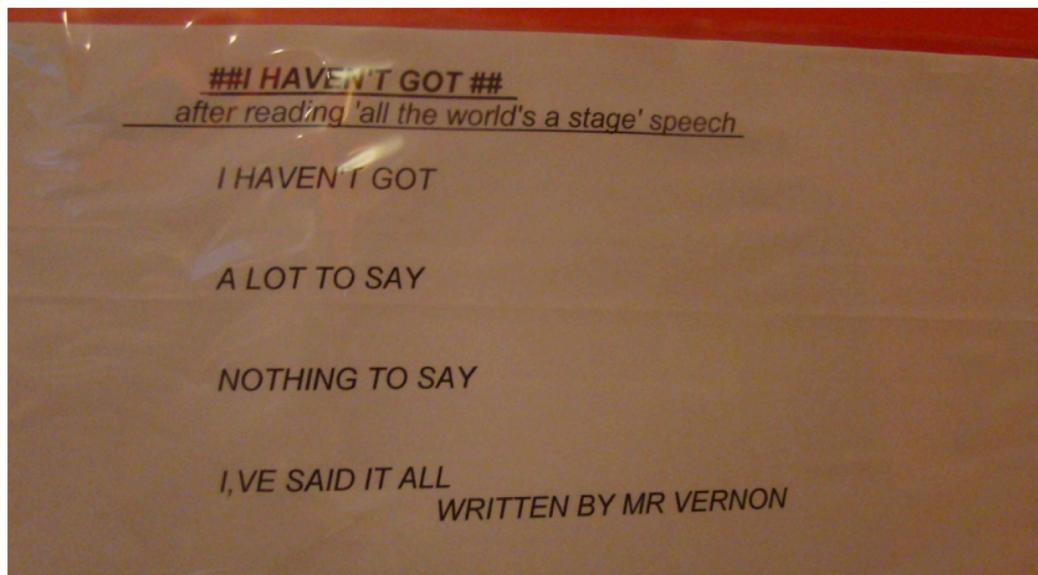
The Hearing Voices group at Family Health Isis was one of the regular groups that met. As described it was a safe place where those who experienced hearing voices, visions or other sensory experiences could meet and socialize. They met weekly in this room, would sit in a circle and discuss ad hoc or planned topics.



Family Health Isis ground rules and two large poster boards containing photos of service users and staff members. These photos are quite old and were definitely up when I was a volunteer in 2002. Many of the members photographed are still active members, and long-term membership is common. Some of those photographed have since passed away.



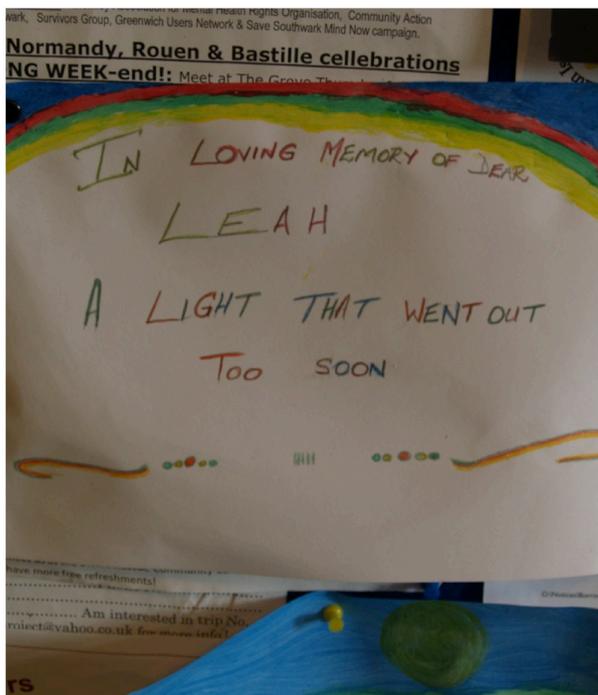
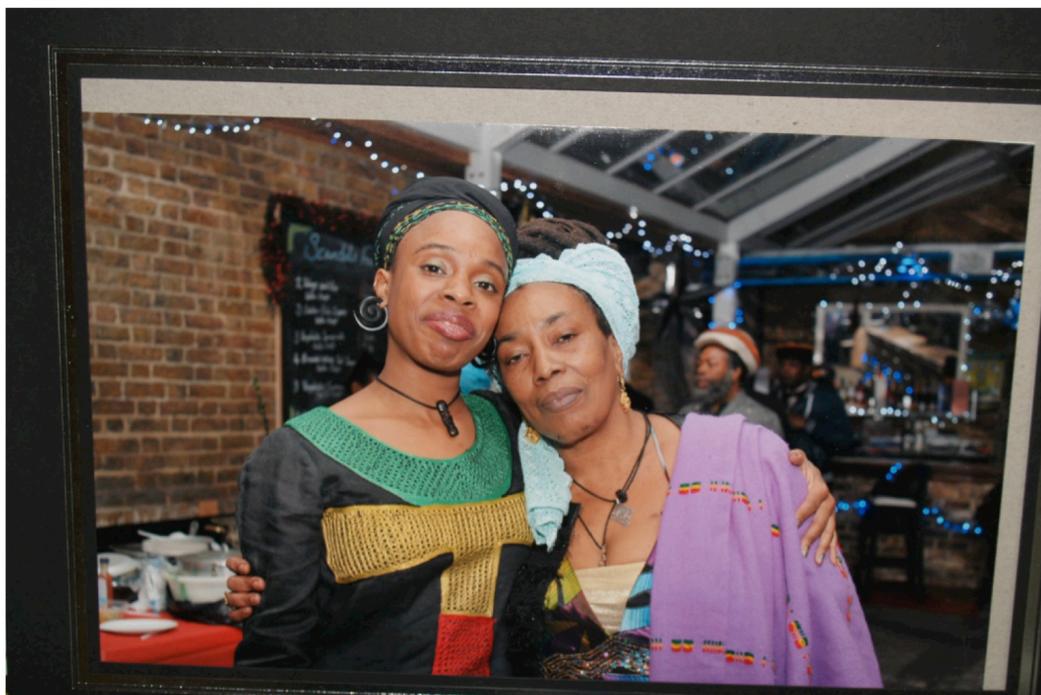
The Art Group was another group that commonly met at Family Health Isis and the work produced at that group was often displayed on the walls of the center. The photo at top is of the gallery at the former building in Catford. Below is one of the wall spaces at the new building in Lee.



Though not a comparative study, I did visit the Ladywell Unit, the inpatient mental health unit at the Lewisham Hospital. In the lobby poetry from service users was posted up on a wall.



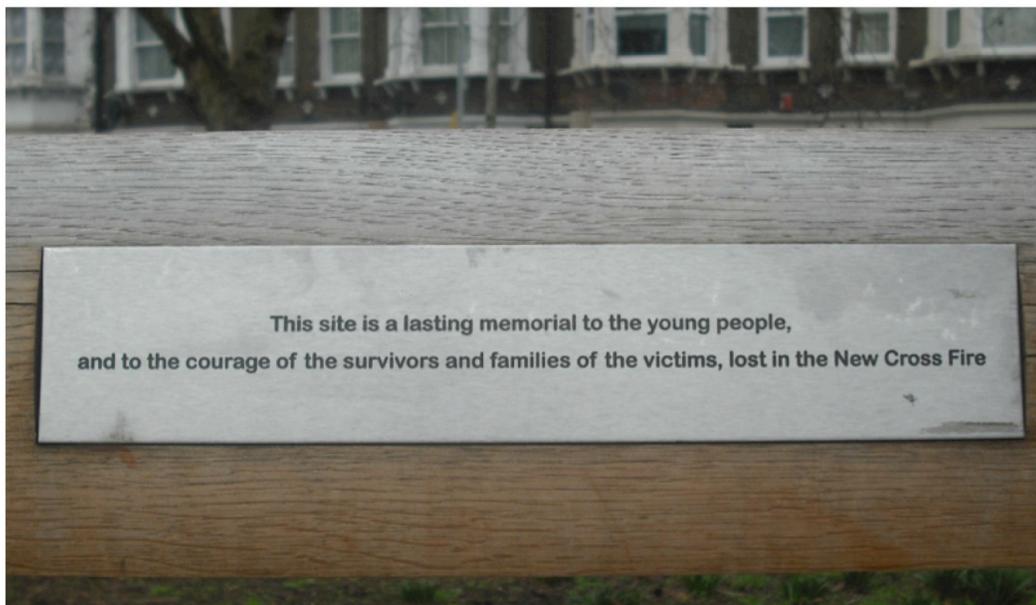
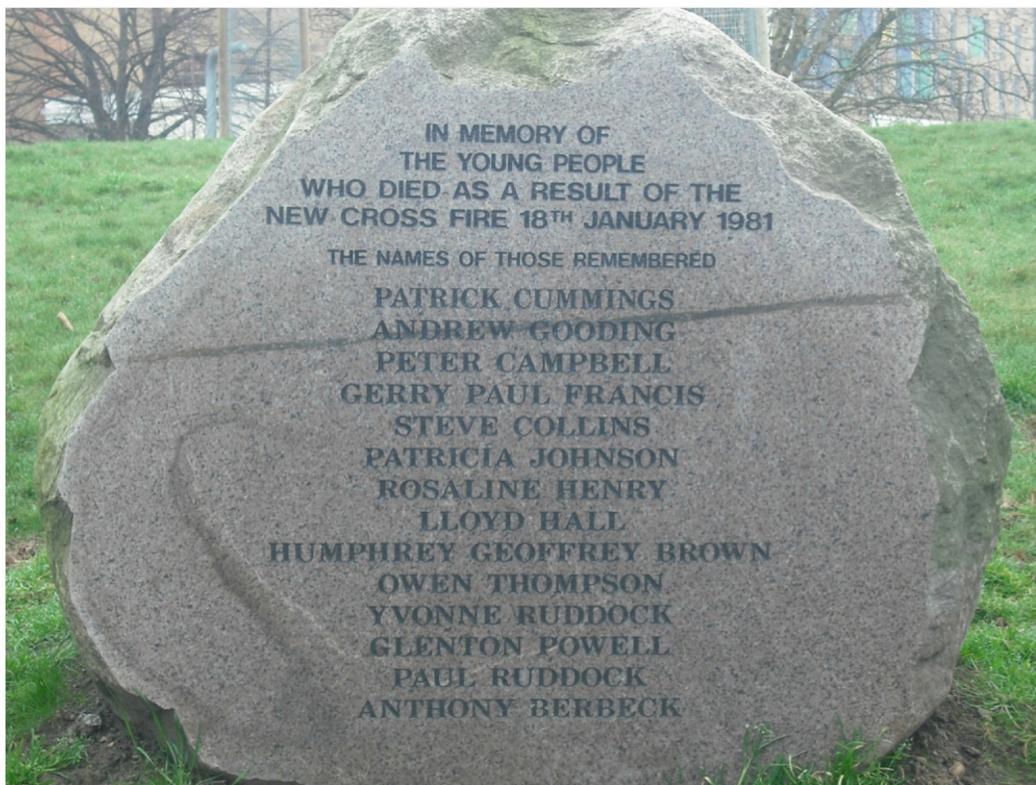
These photos were again taken by 'George' of other Family Health Isis members and staff at a birthday party held at the former building in Catford.



During my fieldwork, Leah, one of the members at Family Health Isis passed away unexpectedly. She was particularly close to the staff member, Sharon, who she is photographed with. She died at home of complications due to epilepsy and was not found for three days.



A remembrance was held for Leah at a community centre in South Norwood.



The Black People's Day of Action began as an organized protest march in March of 1981 to demonstrate against what was believed by the community to be a racist arson attack at a house party in New Cross that the police eventually ruled as an accidental fire. These memorials are erected in Fordham Park in New Cross.



Every year, in memory of those who lost their lives in the fire that day, the group marches from the Fordham Park in New Cross to the house where they died, before marching to the police station to stage a protest against the lack of a proper investigation of the tragedy. An Isis service user joined this particular march.



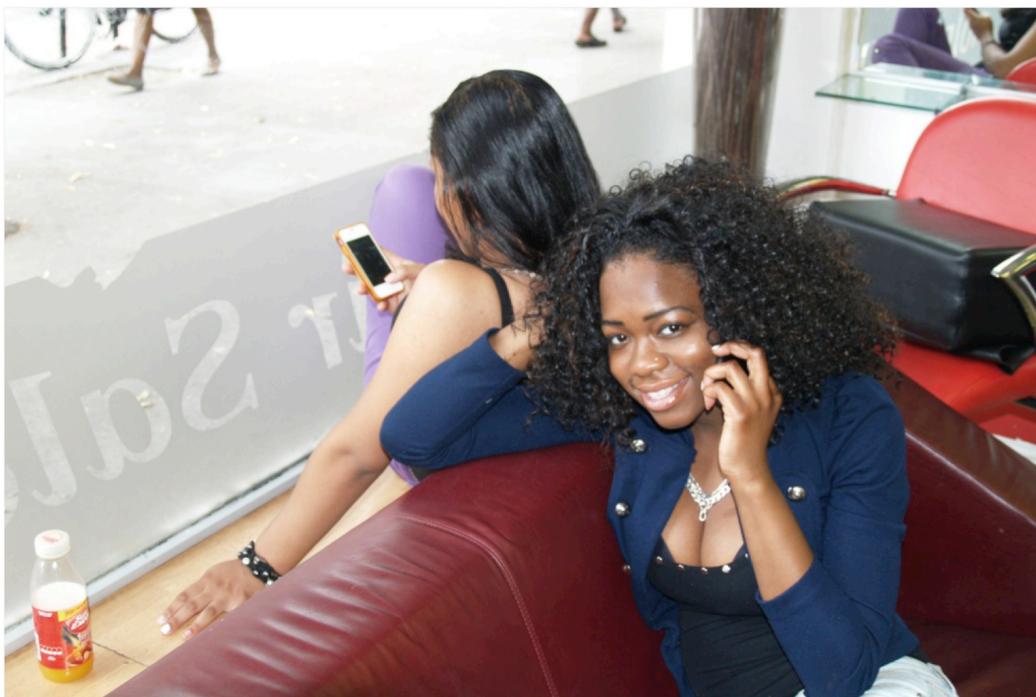
During my fieldwork, the London riots also occurred. One of the riot sites was Woolwich where my brother lives. These are photographs he took of the aftermath.



To provide context for the lives of Caribbean people in general, I decided to take photographs of sites of Caribbeanness in various places in London. This was a natural food store in Brixton.



This was a Caribbean food stall in Streatham, but could have been taken in any populous area of London where Caribbean food is sold commonly, and often by non-Caribbean shop owners.



In South Norwood where my parents live, there were also many black owned stores. I asked a few if it was okay for me to take pictures of them for my project. Quite a few readily agreed and were happy to support.







STARVIN	MARVIN'S	MENU
H. ROAST CHICKEN	BAKED CHICKEN	SALAD
CURRY CHICKEN	ESCOVITCH FISH	COLESLAW
FRIED CHICKEN	ALL WITH EITHER	
JERK CHICKEN	WHITE RICE	
OXTAIL	RICE + PEAS	
VEGETABLE STEW	HARD FOOD	
H. ROAST STEAK	PUMPKIN RICE	
PEPPER STEAK		
STEW PEAS		
STEAM + FRIED FISH		
CURRY GOAT		





Windrush Square is an open public space in Brixton completed in 2010 to commemorate the 50th anniversary of the arrival of the Windrush, the ship that carried 492 passengers from Jamaica to the UK in 1948, a major symbol of Caribbean migration. The Windrush Lights is a monument erected in the square.



OJI PROJECT TIMETABLE 2011

11.00am	Welcome Members/Sign in/Introductions Introduction to new members and Brief of Day/ and staff
11.30am	Films/Games/Activities/Music/Art Member participation in Games/activities with staff and other members or watch a film
12.30pm	Talks/Puzzles/Fitness/Dance/Art Members and Staff Social talks, complete puzzles in teams, Fitness Activities or dance Activities and art projects
1.30pm	LUNCH TIME
2.30pm	End Meeting Discuss about the next week and what members enjoyed about the day and what could be done better next week and weeks commencing



Isis Oji was a subsidiary Family Health Isis initiative, set up in Woolwich. It runs once a week on Mondays and is held in a shared community center. During my time volunteering with them, an effort was made to go on group trips. Photographed here is a trip to the National Maritime museum in Greenwich to see the black history exhibit.



These are photos of Oji members and staff on the outings, above to the National Maritime Museum and below to the cinema in the O2 Arena in Greenwich.



I accompanied the Family Health Isis members on their summer trip and took a number of photographs of service users and staff.













The dominoes were even brought to Bournemouth.



One of the Isis members brought a boombox to the beach which was played loudly throughout our time there. Here one of the members dances.



This was one of the many photographs these two friends asked to be taken of them. In the below picture they decide which photo they prefer.



The service user in the top photo is a member of the Men's Group who was in a cooking course and so would always bring cakes to the Men's Group meetings as a means of practicing recipes. Needless to say, he became very popular.





I took photographs of the Notting Hill Carnival of 2013, the premier Caribbean cultural event in London. It takes place annually and has done so since 1966. It is held in August and is one of the largest street festivals in the world. It has had a controversial history and has coincided with riots in the past.







In this particular photo, a steel band plays as they pass the Trellick Tower where the Oremi Centre is located.

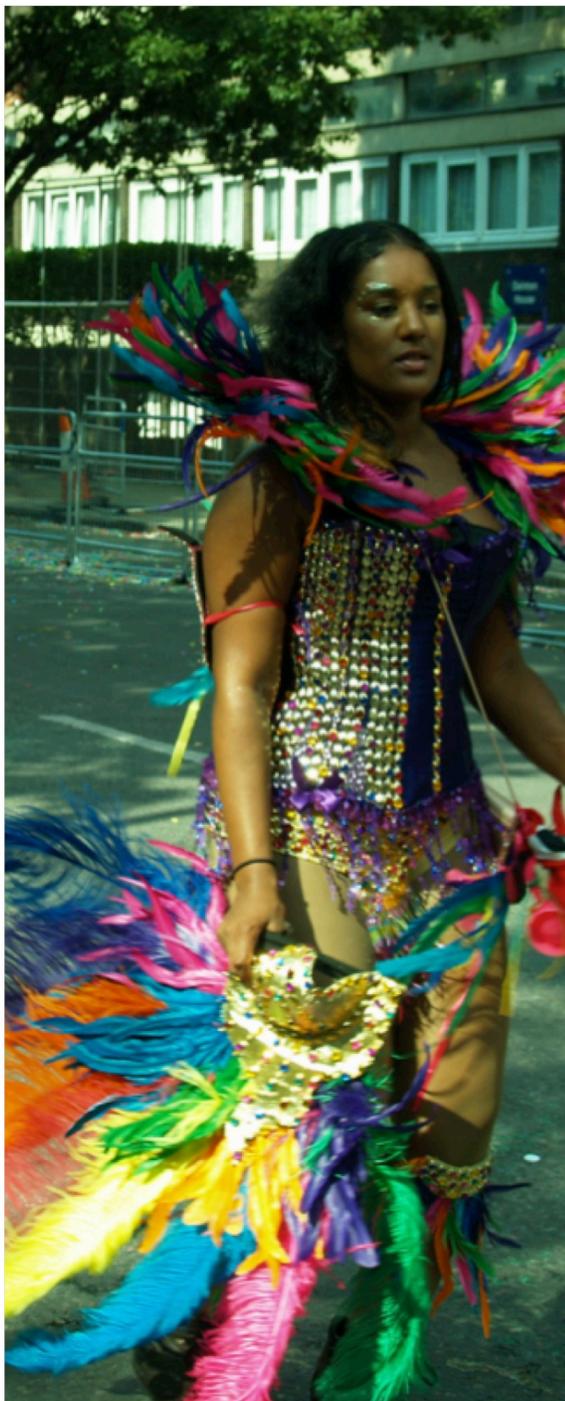




My cousin (not pictured) was a member of this particular band. She saw me as I was taking photographs and pulled me in to march along with them.







Chapter Seven: On Social Suffering, Identity and Resilience

Prologue

What a day when de pendulum swing.
What a day when de well run dry,
And the children ask you why,
And the people dem a bawl and Satan jus a call,
Is either you do or die.
I say de system,
De system,
De system is a fraud.
I say de system,
De system,
De system is a grave!

De System – Mutabaruka (1983)

Introduction

This chapter analyzes data derived from the service user and professionals' ethnographies, as well as the data taken from the Family Health Isis ethnography and the films produced in collaboration with the service users. The chapter is divided into three sections - social suffering, identity and resilience - exploring the broad themes that emerged from the data that support the claim that the current treatment provided under the mental health system in London re-traumatizes Caribbean service users. Using Kleinman's definition of social suffering, I explore the negative relationship between the mental health institution and service users, and the serious effects of medication, over-medication and misdiagnosis, and discuss the limitations and negative impacts of service users being defined by their diagnoses and medical histories.

I examine service users' own conceptions of illness and health, treatment and care, and how they see themselves versus how they believe they are perceived. The chapter highlights the finding that despite difficulties and struggles, and sometimes tragedy, there is a sense of resilience. This resilient space is often grounded in meaning created from surviving mental illness and is cultivated by the diligent work of mental health day centers that not only address mental health issues of service users, but also provide an environment within which service users can foster a self-affirming Caribbean identity within the London environment, reinforced by real and abstracted memories of the Caribbean.

On Social Suffering

Social Suffering Defined

Kleinman (2009a) defines social suffering as being of three types: structural violence, interpersonal experience, and suffering caused or intensified by bureaucratic indifference and the unintended consequences of bureaucratic action. This definition necessitates looking at mental illness as more than just pathology. Much in the same way that Gilman's (1995) definition of disease did not simply regard disease as a product of biology and instead incorporated broader cultural and historical frameworks in a social construct of illness, Kleinman (1996) argues that the reality of illness experience is such that it cannot be separated from "social levels of analysis, health from social problems, representation from experience, [and] suffering from intervention." Social suffering extends far beyond the pathological, and "normality, as well as disease, embodies social suffering" (Kleinman 2009b). Under this definition, social suffering as structural violence must consider suffering impacted by historical and socioeconomic processes and forces that constrain agency, like racism and poverty. Social suffering as interpersonally experienced must consider the illness experience and all that this means, both at the level of health and at the social level that is impacted by illness. Thirdly, social suffering as caused or intensified by bureaucratic

indifference and action must consider public policies and programs that, even whilst seeking to mitigate, have contributed to suffering (Kleinman, et al. 1996; Kleinman 2009a).

Social suffering as structurally violent

Of the processes that are relevant to social suffering for the Caribbean service user, migration is a particularly relevant force. Though the Dependency and World Systems theories of Gunder Frank (1967) and Wallerstein (1979) perspectives are useful for the Caribbean situation, their value is in what they bring to discussions on political economy and are relatively inadequate for discussions of cultural forces. Simmons and Guengant (1992) argue that the perspective that Caribbean migration to Britain was driven by 'market forces' is a perspective of the 'metropole' and one that complements older narratives of race and dependency. For migration to be meaningfully discussed in relationship to social suffering, cultural dynamics must be taken into consideration, and interpretative models such as that of the World Systems perspective must be reformulated to appreciate the complexity of international migration patterns of the Caribbean (Simmons & Guengant in Kritz, et al. 1992).

As Edward Scobie (1972) states in *Black Britannia*, "each immigrant from the Caribbean declares that he has come to the United Kingdom to better himself and then to return to the West Indies and help to build it up." Though there was an economic component to Caribbean migration to Britain and an economic motivation to create better lives for their families, migrants did more than move for work. They left children and spouses behind or uprooted families to bring with them. In speaking to some of the older subjects for my dissertation, many had migrated as children, accompanying or reuniting with parents or extended family. The story told by service user 'Mary' about not knowing her parents, who had left for England earlier, growing up with her uncle, preparing for school in Jamaica, to be suddenly whisked away to a completely new country

with little to no warning is not an uncommon one. She states:

[A]ll of a sudden [...] I had to come to England... This was the last place on earth that I would want to go. But in the end I came and when I first arrived, I didn't know my mom."

This kind of cultural confusion for some was outright anger for others. One of the member's of the Men's Group at Family Health Isis tells a story in "The Men's Group" film:

My chip on my shoulder is very heavy and it's them put it there, by taking me from Jamaica at age 14 ½ to come and clean up their dirty country. You see why I dislike them so much? For what they did to me. You see why I have to talk that way? They broke into my education and made me not get what I was supposed to get and made me can't go out and get a good trade because I didn't have the education... We were better off out there (in the Caribbean), when we had our workforce, which they took away from us and brought to foreign. When we had our workforce, we never needed nothing from them because we used to cultivate yam, cassava, anything you can name, because our farmers used to cultivate it. We had too much to eat in my young, growing up days. I only knew suffering when I came to England.

These stories support a theorization of migration as requiring more than just economic consideration, as do the issues brought up by Dr. Dawn Edge in her interview about the experiences of many Caribbean migrants in the UK that were characterized by discrimination, violence, and financial and employment difficulties:

There was a huge amount of shame around what happened to them when they came. They came with all the hopes of their families pinned on them and experienced "No Dogs, No

Blacks, No Irish" signs. They left [the Caribbean] as qualified nurses and came here as nursing auxiliaries, cleaning the toilets rather than dispensing medication. They left as teachers and then were lucky if they got secretarial jobs. Some of them actually cut off all ties with their families back home. People thought it was because they thought they were too good for the people back home. It's not that, some of them were too ashamed to admit to the families who had invested huge amounts, sometimes all their life savings to send them to the UK to make it on behalf of the family. When they got here and realized that all they could do, as a teacher, is sweep floors, they couldn't tell them.

The separation caused by migration was not only about being separated from families and from Caribbean culture, significantly it was also about the separation of the fantasy that the British life was imagined to be from the reality that it was. In the UK, Caribbean migrants were no longer nurses and teachers. They were also no longer British, no matter what the colonial upbringing had convinced them. There was a separation between the England as opportunity and England as reality, and this separation was most definitely a consequence of their status as a foreigner and the color of their skin. As Lamming stated, the reality of the Caribbean individual was that his or her being was “a cage which was to keep him imprisoned in a social and economic strait jacket, denying him equal rights with the host population” (Hinds 1966). This also agrees with the argument of Littlewood and Lipsedge (1997) that Caribbean people felt a sense of both anomie and alienation. This bears out in the words of Yvonne Coghill, who also introduces the effects that this has on different generations:

I remember my mother saying the streets are paved in gold and England is the mother country when I was younger; I remember it. Those belief systems started to break down and disappear and things were incredibly difficult for younger black people. Racism was rife in those days and black children were not doing as well in school for all sorts of

reasons, but not least because teachers... were not as supportive to black children as they could have been. So the kids became angry, they became disillusioned, they began to say this society has nothing for us.

These experiences give support to research findings such as that of Coid, et al. (2008) in their East London study that migration itself can be considered a risk factor for mental illness. They found that incidences of both affective and non-affective psychoses were higher for black and minority ethnic subgroups compared with white British individuals, with only black Caribbean second-generation individuals having a significantly greater risk compared with their first-generation counterparts. These findings support arguments that there are generational factors to consider in how social suffering is experienced. Similarly, the McKenzie et al. (2003) study hypothesized that decreased migratory coping skills was a risk factor suicide among younger African Caribbean individuals, proposing that older persons of Caribbean origin who decided to migrate to the UK may be better equipped to cope with the pressures of being a minority in the UK than their children are. Gunnell and Lewis (2005) argue a similar point that the disparity between the experiences of migrants and their children seems to be a significant factor. In his interview, social Anthropologist Barry Chevannes expressed the belief that older generations of Caribbean people in the UK had each other and memories of the Caribbean, grounded in reality and could turn to each other for support, being better equipped overall to cope with social suffering in the face of overt racism. This did not necessarily bear out in the ethnographic data since being a service user assumes already decreased coping skills. But day centers did seem to have an older membership in general, so it is possible to extrapolate from their higher proportional membership, that older generations of service users did a better job of providing peer support to each other and seeking support (or a better job was done in engaging them) than younger generations.

The theory that population density was a factor in the risk for social suffering also was supported by the interviews with service users. Studies found that ethnic minority groups were more likely to suffer from mental illness when they were a smaller proportion of the population in an area (Laveist 1996; Halpern 1993; Boydell, et al 2001). It was also theorized that younger people of Caribbean origin who were more likely to move away from their communities and into more diverse occupational and residential areas than older generations, were at a higher risk for mental illness as a consequence of the loss of community support and higher exposure/loss of protection from discrimination. ‘Mary’ alluded to this in talking about her move from one area of London to another:

In this area [Deptford] it's like the English people didn't want to know the blacks.

Battersea it was more open, you were in your own little area but at least you knew that it was open. But Deptford, it's a depressing area; it makes you depressed.

Similarly in the Men’s Group, ‘Mark’ states of living in London relative to the Caribbean where it would be more ethnically dense:

Basically what it is, we are in an unnatural environment. If you take a lion out of Africa and you put him into a zoo in London, naturally the lion will go mad. It does not have its friends, it cannot taste its own food, we are in an unnatural environment.

Mary and Mark’s words concur with Bhugra’s (2004) argument connecting ethnic density to ethnic identity and how that plays into an individual’s self-esteem and health. He argues that the globalization process with its “multiple belongings, multi-ethnic communities, long-distance networks and flexible identities” can cause a sense of alienation and increase the stress of vulnerable individuals (Bhugra 2004). For the affected African-Caribbean individuals, the

scattering of the population, altered cultural and social identity and low self-esteem may contribute to high rates of mental ill health, low and delayed recognition and poor outcomes.

Along with migration, racism has been another process considered significant to social suffering. In his critique of Hickling's Roast Breadfruit syndrome theory, McKenzie (1999) argues that racism is an attractive explanation for illness incidence. In his critique of the same, Oyebode (1999) states that appealing to race is colluding with an 'illusion' and is "an endorsement of the classification of human beings solely on the basis of skin color into distinct categories as if this feature spoke to something more fundamental or essential about human beings." But even as a social construct, race has meaning in the lives of service users, in establishing and making meaning of self-image and identity and in determining the experiences they have in the mental health system, and the society at large. When 'Mary' states that she felt hatred from the English children growing up, that they stoned her home and her family, set dogs on her family and called the police on her father accusing him of kicking a dog, the reasons she is discriminated against may be based on an illusionary perceived racial difference of her family, but the experiences are obviously not an illusion. Likewise, the conversation between Juliana Frederick and Frederica Joseph discussing race relations in the 1980s highlights that even as a social construct, race is meaningful because society has given it meaning and made it impact a vast array of social, cultural and political structures:

FREDERICK: We were angry about the lack of access to higher education. We were angry about unemployment. We were angry about poverty. We were angry about inequality. If you saw the housing and where we had to live, we were burning it down in '81, dear. We just decided we aren't doing it anymore. We burned it down. Those issues are still there but I don't think people are as conscious of them. [...]

JOSEPH: It was so blatant back in the days. It wasn't uncommon to walk into a store and see that little flyer on the wall saying 'no dogs, no Irish, no Wogs or blacks.' That was a common thing. Or being spat at in the face on the streets.

Race as constructed is much more than classification based solely on skin color. Race and class obviously intersect. White British individuals in poverty can and often do suffer poor health and socio-economic consequences in similar ways to those that affect individuals of color. But as the ethnographic data shows, though on the surface skin color is merely an easy physical marker for distinction, as a realized social construct it unduly impacts education, employment, housing, poverty, inequality and health. Sharpley, et al (2001) found that African-Caribbean patients frequently brought up racism as an issue. Chakraborty and McKenzie (2002) found a connection between racial discrimination and mental illness where racism (real and perceived) might be important to risk. The Fourth National Survey of (UK) Ethnic Minorities found that of 5196 persons of Caribbean, African, and Asian origin, those who had experienced verbal abuse were three times more likely to be suffering from depression or psychosis, those who had experienced a racist attack were nearly three times more likely to suffer from depression and five times more likely to suffer from psychosis, and those who said their employers were racist were 1.6 times more likely to suffer from a psychosis (Fourth National Survey of Ethnic Minorities 1997). This all tends to support Bhugra and Cochrane's (2001) notion that 'race' and racism affect individual experiences, and continued racial oppression might operate as a persistent stressor and an overtly racist act as an acute stressor that is superimposed upon this chronic stress. Thomas and Sillen (1979), argue similarly "the stress of racist discrimination has produced not merely an ineradicable mark but a deformity in the black man's psyche."

Race is a factor, but a factor connected to other social factors, all of which must be addressed to alleviate social suffering, certainly as it is defined by Kleinman. As Keating describes of his

clients:

When you look at how particularly black men come into the (mental health) system, they are more likely to be excluded from school, they are more likely to have contact with the criminal justice system, they are more likely to have been unemployed. If we are going to address this intractable situation, then all those sectors need to start talking to each other.

The problems that the African-Caribbean service users face are social, economic, political, as well as medical. Ignoring or misunderstanding this complexity and focusing solely on one factor will not be and has proven not to be effective. Keating states, “you can't just deal with it socially, you can't just throw money at it; you also have to change politically how you think about it and how we address it.”

Social suffering as interpersonally experienced

Gilman's (1988; 2008) articulation of mental illness as being intimately connected to broad social circumstances, when paired with Kleinman's articulation of social suffering, means that for social suffering as experienced through illness, larger cultural and historical contexts, as well as both the perception and the form of mental illness, must be taken into consideration. As previously stated, mental illness cannot be simply attributed as a product of biology, and social constructions of health operate to demarcate wellness and illness, and sanity and madness, by both permeating illness with a physical 'ugly' look and physically separating the ill from the well through hospitalization. The illness experience then includes suffering of health, suffering of social position, suffering of physical condition, loss of freedom, and at its most extreme, loss of life. Frederick made the point that she left a career working more directly with service users in the voluntary sector because she had become tired of attending funerals for her clients:

You just get to a point where you can't sing 'Rock of Ages' or 'Abide With Me' every whenever; it's not good for your insides.

She goes on to state that by being in contact with the mental health system, the quality of life of service users “has been completely and utterly undermined,” and that they have essentially been told that the rest of their lives would consist of “coming to [a] day center, drinking tea and smoking cigarettes forever.” She links a major aspect of this diminished quality of life to the effects of long-term medication. African Caribbean service users will be given two or three medications at maximum dosages for extended periods, thus making the effects of medication disproportionately negative for this community. She argues that, for those persons who have been on medication for an extended period, their bodies will eventually not be able to take it. This position concurs with that of Estella Weston, who argues that change has to come at the level of the GP, the site at which all primary care is decided, and that there has to be a better way to decide who truly requires medication and who would better benefit from alternative forms of treatment. She says:

If you talk to half the people downstairs (in Isis) they never needed psychotic medication. They needed talking therapy maybe, but they never needed psychotic medication. Once they got on it, they found it very difficult to get back off of it because it's a cocktail of drugs... Do you want the mental health problems or the diabetes? Do you want the high blood pressure or do you want bipolar? Your quality of life can be severely harmed if you are on medication... There's some horror stories I tell you.

‘Malik’ states in the SAfH focus group that the continued process of admission to hospital and overmedication, ultimately is killing service users:

There's nothing wrong with anybody. If you start believing what these doctors say about there being something wrong with you and you start taking the pills, you are gonna die... [Y]ou get overmedicated, you stop taking the medication, as soon as they find out they overmedicate you again, they put you in the system, start working you through again, and keep on doing this cycle to you, until you conform to what they want. When you don't conform, they say you are aggressive or intimidating and they give you depots and all this stuff, and all this stuff kills us.

Malik's statement brings into question diagnosis itself, rejecting that service users are ill at all and that instead they suffer at the hands of the mental health system. In the same conversation 'Edward' states "when you are in the system it is very hard to get out of the system," and the ability to leave it is wholly dependent on the clinician's authority. 'Wayne' described side effects of his prescribed medication as giving him blurred vision, shaking, terrors, muscle spasms and weight gain that the medical staff declined to review for three years. 'David' described wanting to be able to dream again as the reason why he wanted to be off the medication he had been on for 30 years. The most common through-line in the lives of all service users I interacted with was a diminished quality of life. Many lived in group homes. Poverty and unemployment was a major factor. Relationships with clinicians and other statutory healthcare professionals were strained. Side effects of psychiatric medicine were a constant problem. The desire to leave the system, in essence, to become well, not just as it relates to mental illness, but as 'George' in the Men's Group interviews states, to become "the man that [you] should be," is complicated by the constant requirement to be compliant to medication, by the side effects of the medication, and the consequent, relative inescapability of the medical system. 'Noel' states that he believes himself to be normal, but it is the medication that is "messing him up" and making him do things that the doctors consider to be symptomatic of illness. Despite this belief, he does not have the control to cease medication:

I tried to come off it but the doctor said he would keep me in hospital. It was terrible, man. When I was on medication it was like there was a drill in my head. I kept banging my head against the wall to get rid of it. It was terrible...

‘Noel’ described his 3 decades living as part of the mental health system as “hell”. ‘Clive’ in the Men’s Group interviews, spoke similarly:

The tablets I was taking, I will tell you how I feel, it’s poison. You see me walking? I can hardly walk properly. I can’t say that I am not going to take the tablet because if I don’t take the tablet, I cannot stay [in the living facility] where I am, so I have to take the tablet.

Again, Malik states:

All you get in hospital is a small amount of food, they pump you with so much medication, you’re swollen up, everybody thinks, oh you’re unwell, not knowing its the medication that makes you look like that, your stomach is small, you get ulcers, you get diabetes, like right now they told me I have a high chance of diabetes, high chance of stroke, high chance of heart attack, I was unhappy. I’ve been in the system for about 9, 10 years. It’s bullshit; it’s a bullshit system.

Malik’s ultimate solution to social suffering is to “leave the country.”

Social suffering as caused or intensified by bureaucracy

Suffering exacerbated by public policies and bureaucracy is where Caribbean service users most especially undergo adversity. Caribbean service users disproportionately enter into the mental

health system via the criminal justice system. Once in the mental health system, they disproportionately are diagnosed with the most severe diagnoses, which require the strongest medication, with the harshest side effects and require the longest-term adherence. This means they disproportionately stay in the system for long periods. This idea of being stuck in a cycle is similar to the point Phillips makes in discussing the evolution of diagnosis applied to black service users. He states that when he first began working in mental health in the 1980s, the common diagnosis given to the black community was ‘educationally sub-normal,’ and black children were disproportionately excluded from school. The black ‘problem’ then moved to a theory of ‘ganja psychosis’ which was then followed by a large rise in the diagnosis of schizophrenia for black people, which was followed by a period of focus on dual-diagnosis, and now more recently a refocusing on marijuana as being a root problem for mental illness in the black community. In line with this argument, ‘Wayne’ states “anything that they come into contact with they must put a label on it whether it's good or it's bad, they must put a label on.”

Evoking this sense held by members of the medical community of a black ‘problem,’ the Aesop (Aetiology and Ethnicity in Schizophrenia and other Psychoses) study carried out by the Institute of Psychiatry found members of the African Caribbean community are nine times more likely to suffer from schizophrenia than people in the white community, prompting them to classify it as an “epidemic” (Morgan, et al. 2006). The research concluded that the root causes lay in a range of social factors that lead to severe social isolation – people living alone, unemployment, and separation from parents due to family breakdowns in the African Caribbean community amounting to a kind of “sensory deprivation” – all of which have a dramatic effect on people with a tendency towards schizoid personalities.

The AESOP report brought a strong response from mental health campaigners, who argued that the study was fundamentally flawed because it used narrow interpretations of what diagnostic

categories represent and that use of the word 'epidemic' implied that black people's 'schizophrenia' may adversely affect others and was indicative of a "racist undertone." They argued that what should be studied is what causes differential rates of diagnosis, such that consistently for decades African-Caribbeans could be diagnosed with schizophrenia in such high numbers. They asked whether this is a true reflection of 'mental illness' incidence, or if factors such as the medicalization of social problems and institutional racism were responsible. Ferns, et al. (2010) argue that appearing to 'single out' groups and blame African-Caribbean culture is "a socially divisive wedge, and if 'social engineering' is being called for, it may be more effective to apply it to mental health services and service providers, not to communities."

Francis' (1993) argument for a connection between racialized social suffering and mental health treatment and policy makes sense in this context. He connects the development of psychiatry to a history of racialized theory and to a philosophy of social policing. Early racial theory of the noble savagery of black people and early psychiatric theory of equating black cultural behavior and nature to madness developed concurrently and synchronously. Francis' argument is that psychiatrists were foremost in the articulation of race along biological and cultural lines, and played a crucial role in the historical construction of race, racism and racial difference, where culture became "important to psychiatric diagnosis as part of the rubric of what is normal and what is pathological" (Francis 1993). Such an argument resonates with Gilman's argument that the power of the construct of disease cannot be separated from the power relationship between the diagnosis maker (the physician) and the diagnosed (the patient). Francis goes a step further to suggest that the negative construct has not only affected the psychiatrist, but psychiatry itself is complicit in the construction.

Francis further argues that along with being complicit in defining psychological and cultural norms, psychiatry also played a crucial role in policing what is 'normal' and 'abnormal' by

answering the political and economic need to preserve social order. His argument is that psychiatry was one response during industrialization to the perceived problem of anti-social delinquency within which mental illness was contained. The mental health system then became a major site of control. This position is supported by Littlewood and Lipsedge's (1997) statement that, "the modern psychiatrist is a descendant, not of the psychoanalyst, but of the nineteenth-century mental asylum keeper," and with Metzl's (2010) finding that psychosis had in effect been made a 'black disease' in the 1960s by mental health authorities changing the wording of the diagnostic symptoms to include "hostility" and "aggression." In addition, it fits with the current model of the National Health Service in the UK as it relates to the relationship between the powers that can decide on detention in hospital because of diagnosed mental illness (the consultant psychiatrist, the general practitioner and the police) and the service user. If as Littlewood suggests, the stereotype is that there is a big, black dangerous man, who the British citizens must be protected from, it is the policing power of the police and the medical system that is capable of "tak[ing] him away and lock[ing] him up."

This perceived attitude towards mental illness and specifically black mental illness, may go some way to explaining why black service users of Caribbean heritage are over-represented among those receiving psychiatric treatment in the UK (Lloyd 1998; Nazroo 1997; Bhui et al. 2002), with disproportionate numbers appearing in treatment statistics for psychosis and schizophrenia (Harrison, et al. 1989; Henderson, Thornicroft and Glover 1998). This is in contrast to underrepresentation in diagnoses or treatment for less severe disorders such as depression (Edge and Roberts 2005). The 'over-diagnosis' of psychoses and apparent 'under-diagnosis' of less acute disorders do seem to raise the possibility of factors that influence diagnosis or count against symptom recognition (Shaw et al. 1999; Paykel & Priest 1992). The juxtaposition of disproportionate numbers of Black Caribbeans at the coercive end of psychiatry and their 'under-representation' in primary care raises questions about how psychiatric practice, racism, or racial

stereotyping contributes to the appearance of Black Caribbeans within certain psychiatric categories and their absence from others (Spector 2001).

Francis (1993) argues that the “practice of detaining madness by force in custodial institutions” is most apparent in the deployment of psychiatry in the criminal justice system, where he states there is a “failure to provide genuine help to victims of mental disorder, revealed by the perfect congruence of criminal and legal diagnostics and in the similarity of hospitals to prisons.” The laws of detention, as defined and enforced by the medical system and the political state, are characterized by a psychiatric philosophy of containment, linked to a historical and societal culture of fear and stigma. If one looks again at the most criticized sections of the 1983 Mental Health Act, sections 2, 3 and 4 allow for forceful detention, on the authority of only a doctor or approved social worker, for 72 hours (section 2), assessment for 28 days (section 3) and for long-term treatment for up to 6 months (section 4). Section 136 sanctions the police to apprehend individuals found in a public place considered to be 'a danger to themselves or others' and to take them to hospital, thus allowing the police to interpret what is psychiatrically dangerous and thus “both to criminalize and to medicalize (Francis 1993). For black service users, in practice, this has resulted in excessive sectioning on wards and excessive apprehension by the police as ‘mentally ill’ under section 136, despite having similar rates of mental ill health as other ethnic groups, disproportionate diagnoses as schizophrenic, disproportionate admission as ‘offender patients,’ disproportionate transfers to locked wards and disproportionate referrals to psychiatrists by courts (Fernando 2003; BMH UK 2011).

The reality of this process is told by the SAfH focus group:

HENRY: Not only are we misdiagnosed, but most of us go through the system like me, through police, being sectioned you know.

ISAAC: Fear factor.

HENRY: Being nicked and you know, yea that's where it mostly started.

ISAAC: Fear factor and mind control.

WAYNE: And what it is too is it comes back down to bullying and intimidation by the professionals, because I can remember, it may be funny now, but when I was suffering from mental health issues, I went into the hospital ward as voluntary, you can go in where they assess, and because I saw how other mental health users on the ward were interacting I became a bit fearful and apprehensive because they were like dribbling, shaking, in zombie-like states and I said to the doctor "no I cant stay here, this assessment is taking too long." So he said to me, "either you take the medication and stay here for one month or we section you and you stay here for six months." So I said to him, "I'll take the medication" [laughter].

HENRY: We've all gone through it. The depot.

JAMES: Their options are only intimidation tactics. It's like you're a lamb led to the slaughter, you've got no say.

And as Estella Weston, director of Family Health Isis states:

You have a whole bunch of young black people growing up in the prison system. Half of them won't make it, they will either be diverted into the mental health system or they will be committing suicide. They won't live. So it's about what we do with them. You can see it's happening, but it's almost like people are saying "well just get them off the streets." The fact that a large proportion of our community is going to be incarcerated sets alarm bells off. Most people, they might as well stay in prison. Don't get deferred into the mental health system because I think that's worse than anything. At least you do your prison sentence and you are released, people in the mental health system they never get

out of it. It's always a noose around your neck.

Even in cases where efforts have been made to improve the relationship between the police and the public, as Sandra Griffiths, then Coordinator of the MELLOW Campaign stated in her interview, there is a sense that Police Community Support Officers (PCSOs), charged with the task of complementing and supporting regular police officers in the community are unsure of how to provide support to individuals who express mental health problems. Caroline Morris, as part of her role in the Cares of Life project, helped to set up a mental health promotion unit in 2000, to encourage early intervention and an assertive outreach approach. Workshops were set up for organizations like the police to educate about mental health. She found that the police were not the easiest group to work with, but that overall they were amenable and genuinely wanted to help. However, at the end of the project, despite it being deemed successful, further funding was not made available by the NHS to implement it more widely. Morris states:

At the end of the day the National Health Service is about dealing with people with mental health problems, so rather than prevention, it will go onto treatment. We are fighting quite hard at the moment to keep a prevention focus. I think it's going to be really difficult and I hope it survives.

What is evident from these ongoing debates and developments in public health and mental health policy is that there is a constant struggle to balance the 'safety' of the public with the alleviation of the suffering of service users that the policies affect. Frederick says as much:

People can't be honest with the services about what is going on with the people that they love because the services only know one way to respond... The Mental Health Act is supposed to be there to balance the care of the individual and the protection of society or

your community or your family. That is what it is there for. But I do not believe that anyone has ever really looked at that balance properly.

The Delivering Race Equality in Mental Healthcare programme (DRE) of 2005 was meant to address this imbalance, but was immediately criticized by mental health and race campaigners who argued that it did not go far enough to address the problem of racial discrimination in mental health services (Afiya Trust 2010). The critique proved to be accurate as the assessment of the final Count Me In census results following the end of the initiative in 2010 found that little progress had been made in reducing the mental health admission rate for BME service users over the 5-year period of the census. A comparatively high 23% of inpatients in mental health services in 2010 belonged to BME groups despite the efforts over the course of the census to reduce admissions. *Mind*, the leading mental health charity for England and Wales concluded, supported by the Care Quality Commission's own report, that there had been "no change in service delivery, with the rates of admission, detention under the Mental Health Act, and seclusion (three of the DRE's 12 goals) effectively unchanged." The admission rate for individuals categorized as 'Other Black' was still six times higher than average, and average detention rates remain higher than in all other groups. Compared to 2005, for White and Caribbean, White and Black African, Black Caribbean and Black African, detention rates were found to have increased. In his interview, Malcolm Phillips concluded:

The government just poured a lot of money into a piece of crap called 'Delivering Race Equality' for the last 5 years. It did nothing. It's own report said it had less than no impact. It had a negative impact. We are in a worse position. We have no substantial change. The stigma is just as bad. The fear of services is just as bad amongst BME communities.

The Mental Health Act of 2007's introduction of Community Treatment Order (CTO), giving health officials the power to enforce medication in the community also brought immediate criticism, with concern also expressed about the Bill's emphasis on perceived 'risk to the public' and 'dangerousness' as conditions for containment and how the determination of 'substantial risk of causing serious harm to other persons' would impact disproportionately on BME communities (HMSO 2007). Critics also opposed the new powers afforded to police that allowed them to enter and forcibly remove a patient from their home without a warrant. They argued that this power would follow historical precedent and likely be disproportionately used against African Caribbean communities who were already subject to over policing and further damage the relationship between BME communities and the police' (Black Mental Health UK 2010).

Dr. Kwame McKenzie argued a similar point:

Who will have one of these community treatment orders? Clearly people who are not ill enough to be in hospital, people who see things differently from their psychiatrist, people who have a different culture and belief on their treatment than their psychiatrist, people who are not satisfied with their treatment and want an alternative. Research shows us that people from minority groups in the system are more likely to fit this description. (Joint Committee on the Draft Mental Health Bill 2005).

Matilda MacAttram (2007), Director of Black Mental Health UK stated "every concern raised by black groups around the review of this law was sidelined by government officials and health ministers throughout the parliamentary process." She argued that the new legislation would in fact exacerbate inequalities in treatment and care for BME service users by extending the powers of forced detention, increasing the individuals with the power to detain and to medicate a patient against their will and increasing the avenues by which patients could be brought into the system.

Service user 'James' confirms as much:

They've got more powers now with this new community treatment order thing, whereas before they could only enforce if you were in the hospital under section. Once you are discharged, you are not under section; they didn't really have powers to force you to take medication. Now with this new community treatment order they can do this.

Dame Jo Williams, chair of the Care Quality Commission, as part of the Care Quality Commission's first annual report in 2010 on the use of the Mental Health Act, presented a detailed study of how community treatment orders (CTOs) had been working for the two years since their introduction. The study confirmed the fears of critics of the Act. The study showed a disproportionate number of patients from some black and minority ethnic groups placed on CTOs. On average, 367 CTOs had been made each month. This was at least 10 times the number anticipated at the time the legislation was introduced. CTOs did not appear to have reduced hospital-based detention or reduced so-called 'revolving door' patients, and in fact there was a rise in the number of detained patients. Of over 200 patients investigated, 30% did not have a history of non-compliance or disengagement, posing the question about the basis on which hospitals were making their judgments when applying CTOs. Williams argued that this suggested the institution of 'defensive' practices, with mental health services driven by concepts of risk rather than just treatment, with CTOs being the default discharge power for detained patients, rather than being only applied when needed. So notorious are CTOs now that they have become infamously referred to as 'Psychiatric ASBOs (Anti-social behavioral orders).'

The Health and Social Care Act (2012) radically changed the structure of the NHS and the mental health system, proposing to make it more patient-centered of the NHS and placing more power in the hands of GPs. Critics argue that despite the welcome "attention paid to taking a life course

approach to public health, the focus on social determinants of health inequalities, and the linkages made between health, wellbeing and mental health,” the fundamental concern is that “any public health strategy should be based on a moral and political commitment to social justice and human rights for racialized groups” (Afiya Trust 2010). McKenzie and Bhui (2007) argue that mental health services still have some way to go before they meet the challenges of the UK’s multicultural society. With research finding increasing and continuing evidence of ethnic differences in the treatment of mental illness, disparities reflect the way health services offer specific treatments and care pathways according to racial group, and thus support an argument for institutional racism, which they define as:

The collective failure of an organization to provide an appropriate and professional service to people because of their color, culture or ethnic origin. This can be seen or detected in processes, attitudes, and behavior that amount to discrimination through unwitting prejudice, ignorance, thoughtlessness, and racist stereotyping which disadvantages people in ethnic minority groups (The Stephen Lawrence inquiry, 1999).

In making this claim of institutional racism, they warn against snap responses that overstate the problem or seek a privileged ethical position. Institutional racism is about systems and not individual prejudice. They argue that research indicates that institutional discrimination does occur and that, until disparities and remedial action had been seen through this lens of institutional racism, no strategy existed for improving mental health services for black and minority ethnic groups. In order to be truly effective, efforts such as the Delivering Race Equality initiative require leadership that takes seriously issues such as disparities and must engage the criminal justice system, social services, and education, as well as mental health services to be effective.

Kleinman in his discussions on social suffering challenges anthropology to question the role of the state, that is “not primarily as the source of powerful control over the mentally ill and through them society at large, but rather [is] fragile, constrained, and almost powerless to provide the most basic care for its most impaired and vulnerable members” (Kleinman 2011). This certainly rings true with regard to the NHS, with ongoing efforts to improve conditions constrained by economics, flawed philosophies, politics, stubbornness and at its worst, institutional racism.

Service users’ belief that they are in a ‘system’ that is a ‘trap’ fits with the idea that the culture of mental health intervention is one where the nature of power is crucial. Francis’ argument that the authorization of state agencies to act in concert as a circuit of controlling social order infers a sinister intentionality to the use of this power, where blackness is seen as pathological and dangerous. Kleinman’s argument of a fragile and constrained state infers less a sinisterness and more of an impotence. The truth lies somewhere in between. It is undeniable that efforts have been made by state authorities to address ethnic minorities having long suffered discrimination and unfair treatment in mental health services. It is equally undeniable that this discrimination and unfair treatment is a fault of the state, not a problem created independently of it. The NHS itself, through a report from the National Institute for Health and Clinical Excellence (NICE), concluded that there was little evidence to indicate that mental health promotion among black and minority ethnic communities in the UK had been effective, and in 1998 the independent Bennett Inquiry concluded, “Mental Health Services within the UK are institutionally racist” (BMH UK 2011).

‘The System’ as service users and their advocates often refer to the unspecified power structure that, in many ways, defines their lives is a frequent target of denunciation and anger. It is easy to dismiss this as simplistic paranoia and misplaced rage towards a complex problem. Certainly ‘The System’ has been a common target for criticism by the Caribbean community as a whole as

an explanatory model for societal problems in politics and in popular culture, such as in the Mutabaruka poem in the prologue of this chapter. Often ‘The System’ might be referred to as ‘Babylon,’ a term popularized by the Rastafarian movement to refer to the state and institutions seen as being in opposition to righteousness, by practicing oppression and discrimination, especially against black peoples. Babylon has also become interchangeable with ‘Rome,’ another catchall term linked to history by the Italian invasion of Ethiopia in 1935, the role that the Pope and the Roman Catholic church played in opposing Ethiopia’s Haile Selassie I, who is considered the ‘living God’ in Rastafarianism. This is much like ‘The Man’ in American contexts.

But like ‘race,’ the social construct is grounded in real life experiences. Both ‘Edward’ and ‘Malik’ make corresponding statements about wanting to stop taking medication when they felt they were well, but not having the control or influence to make this a reality. They believed themselves to be well, and believed the medication to either be making them appear mentally unwell or to be creating other medical problems for them, but the consequence of failing to continue medication was being forcibly hospitalized and injected. Edward states:

Any mess up right now and I’m not at the surgery every two weeks, they’re sending police to my address and they are taking me back to the ward, then you’re getting injected. I know a person that didn’t pick up his prescription, in two twos the police are at his house; he went straight back on the ward. He was up there for six months, just because he didn’t pick up his prescription.

Like Francis, and like Littlewood and Lipsedge, Malik argues that this experience of forced and threatened medication is as much to do with social control, as it is to do with the treatment of illness. For him, the consequence is the reduction of the service user from perceived danger to “half the man they used to be.” They are made “soft” by medication so as to not appear

frightening or dangerous to the public, and often the clinical opinion that the service user is ‘aggressive’ or ‘intimidating’ precedes decisions about diagnosis and treatment. This stereotype of black and mentally ill dangerousness plays a role in determining why section 136 is so heavily executed in the in the black community and is intimately connected to disproportionate accusations of criminality in that community. This of course speaks to the problematic power dynamic between the state authorities and the service user. Pinder argues in his interview that the clinician almost inherently is in a privileged position of prestige because of the respect and reverence given to health professionals. When this is combined with the power afford to them by law, when in tribunals and mental health reviews, service users often require advocates to speak on their behalf because even the most vocal ones do not feel able to advocate for themselves:

The power dynamics needs to shift. You can help some people with cultural competency, but it is a power dynamic between psychiatrists, community psychiatric nurses and patients that needs to change. They might say that now the service user is allowed to express themselves but at the end of the day the psychiatrist, even when you know the medication is to your detriment, can still force you to take that medication.

This problem of power, relatively unchallengeable and often traumatizing from the service user’s perspective points to the reality of there being a ‘System.’ As Ferns, et al. (2010) states, what needs to be investigated is not the service users, but the mental health services and providers. It can be argued, that any potential paranoia is not from the service users who have been subject to systematic and sustained social suffering, but from ‘The System.’ It is ‘The System’ that enforces laws of containment based on problematic diagnoses that have a history linked to cultural stereotyping. It is ‘The System’ that looks to place the ‘fault’ for the problems service users face at their own feet. It is ‘The System’ that has been found to be institutionally racist.

Initiatives like the David Bennett inquiry, the DRE and the Health and Social Care Act show an effort to improve mental health services for African Caribbean and other BME service users. But as Yvonne Coghill points out, “the people who are in positions of power and authority are so far removed from the Peckham estate or single parent mothers living in tower blocks” that they do not have an appreciation or an experience of that reality and the realities of the service users that the policies they enact affect. Coghill states that what is required is a desire for these powers to take the opinions and ideas of the BME community seriously, but they do not see the need to do so, arguing that they aim to commission services for all people, regardless of ethnicity. In contrast, Coghill argues that they are missing the point that “everybody is different and you actually have to commission sensitively in order for there to be a good outcome for everybody.” Professor Tom Craig makes the point that progress in improving services is “slow and recursive”:

There is now a genuine effort to increase cultural awareness and sensitivity in treatment services. I'm not saying it's very good, but it's definitely there as something that we all know we should be doing. There is a long way to go but it's definitely there in a way that before it just wasn't. I think the message is clear that we need to do things differently; I think that is accepted.

However, he states that steps forward are followed by steps backward, and mental healthcare practice wavers between a negative philosophy that “mental illness is a damaging, degenerative process” and a philosophy of trying to promote early intervention to prevent longer-term deterioration. Weston and Phillips both of whom as directors of mental health advocacy centers have a perspective from the frontline on what seems to work for service users, confirm this occurrence. Weston states when Family Health Isis had an Assertive Outreach team, they were able to visit and provide care to service users who might find it difficult to leave their homes. Now that assertive outreach teams have been discontinued or integrated into continued care

teams, there is no longer a specialist team in the borough that is working with this predominantly African and African-Caribbean group. She argues:

People still don't understand them, yet they set up all the structures to embrace equality. How can you have all the things that they reckon are empowering people, but in the next breath the structures that they need to get the support are not there?

Phillips argues that the government effectively has done very little except make “made a form and added more categories” in a hollow attempt to be inclusive. In the last 10-15 years, he sees the government having made far less effort to do anything for the black community:

I used to chair the national network of African and Caribbean mental health services and back then in the late '90s, there were 350 organizations around Britain and 42 in London. There are probably now less than 40 around the country. They have all had their funding cut; they have disappeared. Whereas before when black people were at their worst they could go [somewhere] where they would be understood, what they have to do now is go and explain themselves in a European way, in a European setting, at a time when they are least capable of doing that. They have to try and fit in and they find that they don't fit in. So they try to cure themselves. They either self medicate, they hit the bottle or drugs, they harm themselves or they steer away from the hospital until they are picked up on the street.

Dawn Edge makes a similar point about the issue of African Caribbean service users fitting unnaturally into European models of health. She states that the language of the mental health system is “quite Eurocentric” and doesn’t necessarily reflect the conceptions of health that African-Caribbean service users hold, even when it is recognized that something may be wrong.

She further argues that the acceptance of ‘European’ labels may actually undermine coping for this community:

We don't necessarily conceptualize what we feel as something medical or pathological, but we know it's not right. So if I feel down, I feel low, I feel flat, I wouldn't say its depression, but if that's the only word to describe it, do I really want to take that to myself? Taking that label [might] actually run counter to the very concepts that I'm using to stay alive, to survive in society. So if part of what keeps me going, against all the odds, is seeing myself as a strong black woman, if I start to say I am depressed, and depression and strength are not easy bedfellows, how do I reconcile that?

On Identity

The Identity Narrative

Though there is not a single migration narrative that encompasses all Caribbean migrants, there does seem to be a familiar pattern that applies to many, as it relates to the migration story. In the colonial Caribbean, Britain held a certain symbolic position. British influences dictated the education, politics, careers and economy of the Caribbean. For many ‘Mother England’ was a reality or at the very least, England represented a means of creating a better life for themselves and their families. So many travelled to England, anticipating as warm a welcome as was the invitation they received to come and supplement the labor shortage. This welcome wore thin rapidly as bitterness increased over jobs being lost to migrants, racism and xenophobia raged, and migrants realized that the dream they hoped to realize looked uncertain to come true. British society turned against them, and eventually British law would turn against them too. People were made to feel like aliens and duly they felt alienated. The children of these ‘aliens’ often felt confused as to where they stood in British society. By birth they belonged, in reality they didn't;

like their parents, they felt alienated. Much like Littlewood and Lipsedge's concept of the alien and Gilman's concept of the diseased, Sara Ahmed (2000), uses the figure of the 'stranger' in her discussion on migration and hybridity in transnationalism. She argues that strangers are not people you do not know or fail to recognize, but rather are those who are already recognized as a result of not belonging. The stranger, like the alien and the diseased is positioned to confirm who the 'normal' are, and the recognition of stranger is thereby linked to patterns of social exclusion. The stranger is not 'any-body' that we have failed to recognize, but 'some-body' that we have already recognized as a stranger, as a "body out of place" (Ahmed 2000)

As Mirza (1997) states, being 'black' in Britain is about "a state of 'becoming'; a process of consciousness, when colour becomes the defining factor about who you are... Living submerged in whiteness, physical difference becomes a defining issue, a signifier, a mark of whether or not you belong. Thus to be black in Britain is to share a common structural location; a racial location." These complex social and cultural concerns extend far past considerations of political economy, and the Dependency and World Systems theories are both clearly incomplete, and lack the articulation of "theories of culture, social organization, and identity for global and transnational persons and communities" (Kearney 1995). As such, a transnationalism perspective is a better fit for the Caribbean migrant experience in the UK. Through this transnationalism perspective, we can start to examine the issue of how to maintain a sense of 'home' in two nations that one is constantly in contact with but have a difficult time situating one's self in. For the migrant having moved from the colonial Caribbean to Britain, home was supposed to extend across the north Atlantic from the West Indian islands to the British Isles. For the later generations home was supposed to be Britain, but 'Home' also was an almost mythical place that they heard their parents speak of in reference to the Caribbean. The transnational perspective dictates that migration in this way was never about permanent physical rupture and uprootedness, despite the complexity of the sense of home creating a sense of uprootedness, rather these

transmigrants develop and maintain multiple familial, economic, social, organizational, religious and political relations that span borders. For the transmigrant, for the Caribbean migrant to the UK, life is a “complex existence that forces them to confront, draw upon, and rework different identity constructs – national, ethnic and racial” (Glick Schiller, et al. 1992).

Media and Identity

In attempting to construct this identity, while trying to locate this home, Caribbean migrants have, and continue to face, representations of their identity from outside forces that not only may counter their own constructions, but are given more authority than their own constructions. Popular media has perpetrated much of this negative outside construction, both as it relates to images of mental illness and images of Caribbean ‘blackness.’ There is a well-established stereotype of the black psychiatric patient as volatile and dangerous (Lipsedge 1994). As Littlewood stated in his interview:

The media is just about safety. The popular stereotype is that of a big, black dangerous man, we must protect our citizens against him, so take him away and lock him up.

In September of 2003, Frank Bruno, former world heavyweight boxing champion was sectioned under the Mental Health Act 1983, and admitted to a mental health unit in Essex, said to be suffering from depression after the breakup of his marriage. ‘The Sun’ newspaper ran an early edition headline titled “Bonkers Bruno Locked Up,” above a story that labeled him a “nut.” The story prompted public outrage and condemnation from mental health charities, such as SANE and MIND. Marjorie Wallace, the chief executive of SANE, claimed it revealed the “worst kind of ignorance” towards persons with mental health problems and that The Sun’s stance was an “insult” to Bruno and to others suffering from mental illness and that such “ignorant reporting

does both the media and the public a huge disservice" (The Guardian 2003). The Sun was forced to change the article and the second edition headline read 'Sad Bruno in Mental Health Home,' with the accompanying story labeling him a "hero."

Though there was a positive outcome from the incident, there is an argument that negative labeling, and its stigma, is more readily attributed to mental illness in the black community, rather than in the white community. Juliana Frederick remarked that black celebrity mental health issues, such as Bruno's, are demonized, whilst this is not the case for white celebrities, such as actor and presenter Stephen Fry, whose admission of bipolar disorder has been largely met with praise and positivity. I have no evidence to suggest that this assertion is true, though evidence does support there being a dominance of negative stories on mental health in general and a long history of negative stories on black people. During my fieldwork in November 2011, I was invited to participate in a focus group for Healthtalkonline, a health resource website that provides information on a variety of health conditions, who were looking for opinions on the effectiveness of their website and how to increase BME visitors to the site. One of the major criticisms that came up at the focus group was the lack of BME images on the site itself and the question was raised that if BME users could not see themselves or hear themselves on the site, why would they feel welcome to participate. This is not meant to serve as definitive evidence of a lack of positive mental health stories for black service users, but it does continue to raise the question about the lack of black voices.

The prevalence of stigma was certainly supported by the words of Caroline Morris, who in her role as Mental Health Promotion Coordinator at the Cares of Life Project, found that many of the students they were training held stigmatized views of the service users they were supposed to be helping:

We found at the local college [in Lambeth] people were saying [of persons with mental illness], “oh well, people are violent and people are intellectually impaired, people are quite smelly,” one thing or another. There were awful discriminatory practices out there... There are lots of myths and the media has portrayed all this false information.

Supporting the evidence found by McCracken, et al. (2008) that indicated that participants from African Caribbean backgrounds were often highly critical of mainstream media and had a more politicized understanding of mental health issues, ‘Henry’ and ‘Wayne’ in the SAfH focus group session brought up the issue of stigma and the hypocrisy of politicians who extol the values of multiculturalism while not truly endorsing equality:

HENRY: What's still in the UK though is the issue of stereotyping the BME community, in mental health services especially. They always talk about London is multicultural or England is multicultural but it's only when elections are coming they will take that race issue and bring it up to the front, these politicians...

WAYNE: What it is too again, why I think people are having more mental health issues because they are being painted a picture, including now with what we have seen with the London riots, people are seeing for themselves now what the real picture is... They are seeing it for themselves, the true picture and they can't handle it. The government is saying you should do this and you should do that and they are not doing it themselves. People are seeing the broader, clearer picture of what society and what the government is now and it is blowing their brains.

The notion of the ‘big, black dangerous man,’ with the danger being both connected to race and mental health has endured historically in Britain. This unquestionably corresponds with Cottle’s (2000) analysis that from reports on so-called ‘race riots’ in the late 1950s, to public health scares

in the 1960s, to the ‘moral panic’ orchestrated around ‘mugging’ and portrayals of street violence and inner city disorder in the 1970s and 1980s, there has been a connected history of media misrepresentation and sensationalism as it relates to race and how race relates to political issues such as crime, migration and health. Stock stereotypes used in the media of black people as ‘trouble-makers’, ‘entertainers’ and ‘dependents’ did effectively make black youth a new ‘folk devil’ (Hall et al. 1978). The dark stained and deadly ‘savage’ described in the 16th century, the ‘warlike and unmerciful Negro beast’ described in the 18th century, the ‘bonkers’ trouble-making folk-devil of the 20th century, and David Starkey’s ‘black, violent, destructive, nihilistic gangster’ of the 21st century are the same perception, the same person. It is an unchecked, proliferated image that has seduced the ‘viewer’ into seeing it as ‘real’ in the absence of alternative, countering images.

One of the most enduring images speaking to black presence in Britain and politics, was the 1983 Conservative Party election campaign poster (see next page) of a smartly dressed black man with the slogan “Labor says he's black, we say he's British.” In the 1980s, the Conservative Party sought to reinvigorate a cultural agenda in Britain focused on the recreation of a sense of bounded community and British nationalism, structuring a nation around a "unified and unitary British national culture" (Mason 2000; Kirton 2000). Ethnic minority groups who were encouraged to adopt assimilationist 'British' over multicultural 'ethnic' identities, ridiculing the more multi-identity and multi-cultural approach of the Labor Party in the 1980s as the 'loony left' (BBC 2004). Kirton (2000) argues that the “virtues of color blindness were contrasted to the divisiveness of racial identities.” As the election poster suggested, Conservative color blindness meant British and loony left divisive multiracialism meant Black. The emphasis on (white) British culture allied to sociobiological ideas of a ‘natural preference for one’s own kind’ led some to talk of a ‘new racism’ (Barker 1981; Kirton 2000). Ultimately, the image also spoke to identity.



With the Conservatives, there are no 'blacks,' no 'whites,' just people.

Conservatives believe that treating minorities as equals encourages the majority to treat them as equals.

Yet the Labour Party aim to treat you as a 'special case,' as a group all on your own.

Is setting you apart from the rest of society a sensible way to overcome racial prejudice and social inequality?

The question is, should we really divide the British people instead of uniting them?

WHOSE PROMISES ARE YOU TO BELIEVE?

When Labour were in government, they promised to repeal Immigration Acts passed in 1962 and 1971. Both promises were broken.

This time, they are promising to throw out the British Nationality Act, which gives full and equal citizenship to everyone permanently settled in Britain.

But how do the Conservatives' promises compare?

We said that we'd abolish the 'SUS' law.

We kept our promise.

We said we'd recruit more coloured policemen, get the police back into the community, and train them for a better understanding of your needs.

We kept our promise.

PUTTING THE ECONOMY BACK ON ITS FEET.

The Conservatives have always said that the only long term answer to our economic problems was to conquer inflation.

Inflation is now lower than it's been for over a decade, keeping all prices stable, with the price of food now hardly rising at all.

Meanwhile, many businesses throughout Britain are recovering, leading to thousands of new jobs.

Firstly, in our traditional industries, but just as importantly in new technology areas such as micro-electronics.

In other words, the medicine is working.

Yet Labour want to change everything, and put us back to square one.

They intend to increase taxation. They intend to increase the National Debt.

They promise import and export controls.

Cast your mind back to the last Labour government. Labour's methods didn't work then.

They won't work now.

A BETTER BRITAIN FOR ALL OF US.

The Conservatives believe that everyone wants to work hard and be rewarded for it.

Those rewards will only come about by creating a mood of equal opportunity for everyone in Britain, regardless of their race, creed or colour.

The difference you're voting for is this:

To the Labour Party, you're a black person.

To the Conservatives, you're a British Citizen.

Vote Conservative, and you vote for a more equal, more prosperous Britain.

**LABOUR SAYS HE'S BLACK.
TORIES SAY HE'S BRITISH.**

CONSERVATIVE

Image of the 1983 Conservative Party election campaign poster.

It has been shown how the power of media provides society with ways to see, interpret and shape the social and political world; but media also shapes the inner world of the individual. The 2007 REACH report identified that negative media stereotypes and a lack of positive role models were contributing factors to the educational and professional underachievement of young black men and boys, suggesting that a negative public and self-image, fuelled by the media, is likely to impact upon the aspirations and achievement levels of black young men and boys. Similarly, in the United States in 2011, the Opportunity Agenda report found that distorted patterns of portrayal in the mass media, such as overall underrepresentation, exaggerated negative associations, limited positive associations, over-association with intractable problems, and the absence of contextual and historical dimensions to stories, shaped, recreated and reinforced popular negative ideas, attitudes and public perceptions about black males and created barriers to advancement, but also made that position seem natural or inevitable. Ultimately, these media representations had a negative impact on black perceptions of self, demoralizing and reducing self-esteem and expectations.

Revisiting Mullard's (1973) words, "a black man born in Britain is a shadow of a man. A form, but no identity, because you are black." In the British context, negative self-image is intimately connected to a sense of belonging, not just in terms of fitting in, but also more broadly in terms of nationhood. The alienation is connected to being made an alien. As has been seen, the legal racialization of immigration, fueled by negative public opinion, ushered in the Immigration Act and Rules of 1971 and 1973, and the Nationality Act of 1981, that restricted and redefined the criteria for British citizenship. This supports the position that in the Diaspora, "a Caribbean identity usually implies a crisis of belonging" (McGill 2005). The complexity of this crisis is summed up in the 1983 election poster. In a single image, the black man is both given the 'respect' of a suit, while popular imagery of the time would have him be thought of as less than a gentleman. He is given British citizenship, while being stripped of being Black. His entry into this

Britishness is contingent on his voting for the Conservative party. He is told that the problem is that they are being given special treatment and instead in order for the majority to view him as equal, he, the minority, must be treated as equal. A unified Britain is a Britain that does not see race. He is promised that if he works hard, he will be rewarded for it, yet he need only cast his mind back a couple of decades to remember the promise of a better life for working in Britain and the failure for that to be rewarded. Ominously, he is told in the poster, “the medicine is working.” The poster tells the black population that to belong they must no longer be black.

(Re)defining Black Identity

This impossible escape from blackness is eerily similar to the dysmorphic pathology and psychological maladaptation spoken about by Malcolm Phillips and Juliana Frederick in their interviews. Phillips speaks of working with five or six persons who had painted themselves white or who had bleached their skin with actual bleach to try and lighten it because they believed themselves to be ugly and wished to assimilate. He also speaks of the difficulty of young people who have been brought up in care in areas not densely populated by African-Caribbeans, being moved once they become adults and struggling to fit in. Phillips says:

Often you have [youth] out in group homes in nice country areas in the surrounds of London. When they turn 18 they consider them adults and move them out. Between 18 and 21 they have Independent Support Teams, who move them into their own flats and support them to get on with life. There is a very high rate of suicide among black kids at that stage; we get a lot of referrals from the Independent Support Teams because one of the things they do is they say, "he's black, he needs to be where his people are." One of the first referrals I had, she was black so they found her a flat in Shepherds Bush. She

was terrified of black people and within months she had attempted suicide because she was confronted with her otherness, from both sides.

Frederick speaks similarly of the increasing number of mixed race or dual heritage persons who end up in the mental health, but are not given an avenue to embrace their black heritage:

The ones I have come into contact with are predominantly from broken homes and those young people were brought up in care. Often the ones I met were sent away to places like Kent, to places with white families and so part of their heritage was denied. But when they get to a certain age people do not look at them as the cute young child, they become more problematic because of how people see them, as that culture that people were trying to tell them wasn't there. [When they get to a certain age, services place them in places like] Hackney (an area with a large African-Caribbean population). They have no link to the place; they do not know what is going on, they are confused. It's not good. The assumption is that [the strategy is good] because a lot of the local authorities were pursuing some cultural background type policies. So it's like people are trying to do the best thing for them without really knowing or understanding what that child needs.

This generational complexity complicates Pinder's argument of social maladaptation where the supposed inherent nature of the black community is opposite to a Western model of independence. His argument that Caribbean people adopting Western ideals, living in relative isolation, away from "the hub and the safety net" that is the Caribbean community leading to young people especially not knowing where they belong and being confused about their identity is relevant. But what the anecdotes of Phillips and Frederick highlight is that culture cannot simply be reduced to race, and culturally specific problems cannot simply be solved by just immersing individuals in superficially culturally appropriate community settings. However, what

these anecdotes also show is that the desire for acceptance, accompanied by feelings of shame about one's ethnic culture, for susceptible individuals, very obviously have led to pathological behavior. Trying not to be black does not seem to be the solution for a sense of not belonging. On the contrary, embracing blackness or Caribbeanness (as opposed to having it thrust upon them) seems to have had some positive impact on self-image and identity, though this may not have necessarily been beneficial to being accepted as British. This mirrors the argument of Littlewood and Lipsedge (1997) of 'ethnic redefinition' where there is "a reassertion of the values of a disadvantaged or stigmatized group" providing a secure identity in the face of continual invalidation. Rather than reject blackness in the face of extreme racial oppression, many embraced it in a redefined fashion, even though the argument then is that it is still an identity conceived from the perspective of the dominant culture. What seems to be the case, however, is that it is a resilient identity, rather than a pathological one. Pinder states in his interview, "when people are feeling unwell and in a bad place, the default setting for most of us is our culture. That's why it is a good starting place to help somebody start rebuilding themselves, by recognizing the role that culture has played in keeping them well up to that point." This sense of blackness and Caribbeanness is embraced, asserted and defined in different ways. For Frederick and Joseph, it was expressed through the music one listened to:

FREDERICK: When we were younger we listened to certain music, white people listened to their certain music. There were different groups within the groups even. There was 'Reggae Heads,' there was 'Soul Heads'. The Soul Heads wore the trousers slightly too short with the white socks and the strange shoes and the Reggae Heads all kind of headed roughly towards Rastafarianism.

JOSEPH: And everyone talked like a Jamaican.

For the service user 'Noel,' it was through religion:

I joined the Ethiopian World Federation because I don't like what the Twelve Tribes do. It's a black organization. I didn't like seeing my enemy because everything I went through was not caused by my people, it was caused by my enemy, so I call them my enemy.

For the service user 'David,' it was through biology:

As a Jamaican, I don't let people tell me or try to show me that I am in any way inferior. In fact, I believe as someone of Maroon blood I am superior to other people. I know it sounds a little like something from blonde haired, blue-eyed Hitler recruits, but I think it's in us, I honestly believe this! For example, when Adolf Hitler was sat at the Olympics Games, it was Jesse Owens, a black man, who God put in his sight to show him you think you people are superior, but here is superiority and he proved it.

Because redefinition cannot be separated from the conceptions of the dominant culture, often the latitude by which one can define one's self is restricted and in some cases controlled. Frederick states that she has seen cases where medical staff asserts ethnicity on the behalf of a service user, without their consent:

Sometimes that box that needs to be ticked for ethnicity, sometimes the staff tick it. They don't even ask you because they don't understand the relevance of asking you about it.

She argues though, that even if you are able to make that choice yourself, from the options provided making that choice may be meaningless. Her point that given the size and diversity of Africa, that declaring yourself black African is essentially meaningless is a valid and powerful one. But even then, categories such as 'black African' are seen as an improvement over more limited ethnic categories. She suggests that rather than ethnicity, religion might be a more useful

starting point for classification purposes. But as Dr. Sean Cross states in his interview, service providers and policy makers wish to classify people and these categories evolve mostly in response to political discourse over identity. So although the Office of National Statistics might stipulate something as inelegant as “Black-slash-Black-British-dot-African-Caribbean,” this is seen as positively responding to the wants of the community and the needs of the local authorities. Cross’ proposal is that this “basic, interviewer ascribed ethnicity” be replaced by a subjective described ethnicity, where people label themselves. This has resulted in a model that has 69 options, many of which are nationality based.

In speaking to even the professional subjects, there was a sense of struggle in nailing down identity. Malcolm Phillips argues that these issues of identity, for the most vulnerable, cause psychological difficulties. In his own experience growing up, despite being born and brought up in England, ‘Home’ was still the Caribbean, despite it being somewhere he had never been and was essentially a “fantasy” to him. But he felt this way because he was “weighed down by being in a culture and an atmosphere of oppression.” When he did finally start traveling to St. Kitts in his late teens where his parents were from, eventually it dawned on him how fundamentally different he was as a person in St. Kitts as opposed to London, where he says the microaggressions wore him down like “a wet heavy overcoat all the time.” Jan Oliver, rejected ‘black’ as being meaningful to her and saw herself as being “British, African, Caribbean because that’s what makes me up,” remarking that she liked the fact that I, who also was born in Britain, had been taken back to the Caribbean by my parents to be educated because she felt it gave me “a whole experience” of identity. Yvonne Coghill, who came to England from Guyana as a 5 year old, considered herself Guyanese first, then African-Caribbean, then British. For both Coghill and Oliver, their identities were a stacked amalgamation of nationalities. When Coghill spoke of her children, there was a long pause before she decided that they were English, which she then adjusted to Black English, then finally Black British. Phillips too speaks of the identity claims of

his own children, who say they are British or English, which he finds hard to accept because that would have been akin to saying a “bad word” when he was growing up. But like Oliver, Coghill believed that all that was necessary to reconnect with the Caribbeanness in their heritage was being immersed in a Caribbean environment. She states, “a friend of mine took her children back and they stayed a year and they came back and in one year, they were not English anymore.” She herself stated that she goes back to the West Indies often because she feels most comfortable there:

You get off the plane and you are with people like yourself. You don't have to worry. You can walk into any shop, any bar, anywhere and feel comfortable about being who you are. Whereas here, that is never quite the case. Even though I am relatively well accepted amongst the circle that I move with, there is always in the back of your mind that you are different from the host population.

This again speaks to a sense of not truly belonging. Coghill speaks about the stress that this causes, and that when you are rejected by society, have nowhere to go, not being West Indian or being British either, being in that “no man's land” is a “horrible place to be.” This is the context for the drive by black Caribbean people in the UK to create self-ascribed categories that makes sense to their experiences.

The argument might be made that this self-categorization is no more elegant than the ONS categories, but if the limited categories do not provide any meaningful information for service providers, as Frederick and Cross suggest, alternatives have to be found. Certainly there needs to be a continuing evolution of such categories, as new ethnicities develop. Phillips speaks of Moroccan, Irish and Asian youth in London, speaking in a pseudo-Jamaican accent, in a kind of homogenous West London pseudo-Caribbean way that separates them from their family, but this

identity to them is 'British.' In many ways, the situation of identity has come full circle. The initial migrant population believed they were British and were rejected. The next generation rejected Britishness and the latest generation again claims Britishness is a redefined way, but are too rejected as not being British, and instead regarded as speaking in a "Jamaican patois that has been intruded in England" and that has made the 'real' British feel they are in a foreign country (Newsnight 2011). Starkey's words here, after the 2011 riots, echo Enoch Powell's (1968) suggestion that eventually the black man would have the 'whip hand' over the white man.

As previously stated, service users' definitions of self are often at odds with the more authoritative outside representation of who they are. Gilman's argument that fear is projected onto the creation of representations of disease as a maligned 'other,' that is further complicated when infused with the implications of "race" as a social and medical category, means that a conflation of the otherness of illness and the otherness of blackness makes for a powerful negating and alienating force. This alienation can force redefinition and reassertion of identity for the outsider group. This has been the case for ethnicity, but sometimes it is also the case for illness. 'Malik' states it most explicitly:

There's nothing wrong with anybody. If you start believing what these doctors say about there being something wrong with you and you start taking the pills, you are gonna die...[T]he doctor said to me, do you see things, can you hear things, do people interfere with your thoughts and some other rubbish. And I looked at him and I said, "Do you see things? Where? Do you hear things? Do people interfere with your thoughts?" These are all spiritual terms... But in other societies, if you had so-called mental health issues like where you could see spirits, they'd call you a shaman, you'd be raised as an elder in your tribe because you have the gift from the gods. That's all it is, certain people are blessed with the gift from the ancestors, its passed down, may skip a

few generations, but its in the bloodline. White people will put a label on it.

Mary alludes to a similar concept:

There is a spirit in me I feel because I remember going shopping one day and a woman said to me there is a spirit following you. I didn't question her, I wish I did because I feel something; I really feel something.

Hickling stated in his interview that he had been working on a concept of 'madness as social defiance' where mental illness was an excess of an adaptive coping mechanism of black people to huge social stresses of racism and exclusion. This is characterized in part by the development of a split psyche, where they end up "living two separate lives," one life hanging on to the "social mores of their homeland, of the Diaspora" and the other "taking on the same language, the same social values, the same ideas, the same reference groups" as the host population that rejects them.

On Resilience

On Double Consciousness

This notion of a split psyche invokes the concept of double consciousness, and the continual struggle of many Caribbean people in the UK to situate where they can call 'home' and how they identify as individuals. This struggle for service users to unify identity in an environment of repression and social suffering, that forces conflict between self perception and how they might be perceived by the more powerful, external world, where often the internalization of anti-black sentiment and mental health stigma can shape experience, is precisely what double consciousness theorizes. As stated earlier, transposed to the British context, where there is a perpetual othering of blackness and foreignness, the question of community and identity and its constant

transformation, especially when considering mental illness, “results in a specific and distinct doubling of identity and community” (Murdoch 2012).

Lacan and DuBois’ articulations of misrecognition and double consciousness, propose a sense that the individual continually attempts to reconcile this internal conflict. This attempt at reconciliation is fostered in resilient spaces. This resilient identity of the Caribbean service user is continually performed, especially in safe spaces like day centers and advocacy groups, outside of statutory health services, and is often counter to the illness identity they exhibit and perform in front of medical staff. This constant dance between performances of illness behavior and language in medical contexts and performances of a Caribbean communal identity and the consequent rejection of medicalized models outside of these contexts again invokes the theory of double consciousness. But given the chance to express themselves, to reconcile a fractured self, as seen in the “Studio Isis” film, they take the opportunity to establish visible personalities outside of the invisible illnesses they are often in various ways restricted by. When given the space in society to express themselves, such as they get at Caribbean advocacy day centres, they take the opportunity to “discover” themselves, as ‘Mary’ states, “I used to call myself Ebony April Jah-Love Lioness of Judah Greaves. It was like I was discovering myself,” or to “recognize” themselves as ‘Noel’ states, “Every now and then I have to fight to recognize myself. [...] I’m just a normal black man. An African. Trying to survive in this time.” As Hall (1992) states, "Cultural identity... is a matter of 'becoming' as well as of 'being.'

Mary Chamberlain in *Family Love in the Diaspora* argues that what is of real significance in looking at the Caribbean diaspora is not 'double consciousness' at all, but rather the process of “differential incorporation” of these diasporic communities into Western societies, contending that double consciousness is not exceptional or unique to Africans in the West, and advancement of the theory does not significantly advance our understanding of the African or Caribbean

diaspora. She argues that white groups, such as the Irish and the Jews in Britain and the United States have been discriminated against, and have experienced their own double consciousness, but have over time enjoyed universal incorporation with dominant groups. On the other hand, for populations such as black Americans and black British, this incorporation is not universal and though they may have sometimes had the same rights according to law as those conferred on white Americans and British, in practice, society prohibited their participation in the mainstream. This differential incorporation dictates unequal structural positions within the social order. Though Chamberlain makes a strong case for differential incorporation being a crucial element, I do not believe that this denies the usefulness and validity of double consciousness. While it might be true that double consciousness, in and of itself, might not be unique to the Caribbean Diaspora, it certainly appears to be relevant and resonant in the lives of service users who must look at themselves through the eyes of the medical establishment and be measured by medical standards they often believe do not take their own models of health into consideration. For these service users, there is an ongoing tension in their relationship with the medical establishment, a power-lacking rejection of the dominance of Eurocentric academic and medical classification at the expense of alternative models of illness and the consequent impact on health outcomes, and cultural and national identity. This results in the two-ness that is not only based on trying to reconcile Caribbeanness with Britishness, or otherness with nativeness, or Caribbean home with Mother England, but also illness with resilience, and illness behavior with resilient behavior. These often-competing forces must exist within the service user, complicating their paths to wellness, but providing some measure of relief from what often seems like an inescapable set of circumstances.

On Voice and Agency

The concept of the veil in double consciousness is not only a metaphorical reflection of the barrier

of race and a barrier of access, but the ethnographic data also imply a barrier of agency. A common complaint from service users (and from professionals familiar with the service user position) was a belief that their voice is either not listened to by those in power or silenced by the consequences of being in the mental health system. When they do speak, they often describe situations of having to choose their words very carefully as saying the wrong thing could result in longer stays in hospitals or impact their medication. ‘Noel’ stated that the power dynamic between professionals and service users was inherently imbalanced because professionals held all the power, so he was careful and strategic in your actions and words:

When someone has the right to do what they want to do with you, you never have a good relationship, you have to make that work for you to get what you want... [W]hen you're going to confront the authorities you have to know what to say and what to do and how to act. Some are frightened to talk and some are not. But you have to know what to say to get what you want.

In this way, there is also a two-ness of voice. This is not just the navigation between colloquial Caribbean dialect and a more British form of English or the navigation between operating from within an establishment model of illness meaning to a more marginal culturally framed model. There is also a navigation between sites of authority, from avenues where the voice may not be given recognition to avenues where it can resonate more easily, both directly and subversively. This is why art has been so crucial to the black Caribbean community. As Gilroy (1993) states, when the individual voice is absent or suppressed, music is used as a means of expressing the unsayable. When the social capital that Reynolds speaks of is absent in political arenas, culturally this capital has existed through art. The “incommunicability of pain” as Kleinman states, is communicated through music. It is no surprise then that in *Studio Isis*, Darren uses the opportunity to express himself continually through song, even when communicating with others.

The content of his lyrics are also relevant, especially in the song that ends the film:

No matter how dem come with dem evil
No matter how dem come with dem corruption
No matter how dem come with dem bad spell
'Binghi man ah go cut dem down
'Binghi man ah go tear dem down
Just like how me do the Jericho wall
Just like how me do the Berlin wall
Just like how me do China wall
Ah so Babylon me ah go fall
Buckingham Palace me ah burn it down
Downing Street me ah go burn it down
Down to the White House me ah go burn it down
Down to all Rome me ah go burn it down
Fire pon Rome
Fire pon England
Fire pon the White House

Through Darren's song, 'pain' and resistance are communicated in a form that circumvents closed media channels and has resonance in a form that has its own power. The effects of colonialism and racism, the complexities of identity and belonging, relationships with the state and society are all explored. 'The System' is referenced through the rebellion against Babylon, Rome and institutional structures like the Buckingham Palace and Downing Street, all of which are accused of evil and corruption. Identity is affirmed by the Rastafarian sect 'Nyabinghi,'

through opposition to corrupt forces and through a shared history with freedom movements that tore down walls.

The relative voicelessness of African-Caribbean service users is compounded by classifications of pathology that distinguish the ill from the 'normal.' The challenge is to move away from what Kleinman calls the "classical order of the normal and the abnormal," and instead promote "a more complex and sophisticated understanding of both societal and biological processes [that] will advance the view that normality as well as disease embodies social suffering" (Kleinman 2011). What is required is a "more powerful ontological line of analysis to get at what is an entirely different way of being in the world" and to comprehend the "fundamental condition of humiliation and exclusion as a non-human status" that results from social suffering (Kleinman 2011). In order to do this, he argues that biography, ethnography, and documentary film can suitably evoke this power. bell hooks (1991) states that part of the resistance struggle for "radical black subjectivity" and to affirm positive decolonized identities is to "find ways to construct self and identity that are oppositional and liberatory." Part of this process is seen through Darren's music, or might be seen in the service user poetry in the photographic chapter. It has also been seen through film. Two such examples are Isaac Julien's *Territories* (1984) and John Akomfrah's *Handsworth Songs* (1985), both of which can be said to be oppositional and liberatory, not just in content, but also in form.

Black British cinema comes out of a highly charged context (Arroyo 1991). The 1981 Brixton Riots and "the eruption of civil disorder, encoded militant demands for black representation within public institutions as a basic right (and)...many public institutions hurriedly redistribute(ed) funding to black projects" (Mercer 1988). Black British cinema benefited from this funding and entities such as the Black Audio Film Collective (to which Akomfrah belonged) and Sankofa (to which Julien belonged) were established in this context. Though their task, like

other black artists has been seen by some to speak to and for the black communities, Julien specifically claimed to be speaking *from* a black experience in Britain rather than *for* one (Julien and Mercer 1988). For Julien especially, this has been articulated filmically by shunning traditional film narrative rather than using the language of dominant narrative forms (Arroyo 1991). As described by Julien's press release, *Territories* is an experimental documentary about the Notting Hill Carnival. It locates the event within the struggle over the contested spaces of the carnival, between white authority and black youth, and reflects on its history as symbolic act of resistance. Through the use of montage, cutting carnival scenes with archive news reports, *Territories*, deconstructs and reconstructs the "regime of truth" and strategically repositions the gaze of the viewer through black eyes, an otherwise marginalized position in the real world, distancing itself from traditional documentary (Arroyo 1991).

Similarly, Akomfrah's *Handsworth Songs* (1985) is an experimental film essay on race and disorder in Britain, filmed in Handsworth and London during the riots of 1985, incorporating a multi-stranded narrative, visual experimentation, a mosaic of sound, interspersed with newsreel, and still photographs of black people's lives. Again eschewing what might be thought of as documentary convention, by forgoing an authorial voice-over that tells the viewer how to interpret events, the viewer is left instead to find their own way. The style of filmmaking is a deliberate response to the fractured narrative of the riots (Ogidi 2014). The film explores the idea that rather than representing a "self-contained drama of rage with a single origin and trajectory," instead the riots represented a multiplicity of issues, ambivalences, to do with race, longing and belonging (Lux 2013). The film's sense of multiplicity extends to a rethinking of black British presence, and a refuting of the idea of a homogenous black community with a single sense of presence characterized by uniformity of ambition and expression.

It is in the context of these films, that my own films take meaning. This is most obviously so for *Masquerade*, which attempts to juxtapose the 2013 Notting Hill carnival with the history of civil disorder relating to the African Caribbean population in the UK. This juxtaposition happens on the screen in both content and form, as two histories run parallel in the same way that two screens run parallel, sometimes synced, sometimes slightly out of sync and sometimes completely different. It is an attempt to give the viewer the challenge of choosing between violence and joy, anger and sadness, memory and post-memory, the real and the masquerade. In *Studio Isis*, members of the men's group at a Family Health Isis record their thoughts and feelings. The film was a product of months of trying to negotiate the best way to get the subjects to be filmed and finally settling on a method that they would be familiar with, that I hoped would encourage their participation. My only instruction to them literally was to say something, so everything shown is their own interpretation of what that means, their own inclinations of what to present of themselves and their own identities being performed. In *The Men's Group*, I show the weekly gathering, held on Thursday evenings at Family Health Isis. In an attempt to capture the experience of being in 'The Circle,' the metaphorical space in which the men's group discusses topics each week. In being relatively stationary, I try to situate the viewer as part of the circle itself. Lastly, *A Friendly Game of Dominoes* is a short film filmed by one of the member's that I edited to give a sense of the Men's group at play, playing dominoes which is a constant activity and a major part of their shared resilient community.

In the films I have produced, a deliberate effort has been made to share the authority of the camera and, in line with modern visual anthropological efforts, to move away from documenting events that have been selected by the filmmaker to illustrate what they have pre-judged to be culturally significant. In addition, the audience is allowed to hear subjects speaking in their own language and understand what they are saying, rather than having events interpreted for them and relayed by an authoritative voice, thus demonstrating "a definite shift in voice and authority"

(Ruby 2000). The aim is that through my films, the service users are able to make decisions about what is shot, and how they are presented. The aim is to allow them access to their 'voice' and to speak from their experience.

But as MacDougall (1981) states the subjective voice is always mediated and fragmentary, however much it appears to be the independent voice of another person. He argues, "in a strict sense, the only subjectivity in film-viewing is that of the spectator, the only subjective voice that of the filmmaker," where subjectivity is a "product of the text and a quality that we assign to the text," always subject to verification and rereading. If as Marcus and Cushman (1982) state, ethnographic realism is defined as seeking to represent the reality of a whole world or form of life through the authority of having known this world first-hand, then it stands to reason that there is value to be gained from sharing the authority between the ethnographer and the subject. As James Clifford (1983) puts it, the goal of ethnographic realism is to give the reader a sense of "you are there, because I was there." The films are an attempt to put you there, and to hear the subjects.

As stated in the ethnography of Isis, the production of the films, and the presentation of the films showing the resilient community, involved an affirmation and continuing reinforcement of a resilient communal identity. The service users were able to show who they were and also see who they were, instantaneously in the case of *Studio Isis* and afterwards in terms of *The Men's Group* when I presented them a rough edit on DVD. The resilient space, in that way, transmits into and out of the medium of film, both in production and in content. The films, in engaging in participatory and experimental documentary forms develops a shared body of knowledge through liberatory identity presentation, creating opportunities to hear service user voices and bring their experiences to the understanding and awareness of the audience (Lorenz and Kolb 2009). The films, together with the photographs and the interviews are an amalgamated narrative of the service user experience. My aim in the project was to have the story of the service user be more

than the contents of their patient notes. My proposal that I shared with health professionals was that ideally service users be allowed to write a short narrative on themselves and that sheet of paper would be placed in their medical records along with their notes, so that when a consultant psychiatrist came to meet them on the ward, they would be armed with that information alongside the medical data.

Hauser et al. (2006) state that recently personal narrative has gained recognition as a legitimate and important resource and tool in the world of developmental psychology and psychologists have begun looking systematically at narrative as a way of grasping how people create and maintain meaning over time. As Geertz (1997) says “telling stories, about ourselves and about others to ourselves and to others, is the most natural and the earliest way in which we organize our experience and our knowledge.” Becker (1997) states that through stories, people organize, display and work through their experiences, so that “narratives can be a potent force in diminishing disruption, whether the disruption is caused by illness or personal misfortune,” often by creating and sustaining a personal coherence (Charon 2001). In this way, narrative can be used as a tool of resilience, both reflecting and influencing adaptation (Hauser et al. 2006). Hauser et al. (2006) argue that from experiences we derive meaning; from meaning-making we imagine new actions; new actions lead us to new experiences; from new experiences we evolve new meanings, and so on. Narratives therefore evolve, reflecting experience and conditioning new experience and reflecting resilient processes. Bearing this in mind, not only do the films, photographs and interviews, in presenting narratives present resilience, the act of producing them as a process of narrative is a resilient action.

The Resilient Space

With idioms of distress, explanatory models and coping mechanisms being culturally variant, the African Caribbean service user entering into the mental health having to “explain themselves in a European way, in a European setting, at a time when they are least capable of doing that” is less than ideal and potentially problematic. If as the discussion on social suffering shows, that the quality of treatment in the mental health system is disproportionately negative for black service users, then it is within consideration that for many, the system does not fit. When it does not fit for them, Phillips argues that they seek to cure themselves. In his articulation, this self-curing is negative, but the service users I encountered in the day centers I visited, exhibited coping techniques that I attribute to the fostering of a resilient identity within a resilient space. I would not classify it as self-curing necessarily, since they are being offered services by these statutory and voluntary agencies set up to respond to their needs, but as these services are culturally specific, run by largely African-Caribbean staff and volunteers, focused on providing African-Caribbean cultural support, there is an element of self-sufficiency to them. They are of course not limited to specifically to the African-Caribbean community. Service users of different backgrounds sometimes frequent the centers, and staff members are often both African and African-Caribbean, but of the centers I visited, the environment was most definitely characterized by Caribbean markers, from the food served, to the music played, to the art on the wall, to language most often heard.

As Weston states of some of the Isis members:

When they go outside of Isis, people treat them like they are not even human. We have stories where the neighbors are criminalizing people because they have mental health problems. Most of the people that come in here it is only by the grace of God that they

haven't committed suicide because they just want somebody to take them out of their misery.

The Social Care Institute for Excellence (SCIE) in their 2008 report 'Commissioning and providing mental health advocacy for African and Caribbean men' argue strongly for the continued need of mental health advocacy for and run by the BME community. They state that there are clear differences between standard approaches to mental health advocacy and those developed and conceptualized by and for black and minority ethnic communities, where BME definitions emphasize interdependence with families and communities. For BME communities, advocacy is not only concerned with addressing the power inequalities in the relationship with mental health services but more broadly with achieving equality and social justice within UK society (SCIE 2008). Similarly, the Black Spaces Project, commissioned by the Mental Health Foundation in 2003 in the UK, found that mainstream mental health services often failed to meet the needs of Black communities because they are not sufficiently sensitive and responsive to the diversity of culture and experience. This often results in a reluctance to engage with mainstream mental health services because of negative and sometimes traumatic experiences of medication and hospital treatment. The report recommended that the government empower and create more funding opportunities for Black mental health organizations, including Family Health Isis that was one of the agencies they researched, to build "the bridge between the community, mental health services and individuals" (MHF 2003).

This is not to say that every experience inside the system, outside of centers like Isis is negative. Dr. Sean Cross states that there are both negative and positive experiences, but that the barriers to engagement and positive relationships between service users and the system are large and complicated, including, but not limited to barriers of culture, ethnicity and race. As many of the interviews have stated, the default option for clinicians is perceived to be medication, and even

when alternative forms of therapeutic treatment are available, medication is overwhelmingly the prescribed option for African-Caribbean service users. Obviously, this should be the option for some. Even with overdiagnosis and overrepresentation of acute disorders like schizophrenia being a reality, medication must be a viable option. Service users themselves are able to admit this. In the Men's Group interviews 'Kevin' relates a story of a man in Brixton with mental health problems who had been "troubling people," and who eventually punched a woman. He was arrested and sectioned. Kevin saw the same man a few years later and after his treatment he appeared to be well, thus concluding, "in some cases the medication has its good points." This prompted a conversation between himself and 'George' about the merits of medication:

GEORGE: But was that what he needed?

KEVIN: Well it helped him.

GEORGE: It helps him, but it doesn't make him the man that he should be, does it? What they are doing is they are controlling him so that he doesn't go out and knock anybody down or kill anybody, but they are not healing him... Why don't they take him to a safe environment and give the person the right treatment and let them come back out and live normal in society, rather than giving them medication all the time? We need to get the doctors here or the psychiatrists.

'George' doesn't disagree that medication can help, his dispute is having medication be the only option and no other avenue being offered to the service user to truly heal and return them to a 'normal' state so that they can rejoin society. His criticism is that the impetus to intervene is not about treating the ill, but protecting the 'well.' His solution to the problem is a "safe environment" where the person can get the "right treatment." It is my argument that Caribbean mental health centers like Family Health Isis, Oremi and Fanon are these safe environments where service users receive the "right treatment." This does not mean that these centers alone

could replace mental health medical spaces within the NHS, but it is clear from decades of negative experiences in the system, that additional resources are required for African-Caribbean mental health service users outside of hospitals and care homes. It is also clear that these Caribbean mental health centers offer services that successfully assist service users in either surviving in the system or leaving the system altogether. Weston recounted a report that was done on the assertive outreach program they had at Isis, which found that their rates of success in working with service users was significantly higher than that of the statutory sector, which didn't have a very good rating. But of the report she says:

When the assertive outreach initiative came on board the Institute of Psychiatry decided they wanted to monitor a voluntary organization and we were chosen. In the end when they completed the reports, when they were supposed to publish it, they put it on hold for some reason. After 3 years doing the research, I want to see what the end result is. They gave me some little piece of paper saying this is what they said about assertive outreach. But for me that was not good enough because how can we validate our work? We did some good work; half of the people who were hard to engage are out of the system now... But what I am also seeing is that some of those people are going back to hospital because assertive outreach is no longer there.

The Resilient Community

The theory of resilience, as it relates to the Caribbean service users in the mental health system in the UK, can and should be extended past models of vulnerability and deficiency, models of static hardiness and models of individual hardiness and even past models of individual dynamic adaptability. Most recent articulations of resilience stress an interplay between the individual and the broader environment including environmental factors such as perceived social support and a

sense of connectedness (Rutter 1987; Werner 1993, Masten 1994). Key to the evolution of resilience theory has been the increased focus on the community as a source of protective factors, with support systems such as the extended family, religious communities and the local community being cited (Van Breda 2001). Sonn and Fisher (1998) argue the community itself can be resilient, developing the capacity to cope positively with hardship and foster resilient individuals who draw positively from cultural values, norms, memories, stories, myths, and histories. These oppressed cultures maintain a sense of cultural identity by practicing their 'primary' culture when they are in other settings, although counter to Sonn and Fisher's argument for a derivation from primary culture, in the case of the service users, what is drawn from is a redefined Caribbean culture that may not truly be primary for all members of the resilient community, but is instead resonant for the members. Included in these settings are Caribbean mental health centers, especially so because they are a space where cultural socialization and group identification instills "meaning, purpose, pride, and commitment to the goal of self-development" that has been found to be relevant to understanding the mental health resilience in the black populations, developing processes and mechanisms that ensure the survival of valued cultural identities and the positive development of group members (Sonn and Fisher 1998; Fischer & Shaw 1999; Branscombe, Schmitt, & Harvey 1999).

Resilience as manifested by these service users not only emphasizes positive mental health, continued dynamic adaptability and interplay between the individual and the broader historical environment, but also is manifested through an access to shared memory and a connection to a created community, such that service users, despite the threat of lowered quality of life because of their mental health experiences, are able to survive and to provide their own protective factor, as a community. As 'Noel' states, "all the memories, that is what is keeping me going." As a shared group, sharing cultural activities and memories, they are able to keep each other going. In this way, both the individual and the community are shown to be resilient. This does not mean that

any group that provides a sense of identity and community should be considered resilient. Phillips states that among the young black generation, the search for identity is sometimes destructive and community and meaning might be taken from gangs or having a common experience of having had contact with the criminal justice system or excluded from school. Resilience as defined is characterized by positive development towards successful adaptation to environmental stressors.

For many this resilience starts with positive family support. In his interview, Ray Johnson spoke of the crucial role the family and extended family plays in keeping someone safe. He makes the argument that the African-Caribbean family, where “cousins and second cousins and what have you are seen as close as brothers and sisters,” is usually extended and much wider than white British families which are comparatively small. ‘David’ spoke of the importance that getting married had in providing a foundation for improving his quality of life and the role that his wife plays in his recovery ‘Wayne’ in the SAfH interviews spoke about the necessity for a supportive family network to advocate on your behalf when dealing with clinicians:

If it wasn't for the persistence of my parents who kept saying he needs medication review, he's having serious side effects with his medication, blurred vision, shaking, terrors, muscle spasms, putting on weight, if they weren't persistent in having my medication changed, I would still be suffering these side effects up to now, because I'd been suffering these side effects for 3 years before they changed the medication.

Religion was also a popular means of coping positively with hardship. When ‘Noel’ suffered his mental illness, the first place he turned to for help was his Rastafarian community. During my time with the Men’s Group, one of the members began frequenting his local Catholic church for support. Christianity was a major aspect of David’s recovery, such that he hoped that Family Health Isis would allow him to form a Bible study group that he could invite other member’s to.

He states, “I used [the Bible] in my darkest hours; that has stayed with me to this very day.”

‘Mary’ decided against visiting a doctor about her mental illness problems altogether because she did not want to take medication. Instead, she used the Bible as a crucial aspect of her coping:

I saw Psalms 143 and it was telling me things that were happening to me and I felt gosh this is great. So I meditated on it all the time. [...] It's like everything opened up to me because I read that Psalms 143, I was really into it. It was like it was giving me the strength to believe in myself and to know that I don't have to take anything from these people anymore, that's how I felt.

Similarly, Dawn Edge argued that people used the Bible as a manual for living and turned to it during particularly difficult times, and that the certain passages of the Bible could be interpreted as psychologizing and so understandably useful for service users. She also noted that the nature of many black churches, especially Pentecostal churches where shouting is encouraged were particularly attractive to black parishioners because they allowed them to relieve stress and use their voices freely, though she jokingly concedes that if many mental health professionals came to a church like hers they may section everyone there. Even though this is a joke, it is a serious comment on the belief that certain cultural behavior is medicalized.

Outside of these familial and religious spaces, as well as other mental health spaces, what is distinctive about the resilient community found within Black mental health spaces is that blackness and Caribbeanness play such a crucial role in empowerment, characteristics for which service users have been historically discriminated against and have impacted social suffering. Additionally, as opposed to the resilience that service users might find in spaces like church groups, cultural groups and other such spaces, the Black mental health spaces provide specialized care that focuses on alleviating the social suffering that is connected to mental illness itself.

Revisiting Kleinman's definition, African-Caribbean mental health spaces explicitly provide services that address suffering impacted by historical and socioeconomic processes and forces, by helping service users through issues such as employment and education through services such as skills training. These spaces explicitly help service users recover from their illness experiences and struggle with service users to improve public policies and programs, often filling the gaps left by bureaucratic failings. The resilience fostered in these spaces are also able to draw from a long history of resilience found in the civil rights and political movements in the United Kingdom, especially in the 1970s and 1980s, such as the Black People's Day of Action in 1981 in response to the New Cross fire and numerous marches and instances of civil disorder protesting racial inequality in areas such as Notting Hill, Brixton and Toxeth. My research didn't find that service users themselves were directly connected to this history of resilience, although I met one service user during the Black People's Day of Action march in 2012 when I attended. But because the staff of these mental health spaces were often made up of individuals who had been involved in these civil rights struggles, this history of resilience had informed the creation and the ideology of these spaces. Many of these spaces had been borne directly out of resilience movements. In the case of Family Health Isis, it was formed by mental health professionals, services users and community workers in direct response to dissatisfaction with the services that existed for African and African-Caribbean people. The resilient community within these spaces then are not only connected to a history of Caribbean culture, but a history of Caribbean resilience.

A major finding of my fieldwork was the way in which service users formed a community amongst themselves and how that community was able to reinforce wellness. To paraphrase a quotation from one of the short films "Studio Isis" that the fieldwork produced: "Isis is my big thing. It's run properly. The staff is nice. Everyone gets on together. We are all a family." 'David' states:

I came here to the lady in charge and made her know that I want to get somewhere... I wasn't making enough progress on my own and I felt ostracized, that happens to a lot of black males in this country, and needed to make connections to try and help myself.

Mary states:

When I came in I didn't talk to anybody, I just came in and had a look. I didn't say much, I was so quiet and then all of a sudden, after coming regular times, I heard [one of staff] say something about me. The way she spoke gave me a bit of confidence because I thought I was useless having been away so long from meeting people, talking to them and things like that. She made me feel a part of the group.

Despite the allusions of referring to Isis as a 'family,' the center is not a 'home,' it is a communal resilient space. It is not the answer to all of the problems of service users, but it is an answer. It is a community. Sometimes it is just a space where you come and sit down for a while and someone offers you a cup of tea. Sometimes, as David Pinder told, it's a space you call from the police station asking for someone to come and support you. Sometimes it's a space for a women's group or a men's group or a hearing voices group or a music group or an art group or a discussion group or a group getting ready to go for a walk in the park or football in the park or dominoes in the park. It is a space where service users are encouraged to improve themselves and to help improve others.

Chapter Eight: Conclusion

Prologue

*By the rivers of Babylon,
Where we sat down
And there we wept,
When we remembered Zion.*

*But the wicked carried us away in captivity
Required from us a song
How can we sing King Alpha's song
In a strange land?*

*So let the words of our mouth
And the meditation of our heart
Be acceptable in Thy sight, oh Far I.*

Rivers of Babylon – The Melodians (1970)

Introduction

Over the course of the data collection and having spoken to service users and members of support and health services, research and the greater community, using a visual and narrative ethnographic methodology and exploring literature on migration, media, social suffering and resilience, I found that a history of continual negative stereotypes and perceptions across media forms of blackness, Caribbeanness and illness appear to have negatively impacted not only perceptions and self-perceptions, but also has negatively impacted the culture of treatment and policy making for the Caribbean population. This was further complicated by traditional risk

factors for mental illness and social suffering such as racial discrimination, social class and loss of community. The addition of a migrational component of stress results struggles to maintain a connection to Caribbean heritage and British citizenship, such that there is a struggle to find a sense of 'home' in the British environment that differs in experience and expectation of different generations. I propose that this manifests itself as a double consciousness for service users, based on trying to reconcile Caribbeanness with Britishness, otherness with nativeness, a Caribbean home with Mother England, disease with health. These competing forces must exist within the service user, complicating their paths to wellness.

The background of these experiences provide a context for the particular characteristics of social suffering that is felt as a consequence of coming into contact with the institution of the National Health Service, which itself can be considered a risk factor for furthered suffering and re-traumatization for Caribbean service with diagnosed mental health problems. What this project has not sought to do is claim a causal relationship between this social suffering and the onset of mental illness. What research highlights is a long history of adverse experiences, discrimination and unfair treatment in mental health services, continued tension in the relationship between the service users and the medical establishment, with a general sense of resentment to the amount and administering of medication and the power afforded to medical staff.

Despite these difficulties and struggles, there is a sense of resilience that is often grounded in meaning created from surviving mental illness and in fostering a Caribbean identity within the London environment. This resilient, positive self-image and identity stands in opposition to popular perceptions of the mentally ill and in many cases popular perceptions of Caribbeanness. Service users have been able to forge a space for themselves that less mirrors perceptions from the outside of who they are and instead traverses the divide between the 'normal' native society and their 'sick' foreign space. Central aspects of the created resilient space are the formation of a

sense of community and belonging and nurturing the voice of the service user. Caribbean mental health day centers serve as resilient communal spaces, where service users are able to affirm an identity outside of the excluded spaces reserved for them as the ill or the foreign. The films, photographs and narratives of the ethnographic method of this project are an attempt to both explore and complement this resilience. This dissertation concludes with a number of recommendations for the improvement of services for service users.

Recommendations

Kurtz and Street (2006) in 'Mental health services for young people from black and minority ethnic backgrounds' highlight what they consider to be effective provisions for the mental health of BME young people, that can be applied in more general terms. Firstly, more needs to be done to improve the understanding of mental health and problems among BME communities as a whole, including both service users and their families. This could involve work with relevant community organizations, in education and in relevant media channels, which care taken that information is understandable and accessible. Secondly, expert help needs to be made available in a range of settings, including non-medical and informal facilities where persons would feel safe from stigma or are already comfortable. Thirdly, all relevant staff must develop cultural competence, and within BME community organizations awareness of mental health issues should be encouraged along with the confidence to acknowledge problems and to seek help. Training to support this should be made available and given sufficient priority, with particular attention to the training and recruitment of BME staff with mental health expertise. Finally, BME communities themselves should be regularly consulted on their needs, and in the planning and monitoring provision of care.

Despite these and similar recommendations, there is obviously no easy way to reduce disparities linked to race, ethnicity and culture in mental health. Additionally, these recommendations and others like them have been made continuously for decades by BME advocates and at times have been taken on board and implemented into policy in some fashion. Despite these policy efforts, very little has changed to improve issues like service users experiences and admission numbers for BME clients. In fact, simply entering into the mental health system for BME service users appears to be a risk factor for furthered suffering and exacerbated illness. This suggests that more fundamental changes are required at a philosophical, institutional and educational level. In order to do this, I recommend that there must be a change to the philosophy of containment, more must be done to make use of local knowledge, much more must be done to engage communities and facilitate service user agency, and a use of innovative methodologies to engage with these communities should be encouraged.

Change philosophy of containment

If meaningful change for the better is to be effected for service users, the psychiatric philosophy of containment held by the mental health services, linked to a societal culture of fear and stigma, a failure to balance impulses to protect society from ‘danger’ and to provide improved care for service users, and a history of political failure to implement, follow through on and maintain progressive components within healthcare policy must be addressed and improved. One such fundamental change would be a change in the philosophy of how mental healthcare is practiced and delivered. Duggan et al. (2002) argue for a social model that emphasizes the complexity of health and illness within individuals and communities and opens the door for multiple strategies for intervention, drawing on the expertise of a range of different disciplines and agencies and is rooted in an understanding of the impact of power and powerlessness on health. The social model takes into consideration the quality of interaction between the individual and his or her social

context for both physical and mental health and “engages with the inner worlds and lived experiences of individuals and communities as well as with external social, economic and environmental factors” (Duggan et, al 2002). The characteristics of the modern social model in mental health include: understanding the complexity of human health and well-being; emphasizing the interaction of social factors with those of biology and microbiology in the construction of health and disease; addressing the inner and the outer worlds of individuals, groups and communities; embracing the experiences and supports the social networks of people who are vulnerable and frail; understanding and working collaboratively within institutions to promote the interests of individuals and communities and critique and challenge when these are detrimental to these interests; emphasizing shared knowledge and shared territory with a range of disciplines and with service users and the general public; emphasizing empowerment and capacity building at individual and community level; placing equal value on the expertise of service users, carers and the general public but challenging attitudes and practices that are oppressive, judgmental and destructive; operationalizing a critical understanding of the nature of power and hierarchy in the creation of health inequalities and social exclusion; and committing to the development of theory and practice and to the critical evaluation of process and outcome.

One outcome of a social modeled approach is the Positive Mental Health movement that, as Fernando (2003) argues, reconceptualizes mental health in positive rather than negative terms and shifts focus to positive indicators of well-being that calls for “methodological refinement in establishing positive indicators of mental health outcomes” (WHO 2004). Aydin (2010) states in the article ‘Strategies For Coping With Stress As Predictors Of Mental Health,’ modern mental health policies cannot only focus on “improving treatment for disturbed psychological constructions and functions but (must) also include strategies for developing and supporting ‘positive mental health’ and protecting it against various risks.” This would mean doing more than simply focusing efforts on preventative care and early intervention. Rather than looking at

mental health as merely the absence of mental illness, Positive Mental Health provides a more holistic approach to dealing with mental health and its correlation to physical health, illness, environment and culture where “psychological beliefs such as optimism, personal control, and a sense of meaning are known to be protective of mental health as well as physical health” (WHO 2000; Keyes 2005). The hope then is that the “natural consequence of such correlations is that promoting positive mental health may be seen as significant in terms of health globally and both physical and mental disorders” (WHO 2004).

Utilize local knowledge and innovation

Along with philosophical change, there also needs to be more meaningful institutional changes to the mental health system. In highlighting institutional racism in psychiatry as an issue, McKenzie and Bhui (2007), both psychiatrists themselves, argue that the changes required in psychiatry to effect better mental healthcare for the Black and minority ethnic population requires more than the efforts of the individual clinician and instead needs a concerted, coherent effort at an institutional level. They highlight basic organizational problems including inability to access appropriate interpreters and to readily access psychotherapy and social service for clients when needed, for as long as they are needed as being symptomatic of the larger institutional problems. They state that most psychiatrists have little training in “negotiating differences in illness models, diagnostic labels and preferred pathways to care and treatment for a multi-cultural society” (Department of Health 2005). It is this kind of institutional failing that supports the institutional racism paradigm, which focuses on systems and not individuals to understand disparities and develop solutions (McKenzie 1999). This paradigm asks that institutions take responsibility for producing an environment that develops and supports sustainable, effective, ethical interventions targeted at delivering equitable services, but it is found that often institutions fail to take responsibility. McKenzie and Bhui report being told by the Department of Health that: ‘We just

don't believe that "institutional racism" would be a helpful label to apply - the solutions lie in the hands of individuals, not institutions' (Department of Health Media Centre, personal communication 2007).

The individual hands of the psychiatrist cannot fix the organizational problems hampering adequate services and as it is argued, it is not helpful to point the finger at individual clinicians since "mental health professionals are as good as the systems that they work in and the body of knowledge they have" (McKenzie and Bhui 2007). Many problems faced are not a problem of the individual but are a consequence of policy decisions made by institutions and the wider social determinants of health. Practice needs to be revised as new knowledge and interventions emerge and being able to deliver services for a multicultural society requires a significant strategic multidisciplinary effort at a number of levels (Bhui & Olajide 1999; Bhui 2002).

Fernando (2003) makes a comparable argument for fundamental changes in support from the statutory sector and in how psychiatry functions. Fernando states sustainable changes in the statutory sector require a national plan and strategy that promotes the mainstream incorporation and propagation of successful local innovation. He states that despite a variety of approaches having been tried within the statutory sector to meet needs of BME communities, a lack of resources, support and validation have meant that many of these projects have been dependent on the commitment and enthusiasm of a few persons, where the project ends if these persons leave. Thus there is a lack of a clearly articulated 'good practice model' for multicultural services. Consequently, this results in the "marginalization of innovation," where when innovation is brought into the 'mainstream,' then too often, "'mainstreaming' has been a euphemism for 'abolishing'." He argues that the "dynamic conservatism" preventing change in mental health services emanates from psychiatry itself and so if innovative multicultural practices are to be brought about and institutionalized within the statutory mental health sector, then changes in the

way psychiatry functions may be needed, including greater flexibility in the ways of assessing people who present with mental health problems.

Local innovation need not mean reinventing the wheel. I have shown, and as Keating states and have reports have supported, African Caribbean mental health organizations are effective and initiatives like the Cares of Life project and assertive outreach programs are effective. The statutory mental health sector agrees that they are effective. But there is a failure to make these efforts mainstream and a failure to give adequate resources to these efforts. This results not only in stagnation of such initiatives, but a retreat, with agencies such as Family Health Isis, the Oremi Centre and the Fanon Resource Centre increasingly being closed. This is both the marginalization of innovation and the death of innovation. This has a direct impact on service user suffering and resilience since these organizations are so meaningful and valuable for them. I therefore propose that more should be done to support these kinds of agencies and initiatives and more should be done to increase their number in a move to ensure that the intelligence learned at this level is transferred. It is not enough that the good intentions of policymakers who have little to no direct experience with service users be depended on. Improvement in services requires the aptitude of those who have the experience working in these communities. Improvement in services also requires the aptitude of the community itself.

The most recent amendment to the Mental Health Act does state recognition of the role that local communities and local knowledge has in promoting public health and developing policy and practice. But as the Afiya Trust (2010) has argued, with regards to tackling race inequalities there needs to be a firm acknowledgement of the interconnectedness of people's material and social circumstances, including everyday experiences of discrimination, racism and social exclusion and that specific outcome measures should be set in place to assess the impact of local initiatives on racialized communities. I am in firm agreement with existing recommendations that there needs

to be representation from racialized groups on health and well being boards and a dedicated advisory group on minority ethnic health and wellbeing, along with the establishment of local health equality targets in partnership with local organizations and the voluntary sector. Given the greater power that would be granted to GPs in public health, GPs should be supported with training to understand and acknowledge the needs of specific groups of people and deliver public health services accordingly. Public health campaigns must recognize race equality and authorities should abandon 'one size fits all' programs and develop campaigns in partnership with voluntary sector and community organizations, so that campaigns reflect the diverse range of needs within communities (Afiya Trust 2010).

As McKenzie and Bhui state, mental health professionals are only as good as the body of knowledge they have, and as such, there also needs to be changes in the ways professionals are trained and changes in the way knowledge is acquired and valued. Cordwell Thomas argues that the curriculum and training in medical schools should be changed to improve the way in which they communicate with and provide treatment for black and minority ethnic people and to combat damaging perceptions of African Caribbean people, such as them being violent in particular. The Men's Health Forum argues that it is important to get cultural groups and communities to think differently and to address cultural shifts. Services should not be 'one size fits all' and should be geared to different groups in order to meet their needs, be it race, gender, disability, etc. They argue that often too much emphasis placed on 'perception' of these groups rather than addressing what these groups would need.

In 'One size doesn't fit all' (Bennett, et al. 2007), the point is made that while education and training have key roles to play in developing knowledge and skills to address racial inequality, current approaches are fundamentally flawed. This flaw is that race related training has generally reflected and reinforced social policy approaches rather than critically examining the limitations

of current conceptions of racism, and critically has not focused specifically on areas of inequality in mental health services, such as diagnosis and compulsory detention and reducing fear. They argue that emphasis must be on the improvement of professional practice and not merely the acquisition of knowledge on the cultures of the ‘other.’ Training should enable organizations and their employees to explore racial inequality within their specific context and to develop appropriate strategies to improve outcomes, and needs to be seen as “one element within a wider organizational plan that is embedded within clinical governance systems to ensure continuous improvement in the quality of service to BME groups” (Bennett, et al. 2007).

Although race equality training in mental health services in England is being delivered within the framework of diversity, cultural competence and cultural awareness, with a significant emphasis on improving cultural knowledge and changing negative attitudes on race, there is little evidence of training having an impact on the experience of service users or on equality outcomes (Bennett 2006). Feedback from participants suggests this ‘one size fits all’ approach does not adequately address specific issues related to their practice or the particular needs of the organization. The cultural competency literature tends to present this framework as a panacea against racism and health care inequality. As David Pinder states in his interview:

We came to the end of the DRE in 2010 and they packed everything up nicely and put it on the shelf and that was it, as if racism had suddenly stopped. [Service users] are in an alien culture, an alien country that doesn't really take into consideration an individual's cultural perspective. [Health authorities] think if they give them a can of Red Stripe or they serve curry on a Tuesday, that they are being culturally competent.

While it is important to recognize that culture may play a role in health-related behaviors, there is evidence that cultural competence is not in itself a safeguard against discriminatory practice;

“race is not culture and racism is not simply a lack of cultural competence” (Gregg 2004). Similarly, the focal movement more recently away from the concept of race and racism, to replace it with a concept of ‘culturalism’ as an explanation for the social inequalities experienced by BME groups, does not necessarily improve circumstances for service users. This culturalist approach is criticized for focusing only on certain manifestations of culture, such as health beliefs, values, communal rituals and shared traditions, suggesting that ethnic groups share a static culture and dangerously moving towards an emphasis that places the need on minority groups to “develop core values of ‘Britishness’, de-emphasizing cultural and linguistic differences, which have previously been the basis for addressing ethnic inequalities” (Bennett, et al. 2007).

Facilitate service user agency

It is relatively easy to make the statement that you plan to make services patient centered, but it takes much more effort to formalize and institute this emphasis. In addition to having service users serve on health and well being boards, I propose that users be allowed to write a short narrative on themselves and that it be placed in their medical records along with their notes, so that clinicians can be equipped with that information alongside the medical data. Currently, service users are afforded the opportunity to provide clinicians with ‘Advance Statements,’ which is a request they can make about what they would like to happen in the future should they become mentally incapacitated or lose the ability to make a decision for themselves. Advance statements take a number of forms but provide the clinician with guidelines for future treatments. At present, Advance Statements require the service user be over 18, have capacity of be legally competent, and it is recommended that Advance Statements be made after discussion with an advocate, nurse, support worker, or care coordinator, in order to explore issues surrounding individual care. A service user may make a specified refusal of a treatment, that is legally binding, but it can be

overridden by the Mental Health Act. This means that informal patients have a right to refuse medication, but formal patients (detained under Sections 2, 3 and 4) can be given treatment without their consent. Already included as a section of the Advance Statement is a blank section for the service user to include any information, needs, and requirements that they feel should be included in the document, but has not been covered in other sections (these sections cover personal details, wishes regarding treatment and clinical care, and requirements about housing, family/friends and day to day living).

I propose that the Advance Statement document be expanded to include the potential use of narrative. I have shown how narrative can be used to both make meaning of experience, and as a tool of resilience, allowing service users to reflect and influence adaptation. The uses of narrative statements then might not only have direct therapeutic benefit for the service user, but might also provide insight for the clinician, in a positive way, into the service user's person. Rather than have this narrative sit separately in the notes in an informal way, there may be some added validity provided to having it be a part of a legally binding document like the Advance Statement. The majority of African-Caribbean service users fall under the category of 'formal patient,' sectioned under the Mental Health Act, meaning that their Advance Statements are more open to being overridden, but even if it operates strictly as an advisory tool or even an informational tool for care providers, this expanded concept of the Advance Statement validates the service user voice and perspective, theoretically and legally.

Timimi (2011) in the 'Campaign to Abolish Psychiatric diagnostic Systems such as ICD and DSM' (CAPSID) goes as far as to suggest that the field of Western psychiatry be completely revolutionized. Timimi argues there is "no evidence to show that using psychiatric diagnostic categories as a guide for treatment leads to improved outcomes," and that there is evidence to suggest that in fact applying a psychiatric diagnosis and theoretical models associated with them

leads to a worse outcome for some (Timimi 2011). Certainly this makes sense when considering the issue of stigma associated with being deemed mentally ill, the consequences of treatment, medication and hospitalization for individuals given a psychiatric diagnosis and the controversy, especially in the BME community, of psychiatric misdiagnosis and over-diagnosis. The argument is made that in essence, Western psychiatric practice acts as a colonial power, that speaks of non-Western cultures as becoming more 'literate' the more they adopt Western biomedical conceptions of diagnoses, implying a backwardness to these other cultures, despite evidence suggesting that outcomes for mental illness in the non-industrialized world are consistently better than in the industrialized world and particularly amongst populations who have not had access to drug based treatments (Hopper et al. 2007; Whitaker 2010; Jablensky 1992). This also effectively means that disease categories and ways of thinking about mental distress that might be previously uncommon in many parts of the world are exported from Western cultures, giving the appearance that conditions like depression and anorexia are spreading across cultures, rather than replacing indigenous ways of viewing and experiencing mental distress (Watters 2009, Summerfield 2008). This exportation of beliefs and values is said to then assist in opening up new and lucrative markets for Western drug companies to capitalize on (Petryna, et al. 2006).

This is a more extreme response to the diagnostic problem, but another alternative that speaks to taking seriously local expertise would be the institutionalization of the input of the service user and the incorporation of local beliefs and practices. This draws from the finding that despite advances in therapeutic techniques, this has not yet led to the improvement in overall outcomes for service users. CAPSID concludes from this that services can improve outcomes, not by using diagnostic categories to choose treatment models, but by concentrating instead on developing meaningful relationships with service users that fully includes them in decision-making processes. Rather than just listening to feedback from service users, service users should act as collaborators in research, service development, and treatment model development.

It seems obvious that a critical role in re-educating the system, is to ensure that service users are an intrinsic part of policy and that they participate in policy driven and organizational initiatives, since it is now more widely accepted, at least ostensibly, that service users and survivors are “experts in their own experiences and that self-organization and self-determination are crucial in their journey to recovery” (Kalathil 2008). However, in the report ‘Dancing to Our Own Tunes: Reassessing Black and Minority Ethnic Mental Health Service User Involvement’ (Kalathil 2008), it is found that this involvement does not necessarily extend to service users from Black and minority ethnic communities, with evidence showing an “under-representation” of BME service users in user involvement activities, despite continuing over-representation in services. Lack of inclusion of BME service users was often blamed on them being “hard to reach.” When they were involved, it was found that often this ended up as “tokenistic gestures to increase ‘Black bodies’ on committees” and so experiences of involvement have been negative (Kalathil 2008). BME service users identified the barriers to involvement to include discriminatory experiences, including racism within user involvement initiatives and user groups. Many who found it difficult to have their basic needs met, were hindered from being involved. The stigma within communities and racial stereotypes of mental distress made some want to distance themselves from mental health initiatives. Others experienced the initiatives as “hierarchical spaces where power relations between professionals and service users/survivors are not questioned” (Kalathil 2008). They also experienced a lack of adequate payment, support and information, which made their work and expertise feel devalued.

Use innovative methodologies and engagement

Finally, there was an issue of fatigue, where services users felt that there was little evidence that their life situations and experiences within services had improved despite years of user involvement. Maybe one way to reach the ‘hard to reach’ and to better engage this community in

efforts to foster service user participation is to look to more innovative means of engagement. Groups like Time to Change, Healthtalkonline and the Fanon Resource Centre have all used video, photography and new media in different ways to allow service users to express their own voices to impact stigma, discrimination and inequalities in treatment. In my use of video, photography and narrative to garner expertise of service user experience, I found that overwhelmingly they were genuinely excited to participate in this process and were quick to suggest ways in which the technology could be used to broadcast their feelings and experiences to what they considered to be largely oblivious power brokers in their treatment.

As previously mentioned, traditions such as photovoice and other participatory visual research, are already used in public health and community development, especially so in the investigation of illness experiences of patients and represent an effort to provide a tool for participants to teach researchers and policy makers and shift the power differential between researcher and subject. This raises the possibility of improving the lives and health of individuals and their communities by discovering unforeseen approaches through challenging established practices. This movement towards innovative engagement with the service user community encourages resilience and encourages the education of clinicians and policymakers from the intelligence of those with the most experience. The conversation I had with the Men's Group sums this up:

GEORGE: Can you really change the way we are today? If you are a doctor and you want to open a hospital, if you want to change things, if you want your own hospital and you want to treat these people, you can help, but if you want to work within the system, it's not going to work.

KWAME: The way I think it can work, the quickest way I think it can actually happen is changing interpretations of how doctors look at you.

GEORGE: Okay, that means more understanding of proper mental health.

KWAME: But also that impacts how they diagnose you.

GEORGE: Yes.

KWAME: Because then if they have an understanding of who you are and where you come from they are not just going to throw out schizophrenia...

GEORGE: So with you helping the doctors, being in there, you can be in meetings to talk to the doctor, that will help because the way they do things is so different, so they don't really help is just medication, medication, medication, medication.

KWAME: Well it's about trying to change the culture of medication.

GEORGE: Right.

KWAME: But by trying to bring sense to what they're doing, trying to show them who people are...

GEORGE: You are going to educate them.

DENNIS: That's it, like that.

KWAME: So you teach me, I teach them.

I propose that the mental health system look to 'George' and other service to be their teachers.

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