

ANGLIA RUSKIN UNIVERSITY

**“IT’S ABOUT LIBERATION”
COMMUNITY DEVELOPMENT SUPPORT
FOR GROUPS OF BLACK PEOPLE
WITH MENTAL HEALTH PROBLEMS**

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A thesis in partial fulfilment of the
requirements of Anglia Ruskin University
for the degree of Doctor of Philosophy

Submitted: June 2013

ACKNOWLEDGEMENTS

This study would not have been possible without the generous support of many people. Above all, I would like to thank the two groups who agreed to be case studies, especially those members who worked with me week by week. Their warmth and insight made my experience unforgettably enjoyable and educational. Two community development workers supported me through three research cycles. Their dedication to improving mental health services for Black people is an integral aspect of their lives and I hope this study contributes to that goal in some way, justifying all the help, time and wisdom they gave me. Many others connected to the groups, particularly staff within their host organisations and local statutory services were also generous in their support: I thank them all.

The community development workers who contributed to the survey and interviews were busy and passionate about their work; I thank them for letting me interrupt and learn from them. As for those who helped me reflect on my learning in the fourth cycle, it was a pleasure and privilege to learn from their immense experience, commitment and community spirit.

My PhD Advisory Group was an invaluable resource. They provided practical help, expert advice, feedback on sections of an early draft and most important of all, constant encouragement. I particularly thank Alison Gilchrist, Sandra Griffiths, Philip Thomas and Nutan Kotecha.

For a variety of invaluable help I am greatly indebted to Harry Cumberbatch, Sidney Millin, Premila Trivedi, Philip Morgan, Caroline Bell, Paul Henderson, Adam Pozner, Simba (for their poetry) and Kudzai. I thank all at Sharing Voices (Bradford) who inspired this work and Jenny Powell for her help. Professor Jenny Secker, my ‘critical reader’, provided invaluable criticism and encouragement, for which, many thanks. As for Tom who has lived with this PhD for so many years, I shall endeavour to show my appreciation over many years to come.

Finally and especially, I thank my two supervisors at Anglia Ruskin University, Professor Carol Munn-Giddings and Dr. Dave Backwith, for their constant support and gentle guidance which sustained me through this journey.

ANGLIA RUSKIN UNIVERSITY
ABSTRACT
FACULTY OF HEALTH, SOCIAL CARE AND EDUCATION
DOCTOR OF PHILOSOPHY

“IT’S ABOUT LIBERATION”: COMMUNITY DEVELOPMENT SUPPORT
FOR GROUPS OF BLACK PEOPLE WITH MENTAL HEALTH PROBLEMS

Patience Seebohm
June 2013

Disproportionately high numbers of Black people use mental health services and experience involuntary treatment in the UK. There is no simple explanation, but research and policy suggest that groups run by and for Black people with mental health problems provide valued support. This study asks how community development (CD) practice can help these groups to develop and thrive.

The research adopted an action research framework to develop four cycles of research, each informing the next, within a social constructivist paradigm. Methods were mainly qualitative: interviews, group discussions and observation, with a questionnaire survey in cycle one. This asked CD practitioners about their activities and helped to identify two groups for case studies in cycles two and three. During the case studies, groups received development support on their chosen topic while participating in qualitative research; activities were clearly demarcated. Reflective field notes added to the data. In the fourth cycle reflective conversations with eminent ‘critical friends’ refined and affirmed the learning. Thematic analysis was continuous and progressive.

Findings suggest that CD practitioners can inspire and help Black people with mental health problems to come together in member-led, mutually supportive groups, justifying Black-only membership. Effective practitioners, especially Black role models, helped groups to generate self-belief and self-efficacy through collective action, enabling members to change their status, services and community. Those practitioners who demonstrated critical humility, commitment and competence broke the pattern of racial and psychiatric dominance. Others inadvertently reinforced societal oppression.

A new concept is introduced to encapsulate the learning: the ‘liberation approach’ to CD which synthesises four perspectives: radical CD, mental health recovery, Black self-help and liberation theories. This approach helps groups to challenge oppressive processes, breaking the mould in which they feel constrained. The study contributes new theory, evidence and research methodology about CD and self-organising groups within this context.

Key words:

Black; mental health; community development; action research; groups.

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Abbreviations

AI	Appreciative Inquiry
AR	Action Research
BAME	Black, Asian and Minority Ethnic
C1	Research Cycle One: Exploratory
C2	Research Cycle Two: Case study at Sweet Potato
C3	Research Cycle Three: Case study at Ngoma
C4	Research Cycle Four: Reflective
CD	Community Development
CDW	Community Development Worker
DH	Department of Health
DRE	Delivering Race Equality in Mental Health Care (DH programme, 2005-2010)
FN	Field notes
MHT	Mental Health Trust
NHS	National Health Service
PCT	Primary Care Trust

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Chapter One

Setting the Scene

“Making you matter
Making it happen
Having our voice
Having our choice
Not to be seen as strange
Together we will change.”

A rap written by a participant
and a Trustee of Sharing Voices (Bradford)
(cited in Seebohm, et al., 2005)

1.1 Introduction

Overview

This study was inspired by stories about life-changing peer support groups set up by and for people in distress. The group members who told the stories were African Caribbean, African and South Asian people who, prior to joining the groups, had felt isolated, distressed and in turmoil. I wished to find out how similar groups could be supported so that more Black and Asian people could benefit from them. A high incidence of acute distress and disproportionate level of involuntary treatment has persisted among the UK's Black population for decades (Sashidharan, 2003).

This introduction to self-organising, member-led groups took place during action research (AR) in Bradford (Seebohm, et al., 2005). We heard how group activities were shaped by their members' cultural frameworks and created a sense of belonging and well-being that changed the way that mentally distressed members saw their future. However, group sustainability could be threatened, for instance when leading members moved on to work or education. Skilled and sensitive support given by community development workers (CDWs) helped the groups to thrive. The nature of this skilled and sensitive support is the topic of my thesis.

In this chapter I introduce the study's fluid, ambiguous context, with ideologically contested terms and concepts. Diversity encompassed within the 'Black' label is described and discussed. I explain more about my choice of topic and outline the research question, the stages of inquiry and my various roles. Finally, I describe the thesis structure to guide the reader through its chapters.

In brief, I chose an AR approach to fit my exploratory purpose, using a collaborative approach for mutual benefit. Four cycles of research, development and reflection addressed my research question: How can CDWs and others support autonomous groups of Black people with mental health problems? Participant experiences were integrated with theory and reflection to generate learning relevant to participants, academics, practitioners and policymakers.

Ambiguity, fluidity and conflict

The concepts within this study often appear ambiguous as change obscures historical continuity. People with different perspectives sometimes contest interpretations of what is happening. Research emanating from established (largely White) institutions or, conversely, carried out by 'race' relations activists may be seen as lacking in some way by opposing groups. Literature spanning the mental health, 'race' equality and community development (CD) context of my topic is scarce.

Within this contested field I aim to satisfy an academic audience while, following Fanon (1952), I root theoretical discussion in Black people's lived experience. Stanfield II (1993), writing about research methodology, states that the passion of journalists, novelists (and, I believe, poets) provides "an important element for understanding the complex depths of race, racism, ethnicity and ethnocentrism" (p.11). My literature review therefore identifies and assesses the contribution of many sources, including peer-reviewed studies (accessed systematically through academic databases); community research; government, academic and

unpublished reports; historical and theoretical texts; political debate; and creative, journalistic and narrative writing. Where dates of first publication are historically significant here, they are given in the text with the current edition's date added in the References.

The study concerns what Thompson (2003) describes as “people work” - that is, practitioners working with people to help them tackle the problems that they encounter (p.1). To understand relations between practitioners and Black groups I discuss how racism has changed (but not disappeared) with changes in legislation, social attitudes and demography (Lentin, 2008). The meaning of explanatory concepts such as identity and empowerment shifts with ideological positioning. There is not space here to span the broad literature where these concepts are framed, but I explain how I use them, beginning next with key terms (listed in Appendix I).

1.2 Language for my purpose

Group members participating in this study recommended that I use ‘Black’ as an overall label for people of African descent, including those with a Caribbean heritage. As an inclusive term, it embraces a diverse UK population who may share experiences of racism and community resourcefulness. I use the words Black and White with capital letters to show they denote broad social groups and not colour. Black is not an appropriate label in every context, but its inclusivity provides consistency and coherence here, which more specific words such as African could not. Where distinctions are important, I use African Caribbean (often abbreviated to Caribbean), African and mixed heritage.

In the 1950s and 1960s Black had political meaning, denoting solidarity among all who experienced discrimination because of their non-White appearance or colonial heritage, including the Irish:

“The term ‘black’ arose as a conscious and political reclaiming of a previously derogatory term during the struggles of the US civil rights

movement...the political usage of the term frequently indicates solidarity or affiliation with those who have suffered colonial or racist oppression by the British state.” (Afridi and Warmington, 2009, p.6)

By the 1990s, the political coherence of the Black label was questioned as socio-economic experiences differed across minority groups (Lingayah, 2011). More emphasis was placed on cultural difference and the term Black became largely confined to people with an African or African Caribbean heritage as it is here.

Survey data sometimes differentiates between Black Caribbean, Black African, Other black and Mixed black/white (e.g. Care Quality Commission [CQC], 2011). People describing themselves as Other black tend to be second, third or fourth generation immigrants (Gardener and Connolly, 2005). I use the same categories, sometimes abbreviated, when referring to this data.

Broader terms also vary. Policymakers and researchers often use ‘Black and minority ethnic’ or ‘BME’ to encompass all who do not identify themselves as White British (Lingayah, 2011). Afridi and Warmington (2009) observe that some prefer the colour-free term ‘minority ethnic’, while others make specific reference to Asian people in ‘Black, Asian and minority ethnic’ (BAME). Here I use BAME as a convenient and respectful term, recognising it is a “constructed banner that has little inherent meaning” (Lingayah, 2011, p.7). The term ‘race’ is another social construct often used to define people by their skin colour, ethnicity, culture, faith or language. I frame ‘race’ within quotation marks to emphasise that it has no biological substance (see 2.3).

Mental health terminology is often rooted in ideology with people passionately defending their preferred terms. The terms ‘patient’ and ‘mental illness’ have connotations of the medical model which describes distress as a biochemical illness (2.2), but here I emphasise social factors in distress. I use the terms ‘distress’ and ‘mental health problems’ interchangeably to refer to common problems such as anxiety or depression, but also to less frequent diagnoses such

as schizophrenia and bipolar disorder. The term ‘service user’ is applied across models of distress. Although some people dislike its perceived association with illicit drug use I often use it here for lack of a more widely accepted term. Some people prefer ‘survivor’ (e.g. Wallcraft, Read and Sweeney, 2003) and I use this term when referring to people who describe themselves this way.

Self-organising groups of people with a shared health or social issue are variously described in research and policy as self-help/mutual aid, peer support and service user groups (3.3). Their key features, regardless of group label, include an ethos of mutual support and reciprocity, control by group members rather than by practitioners, a shared health or social issue and a respect for experiential knowledge. In this study members share the experience of being Black in the UK and having mental health problems, so I often refer to their groups as autonomous Black mental health groups.

Finally, CD is described by Lifelong Learning UK (LLUK) (2009) as a profession and a way of working. Butcher, et al. (2007) argue that CD is not “the preserve of any one occupational or functional group” (p.4). Some people are paid CDWs and I use the broader term ‘CD practitioners’ when referring to “anyone who...is using a CD approach...whether as a paid worker or a community activist/volunteer” (LLUK, 2009, p.4). Mental health practitioners, activists, managers and CDWs may therefore be described as CD practitioners when using a CD approach (4.2). In Seebom and Gilchrist (2008) several mental health practitioners describe themselves as CD practitioners, but in this doctorate research most mental health practitioners seemed unfamiliar with CD and would not describe themselves in this way. However, for consistency and clarity, I describe *all* those who support the groups as ‘CD practitioners’ as *in this respect* they are using a CD approach. I also note their professional role, for instance as a mental health manager. Black is another broad term I now discuss.

1.3 Diversity within the Black population

There has been a Black presence in the UK since African soldiers arrived with the Romans (Craig, 2012). Freed slaves, sailors and soldiers followed (Fryer, 2010). Large numbers of African Caribbean people arrived from 1948, invited to boost the economy and public services, while more Africans have come recently as asylum-seekers, students and skilled workers (Dabydeen, Gilmore and Jones, 2010). Today Black people form just over three per cent of the UK population (Office for National Statistics [ONS], 2012). From the earliest records, Black people have experienced both hostility and admiration here (Dabydeen, Gilmore and Jones, 2010). Later I discuss racism (2.2) and resistance (3.2).

Black people's culture, colonial history and current experiences are immensely varied. African and African Caribbean people in the UK differ in their migratory experiences, socio-economic status and cultural and family settings, with African people often faring better in health, education and employment (2.2; 2.4). Factors such as income, age, gender and residential locality sometimes affect people's lives more than their ethnic identity (2.4).

Across and within African countries people differ in culture, language and political perspective to such an extent that Aspinall and Chinouya (2008) question whether the Black African census category has any meaning. People born in the Caribbean may prefer their island identity, only receiving a Black or Caribbean identity in the UK (Fryer, 2010). Language, culture and allegiances differ across the islands. People with a mixed heritage may identify themselves or be identified as Black. Many Black people, especially those born in the UK, identify as British (ONS, 2012), while others may identify simply as Black, feeling no sense of belonging to place or heritage (Gardener and Connolly, 2005; Atkinson, et al., 2008). Next I explain how I came to work in this complex field.

1.4 **Origins of my study**

The roots of my interest lie in travels as a young person to Turkana, a desert area in Kenya, where I experienced first hand an understanding of hospitality, time and responsibility towards others that contrasted starkly with what I knew. Many years later I was reminded of this as I worked with Black people with mental health problems in London. I found this work enjoyable and often inspirational. It led to further work with BAME groups focused on mental health and CD, enabling me to work alongside people who demonstrate inner strength and care for others in a harsh environment. As I join them in trying to change this environment, a quote from Lilla Watson has deep resonance for me:

“If you’ve come to help me, you’re wasting your time. But if you’ve come because your liberation is bound up with mine, then let us work together.”
(cited by Stringer, 1996, p.148)

This shared purpose and mutuality characterise the ethos of autonomous peer support groups, which have interested me since 2003 when I began working with Sharing Voices (Bradford). This CD initiative for people from BAME backgrounds was set up in 2001 by psychiatrists Bracken and Thomas with their colleagues. CDWs at Sharing Voices nurtured the groups, enabling members to support each other, challenge service providers and increase understanding of mental distress in their communities (Seeböhm, et al., 2005). I saw how group sustainability was easily threatened, but strengthened by the CDWs’ commitment, skill and humanity.

This kind of group is said to be valued by people from BAME communities for their non-medical, non-hierarchical nature (Sewell, 2009). Participants at Sharing Voices told us how the groups improved their well-being and increased their aspirations:

“[The group’s] made me speak up - it’s built my confidence...now I’m thinking about the future...I’d like to get a job.”
“I feel like I belong somewhere because the group’s helped me.”
(Group members cited in Thomas, et al., 2006, p.17)

Learning more about CD support, I felt, could inform theory, policy and practice, improving mental health care for people from BAME backgrounds. My opportunity arose when 500 CDWs were funded through a new programme, Delivering Race Equality in Mental Health Care (DRE) (Department of Health [DH], 2005a).

1.5 **Research question**

The initial aim of the research was to explore how CDWs support autonomous groups of people from BAME backgrounds with mental health problems. As often happens in AR and for reasons given later (5.4), the exploratory stage of the study led me to redefine its focus. My research question became:

How can CDWs and others support autonomous groups of Black people with mental health problems?

The AR approach promotes an ethos of mutual benefit, so I decided to support the development of participating groups in parallel with carrying out qualitative research. My objectives were therefore to:

- describe how a sample of CDWs employed under the DRE programme worked with member-led or community-led BAME groups of people with mental health problems, using a survey and follow-up interviews;
- use a case study approach in one or more sites to:
 - describe how autonomous groups of Black people with mental health problems are supported by CDWs and others;
 - deliver development support to each group on a topic of their choice;
 - use reflective notes as data to link the learning from development activities to the qualitative research;

- describe the groups' activities and potential development from the perspective of key stakeholders;
- reflect on the findings with 'critical friends' and explore their wider relevance to other autonomous groups of Black people with mental health problems;
- Share the learning with those taking part.

The next section introduces the four stages of research.

1.6 **Stages of inquiry**

My desire to create change led me to choose AR, which has long been associated with CD (Stringer, 1996). I incorporated principles of appreciative inquiry (AI) to promote hope and energy. AI is a strengths-based approach used in many settings to create a vision of a better future with practical thinking about how to get there (Whitney and Trosten-Bloom, 2003). Both these methodologies are collaborative approaches which seek to change the dynamics of power through developmental, circular processes of doing and learning.

The AR/AI framework led to four cycles of action and reflection that developed organically, each stage building upon the last and informing the next (see Table 1), using largely qualitative research methods. Cycle 1 (C1) comprised a survey of the national DRE CDW cohort and follow-up interviews with a sample of nine of the 46 respondents; Cycles Two and Three (C2 and C3) involved two CDWs interviewed in C1, who agreed to participate in a case study together with the Black group they supported. Case studies also involved local stakeholders including statutory and voluntary sector staff and informal carers. In the final cycle (C4) I reflected on my findings with six 'critical friends', by which I mean people eminent in this field with a constructively critical perspective.

In the two case studies (C2 and C3) I adopted a dual approach. First, I used multiple qualitative research methods (interviews, group discussions, field notes, documentary analysis). Second, I provided development support to the group on a topic of their choice, modelling the CD support I was investigating. The two strands of activity were brought together by means of reflective notes. In these notes I described my reflexive thinking on the development support I provided and my reflections on the surrounding context and feedback on my practice. I used the notes as qualitative data, so the two strands of activity intertwined and informed each other, increasing my understanding regarding the research question in a mutually beneficial process.

Table 1: Four research cycles (outline)

Cycle	Activity
Exploration Cycle 1	Survey and interviews
Case-study Cycle 2 SWEET POTATO	Qualitative research and development work
Case-study Cycle 3 NGOMA	Qualitative research and development work
Reflection Cycle 4	Conversations with critical friends

Participants' involvement in the study varied from checking data and discussing analysis in the qualitative research to overall control during development activities (5.5, Table 7). The nature of my involvement also changed.

1.7 **Location and role of researcher**

My position and purpose as researcher presented a number of challenges familiar in AR. As an economically and socially advantaged White person with no diagnosed mental health problem, I am an outsider to Black mental health groups. Yet, as the AR methodology involved multiple roles from researcher to facilitator and ally, I shifted between outsider and insider. As a consequence of my increasing insider and trusted status, frank discussion about the significance of a Black or White identity in CD became easier than it might otherwise have been. Frequent discussions about my changing role increased its transparency (5.5; 11.6).

Socio-economic and power differentials were not always straightforward. My educational advantages were both a barrier and, as relationships developed, a valued resource (7.5.4). Sometimes I felt excluded by language, which eased when members chose to speak more like me (8.5.4). Power played in different ways and was a consistent theme throughout the study. Like McIntosh (2004), I gained a better understanding of White privilege and oppression:

“I began to understand why we are justly seen as oppressive, even when we don't see ourselves that way...Whites are taught to think of their lives as morally neutral, normative, and average, and also ideal, so that when we work to benefit others, this is seen as work that will allow 'them' to be more like 'us'." (p.78)

AR within CD seeks to change oppressive relationships (Fals Borda, 2006). The pursuit of objectivity and neutrality found within positivist research was neither appropriate nor attainable here, but a critical perspective was still required. To reduce the risk of losing this, qualitative research interventions were demarcated from development work by their formality and my position of control. Group members took the lead in development activities. Reflexive and critical thinking and supervisor support helped me to check and understand my emotional reactions and develop more appropriate responses. I describe the challenges and assess my success regarding criticality and distance later (5.5; 7.5.4; 8.5.4; 11.6).

Now my relationship with group members continues on an informal, friendly basis. The next section guides the reader through the thesis.

1.8 Structure of thesis

The thesis is presented in eleven chapters, adopting a structure somewhat similar to the folk story. This chapter sets the scene and indicates what lies ahead. I then take the reader through the literature to explore the depths of exclusion and despair (Chapter Two), inspirational resistance and mutual support (Chapter Three), with variable help to create a new world (Chapter Four). More specifically, Chapter Two shows the disproportionate levels of distress and involuntary treatment among Black people, discusses different explanations and the statutory response. Chapter Three focuses on Black resistance, self-help and autonomous mental health groups. Chapter Four looks at how approaches to CD have changed over time, describing and discussing its role within DRE and the meaning of empowerment in this context. I identify a gap in knowledge about how CD might support Black autonomous mental health groups.

The methodology in Chapter Five is where the storyteller looks back over this social, economic and political terrain to choose and justify the ontological and epistemological position, value base and rationale for an AR/AI approach. An overview and justification of the qualitative methods is followed by ethical and critical scrutiny. Chapters Six to Nine take the reader forward through four cycles of research, describing their aims, methods and findings which are briefly discussed. Learning points and further questions look backwards and forwards, building the themes. An overall analysis in Chapter Ten illustrates how the themes connect, identifying three components of CD support in this context. Chapter Eleven theorises the analysis as the ‘liberation approach’, a new way of conceptualising CD support for Black autonomous mental health groups. This forms part of what I describe as my theoretical and methodological contribution to knowledge. I critically assess the quality and rigour of the research before ending, as is usual in AR, with questions and implications for the future.

1.9 Concluding comment

This thesis is my story of how I come to understand CD support in this context, developed with the help of groups and those who work with them. I write in the first person because it is my narrative. Different people located differently would tell different stories, but my process of feeding back and reflecting with those involved gives me confidence that this narrative will resonate with others in community, practitioner and academic domains.

The study reveals the energy and inspiration behind Black autonomous mental health groups, why they are valued by those who participate and why we must find out how they can be supported to pursue their own goals in their own way. The first step, addressed in Chapter Two, is to understand the situation they aim to change.

Chapter Two

Distress, Exclusion and the Statutory Response

“No more can I take it.
Won’t someone hear me?
Won’t someone hear me?”
(from Henry, 2005)

2.1 Introduction

This chapter introduces the research, theory and Black experience relevant to this study. As noted earlier (1.1), I draw on a range of sources, beginning with statistical evidence of stark disparities in the use of mental health services by Black, Asian and minority ethnic (BAME) groups. I consider different explanations for these disparities and, to understand their intractable nature, I explore the historical roots of psychiatry and ‘race’ in the UK. A tentative consensus has emerged on the significance of social factors in distress, so I examine theories and statistics around discrimination, exclusion and urban deprivation. The statutory response to Black people’s distress is discussed. Finally I describe how oppression can be internalised, destroying any sense of identity and self-worth. Chapter Three explores community resistance and self-help.

2.2 Explaining high levels of distress

High levels of distress

The high incidence of distress and disproportionate level of involuntary treatment among the UK’s Black communities has been well documented (Sashidharan, 2003). A national census of inpatients, Count Me In (CQC, 2011) took place from 2005 to 2010 as part of the Delivering Race Equality in Mental Health Care (DRE) programme (DH, 2005a) (see 2.5). This one-day count provided a statistical snapshot that reveals deep disparities in the use of mental health services among ethnic groups. Black groups (African, Caribbean, Other Black and Black/White mixed heritage) have the highest rates of hospital admission, while

White British, Indian and Chinese groups have the lowest, with Pakistani and Bangladeshi groups having roughly average rates. Standardised ratios of Black and White British groups are in Table 2 below. These show that Black people are more likely to be detained under the *Mental Health Act 2007* (MHA) and to enter mental health services via police contact. Fewer Black people are admitted from primary care, a route that tends to be voluntary. Caribbean men stay longer on the wards than any other group.

Table 2: Standardised ratios of Black and White British hospital inpatients ^(a)

	Black African	Black Caribbean	Other Black ^(b)	White/Black mixed	White British	Standard/Average
Admission (all ages)	236	438	596	436 White/Carib. 292 White/African	91	100
Detained under Mental Health Act 2007	114	127	122	120 White/Carib. 113 White/African	96	100
Referred by GP	61	36	54	28 White/Carib. 35 White/African	108	100
Length of stay (male/female) ^(c)	141 (m)	345 (m)	248 (m)	275 (m) / 191 (f) (White/Caribbean)	161(m)	Average 174 (m)
	66 (f)	122 (f)	58 (f)	182 (m) / 92 (f) (White/African)	71 (f)	75 (f)

Source: Compiled for this study from CQC, 2011, pp. 15-26.

Explanatory notes:

- (a) Standardised ratios for admissions use 2007 Office for National Statistics (ONS) census population denominators. They exclude out-patients on a Community Treatment Order (CTO). ‘Detained under the Mental Health Act’ includes CTOs.
- (b) Most people who identify themselves as Other Black are born in the UK (see 1.2).
- (c) Length of stay refers to the median number of days from the day of admission to the day of the census.

The slightly lower rates of admission and detention for African compared to Caribbean people may reflect their different migratory, socio-economic and

cultural backgrounds (1.3). Distress among people of mixed heritage is often discussed in terms of identity, family and belonging (Sewell, 2009). Gender differentials (not fully represented in this table) mirror a pattern found in other spheres of life (2.4). Women are more likely than men to be referred by a GP and leave hospital sooner.

Data on suicide by ethnicity is limited, but one study suggests that statistical disparity begins young. Bhui and McKenzie (2008) analysed data from the National Confidential Inquiry¹ on suicide within 12 months of contact with mental health services in England and Wales for 1996 to 2001. With ethnicity clinician-assigned to four ethnic groups, they calculated the rates and standardised the mortality ratios of suicide. Overall, the ratios did not differ significantly from the White group for Caribbean or African people, but among those aged 13 to 24 years, for every 100 White males committing suicide there were 290 Caribbean and 250 African male suicides. Among those aged 25 to 39, for every 100 White women committing suicide there were 270 Caribbean and 320 African female suicides. Earlier data from the same source, analysed by Hunt, et al. (2003), show an association between high rates of Caribbean suicides, schizophrenia and unemployment. Next I explore how these disparities are explained.

Explanatory models differ

There is no simple explanation, believes Keating (2007). People understand the causes of and solutions to distress differently, adopting explanatory frameworks which fit their experiences and context (Bracken and Thomas, 2005). Foucault (2001) shows how explanations of madness differ over time. In community development (CD) the ‘social model’ of distress generally prevails, meaning that:

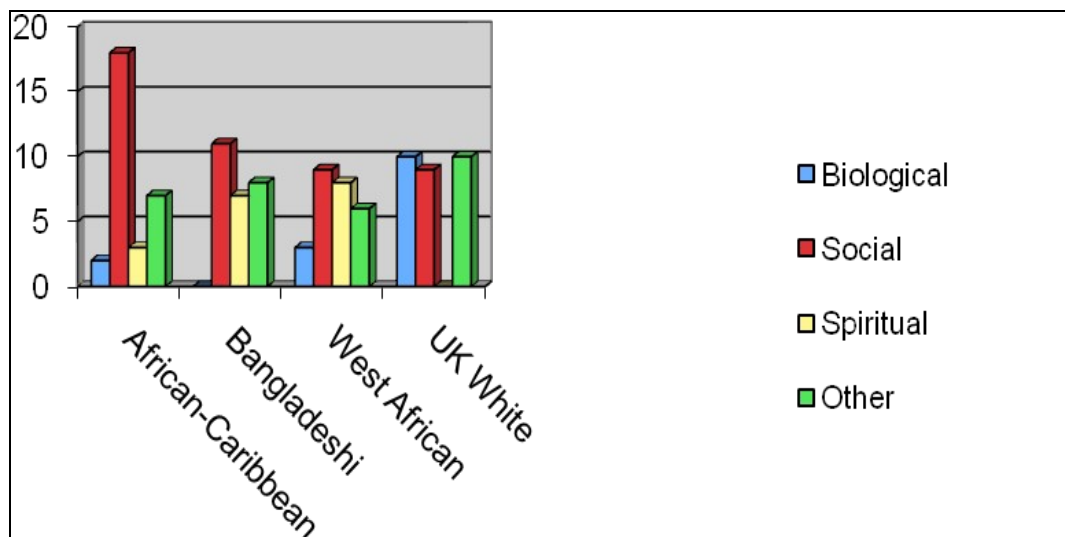
“Our emotional well-being is affected by social and economic aspects of daily life and the social barriers or exclusions which exacerbate ill-health.”
(Seebohm and Gilchrist, 2008, p.12)

¹ The National Confidential Inquiry on Suicide and Homicide by People with Mental Illness receives data from the Office for National Statistics and carries out research on all potential suicides.

Beresford (2005), a survivor/researcher, writes that there are many similar definitions of the social model, but when service users define it themselves it can inform the non-oppressive, holistic support they want.

Understanding of distress differs across cultures. McCabe and Priebe (2004) compared the explanatory models among people with schizophrenia from White British and second-generation African Caribbean, Bangladeshi and West African groups. They recruited 29 to 30 participants from each group, using qualitative interviews with a structured framework so they could quantify and compare the data. The results (Diagram 1) show that White participants are more likely to have a biological explanatory model; most African Caribbean participants blame social factors while most West Africans cite social or spiritual causes.

Diagram 1: Explanatory model of distress by ethnic group



Source: McCabe and Priebe, 2004, p.28.

There was substantial variation *within* ethnic groups and fluid understandings, giving rise to “a tension in reducing explanatory models to single categories” (p.29).

Lavender, Khondoker and Jones (2006) explored understandings of depression among three ethnic groups: Yoruba,² Bangladeshi and White British. They recruited 20 people from each group, of whom about half disclosed experience of depression. Qualitative interviews used vignettes depicting individuals with depression as prompts. Data were analysed using the interview schedule and grounded theory. Views on the causes of depression differed: “curses, black magic, evil spirits and the devil were mentioned frequently amongst the Yoruba people, but less frequently amongst the Bangladeshi and not at all amongst the White British” (p.653). The White British and Yoruba spoke about relationship breakdown and isolation, while the Bangladeshi spoke of family tensions. The groups shared many understandings of depression, suggesting more complexity than at first appears. Two Yoruba participants felt that a depressed person in the vignette would be regarded as ill in the UK but not in Nigeria, raising concern (considered later) that Black people’s social problems might be medicalised in the UK.

Kalathil, et al. (2011) explored how distress and recovery are understood by African, Caribbean and South Asian women. Twenty-seven participants with different diagnoses told their stories of distress and recovery to interviewers who shared their community background and experiences of distress. Data were analysed thematically without identifying ethnic difference. This community-oriented methodology fits well with my research, providing a useful source. It reveals a nuanced picture of how the participants made sense of their distress, including socio-cultural, biomedical, family and personal factors. Socio-cultural explanations included racism and discrimination, notably “the continuing legacy of the historical oppression of black people through slavery and colonialism”; cultural and gendered tensions; and experiences of mental health services (p.28). Personal and familial causes included abuse, bereavement and spiritual experiences. Some women understood their distress as an illness, with genetic, chemical or other causes. Participants combined these understandings without

² An ethnic group in West Africa.

finding contradiction, for instance, between believing in a medical cause and understanding the experience as spiritual.

A participatory action research (AR) project involving people from BAME groups had similar findings:

“Beliefs about the causes of mental health problems varied widely, but can be classified as cultural, religious, social or medical. The intensity of beliefs varied, and some held multiple or contradictory beliefs.”

(Word of Mouth Communication, 2010, p.13)

An influential study *Breaking the Circles of Fear* (Sainsbury Centre for Mental Health [SCMH], 2002) explores the “dynamics and dimensions of the treatment and care of Black people with mental health problems” (p.13). Its qualitative, participatory, staged approach includes service user and carer researchers. Data came from written evidence; 31 focus groups with service users, informal carers, professionals and police; interviews with psychiatrists, and 11 site visits. The breadth of the data and the study’s cultural sensitivity made this another useful source here. Researchers found that Black people often explain distress in non-physiological terms, referring to psychosocial or supernatural causes, while “professionals on the other hand engaged in the language of disease, illness or pathology to describe distress” (p.51). I turn now to this professional understanding.

Medical explanations dominate

Mental health practitioners differ in how they understand distress, but Ramon and Williams (2005) refer to “the hegemonic model of mental health, namely the ‘medical’ model, or more correctly the biochemical model of mental illness” (p.14). Double (2005) believes that this model is becoming more dominant and rigid within mental health services. In brief, it assumes that distressed people have a mental illness which has a biological cause in the same way that physical illness has. Mental illness should be diagnosed by experts in biological, neurological

illnesses using diagnostic criteria based on statistical research (Double, 2005, pp.66-68).

The emphasis on objective criteria attracting targeted (largely biochemical) interventions leads Bracken, et al. (2012) to describe this as the “technological paradigm” and, like Double, they sense a drive for psychiatry to “adopt an even more technological and biomedical identity” (p.430). A two-year, user-controlled national study of service user views found that the medical model of distress is widely shared among service users and across society, but many felt that it had negative consequences (Beresford, Nettle and Perring, 2010). The consequences of a diagnosis of schizophrenia are said to be particularly damaging (Thomas, et al., 2013).

A much-debated diagnosis

Schizophrenia is important here because high numbers of Black people receive this diagnosis, as confirmed by the largest UK study on this topic, Aetiology and Ethnicity in Schizophrenia and other Psychoses (AESOP). This used a multi-centre, case-control methodology to examine the rates of psychoses, including schizophrenia, and the social and biological factors associated with them among BAME groups (Fearon, et al., 2006). AESOP recruited 592 people with their first experience of psychosis and a control group of 412 people. To reduce the risk of practitioner bias, the researchers devised a diagnostic process that they felt was blind to ethnicity, using standard measures and consensus among colleagues.

AESOP found a nine-fold increase in the risk of developing schizophrenia among Caribbean people and a six-fold increase among Africans compared with the White British population. Subsidiary studies examined possible explanations. Pinto, Ashworth and Jones (2008) systematically reviewed 231 studies from 1987 to 2007. They rejected genetic explanations largely due to lower levels of schizophrenia in the Caribbean. Migration was rejected, as South Asians do not share high levels of distress while rates of diagnosis increase in UK-born

Caribbean generations. Cannabis use failed to explain ethnic differentials in service use.

For many years an acrimonious debate considered whether unintentional racism might explain over-diagnosis of schizophrenia if psychiatrists misinterpreted Black people's behaviour or medicalised their social problems (McKenzie, 1999; Singh and Burns, 2006; McKenzie and Bhui, 2007; Morgan and Hutchinson, 2010 and others). *Breaking the Circles of Fear* (SCMH, 2002) points to substantial research evidence of Black people being over-diagnosed with schizophrenia. Pinto, Ashworth and Jones (2008) argue that, although some practitioner bias may occur, an ethnicity-blind diagnostic process eliminates this risk in AESOP. McKenzie (2010) and others are not convinced, questioning the diagnostic criteria employed. Instead, they suggest social causes.

Consensus on social factors

Distress has long been associated with unemployment, poverty and isolation (Social Exclusion Unit [SEU], 2004). Pinto, Ashworth and Jones (2008) identify studies suggesting that supportive families and networks reduce the risk of schizophrenia. A range of AESOP studies argue that long-term separation from a parent before the age of 16, adult disadvantage (including unemployment and housing insecurity) and social isolation are risk factors that affect Caribbean people more than their White peers, because they experience these disadvantages more often. Fernando (2013) disputes AESOP's conclusions about single-parent families, suggesting an unproven leap from association to causality.

Several studies explore whether racism causes mental health problems. Karlsen, et al. (2005) used quantitative, cross-sectional data from a national health survey. They involved 3,464 survey participants of Caribbean, Indian, Bangladeshi, Pakistani and Irish heritage, using data from questionnaires about experiences of racism and mental health status. The study found that personal experiences of racism and living in a society perceived to be racist are associated with common

mental health problems and an increased risk of psychosis. Caribbean people are most likely to report experiences of racism. The findings correspond with a quantitative, longitudinal study in the Netherlands (Veling, et al., 2007). Qualitative research by Chakraborty, McKenzie and King (2009) found that Caribbean service users are more likely to attribute their distress to racial discrimination within psychiatric services and wider society, creating a mismatch of explanatory models between them and their doctors.

The journalist Lewin (2009) reported that AESOP identified an “epidemic” of schizophrenia among Caribbean communities and that its researchers proposed the “social engineering” of Black families as part of the solution. A coalition of practitioners, academics and service users (Ferns, et al. 2010) argued that the report had a racist tone and that AESOP failed to address the diagnostic ambiguities of schizophrenia. Despite heightened tension, there was some consensus that social factors help to explain distress among African Caribbean people (Morgan and Hutchinson, 2010; McKenzie, 2010).

Concluding comment

Nazroo (1998) raises the complexity of assigning ethnicity in research, now rendered even more complex by growing ‘Other Black’ and mixed heritage populations. McKenzie (2010) and Fernando, et al. (2012) question the diagnostic category of schizophrenia. Tension between these researchers and those from AESOP seems to reflect a deeper division about how mental distress should be studied and explained. Given this divergence, I treat generalisations about the relationship between ethnic identity, diagnosis and understandings of distress with caution, and align this study with the qualitative, culturally-sensitive studies which reveal nuances among Black voices.

Before I explore social factors linked to distress, I wish to find out why the Black women in Kalathil, et al. (2011) explained their distress in terms of historical oppression. What are the historical roots of their experiences? Why have

disparities in the use of mental health services continued for so long and why are the arguments so bitter?

2.3 Historical roots of psychiatry and racism

Psychiatry and slavery develop together

Modern notions of distress have been traced back to the ancient Greeks (Callaghan, 2008), but the fundamental shape of psychiatry today, Fernando (2009) argues, developed concurrently with colonialism and science. The 18th century Age of Enlightenment established distress or madness as a disease for scientific study (Bracken, Khalfa and Thomas, 2007). Foucault (2001) describes how spirituality became irrelevant and the mad were excluded from society. He writes that the dominant social elite set the rules, ideas and culture around madness. This elite in psychiatry, Fernando (2009) believes, colluded with slavery, even diagnosing runaway slaves as mentally ill. He describes a dynamic whereby “psychiatric power is combined with racism and race power manifested through psychiatry” (2000, p.84).

Colonial slavery is part of this story. Historians Dabydeen, Gilmore and Jones (2010) describe how 12 million Africans were shipped in the Atlantic slave trade, most during the 18th and 19th centuries: “Brutality was endemic and death was everywhere” (p.449). Slaves were viewed as property, lacking humanity in a highly racialised system: “To be enslaved was to be black: to be black was to be enslaved” (p. 456). By setting the slave apart as a barbaric ‘thing’, violence and more subtle forms of cruelty were permissible and unabated. Female slaves were brutally abused and denied their families, causing terrible physical and emotional harm.

Many years later Fanon (1961), working as a Black psychiatrist in Algeria, felt that colonialism still compelled people to fit into alien, dominant regimes,

destroying their identity. Like the Black women described earlier, he saw distress as a product of racial oppression.

Oppression and the dynamics of power

Oppression is not a term to use lightly. It conveys subjection, a burden on body, mind and spirit encapsulated in Frye's words: "Mold. Immobilise. Reduce" (1995, p.37). Its meaning varies with its theoretical frame of reference (Butcher, et al., 2007), but within the context of social support Thompson's definition is often cited:

"Inhuman or degrading treatment of individuals or groups; hardship and injustice brought about by the dominance of one group over another; the negative and demeaning exercise of power. It often involves disregarding the rights of an individual or group and is thus a denial of citizenship."
(2012, pp.47-48)

Oppression signifies an unequal distribution of power, but Foucault (1978; 1980) argues that this does not mean power is a commodity that some possess and others lack. It is a dynamic found in multiple sites, permeating everyday relations within institutions and society. Resistance is an integral part of the dynamic: the flow of power is not a 'one-way street' as my thesis will show.

Nor is power a zero-sum concept: if one party gains power, it does not follow that another has less (Butcher, et al., 2007). For example, collective action by mental health service users increased the influence individuals have over their own care (Williamson, 2010) and this, Barker and Buchanan-Barker believe (2004), enhances practitioners' power to deliver good-quality care. New ways of working can come from resistance to oppression (Foucault, 1978).

Power is multifaceted. Thompson (2007, p.17) uses the term "power *with*" to refer to collaborative or collective power; "power *within*" to refer to inner resilience; and "power *to*" when referring to agency and the ability to achieve

goals. I return to these, but first I consider how “power *over*” whereby one individual or social group dominates another, operates here.

The medical model described earlier presents diagnosis as a neutral, evidence-based assessment, but Boyle (2000) argues that psychiatric diagnoses do not reflect reality so much as construct it. Boyle states that diagnosis embodies “an imbalance of power which is exceptionally difficult to challenge...between those who carry out the diagnostic process and those to whom it is applied” (p.71).

These arguments bring us back to schizophrenia. Fernando, et al. (2012) believe that the ambiguity and stigma of schizophrenia make the diagnosis unhelpful. The psychiatrist Thomas (2012) writes in his blog: “If there is a single word that is emblematic of the oppression and mistreatment of black people by psychiatry, that word is schizophrenia.”

The Schizophrenia Commission (2012), chaired by Professor Sir Robin Murray of the Institute of Psychiatry, questioned the treatment rather than the diagnosis as the Commission panel reviewed evidence from a survey, events and site visits. They repeatedly heard that racism and problems with “categorical diagnosis and the undue influence of drug companies” affect Black people (p.49). The panel concluded, however, that there was no “systematic racism” on the grounds that most practitioners are “sympathetic to the problems of BME groups” (p.51). This leads me to ask what ‘racism’ means.

Deep-rooted racism

Social relations today, as professors Walton and Caliendo (2011) write, can be traced back to colonialism and slavery, an argument that the popular commentator Melanie Phillips labels “absurd” (2007). Lentin explains:

“The position of power occupied by slave owners and colonizers could not but make them dominant over the ‘native’. The imbalance of power between them meant not only that it took many decades for racism, slavery, and colonial domination to be challenged, but also that their

legacies remain imprinted on future generations and in many ways continue to determine the nature of social and political relations in our post-colonial societies.” (2008, p.39)

Racism, put simply, is the belief that certain racial groups are superior to others and is historically aligned to the theory that ‘races’ are biologically different (Lentin, 2008). The Human Genome³ project showed that genetically distinct ‘races’ do not exist, but many still believe that they do, according to Dar-Nimrod and Heine’s (2011) research and media review. Smedley and Brian (2005) observe that even if ‘race’ as a biological category is a fiction, racism is a real social phenomenon.

It is a dynamic phenomenon that changes over time, reflecting what counts as significant (Hall, 1997a). Modood (2005) notes how culture and faith became significant following Al-Qaeda’s⁴ attacks in the United States (US) and London. Lentin (2008) argues that racism remains the view that certain ‘races’ are superior to others, influencing our behaviour.

Racism is culturally embedded

In the UK, discrimination usually implies unfair treatment based on irrational or inaccurate notions (Sayce, 2000). Stereotyping is a common process of discrimination: people make assumptions about unseen characteristics on the basis of what *can* be seen. Racialised stereotypes may suggest an exotic nature (Said, 2003) or evoke fear, uncertainty or sexual curiosity (Lentin 2008). Schiele (2005) refers to the “subtle, insidious and seductive” ways in which these ideas prevail (p.803). They are so deeply embedded in popular culture, Thompson (2012) argues, that they resist challenge. Gramsci (1971) uses the word ‘hegemony’ to describe how the dominant view of the world infiltrates state institutions, civil society, education and culture. The Caribbean novelist Caryl Phillips (2004) describes how he felt framed by racist perspectives: “This

³ An international, US-led project (1990-2003) whose aims included the identification of all the genes in human DNA

⁴ Al-Qaeda is a global militant Islamist organisation which carried out violent attacks in the US on 11th September 2001 and in London on 7th July 2005.

country...seemed determined to offer me only unpalatable, and racially determined, stereotypes as models for my own identity” (p.125). This can have dire consequences.

Institutional racism identified

Police racism came onto the political agenda following the racist attack on a Black student, Stephen Lawrence, in 1993. Stephen’s family, supported by sections of the media, refused to accept the flawed police investigation into his murder. Their campaign led to a public inquiry chaired by Macpherson (1999), which concluded that ‘institutional racism’ pervaded culture and practice in the Metropolitan Police:

“[Institutional racism is] the collective failure of an organisation to provide an appropriate and professional service to people because of their colour, culture, or ethnic origin. It can be seen or detected in processes, attitudes and behaviour which amount to discrimination through unwitting prejudice, ignorance, thoughtlessness and racist stereotyping which disadvantage minority ethnic people.” (para.6.6)

Macpherson’s report is often described as a landmark in race relations (Bourne, 2013), but tensions continue. Black people comprise about 3% of the population but they accounted for approximately 10% of the deaths following police contact in 2006/7, 2007/8 and 2008/9 (Equality and Human Rights Commission [EHRC], 2011) and this disparity continues (Independent Police Complaints Commission [IPCC], 2012). Fifteen per cent of those stopped and searched by police in 2008/9 were Black (EHRC, 2011). A qualitative study (Gervais, 2008) involving 120 Black and Asian people, blamed Black deaths in police custody, failure to address community concerns and disproportionate use of stop and search powers for tensions between Black people and the police.

In 2001 David ‘Rocky’ Bennett, another young Black man, died in a secure mental health unit when restrained by four hospital staff (Blofeld et al., 2003). This was not an isolated incident (on World Mental Health Day, 2010, 28 Black men who died in mental health care were commemorated), but Bennett’s family,

like the Lawrence family, demanded action. The public inquiry that followed (Blofeld et al., 2003) found mental health services to be institutionally racist, like the police. The government responded with the DRE programme (DH, 2005a) mentioned earlier, but in 2010, as the programme ended, two Black service users died following police contact, one a post-graduate student restrained on the ward by eleven police officers (Black Mental Health UK, 2013).

Half (seven) of the 15 deaths occurring during or following police contact in 2011/12 were of people with mental health issues (IPCC, 2012). Fifty deaths and five serious injuries of distressed people which occurred during or following contact with the Metropolitan Police Service (MPS) over five years were examined by the Independent Commission on Mental Health and Policing (2013). This found a culture of discrimination and disproportionate use of force at the MPS and called for systemic, organisational change. The Chair, Lord Adebawale (2013), fears that this might never happen. Change is elusive, but it has begun.

Changing attitudes

From 1948 Caribbean workers came to boost Britain's economy but, Flynn and Craig write, they "were soon made to feel inferior" as housing and better jobs were denied them (2012, p.73). In 1968 Powell's prediction that immigration would lead to "rivers of blood" sparked widespread racist attacks (p.79).

Black resistance (3.2), the Macpherson report (1999) and race relations legislation (3.2) gradually reduced public tolerance of racism. The government-funded Equalities Review (2007), involving research and consultations, concluded that young people were increasingly comfortable with a mixed population. The EHRC (2011), drawing on census, survey and research data, also found people more accepting of difference. Growing numbers of people live in mixed-heritage households (ONS, 2012). Bourne (2007) describes the UK as irrevocably multicultural in terms of culture, faith and colour.

Economic, social and political activity gradually created a Black middle class population (Dabydeen, Gilmore and Jones, 2010). In a national analysis of economic inequality, Hills, et al. (2010) found that substantial differences in income were appearing *within* BAME groups, although a review of poverty and ethnicity by Barnard and Turner (2011) found that many Caribbean people remain on low incomes. Diversity within ethnic groups has led politicians and academics to argue that class (discussed below) may now foreground ‘race’ (Travis, 2010; Shukra, 2011). Fanshawe and Sriskandarajah (2010, p.11), discussing ethnic labelling, argue that the binary of Black and White has become an outdated way of describing our “super-diverse” population as many people do not think of themselves in these terms.

Complexity and continuity

The picture remains complex. In 2005, following the Al-Qaeda attacks, the race relations spokesperson Trevor Phillips claimed that “we are sleepwalking our way to segregation. We are becoming strangers to each other”. The Commission on Integration and Cohesion (2007), set up to investigate, found that “the mood of pessimism that some hold is not justified” (p.3), while Finney and Simpson (2009) collated evidence contradicting Phillips’ claim. Nevertheless, Phillips attracted widespread support (Cameron, 2011; Flynn and Craig, 2012).

Popular racism today often targets asylum-seekers and migrants (Burnett, 2013), but many Black people still feel unfairly treated by mental health services, sometimes blaming them for their distress (Chakraborty, McKenzie and King, 2009; Kalathil, et al., 2011). Tensions are exacerbated by political and media emphasis on the dangerousness of service users and the need for public protection (Beresford, 2005).

Covert racism remains. The Equalities Review (2007) found “the old attitudes persist unspoken and are registered in increasingly subtle and insidious ways” (p.91). Gervais’ (2008) qualitative research suggests that perceived racism in

public services did not significantly decrease between 2001 and 2005. A Metropolitan Black Police Association spokesperson declared that the police force remains institutionally racist (Muir, 2013). Paul (2011) and Burnett (2013) argue that political debate increasingly blames isolated ‘bad apples’, leaving institutional structures untouched. Measures to tackle institutional racism, introduced following the Macpherson report (1999), are included in the government review of bureaucracy, The Red Tape Challenge (Cabinet Office, 2011). Webber (2013) and others fear that they will be abolished.

Concluding comment

Economic and attitudinal surveys show how historical divisions between Black and White populations are breaking down and overt racism is decreasing. Qualitative research suggests that tensions continue underground, exposed through police and mental health statistics. The bitterness of debates may stem from confusion between institutional racism, which is largely about process and practice, and individual attitudes. Initiatives to eradicate overt discrimination, towards mental distress as well as ‘race’, overlook the need for systemic, institutional change, leaving power differentials intact. Next, I explore how power differentials shape social factors blamed for distress, beginning with social exclusion.

2.4 Social exclusion and urban deprivation

Exclusion accumulates

Social exclusion refers to the lack of opportunity to participate in social, cultural, economic and political activities (Burchardt, 2000). An inquiry by Mind heard how distress, unemployment and family breakdown link with cumulative impact (Dunn, 1999). The Commission on Social Determinants of Health (2008), set up by the World Health Organisation (WHO), finds that “people who are already disenfranchised are further disadvantaged with respect to their health” (p.155). An investigation by the Social Exclusion Unit (SEU) (2004) for the UK government

concludes that mental health problems can be both a cause and consequence of exclusion.

The SEU (2004) describes exclusion as a multi-dimensional *state*, but I, like Boardman (2011), think the concept is better understood as a *process*. Popay, et al. (2008), in their global study of social exclusion, refer to processes driven by unequal power relationships across economic, political, social and cultural dimensions. The concept of intersectionality conveys the interlocking nature of oppression and discrimination “woven into the fabric of life...at different levels in a complex system of domination and subordination” (Ledwith, 2011, p.192). Barnard and Turner (2011) reviewed ten UK studies of poverty and ethnicity, concluding that the impact of being Black has to be considered alongside many interactional, multi-dimensional and oppressive processes:

“People’s experience is not shaped by one aspect of their identity alone but by a combination of elements. Gender, age, religion, disability, health, location and migration history can all be as important as ethnicity. They can change how ethnicity affects people’s self-perception and treatment by others.” (p.4)

Craig, et al. (2012) find it hard to unravel the impact of these different elements, so when and how does ethnicity matter?

Interaction of ethnicity, poverty and place

Research on place, poverty and ethnicity synthesised by Garner and Bhattacharyya (2011) suggests that poverty and place sometimes disadvantage BAME individuals more than their ethnic identity. Records show that in London, where the largest proportion of Black people in the UK live, 55% of Black children lived in income poverty⁵ after excluding housing costs (Greater London Authority, 2002). Garner and Bhattacharyya (2011) found that nationally, BAME groups were on average 40% more likely than White people to be in income poverty, but they found as much diversity *within* as *between* groups.

⁵ Income poverty was defined as household income below 60% of the national median, after council tax, income tax and national insurance are deducted.

BAME households living in cities outside London were more likely to live in deprived neighbourhoods characterised by poverty, few job opportunities, poor services, crime and inhospitable environments. Movement out was constrained by insufficient resources, but also by a preference to maintain social networks.

In their study of income inequality, Hills, et al. (2010) found that regardless of where people live, ethnicity systematically affects job opportunities. A review of employment in the National Health Service (NHS) found that BAME professionals are less likely than their White colleagues to gain a position commensurate with their qualifications (Oikelome, 2007). Black male graduates earn 24% less than their White British peers (EHRC, 2011). Platt (2011) finds that, after considering all other factors, BAME groups experience an ‘ethnic penalty’ that disadvantages them in economic, social and political processes.

Women fare better

Black people’s exclusion and disadvantage are described by Hylton, a Black researcher/activist (1999). For several years he studied African Caribbean self-organising initiatives, employing a literature review, interviews with members of 11 Black-led organisations and key informants, and participant observation. The topic and depth of his study make it a useful source here.

Women, Hylton (1999) found, experience less racism and cope better than men when they do encounter it. Edge and Rogers (2005) explored Caribbean women’s experiences of perinatal depression, involving 200 women before and after childbirth in a survey and 12 of them in narrative interviews. The study found that Caribbean women experienced more socio-economic difficulties than their White peers, but were less likely to seek help from health services. Instead, they drew on resilience derived from historical necessity:

“Women’s identity formulation as ‘Strong-Black-Women’...served as a powerful cultural signifier and link to generations of Black women who

have overcome adversity, slavery and racism...these Black Caribbean women had learned that survival and self-reliance are inextricably linked.”
(p.22)

Statistics on suicide and detention among women (2.2) support Edge and Roger’s argument that many women persevere until “breaking point” (2005, p.20).

Young Black men often live in deprived areas without hope, achievement or positive role models, according to Hylton (1999). Wright, Standen and Patel (2010) record similar findings in their mixed-methods longitudinal research. Over two years they carried out 100 interviews with 33 young people excluded from school and with 60 adults who supported them. This comprehensive study provides recent data and academic rigour to set alongside Hylton (1999).

Excluded from education and work

There is a history of unequal outcomes within education (Wright, Standen and Patel, 2010). Gillborn and Mirza (2000) were commissioned by the Office for Standards in Education (Ofsted) to find the relative significance of ‘race’ and ethnicity alongside other factors in educational outcomes. Their synthesis of research found that Black pupils often enter school better prepared and achieving higher than other groups, but leave school with lower qualifications. Girls do better than boys, but overall, ethnicity is more significant in determining outcomes than class or gender. An inquiry by the Office of the Children’s Commissioner (2013), using several data sources for 2010 to 2011, found that Caribbean pupils were over three times more likely to be permanently excluded from school than the wider school population. Boys had higher rates of exclusion than girls. Wright, Standen and Patel (2010) point to similar findings elsewhere.

Explanations differ. Wright, Standen and Patel (2010) consider ‘race’ and racism to be the central factor, but observe that some people blame a cultural deficit within Black families. Gillborn and Mirza (2000) write that qualitative research points to the stereotyping of Black children. Strand (2007) led a longitudinal,

statistical study of educational outcomes tracking 15,000 children. After controlling for other factors, he concludes that low teacher expectations, exacerbated by misinterpretations of behavioural issues, amount to institutional racism and help to explain Caribbean boys' lower grades. This process, Strand argues, reacts with a street culture that rejects education to create "a vicious cycle" (p.103). The social researcher, Angel (2012), describes Black youth as locked into their situation, "simultaneously excluded and self-excluding" (p.29).

High unemployment follows. In 2011 nearly 56% of young Black men (16-24 years) and 39% of young Black women were unemployed compared to about 24% of their White peers (Ball, 2012). Numerous studies link unemployment with distress (SEU, 2004). Bell and Blanchflower's (2009) literature review and empirical research conclude:

"Unemployment increases susceptibility to malnutrition, illness, mental stress, and loss of self-esteem, leading to depression...Being jobless fosters feelings of externality and helplessness among youths...The unemployed appear to have a higher propensity to commit suicide."
(pp.17-18)

Research into the 2011 riots by the Riots, Communities and Victims Panel (RCVP) (2012) found that some rioters, Black and White, felt that they had nothing to hope for and nothing to lose.

The corrosive impact of social distance

Divisions in UK society whereby those at the bottom experience persistent disadvantage can be understood in terms of class (Payne, 2006). Platt (2011) brings together empirical evidence and sociological theory to show how the impact of class, whether defined by occupation (Park, et al., 2012) or status (Scott, 2006) accumulates during our life. In a review of social mobility, Milburn (2012) confirms the "corrosive correlation between demography and destiny that so poisons British society – between being born poor and, in all likelihood, dying poor" (p.7). Wilkinson and Pickett's (2009) influential study, based on a

meticulous analysis of global epidemiological and social data, shows how increasing income inequality reduces social mobility and increases social evils including mental distress. Income inequality grew steadily in the UK from the 1980s to 2010 (Cribb, Joyce and Phillip, 2012).

Since 2010 privately educated, wealthy MPs have dominated the UK government, note Evans and Tilley (2012). These researchers find that a survey of social attitudes links private education with less concern about social inequality, perpetuating what they call “social apartheid” (p.50). Collett (2013) describes how the five-day riots across the UK in 2011 exposed this “gulf between rich and poor...and the increasing segregation of groups within society” (p.185). Conservative politicians spoke of “a feral underclass” (Clarke, 2011), engaged in “pure criminality...moral collapse” (Cameron, cited by Stratton, 2011).

The riots revealed little inter-ethnic tension, but ‘race’ and police tensions were widely identified as background factors (Collett, 2013). RCVP (2012) referred to poor parenting, but also blamed wealth inequality. Statistical analysis linked rioters to areas of high deprivation and unemployment (Ministry of Justice, 2012; RCVP, 2012). Qualitative research studies (The Guardian/LSE, 2011; Morrell, et al., 2011) conclude that poverty and lack of hope were more significant than criminality. Lack of hope breeds distress.

Stigma excludes further

Many Black people regard distress and madness as deeply shameful and stigmatising (Leamy, et al., 2011). Stigma marks people as unacceptably different (Corker and Thornicroft, 2010), reinforced for distressed Black people by media stereotype images portraying them as “big, black, bad, dangerous and mad” (Keating, 2007, p.6). Corker and Thornicroft (2010) find that schizophrenia is especially stigmatised, while stigma and racism combine “to exaggerate issues with social exclusion” (p.221). The SEU (2004) heard that stigma was more harmful and enduring than distress.

Concluding comment

Theories of cultural and individual culpability used to explain different social outcomes ignore enduring patterns of disadvantage which suggest structural, socio-economic explanations. Institutional racism at school has lasting consequences, but disadvantage is not always or only about ethnicity: gender, geography and other factors interact. At the 2011 riots Black and White stood together against unattainable wealth and power, jointly blamed for their deprivation and despair. Stigma inhibits disclosure of distress, so I now explore how statutory services respond.

2.5 Statutory response

Explanatory or exploratory

Patient satisfaction matters to the NHS. Callan and Littlewood (1998) interviewed 21 White British and 63 BAME service users, asking how they viewed hospital care, their treatment preferences and their explanatory models of distress. They found satisfaction was most likely when there was concordance between the service users' and the psychiatrists' explanatory models, regardless of ethnicity. We have seen that McCabe and Priebe's (2004) Black participants were less likely to subscribe to the dominant medical model, suggesting that concordance may be rare.

More recently AESOP included a satisfaction survey (Boydell, et al., 2012), recruiting 216 people with their first episode of psychosis and 101 informal caregivers. They found Caribbean participants were less likely than others to feel that they were receiving the right treatment and were less satisfied with medication. Overall satisfaction, however, did not differ between Caribbean, African and White British groups, but the researchers note that dissatisfied people may have refused to participate.

Qualitative studies offer more in the way of explanation. A study by Secker and Harding (2002a) recruited 26 Black people, including many with schizophrenia and multiple hospital admissions. Participants told their stories of involvement with services, then the data were analysed thematically. Many participants felt that hospital treatment, predominately medication, was unhelpful or inappropriate. Racism and poor relationships with staff contributed to service users' sense of powerlessness. The researchers suggest that staff should try to look at the world through service users' eyes to see how they can help. A few participants had positive experiences, but felt that these could be more frequent if staff understood their experiences as Black people.

Separate services for BAME groups developed during the 1990s, mainly within the voluntary sector, to ensure that practitioners understood BAME perspectives (Bhui and Sashidharan, 2003) (3.2). Political and social change, described earlier, led to the view that mainstream services should respond effectively across all ethnic groups. Secker and Harding (2002b), drawing on their study above, suggest that not all Black people want segregated services. Even ethnic matching of BAME staff and service user does not guarantee empathy and understanding, any more than it does among White people. How, then, can services be guided?

Interest in explanatory models continues, but Ghane, Kolk and Emmelkamp (2012) criticise much of this research, arguing that participants tailor their models according to what they wish to disclose or feel interviewers want to hear. Williams and Healy (2001) emphasise the dynamic, changing nature of people's understanding. They suggest replacing explanatory models with an exploratory map, generating a service user-directed, fluid approach. This resonates with the concept of recovery.

Adopting Recovery

Recovery is a concept developed by mental health service users to denote their journey from despair to hopefulness, gaining a positive and purposeful sense of

self with control over their life and good relationships whether or not symptoms of ill-health continue (Wallcraft, 2005). Repper and Perkins (2003) emphasise that “recovery is not the same as cure...recovery is about growth” (p.46). Each person becomes an expert by experience in knowing what help they need to achieve self-determined goals, creating profound implications for the relationship between practitioner and service user.

Little recovery literature relates to BAME groups, a gap that Kalathil, et al. (2011) began to address. As before, their research participants wanted a response to fit their understanding of distress. They said that recovery included rebuilding their sense of identity and belonging; gaining a sense of worth for themselves and their Black community; regaining control over their lives and, for some, spiritual change. Some participants valued medication if agreed collaboratively. They said that recovery was about more than illness: it must look at external factors affecting their lives, incorporating collective action for social justice and “mechanisms to cope with societal oppression” (p.9). Newbigging, et al. (2007) found that voluntary sector BAME services combined a recovery philosophy with an understanding of racism and socio-economic determinants. Trivedi (2010a), a survivor/researcher, also connects BAME perspectives on recovery with community and social justice.

A review of 97 academic papers, including six BAME studies, on the conceptual framework of recovery by Leamy, et al. (2011) finds that BAME groups place greater emphasis than others do on spirituality and stigma in their understanding of recovery. BAME groups include cultural factors such as traditional healers and collectivist notions including supportive or excluding communities. The researchers note that BAME individuals “saw themselves as recovering from racial discrimination, stigma and violence, and not just from a period of mental illness” (p.449).

Recovery became a central plank of government policy (National Institute for Mental Health in England, 2005; DH, 2011). As a vision, recovery-focused care has been broadly supported. In practice, the picture is mixed. The Tidal Model of mental health recovery (Barker and Buchanan-Barker, 2005) encourages nurses to listen and respond to the stories of people seen to have ‘problems in living’ rather than mental illness. Gordon, Morton and Brooks (2005) describe two mixed methods evaluations of ward-based Tidal Model initiatives, concluding that relationships between nurses and service users improved to the increasing satisfaction of both, with wider benefits. Yet nationally, change has been slow.

Different meanings emerge

Recovery-focused care is often constrained by a rule-bound culture, an ethos of risk-avoidance and bureaucratic surveillance within services (Ramon, 2000; Barker and Buchanan-Barker, 2011). Wallcraft (2005) and Trivedi (2010a), both survivor/researchers, argue that the emphasis on self-determination in user-defined recovery has been replaced by service-led outcomes relating to employment and independence. Some women in Kalathil, et al.’s study (2011) felt that “coercion as part of mental health care”, including detention or involuntary medication, was incompatible with user-driven recovery (p.10). Moncrieff (2006), drawing on her own and other research reviews, argues that reliance on medication is unduly sustained and promoted in psychiatry by economic, professional and institutional powers, a view shared by Bracken and Thomas (2005), Barker and Buchanan-Barker (2012) and others.

Although recovery discourse is widespread, Pilgrim (2008) identifies contradictions as communities of interest interpret the concept differently. Practitioners with a biochemical perspective rely on diagnosis and medication. Social psychiatry seeks to improve social skills. Pilgrim observes that both these approaches to recovery emphasise patient compliance and practitioner skills, while radical perspectives see service users as experts by experience, neither deficient nor ill.

The consistent message here is that people want support that fits their understanding of distress, reminding us of Beresford (2005) (2.2). How, then, do services promote recovery among Black people?

Tackling fear and inequality

Poor rates of recovery among Black people are evident from statistics shown earlier (2.2). *Breaking the Circles of Fear* (SCMH, 2002) found that Black people were often afraid of involuntary treatment, the disabling side effects of medication, being stigmatised and ultimately dying in services. Delays in seeking help increased the risk of crisis and fear spiralled:

“Service users became reluctant to ask for help or to comply with treatment, increasing the likelihood of a personal crisis, leading in some cases to self-harm or harm to others. In turn, prejudices are reinforced and provoke even more coercive responses, resulting in a downward spiral we call ‘circles of fear’, in which staff see service users as potentially dangerous and service users perceive services as harmful.”
(SCMH, 2002, p.8)

A statistical study within AESOP, (Morgan, et al., 2006) found no evidence of widespread delay among those first experiencing psychosis, but acknowledged that there may be delays in readmissions.

Following the death of David ‘Rocky’ Bennett, Sashidharan (2003) consulted with BAME groups and produced a framework to help mental health services “confront and deal with the institutional racism that is built into [its] organisational culture and professional practice” (p.24). This was welcomed, but some were disappointed when the policy implementation document, DRE (DH, 2005), shifted the emphasis away from racism (Bhui, McKenzie and Gill, 2004). Instead, DRE presented a 12-point vision for services (Appendix V), pursuing equality of access, experience and outcome by responding to cultural difference. Implementation plans included 500 community development workers (CDWs), 80 community-led research projects and a staff training programme to promote

cultural competence: the capacity to work with people of any cultural or ethnic background. Despite some scepticism, DRE was welcomed as a step in the right direction. Marrington-Mir and Rimmer (2007), for instance, described the use of CD and community-led research as innovative opportunities, which I discuss later (4.3).

Limitations of training

Doubts were raised about whether training could support systemic change (Bennett and Keating, 2008). Thompson (2012) argues that to reduce discrimination in an organisation it is necessary to tackle interacting processes at the personal, cultural and structural levels. Training practitioners alone is not enough, a view shared by Kirkpatrick and Kirkpatrick (2006) who emphasise that effective training must incorporate the implementation of learning and an assessment of change. Bennett and Keating (2008), drawing on a literature review and scoping exercise, called for training to target specific problem areas, for instance diagnosis and detention, where change might be recorded. Instead, the training programme was described as insufficiently operational by the DRE director, Wilson (2009). Gunaratnam (2008) warns that an emphasis on cultural difference may not produce the individualised support that people want and could increase the risk of stereotypical generalisations about ethnicity and distress.

Racism is not easily tackled through training. McIntosh (2004) writes that White people often find racism too difficult to discuss. Lentin (2008) agrees: “Racism provokes a ‘don’t go there’ attitude which reveals that it is something we are both deeply familiar with and profoundly troubled by” (p.ix). Williams and Keating (2005) argue that people in positions of power find it easier to engage in discussions about culture which leave their privilege unquestioned. Jensen (2011), studying White supremacy, argues that “silences and denials surrounding [White] privilege” render discussions apolitical and fail to challenge assumptions of White-as-norm (p.87).

An unfinished task

Wilson's (2009) review of DRE suggests that it raised the profile of 'race' inequality, increased understanding and supported local initiatives. Robust evidence of change is scarce, but Boydell, et al.'s (2012) finding that satisfaction with sensitivity to culture and faith do not differ across ethnic groups suggests that some improvement may have occurred.

Statistics show that the task remains unfinished (2.2). An online survey of service users (RAWOrg, 2011) found that most thought little had changed, but the 28 respondents, the researchers note, come from a narrow group of Internet users. Sewell and Waterhouse (2012) interviewed 29 senior health service managers and conclude that "a lot of staff are locked in the traditional ways of doing things," as financial constraints and organisational changes hamper progress on race equality (p.17). Resistance to change can leave disadvantaged people blaming themselves for their situation.

Internalising oppression

Although class, gender and ethnicity define opportunities in life, Wright, Standen and Patel (2010) argue that low achievement among Black youth is often blamed on individual deficit, impacting on their self-belief. Black people have resided in the UK for generations, but they can still be regarded as outsiders (SCMH, 2002; Ramon, Ryan and Urek, 2010). Fanon (1961) argues that this gives people a sense of inferiority, partly due to economic factors but also as they internalise the values and perceptions of a hostile culture. Those with mental health problems see their peers negatively portrayed in the media, exacerbating a sense of hopelessness and exclusion (SCMH, 2002). Racism is internalised (MHF, 2003), as Black people absorb the dominant ideology unwittingly (Thompson, 2012). They may self-stigmatise, absorbing the poor prognosis associated with schizophrenia, low expectations of practitioners and popular attitudes. Internalised oppression leaves people without pride or hope.

Concluding comment

The shared pursuit of recovery obscures different meanings within different explanatory frameworks for distress. Recovery as defined by service users challenges the dominant authority of statutory providers. Recovery defined by Black people goes further, challenging wider oppressive social structures. The DRE programme supported local change brought about by committed individuals, and there is some evidence of wider improvements but continuing inequalities suggest a lack of systemic reform.

2.6 Chapter summary

There is an enduring disparity between the way Black and other social groups experience mental health services, education, police contact and aspects of socio-economic life. Some blame cultural deficit and poor parenting among Black families, but I acknowledge the in-depth qualitative and statistical research which points to structural explanations of social inequality and institutional racism.

This pattern of disadvantage sits alongside growing diversity and tolerance of difference. Policies, local initiatives and committed individuals aim to reduce inequality and promote recovery from distress. Efforts are hampered by a lack of systemic reform, reliance on medication and emphasis on risk avoidance, limiting scope for the personally-tailored support that service users want. Chapter Three explores how community activity might fill the gap, but first, Colin King sums up the message so far.

‘Being Mad’ by Colin King (1999)

I like to introduce myself, Mr. Insane, subnormal
and psychotic.
In England I’m Mr. Dangerous, difficult and threatening.
In my family, I’m a brother, son, Uncle and Friend.
At school I’m educationally subnormal, delicate
and confused.
At college I’m angry, distant and maintain a
white free zone.
In my dreams I’m brave, famous, knowledgeable
and articulate.
In my writings ineligible and badly presented.
In my verbal, mumbled, soft and unarticulated.
In public places I’m your potential robber and mugger.
At police stations, abused, heart problems,
potential death case.
With black people, approachable, loved, appreciated
and understood.
With white people, cultural misfit, colourless
and maladjusted.
With white women, a sexual objectification of pleasure.
With white men, masculine, penis orientated, feared.
In hospital, overly medicated, controlled
and misunderstood.
On the ward, no rights, no identity, an object of theory.

Chapter Three

Resistance, Mutual Aid and Change

“We must strive to ‘lift as we climb’.”
(Davis, 1987 p.5)

3.1 Introduction

Here I explore how Black communities respond to the way many Black people feel socially and economically excluded from wider society, framed within negative portrayals of their identity. Resistance takes many forms, some more organised than others. I describe and discuss Black initiatives within the context of community-led self-help organisations and smaller, member-led groups of people with shared health or social issues, and then consider the difficulties of assessing their benefits. First, I turn to alternative approaches to our historical narrative.

3.2 Resistance and self-help

Alternative narratives

The narrative of slavery supports White’s (2005) argument, as a historiographer, that history is imbued with ideology. Goulbourne (1990) observes that those who fought for change are often omitted from race relations literature. Gott (2011) agrees, arguing in his history of the British Empire that the role of rebellion in ending slavery is rarely acknowledged. Williams (1944) argues that economic circumstances made slavery untenable. Black historians Dabydeen, Gilmore and Jones (2010) write that generations of British historians give Wilberforce credit for ending slavery, but their research suggests that unrest, economics and Wilberforce all contributed to change.

Those who resisted oppression have often inspired others. In his study of White supremacy in the USA, Jensen (2011) writes that “Black pride can grow from the

collective resistance to white supremacy that black people have maintained throughout history” (p.27). The novelist Andrea Levy (2010) describes the strength of their ancestors as “a rich and proud heritage” (p.405). Saha, the Caribbean footballer, explains what it means to him:

“Without their fighting spirit I strongly believe my talent would not exist... We love and respect what our people have done for us, even as far back as times of slavery.” (2012)

I note Gott’s advice: “Focusing on resistance [is] a way of challenging not just the traditional, self-indulgent view of empire, but also the customary depiction of the colonised as victims, lacking in agency or political will” (2011, p.3).

Resistance takes different forms

Black resistance takes many forms including rioting, legal redress and collective self-help. Angel (2012), a social researcher, argues that UK ‘race riots’ differed in their sparks but shared deep-rooted causes of poverty and exclusion. Tensions erupted where immigrant families experienced racism, unemployment, poor housing and oppressive policing, notably in Notting Hill, Brixton and Handsworth from 1958 to the 1990s, with Northern riots a decade later. Jan-Khan’s (2003) political analysis of these events suggests that Black youth found life intolerable. The Ghanaian artist Akomfrah describes growing up in Handsworth:

“As a young man growing up in the 1970s you felt marked out for a special kind of treatment. And sometimes that treatment was dire. There was a moment when we thought, like all refusenik manifestos, ‘Fuck it. We’ll take this on. You’re right, we are different. We really don’t belong.’”
(2012, p.106)

Jan-Khan (2003) suggests that Black, Asian and minority ethnic (BAME) communities excluded by civil society have a right to riot: this is their voice. Bourne, the race relations academic, (2007) argues that it is protest, not “government beneficence,” that brings about change (p.3). Dabydeen, Gilmore and Jones (2010) concur that civil unrest prompted the anti-discriminatory *Race Relations Act 1965*, extended and strengthened in 1968 and 1976.

Some Black people have pursued justice through the courts, such as the international cricketer Constantine. In 1943, Constantine won damages when refused hotel accommodation because he was Black. He “revolted against the revolting contrast between his first-class status as a cricketer and his third-class status as a man” (James, 2005, p.139). Fifty years later, the dignity and determination of the Lawrence and Bennett families helped them to gain support from politicians and the media in their fight to expose racism and bring about change (2.3). Following the Macpherson report, the *Race Relations (Amendment) Act 2000* (extended in 2003 and 2006) placed a statutory obligation on all public agencies to eliminate racial discrimination and promote good community relations. Trevor Phillips (2009), Chair of the Equality and Human Rights Commission (EHRC), acknowledged the debt: “Without [Doreen Lawrence], we would have had no Inquiry, no *Race Relations (Amendment) Act* and probably no serious change in the behaviour of many of our public institutions.”

Public respect was affirmed when Doreen Lawrence held the Olympic flag in 2012, but she still pursues respect for Black youth. The poet Zephaniah (2003) rejected an OBE⁶ as a symbol of empire. As before, he criticised those who take public awards and then turn their backs on their community:

“It’s sick and self-defeating if our dispossessed keep weeping
And we give these awards meaning
But we end up with no voice”

(Zephaniah, 2001, p.16).

It was to heal and create a voice for their dispossessed that many Black people came to organise together.

Tradition of self-help

There is a strong tradition of collective action and mutual aid among Black communities. Dabydeen, Gilmore and Jones (2010) describe how, despite their

⁶ Order of the British Empire

different cultures, slaves formed vibrant societies. Afridi and Warmington (2009) cover the historical roots, socio-political context and challenges of the BAME third sector⁷ with a critical perspective useful to my research. They trace Black community action back to 18th century London. From the 1950s it flourished to assist newly-arrived Caribbean workers facing a hostile population (2.3). I describe their loosely structured initiatives as groups and organisations interchangeably.

From its earliest days, three main characteristics defined BAME third sector initiatives, according to Afridi and Warmington (2009). First, *self-help* is a readiness “to do for ourselves what British society cannot or will not do for us” (p.14). Initiatives provide advocacy, education, employment, housing, social support, arts activities and more. Wilson (2001) and Keating (2002) write that many Black-led initiatives respond to inadequate mental health services. Second, *mutuality* involves supporting community members, creating a sense of belonging and third, *political resistance* refers to collective action against racism and discrimination, generating community solidarity (Afridi and Warmington, 2009). Keating’s (2002) analysis of Black-led initiatives agrees that they share “a political and campaigning thrust” (p.10). Mayblin and Soteri-Proctor’s (2011) recent review of research found that Black community organisations remain “motivated by an anti-racist struggle against a white hegemony in access to both resources...and ideas” (p.24).

Support and solidarity combine

Activities providing support and promoting community solidarity tend to be inextricably entangled (Mayblin and Soteri-Proctor, 2011). Indeed, Hylton (1999) argues that practical issues often cannot be addressed effectively without taking culture and history into account. Newbigging, et al. (2007), in their review of Black mental health advocacy, describe this cultural, socio-political perspective within Black-led organisations:

⁷ The third sector comprises voluntary and community organisations and groups which re-invest any financial surplus to further their social objectives.

“They are rooted in the community and therefore understand the importance of Black history, of religious and spiritual beliefs, and of the social problems, in particular racism, faced by African and Caribbean people.” (p.21)

Black groups grew from the 1950s to the 1980s, inspired by the US civil rights and Black consciousness movement. Self-determination and collective action were paramount (Hylton, 1999). Like Biko (1978), groups sought to counteract internalised oppression (described earlier, 2.5). Hylton (1999) argues that by “casting off an inner yoke of psychological oppression” (p.6) and instilling positive identities, groups give Black people “the strength to withstand the negative external forces without cracking or becoming self-destructive...it is about not going mad” (p.50).

Independence threatened

From the 1990s services for BAME individuals were increasingly delegated to community organisations. Afridi and Warmington (2009) describe how partnerships with statutory authorities were welcomed by Black initiatives, even though they threatened organisational independence. In a comparative analysis of 14 Black women’s organisations, Davis and Cooke (2002) found that state patronage muted their radicalism. Pitchford with Henderson (2008), in their reflective analysis, refer to “mission drift”, arguing that public funding drove “many voluntary and community organisations away from their original aims of empowerment and social change towards an ever-growing focus on service delivery” (p.102). Pitchford and Henderson may underestimate the pressure that workers felt to respond to those in need, if necessary adjusting their priorities.

An ethos of political resistance often remains. Archer and Vanderhoven’s (2010) exploration into community self-help does not identify it, but their five case studies did not include a Black group. Wright, Standen and Patel’s (2010) more substantial study (2.4) found that Black community initiatives still address the problems facing local people within their broader context, counteracting “the

victimising and pathologising discourses that sustain ongoing racial discrimination and exclusion” (p.93). This, together with Mayblin and Soteri-Proctor (2011) and Newbigging, et al. (2007) suggests that countering the dominant narrative remains an important feature of Black self-help today.

Community-led initiatives differ from charitable services, which, Keating (2002) argues, “emerged from philanthropic ideas where wealthier people were taking an interest in the plight of the disadvantaged” (p.10). Hylton (1999) also rejects these as paternalist, associating the lack of autonomy with slavery. Instead, community activists “offer understanding and support precisely because they experience the same pressures but do not internalise the pain. As Bob Marley said: ‘Who feels it, knows it’” (pp.78-79). Shared experience instils a sense of belonging. Wright, Standen and Patel (2010) argue that “community-based organisations functioned to generate a sense of inclusion” (p.91). Like hooks⁸ (1991), they identify the margins as a safe and radical space free from dominant ideologies.

Culture of mutuality

While necessity drives these initiatives, Rai-Atkins, et al. (2002) note how cultural principles of mutuality and collectivism contrast with the Western focus on individuality. Bantu languages across much of Africa link the individual to the community in the concept of ‘ubuntu’:

“As Emeritus Archbishop Desmond Tutu deftly explains, ‘Ubuntu is not, “I think therefore I am.” It says rather: “I am a human because I belong. I participate. I share. In essence, I am because you are.”’ Ubuntu, therefore, in essence is diametrically opposed to individualism, and embraces the fact that human beings cannot exist in isolation, but are somehow interconnected to each other.” (Ebrahim, 2011, p.133)

Ubuntu conveys a sense of shared responsibility: we do well or badly when our community does well or badly. The Swahili concept of ‘ujamaa’ similarly describes a community characterised by social and economic cooperation. Hylton (1999) finds that successful Black people “who do not assist their less fortunate

⁸ bell hooks chooses to use lower case letters in her name.

community sisters and brothers are usually deemed to have ‘sold out’” (p.27), echoing Zephaniah.

Volunteering is often viewed as a White preserve, so to explore the nature of Black volunteering qualitative researchers recruited 162 African, African Caribbean and South Asian people with current, past or no involvement in volunteering (Obaze, 1992). They found Black volunteers were motivated to help other Black people, often carrying out informal, neighbourhood activities. Obaze concluded: “Black volunteering is largely about black self-help” (p.134). Hylton (1999) and, more recently, Mayblin and Soteri-Proctor (2011) observe that Black people do not describe contributing to the community as volunteering. Jones (2009), writing from experience, states that self-help within BAME communities includes informal, fluid networks of people who help each other, “invisible to the system, not supported and invariably not funded or recognised outside of the area they operate” (p.231). Reviewing research into ‘below the radar’ community activity, McCabe, Phillimore and Mayblin (2010) concur, but note significant challenges, which I consider next.

Gender-based tensions

Several studies have found Black initiatives challenged by gender-based tensions. Chouhan and Lusane (2004) examined the Black third sector, drawing on a literature review, surveys and focus groups involving about 57 Black groups and 200 people. They found that patriarchal traditions dominate community life: “While Black women head up many Black-led and community sector projects and very often are those ensuring the sustainability of the projects, it is men who seem to be projected in the public eye” (p.10). Davis and Cook (2002) found women often prefer to organise separately, feeling excluded by both mainstream society and Black patriarchal communities. A national study of self-help groups by Wann (1995) found that Black women feel “they need to have their own space” (p.58).

Men's forums have developed in parallel, but in smaller numbers (Hylton, 1999). Hylton believes that men's lesser involvement in community organising is explained by their lower self-esteem (2.4): "It is difficult, if not impossible, to motivate young African Caribbean men to sustain their participation in African Caribbean organisations – whereas African Caribbean women have a high rate of involvement" (p.19). Insufficient funding is another barrier to community action.

Insecure and insufficient funding

Studies of BAME initiatives consistently report insecure and insufficient funding. Chouhan and Lusane (2004), McCabe, Phillimore and Mayblin (2010) and others describe how community initiatives tend to focus on immediate concerns, with little capacity for funding applications and administration. Chouhan and Lusane (2004) found that funders often saw these initiatives as service providers. As contracts replaced grants from the 1990s, tension emerged between fluid community-led activities and accountability to funders for pre-determined services. Munn-Giddings, et al. (2009) argue that this tension increases where mental health user-led organisations adopting a social model of distress are funded by statutory agencies prioritising a medical model. As contract funding is replaced by payment for individual service users to increase personalised support, initiatives require even greater business and marketing skills (Dickinson and Glasby, 2010).

Funding difficulties have escalated with the recent economic downturn. A London survey by Race On The Agenda (ROTA) (2009) found that many BAME third sector organisations feel isolated and unsupported, as they face greater demands relating to poverty and unemployment with reduced funding. A survey in the Southwest (Crawley and Watkin, 2011) found that "significant numbers" of established voluntary and community groups are closing and "many say that they have never been faced with such a challenging environment" (p.3).

Organisational tensions

Funding issues interact with organisational capacity. A London review and survey of Black organisations addressing mental health issues found that insecure, short-term funding limited investment in infrastructure and development (Greater London Authority, 2005). Hylton (1999) found that some Black leaders rejected bureaucratic systems as not “the African way” (p.36). Chouhan and Lusane (2004) suggest that a “relaxed management style” within grassroots organisations creates tensions with funders. Lack of transparency can also generate internal tensions (Hylton, 1999). Political change adds to the pressure.

Operating in a changing world

Northern riots and the Al-Qaeda attack in London “dramatically changed the terms of the debate” on race relations (Afridi and Warmington, 2009, p.58). The Commission on Integration and Cohesion (2007) which followed these events described ethnic identity groups as potentially separatist, hampering community cohesion. The *Equality Act 2010* places ‘race’ within a span of inequalities to be tackled including gender issues, age, faith, disability, maternity and sexual orientation. Official guidance allows service providers to take positive action for particular groups if their needs are different or they experience disadvantage (EHRC, 2012), but the debate continues.

A study of the support needs of BAME organisations by Equal to the Occasion (Etto), (2010) refers to a “tension between mainstreaming equalities and separate, self-controlled, self-organised provision” (p.37). Etto’s study, involving a literature review and qualitative research with over 130 organisations, raises challenging questions about perpetuating tokenistic funding, neglecting minorities within minorities, and the imperative of working across equality strands. Afridi and Warmington (2009) acknowledge an increasing emphasis on multiple identities and challenge ethnic identity groups to consider how they meet the needs of people holistically, as human beings.

Concern about gender equality has been mentioned. Begum's (2006) report on service user involvement suggests that people with mental health problems often lack influence within the BAME initiatives set up to help them. These organisations "have shown a limited, and sometimes absent, commitment and ability to actively promote the involvement of their service users" (p.9). Instead, workers tend to speak on behalf of people with mental health problems. Begum's evidence base is not clear, but if she is right, Black community-led initiatives may not encourage groups led by and for Black service users.

Concluding comment

Historical, cultural, socio-economic and political factors shape how Black communities respond to their negative portrayal and widespread disadvantage. Their initiatives are under constant pressure as government policies and lack of funding demand development skills and infrastructure that many lack. Today their role is questioned as 'race' relations and equality issues become more complex, but their drive to address exclusion and internalised oppression remains alive (2.4; 2.5). Next I explore small, self-organising groups where Black people with mental health problems can take the lead.

3.3 Autonomous mutual support groups

Spectrum of groups

The small, autonomous, mutual support groups in this study connect with three overlapping contexts. The reciprocity and generosity of self-help/mutual aid groups resemble the community-led initiatives described earlier. Peer support groups grounded in expertise by experience often emerge from the mental health field where understanding of distress is greatly contested (2.2). Service user groups provide a base from which to challenge mainstream services and link with service user networks. In Seebohm, Munn-Giddings, and Brewer (2010) we argue that there is more similarity than these differences suggest, but literature rarely spans the field

and little is known about BAME groups. I consider the distinctive and shared features behind group labels.

Variety within self-help

Self-help/mutual aid groups are grassroots, self-organised and collectively owned, bringing people together to address a shared health or social issue through mutual support (Munn-Giddings, 2003). I distinguish groups from individually-focused self-help, which is outside my remit here. Munn-Giddings and McVicar (2007) write that self-help/mutual aid groups have increased internationally since the 1980s, yet Chaudhary, Avis and Munn-Giddings (2010) find limited research relating to UK groups. This gap is partially addressed by the Effective Support for Self Help/Mutual Aid Groups (ESTEEM) project, a three-stage, participatory qualitative study (ESTEEM, 2011; 2013). ESTEEM involves 21 self-help/mutual aid groups covering a range of health and social issues, including one Chinese and three South Asian well-being groups, and 26 practitioners who support these or similar groups. The focus and depth of ESTEEM made it useful here.

Self-help/mutual aid groups describe themselves in many ways (Chaudhary, Avis and Munn-Giddings, 2010; ESTEEM, 2011). US researchers Kyrrouz, Humphries and Loomis (2002) and others use ‘self-help group’ instead of or interchangeably with ‘mutual aid’ or ‘mutual help’ group, but I prefer the way Munn-Giddings and Borkman (2005) deliberately combine the words and separate their meanings in the term ‘self-help/mutual aid group’:

“because it is the combination of self-responsibility with the reciprocity (mutuality) of relationship with others and the consequent processes within the groups that helps the individuals to help themselves.” (p.140)

In their UK-based case study research of four user-led organisations, Munn-Giddings, et al. (2009) distinguish informal groups from organisations with more formal structures, paid staff, and funding to deliver services. In contrast, Brown, et al. (2007) in their US-based study of 21 consumer-run

organisations suggest there is a continuum rather than a clear dichotomy between groups and organisations which may grow “from a small group of passionate but often inexperienced volunteers” (p.80). They argue that within the mental health field, the self-help/mutual aid philosophy is shared across this continuum:

- “(1) the promotion of inner strengths,
- (2) a reliance on helping each other,
- (3) a rejection of hierarchy,
- (4) a sense of community,
- (5) empowerment and participation, and
- (6) self-acceptance and openness.” (Brown, et al., 2007, p.74)

Retaining group control

Control of the group by its members is a defining feature of self-help/mutual aid groups. Wilson (1994) carried out an in-depth UK-based qualitative study involving over 100 self-help groups, practitioners and policy specialists. This emphasises the importance of group members with direct experience of the shared issue retaining control over their group. Case study research of two carers’ self-help groups by Munn-Giddings and McVicar (2007) suggests that control by members gave the groups a distinct ethos and impact. This differed from professionally-managed support groups, offering a unique mix of emotional and practical support.

Practitioners often have some involvement in groups. Shepherd, et al. (1999), in their US study involving 246 groups in structured interviews, found a continuum of practitioner involvement, with no clear distinction between professionally-managed and member-led groups. Bignall, Butt and Pagarani’s (2002) qualitative study of five groups found that the relationships between practitioners and the BAME members tipped between fostering independence and dependency. Chaudhary, Avis and Munn-Giddings (2010) conclude that more research is needed on the roles and relationships of practitioners supporting groups.

Difference and commonality

The service, political and cultural landscape influence practitioner involvement and group focus. Munn-Giddings and Stokken (2012) note, in their discussion of international perspectives, that facilitative support from statutory sector practitioners is not unusual in Scandinavia while US groups tend to be more distant. Munn-Giddings's (2003) doctorate study of self-help/mutual aid groups distinguishes between the community-oriented groups of South America, Africa and Asia, and the predominately single-issue groups of North America, Canada, Scandinavia and Europe. In an exploratory study of community development (CD) and mental health in the UK (Seebohm and Gilchrist, 2008), we found both single issue and community-oriented self-help initiatives. Across this range, self-help/mutual aid groups are widely agreed to have common features:

“They are run for and by people who share the same health or social issue;
Their primary source of knowledge is based on sharing direct experience;
They occur as voluntary collectives predominately in the third sector of society as opposed to the statutory or private sectors.”
(Munn-Giddings and Borkman, 2005, p.139)

While some self-help/mutual aid groups are small and cohesive, others operate as loose networks. In Seebohm, et al. (2013) we felt that three of ESTEEM's four BAME self-help/mutual aid groups fell into the latter category. Loose networks may not be unusual among BAME groups, as 4Sight, a London-based group of 60 members (Friedli, 2009a) and Simba (described below) also operated this way.

Many self-help/mutual aid groups pursue interests beyond the group, including education and campaigning (Adamsen and Rasmussen, 2001; ESTEEM, 2011). Some groups focus on sharing stories and talking together, but my earlier action research involving three BAME groups (Seebohm, et al., 2005) found that their members preferred to organise around activities. Avis, et al. (2008) in their participatory, qualitative study of BAME self-help groups suggest that group members may prefer to sew, cook or eat together “to facilitate the sharing of experiences as a ‘by-product’ of being involved in a common activity” (p.945).

Similar groups in the mental health field are often described as peer support groups.

Nuances of peer support

Peer support groups, like self-help/mutual aid groups, are defined by their unique quality of reciprocal support among those deemed to be peers. Mead, et al. (2001) describe its magic:

“It is about understanding another’s situation empathetically through the shared experience of emotional and psychological pain. When people identify with others who they feel are “like them”, they feel a connection. This connection, or affiliation, is a deep holistic understanding based on mutual experience where people are able to “be” with each other without the constraints of traditional (expert/patient) relationships.” (p.135)

Peer support and self-help/mutual aid group processes are indistinguishable, described here by Perkins (2010a) as:

“based on mutuality and a shared journey of discovery within which people help and support each other as equals, share their personal stories, teach, learn and grow together.” (p.3)

The reciprocal nature of support is important. McLean, et al. (2009) note how the term ‘peer support’ increasingly refers to paid, professionalised roles delivering support to others, but these are outside my remit here. Munn-Giddings and Borkman (2005), drawing on their extensive research, believe that the reciprocity of support among equals forms an essential feature of self-help/mutual aid groups. Those involved in my action research (Seebohm, et al., 2005) felt that the opportunity to both give and receive help was a critical factor in the groups’ impact. Riessman (1997) suggests that helping others instils feelings of self-efficacy and competence, while Maton (1988) argues that those who both give and receive support gain more than people who only do one of those. Katz and Bender (1976) describe how group members may receive help from one person and ‘repay’ another at a different time or place, demonstrating ‘serial reciprocity’.

In the context of this study, it is important to understand who is regarded as a peer. Faulkner and Kalathil (2012) carried out a brief literature review and discussions with nine mental health peer support initiatives. They concluded that although a shared experience of distress is fundamental, there also need to be “other shared experiences, identities and backgrounds” (p.18). Black group members sought a shared experience of being Black within the mental health system: “The specific experience of being black survivors of the mental health system was a vital part of their sense of belonging and supporting each other – sometimes more important than the shared experience of mental distress” (p.20). The authors focus on informal, organic forms of peer support which, they argue, have particular value for marginalised communities, and believe them to be best located within user-led organisations. Bassett, et al.(2010) also argue that peer support initiatives must link with the voluntary sector and service user-led groups to maintain their grassroots ethos.

Sometimes it is the terminology that matters. In a discussion paper (Seebohm, Munn-Giddings and Brewer, 2010) we suggested that it is the relationship with people like us which gives the term ‘peer support’ a less deficit-based nuance than ‘self-help’ and appears more socially than individually focused. We enjoy peer support in the workplace, college and club. Its normality appeals to groups who might otherwise be stigmatised, for instance Black youth with disabilities (Bignall, Butt and Pagarani, 2002). It resonates with non-Western cultures which prioritise community connections (3.2), avoiding the problem, found by Avis, et al. (2008), that some people assume that self-help groups adopt “an individualistic western view” (p.945) and it avoids the stigma sometimes associated with ill-health.

Service user groups

Mental health service user-led groups are positioned adjacent to service providers. The largest UK survey and qualitative study of user groups was broad and inclusive (Wallcraft, Read and Sweeney, 2003). The 318 participating groups carried out a range of activities, particularly self-help and social support (79%), consultation with decision makers (72%), education and training (69%) and to a lesser extent, creative activities, campaigning and advocacy. While mutual or peer support was important, the struggle for rights and better services was also a high priority, as it is in some self-help/mutual aid groups.

Relationships between service user groups and service providers can be difficult. Faulkner and Kalathil (2012) found that policymakers do not always understand the significance of a collective grassroots approach and group ownership. In Seebom, Munn-Giddings and Brewer (2010) we express concern that commissioners may be primarily interested in how Black groups help public authorities to meet statutory requirements. Funding may come with an expectation that members participate in service user-involvement processes, which some feel are increasingly designed in the interests of statutory services:

“Many now feel that user involvement (based on very sound principles and fought for by the user movement) has become appropriated by mental health professionals who seek to draw users/survivors into their pre-existing professional structures and systems with little regard for whether such systems (usually formal meetings and loads of paperwork) are actually appropriate or relevant to the user/survivors with whom they are trying to work.” (Trivedi, et al., 2002, p.30)

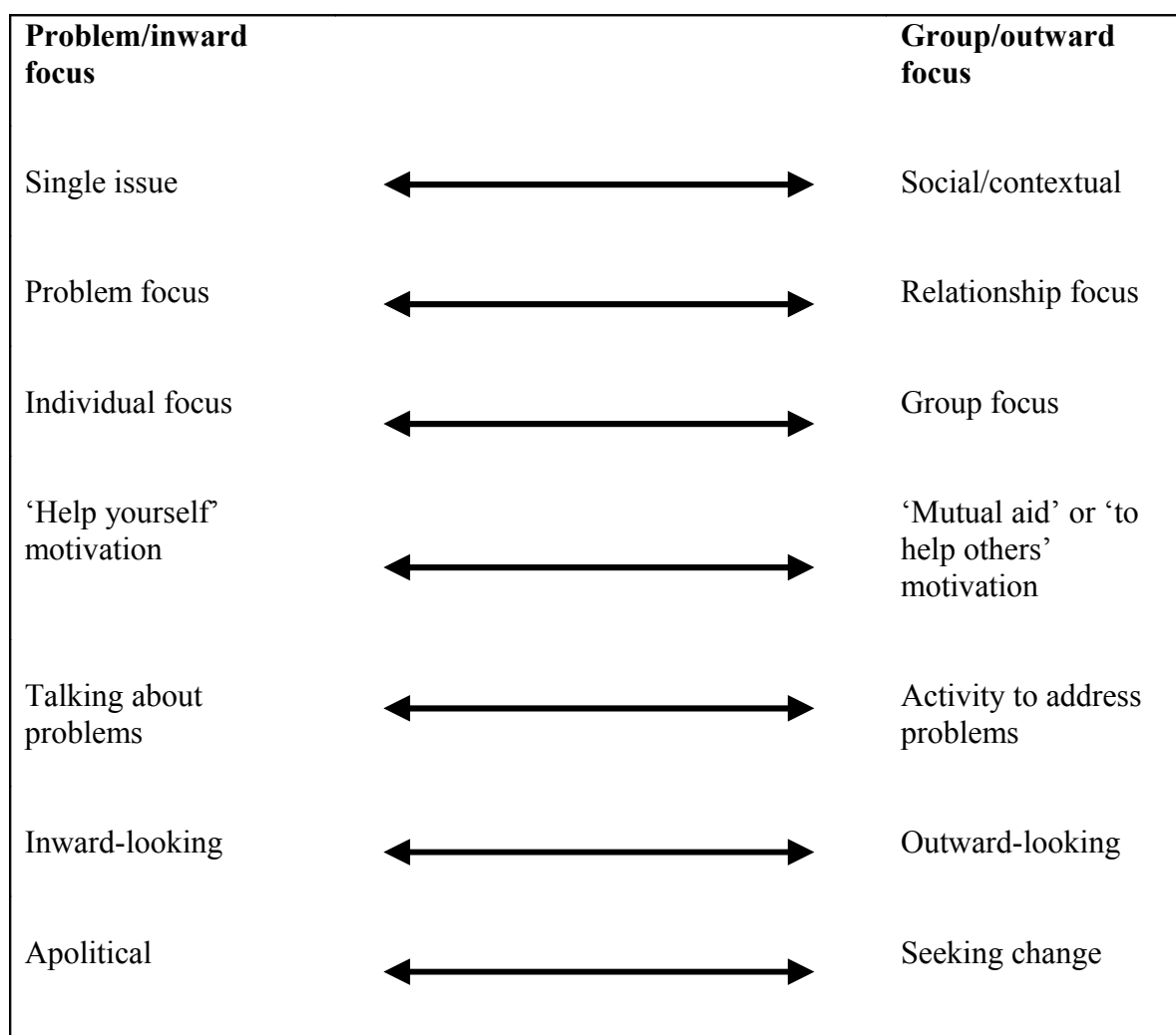
User involvement forums are typically White; Wallcraft, Read and Sweeney (2003) found BAME service users largely absent. Trivedi (2009), reflecting as a survivor/ researcher, believes that this is partially explained by unmet needs and lack of trust. The experience of being Black cannot be disentangled from the service user experience, while mainstream user groups do not comprehend the experience of racism and discrimination in the same way. Kalathil's (2008) consultation with BAME service users found that they sometimes experience racism within user-involvement spaces. A follow-up consultation involving few

participants (Kalathil, 2011) suggests that the visibility and strength of BAME user-led groups had risen, just as “the resources and structures to sustain them are diminishing” (p.18), but the evidence seems largely anecdotal.

Shared features, different emphasis

Many have tried to divide self-help/mutual aid groups into categories (e.g. Schubert and Borkman, 1991). Bearing in mind earlier concerns about categorising social phenomena (2.2), I find Wittgenstein’s (1974, p.32) concept of “family resemblance” useful here. It links groups through a range of possible family features, as set out in the grid (Diagram 2) below. Groups may focus inwards to support their members or direct their energy outwards to challenge oppressive structures and unhelpful services. Some do both. Features may vary in prominence across all groups but overall, self-help/mutual aid groups may *tend* to begin their life towards the left of the grid, while peer support groups and service user groups *tend* to be on the right. Black-led community-based initiatives would be on the right of the grid. Examples will be found to contradict this pattern and groups may change over time as their membership, interests and circumstances change. Seebohm, Munn-Giddings and Brewer (2010) argued that mutual aid and reciprocity characterise all the groups and are generally regarded as their greatest asset.

Diagram 2: Spectrum of opposing characteristics in self-help, peer support and service user groups



Source: Seebohm, Munn-Giddings and Brewer, 2010, p.26.

Autonomous Black mental health groups

Little is known about self-organising Black mental health groups. Avis, et al. (2008) point to a lack of data, with some studies suggesting that people from BAME backgrounds are under-represented in self-help/mutual aid groups as a whole. Wilson (1995) suggests that some self-help groups have made people from BAME backgrounds feel less than welcome. The lack of UK data may be partly explained by the hidden and intimate nature of self-help activities which inhibit

demographic monitoring. Two of ESTEEM's (2011) four BAME groups operated 'below the radar', publicised by word of mouth through informal networks. These four groups received more support than most of ESTEEM's other 17 participating groups and, as mentioned earlier, three operated as networks, but they were otherwise broadly similar: they met the specific concerns of their membership, offered mutual support and occasionally campaigned for better services. They were not overtly political, nor were they Black groups.

Chaudhary, Avis and Munn-Giddings' (2010) database analysis of 936 emerging or established self-help groups in Nottinghamshire lacked demographic details but they found, separate from and in parallel with other groups, 31 Asian groups and 35 Black groups, resonating with Obaze's (1992) finding of parallel volunteering. The availability of specialist support for self-help in Nottingham may have generated more groups here than elsewhere.

In her analysis of UK self-help groups, Wann (1995) suggests that BAME groups tend to take a holistic approach rather than focusing on specific issues, with a few exceptions, for instance around sickle-cell anaemia. My literature and Internet search for Black mental health groups revealed little information. Three groups are profiled below: Simba, a group for people who identify themselves as Black (Jones, 2009); Maat Probe, a group for Black men, described in the newspaper *The Voice* (Motune, 2012); and Creative Expressions, a group for women from different BAME backgrounds (Seebohm, et al., 2005).

Box 1: Simba (Share in Maudsley Black Action)

Simba is a group of individuals who identify as Black and share the experience of being an inpatient with a mental health diagnosis. Driven by the desire to make things better for others who experience the mental health system, they “could not sit back and do nothing”.

Simba was set up in 1999 within the South London and Maudsley NHS Mental Health Trust (SLAM), run by and for Black mental health survivors to raise awareness of the issues Black people face in mental health services. The group established their independent status, setting the agenda and terms of engagement in their dealings with SLAM using poetry, music, art and drama to make their point:

“Members were clear from the outset that they did not want the traditional user-involvement model of meetings, formal committees and paperwork.”

Simba members provided mutual support, shared coping strategies and supported those on the wards. Debate, music, poetry and creative writing promoted self-awareness and sense of identity.

After two years the energy and creativity of the group decreased as it developed into an organisation with substantial funding from SLAM’s charitable trust.

Source: Summarised from Jones, 2009, pp.226-231.

Box 2: MAAT Probe Group

MAAT Probe was set up as an African-Caribbean men’s self-help group in 2009 with support from Sheffield African-Caribbean Mental Health Association (SACMHA). The group’s aim was to provide mutual support and increase public awareness of the issues facing Black men in mental health settings.

With a grant of £2,000 from Open Up, an anti-stigma organisation, they conducted a survey of local Black service users. Results showed deep dissatisfaction with hospital care which they shared with NHS managers. As a result of MAAT’s campaigning, Sheffield Care Trust is training nurses in ‘Respect’, a new approach to restraint. One member commented:
“Maat Probe group has helped me in my recovery and has helped me to be proud of my African-Caribbean culture.”

Spending cuts threaten the group’s future as SACMHA’s block funding is withdrawn faster than funding from other sources can be generated.

Source: Summarised from Motune, 2012.

Box 3: Creative Expressions

The Creative Expressions group was set up in 2003 by a woman who had been referred to a psychiatrist but preferred to deal with her problems through poetry. It is one of several self-help/mutual aid groups supported by a community development mental health organisation, Sharing Voices (Bradford). The women, from different BAME backgrounds, feel the group offers a safe space where “a difficult experience can become a source of inspiration, enabling people to use their talents to help themselves and others”. Activities include writing, dance, drama, music and talking.

“It’s taking my inner self out of me...to show what I can do.”

“We talk to each other with respect. We care about each other and that’s the difference as well, that’s what makes it special.”

“I ...like to sing positive music to help people when they are depressed, with songs that lift people’s spirits.”

Members say that the group improves their well-being but group stability is affected when some move on to work and study.

Source: Summarised from Seebohm, et al., 2005, pp.52-53.

In these groups, storytelling and mutual support wove around shared activities. Two groups campaigned for better services on their own terms, rejecting mainstream user-involvement structures. 4Sight, a Black user-group evaluated by Friedli (2009a) also focused both inwards, providing peer support, and outwards, on improving services, mirroring the combination of self-help and campaigning described earlier. Griffiths, an activist and practitioner, initiated 4Sight in the hope that it will restore “a sense of community belonging and cultural identity. It is this loss that lies at the core of their struggles with mental health” (quoted in Friedli, 2009a, p.14).

Two of the profiled groups enjoyed creative activities, as did 4Sight. A qualitative study of Black service users, carers, providers and artists (Griffiths, 2005) finds that creative expression is a valued way of developing cultural identity and pride,

building protection against discrimination. Simba and Maat Probe emphasised identity-building. Two groups received close support from a third sector host organisation (SACMHA and Sharing Voices Bradford), while Simba began with strong internal leadership based within a statutory host (Trivedi, 2010b). All three groups appeared to increase well-being and self-esteem, but funding issues and the loss of key members threatened their sustainability and ethos.

Only one group describes itself as self-help. In their study of BAME cancer self-help groups, Avis, et al. (2008) found “a variety of forms of mutual support or group activity that were not called self-help” (p.944). Wann (1995) and Wilson (1995) found that BAME groups often prefer to develop self-help/mutual aid processes “in a more general setting such as a church, temple, or through adult education or social activities, in groups which are informal and loosely structured” (p.134).

Concluding comment

The context, purpose and membership of the groups described here tell us more than their different labels. Shared features include an ethos of mutual support, control by group members and the prioritising of experiential knowledge in contrast to dominant forms of power and knowledge (2.2). Wilson (1994) characterises statutory and group settings as ‘two worlds’ which come together, often amid tension, through practitioner involvement, funder’s expectations and user-involvement processes.

Little is known about autonomous Black mental health groups. Data here comes from small, Internet and unpublished reports or forms a small part of larger studies. All Black member-led groups mentioned here were supported by practitioners or organisations but little is known about the nature of this support. Next, I discuss the potential benefits of self-organising mutual support groups, to explore whether it is important to promote their development.

3.4 Benefits of autonomous mutual support groups

The intimate and hidden nature of self-organising mutual support groups makes their evaluation difficult and potentially intrusive. Data may not be trustworthy; Friedli (2009a) notes that “membership projects often generate high levels of loyalty which may make it difficult for members to give negative feedback” (p.52). Fear of losing funding may increase these difficulties. Attendance at these groups is voluntary, so it is not surprising that Kryouz, Humphreys and Loomis, (2002), in their review of research, suggested that feedback from group members at any one time will be positive. Pistrang, Barker and Humphreys (2008), in their review of research on mental health groups, agree that there is a “large literature of surveys, qualitative studies, and first-person accounts [which] attests to the subjective benefits of mutual help groups”, but evidence of causality remains elusive (p.111).

Different purposes require different methods. In Seebohm, et al. (2013) we recommend participatory approaches to evaluating self-help/mutual aid groups. These would enable group members to measure outcomes that they deem to be important, assess their assets and identify developmental priorities, but these methods may lack wider credibility. Pistrang, Barker and Humphreys (2008) wanted convincing evidence of group outcomes that they could compare with service outcomes.

Acknowledging these challenges, I report on some pertinent studies. In their review, Kryouz, Humphreys and Loomis (2002) only included studies that measured how group members change over time or that compared outcomes with non-members. Half of the eight studies of mental health groups reported reduced use of mental health services and all reported improved mental health, including greater self-esteem and less anxiety compared to an earlier time or with non-members. Pistrang, Barker and Humphreys (2008) investigated the causal relationship between group participation and mental health outcomes. They only

included studies reporting at least one mental health outcome measure related to symptoms, hospitalisation, medication or social functioning, using a comparative group or longitudinal design. Twelve studies met these criteria, of which seven reported positive changes while five showed no change. No studies indicated negative effects. Two randomised controlled studies indicated strong benefits at low cost compared to services.

Self-help/mutual aid groups have been linked to increasing well-being. Pistrang, Barker and Humphreys (2008) write that studies describe improvements “in terms of identity, life narrative reconstruction, spiritual development, and a sense of feeling cared about” (p.111). Personal accounts (e.g. Tyldesley and Phillips, 2009) often describe how people feel their burdens lighten when they come together and share their stories with people who have similar experiences.

ESTEEM explored how groups contribute to mental well-being (Seebohm, et al. 2013). Our in-depth, qualitative approach aimed to draw out negative as well as positive experiences from a range of 21 groups (see above). Data from 21 interviews and 20 group discussions were analysed using a coding framework based on the checklist of protective factors for well-being developed by the National Mental Health Development Unit (NMH DU) (2011). This checklist contains three categories: ‘enhancing control’; ‘increasing resilience and community assets’; and ‘facilitating participation and inclusion’. Each category contains 10 to 11 factors such as sense of control and sense of belonging. Participants reported a positive impact across all categories. They highlighted how the groups provide supportive relationships, fun, learning, and especially, the opportunity to help others, a factor that NMH DU had omitted. Belonging to the group was said to increase hopefulness, self-belief and resilience, meaning the capacity to do better than expected in the face of adversity. Some participants expressed concern about the lack of group sustainability and insufficient sharing of tasks, leaving a few coordinators feeling burdened by their role. There was no identifiable difference in the BAME data, but as only four BAME groups were

involved and the concept of well-being is culturally determined (Newbigging and Bola, 2010), different perspectives are possible. Reports on well-being (Friedli, 2009b; Newbigging and Heginbotham, 2010) emphasise that support for local initiatives must be part of a wider strategy for social justice, involving community collaboration to ensure that all social groups benefit.

Self-help/mutual aid groups have been linked to empowerment. An evaluation of six mental health self-help groups in the US by Chamberlin, Rogers and Ellison (1996) identifies empowerment as a consistent goal (4.4). Exploring this, Chamberlin (1997) describes the storytelling within the groups. Sharing stories developed into an educative process whereby members replaced self-blame and pathological identities with self-esteem as they reflected on the social, political and economic structures that affected them. Problems seen within their wider context became understandable, shared by others and not deemed unworthy, contrasting with the individual, medical interpretation given by statutory services.

Group processes may strengthen members' sense of identity and culture. Bracken and Thomas (2005) argue that this does not lead to static labels but rather to a sense of self-worth and meaning in their lives. Gilchrist, Bowles and Wetherell (2010) explored contemporary trends in identity by reviewing 25 qualitative research projects which involved 12,000 participants over five years. They found that people who feel isolated, stigmatised and at fault can, through group processes, become proud of who they are. They conclude that ethnic identity initiatives do not separate people from society, as politicians fear, but enable them to re-enter society on a stronger footing.

There is scant evidence about groups led for and by Black people with mental health problems. Friedli (2009a) based an evaluation of 4Sight, the service user group for Black men, on the views of about 20 of its 60 members, 12 mental health practitioners and four other NHS workers who support the group, using questionnaires, interviews and focus groups. 4Sight aims to “promote a user-led

agenda and peer support,” enabling members to gain more choice and control over their lives. It also aims to improve the way that services respond to Black men. Overall, the research suggested that 4Sight was meeting its objectives based on a snapshot rather than evaluation over time. Group activities (including drama, arts, mentoring, training) “contribute significantly to the quality of members’ lives” (p.6), although members sometimes complained of poor continuity. Members consistently reported feeling valued, respected and empowered, gaining confidence, self-belief and a sense of belonging. A few gained employment and more started training. Stakeholders within the NHS and voluntary sector felt that 4Sight was “fulfilling a vital need in the African and Caribbean communities” (p.7). However, the evaluation also found that 4Sight could have done more to support the strategic goals of its host, East London NHS Foundation Trust, if given secure funding and greater professional recognition. The evaluation exposes but does not explore contradictions between 4Sight’s description as a user group and a programme, reminding us of the complexities around professional involvement in groups.

In Seeböhm, et al. (2005) we had similar findings. Participatory action research involved three BAME mental health peer support groups within a wider evaluation of Sharing Voices. Members spoke of gaining a sense of belonging, becoming more empowered and enabled to achieve their goals, including jobs, training and voluntary work.

Concluding comment

Research into self-help/mutual aid groups is challenged by their intimate, fluid nature. A tension exists between demonstrating their value to statutory funders and enabling group members to assess what matters to them. Evidence associates group membership with improved self-esteem, belonging, well-being and empowerment. It suggests that these groups provide a uniquely understanding, non-hierarchical form of support, based upon shared experience. Black group members are said to value and shape groups to fit their own aspirations.

3.5 Chapter summary

This chapter has described and discussed the historical, cultural and political shape of Black resistance to racism and exclusion. I have considered similarities and differences between community-led organisations and differently-labelled self-organising mutual support groups, identifying consistent themes. Uncertain sustainability, funding and little statutory recognition contrast with the perceived benefits of the groups. These suggest that Black mental health groups could be an invaluable resource, although they may need more support than other self-organising mutual support groups. The next chapter explores how CD may provide this support. First, Simba sums up what a Black space can offer.

SIMBA'S BLACK SPACE

A sanctuary, security
A safe place to be, in harmony.

Identity, diversity
A vibrant place - solidarity.

Creativity, spontaneity
An amazing place - excitingly.

Spirituality, community
A special place - lovingly.

Unity, non-judgementally
An important place – definitely.

(SIMBA, March 1999)

Chapter Four

Community Development, Mental Health and Empowerment

“If you are neutral in situations of injustice,
you have chosen the side of the oppressor.”
(Tutu, n.d.)

4.1 Introduction

This chapter explores how community development (CD) can support community-led initiatives and the small, autonomous mutual support groups described in Chapter Three. I describe and discuss the contested nature of CD and its potential in mental health contexts, including its role within the Delivering Race Equality in Mental Health Care (DRE) programme (DH, 2005a). Relevant aspects of empowerment are considered, before I outline the gap in knowledge that this thesis addresses.

Few studies encompass CD, mental distress and Black groups so I draw substantially on my own earlier research. I have already mentioned action research (AR) at Sharing Voices (Bradford), a CD mental health project for people from Black, Asian and minority ethnic (BAME) backgrounds (Seebohm, et al., 2005; Thomas, et al., 2006; Henderson, et al., 2007). This evaluation process involved three peer support groups, volunteers, stakeholders, staff and management over a period of about one year.

In Seebohm and Gilchrist (2008) we explored CD’s potential contribution to mental health for the National Social Inclusion Programme, Department of Health. This employed a literature review, survey and interviews in eight sites with a self-selected sample, illustrating positive rather than representative practice. The study informed an article for the *Community Development Journal’s* special issue on mental health (Seebohm, Gilchrist and Morris, 2012). I also draw

substantially on Gilchrist's other work (e.g. 2009), for its detailed analysis of CD and identity issues.

Concepts and terms used here are ambiguous (discussed in 1.2). I remind the reader that CD is both a profession and a way of working (LLUK, 2009). I refer to those in paid CD roles as CD workers (CDWs) and use the umbrella term 'CD practitioner' when referring to "anyone who...is using a community development approach...whether as a paid worker or a community activist/volunteer" (LLUK, 2009, p.4).

Community, a concept central to CD, has many definitions. Williams (1988) finds it an evocative, "warmly persuasive word" (p.65), suggesting a sense of belonging. Chanan, Garratt and West (2000) believe that a sense of community combines rational with emotional elements: people value the benefits of community for both practical and heartfelt reasons. In contrast, communities may exclude (Dunn, 1999) or fragment (Ouseley, 2001). Like Williamson (2007), I identify three types:

- locality: geographical communities;
- interest: people with a shared interest or concern;
- attachment: people with a common sense of identity and level of interaction.

Here these overlap as people living nearby come together because of shared identities and interests relating to ethnicity and mental health. Hylton (1999) describes how Black community connections reflect commonalities and divisions based on gender, status, generation and neighbourhood. CD practitioners operate within and across these networks (Gilchrist, 2009). Next, I explore how this happens.

4.2 Approaches to community development

Architecture

The form that CD takes is determined by its context. Drawing on their international experience as practitioner/academics, Henderson and Vercseg (2010) write that CD goals, philosophies and strategies shift according to their geographical, political and social context. Craig, et al.'s (2011) historical analysis reveals CD's ambiguous nature: CD is "not a neutral intervention but is ideologically contested" (p.7). Yet these authors, and I with them, understand CD as a process based on core principles: "the fundamental architecture of community development is the same" (Henderson and Vercseg, 2010, p.4). The *Budapest Declaration* (International Association for Community Development, 2004) signed by CD practitioners from 30 countries reflects values listed within the UK's National Occupational Standards for CD:

- Equality and anti-discrimination
- Social justice
- Collective action
- Community empowerment
- Working and learning together. (LLUK, 2009, p.1)

These values drive the CD process. The CD Challenge Group of experts (2006) describes how practitioners bring people together to identify, discuss and act upon shared problems in their own way. Practitioners also support existing groups, helping them to acquire the information, skills and connections they need to achieve their goals. Practitioners help public authorities to understand and engage with their communities. Gilchrist (2009) emphasises that practitioners promote community perspectives and seek to shift the power dynamics, making CD inherently political.

CD has a positive ethos. The Brazilian, Paulo Freire (1972), internationally influential in CD and adult education, links the pursuit of social change with love of humanity. Ledwith (2011) follows Freire as a practitioner and an academic, seeing CD as “a loving and life-affirming energy which, in its respect for the humanity of the other, seeks to change power relations that are oppressive in the search for a common humanity” (p.125). I draw substantially on Freire and Ledwith for their compassion and drive for social justice.

CD’s “optimistic stance about human nature” is confirmed by Henderson and Vercseg (2010, p.27), but Ledwith (2011) observes that it gets lost when technical skills and management directives obscure CD values. Gilchrist (2009) agrees: CDWs can be “an instrument of state policy”, addressing problems identified by government (p.38), as their history shows.

UK history

The UK origins of CD have been traced back to the late 19th century university settlements⁹ by Gilchrist (2009). Well-meaning, but condescending people sought to “improve the lives and opportunities of others deemed ‘less fortunate’” while retaining control of resources (p.25). After World War II, CDWs supported local networks and initiatives to generate a sense of community in housing developments, becoming a branch of social work (Craig, et al., 2011). Gilchrist (2009) observes that social structures were unchallenged; these consensual forms of CD assumed unity between the people and the state.

Several factors in the late 1960s radicalised CD. Ledwith (2011) describes how a critical, emancipatory approach was inspired by ideas from Latin America (Freire, 1972), Italy (Gramsci, 1971), the United States of America (US) (Alinski, 1969) and the US civil rights movement. Emerging feminist, anti-racist and disability groups questioned the oppressive structures which shaped their experiences.

Robson and Spence (2011) explain how the CD process can support this

⁹ Centres for a range of activities delivered for and with local people by students and others from more privileged backgrounds aiming to address social problems through mutual learning.

“consciousness-raising” through “exploratory conversation and small group work” (p.292), similar to that described by Chamberlin (1997) (3.4). Recently, Horton (2007) used this CD process to help Gypsies and Travellers replace pathological images of themselves with positive identities:

“The realisation that everyday existence is due, or at least can be traced to, legislation, political or historical factors, is liberating....people [gain] the confidence to critique and challenge images of themselves they encounter in the local health, education or police service.” (p.31)

Dominant perspectives were challenged by the Community Development Project (CDP), a nationally-funded CD/AR programme comprising 12 inner city projects that ran from 1969 to 1974. Craig, et al. (2011) describe how politicians blamed the “fecklessness of inner city residents” for their deprivation (p.6), as some do today (2.4). CDP practitioners developed a structural explanation for poverty and called for a redistribution of power and resources (Lees and Smith, 1975). Subsequently, as Gilchrist (2009) and Craig, et al. (2011) observe, CDWs have been managed more closely, often within local authorities where they experience an inherent tension working both in and against the state.

In the 1970s and 1980s, Gilchrist (2009) states that CDWs operated with a “pluralist” perspective of competing interest groups alongside radical approaches (p.27). CDWs helped the equality groups described above to increase their voice, gain resources and demand equal but not the same responses from public services. Bourne (2007) argues that this grassroots struggle for equality turned, under former Prime Minister Thatcher, into cultural diversity policies which ignored structural inequalities. From the 1980’s, Modood (2007) and Flynn and Craig (2012) argue, multiculturalism focused on steel bands, saris and samosas rather than racism.

From the 1990s, CD became aligned with government policies in short-term projects with targeted outputs for regeneration, public health and housing (Gilchrist, 2009). Henderson (2005) describes this approach as “functional”,

servicing and supporting agency programmes, often distanced from the intended beneficiaries. Labour policies from 1997 to 2010 promoting participation and empowerment were, Craig, et al. (2011) argue, more about increasing community responsibilities than power or influence. Robson and Spence (2011) agree, arguing that CD aspirations to address oppression were undermined “despite the apparent congruence of objectives” (p.289). Ledwith (2011) states that community self-help was encouraged to maintain, not change, social structures:

“The depoliticisation of self-help places the responsibility for tackling [social problems] onto the very groups which are most targeted by oppressive forces, denying the reality of structural power that penetrates communities.” (p.29)

As CD implemented public policy, some aligned it with community engagement (e.g. National Institute for Health and Clinical Excellence, 2008), but others find an important distinction:

“The terms can be distinguished by saying that community engagement is the top-down effort to involve people in a given agenda, while community development is the bottom-up stimulus and facilitation for people to become involved through their own priorities.” (Fisher, 2011, p.4)

Community engagement brings limited influence, but Attree, et al. (2011), in their review of 22 studies, found that many participants reported improved health, confidence, relationships and personal empowerment. Others said that they lost energy, time and money, and a few were disappointed with the outcome of their activities.

A networking approach to CD, developed largely by Gilchrist (2009), involves “nurturing informal social, political and professional networks” to create “well-connected” communities (p.173). Gilchrist (1998) describes CDWs as catalysts and connectors, bringing about and supporting a web of interactions. Longstaff (2008) and Ledwith (2011) write that CD can facilitate strategic, inter-sector alliances at the group and agency levels to generate political leverage.

Many CD processes, especially networking, increase social capital. Putnam (1995) describe this as the beneficial impact of close bonding relationships, looser bridging ties across difference and the ability to influence decision-making through links across power differentials. McKenzie and Harpham (2006) and Friedli (2009b) link social capital with well-being, but tight networks can be exclusive and defensive. McKenzie, Whitley and Weich (2002), found that closely-knit communities may not tolerate deviant behaviour, with serious implications for stigmatised groups. Siisiainen (2000) refers to the conflict and domination among community relationships illustrated in Curren's (1992) research on Pathaan women.

In 2010 the Coalition government rejected CD, choosing community organising (CO) to mobilise support for its Big Society agenda: the transfer of responsibility for welfare support, planning and enterprise to local people (Cabinet Office, 2010). CO, developed in Chicago by Alinsky (1969), brings groups and organisations together to pursue change and is inherently confrontational: "Action comes from keeping the heat on. No politician can sit on a hot issue if you make it hot enough" (Alinsky, 1971, p.59). Coalition politicians opted for a new, partnership-oriented version which, Mills and Robson (2010) argue, promotes self-help without critical, structural analysis.

It is not the first time that CD has lacked political support: "Community development has always been vulnerable to criticism that it is a term that is both vague and pretentious – claiming too much" (Henderson and Vercseg, 2010, p.27). Its divergent claims are presented in Table 3.

Table 3: Community development approaches

Approach	Activities supported	Goals	Influences
RADICAL	Community-led groups/organisations/networks; political consciousness-raising; challenging injustice; alliances.	Changing socio-economic structures; redistributing resources; equality and respect. <i>Local and wider impact</i>	Civil rights/social movements (1960/70s) Freire, 1972 Gramsci, 1971
PLURALIST	Single identity groups/organisations/networks; community self-help; local lobbying.	Equal but not same services for their group/s; pride in identity. <i>Local impact</i>	Civil rights and service user movements (1960/70s)
CONSENSUS	Community-based groups/organisations/networks; increased social participation.	Individual fulfilment; well-being; inclusion. <i>Local impact</i>	University settlements (Late 1800s) Social work reforms (1970s)
FUNCTIONAL	Community representation/participation in regeneration/service development; inter-community activity.	Targeted outputs; participation in state/service agendas; community cohesion. <i>Local impact</i>	Labour government 1997-2010
NETWORK	Interaction between individuals, groups, organisations; developing community initiatives; alliances.	Individual benefit aligned with the common good; Social capital, inclusion. <i>Local and/or wider impact</i>	Putnam, 2000 Gilchrist, 2009

Concluding comment

This section suggests that some CD approaches may align with the politically-inspired Black self-help initiatives and autonomous Black mental health groups described in Chapter Three, while functional (top-down) approaches align more with the state. Next I discuss how CD, underpinned by its core values, might contribute in a mental health context.

4.3 CD for recovery in mental health

Tensions between CD and health services

Community interventions have long helped to improve health (e.g. Stallibrass, 1989). Case studies of two community organisations showed how they supported people reluctant to access mainstream services (SCMH, 2000). A three-year AR project promoting partnerships in community care found that people preferred this holistic approach to specialist services (Barr, Stenhouse and Henderson, 2001). Henderson (2005) argues that unlike biomedical approaches, CD connects health with the wider experiences that affect it including poverty, safety and the environment.

Despite useful initiatives in health promotion, CD never took root in England's mental health services prior to the Department of Health DRE programme (2.4). Henderson (2007) blames this on the mismatch between the services' focus on individuals and CD focus on the collective, coupled with lack of interest from policymakers and CD organisations. In Seeborn and Gilchrist (2008) we point to tensions between biomedical treatment in services and attention to social factors in CD. Walker and Craig (2009) refer to a government preference for top-down programme management, while CD prioritises community concerns. All these factors seem likely. In case study research in seven urban areas, Longstaff (2008) found that police authorities and health services were particularly resistant to CD. CHEX (Community Health Exchange, at www.chex.org.uk), the Scottish health

authority-funded CD partnership, demonstrates the more community-oriented approach found north of the border.

Frequent tensions emerge between professional practice in CD and mental health services. In Seebohm and Gilchrist (2008) we argued that the CDWs' often deliberately low profile and subtle facilitative skills may leave them undervalued within medical hierarchies. We also suggested that CD's unpredictable outputs and dynamic processes do not fit well within statutory monitoring frameworks, although this flexibility potentially complements statutory provision, for instance when supporting user-led activities. Gilbert and Russell (2006) evaluated a new role in primary care which incorporated CD. They found a tension between the fluidity of CD activities with their limited evidence base and scientifically-evidenced, time-limited clinical interventions.

The position of CD practitioners, situated between established hierarchies and grassroots aspirations, demands integrity and skill:

“Practitioners have to balance their commitment to community empowerment and self-determination with professional obligations within a public service hierarchy. To manage this complex accountability they need space for reflection, integrity and the capacity to question authority without closing down the dialogue.”

(Seebohm, Gilchrist and Morris, 2012, p.484)

Despite these tensions, in Seebohm and Gilchrist (2008) we found mental health commissioners and practitioners who believe that CD can enhance recovery and well-being.

The connection between CD and recovery

Much CD takes place in deprived areas where people may experience unrelenting stress. In Seebohm and Gilchrist (2008) we found CD practitioners working supportively with distressed people, but we also found some CDWs who felt mental health issues were outside their remit and skill-base. Similarly, McCabe and Davis (2012), drawing on case study research, found CDWs who “witness

individuals with severe mental distress which they feel they lack the skills and confidence to address, responding if at all by referring them to specialist mental health services” (p.510). CDWs are not immune to the stigma of distress (2.4).

Yet recognition that CD can promote mental health grows. The international *Community Development Journal* produced its first special issue on mental health in 2012. CD’s support for relationships, participation and social justice resonate with concepts of well-being, inclusion and recovery. Friedli (2009b) argues in her World Health Organisation report that regardless of diagnosis, people can enjoy well-being: they can function well, contribute to their community, work and enjoy a sense of purpose. Morris and Gilchrist (2011) state that inclusion, meaning the degree to which people can “participate in, and benefit from, the activities and services generally available in society”, grows as people interact more within the community (p.7). Recovery centres on people regaining a sense of control, fulfilment and hopefulness (2.5). In Seebomh and Gilchrist (2008) we argue that mental health and CD practitioners can work together in complementary roles to promote well-being, inclusion and recovery.

Compassion and optimism may characterise practitioners’ approach in both CD and recovery-focused care, but CD can nurture social networks and collective action in a way that mental health practitioners usually cannot. McCabe and Davis (2012) note that community-orientated interventions may be seen as “beyond their remit, resources and expertise” (p.510). The following sections discuss how the CD process can contribute to positive mental health.

Building relationships

CD practitioners work with groups, but Henderson and Thomas (2013) explain that the CD process usually begins by engaging individuals. Henderson (2007) observes that when working in a mental health context CD practitioners spend more time supporting individuals. In Seebomh and Gilchrist (2008) people with mental health difficulties told us that CD practitioners were ‘on a level’; they

listened because they cared, not because it was their duty. Multifaceted relationships were built upon trust, mutual respect, warmth, informality and reciprocity: “The distinctions between paid practitioner, activist, volunteer or friend become blurred, in contrast to the professional (and protecting) boundaries between clinicians and clients” (Seebohm, Gilchrist and Morris, 2012, p.480). Boundaries remain important but as Faulkner and Kalathil (2012) describe, these “informal formalities” need to find the right balance and not be tied by red tape (p.42).

Supportive relationships are essential to recovery, as Tew, et al. (2012) conclude from their literature review. In Seebohm and Gilchrist (2008) we found that CD can foster these:

“Sometimes mental health services have a tendency to [say] ‘when you have recovered, you shouldn’t be reliant on anyone else, you shouldn’t be dependent.’ But the stuff of life is being dependent on other people and CD can really show that inter-connectedness, and say it is not something to be shied away from or be ashamed of.” (CDW, p.48)

“By connecting people together, which is what community development is about, you are putting in place an informal support system which is probably going to be more effective and long-term than drugs.” (CD practitioner, p.52)

The relationship-building process begins with listening.

Listening and reflecting

CD practice encourages people to exchange shared experiences. Ledwith (2011) believes that “the foundation of community development lies in listening, valuing and understanding people’s particular experiences” (p.34). Kalathil, et al. (2011), exploring recovery with Black women (2.5), heard how sharing stories was felt to be empowering:

“Many women found the very act of narrating their stories enabling and considered it part of their recovery process... There needs to be greater

investment in creating more opportunities for black women as telling our stories has important personal and political functions.” (p.76)

Storytelling may be initiated by community members, but Gramsci (1971) and Freire (1972) believed that where people are overwhelmed by oppression they remain silenced unless an external catalyst intervenes. The process must be nurtured by practitioners who Flecknoe and McLellan (1994) describe as “facilitators, catalysts for action, energisers” (p.7). By adopting these roles CD practitioners can nurture community members’ confidence.

Nurturing confidence and agency

CD practitioners can educate, Freire (1972) explains, by helping people to discover and develop their existing skills. In Seebohm, Gilchrist and Morris (2012) we argue that community members gain hope as CD practitioners identify and nurture their talents, “creating opportunities for participation and leadership... sensitive to but not limited by their support needs” (p.479). Henderson (2001) suggested that instead of being passive recipients of care, people are encouraged to take up new roles as CD practitioners work alongside them, doing *with* rather than doing *for*. In Seebohm, Gilchrist and Morris (2012) we wrote that people try out new tasks that interest and challenge them, learning from mistakes: “Practitioners described how they balanced being a bit ‘pushy’ in challenging community participants to take on new responsibilities, with standing back, letting people find their own way of doing things” (p.480).

As confidence grows, agency grows. People may come together to develop collective resources. To explore how this process is best supported, the Joseph Rowntree Foundation recruited CD practitioners to support community groups and organisations in twenty neighbourhoods for four years, with evaluation integrated into the process (Taylor, et al., 2007). Researchers found that experienced CD practitioners were welcomed as facilitator, critical friend, mediator, broker, someone to help with confidence-building, broaden horizons and help in a crisis. Practitioners balanced a light touch with in-depth support,

working close to the action, ‘on tap, but not on top’, finding that where there is a long history of disadvantage, groups need more intensive support. Similarly, in Seebohm and Gilchrist (2008) we describe how a CD practitioner intervened more with a group of people from long-stay institutions than with those in a post-natal depression group, doing enough to support sustainability while ensuring that the group members retained control. In complex, often politically sensitive settings, practitioners need strong personal and professional skills to be on the one hand a facilitator, smoothing the process and on the other, an enabler, boosting opportunities by creating connections.

Creating connections

Much CD activity, as we wrote in Seebohm and Gilchrist (2008), was sparked or facilitated by connections between individuals, groups and services. CDWs were “the oil...that lubricates everything” (p.40). Relationships with other workers were informal and mutual, enabling them to open doors and foster links.

Sometimes these connections resulted in new resources. A practitioner described an initiative set up to address suicide within a farming community: “It was an issue raised by local people, on behalf of local people; local people were involved in controlling it...This is the practical result and it is held by the community” (p.35).

Activities including signposting, workshops and events are used by CD practitioners to build bridges, create connections and promote understanding, reducing stigma and fear of statutory services (Gilchrist, 2009). In Seebohm and Gilchrist (2008) we described how mental health practitioners and community members were brought together in settings where both felt safe:

“An awful lot of people who work in services are deeply institutionalised and are afraid of the communities, and so it is a question of trying to support them in going out there. Sometimes we can open doors.”
(DRE CDW, p.40)

We found CDWs sometimes helped mental health practitioners to set aside the ‘cultural baggage’ attached to clinical terms and be respectful of community understandings (2.2):

“It’s about choosing a story that makes sense to you, because you will choose your own route to recovery and that road to recovery has got to fit with your understanding of what is happening.” (DRE CDW, p.38)

A key feature of CD is the way it supports community groups in expressing their views to service providers (CD Challenge Group, 2006).

Promoting voice

CD practitioners may employ many creative ways of increasing involvement in service planning, developing a range of structures, processes and skills (Seebohm and Gilchrist, 2008). Two-way communication between community members and statutory providers or commissioners “gives an opportunity for democracy to be fully-fledged” (p.43). This is what CD in mental health is about, according to psychiatrist, Bracken (2005):

“A community development approach to mental health does not dismiss the important role of professionals and their systems of knowledge, but it works to encourage other voices. It insists that there are many different ways to overcome mental health problems and that local people (individuals, families and communities) have many of the answers themselves. It also insists that professionals learn to listen, that they develop the ability to tolerate different ideas and different perspectives from those in which they have been trained.” (p.5)

The next section considers whether the DRE programme put this potential to work for BAME communities.

Delivering Race Equality in mental health care

The consultation report, *Inside Outside*, by Sashidharan (2003) (2.5), proposed that CDWs should be appointed to “build on the inherent strengths and capacity of minority ethnic groups in dealing with mental health issues within the communities themselves” (pp.33-34). CDWs would enable organisations “to

bridge the gap between western models of care, and the values and norms of the communities they are serving” (p.34). However, the policy implementation document, DRE (DH, 2005a), shifted the primary focus to change within services. Funding for 500 CDW posts was allocated to support implementation through four overlapping roles (DH, 2004), summarised here:

- Capacity Builder: supporting the development of community organisations, inclusive BAME communities and community leadership;
- Change Agent: identifying gaps in services, identifying community capacity for innovative practice, improving communication between communities and services;
- Service Developer: improving joint working and training, highlighting the importance of culture;
- Access Facilitator: increasing access to services and community resources, overcoming language and other barriers.

Later guidance (DH, 2006) emphasised the CDWs’ strategic function to promote the DRE agenda rather than a responsibility to support individuals.

The role was ambitious and expectations were high - many thought too high (Greater London Authority, 2005). Some remembered disappointing experiences: “Old arguments and old solutions...ineffective in the past” (Day, 2003, p.1; McKenzie, 2010). This scepticism did not bode well for the programme.

Evaluations of the CDW role

Four major studies examined and evaluated the DRE CDWs. The most rigorous was an investigation into the implementation and sustainability of the CDW role by Walker and Craig (2009). This included a detailed survey of CDWs and employers, five workshops with CDWs and 20 interviews with key national and regional informants. About 37% of the CDWs (n=200) and 30% of CDW employers contributed.

Later, a national evaluation of CDWs (Wood, et al., 2011) involved 56 CDW survey respondents, visits to four self-selected sites involving 34 interviews with CDWs, managers and stakeholders, and supplementary discussions or interviews with 10 key informants. A regional evaluation of CDWs (brap¹⁰, 2010) in Yorkshire and Humber involved 28 of the region's 50 CDWs and interviewed an unspecified number of commissioners, service users and employers. As DRE closed, a small study by the Rights and Wellbeing of Racialised Groups (RAWOrg) (2011) involved 12 CDW interviews and 28 service user survey respondents (2.5).

The slow recruitment and early redundancies of CDWs combined with poor administration of the DRE programme hampered all studies. Walker and Craig (2009) found that about 26% of funds permanently allocated by government for CDWs were diverted by primary care trusts (PCTs) for other purposes. Later they wrote: "This, more than anything else, suggested a continuing lack of commitment by many senior health service managers to the goal of race equality" (Craig and Walker, 2012, p.496).

The DRE CDW role was said to be loosely defined, locally interpreted and often poorly supported (Walker and Craig, 2009; Wood, et al, 2011; RAWOrg, 2011). All studies found that some colleagues and managers were resistant or had unrealistically high expectations. Yet Walker and Craig (2009) identified some skilled and well-supported workers, concluding: "the CDWs' role is unusually complex and challenging – but feasible nonetheless, as the research shows, given the right kind of people carrying the role with the right kind of infrastructural support" (p.7). RAWOrg (2011) concluded that some CDWs had done "remarkable work" (p.23), particularly with communities. All studies agreed that CDWs needed more time to achieve sustainable change.

¹⁰ brap choose to use lower case letters for their name, which is not an acronym.

The studies differed on the extent to which CDWs provided capacity-building support to community groups. Walker and Craig (2009) found this a low priority, warning that if more was not done “the [CDW] title will become a misnomer” (p.86). Wood, et al. (2011), nearly two years later, found that “much work was undertaken to strengthen the capacity of local community groups” (p.28), while strategic impact was limited. RAWOrg’s (2011) limited evidence suggests that CDWs carried out the capacity-building aspect of their role quite successfully, helping groups and organisations with training, funding, networking and interpretation. These discrepancies may be explained by CDWs coming to capacity-building later in their job, different interpretations of capacity-building, or possibly greater job retention for those working in areas where management supported this work.

The studies identified different ways in which CDWs sought to increase BAME influence. RAWOrg (2011) suggests that some tended to adopt an intermediary role, advocating on behalf of BAME communities, while others preferred to empower “communities to demand and create changes for themselves” (p.9). CDWs often struggled to balance their close work with communities with their strategic role (Wood, et al., 2011), resulting in priority being given either to “face-to-face community engagement or strategic influence” (p.13). It was felt unlikely that any individual could carry out both roles; they required different skills and office bases, in the community or within services. Time constraints and management priorities limited the options.

Every study emphasised the need to evaluate CD practice, arguing that without better evidence of its impact, statutory support will remain limited. Without management backing, CDWs could not promote systemic change. Craig and Walker (2012) conclude: “Apart from some enlightened managers and organisations, the issue of race equality was rarely taken seriously other than by the CDWs themselves and their ability to lever change was undermined by a

range of systemic considerations which led to the marginalization of their work” (p.503).

Eighty community engagement projects were funded by DRE whereby BAME groups could research issues that concern them. CDWs supported most of the 79 completed projects. Fountain and Hicks (2010) evaluated their impact, finding benefits for those involved and a higher profile for BAME mental health needs. However, their online survey with 140 CDWs identified obstacles to change, particularly lack of management and practitioner support and insufficient resources.

Concluding comment

This section has suggested that the role of CD within mental health is not easy, but skilful CDWs can, given management support, assist mental health and community groups. Studies of the DRE CDW role varied widely in their rigour and evidence base, but many of their conclusions were similar. They found that CDWs were constrained by patchy management commitment and a tension between their strategic and community-based roles, but some CDWs achieved positive results.

The term ‘empowerment’ has arisen several times in this review, so I now discuss what it means in this context.

4.4 Empowerment

Political rhetoric

The term ‘empowerment’ first became prevalent in US civil rights and feminist discourse but, by 1997, Chamberlin found that: “The word has become common political rhetoric, with a flexibility of meaning so broad that it seems to be in danger of losing any inherent meaning” (p.43). Barr (1995) found that in the UK “different agencies and within them, different actors appear to have different

expectations of empowerment” (p.122). McLean and Andersson (2009), researching into theories of citizen empowerment, found that the term’s “vagueness” increased as it became a cross-party political buzzword (p.9). Despite these dubious credentials the concept resonates strongly with theorists in CD (e.g. Ledwith, 2011), mental health (e.g. Chamberlin, 1997) and Black community politics (e.g. Christian, 1998). There are many ways of defining empowerment, but I identify the features and theories most relevant here.

There are formal mechanisms that create what McLean and Andersson (2009) call “de jure empowerment”: “power that is manifested in opportunities and rights provided through law, contract or other official record” (p.12) such as the ‘Duty to Involve’ (*Local Government and Public Involvement in Health Act 2007*). The Citizenship Survey, a government-sponsored, biennial survey of community issues, found that despite increased mechanisms for de jure empowerment, fewer people *felt* able to influence government decisions in 2010 than in 2001 (Department for Communities and Local Government [DCLG], 2010a). The reasons are contested, but McLean and Andersson (2009) argue that *feeling* empowered is essential: “Growth of structural and institutional mechanisms to empower...must be matched by action to develop a subjective sense of empowerment” (p.13).

People may not feel empowered if formal mechanisms do not seem responsive and welcoming. Gilchrist (2009) argues that: “Empowerment processes require a redistribution of power and therefore involve changes in the culture and procedures of mainstream institutions so that these become more transparent, more responsive and less inclined to maintain control” (p.66). Ledwith (2011) points to structural barriers to empowerment. A small qualitative study by Gill and Sveinsson (2011) concludes that structural disadvantage due to ethnicity, gender and socio-economic status would limit participation in the Big Society agenda (4.2). Prime Minister Cameron (2010) spoke of greater “people power”,

but, it seems, not for all the people. Among those frequently excluded are the mentally distressed.

Empowerment in mental health

Empowerment attracts attention and cynicism in mental health as in politics. Chamberlin (1997) found that mental health programmes claiming to promote empowerment were not noticeably different to others. She lists components of empowerment including:

- opportunities (to make decisions; to choose);
- emotions (hope; expressing anger; connection; confidence);
- capacity (access to information and resources; chosen skills);
- action (critical reflection; changing oneself, the community and how others see oneself).

Empowerment, she states, is about self-initiated, never-ending growth and change which links it to the concept of recovery (2.5).

From a practitioner and institutional perspective, empowerment enhances service user control, as in the service user-led Wellness Recovery Action Planning (WRAP). This model, initiated in the US, enables people in peer groups to devise their own strategies for managing their recovery. A qualitative evaluation of WRAP (Scottish Centre for Social Research and Pratt, 2010) and a US-based randomised controlled trial (Cook, et al., 2012) were both positive.

The NHS Constitution (DH, 2009) has strengthened patient rights, but relationships between doctors and service users have been slow to change. Hitch (2005), reflecting on the practice of occupational therapists, believes that empowerment initiatives are more likely to increase access to social or work opportunities than control over treatment. Nelson, Lord and Ochocka (2001) carried out a Canadian AR study over 30 months while policies pursued greater participation and empowerment. They found that despite management support for

progress, the outcomes were similar to those described by Hitch: control over treatment remained largely unchanged, but increased in other aspects of life.

Criticisms of service user-involvement processes were mentioned earlier (3.3). Kalathil, et al. (2008) found that user involvement for BAME groups is often “experienced as hierarchical spaces where power relations between professionals and service users/survivors are not questioned” (p.3). Where BAME groups had their own space, control over the agenda and member involvement was more likely: “The biggest achievements were made when working within user groups set up separately from mainstream initiatives. This helped focus on race issues and in defining the parameters of involvement” (p.3).

The co-production of services, whereby communities, service users and professionals work together in an “equal and reciprocal relationship”, attracts widespread interest (Boyle and Harris, 2009, p.11). Needham (2009) observes that such a transformational relationship will be rare. In Seebohm, Gilchrist and Morris (2012) we suggest that institutional resistance and funding cuts may limit what can be achieved, but the vision of co-production and the empowerment it implies fits with the values of CD.

CD and empowerment

Claims to empowerment run through most if not all models of CD, but what is meant differs. My earlier research (Seebohm and Gilchrist, 2008) suggests that Chamberlin’s (1997) components of empowerment may be feasible if the CD practitioner works closely with community members, sensitive to their potential and support needs. For Ledwith (2011), however, *feeling* empowered is not, on its own, sufficient. In her description of critical CD, empowerment has a profoundly political meaning implying structural, social or economic change.

Efforts to empower might become inadvertently disempowering. Thompson (2003) suggests that if practitioners do not understand the structures and

ideologies that inhibit change they may inadvertently reinforce inequality. Ledwith (2011) agrees: “Without getting to grips with analyses of power, we not only reduce the social justice intention of our practice, but much worse, we also unwittingly reinforce the status quo” (p.168).

Empowerment can be seen as an incremental, bottom-up process. Ledwith (2011) describes how radical CD pursues change at the individual, community, regional and even global levels through bottom-up processes: it cannot come from above. Freire (1972) derides attempts to empower from above as superficial, leaving the power structure unchanged. This resonates with criticisms of user-involvement processes. Douglass (1857), the freed slave, said that power cannot be given; it must be taken. For Gilchrist (2009) as for Chamberlin (1997), empowerment is a journey: each time people take and use their power, their confidence grows. For some, the journey has been long.

Black empowerment

Many argue that Black empowerment must acknowledge Black history. Rai-Atkins, et al. (2002) feel that the “history of black empowerment should inform contemporary black empowerment” (p. 39). Similarly Keating (2007) argues that anti-oppression activities should be “anchored in history”, building on Black people’s survival of adversity (p.12). Deficit-based approaches fail to capitalise on expertise within the community: “Black people can define for themselves issues of oppression and the best routes to self-determination” (Rai-Atkins, et al., 2002, p.39). Christian (1998) explored the concept of empowerment from a Black perspective, as understood by community activists in Liverpool. He found that top-down initiatives to address urban deprivation failed to capitalise on Black experience and consequently “hardly ever reach the core of the socio-economic problems affecting Black people” (p.23). Empowerment, he concluded, should enable Black people to create their own solutions.

People from different cultures may come to feel empowered in different ways. In their study of African, Caribbean and South Asian mental health service users, Rai-Atkins, et al. (2002) argue that “the process of black self-help and empowerment differs significantly from European conceptualisations” (p.1), referring to cultural differences (3.2):

“The western concept of empowerment...actively promotes individual or self-empowerment; yet in our exploration it became clear that this is not the aim of many black and ethnic minority service users or carers.” (p.39)

They call for a CD approach to support collective consciousness-raising by Black groups: “The strength of this approach lies in the fact that groups of people who share similar experiences can offer validation to themselves, to each other and in wider social networks” (p.35). This resonates with community-oriented concepts of recovery (2.5) and transformative group processes (3.4; 4.2). Those who have often felt isolated and demeaned can become more assertive and influential as a group. Trivedi et al. (2002) describe how it felt at Simba: “Each of us was part of a much bigger whole – and that was tremendously empowering and exciting” (p.33). Rai-Atkins, et al. (2002) affirm the limited funding and political support for Black-led initiatives (3.2).

Spirituality, with or without religious adherence, is at the heart of well-being for many Black people (Hylton, 1999) (2.5). Rai-Atkins, et al. (2002) argue that cultural, religious and spiritual support is essential to empowerment for Black people in distress. Speakes-Lewis and Gill, (2011) in their study of changes within the Black church, argue that it has played a significant role in its people’s empowerment through history, nurturing resistance: “The perspective of empowerment has always been at the forefront of the Black church community” (p.243). However, as Thomas, et al. (1994) note, Black churches are not homogenous. Leavey, Loewenthal and King’s (2007) qualitative study of largely London-based clergy, some from Black churches, found that they could play an important support role, but several had stereotypical or potentially more harmful attitudes to distress.

Concluding comment

To close this literature review, I return to Thompson's (2007) analysis of power (2.2) to conclude that empowerment reduces power *over* Black people by unresponsive and disrespectful systems or individuals, and increases the power *within* that generates self-esteem and resilience. These changes come about as group members enjoy power *with* their peers, which in turn nurtures their power *to* achieve their goals. These different dimensions of empowerment return throughout this thesis.

4.5 Gap in knowledge

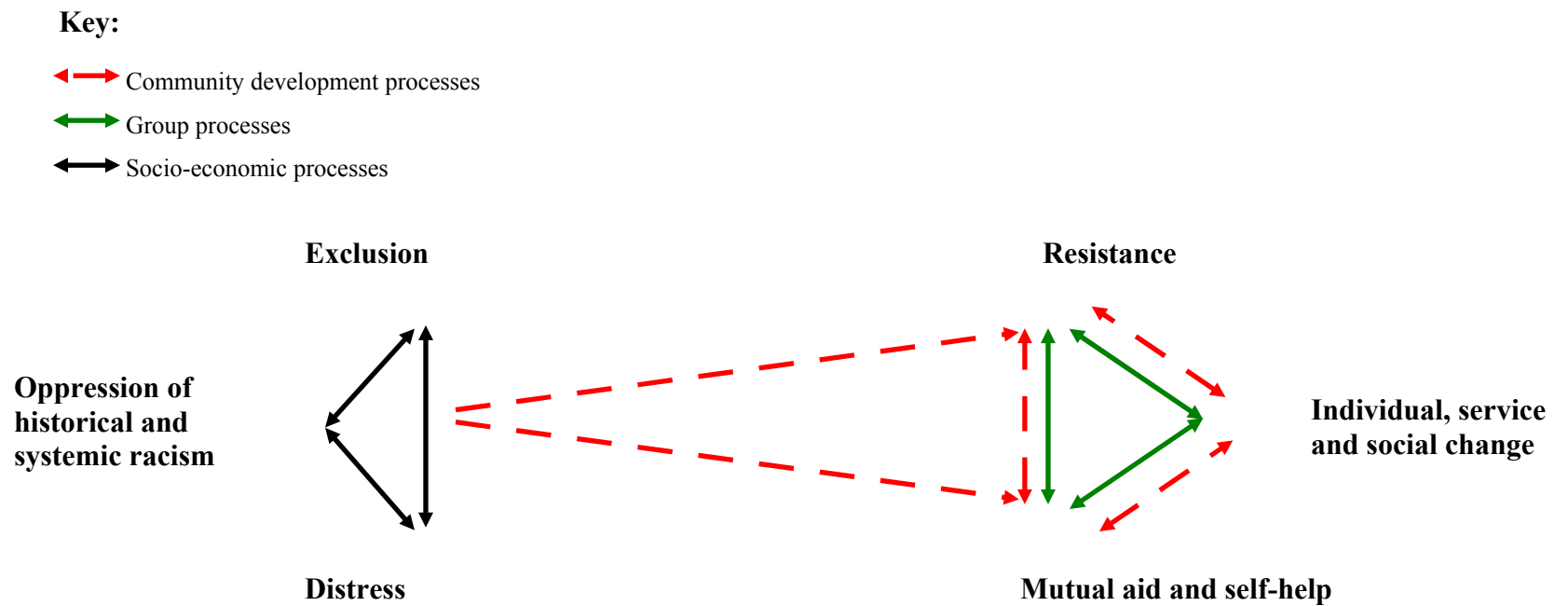
This thesis began by describing the exclusion, oppression and distress experienced by many Black people (Chapter Two). It showed how some resist, offering mutual support in community-based, autonomous initiatives (Chapter Three). Finally, it showed how CD, when driven by its core values, aspires to challenge oppression through collective action and empowerment (Chapter Four). These chapters set the parameters of the study and create a conceptual framework around the journey from exclusion, oppression and distress to resistance, mutuality and change. My focus is on the CD support that enables Black people in distress to make this journey by coming together to organise their own groups for mutual support and to create change for themselves and their peers (Diagram 3).

There is little research on Black groups within mental health and self-help/mutual aid literature, as Faulkner and Kalathil (2012) observe. Editors of the *Community Development Journal* note the scarcity of articles that link CD with mental health (Carpenter and Raj, 2012). McCabe and Davis (2012) write that radical CD and mental health practice have developed in parallel, but rarely connect. Craig, et al. (2011) call for more research into CD with BAME communities: "Increasing attention needs to be focused on work with specific population groups such as black and minority ethnic communities" (p.17). I have been involved in related studies, and others have written about DRE CDWs, but I have found no research

to date which asks, as I do, how CDWs and others support autonomous Black groups of people with mental health problems.

Diagram 3: Conceptual framework and gap in knowledge.

How do community development workers and others support the autonomous groups whereby Black people with mental health problems can move from exclusion, oppression and distress to resistance, mutuality and change?



4.6 Chapter summary

CD practice supports processes of social change, taking many forms. Its values, when implemented, dovetail with autonomous, mutual support initiatives, encouraging critical thinking and democratic voice. CD, recovery and thriving Black communities are all characterised by self-determination, collective activity and empowerment. CD was at the core of DRE, but the programme lacked senior-level commitment to its work. At Sharing Voices, CDWs support groups of Black people with mental health problems to find a way forward. This thesis explores the nature of this support.

“It was the whole model of like: ‘Here is some safe space, what are your issues, how can we support you in that, how can we get involved in creating that?’ That is what community development is all about. It’s listening to what people are saying.”

(Senior Health Promotion Worker in Seebohm, et al., 2005)

Chapter Five shows how my methodological approach to the research was informed by this context.

Chapter Five

Methodology

“The master’s tools will never dismantle the master’s house.”
(Lorde, 1984, p.112)

5.1 Introduction

People from Black, Asian and minority ethnic (BAME) communities can be frustrated when approached for research, when what is already known could improve their lives (Butt and O’Neill, 2004). Black service users sometimes feel “over-researched” for no apparent benefit (SCMH, 2002, p.16). As a White academic, I have to justify my audacity to enter this field. This chapter explains how I sought to make this study worthwhile to those involved, bearing in mind the context described earlier and the need to satisfy an academic audience.

My overall aim is to explore how autonomous groups of Black people with mental health problems can be supported by community development workers (CDWs) and others. Here I describe my social constructivist perspective and framework of action research (AR) with appreciative inquiry (AI). After detailing my aims, I outline the four cycles of AR, the qualitative methods and analytical strategy used, concluding with an ethical and critical review of the methodology. An assessment of the research lies in the final chapter (11.6). I begin with my theoretical perspectives.

5.2 Theoretical perspectives

Introduction

This section sets out my position regarding the nature of reality (ontology), what can be known about it and how that is verified (epistemology). To do this I

explain the core features of the study which build upon the context described earlier:

- exploratory purpose;
- respect for multiple realities and forms of knowledge;
- concern for power imbalance;
- commitment to change.

Exploratory purpose

This is an exploratory study which seeks to develop new theory rather than test an existing hypothesis. I follow Wittgenstein (1974), choosing not to superimpose a pre-existing theoretical framework on the data to explain it, but instead aiming to create new understanding by identifying connections previously unrecognised, for instance between themes from community development (CD), Black communities and mental health. Like Ledwith and Springett (2010), my purpose is to move to and fro between experiential learning and theoretical reflection to develop these connections into new theory grounded in the experience of research participants.

This approach differs from positivist perspectives, first articulated in 1822 by Comte as Martineau explains (2000). These assume that reality is fixed and waiting to be discovered by the quantitative, deductive methods generally used to understand the natural world. My research is about social phenomena: people's experiences and how they understand these experiences within different frameworks of belief about reality. The notion of a single reality has no relevance or credence here. As Kuhn notes (1996), rigid views of reality have come and gone. Heron and Reason (1997) wryly comment that positivists fail to see that the ground on which they stand to frame the world is their own creation.

Multiple realities and forms of knowledge

My ontological position therefore acknowledges different realities and my epistemology emphasises that these should be understood within the context that

frames them. I pursue rigour in research including triangulation and self-questioning to improve understanding, drawing on several theoretical traditions.

The notion of a single reality discoverable through deduction has been criticised by those broadly described as post-positivists (Alvesson and Sköldberg, 2010). Denzin and Lincoln (2005) note that post-positivists often retain a belief in an external reality but replace deductive methods with the rigorous triangulation of multiple data sources. Alvesson (2002) writes that postmodernists go further, arguing that “all observations and all data are theory-laden and in other ways depend on the view of the researcher”, who must therefore be subject to rigorous questioning and self-doubt (p.163). Interpretivists (e.g. Crotty, 2011) and constructivists such as Guba and Lincoln (2005) argue that there can be no right or wrong view of reality: all we can know is how it is perceived. Research into how people perceive reality must acknowledge the complexity of human nature and pay attention to the study context (Pawson and Tilley, 2004; Hart, 1996).

My approach respects multiple perspectives grounded in different cultural, spiritual and social backgrounds. These form multiple paradigms, by which I mean the “entire constellation of beliefs, values, techniques, and so on, shared by the members of a given community” (Kuhn, 1996, p.162). Some interpretivists (e.g. phenomenologists) argue that no individual can ever share the same view of the world. Instead of emphasising the individual, I prioritise shared community understandings and experiences of life, adopting a broadly *social* constructivist approach. Social constructivism follows several different strands but generally holds that social groups united by culture and situation share an understanding of the world around them, underpinned by a “community consensus regarding what is ‘real’, what is useful and what has meaning (especially meaning for action and further steps)” (Guba and Lincoln, 2005, p.197). Deductive research may be useful for aspects of physical disease. From a social constructivist perspective I also believe that studies such as that of Raguram, et al. (2002) help us understand the value of spiritual healing. What is real, what is useful and what has meaning

differ, but Kalathil, et al.'s (2011) study show how these can overlap, offering complementary understandings of distress (2.2).

Different views of reality may be grounded in different sources and forms of knowledge. Kolb (1984) promotes knowledge gained through experience (experiential learning), which has appeal where educational institutions are perceived as oppressive (2.4). Ladson-Billings (2003) values the way in which stories create learning from the experiences of marginalised groups. Storytelling, music and art are all forms of communication that I have enjoyed in this study. Ledwith and Springett (2010) believe that these can create bridges between different 'worldviews' which then broaden and change. They touch people differently from the formal word, generating empathy. Where there is communication with respect and empathy, people's idea of reality may become fluid and change. Heron and Reason (1997, p.294) describe this outcome as a "participatory paradigm": a view of the world that spans barriers of culture, skills or status.

Some participants in this study chose creative expression to communicate where formality fails, but as a self-funded study, scope for developing a participatory paradigm was limited. The participants had different backgrounds and perspectives. Sometimes even people who speak the same language have difficulty understanding each other if their historical and social roots divide them. Ladson-Billings (2003, p.403) cites Du Bois who, over a hundred years ago introduced the notion of double consciousness. Black people, Du Bois (1903) wrote, might have "two souls, two thoughts, two un-reconciled strivings" as they seek to belong within their Black and dominant White communities (p.215). Today people of mixed heritage can struggle to span their identity and ancestry:

"I learned to slip back and forth between my black and white worlds, understanding that each possessed its own language and customs and structures of meaning, convinced that with a bit of translation on my part the two worlds would eventually cohere." (Obama, 2008, p.82)

Ladson-Billings (2003) notes that the worlds we seek to bring together may be themselves fractured many ways, for instance across gender, class, faith and sexuality as discussed earlier (2.4). These divisions are profoundly affected by power differentials.

Power imbalance

It is not enough to recognise different worldviews. Pilgim and Rogers (1999) write that social constructivism contains a political dimension as “power relationships are inextricably bound up with reality definition” (p.19). McLaren (2009) agrees that knowledge is never neutral: what we regard as knowledge is “a *social construction* deeply rooted in a nexus of power relations” (p.63).

Cox with Sinclair (1996) and other critical theorists believe that knowledge reflects and benefits the interests of the observer: theory always serves someone and some purpose. Theories about the inferiority of Black people helped to justify slavery (Lentin, 2008). Ladson-Billings (2003) argues that the positivist paradigm has dominated Western education and knowledge production so extensively that it is internalised by Western and non-Western groups alike. Fanon (1952) argues that Black people often believe the theories that discredit them (see 2.5).

Dominant medical knowledge in psychiatry (2.2) has been challenged in recent decades as service users’ experiential expertise has gained influence through collective action and policies of public and patient involvement (Williamson, 2010). I have benefited from more education and resources than the participating group members, a common feature of community-based research (Watkins and Shulman, 2008). My background and skin colour give me social, economic and health advantages associated with dominant social groups. Like McIntosh (2004), I thought of these privileges as resources within an “invisible knapsack” which I could “cash in” as required (p.83), reflecting on the advantages I enjoyed. I sought to avoid reaffirming oppressive power differentials as Thompson recommends

(2003). This is not sufficient for those who feel that, as a White person, I should not be there:

“The research establishment is overwhelmed by well-meaning non-minority researchers who, although they recognize racism and its consequences on health, cannot reconcile the contradiction of non-minority researchers doing research with people marginalized by their minority status in the name of empowerment.” (Varcoe, 2006, p.526)

Unlike Varcoe, Ladson-Billings (2003) does not dismiss the work of Western scholars but rather wishes to define the limits of their scholarship. I accept her argument that my thesis is one response to the research question; a Black researcher may arrive at a different interpretation, as all qualitative research is shaped by the scope and limitations of the researcher. I justify my study on the grounds that group members and CDWs welcomed it, expressed their views, debated my analysis and affirmed the content and usefulness of the learning. I also believe that there should be more opportunities for Black researchers and I facilitated this in a small way.

AR is my chosen approach (described below). Within AR, the researcher's role is to expose and mediate issues of power within the research setting, while gaining the trust of those who feel threatened (Stringer, 1996). Varcoe (2006) is unusual in exposing how difficult she found this, confounded by the “complex ways in which power and privilege were continuously operating and shaping our work” (p.532). “Collaboration is hard” notes Stoecker (1999, p.845). Bracken, Khalfa and Thomas (2007) refer to reciprocal elucidation, a form of dialogue where mental health practitioners and service users recognise that both sides have expertise (knowledge) and autonomy (power). This study is committed to promoting this kind of change.

Commitment to change

Outside AR, views differ on the extent to which researchers should espouse a political or moral interest in their work. Some seek to minimise the influence of

their values in their work, while others, notably critical theorists, openly pursue knowledge for emancipatory, often socialist purposes (e.g. Cox with Sinclair, 1996). Most expect change to be an outcome of the research, not part of the process.

As an AR researcher working within a CD context, like Fals Borda (2006) I aim for the research process itself to be emancipatory and elucidating in order to change oppressive and exploitative social structures. AR researchers become actively involved, for instance as facilitator (Stoecker, 1999), unlike the traditionally detached positivist researcher. Waterman, et al. (2001) point to the risk of becoming so immersed in community perspectives that criticality and openness to other views are lost. Later I discuss these challenges, but first I explain more about AR and the methodology employed.

5.3 Methodological framework

Introduction

Action research (AR) and appreciative inquiry (AI) provide a methodological framework that fits well with my theoretical perspective and study context. This section explains why and describes how they shape the research design.

Action research (AR)

AR draws from several disciplinary traditions including education, health and CD, giving it no single definition (Winter and Munn-Giddings, 2001). Munn-Giddings, McVicar and Smith (2008) identify 24 different terms used to describe a broadly similar process. The term '*participatory* action research' (PAR) is sometimes preferred to denote the emancipatory, collaborative ethos (e.g. Fals Borda, 2006), but others use AR for the same purpose (e.g. Stringer, 1996). Stoecker (2007) concludes the terms are interchangeable. I chose AR here for greater readability, retaining the commitment to an emancipatory process. Winter

and Munn-Giddings (2001) have been my principle source of guidance for their attention to detail and Stringer (1996) for his CD approach.

AR can be adapted for diverse settings including street youth (Whitmore and McKee, 2006), health services (Kilbride, et al., 2005) and fire-fighting (Halbesleben, et al., 2006). In all of these settings, AR generates practical knowledge to bring about change rather than valuing knowledge for its own sake (Heron and Reason, 1997). Waterman, et al. (2001) argue that research subjects should always be active participants in any AR process, but in practice, participation varies (Munn-Giddings, McVicar and Smith, 2008). Core features of AR are similar to those within CD (4.2), making it an ideal choice here:

- “1. It is democratic, enabling the participation of all people.
 2. It is equitable, acknowledging people's equality of worth.
 3. It is liberating, providing freedom from oppressive, debilitating conditions.
 4. It is life enhancing, enabling the expression of people's full human potential.”
- (Stringer, 1996, p.10)

I aspired to carry out AR that was:

- Collaborative and democratic, challenging oppressive dynamics of power;
- A developmental, circular process of doing and learning.

Collaborative and democratic, challenging oppressive dynamics of power

AR typically involves and respects multiple perspectives in a supportive process. Stringer (1996) writes that AR “seeks to build positive working relationships” (p.19). Kemmis (2006, p.103) argues that a central feature of AR is the “communicative space” where issues are discussed democratically and respectfully. The open expression of divergent views enables participants to arrive at a mutual understanding and consensus about what to do. As Gustavson (2006) recommends, I sought to instil a shared responsibility for democratic dialogue

among all those involved. Freire (1972) calls for an atmosphere of cooperation and commitment, where all participants have “voice and choice” (Ochocka, Janzen and Nelson, 2002, p.384). Lewin (1946) found that this process could be emotionally charged when diverse groups were involved. Like Varcoe (2006), I sometimes struggled: “The romantic emancipatory possibilities of PAR were exposed as dreams in the light of the realities of our racist and inequitable world” (p.532).

In a CD context, Whitelaw, et al. (2003) believe that AR is inherently political and critical. Those using mental health services may question the medical ideology that shapes their treatment. Shaull (1972) explains Freire’s (1972) idea that oppressed groups often adopt a “culture of silence” (p.10), but AR encourages people to share experiences and develop a questioning stance. Working within such communities, Watkins and Shulman (2008) write that researchers must be aware of the social, economic and political pressures that they face. Baum, MacDougall and Smith (2006) find that these power issues make AR a challenging process. My previous experience helped, but every situation brings new challenges. Ultimately, I found, like Stringer (1996) that community-based research (much like CD) is all about relationships. Williamson (2007) adds that it is about “mutuality, reciprocity and respect” (p.6). Collaboration depends upon trusting, supportive relationships, especially in the fields of mental health (Winter and Munn-Giddings, 2001) and ‘race’ relations (Curren, 1992) with shared goals for action and change.

A developmental, circular process of doing and learning

Action and change are integral features of AR. Lewin (1946) was one of the first to argue that “research that produces nothing but books will not suffice” (p.35). Stringer (1996) feels that an AR project has failed if it does not make a difference for those involved. Baum, MacDougall and Smith (2006) argue that AR must both improve our understanding of the world around us and change it. Diagram 4 below shows how learning, action and change come together within...

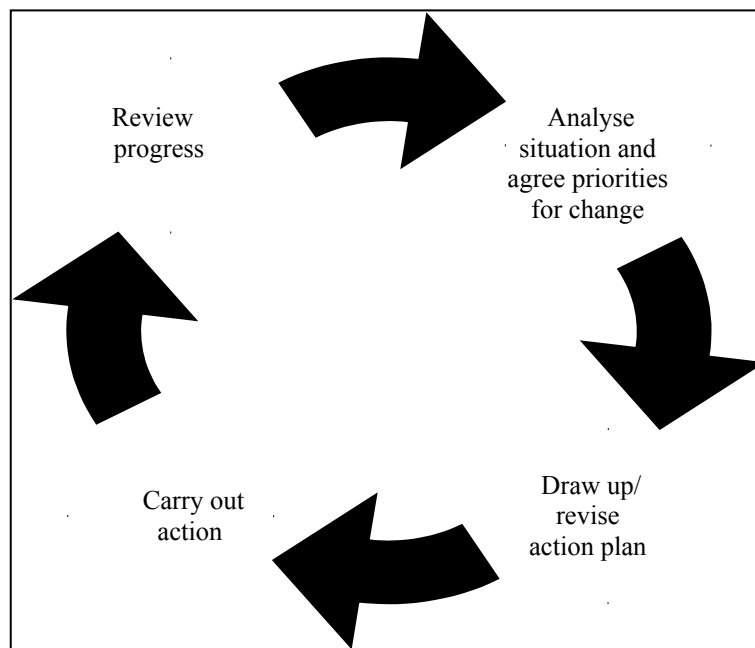
“A process which alternates continuously between inquiry and action, between practice and innovative thinking – a developmental spiral of practical decision-making and evaluative reflection...providing mutual support within a developmental process.”

(Winter and Munn-Giddings, 2001, p.5)

“Action research is a period of inquiry that describes, interprets and explains social situations while executing a change intervention aimed at improvement and involvement.”

(Waterman, et al., 2001, p.11)

Diagram 4: Action research cycle



There may be a gap between the model and the reality. Stringer (1996) notes:

“Action research is not a neat, orderly activity that allows participants to proceed step by step to the end of the process” (p.17). The action in AR varies widely. In this study it includes supporting and assisting group members to evaluate their work, share and record their stories and produce new publicity for their group (see 7.4 and 8.4), as well as activities which have no visible output such as facilitating reflective discussions to enhance participants’ awareness (7.4).

Like CD, AR is organic and often unpredictable. Cook (2009) reassures us that if it looks untidy this may be an important part of the creative, learning process and

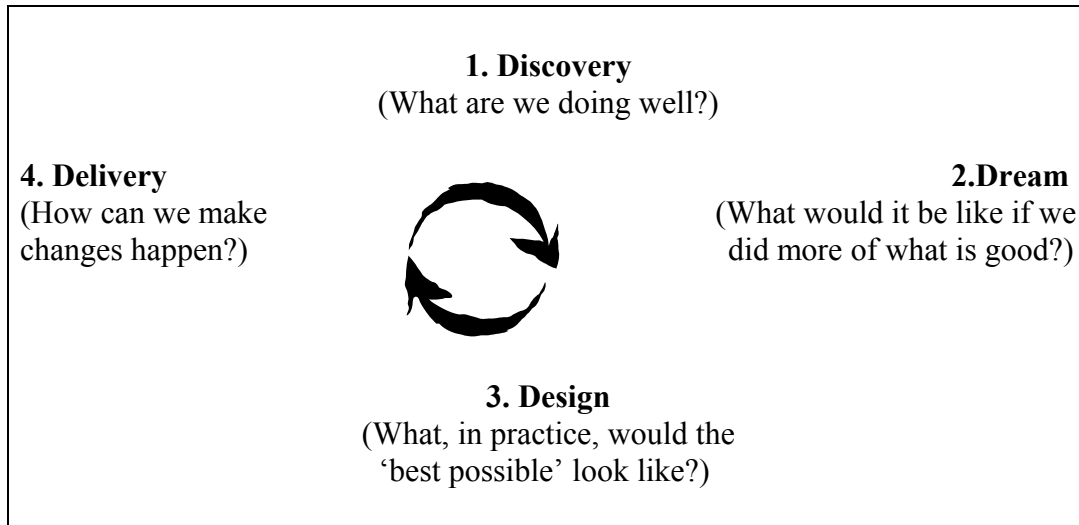
does not suggest it lacks rigour or is not properly done. The nature of the learning process contributes to this fluidity. Freire (1972) rejects “banking” approaches whereby knowledge is “deposited” in the minds of learners (p.46). Instead he encourages critical reflection through dialogue, to draw out and build on what people already know. Watkins and Shulman (2008) call for discussions that probe deeply into multiple perspectives, generating what Whitelaw, et al. (2003) describe as creative co-learning. Similar processes are found in AI.

Appreciative Inquiry (AI)

AI inspires hope and excitement through a collaborative process which explores and builds upon what works well or is valued in a situation (Reed, 2007). A fundamental principle of AI is that something works in every situation (Cooperrider, Whitney and Stavros, 2003). Like AR, it can be adapted and tailored to fit many contexts including organisational change, research and CD (Watkins and Shulman, 2008).

Like AR, AI is a staged process (Diagram 5). It begins with ‘discovery,’ where people share experiences of success in respectful, intimate settings. Then groups ‘dream’ their ideal future, and proceed to ‘design’ realistic plans, generating energy and optimism. Participants implement small changes, building on existing strengths, while those with power commit to higher level change (‘delivery’) (Whitney and Trosten-Bloom, 2003). Barnes (2009) and others believe that with sufficient participation, investment and time, AI creates sustainable change.

Diagram 5: 4-D Appreciative inquiry cycle



AI theorists believe that talking about strengths and valued experiences makes participants more hopeful (Cooperrider, Whitney and Stavros, 2003). Ledwith and Springett (2010) find AI a liberating, “enormously empowering” experience which enhances what is good (p.146). This makes AI increasingly popular in health and social care (Reed, et al., 2002; Havens, et al., 2006; Bellinger and Elliot, 2011). It is particularly useful where success can be elusive and strengths are rarely acknowledged, such as in dementia care (Seebohm, et al., 2010); homelessness (Quinney, 2012), and with detained and disturbed youth (Bonham, 2011).

AI is both a philosophy and a technique (Watkins, Mohr and Kelly, 2011), underpinned by six principles reminiscent of CD and AR:

- *The constructionist principle*: Different people understand the world differently.
- *The simultaneity principle*: inquiry and change are not separate. The inquiry process creates change.
- *The poetic principle*: stories include both facts and feelings, which may change as we re-interpret the past.
- *The anticipatory principle*: the way people think about the future shapes the way they behave.

- *The positive principle*: by asking positive questions people become more engaged, hopeful and inspired.
- *The wholeness principle*: Change is accelerated when everyone with an interest in the situation participates.

(Adapted from Seebohm, et al., 2010, p.16)

Similarities in the collaborative, flexible nature of AR and AI processes can be set against the differences. Ludema, Cooperrider and Barrett (2001, p.155) describe AI as “a positive mode of action research”, while Munn-Giddings, McVicar and Smith (2008, p.2) describe AR as often “problem-focused”. Cooperrider and Whitney (2000) describe problem-solving as a negative, limiting exercise, but this does not reflect my experience of AR (e.g. Seebohm, et al., 2005).

AI originated in the US and some object to its language and its process. Reed (2012) observes that a common criticism of AI is that it ignores problems in a situation, exacerbating its lack of credibility as research. Aldred (2011) suggests that AI may overlook structural inequalities, creating “the perception of empowerment and control where it may not exist” (p.69). Similarly, Ledwith and Springett (2010) suggest that AI “can feel rather Polyanna-ish” (i.e. unreasonably or illogically optimistic), which, if it lacks an analysis of power and structural inequality, can leave marginalised groups to address their own problems (p.146).

In response to these criticisms, Bushe (2007) argues that the essence and value of AI is its capacity to generate new ways of thinking and acting (p.30). Anger and pain must be acknowledged in productive ways, and for this facilitators must be prepared. Others, including Onyett and Hill (2012) agree that AI must engage with emotion and hurt as an integral part of the process. In my experience, AI generates an atmosphere of trust where participants reveal experiences which they might not have shared in a more critical setting. Shared and different features of CD, AR and AI are set out below (Table 4).

Table 4: Features of CD, AR, and AI

Shared features of CD, AR and AI	Features specific to AI
A circular or progressive process of reflection and action	AI questions focus on strengths and most valued experiences (as does some CD)
Democratic, respecting multiple perspectives and realities, valuing experiential knowledge	AI is more likely to include creative expression (pictures, poems, music etc) to create a vision of the future.
Collaborative, involving research subjects as active participants	
Often using stories of personal experience, reflecting on shared issues and acting together for change.	Storytelling typically begins in pairs, providing greater intimacy.
Inspiring hope	Hope may be generated with surprising speed as participants build on their existing strengths.
Change begins during the process	AI is relatively new to the UK (it has been used in UK healthcare for approximately 10 years) compared with AR and CD.
The impact on the individual is often significant. Sustainable social or organisational change requires time, investment and participation of those holding power.	Historically, AR developed out of conflict (Freire, 1972); AI, and AR today, tend to be more consensual.

My understanding of AI developed after the study began, but I used its principles in my work with the Black groups and in designing interview schedules in Cycles Two to Four.

5.4 Aims

This doctorate was inspired by the CDWs at Sharing Voices (Bradford) who helped people from BAME communities to set up and sustain peer support groups (described 1.4 and 3.3). I felt that learning more about CD support for such groups

could help to improve mental health care for BAME communities. My research question asked: How can CDWs support autonomous groups of BAME people with mental health problems?

The topic was refocused after the exploratory phase, as frequently happens in AR. I broadened it to include other people who supported groups as my early data suggested that few CDWs on the Delivering Race Equality in Mental Health Care (DRE) programme (DH, 2005) supported autonomous mental health groups. By chance, Black groups were identified as potential case studies (in a process I describe below). This enabled me to narrow the topic from people with BAME backgrounds to focus on Black groups. I felt that this tighter focus would increase the quality and topicality of the research as Black people experience the greatest inequalities in mental health.

The research question became: How can CDWs and others support autonomous groups of Black people with mental health problems?

My objectives were to:

- describe how a sample of CDWs employed under the DRE Programme worked with member-led or community-led BAME groups of people with mental health problems, using a survey and follow-up interviews;
- use a case study approach in one or more sites to:
 - describe how autonomous groups of Black people with mental health problems are supported by CDWs and others;
 - deliver development support to each group on a topic of their choice;
 - use reflective notes as data to link the learning from development activities to the qualitative research;
 - describe the groups' activities from the perspective of key stakeholders;

- reflect on the findings with critical friends and explore their wider relevance to other autonomous groups of Black people with mental health problems;
- share the learning with those taking part.

5.5 Methods

Introduction

This section gives an overview of the AR process through four cycles (C1 to C4) from access to analysis, including qualitative interventions, case studies, development support and reflective notes. Chapters Six (C1) to Nine (C4) include details specific to each cycle.

Action research cycles

AR was carried out in an organic process involving four research cycles (Table 5 below). The exploratory Cycle One (C1) comprised a national survey of the DRE CDWs and follow-up interviews with a sample of respondents. Cycles Two and Three (C2 and C3), the case studies, each involved one of the CDW interviewees from C1, together with the autonomous groups of Black people with mental health problems which they supported (Sweet Potato and Ngoma) and local stakeholders. The reflective Cycle Four (C4) comprised conversations with critical friends. The learning from each cycle informed the next.

Table 5: Four research cycles (detailed)

Cycle	Activity
Exploration Cycle 1	Survey with 46 CDW respondents and interviews with 9 of the 46 respondents.
Case-study Cycle 2 SWEET POTATO	Qualitative research with CDW/1 from C1, an autonomous Black group and stakeholders, and development work with the group (evaluating group activities).
Case-study Cycle 3 NGOMA	Qualitative research with CDW/2 from C1, an autonomous Black group and stakeholders, and development work with the group (developing publicity and a book of stories).
Reflection Cycle 4	Conversations with 6 critical friends expert in the field.

**Cycle 4
Reflections with
critical friends**
Permission and access

The DRE programme was never the focus of this study, but most, if not all CDWs working on ‘race’ and mental health issues in 2007-9 were funded through DRE. I therefore needed permission and assistance to access the national DRE CDW workforce and in May 2008 the DRE Research Manager gave his approval and support. For C1, I used email and attended four regional network meetings to invite CDWs to participate in the survey. Forty-six CDWs responded (approximately 11% of the total CDW workforce) and I interviewed nine of these.

For C2 and C3, I invited two of the nine CDW interviewees to take part in case studies along with the groups of Black people with mental health problems they supported. The CDWs consulted the groups, which both expressed interest in the

study, and I was introduced to discuss the proposal before consent was given. CDWs and group members identified relevant stakeholders for interview.

For C4, six people, all nationally or regionally respected experts in the topic of this thesis, agreed to take part as critical friends in conversations about my findings. Five were known to me through my professional work, one of whom invited the sixth person.

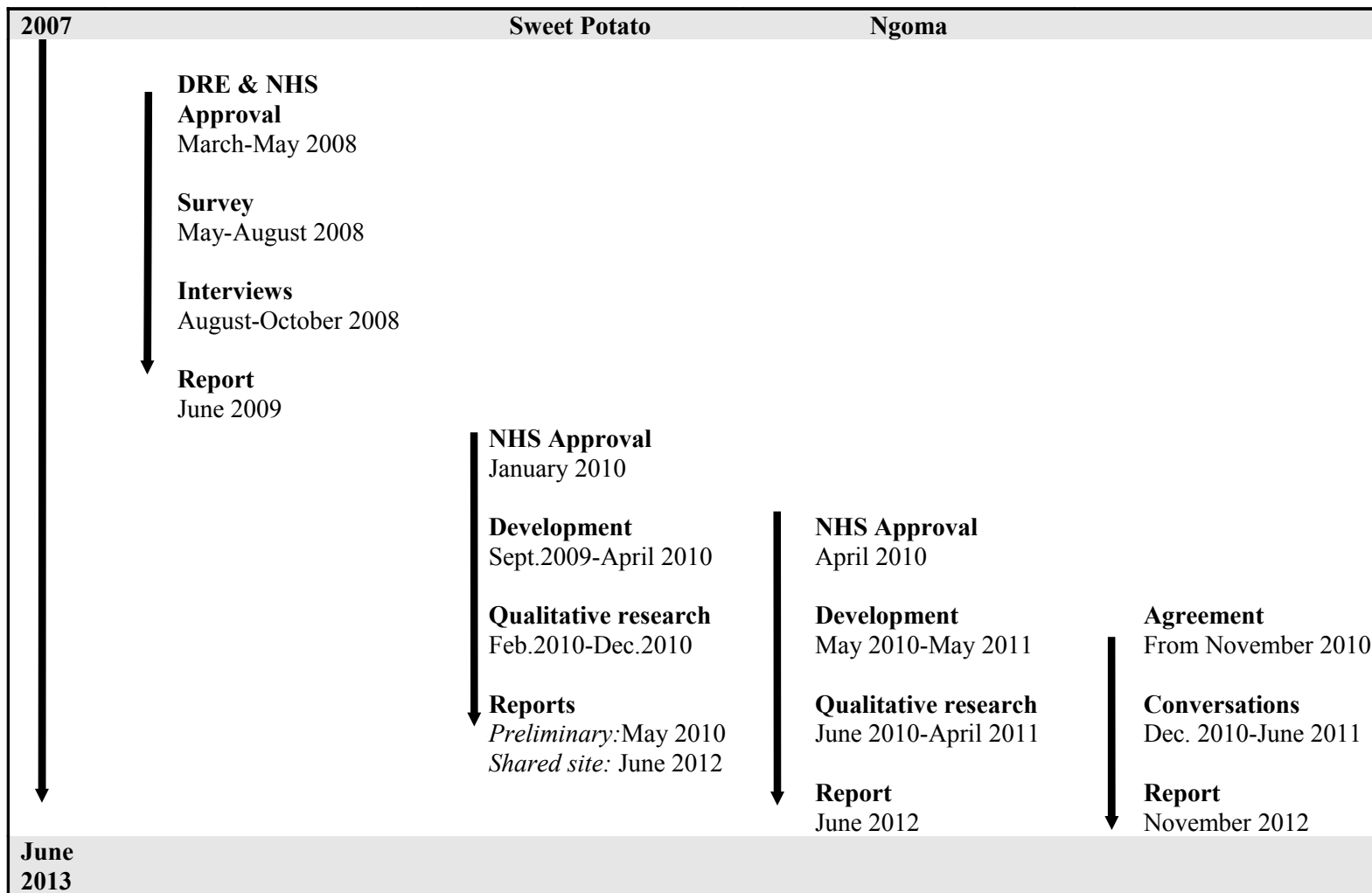
NHS ethical approval was granted in March 2008 for C1, and in January 2010 for C2 and C3, followed by approval from the relevant research and development governance bodies at the two sites. Ethical approval was not required for C4. This process of permission and access is set out in Table 6 below. Table 7 presents a timeline for the study.

Table 6: Permission and access

CYCLE	PERMISSION	ACCESS TO PARTICIPANTS
Exploration Cycle One C1	Hertfordshire NHS Research Ethics Committee Approval (March 2008) National Delivering Race Equality (DRE) Programme approval (May 2008)	Regional Race Equality Leads enable access to CDWs via network meetings and email databases. ↓ Presentations/discussions/email with CDWs to invite participation. ↓ 46 CDWs participate in survey. (May-Aug 2008) ↓ Sample of 9 CDWs from the 46 respondents interviewed. (Aug-Oct 2008) ↓
Case studies Cycle Two C2 and Cycle Three C3	Wandsworth NHS Research Ethics Committee Approval (January 2010) Research & Development approval from: South London and St.Georges Mental Health NHS Trust, (Jan 2010) (C2) South Essex Partnership NHS Foundation Trust (SEPT) (April 2010) (C3)	Sample of 2 CDWs from the 9 interviewees selected for case studies. (Early 2009-Early 2010) ↓ CDWs gain line management consent and inform their groups who express interest. ↓ Face-to-face discussions with each group before they give consent to participate in case studies. ↓ CDWs and groups facilitate access to stakeholders for interviews. (Feb 2010-April 2011)
Reflection Cycle Four C4	Not required	Invitation to six ‘critical friends’ to discuss findings (five known through professional work, one of whom invited the sixth). (Dec 2010-June 2011, with one unrecorded conversation repeated on tape October 2012)

Table 7: Research timeline

Sept.	Exploration	Case Study	Case Study	Reflection
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Qualitative approach

My epistemological and methodological position led me to choose a largely qualitative approach which prioritises the participants' perspective:

“Qualitative researchers study things in their natural settings, attempting to make sense of, or to interpret, phenomena in terms of the meanings people bring to them.”
(Denzin and Lincoln, 2005, p.3)

Qualitative techniques allow us to “get closer to the actors’ perspective through detailed interviewing and observation”, enabling us to see the participants in action and get a rich description (Denzin and Lincoln, 2005, p.16). Swan and Morgan (2002) argue that qualitative methods are helpful in community settings, enabling researchers to “look beneath the surface at the hard to measure processes and actions of people’s relationship to others, at community structures and the ‘life’ of communities and networks” (p.6).

Within an overall qualitative approach I used a small embedded quantitative intervention, a questionnaire survey, to explore the field. I used multiple qualitative methods, including interviews, group discussions and reflective field notes describing group activities, videos and documents (including annual reports, publicity, management meeting minutes). Denzin and Lincoln (2005) write that this approach enables researchers to blend their observations with “the self-reports provided by subjects” (p.21), recognising different view-points:

“Any gaze is always filtered through the lenses of language, gender, social class, race and ethnicity. There are no objective observations, only observations socially situated in the worlds of – and between – the observer and the observed.” (p.21)

I checked and added depth to my interpretation by discussing it with participants and later with critical friends.

Case study approach

Two case studies lie at the heart of this AR journey. Case studies help to answer the ‘how’ and ‘why’ questions about social phenomena (Denscombe, 2007). Stake (2005) argues that qualitative case studies concentrate on experiential knowledge and its context, which fits well with my epistemological purpose. Darke, Shanks and Broadbent (1998) write that case studies help to explore areas that we know little about and where we want to develop theory.

Case study research “is defined by interest in an individual case” (Stake, 2005, p.443) in contrast to studies that are primarily interested in generalisable findings. Stake describes a case as “a complex entity located in a milieu or situation embedded in a number of contexts or backgrounds” (p.449).

Boundaries must be drawn around the case, although Denscombe (2007) comments that these may not be as clear as researchers might want. Both case study groups initially appeared to have clearer boundaries than proved to be the case. Following Stake (2005), I investigated both what was within the boundaries and the context outside.

A choice has to be made between researching a single case or multiple cases. Littlechild (2009) argues that even a single case study can provide valuable insight into under-researched topics, and Darke, Shanks and Broadbent (1998) value the rich description of a phenomenon within its own context. As this was a self-funded doctorate a single case study was preferred, but during the fieldwork I came to feel that a second case study was needed to generate a broader understanding of the topic, an approach which Yin (2009) recommends. Each case study involved an autonomous Black mental health group, but these differed in their size, structure, age, finances, activities and regional location, offering a useful contrast (Yin, 2009). Chapters Seven and Eight give more details. Darke, Shanks and Broadbent (1998) reassure me that “there is no ideal number of

cases...both single and multiple-case designs can be adopted for exploratory research” (p.281).

There is also a choice to be made between what Yin (2009) describes as a holistic approach with intensive study of the particular case as one unit of analysis, or an embedded approach where the interest may be in several aspects or processes within the case. I adopted an embedded approach, as my interest is in how the case studies shed light on CD support, and not in every aspect of the groups. This is therefore what Yin would describe as a multiple, embedded case study.

Within the case studies I carried out a continuous, iterative process of data collection and analysis, moving from first impressions through to resolving puzzles, triangulation across data sources, feedback and revisits. My experience resonates with Yin (2009) and Darke, Shanks and Broadbent (1998) who suggest that case studies can be slow, resulting in huge amounts of data. This detail does not imply findings have wider relevance, although others who identify similarities with their own situation may find the learning useful.

Interviews and group discussions

I used interviews and group discussions to achieve some distance from the participants without dominating them. Campbell, Cornish and Mclean (2004) found that African Caribbean mental health service users felt most comfortable in peer group discussions. Kamberelis and Dimitriadis (2005) believe that these foster a sense of group identity, trust and purpose. Their collective nature helps to address the imbalance between researchers and researched.

Qualitative interventions are not neutral processes; rather, they are “inextricably and unavoidably historically, politically and contextually bound” (Fontana and Frey, 2005, p.695). Foucault (1980) describes how power operates in multiple sites (2.3) and Aléx and Hammarström (2008) argue that power dynamics exist in the interview situation, influenced by social and historical circumstances and the

stance and style of those involved. Reflexive thinking on these factors can help researchers to achieve “good contact between people despite their different access to economic, social and cultural factors” (p.173). Acknowledging the challenges, I aimed to be empathetic, drawing out the participants’ perspectives in different ways. I was:

- supportive (with group members, volunteers and host organisation staff in C2 and C3);
- detached and impartial (with CDWs in C1 and with stakeholders in C2 and C3);
- reflective, putting forward opposing points for a deeper response (with CDWs in C2 and C3).

Interview schedules and topic guides for C1 to C3 are in Appendices III - IV. In Chapters Six and Nine I outline the questions asked in C1 and C4, while here I outline the case study schedules. In the case studies, group members, volunteers and host organisation staff were asked about:

- a time when their involvement in the group went particularly well;
- what they valued most about the group;
- what the group would look like in three years’ time if their wishes for the group came true;
- how the group could move nearer to this future vision;
- who could help in that process;
- what they could do now to support that process.

Group discussions lasted up to three hours with a break and interviews lasted about one hour. Unwaged interviewees were paid £20.

When interviewing stakeholders, as Fontana and Frey (2005) advise, I guarded against becoming an advocate for the group. Interviews varied from 30 to 90 minutes and asked stakeholders about:

- their relationship with the group;
- the contribution made by the group;
- if and how the group might do more;
- what could help them to achieve that;
- the relationship they would like to see between the DRE CDWs and the group;
- the value, role and challenges of having BAME service user groups;
- what counts as good evidence of groups improving race equality.

My approach to the interviews in the case studies with the two CDWs from C1 was empathetic but detached, intervening more actively in the two follow-up interviews to prompt reflection on recent events. CDW interviews took 90 minutes on average. First interviews asked about:

- how their involvement with the group began, and their hopes at that time;
- a time when they were most proud of their work with the group;
- what they valued most about the group;
- what the group would look like in three years time if all their wishes for the group came true;
- how the group could move nearer to this vision;
- who could help in that process;
- what the CDW could do now to help in that process.

Follow-up interviews asked:

- since the last interview, were there times when you were especially pleased with your work with the group?
- were there other memorable occasions?
- do you have other reflections relevant to this study?
- what would you like to see happen next?

Recording data

After receiving written informed consent from participants, I audio-recorded and fully transcribed all group discussions and interviews, except for those of four participants who were imminently moving on: to ensure a quick turnaround these were professionally transcribed and I checked them. Typed transcripts were shared with the participants, with key points read to those who preferred verbal communication. Participants were invited to amend their transcripts if they wanted to do so and about a third made minor amendments.

Development support

Within the case studies I adopted two parallel approaches. Firstly, I used the multiple qualitative methods described above. Secondly, I provided development support on a topic of the groups' choice modelling the CD support that I was investigating. This was, in effect, combining CD with community-led research, after Freire (1972) and Ledwith (2011). This ensured that the groups benefited from my doctorate research and had ownership of at least some of the work, in accordance with the values of AR. One group wanted help to evaluate their activities while the other wanted help to develop publicity: a project profile, leaflet and book of stories.

The development support was not, in itself, research for the doctorate. However, reflexive thinking on my experience and critical reflections on the context were recorded in reflective notes which became data to improve my understanding of CD support. Thus I linked the qualitative data collection with the development support by using reflective notes as qualitative data. These two strands of learning

intertwined and informed each other but were kept distinct, recorded and reported separately (7.5.4 and 8.5.4) and gathered through different roles.

Role changes

My roles therefore moved to and fro from the dispassionate qualitative researcher to facilitator and co-learner. Stoecker (1999) describes the range of roles and skills involved in participatory research:

“Participatory research is actually part of a larger community change project that is dependent on four roles: ‘animator’, community organizer, popular educator, and participatory researcher.” (p.840)

Chapters Seven and Eight illustrate some of these roles. To avoid confusion, I tried to ensure that my role was always clear and transparent through reflexive thinking (discussed below), regular communication and open discussion. Consent was reviewed with each different activity, giving participants control over their involvement.

Levels of participation

As in most AR, there was a high level of reciprocity and mutual support throughout the study, with many people keen to participate to help themselves and to support me (see Table 8 below). Participation was highest for case study group members in the development work, as they chose the topic, worked together to design and carry out their research, owned and disseminated the final product. During the case study qualitative research the group members and CDWs regularly reflected on progress and then helped to develop the analysis. In C1 and C4 up to two thirds of participants reviewed the analysis.

Participation was lowest with some case study stakeholders and a few participants from C1 and C4, but all had an opportunity to check and amend their interview transcripts.

Reflective notes

Reflective notes provided a systematic record combining:

- field notes ('FN'): informal observations of what I saw or heard outside an interview or focus group that seemed relevant to the research;
- reflexive thinking: how I felt about what I observed, and reflexive questioning about why I felt that way;
- emerging conceptual ideas.

About half the entries were handwritten notes and half were typed as memos on NVivo software.

Field notes of informal observations

Informal observations were especially useful during the case studies. I hoped to develop a critical rather than merely descriptive account of the groups which they felt was fair, as recommended by Holloway and Wheeler (2002). Following Stringer (1996), I began by building a preliminary picture, including the social dynamics, stakeholders, history, and relationships (p.53). This meant including in my field notes, as Spradley (1980) suggests, the location, the people, their behaviour and conversation, what was going on and my impressions of how people felt. Following Holloway and Wheeler (2002, p.99), wherever possible I gained access to the full "continuum from closed to open settings". I was able to attend insider sessions such as management meetings as well as open activities like weekly lunches. I saw documents including minutes and reports, videos and creative performances. Mulhall (2003) notes that observers cannot record everything; they make choices about what is significant. Over time my note taking became more focused to inform emerging ideas. I was generally what Gold (1958) describes as a "participant as observer", working alongside group members but observing what was going on at the same time.

There was regular feedback to the groups and discussion of my impressions, but I kept some observations to myself where I felt they might exacerbate local tensions. As Harris (1976) suggests, the emic perspective of insiders contributed

to but did not always match the etic meaning that I as researcher gave to the situation to enable me to make sense of it.

Constraints on note taking included fear of seeming intrusive and lack of time. I did not take notes where some people present did not know that I was a researcher.

Reflexive thinking

My reflexivity involved turning a critical gaze inwards to understand why I felt and behaved as I did and above all to understand the way I was constructing, collecting and interpreting my observations and interview data. Winter and Munn-Giddings (2001) describe it as “self-examination, taking one’s own interpretations of events as ‘data’ to be subjected to examination” (p.53). Ledwith and Springett (2010) refer to:

“...the ability to reflect on our reflections, going ever deeper under the microscope to examine our own attitudes, assumptions and prejudices in order to open ourselves to new insights and understandings. We could see this as an inner dialogue...we need to be aware of the impact of our own identity and its power dimensions across the diversity of people with whom we work.” (p.18)

To help with this I listened to and read about other ways of understanding the situation, avoiding a deficit perspective and sharing my thoughts with others. Fook’s (2012) use of the term critical reflection seems to have a broadly similar meaning, and I adapt her four types of outcome:

- Rational: reflexive thinking helped me to analyse situations, relate them to theory and work across multiple perspectives.
- Emotional: it helped me to move on from difficult situations, removing emotional blocks while increasing self-awareness.
- Values-based: it helped me to revisit my core values and recognise others’ value systems.

- Practical: it helped me to find different ways of dealing with situations and learn from practice.

I add that, as Aléx and Hammarström (2007) recommend, reflexivity helped me to keep my position as an outsider in terms of skin colour, mental health and socio-economic background at the forefront of my thinking, exploring “how the social location of the researcher and the researched influence the investigation process” (p.171). Analysis was a critical part of that process.

Analytical strategy

I adopted a strategy to develop analysis through the four research cycles, with learning from each cycle carried forward into the next stage. This iterative, continuous process of data collection, analysis and discussion was carried out alone, with participants and with supervisors. A trail recorded each step in the analysis and further reading supported theoretical development. Following Winter and Munn-Giddings (2001, p.23) my goal was not “a single final analysis of ‘results’”, but rather what Mason (2002, p.173) describes as a convincing argument, “the construction of a perspective, an interpretation, or a line of reasoning or analysis” which could contribute to further development and debate.

This strategy helped me to organise and work with a mass of data in a way that suited my theoretical and methodological approach. The data included interview and group discussion transcripts, field notes, reflexive notes and contextual information. I used an interpretive approach, aiming to record and understand participant perspectives, but I also used a reflexive approach, locating myself and my interpretations in the study as described above. The different strands of data collection were considered together during the analysis, but in the case study Findings I report my reflective notes separately to ensure data sources remain clear.

For C2 and C3 I adopted what Mason (2002, p.165) calls the case study approach, examining the “particular-in-context” to understand how and why things were happening where they were relevant to the research question. Other aspects of the case studies became contextual data. In C4 I reflected on similarities and differences across earlier cycles. Thus cross-sectional and case study approaches were used together.

Thematic analysis describes my overall technique, whereby I identified patterns and themes as described by Braun and Clarke (2006). I also identified a few issues that I felt could not be subsumed within themes except as tensions between opposing views. To analyse these I used a dialectical approach (Winter and Munn-Giddings, 2001, p.238) to ensure that multiple views were not hidden “beneath a veil of homogeneity and generalization” (Spencer, 2001, p.450). I describe the thematic and dialectical techniques below.

Thematic analysis

Thematic analysis is the overall method that I chose to identify, analyse and report the patterns (themes) that I identified in the data, following Braun and Clarke (2006). A theme, Braun and Clarke state: “captures something important about the data in relation to the research question, and represents some level of *patterned* response or meaning within the data set” (p.82). The usefulness of a theme is not dependent on how often it appears within the data but rather on what it captures in relation to the research question.

Having transcribed most of the interviews myself I was familiar with the data, but when the fieldwork finished I reread all the transcripts, noted initial ideas and began to work systematically through the data to identify codes: the most basic segment of data that is assessed as meaningful (Braun and Clarke, 2006). What counted as meaningful was determined not by any pre-existing framework, but by what I found interesting or surprising in the data relating to the research questions or the context. Coding began by hand but was transferred to NVivo software

when I was confident that my codes were useful. Visually plotting the codes helped to draw them into broad themes and subthemes. Codes that did not fit were noted and, where relevant, included in the analysis as a contradictory tension. Data that did not relate to the research question or help to explain the context was finally discarded. Themes were reviewed and revised many times, partly to ensure that they provided the best possible fit with the data, internal consistency and focus on the research question, and partly to take on board further reading and discussion with participants.

Dialectical approach

Within both case studies were three similar issues important to participants but about which there was no agreement. I describe these as organisational tensions and use a dialectical approach to analysis to keep alive multiple voices. I wanted to avoid falling for familiar interpretations or submerging different views. This approach drew on dilemma analysis, described by Winter and Munn-Giddings (2001) as useful where there is no consensus, where development is a priority and to instil respect for alternative views. Dilemmas can be disorientating (Brookfield, 2011) but potentially increase clarity (Ryle, 1995).

The process began by identifying contradictory statements, using participants' words to avoid researcher interpretation:

“Statements which are contradicted...are thus picked out from the rest of the data as indicating issues in the situation about which participants may disagree. Such issues are potentially ‘interesting’, not only as a way of creating an interpretation of the situation but also for the practical development of the project.” (Winter and Munn-Giddings, 2001, p.239)

I felt that the tensions conveyed the complexity of the group development issues facing CD practitioners. They were identified through different sources of data and confirmed by participants during feedback discussions.

Triangulation

Triangulation involved bringing together and comparing data and themes from the survey data, interviews, group discussions and reflective notes wherever possible, to increase the depth of understanding and trustworthiness of the argument.

Methodological triangulation “adds rigor, breadth, complexity, richness and depth” when working within the social constructivist paradigm (Denzin and Lincoln, 2005, p.5). A frequent criticism of case studies is that they lack rigour; triangulation helps to address this (Stake, 2005; Yin, 2009).


Advisory Group


Five people known to me from my professional work agreed to join an advisory group to support my PhD with informal advice, guidance and contacts. Their expertise included using and managing mental health services, informal caring, CD, race equality and psychiatry. They came from Black, Asian and White backgrounds. They provided support on a one-to-one basis to complement academic guidance from my university supervisors.

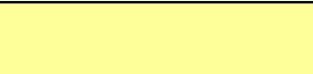
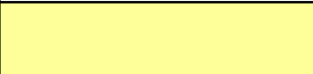

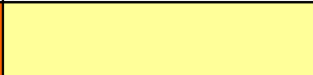




















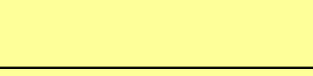







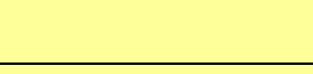
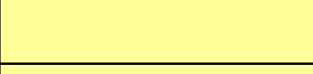

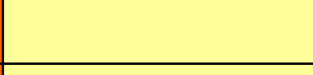
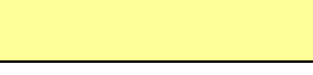
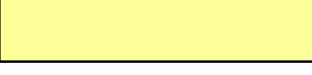

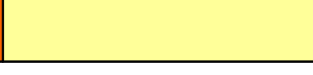
Table 8: Participation levels

Key:

 = low or no participant involvement

 = some participant involvement

 = high participant involvement

Research stage	Cycle 1: Exploration	Cycles 2 and 3: Case-studies		Cycle 4: Reflection
		Qualitative research	Development work	
Choose research topic				
Choose approach/design				
Data collection				
Check/amend data				
Analyse findings				
Review analysis				
Review research progress				
Write up/produce outputs				
Dissemination				
Ownership of final product				

5.6 Ethical issues

Ethical approval was provided by Hertfordshire Research Ethics Committee (REC) in March 2008 for C1; by Wandsworth REC in January 2010 for C2 and C3, and was not required for C4 (Table 6 above). Approval was given by the research and development governance groups at South West London and St. George's Mental Health NHS Trust (SWLSTG) in January 2010 for C2, and at South Essex Partnership Trust (SEPT) in April 2010 for C3.

I drew ethical guidance from the Department of Health (DH), the ethos of AR, and my academic supervisors. I complied with the *Research governance framework for health and social care* (DH, 2005b). Helpfully, this echoes AR values in its support for the involvement of service users from so-called “hard-to-reach” groups:

“Research is pursued with the active involvement of service users and carers including, where appropriate, those from hard-to-reach groups.”
(DH, 2005b, p.16)

A dilemma arose when, prior to applying for ethical approval for the case studies, I had to secure agreement in principle from at least one group to participate before applying to the relevant mental health trust's research and development group. I wanted to have ethical approval before working with the first group but as soon as they confirmed their participation in September 2009 they wanted to begin the development work. This was to be an evaluation of their activities which had to be completed before their funding expired in six months time. The lead on ethical approval at Anglia Ruskin University advised me that the group's evaluation did not require ethical approval, confirmed by *Defining Research* (National Patient Safety Agency, 2008), so we began. The research, such as interviews and group discussions, only began after receiving ethical approval in January 2010.

Another dilemma was never satisfactorily resolved. My concern was to safeguard the “dignity, rights, safety and well-being of participants” (DH, 2005b, p.11, para. 2.2.1) but I felt that this was threatened by the following REC requirement:

“There should be a clause in the Information Sheet stating that should there be any disclosure of criminal activity, confidentiality could not be maintained.”
(Wandsworth REC, Chair, 2009, p.2)

This clause led to amusement, ridicule, resentment and fear among participants. Some felt that the unusual reference to criminal activity was institutionally racist. The research governance group at SEPT regretted this clause, but felt bound by the REC requirements. If I had challenged Wandsworth REC in January 2010 the process of gaining approval would have been delayed further. Later, I wrote to the REC Chair informing him of the participants’ reactions, requesting but receiving no reply.

Other ethical concerns included transparency about my role(s) and receiving informed consent. I ensured the wider group membership knew that I was a researcher through frequent announcements and conversations. When carrying out interviews and group discussions I became more formal and directive, taking informed consent in writing, emphasising that participation was voluntary with withdrawal possible at any time without a reason.

Maintaining confidentiality is a high priority but a complex issue. No data was shared outside the supervisory team without participant consent. Fictional names or numbers are used to identify participants, groups, organisations and quotes. Feedback reports for participants and RECs increased anonymity by combining data from the different sites. Draft reports were approved by the participants. Despite these measures, in community research of this kind there is a risk that groups and participants can be identified by those determined to do so. The risk is increased here by the groups’ decision to put their development activities in the public domain through publications and websites. At their request I use their real rather than fictional names when referring to their publications. I am reassured by

my belief that nothing in the thesis can surprise or upset them as the key points are already agreed and shared through local reports.

I am a registered independent researcher under the *Data Protection Act 1998*.

Personal details are held on a password-protected computer database, with a back-up disc in a locked cabinet. Transcripts and interview notes are kept separate from the participants' personal details and coded so no connection can be made. The recordings were destroyed after the transcripts were confirmed, but transcripts and personal information will be kept for seven years in line with usual university processes, allowing for further analysis if an opportunity arises.

Participants were told that if, during the research, they become distressed or had concern for their own or anyone else's personal safety, I would seek assistance for them from a person of their choice. No one became distressed. The REC agreed that mental capacity was not a concern here.

Power differentials created complex dynamics. For instance, although the development activities were chosen and led by group members, I frequently found it necessary to guide activities so that we achieved their desired outputs on time. I discussed this with the groups, who agreed that I was sometimes directive but said that this helped them to keep focused so they could complete their work.

I worked to create an ethos of mutual respect, regardless of allegiance, culture, ethnicity, age, health and gender, as required by AR. Sometimes friction among group members erupted in C3, but other members helped to resolve these. As a mark of respect and appreciation, unwaged participants were paid according to available resources and national guidance, which created some tension with the groups' host organisations (see 7.5.4 and 8.5.4.).

5.7 Trustworthiness

I relate judgements about the trustworthiness of the research to its epistemological foundations. The criteria for assessing validity within deductive positivist studies are neither achievable nor appropriate here. Guba and Lincoln (1994) argue that constructions are not more or less true in any absolute sense, but simply more or less informed and/or sophisticated. There is a debate within AR about what counts as informed judgements, with the notions of trustworthiness and authenticity widely regarded as helpful (Winter and Munn-Giddings, 2001). To assess the trustworthiness of this research I use guidance for evaluating AR drawn up by Waterman, et al. (2001), which is presented and discussed later (11.6). Waterman, et al. also consider transferability.

5.8 Transferability

I make no claim to universal truth, but hope that the learning is useful. AR often involves small case studies of social situations and many question the scope for generalising from these specific circumstances (e.g. McKeganey, 2000). This study included fieldwork data from seven autonomous Black mental health groups, giving it a broad base from which I can suggest general principles of wider relevance.

Policymakers rely on random controlled trials for guidance on replicable solutions for large populations, but there is an increasing awareness of the diversity of our population, the complexity of our lives and expertise from experience. The DH, for instance, funded a service user research network, SURGE, and community research through the DRE to gather perspectives outside academic and medical circles.

Lessons from an AR project are “just as likely to be illuminating and interesting for colleagues elsewhere” as other forms of research, Winter and Munn-Giddings (2001) argue, because they are based on recognition of the complexities involved (p.21). As an AR report describes the context and participants, it may reveal

conflicts of values and power relationships that resonate with other situations. Whitelaw, et al. (2003) suggest that readers can discern whether there are similarities in their own locality. Showing the steps taken by those involved in the study and showing what worked allows others to take similar steps. Detailed circumstances are likely to differ, creating different if broadly similar journeys.

5.9 Limitations

Some studies have an impact by virtue of delivering a simple message based on a neat, focused design. This is not one of them. Different phases, activities and analytical methods sought to make meaning of a complex situation spanning social divides. There is a risk that this seems a ‘dogs-dinner’ without coherence or justification, but I argue that there is method in it. It works: themes are identified, developed and made sense to participants. It made a difference to some people, albeit not much to not many. It is not unlike many AR studies which are neatly presented but, as Cook (2009) bravely observes, seem messy during the process.

AR has high aspirations to co-create knowledge and transform reality. It requires skill, time, resources and leverage. There is a risk of losing criticality, integrity and focus. My aspirations are not so high and I discuss the imperfections but also defend the study as a creditable example of AR (7.5.4; 8.5.4; 11.5). The following four chapters take the reader through the research cycles.

5.10 Chapter summary

This study asks how CDWs and others can support autonomous groups of Black people with mental health problems. As an exploratory study it adopts an AR framework to develop theory while creating change, drawing on AI to enhance optimism and energy. From a social constructivist perspective I explored participants’ different realities within the context that frames them.

Multiple qualitative methods were used through four research cycles, beginning with a small embedded survey of CDWs and follow-up interviews. Two CDW

interviewees then took part in case studies together with the Black groups they supported. Finally, I reflected on my findings with critical friends expert in the field. During the case studies I delivered development support on a topic chosen by the groups, using my informal observations (field notes) and reflective thinking, brought together in reflective notes as qualitative data. Thematic analysis, augmented by a dialectical approach, was progressive and continuous. Finally, the chapter has considered ethical and critical issues, which are further discussed in Chapter Eleven. The thesis now continues to the first research cycle.

Chapter Six

Cycle One: Exploration

“The future of mental health services
should be really led by service users”
(CDW/1)

6.1 Introduction

My research began by exploring how community development workers (CDWs) were working with community-led and member-led groups of people with mental health problems. This cycle comprised two stages, first a survey then follow-up interviews. I present the aims, methods and findings of each stage, bringing them together in the discussion. Finally, I summarise the learning which I explore further in Cycle Two.

6.2 Overview

The overall aim of this doctorate research was to explore how CDWs and others support autonomous groups of Black people with mental health problems. All CDWs doing this work at the time of the study were likely to be funded through the Department of Health Delivering Race Equality in Mental Health Care (DRE) programme (DH, 2005a).

The specific aim of this cycle was to explore how a sample of CDWs worked with community-led and member-led groups of people from Black, Asian and minority ethnic (BAME) backgrounds who had mental health problems. In the community-led groups decisions about their purpose and activities were made by people from the same BAME community, while in member-led groups these decisions were made by group members. The phrase ‘people with mental health problems’ included those with common mental health problems using primary care health services, those with a diagnosed mental health problem using specialist mental health services and others who were distressed but were not using services. A secondary aim of this stage was to achieve a sampling frame from which I could

select one or two potential sites for case study research. Details about access and methods are in Chapter Five. The cycle began with a survey.

6.3 Survey

Aim and methods

The aim of the survey was to identify CDWs on the DRE programme working with groups of people with mental health problems, find out what this involved and find out how they felt about this work. My objectives were to:

- identify CDWs working with groups of people with mental health problems and find out whether group members accessed primary, specialist or no mental health services;
- describe the group activities and who made decisions about what to do;
- find out if CDWs felt that working with member-led groups of people with mental health problems was feasible within the DRE programme and, if so, how important they considered this compared with other aspects of their job.

The national DRE leadership gave me permission to approach CDWs at five CDW network meetings held in different strategic health authority¹¹ regions of the UK and via email databases. I invited CDWs to complete a questionnaire (see Appendix III) including open and closed questions about the objectives listed above, and invited comments about working with mental health groups. Statistical data were analysed using Excel software. Qualitative data were coded manually using thematic analysis (Braun and Clarke, 2006). From those CDWs who worked with community-led and member-led groups and who felt that this work was important, a sample of 7 to 10 across a range of geographical and workplace settings were to be selected for interview.

¹¹ Strategic health authorities ceased to exist in April 2013, but they broadly covered the North, Yorkshire and Humber, Midlands, London, and the East, South-Central, South-East and South-West.

Findings

Questionnaires were completed at the network meetings, except for five that were returned by email. Although the CDWs I met were supportive, few felt the study had relevance as they rarely worked with the groups concerned. Comments included:

“I used to be a CPN [Community Psychiatric Nurse] but I don’t work closely with service users now that I’m a CDW.”

“My role is mainly strategic.” (Field notes [FN], 8.7.08)

Forty-six CDWs completed questionnaires, comprising about 11% of the total CDW workforce (approximately 400 during April to August 2008). Of these, five did not work with people with mental health problems. About a third (n=15) worked with individual service users; just over half (n=29) worked with groups in the community whose members might be using primary care services; and half (n=23) worked with groups of people using specialist mental health services. Some worked with all three: individuals, community groups and service user groups.

Most community and service user groups were set up to increase well-being, inclusion and community engagement through various sport, leisure and workshop activities. Two CDWs supported BAME groups to identify and pursue their own goals and a further two wanted to do this. Five CDWs made decisions regarding group activities themselves, while nearly half of the respondents (n=19) said it varied: sometimes they made decisions alone and sometimes with group members.

Half of the respondents (n=23) felt that it is possible to support group activities within their CDW role, just over a third (n=17) were not sure, and five did not think it was possible. Just under a third (n=14) felt that this was an important part of their job. The comments suggested that most respondents were referring to

groups established to promote health (including occupational therapy), inclusion or engagement, with just the four respondents interested in supporting groups to pursue their own goals.

Most respondents (n=32) added comments to the questionnaire, mainly about the barriers to community engagement caused by distrust, language, culture or stigma. Two wrote about difficulties in engaging commissioners and health service managers. Several wrote about their CDW role. One felt it to be “intense and demanding” while three wanted more support. One felt that the grassroots and strategic strands of their role were incompatible and another felt that the expectations of them were too high.

6.4 Interviews

Aim and methods

The aim of the interviews was to explore the CDWs’ purpose, perspective and activities in their work with community-led and member-led groups of people with mental health problems. My objectives were to:

- describe the purpose of the community-led and member-led groups of people with mental health problems, their activities and how CDWs supported them;
- describe the CDWs’ purpose and perspective regarding their work with the groups;
- share the learning with research participants.

Seven CDW respondents were selected for interview, but one preferred to participate with his two colleagues, so nine CDWs were invited for interview based on the following criteria:

- their questionnaire responses suggested that they worked with groups of people with mental health problems;
- they came from a range of geographical and organisational settings;
- they attached high importance to supporting community-led and member-led groups.

Semi-structured interviews were carried out face-to-face, most lasting just over an hour. With written consent and anonymity assured, interviews were taped and transcribed verbatim, and the transcripts were checked by the interviewees. The interview schedule (Appendix III) asked about:

- the nature of the community-led and member-led groups that interviewees worked with, including activities, membership and decision-making processes;
- interviewees' role in establishing, developing and/or sustaining the groups;
- interviewees' past experience of working with mental health service users;
- the difference in 'race' equality that they sought to achieve through this work;
- their views on how the work fitted within their DRE CDW role.

Data analysis used a thematic approach (5.5). I began with a broad inductive sweep of all the data before creating a coding framework based on patterns of similarity and difference in how the interviewees spoke about their work and its context, focusing on themes around role, mental health and 'race' equality, and how the different perspectives might be explained. Interviewees were invited to check and discuss the draft report. All confirmed that it was a fair reflection of their views, and five discussed it at length, resulting in useful amendments. Next I describe the interviewees and their workplace context, then their goals, perspectives and strategies.

Findings

Participants and their workplace context

The nine participating CDWs came from seven sites across four strategic health authority regions. Their ages ranged from twenties to fifties, with just over half in their forties. Five were female and four male. They described their heritage as African, African Caribbean and African/White (n=4), Pakistani, Bangladeshi, and Asian/White (n=3) and third-generation Irish (n=2).

In three sites, CDWs were employed by statutory services, two mental health trusts (MHTs) and one primary care trust (PCT), but two of these had offices based in both the community and the MHT. Four CDWs were employed by voluntary sector organisations delivering regeneration, housing, mental health or BAME services. Three of the CDWs worked in cities, two in large towns and two in more rural areas. Their length of time in post varied from under six months to over two years (Table 9).

Table 9 CDWs' employer, base, length of time in post at interview and allocated band (see Diagram 6 below).

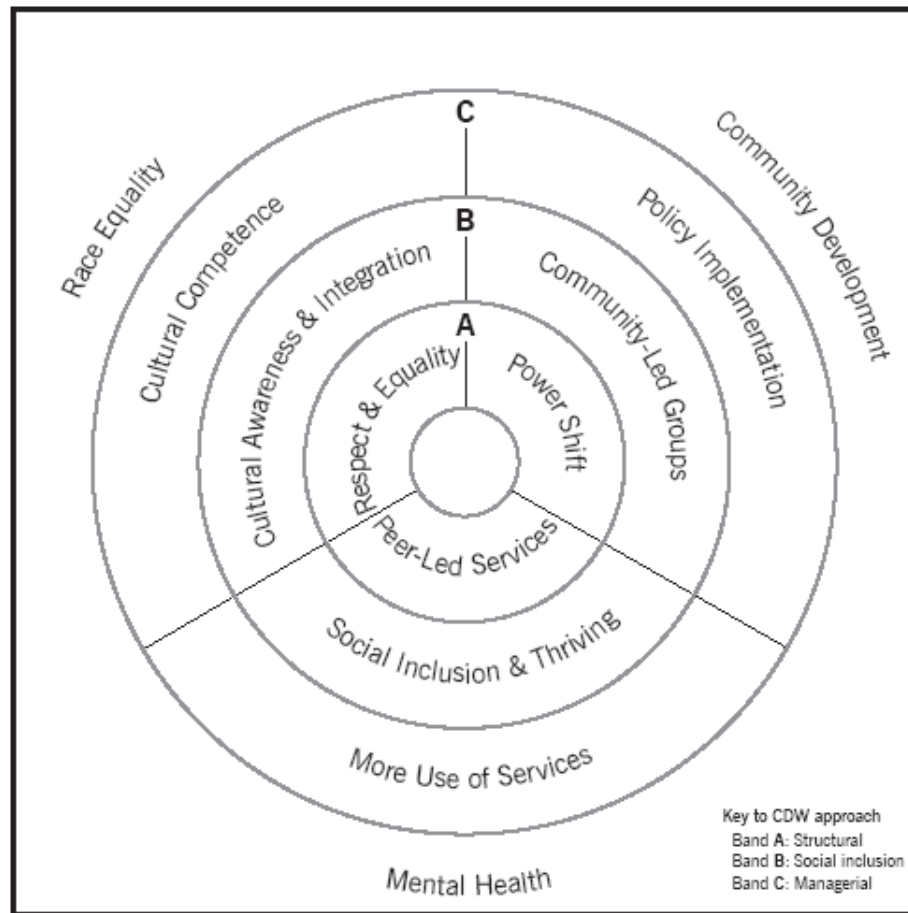
Employer	Office Base	Time in post at interview	Band (see Diagram 6)
Mental health trust	Voluntary sector	8 months	A (structural)
Mental health trust	Mental health trust and voluntary sector	18 months	A (structural)
Voluntary sector	Voluntary sector	5 months	B (social inclusion)
Voluntary sector	Voluntary sector	10 months	B (social inclusion)
Voluntary sector	Voluntary sector and primary care trust	Over 2 years (part time)	C (managerial)
Voluntary sector	Voluntary sector	18 months	C (managerial)
Primary care trust	Primary care trust [3 CDWs at this site]	9 months	D (undefined)

Three approaches to CD

All CDWs spoke passionately about their work and seemed deeply committed to it. They wanted to comply with DRE guidance and shared a similar understanding of the CD process, beginning with gaining trust, mapping local needs, engaging people in mental health-related discussions or activities, and bringing communities and providers closer together to improve access and services. However, DRE guidance was interpreted differently at each site and as they spoke about their role, CDWs revealed differences in their professional and personal goals, values, perspectives and strategies. They all supported groups of people who lacked well-being or were mentally unwell, and I identified three different approaches: band A ('structural'), band B ('social inclusion') and band C ('managerial'), with two CDWs in each band. At the fourth site, three relatively new CDW colleagues were without a defined, settled approach (band D).

In reporting my findings I have omitted the ethnicity of participating CDWs to ensure their anonymity. Ethnicity may have had some impact on the approach taken, but other factors such as previous experience seemed equally important.

Diagram 6 Community development workers' goals and perspectives



Band A: The 'structural' approach

Two CDWs supported service user-led groups, helping them to improve the experience of their BAME peers. These CDWs valued service user expertise and promoted user-led initiatives. They also supported community-led groups addressing 'race' inequality and mental distress through enterprise, the arts and women's activities. Their hands-on support covered development, training, making connections and helping with funding applications. Their relationships with groups seemed collaborative and friendly.

Both CDWs wanted service providers to hear from and be accountable to service users, and they worked to make this happen. One expressed frustration that

despite policy rhetoric promoting service user-involvement, power rarely shifts in their favour. He encouraged people from BAME communities to join the local foundation trust board to shift the balance of power. The other CDW sought to embed the community voice at a strategic level within planning processes:

“Change will only happen if you work with communities collectively and support them and empower them. And from that process here, together, collectively, they can do what they think is necessary to meet their needs.”
(CDW/1 band A)

“In terms of the town, getting money, the Local Area Agreements, it is about getting everybody included in that picture so what is rolled out is more appropriate. Not trying to come in way down the line when everything has already been set...I think that is the best way to try and make change.”
(CDW/2 band A)

Both worked in urban environments and were partly based in community network agencies, although both had permanent employment contracts with the MHT. Both knew mental health services prior to this job through voluntary sector or informal caring roles. Both were personally involved in community action to address mental health, social or economic issues for BAME groups.

Both CDWs felt that social pressures cause mental distress and, unlike other interviewees, they never used the term ‘mental illness’. They spoke briefly but confidently about racism, discrimination and a lack of equality. Their language suggested that they understood the problems faced by BAME communities in terms of structural inequalities. They are described in band A as ‘structural’ because they alone spoke of wanting to change the balance of power within institutional settings to give service users greater influence.

Band B: The ‘social inclusion’ approach

Although in post for less than a year, these two CDWs had supportive relationships with many community-led groups. They encouraged them and their leaders while also learning from them. Both CDWs wanted to increase social inclusion and inclusive practices, but they differed in approach. One helped to set

up community-led social activities for isolated and distressed people from specific BAME groups so that individuals could meet others within their own community. The other CDW prioritised integration and helped to make existing groups more inclusive:

“I think there needs to be more awareness of individual cultures and what their beliefs are...there is too much of a ‘one size fits all’ approach”.
(CDW/3 band B)

“I don’t believe in fragmentation, I don’t believe in creating islands of people. I believe in integration and that is the main purpose.”
(CDW/4 band B)

They had little contact with service user groups or service user involvement processes. They emphasised increasing understanding of different cultures within services and society.

Both of these CDWs were employed by voluntary sector organisations, one within a city housing project and the other in a suburban mental health project. Previous experience included one-to-one counselling, which they continued to deliver, but they had had no prior contact with mental health services. They valued the strengths of community groups which, they felt, had much to offer in terms of promoting well-being. They did not speak of racism or discrimination, but recognised disadvantage across cultural groups. Social inclusion was important to all the CDWs in the study, but those in band B have been labelled in this way because for them it was a particularly high priority.

Band C: The ‘managerial’ approach

These two CDWs had been in post longer than the others and described their work as a process which began with community engagement: gaining the trust of people in the BAME communities and raising their awareness of the DRE agenda. Both now felt well-connected with local communities and were starting to improve cultural competence within the statutory workforce. They were connected to groups through group leaders and rarely met with group members.

One had arms-length contact with several community groups after acquiring temporary funding for a worker to set them up.

Both CDWs tried to engage BAME representatives in service development, but found a lack of interest, skills or funding so instead they organised community engagement events, workshops and one organised research to gather community views. Their celebrations of culture, food and music received positive feedback.

These CDWs were employed on three-year contracts within BAME voluntary sector organisations and had been in post for 18 and 25 months. Their midway positions on time-limited contracts made it both easier and more pressing for them to see their work as a staged process with outputs recorded and measured.

They saw the CDW role as primarily increasing awareness and understanding between providers and communities:

“We have to try to ensure...that [public services] have cultural competence in serving these people, so they take their culture, their faith, their backgrounds into consideration when providing the service.”
(CDW/5 band C)

“We wanted people to get a better understanding of services.”
(CDW/6 band C)

They appeared to adopt a medical model of mental health, although one had seen the distress caused by economic and social pressures in an earlier role. The other had no prior understanding of acute mental distress and learnt from MHT staff. Both felt BAME communities lacked understanding of mental health issues:

“We find with community groups a lot of the people have difficulties understanding mental illnesses...There is a lack of understanding in terms of medications and ...and about mental health in general.”
(CDW/6 band C)

Neither mentioned racism, discrimination or equality, but in different ways they spoke about the poor service and lack of interpreters available to people from

BAME communities. Their approach was distinguished by the way they described their work as a process, implementing the DRE programme. I describe them as ‘managerial’ because of this focus on policy implementation and because they seemed removed from local people, identifying mainly with community leaders. They appeared to be more directive in their approach than the other CDWs.

Band D

Overall, the aim of these three CDWs was to empower local groups, increasing their control over their own activities and creating links with the Scrutiny Panel¹² and foundation trust board:

“[Professionals] assume that people just want to be passive recipients of services rather than actually getting involved in the decision-making process, which is what our role is about.” (CDW/7 band D)

It was taking them longer than the other CDWs to gain the trust of BAME groups, who associated them with the PCT in which they were based with permanent contracts of employment. They felt more supported by their PCT and MHT than the other CDWs. Despite their enthusiasm to facilitate dialogue between commissioners and local people, progress was slow. Their prior experience included CD and mental health social work, and their language sometimes suggested a medical model perspective.

6.5 Discussion

Interview participants had broadly similar roles defined by the DRE programme, and spoke with the “pride, passion, commitment and enthusiasm for the role” of CDWs in the RAWOrg study (2011, p.14). Despite the small size of the sample, three distinctly different ways of working with groups of people with mental health problems were identified, underpinned by different perspectives and goals. In Diagram 6, the inner circle portrays the approach of the structural CDWs in band A. Previous personal involvement in mental health issues may help to

¹² The Scrutiny Panel is a local body with mixed membership whose powers include investigating the policy and practice of local public bodies in response to community concerns.

explain their collaborative approach, supporting service user-led groups and valuing their expertise. They spoke of racism and inequality, pursued greater accountability and a power shift from providers to users. Their base in the community and permanent MHT contracts generated connections, credibility and confidence. Their stance suggests a radical approach to CD (Gilchrist, 2009) described earlier (4.2). Their emphasis on service user expertise and empowerment complies with Popay, et al.'s (2008) WHO report on tackling exclusion: "Transfer real power to people who are targeted...reform professional education to give greater status to lay/indigenous knowledge" (p.156).

The second circle (band B) portrays the approach of the social inclusion CDWs. These supported community leaders to bring together isolated members of their community and sought to make society and services more inclusive and understanding. The approach taken by one CDW suggests what Gilchrist (2009) calls a pluralist approach (4.2), supporting culturally-specific activities, while the other shared government concern about separatist initiatives (3.2). For these CDWs it seemed less important *who* held the power than *how* power was used by those who had it: both wanted more acceptance and understanding of difference. Their voluntary sector employer and counselling background made it natural for them to give one-to-one support and increase the community connections and cooperation that build well-being (Friedli, 2009b). Like the DRE, they spoke of cultural difference and discrimination rather than institutional racism, an approach that Bhui, McKenzie and Gill (2004) suggest is outdated. Like the DRE, these CDWs placed emphasis on training in cultural competence, which, as I suggested earlier, was insufficient to generate systemic change (2.5).

The third circle refers to managerial CDWs in band C. Despite being the only CDWs based within BAME community projects, these were the most removed from local people. They focused instead on implementing policy and measuring their outputs in terms of community engagement activities and training. Many people attended their activities, but Crepaz-Keay, et al.'s (2004) review of what

works in tackling stigma suggests that contact during once-off activities has limited impact. These CDWs seemed to lack respect for community understandings of distress and were more aligned with dominant medical perspectives. Under pressure from time-limited contracts, they followed the DRE programme more closely than others, reflecting the functional approach to CD (4.2) which Thomas, et al. (2006) associate with incremental but less sustainable change. The final review of DRE (Wilson, 2009) endorses my belief that a focus on policy objectives such as improved access to services misses the point:

“CDWs need to be aware of the increasing body of evidence that shows the mental health of BME groups can only be improved by reducing the impact of injustice and inequality: more is required than improved access to medical care.”
(Seebom, cited in Wilson, 2009, p.30)

The team of CDWs in band D (not illustrated in the diagram) spanned bands A to C. They were keen to shift the balance of power, secure with permanent contracts and a background in CD, but their effectiveness was hampered by a lack of trust on the part of BAME groups who associated them with the PCT. The team were still new and felt that the tide was beginning to turn in its favour.

While CDWs in band C wanted community groups to improve well-being, those in band A said that they supported member-led groups to challenge the balance of power. This is a familiar distinction in CD:

“Tensions have existed for many years between those who see community development as a tool to help communities better cope with the reality they face and those who view community development as a method to enable communities to challenge and change this reality.”
(Pitchford with Henderson, 2010, pp.101-102)

The research shows that some CDWs can and do work with member-led groups of people with mental health problems to challenge and change their reality, but it suggests that few CDWs on the DRE programme worked in this way. One survey respondent echoed the fears expressed earlier (4.3) that the DRE role asks for too much.

6.6 Learning

Below, I summarise the points I wish to explore further in future cycles:

- CDW understandings of CD, ‘race’ and mental health shaped their practice. Past experiences, knowledge sources and political perspectives influenced these understandings more than the sector in which they were employed, but differences in job security and inter-sector connections seemed to affect practice.
- Radical CDWs employed a structural analysis of the imbalance of power and worked collaboratively with member-led groups to reduce racism and power differentials in mental health.
- CDWs who adopted the DRE’s emphasis on cultural competence and community engagement worked at a greater distance from groups. Their managerial or functional approach may have a limited impact.

I asked the two ‘radical’ CDWs if they would like to participate in case studies with the groups that they supported. I wished to explore in more detail how they challenged power differentials in mental health and how their workplace context helped or hindered them. Both CDWs agreed in principle. The next chapter describes the first case study.

Chapter Seven

Cycle Two: Case study of Sweet Potato

“If they are committed ...,
they may feel it almost to the bone”
(CDW/1)¹³

7.1 Introduction

The story continues with a case study of Sweet Potato, a group introduced to me by a ‘radical’ community development worker (CDW) from Cycle One (C1). This chapter covers the cycle’s aims, methods, development support and findings, which are briefly discussed. It concludes with a summary of learning to develop further in Cycle Three (C3).

The study refocused as explained earlier (5.4). The exploratory cycle suggested that few CDWs on the Delivering Race Equality in Mental Health Care (DRE) programme (DH, 2005a) supported autonomous, member-led groups, so I decided to explore other sources of support. My focus on CDWs widened to include a range of people, from activists to mental health practitioners, who helped the groups. I describe all these as ‘CD practitioners’ to denote that, insofar as they supported the groups they used a CD approach (see 1.2). I also decided to narrow the research topic from investigating groups of people with Black, Asian and minority ethnic (BAME) backgrounds to focus on groups of people with some African or African Caribbean ancestry, described here as Black (1.2; 1.3). By chance, both groups identified by the radical CDWs in C1 were Black. I felt that this tighter focus would increase the quality and usefulness of the study, as Black people experience the greatest inequalities in mental health. The research question became: How can CDWs *and others* support autonomous groups of *Black* people with mental health problems? Box 4 introduces Sweet Potato.

¹³ CDW/1 is a participant in Cycle One who also participates in Cycle Two.

Box 4: Sweet Potato (profile)

Sweet Potato is based in an economically and socially diverse inner city area with a Black population of 10.6%, compared with 3.3% nationally (ONS, 2011).

In 2009, Sweet Potato was a group of Black people with mental health problems who aimed to improve the experience of their peers. During 2010 the group broadened to include people from all BAME backgrounds, while retaining a focus on the concerns of Black people. Apart from the core group (Chair, Vice-Chair and Secretary), there is no formal membership, but 15 to 30 people, mostly Black, attend their activities.

The group is based within Harmony, a creative arts mental health project. Their basement venue includes a shared area with sofas, kitchen facilities, laptops, guitars and members' art. Harmony describes itself as a voluntary sector, member-led enterprise. The Harmony manager is on Sweet Potato's steering group and oversees financial matters.

In 2009 Sweet Potato received its first funding. The primary care trust and Grassroots Grants gave grants for:

- ward visits to offer peer support and compassion to inpatients while gathering feedback on their experiences.
- organising consultations on mental health care with service users and carers from BAME backgrounds.

"They're lively, talented, creative."

"It's organic and evolutionary rather than revolutionary."

7.2 Aims

My overall aim was to explore how CDWs and others can support autonomous groups of Black people with mental health problems.

My objectives in the case studies were to:

- describe how the groups were supported by CDWs and others;

- describe what more support might help the groups;
- deliver development support to each group on a topic of their choice;
- use reflective notes as data to link the learning from development activities with the qualitative research;
- describe stakeholders' perspectives of the groups and CDW support;
- share the learning with participants.

Supplementary research questions generated in C1 asked:

- how does CDW/1 work with the group to challenge power differentials in mental health services?
- how does CDW/1's workplace context support or hinder this work?

7.3 Methods

The methods used in both case studies, ethical approval and related issues are discussed in Chapter Five. This section provides a summary with site-specific details. All names are fictional.

In C1 I identified two CDWs, CDW/1 and CDW/2, who supported autonomous Black mental health groups. In May 2009 I asked CDW/1 if, in principle, he and the group he supported, Sweet Potato, would like to participate in my research as a case study and they agreed. For five months I discussed what might be involved with the group's Chair and Vice-Chair. In September our proposal went to Sweet Potato's Steering Group which approved it after intense debate (7.5.4).

Development activities began immediately and qualitative research began in January 2010.

In keeping with the ethos of AR, I combined qualitative research with development support, linking the two by using my reflective notes as data. Reflective notes included informal observations (field notes [FN]) and reflexive

thinking, particularly regarding my development work. Multiple qualitative methods included interviews and group discussions, recorded, fully transcribed and checked by participants. Thematic analysis was augmented by dialectical analysis which ensured that opposing views were heard regarding three organisational tensions. Participant control was highest in the development activities, while participant involvement in the qualitative research included checking data and discussing analysis. In Chapter Five I discuss potential pitfalls to my approach, including role confusion and bias.

The participants, listed in 7.5.1, comprised:

- core group members of Sweet Potato (Chair, Cornwall; Vice-Chair, Barbara; and Secretary, David);
- CDW/1 who participated in C1;
- stakeholders from the group, community and statutory services.

The data collection involved:

- three group discussions and two reviews with core group members;
- semi-structured interviews (one each) with the host organisation manager, group coordinator, steering group member and seven stakeholders;
- three semi-structured interviews over a year and two reviews with CDW/1;
- informal observations, reflections and reflexive thinking;
- reviewing documents and creative activities, including steering group minutes, development outputs (evaluation report and articles), film, art, music and drama.

Feedback from core group members, the coordinator and host manager was informally requested about every two months from September 2009 to April

2010. This intensive phase ended in April, when I gave core group members a preliminary report of the findings. Fieldwork finished in December 2010, when I reviewed the research process with core group members and, separately, with CDW/1. In May 2012 we met again to discuss the draft local report, which was subsequently amended and sent to all participants.

7.4 Development support

Goals

Sweet Potato asked for support to develop and evaluate their activities. Our objectives were to:

- reflect on the purpose and experience of ward visiting, define the ward visitor role and develop strategies to address emerging problems;
- plan and carry out an evaluation of ward visits, led by David as ‘dedicated researcher’;
- identify development needs and form a strategy to address them;
- inform funding applications to sustain the group’s activities.

Group members

An Evaluation Sub-group was set up comprising me, core group members and, after two months, the new Coordinator. Core group members all had an African Caribbean heritage and were aged between 35 and 60 years. The Coordinator was Indian and aged between 25 and 35. The core group reported back to Steering Group meetings and we were all in regular contact with the Harmony manager. Cornwall and Barbara received a once-off payment of £250 and David £300 from Sweet Potato’s funding for their contribution, a token sum determined by available resources (7.5.4).

Approach

We met for about 90 minutes weekly over seven months from September 2009 to April 2010. Those who visited the wards (Cornwall, Barbara and Coordinator) shared stories from their visits which we all discussed. We planned the evaluation together. My role was to facilitate and support the following:

- *Reflecting on practice:* Group members sometimes found ward visits distressing, usually because of staff behaviour. Members shared their stories, supporting and encouraging each other. I drew on Freire's (1972) approach to popular education, encouraging members to reflect on these stories, thinking about what was happening and why it might be that way. We discussed pressures upon ward staff and developed strategies to alleviate the tensions.
- *Developing research skills:* We incorporated the research training into each meeting. Two group members took high levels of medication and had limited literacy skills, while the third had a track record of dropping out of training, so the learning process had to be accessible and enjoyable. Drawing on Kolb's learning cycle (1984), group members asked each other interview questions (concrete experience), discussed how it went (reflective observation), what this meant (abstract conceptualisation) and then tried again (active experimentation). By January, David, the dedicated researcher, felt more competent. Group members began to learn about analysis, practising with a small survey that they carried out. Using highlighter pens, each group member identified key points and patterns in the responses, then explained and discussed their choices.
- *The research process:* David interviewed five nursing staff, ten inpatients, and five ward visitors, generally supported by an experienced service user researcher. Interviews were taped, transcribed by me and, wherever possible, checked by participants. Data analysis was done as a group, but only David and I read all the transcripts. He identified themes which

others refined. He drafted the report, but due to pressure of time I finished it.

Outputs and outcomes

The evaluation report was circulated within the mental health trust (MHT) and primary care trust (PCT). Group members presented it to the NHS Partnership Board and local service users. It was mostly well received as evidence of the value and challenges of ward visits.

David published two articles on the evaluation in national journals: *Mental Health and Social Inclusion* (Reynolds 2010a) and *Race On The Agenda* (Reynolds 2010b). These raised Sweet Potato's profile locally, across Black service user networks and within national research (e.g. Faulkner and Kalathil, 2012).

The evaluation report and articles were used in a successful application to Comic Relief for three year funding.

A development proposal was produced but not implemented (7.5.4).

After completing the evaluation, David took a foundation course and is now studying for a B.A. degree. He felt his involvement in this study contributed to this achievement after spending nearly ten years at Harmony.

Feedback

Attendance was almost 100% at our weekly meetings. The ward visitors said that they were able to offload their emotions, think constructively about difficult issues and reflect on what social and structural rather than personal factors might explain them. The Coordinator valued practical help, for example with devising a monitoring system. David felt that the relaxed atmosphere and frequent laughter

increased their motivation and “helped us to learn”. They felt that they gained a thorough understanding of their purpose and practice:

“We really understand what’s going on because ... we’ve had to study and sit down and read and discuss...it’s all in ourselves.” (Barbara)

Group members said that they valued my directive approach when we focused on the evaluation (7.5.4), while a more facilitative approach encouraged mutually supportive discussions:

“You didn’t boss us but you sort of nurtured us...we didn’t know how to do it and you haven’t told us how to do it, you just said to us, ‘You can do it’...and it came out of us.” (Cornwall)

David revealed hidden talents, including writing and public speaking. His work on the evaluation gained respect from others and increased his overall confidence:

“Confidence has a knock-on effect...If you feel confident in yourself in one area...it spreads.” (David)

7.5 Findings

This section is in five parts covering the participants and group history; three organisational tensions; themes relating to CD support; reflective notes, and then concludes with a synopsis of the findings.

7.5.1 Introduction

Participants (Table 10 below)

The participants comprised:

- CDW/1, who participated in C1, employed by the MHT;
- Sweet Potato core group members: Cornwall (Chair), Barbara (Vice-Chair), David (Secretary);
- Coordinator of Sweet Potato;

- Manager of the host organisation, Harmony;
- an East European service user member of Harmony's management committee, (described as 'Committee Member') who sits on the Steering Group;
- seven further stakeholders identified by Sweet Potato and CDW/1 including: Borough Manager, Service Director and an Associate Director for the MHT (described, not in that order, as 'MHT/M1', 'MHT/M2', 'MHT/M3' for increased anonymity);
- Service User Development Worker for the MHT ('MHT/W');
- PCT Public Health/Mental Health Commissioner ('Commissioner/1');
- PCT CDW ('CDW/10');¹⁴
- a family carer ('Carer').

A full list of all participants in the study can be found in Appendix II.

¹⁴ CDWs 1 to 9 participated in C1.

Table 10: Cycle Two participants

Sweet Potato	Community	Mental Health Trust	Primary Care Trust
Chair: Cornwall	Carer	Director of Services	Commissioner/1 (Public Health/ Mental Health)
Vice-Chair: Barbara		Borough Manager	
Secretary: David		Associate Director	CDW/10
Co-ordinator		Service User Development Worker	
<i>Additional Steering Group members:</i>		CDW/1	
Harmony Manager			
Harmony Management Committee Member			
[CDW/1]			

Group history

In 2002 the MHT commissioned Cornwall, Barbara and another service user at the mental health arts project Harmony to organise a consultation of Black mental health service users:

“We had 60 BME service users...with the ward staff and the Chief Executive...Normally, the staff say ‘I want you to do what I tell you to do – I’m running the show.’ But what happened then was...[the service users said] ‘I’m telling you, I’m part of the show and this is what I want!’ ... There was a breakthrough there.” (Cornwall)

Inspired by their success, Cornwall and Barbara set up Sweet Potato with David, who also used Harmony. The Harmony manager, CDW/1 and a service user on the Harmony management committee joined the Steering Group. The aim was to improve the experience of Black people with mental health problems: “I wanted to pass on my experience...to support patients...to give hope” (Barbara).

In 2009 they acquired their first funding of £15,000, from the PCT and Grassroots Grants to cover a part-time coordinator/administrator, ward visits and two Have Your Say consultation events over one year. In May 2009 CDW/1 introduced me to Cornwall and Barbara just as the ward visits were about to begin.

7.5.2 Organisational tensions

Introduction

From the start I identified three tensions related to the group’s membership, control and relationship with statutory services. In the following sections, key quotes from participants introduce opposing views, as recommended in dialectical analysis (5.5).

Should it be a Black or inclusive group?

Key quotes

“There are things about me that the White folks wouldn’t understand because I’m a Black man.” (Cornwall)

“I would love to see it broaden and see more races working alongside each other...that’s my vision.” (Barbara)

Black groups enhance identity, strength and purpose

Most participants saw benefits in an autonomous Black mental health group. They felt that those who have “lived with it” can offer a “safe platform” where they understand, empathise and get strong together. Black groups can restore lost identity: “A lot of Black folks in the mental health system, they lose their culture, they lose their identity” (Cornwall).

Several Black participants felt that the shared history of slavery remains significant: “It goes back to history, the slavery” (Cornwall). Some felt the resilience of group members inspired others to move on: “We’ve come through” said the Carer. Several participants felt that a Black group helped to highlight today’s involuntary care and bring about change:

“There have been some awful things in the name of delivering care to people that actually was delivering control and delivering a level of prejudice...Sometimes by having these focuses it enables a change to happen.” (MHT/M3)

Shared humanity and multiple identities

The same and other participants spoke about the benefits of a more inclusive group. Cornwall and Barbara felt practical, personal and moral pressure to adapt. No Black person applied for the job of coordinator, so they recruited an Indian woman. Their friends from Harmony wanted to join, but they were not Black. Ward visitors found that White service users wanted to talk with them, while Black people were often asleep, disturbed or out. Ward staff insisted the visitors

treat everyone the same, but they were funded to support Black people. They were confused:

“It’s the White people who come forward and say ‘You are just the sort of person I need to speak to’ so what do you do?” (Barbara)

“I can’t say ‘I can’t help you love because you’re English’... That’s not human kindness.” (Cornwall)

They recognised that all patients “are crying out for ward visitors” and wanted to help everyone. Anyone can suffer from mental distress, Barbara said, “it doesn’t matter what colour you are or how old you are or how posh you are”. Like her, CDW/10 and the Carer stressed the shared humanity across cultures:

“It is the humanity within cultures – yes, there are differences, but I think the commonalities are more.” (Carer)

Several participants from the MHT, PCT and Harmony felt that “identity politics” were outdated due to greater diversity and tolerance of difference, as well as an emphasis on cohesion and broad equality policies (3.2). Three service providers feared an ethnic identity focus would cause tension:

“I don’t think people are all that comfortable around an organisation that says it is exclusively a Black organisation, any more than they would be if it was exclusively a White organisation.” (Harmony manager)

Two MHT participants argued that people cannot be reduced to a non-existent homogeneous ethnic identity; they have multiple identities. The notion of a service for Black people “is becoming less and less meaningful” (MHT/M2). They argued that people often identify more with their locality than their heritage:

“They just identify with being a Londoner and they don’t like being looked at in a very different way... they’re not walking around feeling Black necessarily, only when things go wrong.” (MHT/W)

Black-led but inclusive

The Evaluation Sub-group discussed this problem each week until they agreed a way forward which recognised the specific needs of Black and BAME groups,

their funders' expectations and the moral and service imperative to be inclusive. They kept the focus on improving the experience of Black people, but welcomed people from all BAME backgrounds and excluded no one on grounds of ethnicity. Their inclusive ethos was welcomed:

“They’re keeping an eye and a mindset about inclusiveness as they go, which impressed me.” (MHT/M3)

“With Sweet Potato there is a bit of a new paradigm developing. Although its definitely having a BME focus, on the other hand it is inclusive, it’s a multicultural thing, and that is more in tune with what society is expecting.” (Harmony manager)

The Carer suggested that an inclusive Black-*led* group brought “a sense of empowerment”.

Is it user-led or is it benevolently protected?

Key quotes

“A kind of balancing act is being done between providing the information and know-how, and actually taking over.” (Manager, Harmony)

“It traps people in a...benevolent dictatorship.” (MHT/M2)

Host as benevolent parent

Cornwall and Barbara were the driving force behind Sweet Potato. The Harmony manager described his role as enabling, providing the information and management expertise that others lacked. He sought to protect them from making mistakes which would threaten the group’s survival, keeping a firm grip on finance (FN:10.05.10). Most (but not all) MHT participants felt that Harmony was a good base for Sweet Potato. They respected the manager as a “very savvy business person” (CDW/10). Group members, too, spoke of his expertise and helpfulness, and everyone anticipated that “down the line somewhere” they would become independent. Both they and the manager described their relationship as like parent and child:

“We are like the child in a way, and [Harmony] is the parent figure...as we grow and develop, there will come a time when it won’t be suitable to be under the roof of [Harmony]... We need to disengage ourselves a bit.”
(David)

Host as controlling gate-keeper

There was a down-side to this protective relationship. The manager appeared to act as a gatekeeper, resisting access to outsiders. A PCT commissioner expressed surprise that I gained access (FN: 09.03.10), but this was not easy (7.5.4). The manager spoke several times of the need to get the right balance between intervening too little and too much: “If you get to the point where you are taking over, clearly it is no longer a user-led project.” He recognised his tendency to dominate and felt that he did not always get this balance right:

“Sometimes you can let people make a mistake and learn from it – but... you have to steer people away from the big bear pits...I wouldn’t say I always get it right...I think a lot of the time I don’t.”

He seemed to resist suggestions from group members to widen the Steering Group, appoint a Treasurer and get funding for capacity-building from a Black service user consultant. Some participants felt that this was a personality issue, describing the manager as “opinionated”. The manager admitted to being “domineering” and chose to avoid group events where he feared he might intervene inappropriately. Sometimes he failed to consult on financial matters (FN:20.08.09; FN:15.02.10), annoying group members: “It’s supposed to be user-led!” (Barbara). The manager and others noted that maintaining the relationship with Sweet Potato was to Harmony’s financial advantage, as it gained credibility with funders by supporting a BAME user-led group.

These factors made group members and two MHT participants feel that the group’s development was inhibited:

“I can’t see anyone developing their skills...it traps people in a level of mediocrity and amateurism...nothing’s ever nasty, but...I think they’re entirely trapped.”
(MHT/M2)

The cost of comfort

Sweet Potato was in a comfortable place. The relationship between the manager, Cornwall and Barbara spanned around 16 years of highs and lows. They played in the same band. Harmony provided a friendly venue, social network and arts facilities. For Cornwall and Barbara it was “their second home” (CDW/1). They felt safe, “perhaps too safe” thought the Committee member. They may fear losing their safety-net, thought CDW/1.

They were also very busy: “We’re flat out” (Cornwall). Health issues, including fortnightly injections for mental health problems, interrupted their activities. The Coordinator observed that Cornwall and Barbara did not insist on capacity-building training. It takes a lot of work to become independent which may not seem worthwhile, thought MHT/W. Sweet Potato valued the help: “We’re not independent because we need the support” (Barbara).

Support from Harmony came at a price. While group members felt there was a genuine exchange of ideas between them and the Harmony manager, the “final say”, particularly on financial matters, generally remained with the manager:

“Even though we are there when [decisions] are being made and we have a lot of input, the final say might not be down to us... When it comes to finance, we don’t have any input at all. It’s not in our hands.” (Barbara)

CDW/1 helped to set up a bank account for Sweet Potato, but their funding remained in Harmony accounts. The Sweet Potato budget, the manager argued, did not include pay for organising their consultation events. Barbara remarked “that’s disgusting!” Unlike the MHT, Harmony ensured compliance with welfare benefit rules by not paying more than the permissible limit, exacerbating tensions: “What we decide to do with [the money] is our business” (Barbara).

The group’s Black focus became muted when core group members or CDW/1 were not closely involved, for instance in advertising for ward visitors. The

Harmony manager (who was White) felt that he understood the Caribbean mental health experience better than the African-born CDW/1, who in turn felt that the manager lacked awareness and “didn’t get it”. MHT/M2 found it disturbing that a Black service user group depended upon a White manager:

“I worry about the whole system being dependent on one person who is not part of that identified group.”

CDW/1 felt unable to change the power dynamics. He remained diplomatic to retain his place on the Steering Group, declaring: “*When* they push the agenda, *then* I can support them.” His job left little time for the group, while the manager saw them almost daily.

Can an organic group work with regulated services?

Key quotes

“It is a simple word, its called love...That’s the way I approach it.”
(Cornwall)

“It was someone’s, ‘oh yes, let’s have ward visiting, peer support is a good thing’, without ever looking at what that was, what framework it was going on...what the parameters of that were and how you were going to demonstrate to me that the people who were doing it could do it.”
(MHT/M2)

A compassionate approach

Ward visitors had no expectations of personal gain, but just wanted to use their experience to help others:

“Your wound is helping their wound...The idea of love and compassion is very fundamental...someone to talk to, someone to hold your hand...encouragement...Those are the things that matter.”
(Cornwall)

They contrasted this with the remote and bureaucratic approach that they felt nurses adopted:

“We’re told that psychiatry is really medicine of the soul. By the time the doctors and nurses have got to the place where they are established in their jobs, the soul’s been trained out of them, they are following rules and regulations.” (David)

Many participants described the group members, especially Barbara, as passionate and compassionate. MHT/W, also a service user, felt that Barbara expressed her “raw feeling”:

“It just comes straight out of her heart, out of her experience; it hasn’t been modified with looking respectable. When you start working for the other side [the NHS] you start to act and dress and talk a bit more like the people that you’re working with...that raw feeling that you had when you were a patient, you modify it a bit just to survive in the world, whereas [Barbara] and some of the others, they come straight out with it.”

Feedback from some of the nurses in the evaluation suggested that the visitors had a positive impact on ward patients, bringing them together to chat and laugh or sitting with them quietly. One person who had never spoken since arriving on the ward started to talk to them. MHT/M3 valued their compassionate approach:

“Even if you are very distressed and unwell you get a sense of who really is interested in you, just for who you are, and who’s just going through the motions of the role...They’re speaking from the heart.”

Organic rather than evidence-based

This compassionate approach was developed as an organic, bottom-up process, adapting as they went along: “We are just trying it out and honing it in, and to me, it’s exciting” (David). As the visits began, MHT/M2 urged the group to visit peer support schemes with a proven track record. Her suggestions, initially persuasive to Barbara and Cornwall, were rejected by the Steering Group as unwelcome outside influence:

“[The ward visiting is] evolutionary rather than revolutionary...it is something that has developed out of people’s experience. It is not from the States...It’s not from an academic.” (Harmony manager)

MHT/M2 was worried about lack of safety, as the group did not think through the parameters of their role and relationships. She had seen peer support workers

becoming just “another set of experts”. She stressed the importance of peer-led training and supervision and questioned what authority the Harmony manager had as he took on these (paid) functions. She asked if the recipients were clear about what was being offered, fearing that this would become another “half-arsed, ill-defined, unsupported” service user initiative.

Other MHT participants did not have the same fears, but they lacked the MHT/M2’s expertise. Senior management and some ward managers requested more visits. MHT/W, who helped to evaluate an evidence-based peer support service, was positive:

“[The evidence-based model] worked alright, but they’ve lost most of their peer support workers...they’ve ended up in hospital...[Sweet Potato] decided that that was a little bit too technical for their group, that they just wanted to do it from the heart...My impression from the ward manager was that he was very pleased with them being there.”

Sweet Potato hoped to complement the statutory peer support workers being appointed throughout the MHT, but the Harmony manager feared they might not survive: “I do fear a bit of a takeover from the peer support worker movement.”

Tensions with ward staff

As MHT/M2 predicted, Sweet Potato found it challenging to establish a respectful partnership with ward staff. Nurses were often engaged in paperwork or meetings and at first often failed to acknowledge their arrival on the ward, undermining their confidence:

“I want them to acknowledge you as – not staff – but as someone who comes on the ward and works...I just want for them to acknowledge that I was a patient, but now I’ve moved on.”
(Cornwall)

Nurses’ body language and tone of voice, Cornwall felt, “might not even be deliberate” but seemed to affirm their superiority and most staff remained aloof. The high staff turnover and poor communications meant that constant liaison was necessary to ensure that the visitors’ role was understood and acknowledged:

“Since that [conversation], I think he respects us...[He] turns around now, and smiles at us and looks at us in the eyes. But all the other staff, they’re doing stuff.”
(Cornwall)

MHT managers agreed that good communication was essential to allay fears on both sides. MHT/M3 said that ward staff felt service user visitors were a burdensome responsibility:

“The biggest anxiety for staff was about having people coming into the ward that in their eyes weren’t trained staff...that added to their burden.”

She established regular liaison meetings to address this anxiety and welcomed the group’s cooperative approach:

“They’ve been so professional in their approach and non-confrontational, they’ve just been very constructive in the process, and the new ward manager was immensely impressed with them.”
(MHT/M3)

Creative voice

Sweet Potato developed its own way of being heard through music, drama and the media. Harmony’s name, connections, facilities and management supported these ventures. Group members took music to wards, to events, and even to the Royal College of Psychiatrists. Cornwall, Barbara and others talked about mental health on national and local radio with celebrities such as Ruby Wax, Ken Livingstone and Frank Bruno. BBC cameras filmed part of an Evaluation Sub-group meeting (FN: 25.01.20)! Some participants felt that their music, widely enjoyed, helped to reinforce a sense of identity among Black people:

“It’s from Jamaica and...it sort of reinforces identity, but ...music promotes well-being for everybody and it brings people together.” (Carer)

Musical expression enabled people to demonstrate their talents and be proud at an early stage in their recovery:

“Things that they are good at are allowed to come out and shine and they can be proud, and they *are* proud...given the acclaim that they get.”
(MHT/W)

MHT/W felt that their creative talent helped Sweet Potato to share their message more effectively than if they had been “angry”:

“There’s always a place for a group who are lively, who are talented, who are creative, who can bring up issues in a way that is quite appealing...just as important as being very political...if you’re forever telling an authority that they’re lousy...they start becoming self-defensive and stop listening.”

Several participants (notably the Harmony manager) felt that Sweet Potato was not radical or political because they did not hear about this side. Yet Cornwall and Barbara described their activities as “community action” to address the unjust treatment of Black people: “I wanted to do the ward visits because of situations like Rocky Bennett” (Barbara). Despite this, they participated little in formal service user-involvement processes: “Boring, boring” (Cornwall). Cornwall and Barbara disliked reports, email communication and formal meetings. The Harmony manager was sceptical about user-involvement processes and did not encourage them, but there was pressure from the MHT and PCT to provide more feedback:

“They are the ears and eyes for me.” (MHT/M1)

“They should have a formal system...what to do with what information.” (MHT/W)

Despite lacking rigorous feedback processes, Sweet Potato’s voice did not go unheard. Their consultation events attracted service users, MHT staff and community workers. One time MHT/M3 implemented improvements after hearing Barbara talk about the need for better skin and hair care:

“I was speaking about the ward visits and the haircare...it just came flowing out and before you know it, they are looking into haircare on the ward. Even though we’ve mentioned it before, before, before, they’re really doing it now.” (Barbara)

“Coming to [the consultation] that day for me shifted my thinking... [They] have a deeper empathy and understanding than I could have, so you use that and work with that.” (MHT/M3)

Two PCT and MHT senior managers felt that modelling an approach based on love in the wards could shift the thinking of nursing staff more successfully than standard training. One of the nurses felt that the ward visits “send a message that people can get better and move on with their lives” not only to service users but, just as importantly, to the staff (FN:20.11.09).

I now turn to the support that the participants thought would help Sweet Potato to achieve its goals.

7.5.3 Group support themes

Added value of a shared identity

While Sweet Potato appreciated help irrespective of ethnicity, they felt that CD practitioners with a Black identity could make a unique contribution. Black people could give empathy and understanding of the Black experience: “it’s not an outsider’s point of view” (David). They said that racism and discrimination cannot be fully understood without experiencing it. Black CD practitioners, Cornwall felt, gave a sense of “belonging to a set of people” and might have a deeper emotional commitment to their struggle. It would be “more of a personal issue” (Barbara). CDW/1 agreed that Black practitioners could have a deeply rooted connection:

“Not only at a conscious level but at a subconscious level...they may feel it almost to the bone.”

Black CD practitioners could be inspiring role models, encouraging and showing that “we aren’t just street sweepers...we can be substantial in a positive, powerful way that’s not relying on stereotypes” (David). Black practitioners can demonstrate that “we’ve got a lot to give to society” (Cornwall). CDW/1 felt that a Black person can bring “more encouragement, more power, more self-belief”.

CDW/1 felt that self-belief was a “core theme” for Black service user groups who, he and the group members felt, were still affected by the power dynamics of their history:

“As a Black person, you see the whole dynamics of power relationships, because it’s not new...it goes back, it’s the past and future as well... history repeating itself, oppression and discrimination still happening in a different form, but it’s the same thing happening again.” (CDW/1)

“It’s all about understanding that historically Black people aren’t coming from a position of power...the emotional impact of not having power, over generations and generations, and still to this day we’re still struggling under it. If that’s understood we can help each other move forward in terms of becoming more empowered.” (David)

Other aspects of their identity could also be important. Barbara felt that class “bothers me a lot”: she did not want to be supported by people who were “very posh”, like her psychiatrist. Members felt that a practitioner with experience of mental health problems could be helpful if they also shared a Black identity. When the group designed a proposal for capacity-building they wanted a well-respected Black service user consultant (subsequently blocked by the Harmony manager, see 7.5.2). MHT/W worker suggested the same consultant:

“Her or someone like her who’s done it before, who knows the kind of problems and the reactions, and can help them set their goals...and who’s going to help them identify and build procedure and support them.”

A Black identity did not guarantee good support. CDW/1 and two MHT participants agreed that the CD practitioner also needed skills and commitment:

“Insist on it being someone with lived experience [of mental health problems], from a minority community, *who had the skills.*” (MHT/M2)

The Harmony manager doubted whether a CDW “particularly needs to be from a BME community” and several MHT and PCT participants felt that attitude and approach mattered more.

Respectful, collaborative approach

Group members agreed that it was important that those who worked with them had respectful, friendly, non-judgemental attitudes, regardless of ethnic identity. They described CDW/1 as “on your level” (David), “like a friend” (Cornwall), bringing “culture, diversity, intelligence” (Barbara) without “bamboozling you” (David). Although respectful of professionals, they wished to relate as equals: “together, on a par” (David). They appreciated the way senior managers came to listen and discuss their ideas, but felt that some ward staff adopted a superior manner. The Carer was cautious of professionals, who, she found, sometimes pursue their own agenda: “Sometimes there is a conflict of interest when you are a professional”.

CDW/1 felt that Sweet Potato could have more impact if they developed the Black service user voice, but he did not impose his ideas and supported them in pursuing their chosen goals:

“I was just happy to see it go and let them take a lead and explore what they wanted...and ...how can I play a role in supporting that.”

Several participants felt that passion and commitment were essential requirements for CD practitioners. They must “identify with the cause...otherwise your heart is not in there” (CDW/1). The Carer wanted more Black leaders who spoke “with passion from our community”. Group members felt the CDW/1 had this passion, trying to keep Black issues at the top of the agenda: “He’s flying the flag, saying ‘Stick to BME, this is what it’s all about’” (Cornwall).

Alongside commitment, most participants felt that an “enabling” and “empowering” approach was important:

“Your empowering nature...it’s about how you make people feel, how you create an environment which is enabling them.” (Commissioner/1)

This approach had two aspects: capacity-building (increasing skills, confidence and group infrastructure) and self-efficacy (the belief in one's capacity to achieve). I describe these separately.

Importance of capacity-building

Many participants spoke of increasing the group member's capacity: their skills and ability to carry out tasks and work towards their goals, which sometimes included paid work. Group members told me that they wanted more skills for running the group, but the Harmony manager did not agree:

“There are any number of organisations out there that build capacity and what they do is training in recruitment, budgeting, or whatever, and I feel that that doesn't necessarily do the job. The capacity that needs building is the team, and we've kind of got that – we've got a functioning team.”

Certainly Sweet Potato and Harmony were built on strong relationships, but as I have noted, there were tensions around control. Cornwall felt that the lack of help to develop their expertise, and thereby their control might be due to low expectations:

“Some people think because you've got mental health problems you might need extra help or ‘I don't think you are capable of doing that so let me help you’. Instead of that, they should say, ‘I'll help you and train you to do the job you want to do...I'll give you the tools to do it.’”

Group members and others wanted to draw in more Black people to broaden the Steering Group with a fresh perspective and financial skills. Commissioner/1 wanted “the group to be supported in increasing capacity and creating the infrastructure”. New, skilled Steering Group members would reduce the pressure upon the core group, but over the research period there was little change in membership or skills (see 7.5.4). Some felt that CDW/1 should do more:

“What he ought to be doing...is increasing the capacity of that group to stand on its own two feet.”
(MHT/M2)

CDW/10, based at the PCT, questioned whether “hardcore community development”, by which she meant building group capacity, created any change beyond benefiting its participants. She argued that, to create wider change, capacity-building at a grassroots level has to be combined with helping services to respond. If you want to create change, the work with communities and services “cannot be disconnected – the two are interlinked...it’s a big balancing act”:

“You can’t effect any change if you’re working on the ground with community groups...you have to make sure it gets fed up, and if you don’t work with the people who you feed up to and support them, then you can’t effect any change back down to those community groups.”

She described her role as connecting people and groups to resources and services, but her remote location meant that she knew little about Sweet Potato’s support needs.

Ways of developing self-efficacy

Alongside capacity-building, participants wanted to see CD practitioners developing group members’ self-efficacy: their belief that they could achieve their goals. Group members and others said that some professionals inspired self-confidence and self-efficacy by believing in service users. An occupational therapist gave Cornwall the confidence to set up a music workshop by believing in him: “so I believe in myself”. The Carer described how CD practitioners inspire confidence when they bring people together, help them to gel and encourage them to use their talents, a process not often seen at Sweet Potato.

Instead, group members acquired a sense of achievement through the activities they pursued. The ward visits made Barbara and Cornwall feel that they were able to put something back into society. David gained a sense of agency.

“I feel like I’m giving something back because I’m not in that position any more...It’s a two-way thing, you can see that you’ve made a difference.”
(Cornwall)

“I feel like I’m more capable, more able, and that’s something I have in common with [Cornwall] and [Barbara], that feeling of being *able* and having an ability to *do* something, that is useful, functional and worthwhile, increases your self-esteem, makes you feel better about yourself, but it also makes you feel better about the people you’re working with. As you say it’s a two-way thing, you feel better because they say ‘oh, well, you know, this has helped us do something’...I don’t want to big up myself but I’m doing important work, an important cog in the wheel...it makes me feel a lot better in myself for being able. And the feeling of being able is so valuable - it’s more valuable than money.”

(David)

David also felt that self-belief can grow when people are encouraged to think critically about the negative way in which they are portrayed by society and mental health services. He felt that many internalise this negative view. CDW/1 did not directly facilitate critical reflection, but he enabled Cornwall to attend conferences, Barbara to attend a nationally-acclaimed Race Equality and Cultural Competence ‘Training for Trainers’ programme, and David to join a workshop delivered by the same nationally-respected training team. Barbara described her training as “life-changing”, making her think differently about ‘race’ issues. To her surprise she completed the course and went on to deliver training to largely White clinical teams alongside CDW/1:

“You are looking at culture, assumptions, diagnosis, assessments, institutional things and how to challenge discrimination...that is quite empowering in itself...and now Barbara and myself, we are delivering training.”

(CDW/1)

David came to see his situation “from a deeper perspective”, questioning what he had been told about his diagnosis of “life-long” paranoid schizophrenia:

“When we see reality we accept it, or when we get told something by someone in authority, we accept it as reality. But [the people at the workshop are] saying ‘Hey look, it’s only a thought that someone cooked up, challenge it if you want to free yourself - emancipate yourself from mental slavery!’”

He added: “that kind of thing we don’t hear around [Harmony]”, which is perhaps not surprising given the reliance of Harmony on MHT referrals and PCT support.

Nevertheless, he felt that this was what Sweet Potato and CD support are all about:

“Throughout history we’ve had bit of a bad press, you know, Black people. The belief around not being good enough, even to this day, is still there... We develop negative mindsets not just because of the colour of our skin but also because we’ve got mental health issues... That’s what everyone in Sweet Potato and your work is all about, removing that feeling of inferiority, replacing it with something much more positive.”

It goes further, he argued, because “people see that and they say, ‘There’s something about him or her, there’s a strength coming from them’” and view the person differently, more positively, than they did before. Through their activities, group members were making people using mental health services think differently about their own position. Ward visitors were role models for people on the wards:

“When we go on the ward, we’re not just talking for the sake of it; we’re removing that feeling of inferiority.” (David)

“When I told people [on the ward] I’ve been a patient, ‘No! [tone of disbelief] How can you do what you’re doing?’ You start talking and letting them know that anything’s possible. It’s not all doom and gloom. It doesn’t have to end there.” (Barbara)

The unexpected magic for ward visitors was the way that people they engaged on the wards came to Sweet Potato after their discharge and sometimes became ward visitors themselves:

“[Some former inpatients] become ward visitors themselves, and that’s where it lies for us, the gold.” (Cornwall)

Value of practical support, connections and resources

Sweet Potato’s ward visits and most other activities became possible because of the practical support given by the Harmony manager and CDW/1. The Harmony manager provided their base and organisational guidance. He helped with funding applications and inspired funders with confidence in Sweet Potato’s accountability. CDW/1 worked at a greater distance, but group members saw his help as invaluable. He attended Steering Group meetings, helped to acquire

funding and set up their bank account. He linked them to the MHT, bringing MHT managers to the group and introducing Sweet Potato to ward managers:

“He introduced us, spoke up for us and said we wanted this to happen. He played a really important part in making the ward-visiting scheme possible.”
(Cornwall)

Varied perspectives on the CDW role

From the group’s perspective, the only negative comment about CDW/1 was the difficulty in contacting him due to his heavy workload: “He’s bogged down” (Cornwall). Sometimes he helped the group outside working hours. The MHT/M1, also BAME Lead for the MHT, felt he made a huge contribution:

“He’s phenomenal, absolutely phenomenal, I get so much value for money out of him through the work he does, networking, strategy, to operations, not many people get it, he gets it, you know head, hearts and mind.”

Yet MHT/W and MHT/M2 questioned his low profile and limited impact on Sweet Potato’s capacity. Some participants questioned his unassuming, quiet approach, which he described as a long-term strategy of building trust while gradually becoming a catalyst to change: “it’s maintaining that balance.”

CDW/1 described some of his line managers as “very committed to the cause”, while the MHT Race Equality Steering Group was “passionate...driving the agenda”. His work with Sweet Potato was encouraged, but he felt it was not incorporated into a strategic approach to tackle inequality or stigma. A more effective approach, he felt, would be to develop a strong, Black service user voice, but this was not a MHT priority. He felt his broad workload left him too stretched to generate substantial change: “Too much was expected from CDWs, they can’t be everything.”

In 2010 the DRE programme came to a close. Government policies absorbed ‘race’ within a broader equality agenda (3.2) and austerity measures in the public sector increased uncertainty. Cornwall sadly reflected: “Community development workers might be phased out, these things are sometimes”.

Reflective notes

These notes combine my fieldnotes (FN), reflective and reflexive thinking. I focus here on my relationship with the Harmony manager, the group and the group's relationship with the MHT.

At our preliminary meetings I became aware of internal tensions at Sweet Potato. Members felt under pressure to start visits but did not feel prepared. The first visit left Barbara feeling "shock" (FN: 20.08.09). The Steering Group agreed in principle to my research, but when we sought formal approval the Harmony manager, whom I had not met before, suggested that it might be more harmful than useful. He felt that it might unduly influence the direction and nature of the ward visits, burden the group and "we will get there anyway" (FN: 14.09.09). I found the discussion tense, even hostile, and was surprised to see Cornwall and Barbara, so enthusiastic earlier, now sitting quietly. Approval looked uncertain until David was asked his opinion: he felt that the work would help them to develop clarity and structure. With the three group members and CDW/1 supporting the proposal, it was agreed.

The most powerful players in a situation can feel threatened by CD, according to Stringer (1996). Following Stringer's advice, I sought to build a positive relationship with the Harmony manager and FN show that soon (15.12.09) he was sharing confidential information and asking for support with fund-raising. After much discussion he agreed that Sweet Potato would pay core group members £800 for their contribution to the evaluation, a paltry sum but to the group an important precedent and, we were told, the limit of available funds. I wondered if the manager lacked support, as he was Harmony's sole full-time worker. Both he and the core group spoke to me in confidence about the other, requiring me to reflect carefully on my integrity and role. This situation arose largely, I felt, due to the lack of traditional capacity-building support given to group members,

leaving them reluctant or unable to assert their own views openly (e.g. FN: 15.11.09; 30.03.10; 15.06.10):

“What I feel the group needs is traditional CD capacity-building support with sensitivity to BME/mental health issues. Where is it?” (FN: 01.12.09)

Tensions erupted again when the manager dismissed group members’ aspirations presented to the Steering Group (FN: 15.02.10). I had hoped to enable members to speak up for themselves, so when they sat silently I was frustrated at what I felt was my failure to support them adequately. I now believe that the conditions were not right, partly due to poor planning on my part, and also maybe because the time was not right: members may have feared losing the security and space they had. Stringer’s (1996) call for CD to change the balance of power seemed beyond my abilities. I found suggestions that the manager and group were like parent and child disturbing, suggesting colonial paternalism. I decided my research should include CDW/2 and her group, to explore my topic in a Black-led setting.

My relationship with the three group members was easier. Initially I felt Barbara was cautious due to my class and education (FN: 10.07.09), but my sense of being an outsider evaporated as we worked together. The feedback was always positive, but I was horrified to hear them laughingly agree when I asked if I was “bossy” (FN: 20.10.09). I came to understand how my approach varied between being quite directive when focused on outputs (common in CD), but ‘hands-off’ during members’ reflective storytelling. Feedback affirmed the value of my support (see above) and our relationship remains warm and trusting.

The relationship between the group and the MHT varied. Some difficulties predicted by MHT/M2 came to fruition. Barbara found one person wanting more than she could offer (FN: 05.09.10). Some staff wanted ward visitors to encourage detained and angry Black service users to “fit in” (FN: 20.11.09) and to free up time for paperwork (MHT/M3). MHT/M1 was replaced by someone less

interested, making liaison difficult (FN: 02.07.11). Meanwhile, a new ward visitor said that his psychiatrist, impressed with his recovery, wanted information about the ward visits “to learn from them” (FN: 02.07.11). People within the MHT were using Sweet Potato in different ways, some more positive than others.

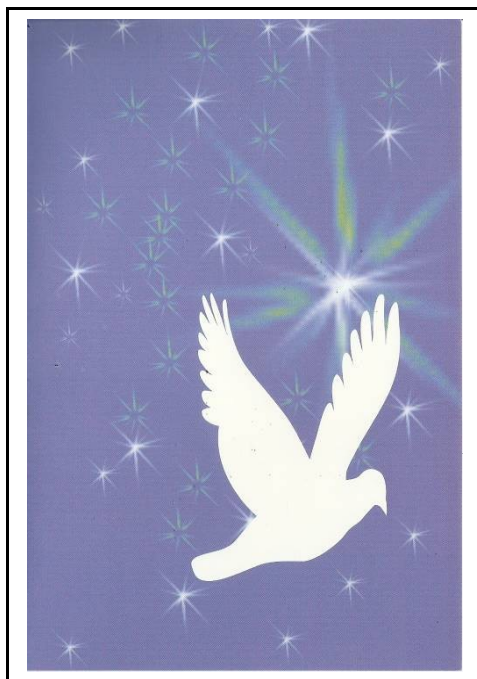
7.5.5 *Synopsis of findings*

Sweet Potato was an embryonic group that aimed to improve the mental health experience of Black people. It was based within a voluntary sector mental health arts project, Harmony, and faced three organisational challenges. First, policy, population and social changes made some feel that Black groups were inappropriate and outdated. Members felt practical, personal and moral pressure to be more inclusive. Second, participants questioned the user-led status of the group due to Harmony’s protective and sometimes dominant management. They weighed the costs and benefits differently. Third, the creativity and passion of the community group contrasted with statutory structures. They lacked an evidence base and participated little in user-involvement processes, but they enjoyed senior management support. Some participants thought that Sweet Potato helped to “shift thinking” in the MHT.

Support in addressing these challenges had similar complexities. CD practitioners with a Black identity could offer empathy, understanding, inspiration and a deep-rooted connection through their shared heritage. Regardless of identity, CD practitioners had to be committed to the same purpose with the right attitude and skills. An enabling, capacity-building approach was wanted but was noticeably absent. Several participants said that CD practitioners should increase group members’ sense of self-efficacy, but in Sweet Potato personal change came from carrying out group activities. Practical support, connections and resources provided by CDW/1 and the Harmony manager made these possible. There were mixed views about the CDW role. My reflective notes relate some of the tensions I observed.

The groups' compassion and aspiration for a fairer world are, I felt, expressed well by David's acclaimed painting of the Christmas dove.

Box 5: Dove and Stars ('David', 2010)



7.6 Discussion

This second research cycle built upon the first, revealing more about how thinking around 'race', mental health and CD influenced participants' views of CD support for autonomous Black mental health groups.

Support for Sweet Potato's Black focus seemed influenced by the weight CD practitioners attached to Black peoples' historical and current oppression, compared with issues around cohesion and equality policies, multiple identities and what Vertovec (2007) calls our "super-diverse" population (p.1024). Many felt pulled in different directions. Some, including group members, affirmed a shared humanity and were unwilling to exclude anyone. Like Freire (1972), they did not want to become "oppressors of the oppressors, but rather restorers of the humanity of both" (p.21). Group members had no CD support to reflect on this

politically and ideologically-charged topic outside our weekly Evaluation Sub-group.

Attitudes to mental health status varied. Group members felt that some ward staff regarded themselves as superior, while two MHT managers were collaborative and respectful, welcoming Sweet Potato's informal peer support. Faulkner and Kalathil (2012) argue that informal, organic peer support is especially beneficial for marginalised groups (3.4). The voluntary sector host organisation, Harmony, seemed in some ways paternalistic and close to statutory services. In contrast CDW/1 gave members access to "life-changing" critical perspectives on mental health, reminding David of Marley's 'Redemption Song', inspired by the civil rights leader Marcus Garvey (1887-1940): "Emancipate yourselves from mental slavery, None but ourselves can free our minds" (Marley, c.1979). The impact of colonialism and psychiatric oppression continue to reverberate (2.3; 2.5).

Views on CD support varied. The value of a shared identity has been much discussed in CD (Gilchrist, Bowles and Wetherell, 2010). Here a sense of a shared history and heritage connected group members and CDW/1, despite his African birth, creating a deep-rooted bond that White people could not replicate. Regardless of ethnic identity, they wanted practitioners with a positive, friendly and respectful attitude, committed to a shared purpose and who were able to help with useful connections and resources.

Perhaps the most surprising feature of CD support here was the absence of personal and group capacity-building, a core function of CD. Views differed on whether or not this was typical of DRE CDWs (4.3). CDW/10 argued that group capacity-building must go hand-in-hand with helping services to respond. In practice, her remote location from the group (like that of the managerial CDWs in C1) left her out of touch. CDW/1 lacked time, opportunity and possibly the skills for this work.

CDW/1 said in C1 that he aimed to shift power differentials. I noted earlier (2.2) that power and resistance operate in multiple sites (Foucault, 1980). Sweet Potato had to contend with Harmony's management, ward staff and MHT managers. CDW/1 may have helped Sweet Potato to change attitudes within the MHT and indirectly sparked critical thinking within the group, but he would have liked to do more. Ledwith (2011) suggests that empowerment should include, using the Quaker phrase, developing the courage to 'speak truth to power'. Lack of courage, or wise diplomacy, meant that neither the core group nor CDW/1 spoke up against the Harmony manager who could have excluded them.

Overall, CDW/1's achievements were limited by his heavy workload, the lack of support for developing a Black service user voice and his own low profile. Despite this, group members saw him as an invaluable source of support. The inspiration, practical support and connections that he provided helped them to achieve their goals.

7.7 Learning

The key points I take from this to develop further are as follows:

- the way CD practitioners viewed the significance of historical and current oppression of Black people in today's mental health context influenced their view on whether or not collective organising by Black people is appropriate. Black CD practitioners could feel this significance "to the bone", enabling them to make a unique contribution as CD practitioners.
- CD practitioners, regardless of background, need a shared commitment, a positive, friendly, respectful attitude and the ability to provide practical support and useful connections.
- Capacity-building to develop management control was absent, but it was questionable whether the group wanted the full burden of independence.

- Dominant powers within the host organisation and on the wards resisted change while MHT managers seemed more collaborative, working with the group on its own terms.
- Self-belief and self-efficacy were identified as important themes for Black people with mental health problems. Here they were achieved through group activities and individual learning, rather than through CD capacity-building support.

As I moved to the second case study group, I wished to find out about CD support within an established group based within a Black host organisation.

Chapter Eight

Cycle Three: Case study of Ngoma

“Attitude matters”
(Thomas)

8.1 Introduction

The second case study was based at Ngoma, a group recruited through the second ‘radical’ community development worker (CDW) from Cycle One (C1). Here I describe the aims, methods and findings and then discuss and summarise the learning which informs the final cycle. Terms including ‘Black’ and ‘CD practitioner’ are used as before, (explained in 1.2 and Appendix I). Box 6 introduces Ngoma.

Box 6: Ngoma (profile)

Ngoma is based in a large, diversely populated town, with nearly 10% Black residents (compared with 3.3% nationally) (ONS, 2011). Social and economic problems place the town in the lowest quarter of the Index of Multiple Deprivation (ONS, 2011).¹⁵

Ngoma began in 2001 as a mental health user-led self-help initiative for people with African and Caribbean backgrounds. It is based within Calabash, a statutory health and social care service for Black people with mental health problems. Calabash staff and Black social work students support Ngoma which has its own Board of Trustees, is a registered charity and in 2011 became a community interest company. Mental health service users form a majority on the Board, and 10 to 20 service users attend weekly meals.

Ngoma aims to encourage and support its members to increase their skills, work and integrate within the wider community. It provides advocacy and access to service user involvement. Enterprise and cultural activities aim to increase understanding and respect across local communities.

*“We enable our members to explore and be proud of their cultural heritage,
we demand and provide a culturally appropriate service,
we promote well-being to prevent ill-health and
we safeguard the rights of Black mental health service users.”*

¹⁵ The Indices of Multiple Deprivation (IMD) include measures of income; barriers to housing and other services; education; employment; health; crime and living environment.

8.2 Aims

My overall aim was to explore how CDWs and others can support autonomous groups of Black people with mental health problems. My objectives in the case studies were to:

- describe how the groups were supported by CDWs and others;
- describe what more support might help the groups;
- deliver development support to each group on a topic of their choice;
- use reflective notes as data to link the learning from development activities with the qualitative research;
- describe stakeholders' perspectives of the groups and CDW support;
- share the learning with participants.

Supplementary questions generated earlier asked:

- how does CDW/2 (who participated in C1) work with the group to challenge power differentials in mental health services?
- how does CDW/2's workplace context support or hinder this work?
- does the Black-led nature of the host organisation influence the support it offers, and if so, how?
- does the established status of Ngoma influence the support it needs, and if so, how?

8.3 Methods

Here I summarise the permission, access and methods described in Chapter Five, adding site-specific details. C1 identified two CDWs, CDW/1 and CDW/2, who supported autonomous groups of Black people with mental health problems. In January 2011 I asked CDW/2 if she and the group she supported, Ngoma, would

in principle like to be a case study. Both agreed, NHS approval was granted and from April to May I attended three group meetings to discuss the proposal (see 8.5.4).

The combination of development support and qualitative research worked well at Sweet Potato, so I continued here. It was some time before all at Ngoma understood my shifting roles, but attitudes warmed when they realised the study's collaborative nature.

Multiple qualitative methods included interviews and group discussions, recorded, fully transcribed by me and checked by participants. Reflective notes including field notes (FN), reflective and reflexive thinking were used as data. Thematic analysis was augmented by dialectical analysis of three organisational tensions to ensure that opposing views were heard. Participant control was paramount in the development activities while participant involvement in the qualitative research included checking data and discussing analysis. For details see 5.5.

The participants, listed in the Findings below, comprised:

- a self-selected core group of five members, sometimes joined by other members (described here as 'CG/[name]');
- CDW/2 who participated in C1, and
- 14 stakeholders identified by members and CDW/2, from the group itself, its host organisation Calabash, and the statutory sector.

The data collection interventions were:

- three group discussions and two group reviews with core and other group members;
- one semi-structured interview with each of the 14 stakeholders;
- three semi-structured interviews and two reviews with CDW/2 ;

- reflective notes including FN and reflexive thinking;
- collecting documentary evidence (annual reports, funding applications, material collected and produced during development activities).

I received informal feedback from my core group members and their support worker every three months and regularly discussed progress with the host organisation manager between June 2010 and May 2011. Formal recorded reviews took place with core group members and CDW/2 at the end of the fieldwork (July 2011) and to discuss the draft local report (July 2012), which was subsequently amended and sent to all participants.

8.4 Development support

Goals

After some debate, Ngoma asked me to help them to develop publicity materials. Our objectives were to:

- produce a profile of Ngoma, a leaflet and a booklet of stories;
- enable group members to increase relevant skills such as public speaking;
- identify funding for these activities.

Group members

Five men decided to participate regularly, forming a core group. Others, mainly men, sometimes joined us. Core group members shared an African Caribbean heritage and were aged between their late 20s and early 70s. We liaised with a Calabash support worker until he was removed from his role after five months, and I liaised with the Calabash manager. Some activities were paid as explained below.

Approach

Weekly meetings lasting 60 to 90 minutes took place over one year, interrupted for two months to pursue funding and later for six weeks when waiting for feedback from stakeholders. I summarise our activities:

- task-focused group discussions and consultations with others to gather information and plan design;
- storytelling, drawing on an approach described as ‘Calling a Circle’ (Baldwin and Linnea, 2010), which shifts informal socialising or opinionated discussion into a receptive attitude of thoughtful speaking and active listening. This approach was chosen because the members preferred to tell their stories as a group rather than one-to-one. It involved:
 - Agreeing how stories would be told, recorded and edited;
 - Everyone contributing equally, listening supportively to others;
 - Processes of check-in, where we shared memorable experiences from the last week, and check-out, where we reflected on what we had heard, to bring the group together.

Stories were told in four stages: achievements as a young person; difficulties prior to joining Ngoma; what had helped, and next steps to achieve aspirations. Each week members covered one stage, telling their story in turns. This was taped and transcribed, with the transcript returned to the storyteller for checking and amendment. Each person co-edited their story with me for the booklet but kept a longer version themselves. As they told their story, others listened respectfully and responded warmly.

- practicing public speaking skills to the wider Ngoma membership.

Participants were paid for working on the stories and design at £10 per session. A local grant of £500 was withdrawn without notice when concerns emerged regarding Ngoma's finances, and applications to three charitable trusts were unsuccessful. Payments to members were funded through a university grant and personal funds. Ngoma paid design and production costs.

Outputs and outcomes

Ngoma published, circulated and put onto the website the publicity materials produced, comprising:

- project profile describing Ngoma's services, members' feedback and information regarding inequalities in mental distress;
- leaflet;
- booklet of five members' individual stories.

Two core group members presented these at the Ngoma Annual General Meeting in 2011.

At Ngoma's request, a visit to Sweet Potato was arranged and 14 members went in December 2010. The groups presented their work, played music together and talked over a meal with about 35 service users and staff. Ngoma and Sweet Potato covered expenses. Both groups described this as an enjoyable insight into another Black mental health group.

Complaints about organisational issues at Ngoma raised during group discussions were taken by members to their monthly members' meeting and I included them in my report to trustees, with little impact.

An article about a drama in which Ngoma was involved was published with my support (Wilson, 2012).

Feedback

Attendance at the core group meetings was almost 100%: “I used to look forward to it” (CG/Thomas). The storytelling was remembered fondly, both the booklet stories and the check-in stories which led to helpful information-sharing, for example about employment services and nightclubs. Members said they had never spoken so openly with each other despite many games of dominoes, and they felt mutual respect increased. One man who rarely spoke at Ngoma told us he had been an international boxer and met Mohammed Ali. We found records of his fights on the Internet.

When asked what made the storytelling possible, they said it was my coming with the idea and the biscuits. Three members said that the occasional payments (when meetings were categorised as ‘work’), although welcome, were not an incentive, but for two individuals they appeared to be important:

“It wasn’t the money, it was interesting.” (CG/Jerry)

“The money was irrelevant.” (CG/Thomas)

“The food and money helped.” (CG/Richard)

Core group members were positive about my approach, with Thomas and Jerry affirming: “You understand Black people in general: you’re one of us!” They felt I was “at ease” with Black people, unlike some of their visitors. Jerry said several times how disappointed he had been when our sessions stopped. He felt that this was another example of the way people come and go at Ngoma.

The trip to meet Sweet Potato was a highlight: “the colours and the people were all looking warmer. We was all welcome” (CG/Jerry). On two occasions, members of the group made public presentations for the first time.

CDW/2, aware that my work was encircled by tensions at Ngoma, appreciated my perseverance, affirmed my neutrality, and welcomed the new publicity, although she felt it might have been more polished.

8.5 Findings

Below, I list the participants and outline Ngoma's history, then present three organisational tensions followed by themes relating to CD support, reflective notes and a synopsis of findings.

8.5.1 Introduction

Participants (Diagram 7 below)

The participants comprised:

- CDW/2, who participated in C1, employed by the mental health trust (MHT);
- A self-selected core group of five men who regularly participated in the development activities: CG/Harry, CG/Simon, CG/Richard, CG/Jerry and CG/Thomas. Another member, often involved until he left Ngoma, I call Member/Joseph. Three other (unnamed) members occasionally joined us. All names are fictional.
- 14 stakeholders identified by group members and CDW/2, comprising:
 - Statutory sector:

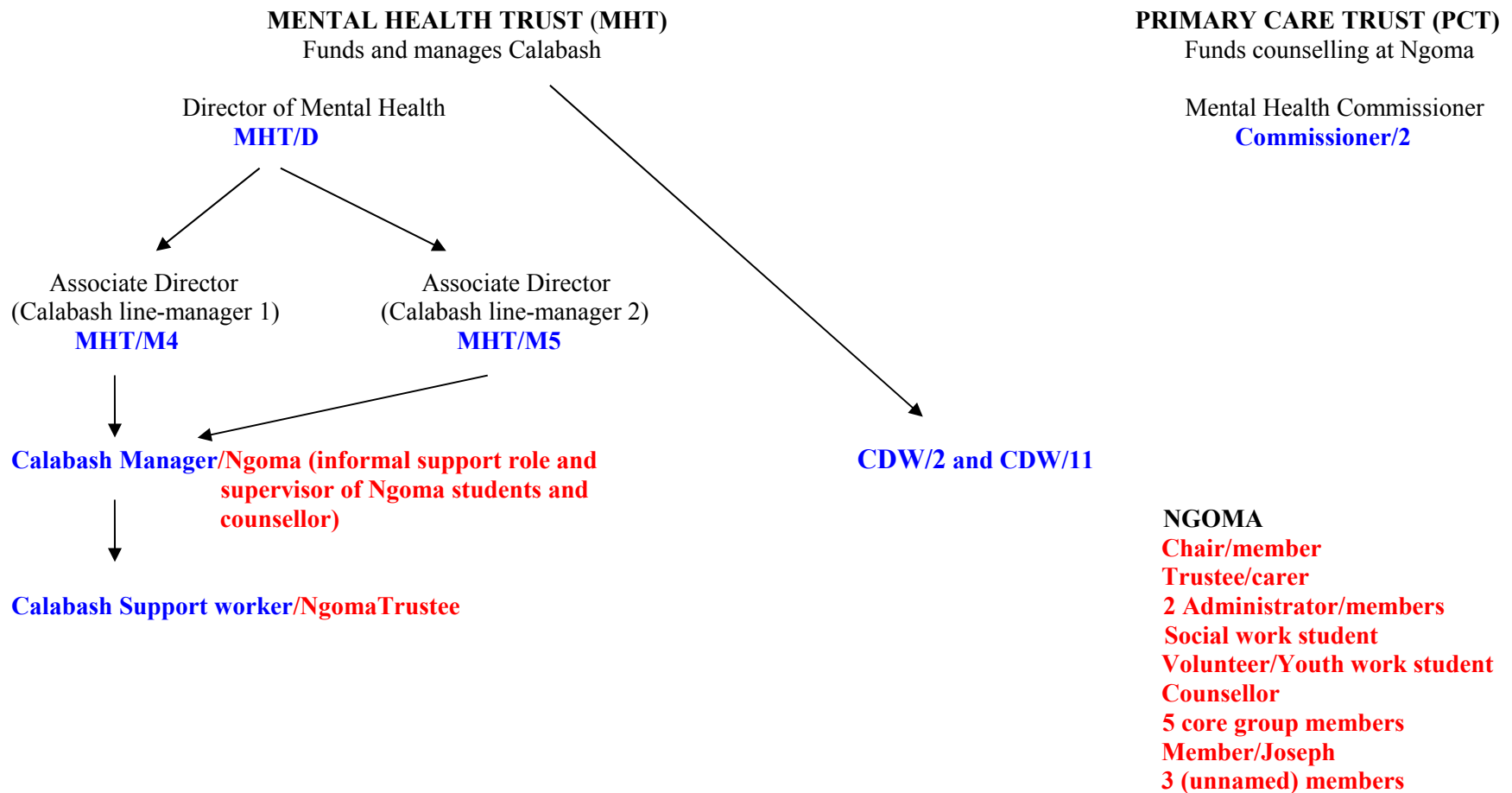
- Three senior managers from the mental health trust (MHT): two line managers of the Calabash manager (MHT/M4¹⁶ prior to February 2011, subsequently MHT/M5) and Director of mental health (MHT/D)
- Commissioner of mental health from the primary care trust (PCT);
- Another CDW employed by the MHT (CDW/11);
- Calabash:
 - Manager
 - Support worker
- Ngoma:
 - Chair (member)
 - Trustee and Carer
 - Social work student
 - Volunteer (youth work student)
 - Two administrators (members)
 - Counsellor (managed by Calabash).

The full list of study participants is available in Appendix II.

¹⁶ Numbering of participants continues through the cycles, rather than beginning again with each cycle. MHT/M4 is therefore the fourth MHT manager in the study as a whole.

Diagram 7: Cycle Three participants

Key: Blue = Statutory participants. Red = Ngoma participants.



Group background

Calabash is a statutory social care service for Black people using mental health services. In 2001 funding for its luncheon club was threatened; the Calabash manager described what happened next:

“So the idea then, was...why don’t you pay for it collectively? Yeah. But to do that you need to have certain structures in place...it is not just turning up and staff give you lunch and staff wash the plate and you go away...you are part of that process, in a sense it is your group...So people are getting roles, so no more ‘service users’, they become ‘members’ of something. Some of the members become Chair, Secretary, Vice Chair... It starts adding status to some people...and their leadership ability starts coming forward...It moves from people playing a passive role, people playing dominoes and a luncheon club provided by social services, to something different...People realise ‘Ahh! We don’t have to depend on Calabash to do things...we’ve actually got the power of the group...we can actually help ourselves.’...Things start changing when people start working collectively.”

Ngoma was registered as a charity in 2002, operating alongside Calabash, supported and largely paid for by social work students on placement:

“The idea was - we haven’t got enough workers...so therefore we could get social work students to help develop Ngoma. Also we were getting money for them!”
(Calabash manager)

Subsequently Ngoma, supported by the Calabash manager, won a national award for innovative social work training. Drumming performances and catering attracted additional resources, and in 2011 Ngoma established a community interest company to run in parallel with the charity. As the Calabash manager noted, Ngoma “evolves in different forms and in different ways”. When I arrived in 2010, the 10 to 20 members formed a network rather than a group, containing many long-standing, if volatile, friendships. There was no strong member leadership and there were few women members. I identified three organisational tensions, which I set out below.

8.5.2 Organisational tensions

Introduction

Participants initially spoke highly of Ngoma, but over the year a more complex picture emerged. I distilled contradictory messages into three organisational tensions regarding its ethnic identity focus, ‘user-led’ management and community ethos.

Should it be a separate or integrated group?

Key quotes

“I don’t think you can get the same [at Mind] because of the mixture of people. We can’t communicate the same.” (CG/Thomas)

“We don’t want that situation where people are ghettoised and they put you in a box and leave you to get on and deal with it.” (CG/Harry)

Racism creates distress

Participants involved with Ngoma spoke about the impact of racism and discrimination, prevalent in the media and at school. Black youth often become “self-hating” and angry, behaving as they are portrayed:

“If you keep telling someone they’re rubbish, they’re going to start acting rubbish.” (Volunteer)

Participants felt that hopelessness and frustration led to stress and distress:

“People who aspire to do well - they get shut down a lot of the time and getting shut down causes a lot of mental strain and mental stress... That is why so many Black people... end up with mental health issues.” (Member/Joseph)

Two participants felt that to succeed, Black people must wear a mask:

“We all wear a mask... You can’t always be what you are, you have to be what you think people want you to be.” (CDW/2)

Participants blamed these pressures for the high number of Black people in mental health services where, they said, basic needs, racism, culture and communication issues are not taken on board:

“There are a lot of people...when I was in hospital...they don’t feel the people that are attending to them...understand them adequately.”
(Member/Administrator1)

Most statutory participants agreed that mainstream services fail to meet the needs of Black people:

“I feel particularly strongly that people from African Caribbean culture are still not treated well by the mental health services, and I think there’s still an over-use of the *Mental Health Act* and people not understanding about behaviour and making assumptions.”
(MHT/M5)

Safety and strength at Ngoma

Many described Ngoma as a sanctuary, a safe space where Black people are accepted and understood without having to explain, feel defensive or “put on airs”: “people can just be themselves”. Several members said that Ngoma felt like a family, welcoming people from different Black backgrounds into one community with a shared heritage. This “collective spirit” created a sense of belonging and mutuality:

“Some were born here and I was born over there. It is open to all and we are a community now.”
(CG/Jerry)

“Ngoma gives Black people... a sense of belonging and ... it’s a place where they know they can go and get help.” (Member/Administrator1)

The Calabash manager stressed that by celebrating their African heritage, Ngoma fostered pride in being part of the wider Black community: “To have a sense of self you need to have somewhere you belong”. Some said that Ngoma promoted self-esteem, enabling members to mix outside on equal terms:

“You get strength from within Ngoma which helps you to meet with people and work outside of Ngoma... We come here to get the strength to challenge whatever we get outside.”
(Member/Joseph)

“[Here] they will stop feeling inferior and they can be confident when they’re relating to people that are English like yourself.”

(Member/Administrator1)

The MHT managers agreed that Ngoma’s role as a safe space was “hugely important”. MHT/M4 said that we all like to spend time with people “like us”; it is hypocritical to say “we don’t want you to do that because it’s a bit separatist, it’s not good for you.” MHT/M5 agreed, saying “It’s about being able to go somewhere to feel safe and people really listening to you.”

Risks of organising separately

These statutory participants also expressed concerns about Black-only initiatives, saying that they did not suit all Black people, sometimes made members unhelpfully “fired up”, could be perceived as unfair to other minority groups and may reinforce separatist tendencies. White practitioners, they said, felt unwelcome there:

“If I was to go out into any of the community teams today and say, ‘What would be your impression of [Calabash and Ngoma]?’...there might be things said like, ‘I don’t feel I’d be welcome over there because I’m not Black’.”

(MHT/M5)

MHT participants argued that mainstream services “should be able to meet the needs” and that it might be “a disservice setting people apart, not making it everybody’s business” (MHT/M5). MHT/M5 felt that cultural and inequality issues could be tackled in an embracing way, “otherwise you just end up with a ghetto”. Like several others, she was concerned about how isolated Calabash and Ngoma were from the mainstream:

“It can’t be something they can just do by themselves, no, because all of it’s about partnerships.”

(MHT/M5)

“We don’t want this ghettoisation... We’re happy with anybody that wants to learn how to [work with us].”

(CG/Harry)

Calabash distanced itself, and therefore Ngoma, from other communities. An

Asian group shared the building, but links were not encouraged. My suggestion that they join in with the development training was rejected by Calabash staff because of “cultural obstacles”. The Social work student explained: “We’re two groups – *very* separate; we sit in the same offices but we are *very* separate.”

A desire to connect

Yet several group members, young and old, expressed interest in wider relationships. They said that inter-community links would enrich their social lives and help others in need. Separation was said to be outdated and inappropriate:

“I would like Ngoma to embrace people from other cultures...People can learn from each other’s cultures and...[it] might promote friendships...It’s the older crop...they like the services to be restricted to Black people and all that, but I feel the younger people like myself and the others, we would like to embrace everyone.” (Member/Administrator1)

“[Ngoma] should...meet up with the other groups and do things together ...because we’re in a community.” (Trustee/carer)

Three core group members who were part of the “older crop” of our Black population welcomed the idea of mixing with other groups. They and others wanted to learn about different people:

“Our history is different, but that’s how we learn things.” (CG/Thomas)

“We can work in partnership...it’s about learning about each other.” (CDW/11)

Some members felt that, despite experiencing discrimination, they were British or English rather than Caribbean:

“Some people were born here and don’t feel they’re West Indians.” (CG/Thomas)

“I’m English.” (CG/Simon)

Although these and other participants wanted to connect with wider society, they wanted this to be within a respectful environment where they felt safe. A Black-led initiative, it was suggested, would be ideal:

“[It is] not about *not* mixing with others... people should be able to come into our way of life and accept it, rather than us being forced to always do things according to other cultures’ alien way of life and be looked down on ...[It is] about us having a cultural setting that allows us to be ourselves ...having freedom and control to manage and arrange services ‘our way’ ...[so] that we can share and offer to others...something good to give the world.”
(CDW/2)

MHT managers said they struggled personally and professionally to resolve this “complicated debate”. The Social work student said the issue was not discussed at Ngoma, and it remained unresolved.

Is the group controlled from the bottom up or top down?

Key quotes

“It’s not service user-led or member-led.” (CG/Thomas)

“I really love that, the empowerment bit of [Ngoma], getting the service users to be in charge” (CDW/11)

A lost vision

Ngoma was set up as a self-help group, led by experts by experience who were in the majority on the Board of Trustees (Table 11).

Table 11: Trustee Board

Post	Ring-fenced or open
1. Chair	Expert by experience
2. Senior Vice-Chair	Open to all
3. Vice-Chair	Expert by experience
4. Secretary	Expert by experience
5. Senior Assistant Secretary	Open to all
6. Assistant Secretary	Expert by experience
7. Treasurer	Expert by experience
8. Assistant Treasurer	Open to all
9. Fund-raising lead	Open to all
10. Publicity and Promotion	Open to all
11. Trustee	Expert by experience or Carer

Source: Compiled with advice from Ngoma and Calabash.

Some felt that that the group's structure and the students' approach gave members the lead role:

“We have lots of meetings and we ask them: ‘What do you want us to do with this?’ They are involved in the meeting, they are involved in the minute-taking, and they voice their concerns, so I do believe it is service user-led.” (Social work student)

“That's what's exciting about it...the whole ethos around...making sure that users lead what they want as opposed to us saying, ‘Oh we're going to provide this and you can come’...I think it's very go-ahead.” (MHT/M5)

Others came to see it differently:

“I really was impressed, but when you get deeper into it, you see the inner mechanics and the inner workings, and I became quite disillusioned with the practice.” (CDW/2)

CG/Harry was Secretary and attended board meetings but was “not that vocal” (CDW/2). The Chair and other member trustees rarely attended. Several people contrasted the vision and the practice:

“It's set up like that, but again, pick up a piece of paper, it could say, a, b, c, and that don't mean nothing, does it? How does it work practically?” (Calabash Support worker/Trustee)

“It's got a lot of service users in key positions, but they're not leading anything.” (CDW/2)

The monthly members' meeting was the forum for discussing current issues, facilitated by students and the Calabash Support Worker/Trustee, but as CG/Thomas commented, “most of the members don't say anything”. He compared these meetings unfavourably with those he used to attend at a day hospital:

“We had more control [there] because you decide what you're going to do and where you're going to go, and we call one of the managers in to tell them what we've decided...most of the time we did get our way.”

At Ngoma, members' control was confined to trivial choices, for instance about trips, from options presented to them:

“The staff will make most of the big decisions. We would probably...”
“Have a little say,”
“If we can raise the thing.” (CG/Harry and CG/Thomas)

Ngoma members did not have much decision-making power, but they enjoyed practical support.

Practical support and stability

Calabash provided opportunities and resources that many autonomous groups lack. Ngoma could use a meeting room on two days a week, an office space and a kitchen. Support from the widely-respected Calabash Manager ensured stability and credibility: Ngoma was “his vision...his baby” (Social work student). He supervised the counselling and social work students. Expediency determined whether he described Ngoma as independent or part of Calabash:

“It suits us to be the same sometimes. So like the NHS now, I will say... ‘Oh the...service users are having the Variety show, could you fund it please?’ and they did! [But] when it suits you, you have to be a separate entity...the NHS or the council don’t control you.”

This opportunistic approach was perceived as both helpful and deeply flawed. The shared site, the crossover between Calabash staff, students and the Board of Trustees, and above all, the manager’s informal involvement, were blamed for a lack of clear boundaries between Calabash and Ngoma:

“I am questioning really quite whether there is a clear distinction between one and the other, and do people understand which hat they’re wearing when they’re doing different things.” (MHT/M4)

Several statutory sector and Ngoma participants felt that Ngoma should move away from Calabash to clarify the boundaries and free Ngoma from some of its constraints.

Limits to empowerment

The merging of the Calabash support service with the ‘user-led’ Ngoma made it hard for members to challenge staff without fear of losing their support. Two members told me that they had left or been excluded from Calabash, and therefore from Ngoma, after challenging staff (FN: 07.07.11). Others kept quiet:

“They’re thinking ...I’d better just behave myself, I’d better keep quiet.”
(CDW/2)

Core members felt that Calabash staff were in some sense “over them”. This was reinforced when social work students described members as “clients” and assumed a professional role. There was a protective ethos, even from CDW/11:

“I just have to make sure they do the right thing...I’m not there to tell them what to do, I’m just there if there’s a pitfall coming up, I’m not going to let them fall into it, am I?”
(CDW/11)

When Ngoma was established, the Calabash manager anticipated that it would empower members, but poor communication, inadequate support and workers’ inexperience often prevented this. For instance, CG/Thomas was elected Vice-Chair but later turned it down for fear of what it might involve:

“Even up to now, they haven’t told me what it involves... I’m going to relinquish it, you know, because I don’t think I can handle it.”
(CG/Thomas)

“We try to prepare people for doing different things...[but] sometime the time isn’t there and sometime the people who do the preparation are not good enough to do it.”
(Calabash manager)

Despite these tensions, members welcomed Ngoma’s community ethos.

Can a community group work with regulated services?

Key quotes

“[Ngoma] serves people of colour, African and Caribbeans. It’s a place where we forge ahead together, working, learning new skills, learning

things about ourselves, the way we react with others, sharing happenings, looking out for others.” (CG/Harry)

“You need to have measurable outcomes.” (MHT/D)

A community space and enterprise

The community spirit at the heart of Ngoma created warmth at its meals and celebrations which members helped to prepare:

“I’m happiest at Ngoma when everybody of every nationality come, all in the room at the same time, to celebrate...I’m happiest when we work as a team.” (CG/Harry)

The drummers performed at twelve events during the year, dressed in traditional African clothing for a small payment. They said the drumming helped them to connect with each other, be more spiritual and feel more positive. CG/Jerry was amazed by his achievement:

“It takes out a lot of tension, it releases and puts your mind wholly into the drumming. It’s good because you end up a celebrity to yourself, even though I didn’t consider I could do that before and I wonder – is it a dream or what? I can’t believe it!”

Drama based on African and Caribbean folklore was performed about once a year. In 2010 this involved trustees, students, members and Calabash staff in partnership with other Black and mental health organisations. Performances at the city library were sold out:

“The production was fantastic, that was great, very entertaining.” (Member/Joseph)

Spirituality in healing and well-being was important to several members. Pastors participated as trustees, spokespeople and group counsellors. Although Ngoma was primarily linked to a Restoration Revival Fellowship church, pastors welcomed Rastafarians, Muslims and others for spiritual support.

Enterprise activities included drumming, catering, printing and minibus hire managed in partnership with three Caribbean agencies. Some participants saw these as a source of income, work and connections. Ambitions were high:

“My vision for Ngoma, especially with this government in place, is that... [it] is going to become a big social enterprise.” (CDW/11)

MHT/M5 supported Ngoma’s creative and enterprise activities with the proviso that members move on to work or education. Drumming, for her, was a means to an end:

“In terms of mental well-being and being able to have hope about the future and stuff, those sort of things can be hugely important...It’s just watching it doesn’t become the be-all and end-all and...just becomes institutionalised.”

She seemed to see Ngoma as a service, rather than as an autonomous community action group.

Pursuing a Black agenda

Ngoma sought to address Black community concerns. Occasionally prominent speakers retold Black history to counteract internalised racism:

“It’s to show a different side to what people are getting from the media, the general public and the general population.” (Volunteer)

The early vision for Ngoma included a civil rights perspective:

“They are there to safeguard the rights of Black mental health service users, so its not just advocacy, it’s about political lobbying.” (Calabash manager)

This had to wait, the Calabash manager felt, until Ngoma separated from Calabash, but some members, trustees, CDW/2 and MHT managers thought that Ngoma should do more now to improve the statutory response to Black people. MHT/M5 suggested that Ngoma could train, challenge and work with the statutory sector, but links were weak and communication poor:

“If that [advisory] role ain’t being played, I can’t see what we’re going to change...where is that link with [the MHT]?”

(Calabash Support worker/ Trustee)

Some members were not interested in service improvement, preferring to enjoy the social, cultural and supportive aspects of Ngoma. Others occasionally attended consultations with a variety of public agencies. A few worked with the university to deliver social work training:

“It’s primarily about improving the education and training of social workers and social care students, which is really important.”

(Member/Chair)

Connections within the Black community enabled Ngoma to attract support for events, exert political pressure in the face of cuts and help individual members:

“With [the Calabash Manager’s] connections we called around and she got a job.”

(Social work student)

(Social work student)

Sometimes community interests seemed to over-ride professional forms of accountability.

Governance, administration and accountability

Internal tensions emerged which were not resolved by the Trustee Board. The Chair and others considered that Board members should have skills, meet more frequently and exert closer control over Ngoma. Weak governance was matched by a lack of rigour in administration, financial management and organisational effectiveness. Some of this was blamed on the inexperienced and temporary contributions of social work students, who were said to be poorly supervised:

“The student placement is fine...but it’s got to be managed in the sense of somebody has to be controlling and pointing directions.”

(Calabash Support worker/Trustee)

“One of the things is petty cash, cash in general, which is always difficult when it comes to money with different people operating...So for example, you have got the treasurer...she went ill for a long period. And we said,

‘Oh, we’ll get admin, we’ll pay [a member] to do admin’, but the admin is not necessarily of the right skill...So then you get a social work student to help the admin, then that’s not working.” (Calabash Manager)

Sometimes it was difficult to know “what the hell was [going on]...who was doing what” (Volunteer). Several members complained about poor organisation:

“We talk about things but they never happen...Everything just drop and fall by the wayside.” (CG/Thomas)

Some members at least partly blamed Caribbean culture for poor time-keeping and management structures: “We do things differently” (CG/Thomas). CDW/2 said she found that Black groups generally prefer informality and the spoken word rather than formal processes and email:

“They just really prefer to do things in a more informal setting more than structured, quicker, easier, more efficient [methods].”

Many within the Black population, she felt, now called for a more professional approach, but at Ngoma there was no publicity, monitoring or evaluation of its activities:

“I don’t think we’re good at profiling ourselves. I think that’s the major weakness.” (Calabash Manager)

MHT/M5 expressed concern about how roles, student funding and financial accountability across Calabash and Ngoma might be entangled in a “conflict of interests”: “all that needs to be carefully monitored and looked at”. She feared that those involved were too settled in their ways:

“Too sort of cliquey and cosy...instead of being able to challenge each other about what’s going on, that it just all becomes a bit like, oh well, we’re all in this together so let’s just carry on with it.” (MHT/M5)

Financial irregularities came to light during the research period, creating bitter tension between two individuals at the heart of Ngoma and affecting others:

“The politics, the way that this club is going...I’m keeping my distance ... We have to cover our back.” (CG/Harry)

Members, students, volunteers, CDWs and others did what they could to tackle Ngoma's organisational weaknesses:

“My fellow administrator [and I]...re-established an email account because the previous one most people didn't know about it, so we set up a new one.” (Member/Administrator1)

“We're taking steps to create proper structures within the Ngoma organisation, because I don't think that's ever been done.” (Volunteer)

Statutory participants wanted evidence of Ngoma's impact. Commissioner/2 negotiated monitoring of the counselling, but MHT managers felt that qualitative data would tell them more:

“The numbers thing is always difficult, I think it's much more qualitative really, it's just being able to point to the case studies and examples of how things have changed.” (MHT/M4)

“It's not about quantity, it's certainly not about how many people they're seeing, it would be very much about direct service user experience...what things did they get involved in...but also their whole experience of it, the quality and ...why it might have been more helpful than something else, all those sorts of things.” (MHT/M5)

As this study ends Ngoma is re-structuring itself, but familiar faces remain at the helm. Group membership is falling:

“A lot of people left and we're not getting new members.” (CG/Thomas)

The next section looks at the kind of support that members wanted at Ngoma.

8.5.3 Group support themes

Introduction

Participants were asked what they thought of the support that they and Ngoma received and what more or different support they would like, beginning with the question of practitioner identity.

The potential of a shared identity

Black practitioners were especially valued for the way they could communicate and inspire. Many felt that it was easier for them as Black service users to communicate with, relate to and be understood by mental health or CD practitioners with a Black identity. Members Joseph and Simon said that a shared experience of cultural and social issues helped to “make a connection” (even though Simon did not describe himself as African or Caribbean). Harry felt that the added experience of using mental health services helped:

“You may relate to a fellow Black person who’s been through the system and has experience.”
(CG/Harry)

“A person with a shared experience can sometimes understand...without it having to be explained...it can be easier to communicate and be understood.”
(CDW/2)

The Chair, who came from Trinidad, described how, as a younger man, he was trusted by people from other Caribbean islands who were struggling to deal with officialdom:

“I used to go along to DHSS¹⁷ to represent these people, because they used to lose it...They trusted me...I was one of the tribe...They came from the West Indies but they were not like us at all. The language was much different from ours.”
(Member/Chair)

The Chair was one of several Black role models who were said to create hope and self-belief, reducing the impact of racism. CG/Thomas wanted role models “who you would like to be”. While some Calabash staff felt social work students were role models, members seemed more inspired by community activists:

“Role models help a great deal; to see someone like [Winston]...a multi-talented person, an inspiration - if I could achieve some of the things he has done...it would be great.”
(Member/Joseph)

“Somebody that’s cracked through that’s Black has told me that *I* can, and that’s given me the hope and belief that I can do it.”
(CDW/2)

¹⁷ Department for Health and Social Security, the welfare benefits service

Attitude matters

A Black identity is never sufficient in itself: “attitude matters” as CG/Thomas wryly observed. Several members felt that some Black professionals do not want or are not able to help their peers:

“They cut off and they haven’t reached back and helped people along... You can have somebody that has got that skin colour that doesn’t fully understand the issues ...they’re an outsider, but they’re Black.” (CDW/2)

CD practitioners, many people said, need to understand the difficulties facing Black people and be committed to work together with others to tackle these:

“It’s important that everyone has the same passion, don’t just look at it as a job because it’s more than that, for me it’s more like a vocation...It’s not about personal agendas, it’s about a collective agenda.” (Volunteer)

“The building up of the Black community cannot be done with just the Black community, it needs Black, White, Pink, Blue, with different skills that all are empathetic and sympathetic...so it’s not about the colour of your skin, it’s about how you understand the issues that we are going through as a people.” (CDW/2)

“To change something, you need to become a part of it.” (Social work student)

Sometimes students lacked interest: “It’s as if they were just using [Ngoma] to ... pass their placements” (Member/Administrator2). Many were said to have a limited, negative understanding of mental distress.

Being positive about mental health

Several group members felt that those supporting Ngoma had an insufficient understanding of distress. They wanted “someone who knows what they’re doing” (Member/Administrator2), commenting that most social work students, who generally had no prior experience of mental distress, were only useful for “minor things” like filling in forms.

Several participants described how people with a positive attitude can make a difference. The Calabash manager “believed in” Member/Administrator2,

encouraging him to take up new responsibilities: “He thinks that I’ve got the potential to become an even better person.” CDW/2 had seen this happen often:

“I can see where loads of people have been brought on in their personal journeys by people that understand them, believe in them and invest in them.”

Group members felt that a respectful attitude was required, and three found their psychiatrist more respectful than some Calabash staff and students. CG/Thomas commented: “[They] don’t know how to talk to people...A lot of staff look down on you.” The Chair agreed that a few students had a superior “them and us” attitude. Other students were more caring.

Listening, friendly, caring relationships

Many participants felt that CD practitioners should show empathy and be “keen listeners, listen to what you have to say so you can get your point across” (CG/Simon). They welcomed friendly, trusting, long-term relationships. They wanted people who cared *about* them, not caring *for* them in a paternalistic sense. Students were often warm and interested, but they only stayed a short time: “You get used to them and they go...no continuation” (CG/Thomas). One student helped a member with his reading, another with his “career path” and some “check up on you” when absent, but sometimes, core members felt, there was not enough care:

“[Name] was very caring. Not everybody’s like that ...That’s what we really need, people to be a bit more thoughtful and a bit more caring.”
(CG/Thomas)

“When you’re sad, are you here as just part of the furniture or the dust? They’ll sweep you up...without even noticing...To be somebody, you must be noticed. When you’re noticed you feel more important.” (CG/Jerry)

Core group members felt that people could be professional as well as caring, maintaining boundaries in a respectful, friendly working relationship:

Thomas: “Its OK to keep a certain distance.”
Harry: “A professional distance.”
Thomas: “That’s right, a professional distance.”

Harry: “But be a help to us.”

Members valued practitioners with facilitation skills to bring people together.

Facilitating and inspiring change

Despite spending many hours together, group members appeared to speak little about personal matters unless this was facilitated. As I have said, members spoke little when students facilitated meetings. Serious discussions, outside sport and politics, happened rarely and core group members wanted more:

“Sharing experiences with someone in the same situation can help...You talk to one another and share what’s going on.” (CG/Simon)

“Its got to be somebody who got that experience, to enlighten us, our mentality, open our eyes to see more.” (CG/Jerry)

A central stated purpose of Ngoma was to enable people to become active citizens. Over the research period of about one year two people got part-time jobs outside Ngoma and five members worked at Ngoma, often unpaid, as part-time administrators, book-keeper and cleaners:

“I’m the Administrator...I’ve learnt a lot of new skills...I want to get into full-time employment next.” (Member/Administrator2)

Five to ten members participated in training, events, research, drumming and drama, with up to 15 attending the weekly meals. Member/Joseph commented: “There are opportunities here for people who want to grasp them”. Yet social work students and Calabash staff often struggled to motivate members, who complained of boredom:

“There’s nothing really to inspire them...sometimes people tell us that they’re bored.” (Calabash Support worker/Trustee)

Few women or young men joined or stayed at Ngoma, partly because they found it dull. Those remaining missed them:

“Quite a lot of [women] complain about not enough to do...It makes it more homely, when women are around.” (CG/Thomas)

[Being football captain] made me feel good because I was keeping active, and I was working with other people as well...But it’s stopped now, hasn’t it, because there’s not enough people.” (CG/Simon)

CDW/2 felt that more should be done to inspire, motivate and enable members. She also wanted more organisational support for Ngoma.

Insufficient organisational support

Practical skills were brought into Ngoma by volunteers. One carer helped with computers, cooking and public catering: “She’s a great volunteer for us” (Calabash Support Worker/Trustee). Another multi-skilled carer, whose roles included trustee, cake-maker and actor, said simply: “I contribute to whatever they’re doing.” Another helped to overhaul Ngoma’s financial administration. In addition to volunteers, many participants wanted paid staff who could develop their skills and stay:

“What [Ngoma] needs is staff...somebody that knows how to run an office.” (Calabash Support worker/Trustee)

Students had backgrounds in law, business and construction for example, bringing useful skills, connections, enthusiasm and energy:

“The refurbishment was her initiative...she’s very resourceful and she’s got links...she’s managed to get people to come in and paint the place up.” (Member/Administrator2)

CDW/2 compared Ngoma unfavourably with another user-led initiative which enjoyed expert organisational, financial and political support, winning credibility and funds. There was general agreement from members and some Calabash staff that this kind of expertise and support was needed, and this is what CDW/2 would have liked to provide.

Varied perceptions of CDW roles

Participants' views varied on the DRE CDW role. Many described it as a kind of critical friend, challenging but constructive towards statutory and community agencies. CDW/2 would have liked to use this approach with Black groups:

“I’m dissatisfied with the shoddy way that we sometimes do things that has earned us this stereotype of mistrust...I’m talking about the ability to run [an organisation] efficiently.” (CDW/2)

Both CDWs felt that considerable skills are required to cope with management resistance and defensiveness:

“You’ve got to be really careful how you push the boundaries with people, because sometimes if you show people up instead of becoming an ally, they’ll become against you.” (CDW/11)

Interpersonal tensions left CDW/2 largely excluded from Ngoma, but she worked to raise its profile, increase support and secure funding within the community and statutory services.

Statutory participants prioritised CDWs' role as “a bridge”, easing communication and understanding. They wanted CDWs to link community and voluntary sector organisations with primary care and link individuals with the services they need. Both CDWs were keen to make these links, prioritising strategic (CDW/2) or grassroots (CDW/11) work to help the community and statutory partners engage on a more equal footing:

“My aspiration...is that the groups are going to build themselves up to be able to work in partnership ...with [the] local authority or the NHS.” (CDW/11)

CDWs' capacity to deliver positive results was hampered by their broad role across the community and statutory sectors, satisfying few. CDW/2 felt that she had no time “to sit down and have a quality engagement” with service users and some Ngoma participants said that CDWs focused unduly on statutory interests. The Social work student would have liked the CDW to ask “What do you want? How do we move forward?” and listen. Instead she found:

“The problem with the CDW role is that sometimes the CDW doesn’t have the same vision as an organisation like Ngoma ...She is not seeing social enterprise...She is not as useful as she could be, because she wears a very specific kind of hat.”
(Social work student)

MHT staff meanwhile argued that some CDWs had “gone native”, identifying more with service user groups than with their MHT. An exception was said to be CDW/11 who “has a foot in both doors”, being based within a satellite office of Ngoma but also engaging with the MHT.

Two participating MHT managers also felt that CDWs were challenged by the MHT’s institutional resistance to change, limited understanding of race equality issues, and tendency to impose a top-down approach rather than negotiated change:

“Possibly because the trusts weren’t very good at moving, they were expecting some sort of miracle to happen between the CDWs and the communities which would bring them closer, whereas the whole idea was for them to say, ‘Well, this is where the gap is, you need to move closer to the people!’”
(MHT/M4)

8.5.4 *Reflective notes*

My research began as Ngoma approached its tenth anniversary. Unlike the ethnic mix surrounding Sweet Potato, Ngoma had a strong, highly diverse Black presence. Age, dress and language differed, from the old and frail to the young, from traditional dress to baseball caps, from Creole to a strong local accent, all accepted in a spirit of tolerance and respect. At my early meetings I found some people hard to understand and felt that communication problems, more than skin colour, identified me as an outsider. Despite this I always felt accepted, and where necessary, members spoke more slowly to help me understand them.

There were constant challenges in the development work. My fund-raising efforts were thwarted by Ngoma’s poor financial and administrative systems (FN:26:08.10). Organising meetings was difficult when none of the five core

members used email or diaries, and only two had (intermittent) access to phones. Social work students sometimes used the room we had booked for our meeting. Calabash staff sometimes challenged my attempts to give members control. When members chose modern musical images for the new publicity, Calabash reinstated traditional African drums and members decided not to protest (FN:01.04.11).

As at Sweet Potato, payments created tension. I wanted members doing the development work to be paid in line with good practice (NIMHE, 2006) and this happened, but it clashed with Ngoma's usual practice. I distinguished unpaid community action from paid work. This was an important principle for me and for the members, but it raised questions about unpaid work in Ngoma's enterprises.

There were reminders of Sweet Potato. Capacity-building, facilitation and critical reflection were all limited, and decision-making was even less collective. The host organisation manager was a dominant figure, but seemed isolated and may have lacked support. I was disturbed by Ngoma's anniversary celebration, (tickets cost £25 and African costume was required), wondering whose interests this served.

Tensions developed across Calabash and Ngoma regarding internal financial irregularities and I became an unintentional confidante between three protagonists (FN:16.01.11). With support from my supervisors, I sought to remain neutral amid acute tension. My relationships remained respectful.

On the positive side, I listened to the members' stories about their past and present lives. The stories changed each time in the telling, as stories do, bringing up interesting details rarely shared. Our booklet captured a mere snapshot of this richness. My most thrilling moment came when 14 members of Ngoma came to London to meet Sweet Potato. After a late start, the two groups played their music together and the fusion of drum beat and song mesmerised a mixed audience of about 35 people (FN:07.12.10). Distance prevented this becoming a close alliance, but both groups found the day intriguing and enjoyable.

Sometimes I was uncertain of my purpose. No one at Ngoma or Calabash showed any interest in action research and I felt that an organisational approach was not wanted, so I worked with members who were happy to take part. I often talked informally to Calabash staff, students and members about user-involvement and empowerment, but to no visible effect. The Calabash Manager said “You are family”, but then, he was looking for help at the time (FN:02.02.11). It was a tough year, but on return visits I still feel welcomed by core members.

8.5.5 *Synopsis of findings*

Ngoma describes itself as a user-led charity and enterprise for Black people with mental health problems. It is supported by its host, a statutory mental health social care service for Black people, with additional support from social work students and volunteers. Members felt understood, accepted and strengthened to tackle the sometimes hostile world outside.

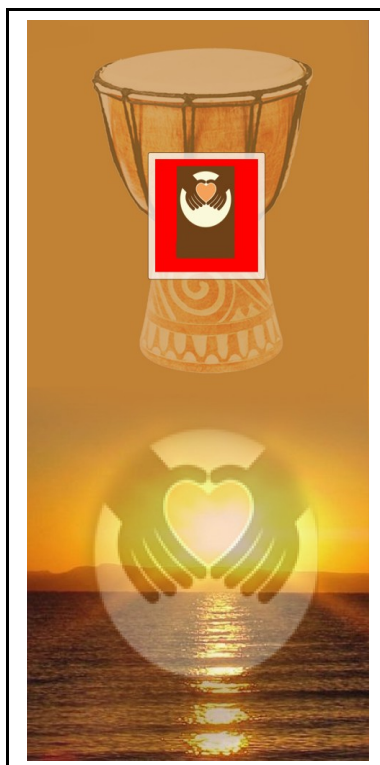
My analysis identifies three organisational tensions similar to those at Sweet Potato, confirmed by Ngoma’s participants as issues that they struggle to address. First, Ngoma’s focus on supporting Black people enabled it to become a safe space, but the benefits of such spaces are set against the potential pitfalls of a separatist approach. Second, top-down dominance and transitory student care left Ngoma without the vision and empowering ethos it had once had. Thirdly, Ngoma offered creativity, enterprise and promoted the Black agenda. However, its weak governance and poor administration led to a lack of accountability to members and partners, creating internal strife.

Participants described the kind of help that this culturally rich but divided organisation needed. A shared identity with practitioners was said to help, but as at Sweet Potato, understanding, commitment, respect, listening, empathy and a friendly, caring approach were just as important. The advantage of having Black social work students was diminished by their lack of understanding, commitment

and continuity. Again, as at Sweet Potato, there was a lack of facilitation, critical thinking and educative, enabling support. Organisational development and accountability were limited. The CDWs' role was said to require immense skill in its multiple functions. There was no evidence that they helped to resolve Ngoma's tensions.

My reflections record challenges in delivering development support due to internal tensions, disarray and lost vision. In contrast, I note the rich diversity of the membership and their stories. I feel that the group's somewhat submerged ethos of warmth, heritage and aspiration are conveyed in an image from the new publicity, developed by Ngoma together with Kudzai (www.reflectionarts.com).

Box 7: Image from Ngoma's publicity



8.6 Discussion

The analysis of Ngoma's case study generated interesting similarities and differences to the earlier research cycles. As a ten-year-old charity, Ngoma's

established member-dominated structure seemed far removed from the embryonic Sweet Potato. In practice, like Sweet Potato, it lacked the capacity to employ staff and remained dependent upon its host in many ways. As suggested earlier (3.2;3.3), clear-cut distinctions between groups and organisations are misleading and for convenience I refer to both as groups. They experienced similar but not identical organisational tensions, which once again show the differences in how ‘race’, mental health and CD are viewed.

First were the ethnic identity issues. As before, participants questioned whether initiatives should be only for Black people. Ngoma’s geographical separation exacerbated these doubts but also created a sanctuary from racism where group members gained the strength to integrate more widely. Separation and integration were not alternative options but part of a process, as other research suggests (3.4). Several group members expressed an interest in wider social connections, but as at Sweet Potato, some suggested integration within a Black-led setting. The disputed relevance of African culture illustrates the complexity of Black identities.

CD practitioners with a shared Black identity were said to bring added value, as at Sweet Potato, but here it was the volunteers and community activists who were inspirational role models rather than CDWs or social work students. The Black identity of social work students and Calabash staff did not compensate for their lack of a positive ‘can-do’ attitude and facilitative, enabling skills. Their approach to mental health problems seemed to be influenced by their professional social work role.

Second, as a host organisation once again dominates over a “user-led” group, it seems that the racial overtones of White supremacy found in C2 complicate rather than explain the relationship between host and group. I wondered how the right balance between support and autonomy might be achieved, a question I take forward to the final cycle. Again, the identities of the group and the host were

merged. Internal power dynamics were complicated by personalities, professional attitudes, internal politics and self-interest. As at Harmony, the Calabash manager appeared to be an isolated figure without peer support. Pressures may have increased with his role in the NHS, an institution described by Oikelome (2007) as unsupportive of Black staff. These factors may explain why the use of power here seemed to illustrate what Thompson (2003) describes as reinforcing rather than changing the status quo.

The DRE CDW role was criticised. Participants close to the group felt that the CDWs followed a MHT agenda, while MHT participants would have liked them to be critical friends to Ngoma and the MHT itself. The DRE CDWs felt hindered by the defensiveness and resistance of dominant figures and by their own broad workload. They may also have been hindered by their female gender in a patriarchal African Caribbean culture (3.2). CDW/2's aspirations to change power differentials, expressed earlier (C1), went unfulfilled.

Once again, CD practice did not enable members to challenge their host or gain more control over their group. In Seebohm, Gilchrist and Morris (2012) we argue that CD practitioners need expertise and long-term, trusting relationships if they are to support collective action and empowerment in mental health, but student practitioners are inevitably temporary and less skilled. Facilitated critical reflection at the heart of radical CD (Freire, 1972; Ledwith, 2011) was absent. Popay, et al. (2008) note that "professionals may resist the challenges to their power-base" and those who challenge them must be adequately supported (p.155). Assertive members left Ngoma while others seemed to display the passive silence of the oppressed (Freire, 1972).

Ngoma's original vision combined peer support with the pursuit of civil rights, but this aspiration faded as social work students brought a more protective ethos. It came to be seen as a community service to promote recovery, but internal tensions, fragmentary and unskilled support left members biding their time,

lacking in motivation or leaving. My research findings suggest that Ngoma had to some extent lost its way.

8.7 **Learning**

The learning points I take forward for reflection in the final cycle are:

- group members valued a safe space for Black mental health service users although several also wanted to widen their social networks;
- opportunities to develop self-belief, achievement and influence were limited as the group's vision and energy seemed lost;
- group members felt that the value of a shared Black identity in a CD practitioner only applied where the person also had respect and a positive attitude towards mental health issues. They also wanted empathy, skills, continuity and commitment to their purpose. The volunteer activists were most inspirational;
- the DRE CDWs were constrained by the broad expectations placed upon them and the challenging nature of their role.

In the final cycle I discussed my learning from across the fieldwork with experts in the field.

Chapter Nine

Cycle Four: Reflection

“It’s about liberation really.”
(R6/SU)

9.1 Introduction

In this final cycle I reflect on my learning with critical friends who were expert in this field. I present the cycle’s purpose, process, learning and a brief discussion. A table shows how themes developed through the cycles. Terms including ‘Black’ are used as before (explained in 1.2 and Appendix I). ‘CD practitioner’ refers to any person who supports autonomous groups of Black people with mental health problems, and therefore includes mental health practitioners, activists and community development workers (CDWs).

9.2 Purpose

The overall aim of the study was to explore how CDWs and others can support autonomous groups of Black people with mental health problems. My purpose here was to reflect on questions arising from the case studies:

- How can CD practitioners help these groups resolve tensions relating to their identity, host organisation and mental health trust (MHT)?
- How can CD practitioners promote the development of groups and group members?
- What more can be learnt about the identity, skills and connections of CD practitioners in this context?
- How do my findings apply to other autonomous groups of Black people with mental health problems?

9.3 Process

Choosing critical friends

By ‘critical friends’ I mean experts who took a critical but constructive approach to my study. Three were nationally eminent in this field and three were highly respected in their locality. Their roles are described below. I knew five through professional work and I sent a letter about the study to each. One shared the letter with a sixth person. All agreed to contribute.

Process

I had five conversations (one with two people) lasting 45 to 120 minutes. With written agreement, these were recorded and fully transcribed, and the transcripts were checked by those involved.

My approach was discursive, exploring my critical friends’ experiences and discussing how these compared with my findings. The following questions guided the conversation:

- Thinking about your experience with Black mental health group/s, can you tell me about the highlights or achievements that meant most to you?
- Could you tell me about the best experience you and/or your group had of being supported by a host organisation or CD practitioner?
- For Black mental health groups, does the ethnic identity of the CD practitioner matter? If so, when and why?
- Do autonomous Black mental health groups have unique features compared with other groups?

I used thematic analysis techniques, managing the data on computer software (see 5.5). Unwaged participants were paid £20 per hour, funded by a member of my PhD Advisory Group. The draft analysis was shared with all who took part,

discussed with two of them and subsequently amended to strengthen the emphasis on racism.

9.4 Learning

9.4.1 Introduction

After introducing the critical friends I present my learning about the nature of Black groups, their relationships with host and statutory organisations, and themes relating to the CD support they receive.

Critical friends and their groups

All the critical friends supported autonomous groups as members or in a professional capacity. Three had experience of using mental health services. Here they are coded R1 to R6, with ‘/SU’ for those who have used mental health services:

- four people (three men and one woman) had an African or African Caribbean heritage. They were associated with three Black service user-led groups, supporting them as a community worker (R1), MHT manager (R2), voluntary sector development worker (R3/SU) and group Chair (R4/SU);
- one White British woman supported autonomous health-focused self-help groups with diverse members (R5);
- one South Asian woman described herself as a Black mental health survivor, using ‘Black’ to embrace all who experienced discrimination on the basis of their skin colour (R6/SU). She was a trainer, consultant and founder member of a mental health user-led group for people who identify themselves as Black, hosted by a MHT. Later she joined a group within the voluntary sector.

I use the names of Greek letters to label the groups known to critical friends:

- Alpha began around 1999 for Black men and women, supported by a voluntary sector host.
- Beta began in 2005 for Black men, supported by the MHT. Funding was cut in 2010 and Beta moved to a voluntary sector host.
- Gamma began in 2010 for Black, Asian and minority ethnic (BAME) men and women, but is predominately Black. Initially supported by the MHT, Gamma moved to a voluntary sector host to secure its future.
- Delta began around 2008 for BAME men and women. Initially based within a user-led organisation, it moved in 2012 to another voluntary sector organisation.
- Epsilon began around 1997 for men and women who identify themselves as Black and was based in a MHT, then moved to another MHT.

9.4.2 Identity and discourse in Black groups

Promoting identity and pride

Black critical friends emphasised the serious damage done by institutional racism, pervasive in our society and services: “Institutional racism affects us as individuals...and allows people to feel bad about themselves” (R1). Several said that a fundamental role of Black mental health groups was combating this, helping members to redefine their identity:

“My experience about Blacks is, it’s about identity, about helping them to feel that they’re different from what the papers portray them to be. A bit of self-esteem as a people...I feel that was the most important thing about a group.” (R1)

They felt that Black service users need to understand how their experiences and relationships are framed by history:

“We always have these searching questions: ‘Why?’ and it always goes back to the beginnings, the origins of it, the history.” (R1)

Learning about history and heritage, they said, instilled pride in their identity and a sense of belonging. Three took leading roles in a group initiative uncovering evidence of Black people and their achievements in 18th century London which local historians overlooked, as is common in official historical texts:

“African people have claims to being in this land going back hundreds of years...and [their] contribution is economic, it’s social, it’s political...You give this knowledge to people and it gives them a greater comprehension of themselves and their people.” (4/SU)

These critical friends said younger Black people often feel ashamed of their ancestral history so turn away from it:

“Block it out. Forget it. ‘I don’t want to be part of it’. And then a part of their whole experience and life is shut away so it doesn’t help them.” (R1)

Although fewer people identify themselves as African Caribbean nowadays, Black critical friends felt it important to explore identity so that people see themselves as “not just Black service users” but “really the multiplicity of people that every human being is”(R6/SU):

“There are lots of places where people are only seen in that one identity as a service user and it’s a real challenge sometimes to help them see that they have other identities...part of our [role] is to help people reflect on that or offer opportunities and choices.” (R2)

Political discourse

Black critical friends felt that many autonomous Black mental health groups have a political discourse derived from experiences of being Black in Britain:

“Black service user groups...can see and make connections with other experiences in the Black community and understand politically...There’s a political discourse that takes place in the Black service user groups.” (R2)

“They’ve got tremendous potential to be political because of the fact that they’re Black and living in this society.” (R6/SU)

R3/SU worked with three Black peer support groups and all had political aspirations. R6/SU thought that wherever Black group members share their experiences, they get “fired up” and political awareness increases and “once people have the awareness, then [they] can fly”. She believed that this liberating process involves more than mental health recovery:

“It’s about liberation really...because its not just about mental health at the end of the day, it’s about finding a way of living in a world that may not be very nice.”

At Epsilon, activist academics and mental health practitioners helped members to develop a critical perspective on Black mental health issues and gave them credibility within the MHT.

R6/SU noted that some Black groups are not overtly political. They can be “dumbed down”, even “silenced”, as funders and others divert or pressurise them. She remembered an event at which the “feistiness” of delegates was suppressed. She felt that many people may want to feel safe and have “permission to be bolshie” before speaking out. R2 described how Black service users often feel powerless and passive as mental health problems compound the difficulties of being Black:

“Service users really feel powerless because they have mental health problems but also on top of that being Black, so that’s quite a challenge to ...see that you can...still change and influence things.” (R2)

Black critical friends said that when groups challenge discriminatory treatment their members gain self-esteem, and this becomes part of “the healing process” (R2).

Two critical friends said that some Black people do not want a Black group, preferring to “be part of the main group” (R6/SU). Those who do join Black groups have diverse aspirations and the groups pursue different goals. Direction and potential may depend on their host organisation.

9.4.3 Relationships with host and statutory organisations

Autonomy, support and trust matter with host organisations

In the relationships between groups and their host organisations, several critical friends said that shared identity matters less than group autonomy and support. Hosts typically provide space, support and help in managing funding or employing staff. Three of the five groups described were initiated by host organisations but subsequently moved to other organisations when their future was threatened. Critical friends had experience of many hosts including White user-led, Black mental health voluntary sector, statutory sector, and community-oriented health organisations.

One critical friend described how her group chose a host because of its ethos, values and capacity to provide appropriate support, which they assessed by track record and credibility. Personalities and trust influenced their choice. Organisations that might have seemed appropriate because they were user-led or Black were found lacking. Radical White user-led organisations sometimes lacked understanding of Black concerns. A Black mental health organisation lacked infrastructure and resources.

Statutory organisations were not the preferred choice, but two MHTs had provided appropriate support. In contrast, one statutory day centre host retained control over group autonomy and finance, despite encouraging the group to set up their own constitution and get a bank account:

“What always comes up is things like money and how autonomous the group is...actually they’re just like another activity that goes on in that [day centre].” (R5)

A Black CD unit based in a MHT initiated and hosted Beta. R3/SU said that “decisions were made at different levels depending on what they were doing”. Two critical friends described the unit’s support for three Black groups as respectful and enabling. When the MHT withdrew Beta’s funding in 2010, the unit supported Beta to relocate. Another MHT hosted Epsilon, where strong and “courageous” staff enabled it to “use its creativity and particular skills and talents and emotional energy (including anger)” (R6/SU). Epsilon maintained a strong presence at the hospital and developed relationships with corporate and grassroots allies, both felt to be equally important. R6/SU observed that this had happened at an “opportune moment in time” (1999-2008); now Epsilon has relocated and lost much of its political fervour.

Staff within a largely White user-led organisation initiated and supported an autonomous Black group, Delta. The manager’s commitment to autonomy, excellent supervision of the group’s workers and skilful guidance made them an ideal host. Personal and professional relationships broke down when the manager left, so Delta relocated.

A voluntary sector organisation based on principles of CD hosted four groups. The organisation’s partnerships with Black, Asian and minority ethnic (BAME) communities, its social perspectives on health issues, its organisational capacity and the trusting relationships that group members established with its managers convinced the groups that it was the best choice, despite its lack of a Black or service user-led executive. The host organisation acquired funding to employ four Black service user workers, each supporting one group, with minimal intervention:

“We have a dedicated project manager that manages myself and ultimately manages [Beta], but as long as we keep them updated, informed, they pretty much let us make our own decisions, run ourselves.” (R3/SU)

“It’s a good organisation, it’s brilliant, in fact it’s the only one.” (R4/SU)

The groups benefited from their host's experience with local communities, office space, administrative support, funding, group dynamics and partnerships:

“There's value in being based within a larger structure because there's resources that a larger organisation has that we can tap into, there's experience that an organisation like [this] has of working with marginalised communities, so there's definitely things we can learn and benefit from.” (R3/SU)

“They've given us advice...they've come to mediate on some of these problems with our members and with our partners.” (R 4/SU)

The organisation was said to benefit from hosting the groups, gaining credibility among potential funders as a community organisation. R4/SU felt that this organisation's flexible ethos was threatened by monitoring and control from funders and statutory authorities.

Working with and challenging statutory services

All the groups associated with my Black critical friends worked with or challenged statutory services, including GPs and police, to improve the response to Black people: “Demand – that's the only way social change happens isn't it?” (R6/SU). It was suggested that statutory professionals often had fixed expectations. R1 described a psychiatrist who refused to believe that a group member was writing a history book. Three critical friends felt that some nurses lose touch with their humanity, unlike those who offer peer support:

“They've just forgotten...[while] the people who aren't trained are the people who are most effective.” (R6/SU)

Despite these difficulties, Black critical friends spoke of statutory staff who developed strong, respectful, supportive relationships with the groups:

“We have an interesting relationship because we lead and they lead in various different ways, so it's almost equal, it's quite equal really even though they are a big organisation.” (R4/SU)

Epsilon welcomed MHT staff and academic activists, White and Black, who came into *their* space to talk to group members “like a normal person” (R6/SU), gave them credibility and support when they needed it, helped with funding and created opportunities for action. Crucially, they let groups engage on their own terms:

“[Epsilon] called the shots” (R6/SU).

Groups were said to help MHT staff get a broader, socio-economic perspective on Black mental health issues and to restore the humanity in their care. CD practitioners supported group members to train staff. R2, using her leverage within the statutory sector, created an opportunity for Beta members to design and deliver training sessions to the police, repeated over three years. Members’ confidence and responsibilities increased with positive feedback, supportive coaching and learning on the job:

“We were able to see new skills that we hadn’t seen before. They themselves weren’t even aware that they had those skills until they were exposed to that situation.” (R2)

R1 felt that members came to see themselves differently, and hoped that police officers too, might have changed their attitudes:

“Here is a group of users who are seen working with the police, not just on a level, but having the police humble to listen to them must be a very changing feeling within their lives and especially in their relationship with the police, because they will have never seen the police in that situation.”

CD practitioners helped the groups to prepare for these activities, facilitating and guiding them to take the opportunities that members wanted. For instance, R2 enabled 32 Beta members to meet with a psychiatrist and ward staff to discuss ways of improving care. She helped the group to prepare “careful, personally crafted questions” that were sensitive to staff concerns, and a service user chaired the meeting. The staff were taken aback, even “shocked” by the orderly, respectful and thoughtful manner of the men, and some were unable to respond without being patronising:

“This member of staff, whatever the question was, would say ‘Oh, I remember you when you were on my ward, ah, it’s great to see you’...He never answered a question, he was just really shocked that there were these guys...once on his ward and now representing themselves as ordinary citizens.” (R2)

Epsilon expressed its message through poetry, song and dance, first to the Executive Board and then to the MHT Annual General Meeting and practitioner teams. R6/SU described how creative expression enabled the group to increase understanding through “engagement with the heart”: “If they don’t get it, they’re never going to change”. She said that touching the emotions was a critical step, but had to be followed by guidance on how to work more appropriately:

“You’ve got to touch their hearts, but then you’ve got to use that. You’ve got to be a bit smart...follow it on with something practical that they can do.”

MHT managers and practitioners gained kudos for supporting Black user-led groups and improved services for Black service users. Sometimes, R6/SU said, they were after the kudos rather than the learning. I now turn to themes around CD practitioner support.

9.4.4 Practitioner support themes

A shared identity helps to gain trust and change thinking

Black critical friends affirmed the important role that a CD practitioner with a shared Black and service user identity could play. R3/SU, employed to support two groups, presented himself as “a service user first”. He and others felt that his role was to inspire:

“Part of my role...was talking about what worked for me...my journey of recovery has been pretty long ...being admitted to hospital at least once, twice, sometimes three times a year, and then finally getting the stability ...moving into employment. Yeah, so part of my role was to inspire and motivate.” (R3/SU)

He tried to change the mindset of group members who felt deficient: “Mental illness doesn’t have to be something that you hide or need to be ashamed of”. By talking about his membership of Alpha and his experiences with Beta, he encouraged people who felt helpless. Together they established a new group, Gamma:

“I was really struck by that, it was the story of [R3/SU’s] involvement with [Alpha] that really convinced people and the [Beta] story which made them think, yeah, alright, its worth being part of a group like this.” (R2)

“It was hearing about what’s happened with other service users, hearing how groups like [Alpha] and [Beta] have taken control of their own destinies in certain ways and suddenly realising that actually they can make a difference.” (R3/SU)

Black critical friends felt that in the context of mental health White people are often distrusted and a shared Black identity “is definitely important in the early stages of the relationship” to avoid fear of discrimination or misunderstanding (R6/SU). All Black participants felt that groups needed to receive at least some of their continuing support from other Black people, including Black service users:

“It feels important to me as part of that picture of support for groups to have people who’ve had that experience.” (R2)

As before, not all Black people were found to be helpful. Some used Epsilon to gain personal credibility. Some were unhelpful:

“Some Black people feel they have worked very hard to raise themselves up and don’t want to risk lowering themselves by associating with the likes of us.” (R6/SU)

Four critical friends observed that anyone who comes to support an autonomous Black mental health group, regardless of their skin colour, has to explain their motives. A Black, or even a Black service user identity is not sufficient to establish trust:

“They saw me as somebody from the outside coming in to try and take over, because I’m not [from the same borough], even though I’m a [Black] service user like them.” (3/SU)

“Even within your own community you can’t walk in and get trust because you are Black you know you have to develop a relationship and you’re tested over and over.” (R1)

R2 described how clinical psychologists were challenged by a Black service user group: “What are you offering and who are you anyway?” Such a dialogue, she felt, was an essential step in building trust:

“It is important that whoever decides to work with groups there is that open dialogue, put it on the table why you’re doing what you’re doing and people ask questions...It’s got to be a two-way street, that’s how trust is developed.” (R2)

R6/SU suggested that people outside the community or peer group, whether due to skin colour, class or gender, had to work harder to “earn their stripes”.

White CD practitioners have important roles too

The White British critical friend (R5) agreed that “there may be times when a worker from the same community would offer more than I can”, particularly where language or cultural issues hamper communication. On the whole, however, she felt that a shared identity was neither necessary nor always desirable. Some groups, she found, preferred an outsider to ensure confidentiality. Her professional role positioned her outside and somewhat detached from the groups she supported, avoiding any risk of creating dependency. Her priority was to work in a culturally competent way, enabling groups of any ethnicity to organise themselves:

“I have heard groups say: ‘At the end of the day what we want is somebody that does things that we need help with...we want the work done’.” (R5)

Black critical friends agreed that there were many ways in which a White person could support Black groups:

“There were White people out there who seemed to ‘get’ us and... proactively enabled, supported us.” (R6/SU)

What matters is that they approach groups with the right attitude.

Attitude matters

Participants affirmed that regardless of skin colour or background, CD practitioners must have the right attitude and approach: it is “not just a case of Black and White” (R6/SU). Attributes described in earlier cycles were described again: CD practitioners should be positive, respectful and honest. The importance of compassion and commitment was emphasised by Black critical friends: this was not about ‘9 to 5’ support. They also spoke of humility:

“Above all the person needs to have the right attributes and ethos and values and humility.” (R6)

“To be humble enough to listen... When you listen you’re going to hear things in a different way than if you weren’t listening, and that might help you to think differently. So humility is very important.” (R1)

R1 felt that White people with the right attitude could increase awareness of their own position in a discriminatory society: “All of us are affected, including the people who benefit from the racism”. R6/SU affirmed the importance of mutual benefit; one of her most positive experiences was when the “support felt mutual... they needed us and we needed them.”

Skills in developing individuals and groups

CD practitioners provided a range of support for individual and group development depending on their own skills, job role and position in relation to the group. For R1, individual and group development went hand in hand as he drew together a group (Alpha) to respond to a public consultation. Drawing on his youth worker group skills, he helped to make Alpha cohesive and caring. His

“diligent” approach and infectious energy and enthusiasm left “everybody feeling as if *they* were important” (R3/SU) and he involved everyone at every level:

“We were as fast as our slowest member...we had individuals who were very slow, but they were very sensible and with full experience of life. So all the high flyers can talk but then we come back to the individual, the slow one, he might not get to a meeting till half hour after it start, but he will turn up.” (R1)

Each meeting began with a check-in where members shared how they felt and what had happened since the last meeting. Talking and listening were equally important, bringing members closer together:

“Everyone had the opportunity to say something ...[and] others wanted to hear...it’s a simple thing like that that I felt kept the togetherness.” (R1)

R3/SU spoke of how the check-in helps to create a warm, mutually supportive atmosphere where members gain a sense of belonging. Where there is no check-in, R3/SU felt that “there’s a coldness there”. R1 and R2 described how the sense of togetherness was maintained between meetings through one-to-one contact, demonstrating genuine care and compassion.

Opportunities were created for individuals and groups to develop their knowledge, skills, and sometimes their political consciousness and self-awareness. R6/SU said that Epsilon valued the way that academics, psychiatrists and activists shared their historical, social and political perspectives on Black mental health issues, introducing group members to new ways of thinking. Similarly, R1 helped Alpha members to see what may have held them back:

“They recognise that there are people who have been stopping them from growing or systems stopping them - it could be schools, it could be expectations outside - and breaking that to me is sort of empowerment.” (R1)

As group members came to see themselves differently they were able to use their collective power through opportunities to make a difference for their peers that

CD practitioners opened up for them. R3/SU affirmed that getting involved in collective action to challenge discriminatory services helped the healing process:

“That’s how you give people a sense of purpose, a sense of achievement, a sense of doing something meaningful. Because often, what I found, sometimes, in my darkest moments in mental health, I felt my life had no purpose, I was going nowhere, I was in this dark hole.” (R3/SU)

As a practitioner R2 hoped to give this sense of purpose and power to group members:

“There is something really important for me about people moving from a sense of powerlessness, not feeling they can influence anything including their own lives to then think, oh, you can influence the police – that is quite a leap of faith! So there is something about how we help people understand the system and the power they have to change stuff.” (R2)

Skill and group development grew in tandem with increasing awareness. Critical friends said that groups might need help with developing a vibrant management committee, agreeing a clear purpose, building a team, running group meetings, fund-raising and providing some kind of monitoring or feedback for funders: the “building-blocks for people who are going to be running a group” (R2).

Capacity-building from established voluntary sector training bodies, several people agreed, was rarely helpful in this context. As Alpha developed, R1 supported members to take up committee roles, informally coaching them and providing some administrative support. R3/SU, a member of Alpha, observed that R1 never took decisions himself but rather encouraged members “to take the opportunity to be in charge of the organisation”. R5 trained group members through tailored coaching along with role play to reduce the stress and increase effectiveness in coordinating a group.

Three Black critical friends described how good CD support fostered a continual, incremental process of growth and development, allowing people to make and learn from mistakes:

“It is just staying with people, it is allowing them to make mistakes and giving trust in them, allowing them to learn from a mistake.” (R1)

During the police training a policeman’s comment angered a group member, but R2 helped to resolve the tension without hindering the training process.

CD practitioners used their connections to create development opportunities for both the groups and their members. R2 supported two groups to relocate. As we saw, she was the link that brought about the police training and encounters with MHT practitioners. R5 supported a group set up by statutory services to become independent. When Alpha’s Chair (R3/SU) was legally detained in hospital, R1 negotiated with ward staff to allow the committee meeting to be held within the secure unit:

“He chaired the meeting and it was wonderful. Here is a man in a locked ward who they have restricted as a danger for what not. And here we are with a nurse outside peeping in to see if something’s going to happen and we are there carrying on and meeting business-like.” (R1)

This had a pivotal impact on R3/SU’s recovery and commitment to the group:

“It made me feel valued and appreciated. I was like ‘Wow! Look at me, I’m here where everyone is seeing me as nothing but an ill person who needs to be taken care of, and here I am seen as important, being part of making important decisions. It was a profound and important moment for me.”

R1 and R2 also emphasised the value of creating paid work opportunities for group members, and this happened within two host organisations.

“Society recognises employment and they get valued in a different way... We need to nurture more people into there because that’s where people feel like they’re really truly starting to heal.” (R1)

Black participants stressed that service user workers needed good management supervision, non-managerial support and a flexible approach “built into the job”:

“One of the things that I felt was always important is for a service user to be a worker because they’re bringing all the experience, supporting [the group] with skills, but I’ve seen so many workers fail because they were not supported correctly.” (R1)

These opportunities for work and community action did not appear spontaneously; CD practitioners had to identify the potential and then negotiate, reassure, prepare, apply pressure where necessary and interpret across professional divides. They created openings and sought to help groups understand the power that they had and to grasp and use it effectively.

9.5 Synopsis of learning

My six critical friends contributed their expertise in CD support for autonomous Black mental health groups and their intimate knowledge of five of these groups.

Black critical friends described identity as a complex, central issue. They felt that negative images and discrimination need to be understood in their historical context and challenged as part of the healing process, giving Black groups a potential political discourse. Black CD support was generally felt to be essential, although White and other people could also provide valuable support. Regardless of identity, all CD practitioners had to earn trust.

Black critical friends reported positive experiences of host organisations, but all five groups had relocated at some point. The ethos and values of hosts were said to be more significant than structure or sector, with four Black groups supported by one community-oriented health-focused voluntary organisation.

Critical friends spoke of staff within two MHTs as supportive. Some, but not all staff became respectful allies, allowing the groups to share or take the lead, but their motives were sometimes questioned. One group used creativity to engage staff emotionally, following up with practical guidance to change attitudes and practice. Another group was supported to train the police, demonstrating their skills and coming to see themselves differently.

CD practitioners supported group and individual development in many ways depending on their role, skills and position in relation to the group. Attitude and approach were again said to be critical. People were encouraged to take on new challenges and allowed to learn from their mistakes. Paid work was felt to be an important goal which CD practitioners should and did support, enabling individuals to see themselves and be seen differently. Practitioners require multiple abilities and connections in order to be able to support individual and group development. They create opportunities for groups to come together, generate a sense of belonging, increase their awareness and skills and take action.

9.6 Discussion

This cycle gave depth and breadth to my emerging themes by drawing evidence from a wider range of groups and practitioners.

The participants reinforced the significance of identity and self-belief as key issues for Black groups. The political purpose of Black mental health groups was explicit here, while in the case studies it seemed sometimes submerged or lost. CD support and greater group capacity may explain the better balance of power between groups and their hosts. The groups relocated to ensure their survival while the earlier case study groups seemed trapped by their hosts. Surprisingly, MHTs were regarded as acceptable hosts, but as R6/SU noted, this was during an opportune time, from 1997 to 2008. Stuart (2008) writes that during this time statutory authorities consulted more with service users, persuaded by policies and legislation culminating in the ‘Duty to Involve’ in the *Local Government and Public Involvement in Health Act, 2007*. The climate changed as financial constraints set in and some groups lost their funding.

CD practitioners here did more than those in the case studies to promote group and personal development. The features of effective CD support, including a shared identity, commitment, positive attitude, group skills, connections and

resources, were similar, but there was more detail and more evidence of what positive CD could look like. Overall, the cycle extended the range of data while affirming and enhancing the analysis. Table 12 below shows how the themes developed over the four cycles.

Table 12: Thematic development

Cycle	Themes
Cycle One <i>Exploration</i>	<p>CDWs attached differing importance to:</p> <ul style="list-style-type: none"> • power and racism. • understanding cultural difference. • increasing acceptance of statutory services. <p>Their approach seemed influenced by their:</p> <ul style="list-style-type: none"> • understanding of ‘race’, mental health and CD. • workplace constraints/ opportunities.
Cycle Two <i>Case study: Sweet Potato</i>	<p>Opposing views suggested:</p> <ul style="list-style-type: none"> • Black groups can be seen as inspirational or outdated and contentious. • A host organisation may be enabling or controlling. • MHT staff may be collaborative or disrespectful. <p>Valued CD support included: practical help with space and funding; Black role models; respect; shared commitment; connections; personal and group development. A DRE CDW was hampered by his broad role and host resistance.</p> <p>Self-belief and self-efficacy were identified as key themes for Black mental health groups.</p>
Cycle Three <i>Case study: Ngoma</i>	<p>Opposing views suggested:</p> <ul style="list-style-type: none"> • Black groups may be seen to inhibit or promote integration. • Host organisations may limit or promote empowerment. • Community groups may be seen as flexible or poorly organised. <p>Valued CD support included: practical help with space; activists as Black role models; opportunities for creative, personal/group development and work activities. Two DRE CDWs lacked access, status and possibly skills to resolve tensions.</p> <p>The group appeared to have lost its vision over time.</p>
Cycle Four <i>Reflection</i>	<p>There was agreement that:</p> <ul style="list-style-type: none"> • Black groups instil pride and healing. • Positive group-host relationships depend on ethos, values, trust and capacity, not shared identity. • Group-MHT relationships vary. • Collective action against injustice can be part of a healing process. <p>Valued CD support included: Black role models; respectful humility; shared commitment; facilitation skills; resources; connections; personal and group development; support to get jobs. CD practice ranges from a personal vocation to influential figures using leverage and resources.</p>

9.7 Chapter summary

This chapter describes the final cycle, reflecting on and developing the themes identified earlier. Six critical friends who are experts in this field joined me in conversations about group identity, host organisations, relationships with statutory services and features of effective CD support. A table shows how the themes developed through the study. Next I bring the themes together within a framework to illustrate and discuss components of CD support for autonomous Black mental health groups.

Chapter Ten

Components of a Community Development Approach

“Let's claim our space and do what is right
To bring about change, not merely a fight
To make sure our issues stay well within sight
And one day perhaps they'll start to see light.”
(Kalikhat,1999)

10.1 Introduction

Three components of CD support

This research explored how community development workers (CDWs) and others can support autonomous groups of Black people with mental health problems. Here I present my analysis of the data, identifying three components of effective community development (CD) support. First, I argue that CD practitioners can help the self-organising Black groups to reflect on their membership and, where necessary, make a case for Black-only membership in today's social and policy context. Second, I describe how CD practitioners can support the process of liberation whereby groups generate self-belief, self-efficacy and collective action. Individuals, services and communities benefit. Third, I introduce the notion of critical humility to this context, to show how CD relationships and techniques can help to break the pattern of racial and psychiatric dominance. Practitioners who lack critical humility, commitment and competence may reinforce societal oppression.

Throughout this research Black and other participants have refined and affirmed my analysis, inspiring confidence that it will resonate with their peers while demonstrating academic rigour. It is grounded in four research cycles. Cycle One (C1) comprised a survey and interviews with CDWs; Cycle Two (C2) involved case study research with a group called Sweet Potato, a CDW (CDW/1) and

stakeholders; Cycle Three (C3) was a case study with another group, Ngoma, CDW/2 and stakeholders; and in Cycle Four (C4) I reflected on my learning with six eminent critical friends who were active in five groups (Alpha to Epsilon). All names are fictitious. I use the term ‘CD practitioner’ to denote anyone who supports the groups, while ‘Black’ denotes people with some African or African Caribbean ancestry. Terminology is explained in 1.2 and Appendix I.

The first component of CD support concerns the rationale for groups of Black people with mental health problems when many question whether single ethnic identity initiatives are appropriate or helpful today.

10.2 Rationale for Black mental health groups

Tricky issues need local decisions

Several case study participants questioned whether mental health groups for Black people are appropriate in today’s context of broad equality and cohesion policies, fluid identities and increasing racial tolerance. Individuals shifted between different, sometimes contradictory views (see 7.5.2; 8.5.2).

I understand this lack of consensus as one of those persistent problems or “wicked issues”, where “wicked” is not used to denote evil, but rather “‘vicious’ (like a circle) or ‘tricky’ (like a leprechaun)” (Rittel and Webber 1973, p.160). Like Rittel and Webber, I feel there is no right or wrong here and agree with Jones and Stewart (2007) that wicked issues must be resolved locally, responding to local conditions and community aspirations. CD practice is uniquely equipped to help local people discuss and agree the way forward (4.2), but these discussions never happened in the case studies outside my own work with Sweet Potato (7.4).

Challenged on grounds of multiple oppressions

Equality legislation today spans multiple strands of discrimination, as the service providers emphasised (3.2; 7.5.2). Some argued that organising around ethnic or

gender-based identities fails to acknowledge the complexity of these multiple strands. Certainly this research identified intersectional oppression. Ngoma's host organisation, Calabash, had a protective, somewhat patronising approach to mental distress, although the manager understood Black issues in terms of civil rights (8.5.2). Women at Ngoma set up their own group, like many other Black women who wished to avoid the Caribbean patriarchal ethos as I noted earlier (3.2; Davis and Cooke, 2002). Hylton (1999) refers to Black men organising separately, as they did at Beta (9.4), because men experience greater stigma and socio-economic disadvantage than the women (2.3). For Barbara at Sweet Potato class differentials seemed to be more significant than skin colour; she did not want "posh" people coming to help her (7.5.3).

As I noted earlier (3.2) Begum (2006) suggests that different dimensions of discrimination can create *disempowering* dynamics within the groups that aim to empower Black people, but these can occur within any community group. Self-help groups are not always democratic (ESTEEM, 2011). Hall (1996) writes of how "different, often contradictory elements can be woven into...ideological discourses" (p.27). The existence of multiple oppressions does not, in itself, show that identity-focused groups are inappropriate. Rather, it affirms that discriminatory processes must be understood and addressed wherever they occur. Another concern raised by service providers was that Black groups are divisive and ignore our shared humanity.

Acknowledging shared humanity

Several participants emphasised shared humanity across multiple identities (7.5.2; 8.5.2). Many group members wanted to reach out to people who are not Black. They wanted to help them, be friends and acknowledge their common humanity. We learnt that people often think of themselves as a Londoner or in some other way first, only identifying themselves as Black when something goes wrong (7.5.2). Although Ngoma was perceived as separate from statutory services and

other ethnic groups (8.5.2), this separatism reflected the approach of its host organisation and not the wishes of group members participating in the research.

Participants in both case studies suggested that the groups might benefit from reaching out to others if they could maintain a Black leadership. They could embrace a shared humanity, but on their terms, as CDW/2 explained:

“[It is] not about *not* mixing with others...people should be able to come into our way of life and accept it rather than us being forced to always do things according to other cultures’ alien way of life and be looked down on ...[It is] about us having a cultural setting that allows us to be ourselves ...having freedom and control to manage and arrange services our way ... that we can share and offer to others...something good to give the world.” (CDW/2, C3)

This enthusiasm to engage across boundaries might seem surprising, but it affirms the view of Gilchrist, et al. (2010) that ethnic identity groups can increase individuals’ confidence to integrate with others. It reflects what Sen (2007) describes as the internal diversity and cross-boundary interactions of identity. Participants were likely to participate in different social gatherings, for instance as parents or footballers, in many, constantly-changing identities. Caribbean roots may shape one of these identities: “Dual and multiple affiliations feed our constantly fluid sense of self” (Phillips, 2004, p.131).

Group members’ readiness to engage with other groups and wider society defies cross-party political rhetoric about separatism and segregation (4.2). It contradicts the assumptions of participating service providers who believed that ethnic identity groups might cause inter-ethnic tensions. It is important here to distinguish between *community groups* and separate *statutory services*, which are outside the remit of this study and raise different questions. As group members recognise our shared humanity, I ask what unites them within a Black group?

Tackling the shared identity question

There was no common notion of Black identity among participants. I found that how people described themselves varied with age, history of migration, family background and personal sense of history and heritage. The Calabash manager emphasised the shared African and Caribbean heritage, but some group members had little interest in this (C3).

Regardless of how they described their identity, group members valued a broad Black cultural community, what the Mental Health Foundation (MHF) calls “the wide spectrum of Black expression” (2003, p.25). The case study groups illustrated this spectrum well. The beat of Ngoma’s African drums mesmerised the audience when they came together with Sweet Potato’s lyrical singing. Conversations in Creole, heard at Ngoma, were rare at Sweet Potato (8.5.1). There were also commonalities. In different ways the two groups enjoyed African Caribbean food, music and sometimes a spiritual affinity. Ngoma members spoke of their “family” embracing people of different (Black) nationalities and migration histories. Despite their different socio-economic and cultural backgrounds, African and Caribbean people came together in harmony. Tensions arose only when newly-arrived Africans assumed a higher status as social work students and lacked understanding of the Caribbean UK and mental health experience (8.5.3).

Within these commonalities, people chose different connections to suit local circumstances. Ngoma’s women’s group and Beta’s men’s group have been mentioned. Sweet Potato’s natural warmth and their obligations on the wards made them reluctant to exclude people, and after much reflection they chose to include all Black, Asian and minority ethnic (BAME) populations and to exclude *no one* on grounds of ethnicity while retaining a Black focus (7.5.2).

The complexity within the Black identity is recognised within the literature. Hylton (1999) found that while some people adhered to their African heritage,

others did not. Walcott (1998), the acclaimed Caribbean poet, argues that looking to the future rather than the past is a personal choice for Caribbean people which should be respected. Platt (2011) describes identity as “fluid, flexible and dynamic and relational” (p.16). Instead of looking for a fixed content to identity, it is this relational aspect, how Black people might be distinguished from others that matters here. The sense of exclusion and stigma, as much as any cultural affinity, explains why Black people with mental health problems choose to come together.

Historically framed as deficient and dangerous

Participants described how Black people, especially those using mental health services, felt framed as deficient and stigmatised in the media, schools and the job market (7.5.2; 8.5.2; 9.4). Mental health managers in both case studies said that services respond inadequately and sometimes oppressively: “There have been some awful things in the name of delivering care to people that actually was delivering control and delivering a level of prejudice” (MHT/M3). Group members said that Black people are not understood in services (7.5.2; 8.5.2). The body language of nursing staff made Sweet Potato’s ward visitors feel inferior (7.5.2).

Several Black participants explained the situation in historical terms: “It goes back...history repeating itself, oppression and discrimination still happening in a different form” (CDW/1). David points to the “emotional impact of not having power, over generations and generations...we’re still struggling under it”. Black people with mental health problems “really feel powerless” (R2), a feeling rooted in “the origins of it, the history” (R1). Current oppression in the form of exclusion was observed more often than discussed. Our development activities revealed that many participants lacked telephones, money to travel, computer access or skills, literacy skills and some had no secure home.

It was striking that Black participants in every cycle, but none of the White participants, explained the present with reference to the past. Hickling (2012), a Jamaican and UK psychiatrist, argues that colonial history must be acknowledged when addressing the mental distress of African Caribbean people. I noted earlier that McIntosh (2004) and Lentin (2008) suggest that racism provokes a ‘don’t go there’ attitude (2.5). Acknowledging slavery and the possibility that our ancestors were implicated may be even more difficult, but silence suggests a failure to recognise the deep-rooted nature of racism and the need for deep-rooted change.

Literature that spans ‘race’ and mental health supports the participants’ view that racism, stigma and low socio-economic status are inextricably entangled, shown in Chapter Two. The misunderstanding of Black children’s behaviour (Strand, 2007) is reinforced by and reinforces stereotypical images of distressed Black men as “mad and/or bad and dangerous” (SCMH, 2002, p.26). Although skin colour does not “stitch us in place” as it used to (Hall, 1997b, p.63), in some contexts Black people may find themselves reduced “to little more than one single component of our rich and complex selves” (Phillips, 2004, p.131). They may still be categorised and feared as ‘the Other’ (SCMH, 2002; Craig, 2012). Equality legislation has driven discrimination underground instead of eliminating it (2.3). For these reasons, McIlwain (2011) argues that ‘race’ remains “a salient factor or lens” through which to see persistent injustice (p.54).

Despite contradictory pressures, many acknowledge the value of Black mental health groups. A mental health trust (MHT) manager felt that this could help to drive forward change (7.5.2). Craig, et al. (2012) argue that people may wish to come together in ethnic identity groups to gather strength and fight for change, while in other circumstances and contexts, other aspects of their identity may be more important (p.8). I am reminded of a Black community activist who said that if Black people did not organise themselves, who would challenge their oppression? As groups take shape, people can tackle their difficulties together.

A safe space to launch a shared struggle

The groups provided a place of safety where isolated individuals gained a sense of belonging and security, described poignantly by Ngoma's participants (8.5.2). Over the years they came to feel accepted, safe, and understood without having to explain. Communication was much easier than at MIND, the mainstream voluntary sector project (8.5.2.1). I described earlier how groups can restore the sense of belonging that helps to reduce Black people's distress (3.3).

Sweet Potato seemed to take a safe space to the wards where visitors sat with service users, their spontaneous warmth bringing people together to share reminiscences, jokes and painful experiences (7.5.2). The response was often surprising as those who had previously been silent, talked, and those who had been aggressive, were calm (7.5.2). The visitors offered an oasis of calm within mental health wards, which have been described as frightening and dangerous places (SCMH, 2004; Mind 2005). Future research might usefully explore the characteristics of safe spaces offered by autonomous groups and the importance (or not) of a physical base.

Not every Black service user wants to join a group, and for those who do, Black groups are not always their preference. Avis, et al. (2008) suggest that what connects people is variable and unpredictable. Mental health practitioners often assume that Black service users want to join a Black group (8.5.2), but the data affirm that some Black people prefer to remain independent or join mainstream service user groups (9.4). These can be unwelcoming and fail to comprehend the entangled oppressions faced by Black service users (3.3), which helps to explain why some want separate groups.

Black mental health groups have a role today

Debates about multiple oppression and ambiguous Black identities divert us from the severe, persistent inequalities between Black and other groups within mental health care (CQC, 2011). These reflect discrimination and disadvantage found

across UK society (2.3; 2.4). Black peer support groups are not some sort of social club where we enjoy meeting people “like us”, as a MHT manager suggested (8.5.2). Their role in sheltering, nurturing and empowering Black people in distress can only be understood in relation to the racism and exclusion experienced outside. As a base for collective action, they offer hope of a future that differs from the past.

Although the political focus on race equality is fading (2.3), most participating MHT managers in this study accepted, albeit with some doubts, that Black mental health groups have a role in compensating for and addressing MHT shortcomings (7.5.2; 8.5.2). Next I explain how CD practitioners helped the groups to pursue their goals.

10.3 **Process of liberation**

These sections describe CD support for what I call a process of liberation. CD practitioners helped the groups to develop a strong sense of belonging at their core and, through their activities, to generate self-belief and self-efficacy in their members. Practitioners created opportunities for groups to pursue wider change for those outside the group.

10.3.1 Supporting the group’s core

Introduction

Here I show how CD practitioners working close at hand encouraged isolated Black people to come together for mutual support. Inspiring leadership, facilitation skills and practical support enabled group founders and CD practitioners to address organisational and cultural barriers.

Initiating the group

Five of the seven groups appearing in the fieldwork were initiated by Black CD practitioners. Some participants said that due to distrust in the mental health

context, Black practitioners are more likely than White people to inspire confidence among Black service users that they will be respected and understood (9.4.4). A Black CD practitioner who had used mental health services himself (R3/SU) told his peers how joining a group helped his recovery and what local groups had achieved; those who felt powerless were inspired, “suddenly realising that actually, they *can* make a difference” (9.4). A skilled, caring, “diligent” and infectiously enthusiastic community worker helped to initiate Alpha (9.4). The Calabash manager inspired service users to establish Ngoma (8.5.1).

The lack of telephones, basic skills and financial resources among group members, combined with heavy medication and sometimes chaotic lives, inhibited group development in both case studies (7.5.2; 8.5.4). Grey (2005), a former service user and CD practitioner, suggested that many Black service users do not want to join a group:

“Support groups which involve some sharing of emotional needs through discussion are not what the men wanted. Also, many young men are not willing to identify themselves as people with mental health problems and wish above all to integrate within society as ordinary citizens, so a formal ‘self-help’ group for mental health service users is not useful.” (p.109)

Grey’s experience reminds us of Hylton’s (1999) finding that Black men are often reluctant to join community action (3.2). I noted earlier (4.2) that where people are not motivated or resourced to organise collectively, the CD practitioner may be a “catalyst” (Freire, 1972) or “energiser” (Flecknoe and McLellan, 1995, p.17). Here the data showed the importance of a Black service user inspiring and motivating others to form a group (9.4.4). While many self-organising mutual aid groups enjoy some practitioner support (ESTEEM, 2011), this study reinforces Taylor, et al.’s (2007) argument that historically disadvantaged populations, including Black people, may want more intensive support than others (3.3). Some want help with facilitation.

Facilitation skills promote peer support and reciprocity

Facilitation skills are at the heart of CD practice and were used here to help group members build mutually supportive relationships. At Alpha's check-ins members exchanged news and recent experiences (9.4.4). The CD practitioner ensured that each member felt "as if *they* were important" to the group. R3/SU spoke of how the group check-in generated a warmer, mutually supportive atmosphere, which was confirmed during development activities at Ngoma (8.4).

Sweet Potato was driven by its founder members whose cigarette breaks outside the building created informal check-ins, while Steering Group meetings seemed to be dominated by the host manager (7.5.2). During ward visits, Sweet Potato members demonstrated the compassion and kindness of peer support (Reynolds, 2010). Shared experiences of being "wounded" as Cornwall described it (7.5.2) create what Mead, et al. (2001) call "a deep holistic understanding...without the constraints of traditional (expert/patient) relationships" (p.135). Unlike the imbalance of power between service users and professionals, peer support is exchanged among equals, and this, Sewell (2009) believes, appeals to Black people. I have noted that informal peer support groups are particularly beneficial to marginalised communities (Faulkner and Kalathil, 2012).

There was less peer support at Ngoma. Founder members had departed. Social work students struggled to facilitate group activity, understandably lacking the skills. The absence of check-in or similar techniques left what R3/SU called "a coldness" there (9.4). Core member Jerry longed to feel noticed (8.5.3). Ngoma seemed to have lost its vision, with most members passive and silenced.

This data supports my earlier work, which found that BAME groups are more likely to share experiences in an ad hoc way, often around an activity, rather than around a table: "Talking and sharing experiences was as important as the activity, but talking without the activity was not an acceptable option" (Seebohm et al., 2005, p.84). Avis et al. (2008) found that BAME self-help groups may share

experiences in very different ways from most self-help groups described in the literature (3.3).

Overall, the data affirms the value of facilitative support in fostering the magical ingredients of peer support groups, their mutuality and reciprocity. Much of the self-help/mutual aid literature suggests that this ethos is spontaneous, but this data supports Taylor, et al.'s (2007) suggestion that historically disadvantaged groups sometimes need skilled facilitation to support them. The DRE CDWs were too distant to play this role. Several White and healthcare practitioners lacked skills or dominated decision-making, reflecting and reinforcing a wider imbalance of power. The way in which practical help was provided can also enhance or limit group power.

Practical support

The seven Black groups referred to in the fieldwork were all based within host organisations, which provided places to meet, support and guidance, sometimes managing group funds and workers. In the case studies, several participants felt that these benefits came at too high a price, limiting group autonomy (discussed later). At Ngoma, volunteers provided an impressive range of practical support from office work to cake-making to acting in a drama. DRE CDWs offered practical support: helping to raise funds for Sweet Potato, helping to set up a satellite office at Ngoma, and using their connections to draw in others.

The group core supported

Most groups here received help to get established and without this support some, probably most, would not exist. This contrasts with the self-motivating independence of the largely White groups described in the self-help literature (3.3). With support, five of the seven groups in the fieldwork were still running after five years and none had closed. The limited literature about Black mental health groups suggests that they are greatly valued by their members (3.3). I now turn to how practitioners help groups to generate self-belief.

10.3.2 Fostering self-belief

Self-belief in recovery from ill-health

Self-belief was said by CDW/1 to be a critical issue for groups of Black people with mental health problems (7.5.3). It was not a term that members used, but it helped me to understand an important group process. I use ‘self-belief’ to denote a positive identity or sense of self, and related to this, a feeling of self-worth or self-esteem.

A positive identity and self-esteem are key elements in mental health recovery (2.5). Repper and Perkins (2003) write that “the experience of mental health problems severely threatens a person’s sense of self”, leaving people feeling that they are little more than the diagnostic labels attached to them (p.104). I noted earlier (2.5) how Black women felt that recovery involved rebuilding a sense of identity and self-worth for themselves and their Black community (Kalathil, et al., 2011). This is not easy when internalised oppression destroys identity and self-esteem (2.5). Sewell (2009) argues that attitudes within wider society are reflected in mental health services, affecting a Black service user’s sense of identity in complex ways. As Muir and Wetherell (2010) write, “identity is always both about ourselves and about how we are positioned in relation to the world” (p.4).

A group member observed that at the Black service user group, 4Sight, “you rediscover your identity that the system takes away from you” (Friedli, 2009a, p.47). This section looks at how CD practitioners helped group members in this study to tackle negative images of themselves, beginning with role modelling.

Black role models

The case study groups were happy to work with me and other non-Black people, but spoke movingly of Black role models. At Sweet Potato, despite their emphasis on a shared humanity, group members were vehement about the value of support

from Black CD practitioners (7.5.3). They spoke of the deep-rooted emotional connection they felt to those who shared their history of oppression. CDW/1 described the sense of shared struggle being felt “almost to the bone”, suggesting an emotional or spiritual connection deeper than any working or professional relationship. Cornwall felt that Black supporters bring a sense of “belonging to a set of people”, and it is this sense of community belonging and cultural identity which Griffiths (quoted in Friedli, 2009a) felt Black service users often lack (3.4).

The powerful and positive impact of Black role models was a consistent message in this study. These role models changed the way group members saw themselves, increasing their belief in their own worth. Sweet Potato and Ngoma members found some of the Black people who came to support them inspirational, giving them an alternative image to that found in the media: “We’re not relying on stereotypes” (7.5.3; 8.5.3).

It was unusual in this study for role models to embody the combined shared experience of being Black and using mental health services, but the Black service user/CD practitioner (R3/SU) inspired those who felt powerless. By seeing someone who they saw as like them, a peer, in a position of power they came to think differently about the possibilities for their own future (9.4). Sweet Potato’s ward visitors inspired service users to think that they too could have a fulfilling life (7.5.3), giving them a new perspective on their place in the world.

There is a long-running, complex debate in CD and mental health about whether practitioners should share the ethnic identity of those they support (Gilchrist, Bowles and Wetherell, 2010; Fountain and Hicks, 2009). One participant (C4) believed that White practitioners increase confidence in impartiality and confidentiality, reflecting a view expressed in Seebohm and Gilchrist (2008). Community research compiled by Fountain and Hicks (2009) found that many (but not all) Black service users preferred Black workers. My data here suggests

that a shared identity could enhance the group-practitioner relationship in a unique way.

The potential impact of role models is well documented. In earlier research, colleagues and I (Atkinson, et al., 2007) found that Black mental health service users working within the community as Mental Health Guides were felt to have more passion and “a more realistic approach” than others, helping other Black people with mental health problems to think “a little bit differently” (p.45). They were viewed as peers: “You’re coming from where I’m coming from” (p.46). A lack of male role models can leave Black youth depressed, lacking a sense of identity, belonging and self esteem (Prince’s Trust, 2010). A government-funded role modelling programme for Black youth “demonstrated beyond any doubt the inspiring effect a role model can have” (DCLG, 2010b, p.6). The qualities that the programme beneficiaries valued included integrity, showing respect, being “humble and able to identify with and relate to their audience” and having overcome similar difficulties to those which the young men experienced (ETHNOS Research and Consultancy, 2011, p.114). These qualities resonate with the data here.

Not all Black people were seen as peers or role models and later I discuss how some distanced themselves from group members. First I discuss how restoring pride in a shared heritage can promote self-belief.

Celebrating heritage and cultural expression

CD practitioners supported groups in this study to celebrate their heritage and culture just like the Black identity groups of the 1970s and 1980s (3.2). One practitioner supported a group to uncover local Black history omitted from official records, bringing new meaning and pride to being Black British (9.4). Hall (1990) describes these hidden histories as: “resources of resistance and identity” (p.225). Black history affirms the contribution, often overlooked, of Caribbean people to British life over centuries, as Hall (1997b) reminds us: “I am

the sugar at the bottom of the English cup of tea... There is no English history without that other history” (p.48-49). Black mental health organisations have long recognised that celebrating Black history and achievement help to generate a sense of identity, belonging and self-worth (Secker and Harding, 2002b). It combats internalised oppression: “Black history and a reminder of where we came from and a vision of where we need to be going is one of the solutions for raising Black consciousness and Black self-esteem” (MHF, 2003, p.24).

Not all participants were interested in the past, but many were creative. Music at Sweet Potato and Ngoma enabled group members at an early stage in their recovery to develop their talents, “shine and be proud” (7.5.2). In his story, Jerry described how his talent for drumming surprised him: “It’s good because you end up a celebrity to yourself, even though I didn’t consider I could do that before and I wonder – is it a dream or what?” (7.5.2).

Traditional food, enjoyed weekly at both case study groups, was felt to raise people’s spirits by connecting them to their culture and peers, but this function can be under-valued. The threat of cuts to weekly meals led to Ngoma being established. Critical reflection is another way of changing perspectives.

Critical reflection to raise consciousness

Critical reflection to generate conscientisation has long been described as a central process of peer-led groups that is encouraged by radical CD practitioners (3.3; 4.2). This process was rare, but not absent, in the case study groups. Group members observed and listened to Black role models, revising their view of possible futures (7.5.3; 8.5.3). CDW/1 enabled members of Sweet Potato to access critical perspectives on Black mental health issues. For Barbara this was “life-changing”. David (C2) came to question his lifetime sentence of paranoid schizophrenia as he took up academic pursuits with a new sense of self:

“When we get told something by someone in authority, we accept it as reality. But [the people there were] saying ‘Hey look, it’s only a thought

that someone cooked up, challenge it if you want to free yourself – emancipate yourself from mental slavery!”

Robson and Spence (2011) describe how critical reflection can dislodge passivity and self-blame by “naming features of oppression, and organizing collectively to build personal skills, knowledge and confidence” (p.292). As I noted earlier, Chamberlin (1997) argues that this process creates empowerment within self-help groups while Rai-Atkins, et al. (2002) state that it does the same within Black groups. With the loss of funding for radical CD (4.2), critical reflection is now rarely part of the CDWs’ remit (Robson and Spence, 2011) and none of the DRE CDWs were known to facilitate such reflection themselves.

Self-belief fostered

CD practitioners helped members to gain a sense of identity and self-esteem, for instance by being role models, supporting historical and creative activities, and occasionally enabling access to critical perspectives on Black mental health issues.

10.3.3 Fostering self-efficacy

Agency and capability put people in control

As with self-belief, self-efficacy is not a term used by the groups, but I find that it helps to explain what enables them to achieve their goals. Within the word ‘self-efficacy’ I include both ‘agency’ and ‘capability’. People using mental health services, especially where treatment is involuntary, may feel like passive recipients of care. A sense of agency replaces this with feeling able to act and take control of life, a recognised feature of recovery from distress (Repper and Perkins, 2003). The other aspect of self-efficacy, found, for instance, in research on employment support, is the person’s belief in their capacity to achieve their goals (Renegold, Sherman and Fenze, 1999). For those who have felt labelled as deficient since school-days, gaining a sense of capacity changes how they see

themselves and their future. This section examines how CD practice can enhance self-efficacy as it supports participation, leadership, learning and work.

Involvement brings personal gain

Even low levels of involvement in their group brought personal gain to members while enhancing group cohesion and organisation. During our development activities at Sweet Potato (7.4) ward visitors reflected together on how they responded to difficult situations, encouraging each other and devising new ways of working. David, often unnoticed in Steering Group meetings, came to be regarded as a thoughtful and skilled contributor to the group. Similarly, during our development activities at Ngoma members listened attentively to each others stories, empathising or celebrating according to what they heard. They said that they felt more connected and mutually respectful (8.4).

Sweet Potato members involved in ward visits spoke passionately of how much they gained from supporting their peers in hospital (Reynolds, 2010a). It is a well-known phenomenon that those who help others benefit themselves (3.5). The recognition and appreciation that resulted from Sweet Potato's activities increased members' sense of self-esteem, agency and ability to achieve, as David described:

“I feel like I'm more capable, more able, and that's something I have in common with [Cornwall] and [Barbara], that feeling of being *able* and having an ability to *do* something, that is useful, functional and worthwhile, increases your self-esteem, makes you feel better about yourself, but it also makes you feel better about the people you're working with. As you say it's a two way thing, you feel better because they say 'Oh, well, you know, this has helped us do something' ...I don't want to big up myself but I'm doing important work, an important cog in the wheel...it makes me feel a lot better in myself for being able. And the feeling of being able is so valuable - it's more valuable than money.”
(7.5.3)

CD support created the opportunity to deliver ward visits, but the credit for the visitors' achievements is due to their own passionate drive.

Members also gained by taking up group leadership roles if and when the support was there. Alpha members benefited from a CD practitioner coaching and working alongside those taking lead roles (9.4.4). When Alpha's Chair was sectioned under the *Mental Health Act 2007*, the CD practitioner negotiated with staff of the locked unit to hold the group meeting on the ward. This bold approach had a profound impact on the Chair:

“I was like ‘Wow! Look at me, I’m here where everyone is seeing me as nothing but an ill person who needs to be taken care of, and here I am seen as important, being part of making important decisions. It was a profound and important moment for me.” (R3/SU)

CD support was sometimes absent, for instance leaving a much-respected member of Ngoma feeling unable to become Vice-Chair (8.5.2).

Nurturing talent develops capacity

Group members wanted to gain skills and confidence to pursue their personal and group ambitions (7.5.3; 8.5.3). One practitioner (in C4) provided tailored training on organising and leading small groups. Her informal coaching and role play suited people who did not want formal tuition. Like several other participants, she felt that community training agencies often fail to meet the needs of small groups.

My weekly discussions at Sweet Potato provided a supported learning opportunity that enabled group members to gain insight into the ward visits: “We really understand what’s going on because we’ve been through it, from the beginning to the end, we’ve had to study and sit down and read and discuss...it’s all in ourselves” (7.4). This increased their capacity to address their challenges. CDW/1 invited Barbara (who writes with difficulty) to attend a demanding five-day Race Equality and Cultural Competence Training for Trainers course. She (and probably several others) felt she would never complete the course, but she did and went on to train MHT staff (7.5.3). CDW/1’s confidence in Barbara created a rare opportunity.

On the whole, there were limited opportunities for the case study group members to develop their talents. Sweet Potato's hopes of training from a Black mental health survivor/consultant were discouraged by the host organisation (7.5.2). Learning, training and coaching in this context can take many forms, but to be effective, as Chamberlin (1997) emphasises, it must be what the group or group members want. Cockshutt (2005), a veteran of self-help groups, described them as "a learning base from which the individual can develop" (p.103). I described earlier (4.3) how CD practitioners can identify and nurture talent (Seeborn and Gilchrist, 2008). We know from Foucault (1980) that knowledge and power are linked (2.2). Members of the Black mental health group 4Sight felt empowered by "knowledge, support and information" (Friedli, 2009a, p.6). The literature and data here suggests that groups have immense potential to change lives through learning and achievement, but it was not always realised.

Job opportunities normalise status

Some, and probably most, group members felt that employment was an important, if distant goal (8.5.3; 9.4). The case study groups acquired funding for part-time work opportunities managed by the host organisations, but pay was limited to £20 a week to avoid disrupting welfare benefits and workers received little support to develop their career. In contrast, participants in C4 described how some members became development workers at national rates of pay.

Evidence from an employment service for Black service users suggests that "an encouraging can-do attitude" helps them into work (Seeborn, 2005, p.80). Renegold, Sherman and Fenzel (1999) found that people with mental health problems are more likely to get jobs if they believe in their capacity to succeed. Grove and Membrey (2005) argue that the onus is therefore on those who support service users to foster this belief by believing in the person's potential, tailoring support and enabling the individual to choose their own goals. Sharing Voices (Bradford) (2004) describes how their positive CD approach led to BAME group members and volunteers moving into mainstream work. I believe that there are

similarities between processes of effective employment support and processes within thriving mental health groups, which was not recognised in the case study groups.

Self-efficacy fostered or inhibited

Black mental health groups can be a learning base from which members launch themselves into the roles that interest them. The data here suggests that CD practice can support this process and sometimes does, but at other times it fails to help members to develop the necessary belief in their own ability to achieve.

10.3.4 Creating opportunities for change

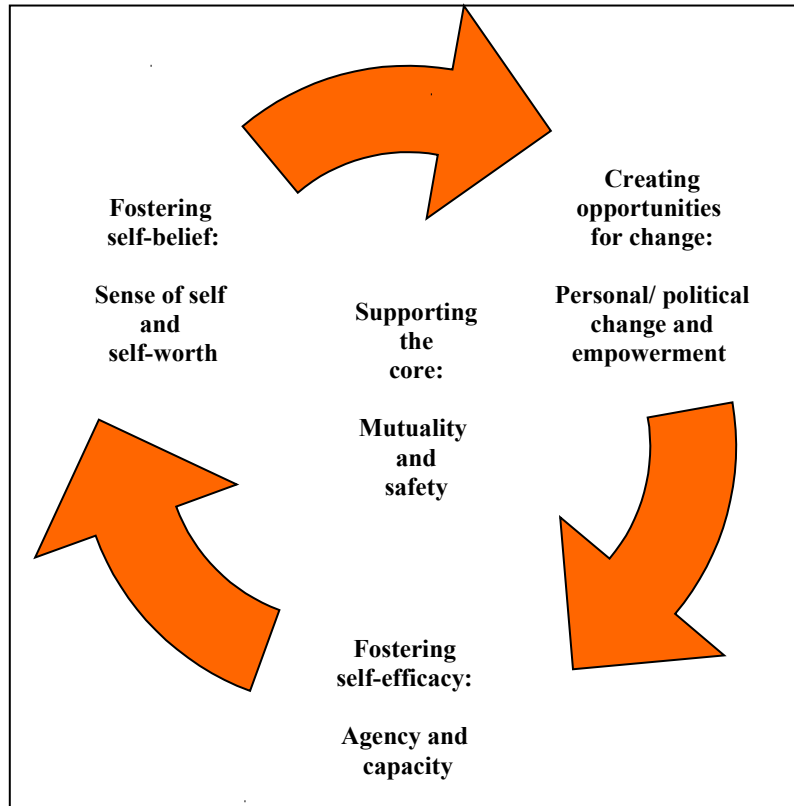
Introduction

This section discusses how CD practitioners create opportunities for groups to pursue the changes they want to see, for instance in their mental well-being, statutory services or local communities.

Action for change and empowerment

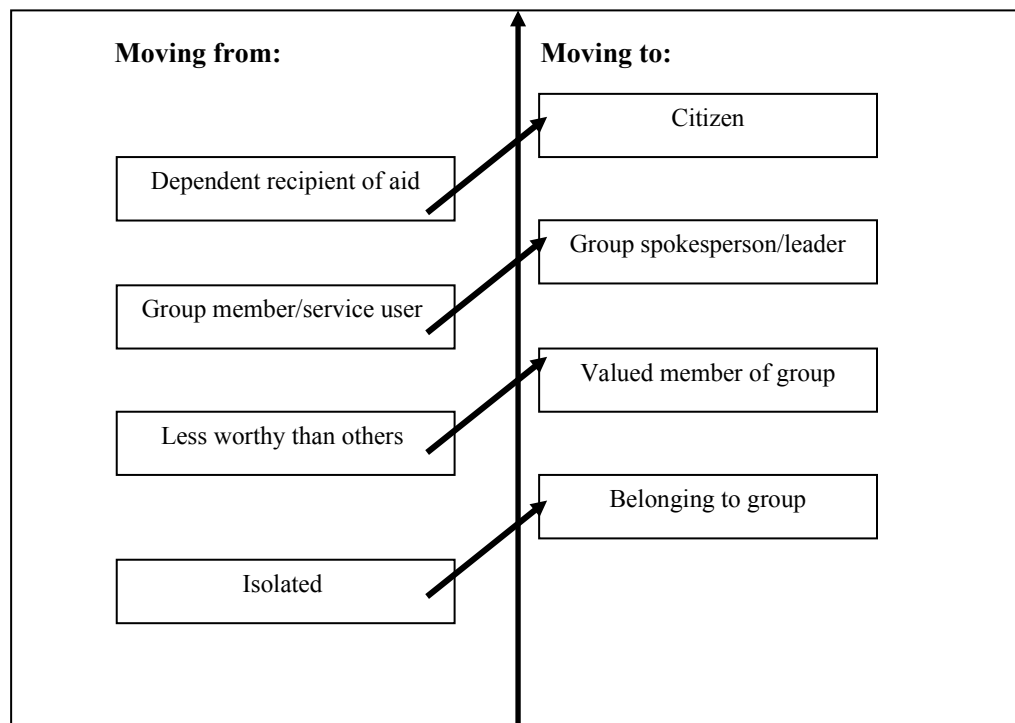
Effective opportunities to act were those seen by the groups as both relevant to their purpose and achievable. Empowerment involves both mechanism and mindset (4.4). The mechanism is the opportunity, for instance to participate in user-involvement structures which may (or may not) be seen as relevant. The mindset is the feeling that action is achievable and worthwhile. For instance, a person may (or may not) feel *able* to attend a user-involvement meeting and may (or may not) feel that it will make a difference. Thus groups wanted opportunities that were relevant, achievable and worthwhile. When they took up these opportunities they became personally and politically empowered in an incremental process; as noted earlier, empowerment is a journey not a destination (4.4). Each step increases self-belief and self-efficacy in a continuing spiral of change (see Diagram 8 below.)

Diagram 8: CD support for autonomous Black mental health groups.



During this process of incremental change and empowerment, group members in this study changed how they positioned themselves in relation to others (see Diagram 9 below). People came to Ngoma feeling isolated, but as they gained a sense of belonging they could reposition themselves as part of a group. Their sense of worthlessness decreased when they saw themselves as good as their peers, taking on minor but valued roles such as helping to cook. Self-esteem and status increased in those taking on leadership roles. Black critical friends described how members collectively engaged with other agencies came to feel like useful citizens. This shift to citizenship applied to the ward visitors (C2), police trainers (C4) and administrators (C3), all roles seen as a step beyond ordinary group membership.

Diagram 9: Group members re-positioned.



There was a similar process of change and empowerment for the group as a whole as they became known for instance for their ward visits, creative expression or training, as described below.

Changing the ward experience

Sweet Potato's first priority was to improve the experience of Black people on mental health wards, so that it is better for others than it was for them. CDW/1 recommended Sweet Potato's plans to MHT managers, and because of the managers' trust in him they allowed the group to visit wards on their own terms without an evidence-based proposal. MHT managers came to value the group's heartfelt and cooperative style and felt that they helped to shift thinking in the MHT (7.5.2).

Delivering training

Groups were involved in training MHT staff (Sweet Potato) and the police (Beta). This was not merely presenting personal stories: members became trainers. Police

training was successfully repeated over three years with group members taking increasing responsibility for the planning and management of the course:

“Here is a group of users who are seen working with the police, not just on a level but having the police humble to listen to them must be a very changing feeling within their lives and especially in their relationship with the police.” (R1)

Creative communication

Creative forms of communication helped to bring about change within public services and communities. Neither of the case study groups participated regularly in official user-involvement processes. I noted earlier that these were often felt to be “hierarchical spaces” (Kalathil, 2008, p.3) (4.4). Instead, both groups communicated with statutory authorities in their own way. Sweet Potato established regular forums where MHT staff came to hear the views of Black service users and carers, enjoying debate, music and food. Epsilon communicated creatively, using poetry and dance. A former Epsilon member described creative expression as a way of engaging the heart of mental health professionals, enabling them to “get it” in a way that written formats often failed to achieve (9.4.3). I witnessed this process at a Sweet Potato forum (7.5.2).

Drama was used by five of the seven groups in different ways for different audiences including mental health professionals and the local community. Sweet Potato participated in national media. These ventures mainly sought to combat stigma or help nursing staff to restore the humanity in their care, which, some participants felt, had been leached from them during training (7.5.2; 9.4.3). In her submission to the Independent Inquiry into the death of her brother (Blofeld et al., 2003), Joanna Bennett argued for humanity in mental health services. She argued that the emphasis on cultural competence training was misplaced when what people in distress really want is a respectful and caring approach to their individual needs (2.4; 4.3) and this is what the creative activity sought to express.

Changing attitudes

In these different ways, group members chipped away at institutional racism, inadequate care and stigma. As the study ended, a member of Gamma told me that, with CD support, they had successfully challenged some of their members' diagnoses of schizophrenia which they felt had been unfairly given (2.4). Sweet Potato and my Black critical friends felt that collective action to bring about change was part of a "healing process" (9.4.2), enabling group members to move up the empowerment ladder (Diagram 9).

As often occurs in CD, there was no rigorous evaluation (4.3) but MHT/M3 remarked that the group "shifted my thinking" and she and others thought the same would happen with ward staff and the police (7.5.2; 9.4.3).

10.4 CD practitioner qualities

10.4.1 Changing the dynamics of power

The data in this study show that how CD practitioners perceived the groups and how they positioned themselves in relation to them made a pivotal difference to the nature and outcome of their practice. The practitioners' standpoint and approach can reinforce societal oppression or, conversely, model and enhance the empowering processes described above. People did not always act as their professional roles might lead us to expect.

I use the concept of critical humility, to my knowledge for the first time in this context, when examining how CD practitioners positioned themselves in relation to the groups. By critical humility I mean a willingness to respectfully learn from the groups and work collaboratively with them, questioning previously-held assumptions. It involves allowing groups to try new ventures and work on their own terms. Practitioners also needed a level of CD competence, understood in terms of skills, connections, time and workplace support. There is much

resonance here with principles of radical CD and supporting the service user-defined concept of recovery.

10.4.2 Critical humility

Mutual learning and humility

In this study two CDWs showed little respect for community understandings of distress (6.4); a few social work students seemed to feel superior to group members (8.5.3), and case study host organisation managers were dominant figures. In contrast, two participants felt that humility and mutual learning were essential for a good relationship between groups and those who supported them (9.4.4): “To be humble enough to listen...when you listen you’re going to hear things in a different way...and that might help you to think differently” (R1).

The concept of critical humility is relevant here where relationships are frequently experienced as unequal and oppressive. The European-American Collaborative Challenging Whiteness (2005), an international group of academics and others, developed this concept for working in contexts where identity is an issue. They devised questions regarding identity, values, privilege and purpose to help learners to dismantle the “white supremacist consciousness” which permeates all thinking and behaviour of people “who view the world through its frame” (p.2). Critical humility requires “learning to live with paradox and ambiguity” (p.2) as we look for the humanity that unites us while remembering the privileges and abuses that divide us. Parker’s (1990) advice for the “White person who wants to be my friend” illustrates this ambiguity: “The first thing you do is to forget that I’m Black. Second, you must never forget that I’m Black” (p.297).

I extend the concept of critical humility to the mental health context. I described earlier how the Western medical model dominates psychiatry, giving little if any credence to minority cultural perspectives (2.5). Although socially-oriented responses to distress are increasing, these rarely replace medication. In Seebomh

(2010) I describe this study's first research cycle and argue that critical thinking about mental health has to inform CD work with BAME communities, to ensure respectful, collaborative practice.

Collaborative practitioners

The fieldwork showed that CD practitioners vary from being collaborative to more directive, depending on whether they positioned themselves alongside or as superior to the groups. At Sweet Potato CDW/1 took his lead from the group and even MHT managers seemed collaborative, valuing the group's compassion and "professional" negotiations regarding hospital visits (7.5.2). They came to listen to Sweet Potato on their own ground, and what they heard led to small but significant change in the care of Black people. In contrast, Ngoma members had little or no voice (8.5.2).

Like Freire (1972), Andersen (1993) believes that outsiders should work alongside the people on whom they focus. At Sharing Voices I found that "relationships...were based on mutual respect; they were not in the role of helper and helped" (Seeböhm, et al., 2005, p.41). To achieve this, relationships must be perceived as on a level.

On a level: respectful, friendly, caring and reciprocal

CD practice is often described as friendly and respectful (4.2). Thomas ruefully observed that "attitude matters" (8.5.3). At Sweet Potato Cornwall wanted CD practitioners to be "like a friend"; Barbara wanted them to be "non-judgemental"; David wanted them to be "on a level", even if they had professional or managerial status (7.5.3).

This does not imply there should be no professional boundaries. Ngoma's core group members did not see professional roles as precluding friendliness and respect (8.5.3). Indeed, Thomas felt that he got more respect from his psychiatrist than from some of the practitioners who 'supported' the group.

Many group members wanted CD practitioners to care *about* them (8.5.3) rather than care *for* them in a patronising way. Compassion, R3/SU felt, was fundamental (9.4), echoing a core value of CD and mental health nursing but often felt to be scarce today in both fields (4.2; 7.5.3). Some positive, understanding and caring attitudes were found in all the research cycles.

Not all relationships were ‘on a level’. Host managers were described and sometimes described themselves as parental (7.5.2) or controlling (8.5.2). Thompson (2003) describes how people with patronising attitudes see people with disabilities or in distress as childlike and dependent, denying their rights and citizenship. This is what happened here.

Believing in members’ potential

Other participants saw potential within the groups. They seemed to expect group members to succeed, albeit making mistakes sometimes, allowing them to “grow and develop” (9.4). R1, R2, CDW/1 and MHT/M3 were willing to take risks, for instance supporting group members still using mental health services to visit the wards and train the police.

For those deeply stigmatised by their own communities, the CD practitioner may be “the only one that believes in them, because family reject them and friends reject them...when somebody else comes in, believes in them and says, ‘I know you can do this’...then that has a big impact” (Sharing Voices [Bradford], 2004, p.7). Repper and Perkins (2003) describe how important it is for practitioners to believe in service users: “Believing in that person’s possibilities is crucial. It is difficult to develop a sense of yourself unless others believe in you” (p.105).

The professional health and social care culture seemed to inhibit belief in the groups’ potential. The data showed that the case study host managers (both with a health and social care background), social work students and at least one CDW

sought to prevent members making mistakes (7.5.2; 8.5.2), limiting group autonomy. Thompson (2003) suggests that practitioners in health and social care can adopt emancipatory or oppressive approaches. In practice, the choice is not easy. Ramon (2011) argues that social workers' dual mandate to care and control pulls them both ways, creating a professional ethical dilemma:

“...derived from the dual social mandate to both care for *and* control people experiencing mental ill health...The co-existence of these trends is conflictual and is often resolved by opting for the more controlling option in the name of risk avoidance, reinforced by the cultural and political climate of living in a risk-oriented society.” (pp.94-95, author's italics)

This is despite the principle central to social work practice that clients have the right to fail and to learn from their mistakes: “This comes as part of the right to self-determination, in that social workers are aware that risk needs to be taken at times to enable people to grow and develop, or as a basic human right of making a mistake” (p.90). The data here confirm Ramon's (2011) view that the controlling option tends to prevail in health and social care, while practitioners with a CD or community work background such as R1, CDW/1 and CDW/2, were less directive. Cockshutt (2005) believes that the key factor is that groups must retain control over practitioner involvement: “for people to really benefit, there has to be autonomy” (p.98).

Autonomy within host organisations

It was striking that, by chance, all seven groups in the fieldwork were based within host organisations, a situation rarely discussed in the self-help/mutual aid literature. Relationships between groups and their hosts were more complex than previously recognised with autonomy a critical issue.

Faulkner and Kalathil (2012) suggest that informal peer support groups are most appropriately hosted within user-led organisations, but I noted how Delta chose to leave a dysfunctional user-led organisation (9.4). After researching their options, they rejected user-led and Black organisations, opting for a health-focused,

community-oriented host because they felt that it would offer the greatest autonomy and support. Their assessment was based on ethos, track record, organisational capacity and, above all, a trusting, respectful relationship with the management. The arrangement would benefit both parties as the host would gain financially and increase its credibility as a viable community organisation. R4/SU confirmed that this organisation, like the local MHT CD unit, provided valuable support as a host without infringing on group autonomy.

Personalities and motives were also said to be hugely important. Epsilon questioned the motives of some of its MHT allies (9.4). At Sweet Potato, tensions over control had complex causes. The manager admitted to a dominant personality and self-interested motives in hosting Sweet Potato, benefiting financially and gaining credibility. He appeared to overlook overtones of colonialist dominance as he, a White man, retained control over the Black group's money. Group members became more challenging but stopped short of demanding control as they enjoyed the comfort and security of their situation. Power dynamics were played out from day to day with both sides keen to maintain what they had.

10.4.3 Commitment

Sharing a common purpose

A wide range of people located near and far in different positions with different contributions to make supported the groups. I describe some as 'peers' meaning that they were the same as group members in significant ways and had the potential to become role models. Ngoma, and to a lesser extent Sweet Potato, prioritised their peer connection with other Black people more than with other mental health service users. I describe others, including myself, as 'allies' meaning that they were on the same side as the groups. CD practitioners such as CDW/1 could be both peer and ally.

CD practitioners, whether peers or allies, had to demonstrate commitment to a shared purpose. They had to “put it on the table” where they had come from and why they were there (9.4.4). Only after such a dialogue can a trusting relationship develop.

Not all Black people, as we have seen, were identified as peers or role models. Some set themselves apart from group members, offering little or no support (7.5.3; 8.5.2; 9.4.4). I noted earlier how Zephaniah (2001) berated Black people who distanced themselves from their community. Sometimes Black people have adopted “often for the sake of their own survival – the mannerisms and ways of thinking” of those who dominate (Asher, 2011, p.67).

Benefits of ally support

Allies included MHT managers, front line practitioners, academics, psychiatrists and others. They offered a range of support including influence, encouragement and increased profile. For Sweet Potato, CDW/1 enlisted the support of MHT managers, who in turn asked ward managers to support the group’s activities. This chain of influential relationships enabled the ward visits to begin.

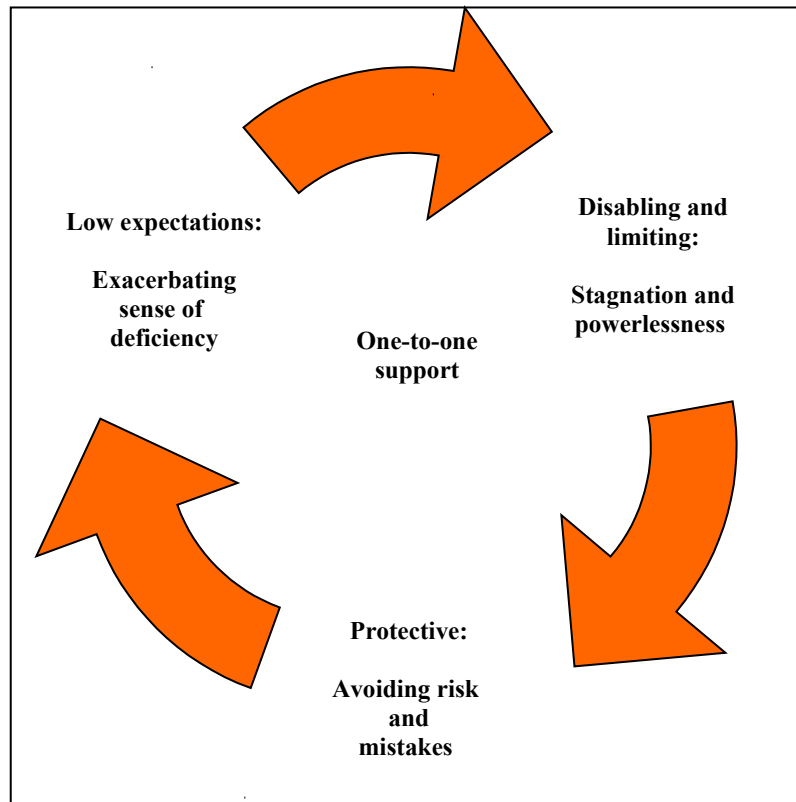
Ally support at senior MHT levels indicated a commitment to race equality in mental health, and it is significant that CDWs are still employed at both case study sites as this research ends in 2013. Craig and Walker (2012) argue that senior management commitment determined the local impact of the DRE programme, while Sewell and Waterhouse (2012) agree that it determines the support provided to local initiatives.

Community allies were equally important. Ngoma had good links with local networks, attracting volunteers and practical support, but at Sweet Potato, Black community links were not encouraged by the White host organisation manager.

Critical and committed

Thus CD practitioners were most valued when they positioned themselves on a level with the groups they supported, learning from them, believing in their potential, caring about them and sharing their purpose. Indeed, I argue that it is only when practitioners regard groups as equals that group members can believe in their own worth. Diagram 10 below shows the impact of less positive attitudes.

Diagram 10: Potential impact of disempowering CD practice.



10.4.4 Competent: skilled, connected and supported

The effectiveness of CD practitioners was also influenced by their skills, connections, leverage and workplace support. Much has been said already about facilitation skills, community and MHT connections and leverage.

The study took place during the DRE programme (2005-2010) which funded the participating CDWs. Only a few seemed to support autonomous mental health

groups (6.4) and several struggled with their broad remit (7.5.3; 8.5.3). The data reinforce the findings of the DRE CDW evaluations (4.3) that people in these roles were not able to achieve the level of change that they and Black service users would have liked.

Much more effective support was provided for groups by the community worker (R1), the development/service user worker (R3/SU) and the MHT CD Unit manager (R2). These worked close to the groups, using their leverage in striking ways such as to get permission for a group meeting on a locked ward and to enable group members to train the police. They seemed driven by personal rather than professional values, embodying the critical humility, positive and caring attitude, commitment and competence that shape effective support.

Overall, the data confirm the complexity and demanding nature of CD support. Gilchrist and I (2008) argue that CDWs must be supported to maintain role boundaries across their multifaceted relationships to avoid the role confusion, stress and burnout found among DRE CDWs (Walker and Craig, 2009). Secker and Harding (2002b) describe how staff at a Black mental health centre managed a “flexible professional boundary” which enabled them to see the clients’ perspective and “share something of themselves” (p.275). In this doctorate study there was no evidence of support to help host managers manage these reciprocal, finely balanced and demanding relationships.

10.5 Chapter summary

Overall, there was a mixed picture of CD practitioner support. Those who failed to demonstrate critical humility or critical thinking may have unwittingly reinforced societal oppression. Effective CD support depends upon the practitioners’ standpoint, qualities, competencies and practice.

In brief, the effective practitioner may be located near to or far from the group, as a peer or external ally. Their location, competencies and connections determine

their role as catalyst or providing some other kind of support. Regardless of role, the practitioner will be committed to promoting social justice, demonstrating compassion, critical humility, respect and collaborative endeavour. Their practice involves supporting individuals and the group in a member-led journey to increase self-determination, empowerment and socio-political awareness (conscientisation). They facilitate storytelling, role modelling and mutual support among peers, inspiring hope as self-belief and self-efficacy grow. They open up opportunities for collective action leading to small but valued changes for individuals, services and their community. These changes challenge the status quo: they are, as one participant put it, “all about liberation” (R6).

To illustrate the learning here, I quote Sidney Millin (2008) who describes how a Black role model, Harry Cumberbatch and the user-led group, THACMHO (Tower Hamlets African and Caribbean Mental Health Organisation), helped him to end years of involuntary spells in hospital:

“Their Development Worker, Harry Cumberbatch, became my inspiration, my mentor and my father figure. It is because of him and THACMHO I found the strength to carry on, even in my darkest moments. When I joined THAMCHO in 2000 I found them to be a warm embracing group whose agenda was simple: To support their members in rebuilding their lives after periods of mental ill-health. THACMHO is also committed to combating the stigma surrounding mental illness. With THACMHO I found a sense of belonging and for the first time a sense of hope. Suddenly, there was light at the end of the tunnel.” (p.22)

Chapter Eleven

Theoretical Development, Contribution to Knowledge and Critical Assessment

“It’s about liberation really rather than [recovery],
because it’s not just about mental health at the end of the day,
it’s about, maybe just finding a way of living in a world
that may be a not a very nice world sometimes.”
(R6/SU)

11.1 Introduction

As my research drew to a close I received a poetry book produced jointly by the African Caribbean and Hamdard (largely South Asian) womens’ mental health peer support groups (2011) at Sharing Voices (Bradford), the community development (CD) project where this journey began (1.1). The poems’ messages of strength, identity and hope growing out of sisterhood and love demonstrate the value of autonomous groups set up by and for people with mental health problems and their potential to reach out to others. They reaffirmed for me the importance of this research.

In this chapter I revisit the research question and then summarise my journey. I introduce the ‘liberation approach’, a new concept which encapsulates and explains my learning about CD support for autonomous Black mental health groups. My contribution to knowledge includes new theory, methodology and evidence. This is followed by a critical assessment of the study and I conclude with implications for the future.

11.2 Research question

The research question was refined during the study, as is common in action research (AR) (5.3). After the initial exploratory research cycle I narrowed my focus from Black, Asian and minority ethnic (BAME) to Black groups. I also widened the research to include not only CD workers (CDWs) but also others who

support the groups, including mental health practitioners, managers, commissioners, volunteers and carers. The research question became:

How can CDWs and others support autonomous groups of Black people with mental health problems?

My objectives were to:

- describe how a sample of CDWs employed under the Delivering Race Equality in Mental Health Care (DRE) programme worked with member or community-led BAME groups of people with mental health problems, using a survey and follow-up interviews;
- use a case study approach at two sites to:
 - describe how two autonomous groups of Black people with mental health problems are supported by CDWs and others;
 - deliver development support to each group on a topic of their choice;
 - use reflective notes as data to link the learning from development activities to the qualitative research;
 - describe the groups' activities from the perspective of key stakeholders;
- reflect on the findings with 'critical friends' and explore their wider relevance to other autonomous groups of Black people with mental health problems;
- share the learning with those who took part.

11.3 Research journey

Methodology

I chose an AR approach because of its strong affinity with CD, integrating the pursuit of social justice with organic theoretical development. Within a social constructivist framework, I tried to understand the different worldviews of participants located within different social realms. I aimed to expose and reduce the power differentials among those involved. In the case studies I drew on principles of appreciative inquiry (AI) to enhance optimism and energy among people often treated as deficient. Overall, I aimed for a collaborative, democratic process.

Four research cycles

I adopted a largely qualitative approach through four research cycles. Cycle One (C1) involved an embedded survey of CDWs and nine follow-up interviews. A multiple, embedded case study approach was used in Cycles Two and Three (C2 and C3), involving two case studies with two CDW participants from C1, the autonomous groups of Black people with mental health problems that they supported and local stakeholders. Each cycle informed the next until, in Cycle Four (C4), I reflected on my findings with six critical friends who are experts on the topic of this thesis.

I provided development support to the case study groups on a topic of their choice, to ensure that the research was mutually beneficial and to some extent controlled by the participants, complying with the values of AR. I modelled the CD support that I was investigating, keeping records of my reflective and reflexive thinking, which added to my data. One group wanted help to evaluate their activities, while the other wanted help to develop new publicity.

Thematic analysis, augmented by dialectical analysis to illustrate opposing views, was continuous and progressive, with an overall analysis presented in Chapter Ten. Participant involvement varied from full participant control during development activities to reviewing progress and findings in the qualitative research. Ethical approval came from two NHS Research Ethics Committees (RECs) and two mental health trust (MHT) research and development departments. Details of the methodology, methods and research process can be found in Chapter Five.

11.4 Theoretical development: the liberation approach

Addressing the gap

The gap in knowledge addressed by this study is the nature of CD support for autonomous self-organising groups of Black people with mental health problems (4.7). The literature (3.3; 3.4) and data (10.3) suggest that these autonomous self-organising groups can help Black people to move from feeling excluded, oppressed and distressed to a new sense of self-belief and capacity by means of mutual support and collective action for change.

The overall analysis (Chapter Ten) identifies three components of CD support in this context. First, CD practitioners can help Black people to reflect on their group's membership and, if they wish, make a case for Black-only membership where others view ethnic identity groups as outdated or divisive (10.2). Second, CD practitioners can support an empowering process whereby Black mental health groups increase their members' self-belief (sense of identity and self-worth) and self-efficacy (belief in their capacity to achieve chosen goals). Practitioners open up opportunities for group members to take "control of their own destinies" (R3/SU, 9.4.4), changing their status, services and community (10.3). Third, CD practitioners who demonstrate critical humility, commitment and competence enhance this process. By positioning themselves on a level with the groups, regardless of whether they work closely or from afar, they break the

pattern of social, racial and psychiatric dominance. Practitioners with paternalistic or domineering attitudes may reinforce societal oppression (10.4).

Theoretical synthesis

To theorise this data analysis I reflected on the drivers for change found in the literature review (Chapters Two to Four). Black community self-help, radical CD, and user-defined recovery all helped to understand and explain the analysis, but none were sufficient alone. The literature review (3.2) and data from Ngoma (8.5.2) suggest that Black-led initiatives may not always support service user leadership. Similarly, the literature (4.3) and data (8.5.3) suggest that CD practice may not always empower people with mental health problems. User-defined recovery does not generally encompass Black perspectives, as my literature review (2.5) and a recent user-led study affirm:

“The North American recovery literature has...been criticised for taking an individualistic approach that does not allow for ethnic differences. In addition, UK and international recovery writings as a whole have tended to focus on the perceptions and outlooks of dominant groups in society and not to address social and structural injustice which may be experienced by, for instance, women, members of black and minority ethnic groups.” (Gould, 2012, p.8)

Fernando (2008) argues that today’s recovery discourse is insufficient to convey the journey that distressed Black people have to make:

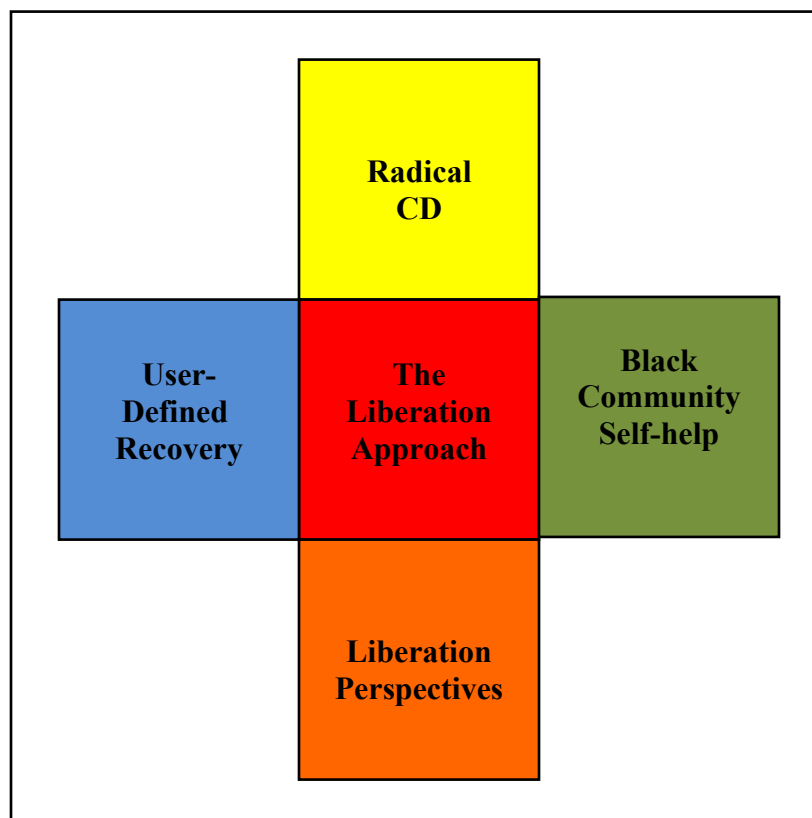
“The journey for many black people in a racist society to escape from the aftermath of a major life disruption requires a holistic approach and one that is inseparable from dealing with racism and discrimination in many aspects of their lives. In my view, recovery is far too mild a word to encompass such a journey towards a respectable and fulfilling life. The journey is better represented by a word such as ‘liberation’ or ‘struggle’.” (p.25)

The participant quoted at the start of this chapter suggested that recovery for Black people was “about liberation really” (R6/SU, 9.4.2). The essence of what she and others wanted was to change, or at least to cope better with the sometimes

hostile world around them. Group members wanted help to develop and act *on their own terms*. Their goal was not to '*fit in*', as some mental health trust (MHT) staff would have liked (7.5.4), but to '*break the mould*' in which they as Black people with mental health problems felt framed. Some members broke free by getting into work (9.4) or education (7.4), while others felt more able to cope with prevailing attitudes (8.5.2).

I explored the theoretical roots of liberation perspectives and devised a new concept, the liberation approach, to encapsulate and explain my learning (Diagram 11). This is a synthesis which captures and develops the synergy of four perspectives: user-defined recovery (2.5), Black self-help (3.2; 3.3), radical CD (4.2) and liberation theories, which I now describe.

Diagram 11: Liberation Approach: a theoretical synthesis.



Liberation perspectives

‘Liberation’ is a term found in many contexts, but I use it to refer to a range of theoretical perspectives emerging in the second half of the twentieth century from practitioners working among oppressed groups. The most relevant here are Freire (1921-1997) and Fanon (1925-1961). Others have developed and adapted their ideas across time and place: “liberation is contextual” (Lartey, 1997, p.115). Liberation theorists are not precious about disciplinary boundaries, making a synthesis natural here: “Work for social justice in the community uses every tool we can find...We seek to collaborate both with other scholars and with ordinary citizens” (Rappaport, 2010, p.44). I do not refer to a tightly defined liberation theory, but to overlapping ideas across several settings as I describe here.

Liberation perspectives underpinned religious and social movements across the globe from the 1960s, including the women’s liberation movement, civil rights and Black power movements, and revolutionary movements against oppression in Latin America (Lartey, 1997, p.113). Liberation theology, first articulated by Gutiérrez (1984), interpreted pastoral care as “an issue of power” (Lartey, 1997, p.11). Foskett, et al. (2004) felt that this resonated with mental health service users seeking spiritual support: “Religions have a much longer history of social control than does psychiatry and their agents need just as much help to open their eyes” (p.53).

The Jesuit priest, Martín-Baró, worked with oppressed people in El Salvador where he developed a critical, social liberation perspective described by Ouellette (2012) and Portillo (2012). His ideas inform a radical strand of community psychology which, Montero and Sonn (2009), Nelson and Prilleltensky (2010a) and others argue, has global relevance today.

The Colombian, Fals Borda developed participatory action research (PAR) (5.3) during the 1970s when ideas about political commitment, subversion and liberation were emerging internationally. He argues (2006) that PAR now “carries a liberating, political accent world-wide”, rejecting positivist neutrality (p.34).

During the apartheid regime in South Africa, Biko (1986) was inspired by Fanon to promote “the liberation of the black man first from psychological oppression by themselves through inferiority complex and secondly from the physical one accruing out of living in a white racist society” (p.91).

Next, in Table 13 and the text that follows I describe the features of the liberation approach in CD support for autonomous Black mental health groups.

Table 13: Features of the Liberation approach and its theoretical foundations

Key: Quality/feature may not be present. ✓ Quality/feature is typically present

'Liberation approach'	Radical CD	User-defined Recovery	Black community self-help/mutual aid	Liberation perspectives
<i>Practitioner qualities:</i>				
a) Active for social justice	✓	 	✓	✓
b) Understand people in context	✓	✓	✓	✓
c) Believe in the potential of all people	 	✓	 	✓
d) Demonstrate critical humility and critical thinking	✓	✓	 	✓
e) Collaborative/standing alongside	✓	✓	✓	✓
f) Compassionate and hopeful	✓	✓	✓	✓
g) Competent and connected, adopting many possible roles	✓	✓	✓	✓
<i>Process features:</i>				
h) Collective – involving groups	✓	 	✓	✓
i) Community-oriented	✓	 	✓	✓
j) Cyclical: action and reflection	✓	 	 	✓
k) Led by people with mental health problems	 	✓	 	
l) Story-telling/sharing experiences	✓	✓	✓	✓
m) Conscientisation: increasing socio-political awareness	✓	✓	✓	✓
n) Generating self-belief, self-efficacy and hope	✓	✓	✓	✓
o) Redefining identity	✓	✓	✓	✓
p) Increasing empowerment	✓	✓	✓	✓

q) Increasing self-determination	✓	✓	✓	✓
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The Liberation Approach: practitioner qualities

Liberation thinkers share a commitment to social justice. Fanon joined the Algerian resistance; Freire was exiled for his emancipatory approach to education, while Martín-Baró and Biko were murdered for being politically subversive. Commitment to social justice is essential in my liberation approach (see [a] in Table 13), but happily without such dire consequences. Participants in almost every cycle spoke of the need for CD practitioners to be committed to social change. CDW/1 was always “Flying the flag” (Cornwall, 7.5.3). The Black critical friends (C4) were like the Volunteer at Ngoma, believing that effective CD support for groups requires passion; its more like a vocation than a job (8.5.3). Some MHT managers supported Sweet Potato despite their misgivings about ethnic identity groups, because “sometimes by having these focuses it enables a change to happen” (MHT/M3, 7.5.2).

The liberation approach expects that practitioners understand people in context (b). Hickling (2012) wrote that Fanon was “one of the first psychiatrists to recognise the importance of politics in the understanding of psychopathology of human beings and, in particular, African Caribbean people” (p.214). Fanon remains influential, particularly within liberation psychology:

“One commonality among the liberation psychologies of Fanon and Martín-Baró and black psychology is the shift of psychologists’ attention to the systemic or structural dimensions of the identified problem or concern, rather than its more typical focal point, that is, the individual person abstracted from a multi-layered social, historical and cultural context.” (Brinton-Lykes, 2000, p.387)

Group members valued practitioners who understood their experiences as Black people, “understanding that historically, Black people aren’t coming from a position of power” (David, 7.5.3). Participants wanted practitioners to have a good understanding of Black people’s experiences of mental health issues,

without lowering their expectations (7.5.3; 8.5.3; 9.4.4). Black role models can show in an inspirational way that they understand the barriers *and* that these can be overcome. Group members such as Sweet Potato's ward visitors (7.5.3) and Ngoma's Chair (8.5.3) became role models for their peers.

The liberation approach demands that practitioners believe in everyone's potential (c) in common with liberation perspectives and user-defined recovery. I noted earlier that CD and Black community practitioners may under-estimate the potential of people with mental health problems. The data showed how some practitioners took a paternalistic approach while CDW/1 persuaded Barbara, a group member, to attend a demanding training course which, to her surprise, she successfully completed (7.5.3). R3/SU spoke of the "profound and important moment" when a CD practitioner enabled him to chair a group meeting while he was detained in hospital (9.4.4).

The liberation approach is based upon critical humility and critical thinking (d). These are integral to CD and AR approaches inspired by Freire (1972) and Fals Borda (2006). Instead of adopting the expert-helper role, the liberation approach requires practitioners "to be humble enough to listen...humility is very important" (R1, 9.4). A MHT manager found that Sweet Potato "shifted my thinking" (MHT/M3, 7.5.2). In contrast, host managers sometimes lacked humility, hindering group empowerment (7.5.2; 8.5.2).

The liberation approach is collaborative, compassionate and hopeful, reflecting recovery-focused practice (Repper and Perkins, 2003) (e - f). Liberation thinkers position practitioners "alongside the dominated or oppressed rather than alongside the dominator or oppressor" (Brinton Lykes, 2000, p.386). Gould's (2012) service user participants summed up what they wanted: "Hope, listening, respect, compassion, a supportive attitude, fairness, honesty and humility" (p.8). This is a good description of what Ngoma members would have liked (8.5.3).

The liberation approach requires multi-skilled and well-connected practitioners (g). Nelson and Prilleltensky (2010b) refer to the many skills and roles in liberation psychology, including “asset seeker” and “listener and sense maker” (p.237), resonating with roles in AR (5.3) and CD in mental health (4.3). Over the four cycles the challenging range of skills and alliances needed by CDWs became clear, from facilitation to empowerment, and were sometimes lacking. Skilled and connected practitioners enabled groups to gel, develop and act.

The liberation approach: process features

Processes in the liberation approach are inherently collective and community-oriented (h and i), unlike recovery-focused care which tends to focus on the individual. Nelson and Prilleltensky (2010c) describe community-led self-help groups as sites for liberation psychology practice. Psychologists Montero and Sonn (2009) describe liberation as a political process with “a collective nature, but its effects also transform the individuals participating, who, while carrying out material changes, are empowered and develop new forms of social identity” (p.1). David described how membership of Sweet Potato changed him: “I feel like I’m more capable, more able...the feeling of being able is so valuable – its more valuable than money” (David, 7.5.3).

A cyclical process of action and reflection runs through the liberation approach (j), as it does within CD (Gilchrist, 2009), AR (Fals Borda, 2006), and liberation perspectives inspired by Freire (1972): “Liberation is a praxis: the action and reflection of men upon their world in order to transform it” (p.52). Cyclical processes are not explicit within recovery discourse or Black self-help traditions. Here collective action for change was said to be an important part of the healing process (9.4.2), from visiting wards (7.5.3) to training police (9.4.3). Reflection and personal growth were an essential part of the process, most explicitly in Sweet Potato’s Evaluation Subgroup (7.4).

The liberation approach supports group members to take up lead roles, steering their own group (k). Literature on self-help/mutual aid groups suggests that control of the group by its own members is an essential factor in their success (3.3). Biko (1987) stressed the importance of Black people leading liberation struggles, but also said that others who shared the same purpose could help. Practitioners at Ngoma seemed unable to promote leadership (8.5.3). In contrast, R1 (9.4.4) described “just staying with people...giving trust in them”.

The value of storytelling and shared reflection identified in the data analysis (10.2) makes these essential features in the liberation approach (l). Storytelling “helps individuals and collectives to reclaim their history, to understand and appreciate their strengths, resilience, and resistance,” (Nelson and Prilleltensky, 2010d, p.27). The psychiatrist Hickling (2012) believes that storytelling by service users could challenge dominant perspectives within mental health care: “Until lions have their own historian, tales of the hunt will always glorify the hunter” (p.212). Bulhan (1997), writing about Fanon, reaffirms this point: “Each social group, if determined to forge or reclaim its authentic biographies and history, must define its own problems, seek its own solutions, and choose its own means” (p.269). The ‘check-in’ process, the Ngoma booklet of stories and ward visitors’ reflections were examples of storytelling here (7.4; 8.4).

This leads to the next feature in the liberation approach, the process of conscientisation (m) described earlier (3.4; 4.2;10.3.2). In this process, the lions’ story replaces what Rappaport (1995) calls the “dominant cultural narrative” (p.785). We heard how a group’s research into the history of Black people, neglected in official texts, gave members “a greater comprehension of themselves and their people” (R4/SU; 9.4.2). David (C2) felt that this is what his group and CD practice are all about: “removing that feeling of inferiority, replacing it with something much more positive”.

The final features listed in the liberation process (n to q) reveal the synergy that this synthesis provides. Whether approaching the Black mental health group from the perspective of user-defined recovery, Black community self-help, radical CD or liberation theories, the practitioner supports the liberation process. Self-belief, self-efficacy and hopefulness grow as a result of redefining identity and a growing sense of empowerment and self-determination. As group member Joseph said: “We come here to get the strength to challenge whatever we get out there” (8.5.2). The overall analysis (Chapter Ten) describes this process in some detail.

In conclusion, the liberation approach can support group members to achieve aspirations like those described by Black women in Kalathil, et al. (2011):

“Overcoming – or at least coming to terms with – oppressive experiences through regaining a positive sense of self and belonging, a sense of pride in one’s communal/cultural identity, having control over their lives, participating in political activism and community activities, and gaining a sense of social justice. Personal healing was predicated on achieving or moving towards a renewed and empowered sense of self and identity.”
(p.28)

The practitioner learns and grows together with the group. Freire (1972) advises us: “The revolutionary’s role is to liberate, and be liberated, with the people – not to win them over” (p.67). Brinton Lykes (2000), working with Guatemalan women, felt that his liberation and well-being was “intimately tied to theirs” (p.395), reminding us of Lilla Watson’s words at the start of this study (1.4). As the Volunteer said, “it is about a collective agenda” (8.5.3).

Critics view

There are critics of the thinkers I am drawing on here. Fanon and Freire are described as rooted in their time (Bulhan, 1985; Ledwith, 2011), making some aspects of their thinking outdated. The use of violence and some medical treatments employed by Fanon now seem oppressive (Bulhan, p.246). Freire has been accused of “a reductive binary of oppressed and oppressors, neglecting the reality that at different moments, one finds oneself on different sides of this

fence” (Watkins and Shulman, 2008, p.47). Ledwith (2011) argues that Freire acknowledged his limitations and he hoped that others would adapt and develop his ideas.

Some Black self-help literature (e.g. Hylton, 1999) pre-dates the increasingly mixed population which makes identity and ‘race’ debates so complex (3.2). hooks (1991) felt that the women’s liberation and Black liberation movements operated as if Black women did not exist.

Liberation psychology remains marginalised (Ouellette, 2012). Although Nelson and Prilleltensky (2010a) promote its tenets within community psychology, Perkins believes that “there is little clear evidence of its widespread adherence” (2010b, p.530). Perkins states that community psychology often retains an individual focus and even small group work is declining “in favour of neurological scanning of individual brains” (p.531).

These limitations do not detract from the optimism, fervour and ideas behind liberation perspectives which I have tried to capture and develop in the liberation approach.

11.5 Contribution to knowledge

This thesis addresses a gap in research (4.7), providing (to my knowledge) the first detailed study of how CD can support autonomous Black mental health groups. Its contribution to knowledge spans new theory, innovative methodology and broader evidence relating to the topic, with implications for research and practice.

Theoretical contribution

I have introduced a new concept, the liberation approach, to describe effective support for autonomous groups of Black people with mental health problems (11.4). This brings together the literature and my analysis of the three components of CD support within a synthesis of four theoretical perspectives. The value of the

synthesis is that it makes the connections and synergy between these perspectives and my data analysis explicit within one concept, developing theory in this field. It has potential as a guide for practitioners supporting similar groups, regardless of their role.

The study adds to the theory regarding the labelling of self-help/mutual aid, peer support and service user groups, again identifying connections across different theoretical perspectives. I suggest a family resemblance of overlapping features based on an innovative span of the literature. Publications generated by the thesis have already prompted cross-fertilisation between bodies of knowledge focused on specific group labels. For instance, Seebohm, Munn-Giddings and Brewer (2010) on group labelling and articles by Reynolds (2010a and 2010b) about Sweet Potato are extensively quoted in Faulkner and Kalathil (2012).

New learning about autonomous, self-organising Black mental health groups and their support needs adds to the literature of CD, self-help/mutual aid groups and peer support. I list some notable contributions:

- relationships between autonomous mental health groups, host organisations and MHTs are shown to be more complex than previous literature suggested (10.4.2);
- activities of Black mental health groups appeared to promote integration rather than separatism, contradicting fears that they threaten cohesion. Where there was evidence of divisiveness, this was due to the host agency and against the wishes of participating group members (10.2);
- the concept of critical humility is introduced to the mental health and CD context, to my knowledge for the first time. It suggests that practitioners should question their assumptions and pursue relationships ‘on a level’

with those they support, learning from them and believing in their potential (10.4.2);

- the study adds to the debate about ethnic matching in mental health and CD, showing how Black role models make a unique contribution in this context due to the historical and current oppression of many Black people (10.3.2);
- regardless of ethnicity, the CD practitioners' attitude, understanding, skills, commitment and connections matter (10.4);
- the research provided new evidence of the benefits of autonomous Black mental health groups. Individuals, services and communities were said to benefit when groups operated successfully, but where there was insufficient support the benefits seemed limited.

Methodological contribution

My methodological approach employed three innovative features which, to my knowledge, have not been used before in this way.

First, I provided development support on a topic chosen by the case study groups, giving them ownership and control over aspects of the work. In parallel with this, I carried out qualitative research. My reflective notes on the development support added to the qualitative data. This parallel approach generated a sense of mutuality and trust which enhanced the qualitative research and ensured that I retained ownership of the doctorate.

Second, reflexive thinking is usual in AR to improve practice, but I used it to gain a deeper understanding of CD support, my research topic, as well as to improve my own practice.

Third, I adopted an AR structure and value base, while using AI principles to frame the questions. This replaced the deficit-based narrative common in this context with a celebration of Black resilience which generated the energy, hope and self-determination associated with AI. This combination of AR and AI is, to my knowledge, new to the study of Black mental health issues.

11.6 Critical assessment of research

Evaluating action research

There are several ways of assessing AR studies. I begin here by drawing on guidance from Waterman, et al. (2001, pp.43-50), putting their 20 questions into a table to improve readability while keeping the wording intact (Table 14 below).

Table 14 : Twenty questions for evaluating action research

Clarity at each stage	<ul style="list-style-type: none"> • Is there a clear statement of the aims and objectives of each stage of the research? • Were the phases of the research clearly outlined? • Were the participants and stakeholders clearly described and justified? • Are there clear statements of the findings and outcomes of each phase of the study? • Is there discussion of the extent to which aims and objectives were achieved at each stage?
Management and planning	<ul style="list-style-type: none"> • Was the project managed appropriately? • Was the study adequately funded/ supported? • Was the length and timetable of the project realistic?
Ethics	<ul style="list-style-type: none"> • Were ethical issues encountered and how were they dealt with?
Local relevance and relationships	<ul style="list-style-type: none"> • Was the action research relevant to practitioners and/or users? • Was consideration given to the local context while implementing change? • Was the relationship between researchers and participants adequately considered?
Rigour and flexibility	<ul style="list-style-type: none"> • Were data collected in a way that addressed the research issue? • Were steps taken to promote the rigour of the findings? • Were data analyses sufficiently rigorous? • Was the study design flexible and responsive?
Connection with existing	<ul style="list-style-type: none"> • Do the researchers link the data that are presented to their commentary and interpretation?

knowledge	• Is the connection with an existing body of knowledge made clear?
Transferability	• Are the findings of the study transferable?
Assessment	• Have the authors articulated the criteria upon which their own work is to be read/judged?

Source: Waterman, et al. (2001, pp.49-50) formatted into a table for this study.

The first questions concern clarity at each stage of the research. The aims, findings and discussion for each research cycle are presented in dedicated chapters (Six to Nine). Management and planning reflected the nature of the study as a self-funded doctorate. Time became more plentiful than funds. Whitelaw, et al. (2003) call for: “achieving prolonged and persistent observation in the field” (p.41). Each case study lasted about a year and during that time trusting relationships were established and many observations made. Lack of resources limited activities in C3, but shared objectives were achieved, unwaged participants were paid and the difficulty of attracting funding became data for the research.

Ethical issues (discussed in detail in 5.6) were addressed satisfactorily, although some participants suspected one NHS Research Ethics Committee (REC) of making discriminatory assumptions. To keep to Sweet Potato’s timetable, my approach was pragmatic, not questioning the REC until later. I received no reply. Confidentiality issues relating to references in this thesis are resolved in accordance with the wishes of group members.

I responded to local needs through the development work, ensuring mutual benefit. The regular attendance of participating group members demonstrated that the work was relevant and enjoyable (7.4; 8.4). Barriers to organisation and communication were mainly, to my knowledge, addressed to their satisfaction, although factors outside my control in C3 sometimes restricted our activities (8.5.4).

Academic guidance and supervision ensured that the study met doctorate standards for rigour and flexibility of design. Triangulation of data from different sources is a widely accepted indicator of rigour (Whitelaw, et al. 2003, p.41). Here the multiple qualitative data sources over four cycles built up enough evidence for a mixed audience (such as a jury) to be convinced that the theoretical analysis is 'beyond reasonable doubt' as in a court of law. There may be no single conclusive piece of evidence, but it is the way the different pieces add up to a picture with depth and coherency that confirms the verdict: "Legal 'trials' are based on accumulating a mass of evidence in the form of different 'stories' and interpretations from a variety of witnesses and competing advocates" (Winter and Munn-Giddings, 2001, p.47).

An iterative process of connecting data and literature continued through the research cycles into Chapters Ten and Eleven. The depth and coherence of my analysis developed over four research cycles, refined and affirmed by the participants, but my narrative is not the only possible narrative here; researchers located differently might perceive the situation differently (1.9).

Transferability (discussed in 5.8) must be treated with caution. Transferability cannot be assumed in AR, but the contextual data and review of the literature enable others to consider whether and how it might apply in their situation (Winter and Munn-Giddings, 2001).

Professional development

AR, like all doctorate research, should enhance the researcher's professional and personal development (Reason and Marshall, 2006) and I describe some ways in which I gained by the experience.

My academic development included improved interviewing skills, enhanced by the strengths-based approach of AI. I learnt and used new approaches to analysis. I have enjoyed theoretical aspects of the research and gained confidence in this area.

As an AR researcher my group work skills improved with reflection, feedback and tuition. I trained in AI and received continuing support from an informal AI practitioner network where I shared my experiences with the groups without breaking confidentiality.

My interpersonal skills were challenged when, in C3, I found myself in the midst of a bitter dispute between host organisation staff (8.5.4). I asserted my impartiality with supervisory support and regard this as a useful learning experience.

I had previous experience of working across ethnic identities, but wanted to improve my understanding of the dynamics and challenges here. Relevant literature and frank discussions with participants and experts in the field helped me to reflect:

“Critical self-learning is important not only for the weak and powerless, but also for the more powerful actors who may themselves be trapped in received versions of their own situation.”

(Gaventa and Cornwall, 2006, p.182)

My first supervisor alerted me to a series of interdisciplinary seminars on critical reflection funded by the Economic and Social Research Council. Here Professor Judi Marshall (2012) introduced me to the concept of critical humility (10.4.2), which explores ways of working with the power imbalance stemming from colonial slavery and social inequality. This and other aspects of the liberation approach now guide my professional aspirations.

Outputs and outcomes

AR may be assessed by the extent to which it provides practical knowledge to enhance understanding and well-being (Bradbury and Reason, 2006). Our outputs included reports and publications:

- participant reports for each cycle (a combined report for the two case studies increased anonymity);
- two academic publications (Seebohm, 2010; Seebohm, Munn-Giddings and Brewer, 2011);
- two publications by a group member, with support (Reynolds, 2010a; Reynolds, 2010b);
- one publication by a volunteer, with support (Wilson, 2012);
- evaluation report for Sweet Potato;
- publicity materials for Ngoma, including project profile, leaflet and book of five stories.

Participants reported that the outcomes were positive. Group members said that they gained in several ways from enjoyment to an increased, enduring sense of confidence (7.4 and 8.4). Sweet Potato members said that they had gained understanding and control over their work (C2) while Ngoma members spoke of building closer relationships (C3). The articles, stories and evaluation revealed hidden abilities and achievements.

The outputs were generally felt to have a beneficial impact. Sweet Potato's evaluation report helped to attract funding and improve the group's credibility with the MHT (7.5.4). Their articles led to increased public awareness and networks (7.5.4). Ngoma's publicity (C3) was used extensively on their website and to improve local credibility and awareness of their group. These suggest sustained benefits, strengthening the study's worth (Bradbury and Reason, 2006). Unsolicited feedback from service users and managers has been positive, including:

“What a great piece of work you have done so far. I think it will be most useful to [Alpha] and other groups.” (R3/SU)

“Read your report – some interesting thoughts in there...discussions due on developing BME services here so will use in that work.” (MHT/5)

Ledwith (2011) calls for transformational change in AR and CD. Williamson (2007) writes: “A community that is actively engaged in research about itself has more opportunity to learn and transform as result of that research” (p.2). This study created small steps towards change, generating awareness and confidence, and I was satisfied with this, feeling that greater change was unlikely where funding was scarce and support from those in power varied. Some of its impact may become apparent later.

Challenging power differentials

Stringer (1996) expects AR to achieve a shift in power. Similarly Winter and Munn-Giddings (2001) argue that AR has to make transparent the different perspectives, their power differentials and communication processes: “Thus, part of the ‘validity’ of an action research project depends on how far it seriously addresses the crucial issues of organisational and professional power” (p.21).

I feel that by using a dialectical analysis, the different perspectives were presented fairly. My reflections note disappointment with the lack of transformational change in the balance of power (7.5.4), but today the power differentials are more openly acknowledged and sometimes challenged in both host organisations. I would have liked greater change, but group members did not wish to risk losing their support from the host organisations. I did not want to create tensions that, as a temporary visitor, I could not help to resolve.

I remembered Stringer’s (1996) advice to establish good working relationships with all stakeholders, particularly those who held most power. Although, or perhaps because conversations with host managers were honest as I questioned the power differentials between them and the groups, relationships warmed after a difficult beginning. The managers’ readiness to share personal and confidential information with me suggested that they trusted and respected me while acknowledging my critical perspective.

Managing my role

The difficulties of managing shifting roles while retaining integrity and transparency have been discussed (5.5). The dynamics between the groups, their hosts and me were occasionally tense, and I felt that my position was in danger of becoming ambiguous and compromised. The informality of the development support role and my desire to gain the trust of all parties could, potentially, have made me a pawn in their internal struggles, but I had support from my supervisors and broad previous experience. I am reassured by the fact that I am still welcome at both case study sites, where group members, host managers and others talk to me openly and warmly.

I reduced the risk of losing my critical detachment through reflexive thinking, sharing ideas with others and reading (5.5). Stakeholder interviews, movement through the cycles and regular reviews helped to broaden my perspective.

As an outsider I felt that I gained the trust of the Black groups, who explained, I felt honestly, what I could and could not contribute as a White person. Feedback suggested that they saw me as understanding their issues and committed to their purpose.

Methodological issues

In C1, the 11% response to the survey was not robust evidence from which to draw conclusions, but the consistent correspondence between field notes at CD network meetings, the low response rate, the findings and the related literature (e.g. Walker and Craig, 2009) suggest that few CDWs work with autonomous groups of people with mental health problems. More seem to support community-led groups. The interview sample was small but varied. As a sampling tool, both the survey and the interviews worked well, identifying potential recruits for the next stage who all accepted invitations to participate.

In the case studies, the combination of development support and qualitative research created a sense of reciprocity. Interviews and group discussions took place after I was identified as a trusted ally, helping me to overcome the frequent reluctance of small group members to divulge less satisfactory aspects of their group, as discussed earlier (3.4). The use of AI also helped to make participants feel that they could make criticisms in safety (see 5.3).

The AI way of framing questions had a powerful impact, generating mutual support and optimism with a speed that surprised me. I tempered participants' hopefulness with a sound sense of the challenges ahead.

Levels of participant involvement were low in the qualitative research but high in the development support (see Table 8 at 5.5). AR theorists often aspire to high participant involvement. Boxall and Beresford (2012) point to the important contribution of research entirely carried out by service users. Beresford speaks as a survivor/researcher, but in this study, participating service users had no research background and several had chaotic lifestyles. Stoecker (1999) reflects on participatory research in a "disorganized low-resource community" (p.847). Noting that AR is about action and change as well as new learning, Stoecker suggests that academics may need skills to help to animate, organise and educate during the AR process. I spanned these roles here while also trying to develop Thompson's (2003) notion of collective power: power *with* rather than power *over* (2.2).

Collective action and collaboration is the essence of AR and this study had its limitations, which is probably not unusual for AR that is honestly reported (Varcoe, 2006). The outputs and analysis are based on a myriad of contributions, demonstrating collaboration. There is no overall product of knowledge owned by all the participants in this study; instead, there are locally-owned outputs and I remain solely responsible for the thesis.

11.7 Implications for the future

Implications for policy and practice

This study shows that CD support can help Black groups to reduce distress and social injustice. Where Black people experience racism, disproportionately high levels of unemployment, exclusion and distress I believe there is a moral imperative to invest in initiatives, however small, that make a difference. Autonomous Black mental health groups and the CD support described here could contribute to a wider strategy which addresses health, social and economic inequality.

There were a number of tensions: opposing views of what should happen to, for and within the groups, which I have argued are best resolved locally rather than by top-down directives (10.2). I recommend that mental health commissioners and/or service providers should:

- enable autonomous groups of people with mental health problems to freely reflect and decide on their group's identity and membership, with CD facilitation where necessary;
- support Black-led mental health groups where these are wanted as an effective intervention to promote recovery and tackle social injustice;
- recruit, train and appropriately support CDWs to offer groups the help they want to achieve their goals;
- fund community voluntary sector training agencies to provide individual and organisational capacity-building support that is tailored to the needs of different small informal groups.

Implications for research

The study has revealed gaps in knowledge worth exploring, notably:

- Safe spaces:

- What constitutes a safe space for distressed people from BAME or other marginalised communities?
- Is there a tension between the need for safe spaces for marginalised groups and policies of inclusion and cohesion? If so, how can this be resolved?
- Do autonomous self-organising, member-led groups of people with mental health problems from Black and other marginalised communities have unique development and support needs?

11.8 Closing comment

This study has shown how CD practitioners can, with the right approach, skills and connections, support autonomous Black mental health groups to achieve their goals. These groups are not just about individual well-being, although that is a worthwhile goal in itself for those who are often excluded and stigmatised. They are also about promoting social justice for their peers and a more harmonious society for us all. CD support can help this to bring this about:

“There is something really important for me about people moving from a sense of powerlessness, not feeling they can influence anything, including their own lives, to then think, ‘Oh, you can influence the police!’ That is quite a leap of faith! So there is something about how we help people understand the system and the power they have to change stuff.” (R2; C4)

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APPENDIX I

Note on terminology

Many terms used in this field are contentious and unsatisfactory. In the absence of any consensus, I explain the language chosen for this study in Chapter 1 (1.2). Here, for easy reference, I list the key terms in alphabetical order, first relating to ethnicity, second to mental health and third to groups and community development.

Terms relating to ethnicity

- **African Caribbean:**
‘African Caribbean’ refers to participants who describe themselves this way and to the group of people with Caribbean ancestors and an African heritage.
- **Black:**
On the advice of participating group members, I use ‘Black’ to refer to people with an African Caribbean and/or African ancestry, regardless of where they were born. Here ‘Black’ includes people who identify this way who may have mixed heritage including African Caribbean and/or African ancestry. It also includes people who describe themselves as ‘Black British’ or ‘British’ or ‘English’ but who may be identified by others as Black, African or African Caribbean. I do not include people who identify as Black for political reasons but have no Caribbean and/or African ancestry (explained in section 1.3), except for one participant who describes herself this way.
- **Black African; Black Caribbean; Black British, and Other Black:**
When reporting survey or census data I use their categories which usually follow the above terms. People of mixed heritage may identify themselves as ‘Other Black’ or ‘Mixed’. Those who describe themselves as ‘Other Black’ are usually born in the UK (Gardener and Connolly, 2005).
- **Black and minority ethnic (BME) and Black, Asian and minority ethnic (BAME):**
These terms refer to the very diverse group of people who do not identify themselves as White British. I use the term BAME except when referring to texts which use BME.
- **Ethnicity:**
Ethnicity is recognised as a more accurate and appropriate term than ‘race’ to differentiate between groups of people, although this too can be contentious. Most definitions categorise ethnic groups by reference to some combination of the following: language, religion, ‘race’, ancestral homeland, culture/way of life, national or geographical origin/s, skin colour.

- **Mixed heritage:**
Individuals with close ancestors of more than one ethnic group are described here as ‘mixed’ or with ‘mixed heritage’.
- **‘Race’:**
‘Race’ is used here as a social construct which defines people by their skin colour, ethnicity, culture, faith or language. To emphasise that it has no biological basis I place it within quotation marks (see section 2.3).
- **Racism:**
Racism here describes the belief that certain ethnic, faith or cultural groups are superior to others, associated with a complex interplay of individual attitudes, social values and institutional practices. For more detail see section 2.3.
- **White:**
White is used to denote people with European ancestors and White British denotes White people who are identified by themselves and others as British or English. I use capital letters to show it refers to a broad social group and not skin colour.

Terms relating to mental health

- **Medical model and social model of mental health:**
Mental distress is understood in many different ways. Explanations described as medical, biomedical or biochemical are often contrasted with the social model of distress, as explained in section 2.2. Briefly, according to the medical model, mental health problems indicate a mental illness which, like physical illness, has a biological cause. There are many definitions of the social model, but broadly they locate the cause of mental health problems in external factors such as poor housing, poverty or abuse. The different models of mental health give rise to different responses health care practitioners and others.
- **Mental health problems and distress:**
These terms are used interchangeably here to refer to common problems such as anxiety or depression as well as less frequent diagnoses such as bipolar disorder and schizophrenia. Some participants or literature also refer to mental ill-health. The terms can be used across different models of mental health.
- **Service user:**
Service user denotes an individual who has used mental health services. This is not a universally acceptable term and some find it offensive, but at this time it is the most widely used and understood.

- **Survivor:**
I use this word when referring to an individual who has used mental health services and is known to prefer this as a more accurate or political description of their experiences. It has been used by the service user movement in the past, but is less frequently used today.

Terms relating to groups and community development

- **Community development practitioner (CD practitioner):**
In this study, ‘CD practitioner’ denotes people who support autonomous groups of Black people with mental health problems. They may or may not adopt the wider values and practices of CD. It therefore includes statutory and voluntary sector staff such as mental health practitioners and service managers as well as community development workers and community activists. This use of the term follows guidance by Lifelong Learning UK (2009) and Butcher, et al. (2007) (see section 1.2).
- **Self-help/mutual aid groups, peer support groups and service user groups:**
These labels refer to an overlapping ‘family’ of groups as described in section 3.3. This study is about autonomous Black mental health groups, which might describe themselves in any of these or indeed other ways. Their key features include an ethos of mutual support and reciprocity, control by group members rather than practitioners, a shared experience (in this case of being Black in the UK and having mental health problems) and respect for experiential knowledge.

Appendix II

List of research participants

Participant	Description	Research Cycle (C1 – C4)
CDW/1	Community development worker described in C1 as radical, pursuing structural change.	C1 Exploration and C2 Case study at Sweet Potato
CDW/2	As above	C1 Exploration and C3 Case study at Ngoma
CDW/3 to CDW/9	7 community development workers	C1 Exploration
CDW/10	Community development worker	C2 Case study at Sweet Potato
CDW/11	Community development worker	C3 Case study at Ngoma
R1	Community worker	C4 Reflection
R3/SU	Development worker / service user	C4 Reflection
R5	Training and Development worker	C4 Reflection
R6/SU	Trainer, consultant, founder group member, mental health survivor	C4 Reflection
MHT/M1 to MHT/3	3 Mental health trust (MHT) managers: MHT Director of Services, Borough Manager and Associate Director	C2 Case study at Sweet Potato
MHT/W	MHT Service User Development Worker	C2 Case study at Sweet Potato
MHT/D	MHT Director of Mental Health	C3 Case study at Ngoma
MHT/4 and MHT/5	2 MHT Associate Directors	C3 Case study at Ngoma
R2	MHT Manager	C4 Reflection
Commissioner/1	PCT Commissioner (public mental health)	C2 Case study at Sweet Potato
Commissioner/2	PCT Commissioner (mental health)	C3 Case study at Ngoma
Cornwall Barbara, David	3 group members (core group)	C2 Case study at Sweet Potato
CG/Harry, Simon, Richard, Jerry and Thomas	5 group members (core group)	C3 Case study at Ngoma

Joseph, Administrator/1, Administrator/2 and 3 unnamed members	6 group members (additional)	C3 Case study at Ngoma
Chair (member)	Group chair	C3 Case study at Ngoma
R4/SU	Group Chair	C4 Reflection
Carer	Carer	C2 Case study at Sweet Potato
Trustee/ Carer	Carer and group Trustee	C3 Case study at Ngoma
Harmony manager	Host organisation manager	C2 Case study at Sweet Potato
Calabash manager	Host organisation manager	C3 Case study at Ngoma
Coordinator and Committee member	2 people in paid and unpaid roles linked to Sweet Potato	C2 Case study at Sweet Potato
Support worker, Social work student, Volunteer/youth work student, Counsellor	4 people in paid and unpaid roles linked to Ngoma	C3 Case study at Ngoma

Appendix III

Questionnaire and interview schedule: Cycle One

Questionnaire

Name.....

Job title.....

Employer.....

E-mail address.....Telephone.....

Is your post funded by the primary care trust as part of 'Delivering Race Equality'?
Please tick as appropriate:

YES ☐

NO ☐

NOT SURE ☐

Does your work involve working with people who have experience of distress or mental health problems to create change? *Please tick one or more as appropriate.*

YES – I bring people with experience of distress together in groups exclusively for them ☐

YES – I bring people with experience of distress together as part of wider community groups ☐

YES – I work with people who experience distress on an individual basis, e.g. to accompany me to a meeting ☐

NO – I don't work much with people who experience distress ☐

If 'YES' could you briefly describe some of the activities? (continue on a separate sheet of paper if you wish)

Please explain the nature of mental health problems involved:

Please tick one or more as appropriate:

Used secondary mental health services ☐

Needed help from the GP or primary care ☐

Experienced distress but not received help from the NHS ☐

Who is involved in making the decisions for each group/ activity, for instance about what to do next week or what to do next year?

We decide together – There may be suggestions from several people (myself, mental health workers, community workers) then the members of the group and myself decide together. ☐

The group itself – I offer suggestions but the decision is theirs. ☐

It varies – according to the situation. ☐

I usually decide but I plan it according to what they want ☐

Other (please explain)

Facilitating collective action involving people with experience of distress can be difficult within the constraints of the CDW (DRE) job.

Do you feel it is feasible in your current post?

Please tick as appropriate:

YES ☐ NO ☐ NOT SURE ☐

If 'yes', how important is it, compared with all the other aspects of your job?

Would you like to add any comment about working together with people who have experience of distress to promote race equality in mental health?

Interview schedule

1. Could you tell me briefly about one or two of the groups where you have helped to bring together people with mental health problems?
 - How did the group begin, and how did your involvement begin?
 - What is your role in the group?
 - Are any other workers involved in supporting the group?
 - What is the ethnic background of the people involved?
 - What experience of mental distress do they have?
 - What kinds of things does the group do?
2. Could you tell me about the how you drew in people with experience of mental health problems?
 - What steps did you take?
 - How long did it take?
 - How was their involvement sustained? What was your role in this?
 - Do you work with the wider service user population?
 - Do you think you need to engage people differently when they are from the communities you are working with?
 - If so, what needs to be different?
3. In the work you are talking about, who decides what will be done over the next month or two?
 - Are the decisions made by one or two individuals or by a group of people?

- Do some people have more influence than others? What about you?
 - If some are more influential, why is it? Experience? Position? Personality? Personal background?
4. Are there times when the concerns of the group are shared with others or presented at formal meetings through a spokesperson or spokespeople?
 - What are the settings where the group puts forward its views?
 - Who are the spokespeople? Do you have this role?
 - If you do not speak for the group, are you involved in supporting the spokesperson in any way? If so, how?
 5. Do you feel there has been a time when you and your group(s) have made a real difference in mental health services or primary care for people from Black and minority ethnic communities? If so, could you tell me about it?
 - Through peer support or advocacy?
 - Through training NHS staff? Changing attitudes?
 - Through attending planning meetings with mental health managers?
 - Through changing attitudes within the community?
 - Through individuals in the group benefiting from the group activity?
 6. Have you tried to measure the impact of any changes?
 - If not, why not? If so, how?
 - Who do you think accepts this as evidence of your impact?
 - How do you feel about the measures you have?
 7. Have there been any difficulties preventing you from achieving more?
 - Are there some people who make it difficult? Who?
 - Has a lack of money made a difference?
 - Does anyone need more training? You? The managers? Local people?
 - Are there other reasons? Time? Pressure? Ability to work together?
 8. What has helped to deal with the difficulties and make things happen?
 - As a group working together, what has helped you most?
 - Have any key people made a difference? How?
 - Has having money made a difference?
 - Any other thoughts about what helped you to achieve what you have?
 9. How well does it fit with your role as a CDW for Delivering Race Equality?
 - Do you feel you have the full support of your line manager and colleagues?
 - Do you have the full support of your commissioner?
 - Do you feel you have the support of the Delivering Race Equality programme? Does it fit well with their guidelines?
 10. Do you have any interest in taking part in a participatory research project, where you and the local people you work with would have a lead role?
 - Would you be interested in finding out more about it?
 - How much security do you have in your job?
 - Are you involved in other research at the moment?

Appendix IV

Topic guide and interview schedules: Cycles Two and Three

Topic guide for community groups

1. Can you tell me about the time you are most proud of, in your involvement with [Group]?
 - A time that you have had with [Group] when you did something you are especially pleased about?
 - Why were you pleased about this time?
2. What, for you, is the essence of [Group]? What is special about it – the most important feature for you?
 - Why is this important to you?
3. Imagine it is 3 years later – 2013. Everything that you wanted for [Group] has happened. Can you tell me what [Group] looks like – in this dream?
 - What kind of things does it do?
 - What difference does it make – what changes come about – as a result of these activities?
 - Tell us about the members – who are they and how many are there?
 - What do they get out of being members?
 - How is [Group] organised? How are decisions made?
 - Where is it based?
 - Anything else about it?
4. What can help bring about what you want for [Group]?
 - Thinking of the kind of organisation and membership you want, how can this be achieved?
 - What about extra skills – for you or anyone else? What skills?
 - Do you need different kinds of relationships? How would relationships be different?
 - How could this happen?
 - What if one or more of you moved on – what needs to happen to be sure that [Group] continues to be strong without you?
5. Who can help to bring about what you want for Canerows and Plaits?
 - [List those near and further away from the group]
6. Taking these people one by one, how they have helped you up to now and how might they help you in the future?
 - First, can you tell me about a time when they were really helpful?
 - What was happening that made this really helpful?
 - What you do you want more of? How could this happen?

7. Is there anything more you can do now to make this dream for [Group] come true?

Anything else you want to say about the future for [Group]?

Interview schedule for community development workers

First interview in case study

1. How did your involvement with [Group] begin?
 - How did you feel about getting involved at first?
 - What were your hopes and expectations?
2. Can you tell me about the time you are most proud of, in your involvement with [Group]?
 - A time that when you did something you are especially pleased about?
 - What made you pleased about this time?
 - How does this fit with your role as community development worker?
3. What, for you, is the essence of [Group]? What is special about it – for you?
 - Why is this important to you?
4. Imagine it is 3 years later – 2013. Everything that you wanted for [Group] has happened. Can you tell me what [Group] looks like – in this vision?
 - What kind of things does it do?
 - What difference does it make as a result of these activities?
 - Tell us about the members – who are they and how many are there?
 - What do they get out of being members?
 - How is [Group] organised? How are decisions made?
 - Where is it based?
 - What would your role be? What would you love to be doing with [Group]?
 - Anything else about it?
5. What would be necessary to move the group towards your dream situation?
 - How could this kind of organisation and membership be brought about?
 - Do you think changes would have to be made in the way the group is run?
 - [If yes] what would be the steps in making this happen?
 - What about your role and relationship with the group? Would it need to change?
 - Do you think the group's internal dynamics and relationships need to change?
 - How could this happen?
 - Do their relationships with other organisations need to change?
 - What about extra skills – for you or anyone else? What skills?
 - What needs to happen to be sure that the group continues to be strong if some members move on?
 - How important is money? What can it do? What can't it do?
6. Who can help bring about what you want for [Group]?
 - At the Trust? Colleagues, your line manager, other senior managers?
 - At the PCT?
 - [Host organisation]?
 - Within the group?
 - Other people in the area? People outside the area – policy makers etc?

7. How have these people helped [Group] already and how they might help in the future?
 - First, can you tell me about a time when they were really helpful?
 - What was happening that made this really helpful?
 - What do you want more of?
 - What could make this happen?
8. Is there anything more you can do now to make this dream for [Group] come true?
9. Anything else you want to say about the future for [Group]?

Follow-up interview

1. From your diary entries since we last spoke, have there been any times you were especially pleased about in your work with the group?
 - What was happening? Who was involved? What made this a positive experience for you?
 - How do you think more of this could happen?
2. Were there any other times or issues that were memorable for you? Anything that sticks out in your mind?

Taking these issues one by one:

 - What exactly do you think is going on here?
 - How would you like it to be?
 - What or who could make it more the way you want it?
3. Do you have any other reflections that are relevant to this study?
4. What would you like to see happen with the group in the near future?

Interview schedule for stakeholders

1. Do you know about [Group]
 - How did you come to know about them?
 - How would you describe your connection with the group now? (distant/close, supportive/neutral/uncertain/critical)
2. What do you feel is the role of [Group] ?
 - What do you think they contribute?
 - Is there anything special that they do or could offer the mental health trust or local communities – *that other groups or workers cannot?*
3. Do you think they could do more? If so, what more could they do?
 - What would you like them to be doing that they are not?
 - Would you like them to be organised differently?
4. What or who could help them achieve or deliver that?
 - [refer to next question if CDWs come up but return to ask about anyone/ anything else]
5. What role or relationship would you like to see between the BME community development workers and BME service user groups?
 - What would you like your CDWs here to be doing with [Group]?
 - How important would you rate that work with a BME service user group compared with developing NHS services or increasing awareness of mental health issues in the wider community?
6. In general, how do you feel about separate service user groups for people with a BME background?
 - Are there –potentially - any challenges for the Trust or PCT in working with BME service user groups?
 - Do you think BME service user groups can promote aspects of race equality in mental health? Could you explain?
7. What do you feel would count as good evidence that demonstrates service user groups are promoting race equality in mental health?
 - What do you think the executive board of the mental health trust or PCT would regard as good evidence?
 - What would make you or senior management of the Trust or PCT feel that funding BME service user groups is a worthwhile investment
 - Of your money?
 - Of another organisation's money?
8. Is there anything more you would like to say about how BME service user groups might promote race equality in mental health? Or about how community development workers might support them?

Appendix V

12 point vision for mental health services

Delivering race equality in mental health care: An action plan for reform inside and outside services, and The Government's response to the independent inquiry into the death of David Bennett (DRE) (DH, 2005a, pp.4-5) states that:

“The vision for DRE is that by 2010 there will be a service characterised by:

- Less fear in mental health services among BME communities and service users;
- Increased satisfaction with services;
- a reduction in the rate of admission of people from BME communities to psychiatric inpatient units;
- a reduction in the disproportionate rates of compulsory detention of BME service users in inpatient units;
- fewer violent incidents that are secondary to inadequate treatment of mental illness;
- a reduction in the use of seclusion in BME groups;
- the prevention of deaths in mental health services following physical intervention;
- more BME service users reaching self-reported states of recovery;
- a reduction in the ethnic disparities found in prison populations;
- a more balanced range of effective therapies, such as peer support services and psychotherapeutic and counselling treatments, as well as 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 organisation capable of delivering appropriate and responsive mental health services to BME communities.”