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MOVING BEYOND ‘THE CHEAPEST KIND OF UNDERSTANDING’: ENRICHING POLICY RESPONSES TO BAME MENTAL HEALTH INEQUALITY

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Abstract

For more than 70 years, significant disparities have been persistently reported regarding mental health trends and the England's Black, Asian and minority ethnic (BAME) population. Today, these disparities are generally accepted as inequality, acknowledging that BAME status often carries social disadvantages that can materialise in mental health contexts. The current Covid-19 pandemic and global rise of anti-racism protests have brought such issues into sharp relief. Despite the State's declared ambition to decrease rates of mental health issues/distress, little has been implemented at a national level to address BAME mental health inequality. This thesis considers what policy-makers of future national strategies might learn from people from BAME backgrounds experiencing mental health issues/distress.

Taking a critical realist perspective and responding to gaps in the literature informing policy, I move away from a focus on in-patient experiences. Employing a pan ethnicity and mental health issue/distress sampling approach, I conduct an in-depth exploration of the testimonies of seven participants at various intersectional locations within the BAME mental health space. Semi-structured interviews and unstructured ethnographic conversations over an 18 month period enabled participants to foreground the issues they felt were most pressing to discussions of mental health. The length of individual engagements and locations were continually adapted to meet the needs and wishes of participants.

This thesis explores the topic of BAME mental health inequality in three key ways: how the issue is defined; determinants of inequality in a mental health context; and interactions with mental health support services. These themes align with issues raised by participants and the way that policy makers often consider health inequality, whilst also providing opportunities to engage with more critical perspectives that challenge epistemological and ontological assumptions.

Within these top-level themes, multiple sub-themes emerge. I found these broadly aligned with those in the critical literature. Primarily that racism and migratory experiences are factors in mental health issues/distress for many people. However, participants also placed greater emphasis on wider social inequalities and intersectional experiences than is generally represented. Though concerns differed according to participants' intersectional locations, they were present in all testimonies. In particular, the experience of poverty was continually raised as a key aggravating factor in mental health issues/distress, as was having to engage with processes that re-traumatise so as to receive support. This re-traumatisation often related to people's intersectional locations. Additionally, this research found a strong indications that experiences of disability and their psychological impacts warrant further investigation.

Using my findings to enable decision-makers to better align national policy with the lived experiences here presented, I suggest conceptualising BAME mental health inequalities as a 'wicked problem'. This is with a view to engendering an understanding of the issue that encompasses the diversity of perspectives relevant to this population group, and a greater acknowledgement of the interconnecting and 'open' systems at play when developing policy responses. Additionally, I promote the employment of an intersectional lens to enrich understandings of how these systems interact to produce and maintain such imparity.

I conclude by offering the conceptual tools of the 'wicked' problem and intersectionality as a means of enabling policymakers to move beyond the 'cheapest kind of understanding' in policy making. Without embracing these concepts within policy making in this topic area, it is unlikely that more that minor improvements will be possible. Embracing these provides an opportunity to build services better suited to the needs of intersectionally located people experiencing mental health issues/distress.

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Chapter 1: **Introduction**

It's like I've always been offered the (.) *you know, the cheapest kind of* (.) *understanding.*

Satch (participant), 2017

Intersectionality is real and it's vital that policy recognises this so services at a grass roots level are meeting the needs of all communities instead of putting us in tick boxes. As a black British disabled woman I experience the constant lack of services to meet my needs as they are not formed on the basis of intersectionality but on just whatever can be met…

Julie J Charles (founder of ENC), 2020

Health inequalities experienced by British, Asian and minority ethnic (BAME) populations in the UK are currently at the forefront of public debate (Allwood and Bell, 2020; Nazroo and Bhui, 2020; PHE, 2020; Royal College of Nursing, 2020; The Kings Fund, 2020; Women's Budget Group, 2020). This results largely from the disproportionate negative impact that the Covid-19 pandemic has had on this population grouping in America and the UK, together with the rise of Black Lives Matter (BLM). This movement demands change in regards to structural and institutional racism, and the violence and murders that accompany such oppression. The movement's quick adoption in the UK following this latest uprising demonstrates that many people in Britain feel that similar issues of violence and significant inequality of a historic and systemic nature are present here also. Indeed, the recent Lammy review reports that there 'is greater disproportionality in the number of Black people in prisons here than in the United States' (Ministry of Justice, 2017, p.3). A further significant area in which such violence is felt and egregious inequalities manifest is that of mental health. These inequalities include both disproportionate risk of (diagnosis of) mental health issues and inequalities of service performance for BAME populations.

The State has been informed of the persistent and significant nature of BAME mental health inequalities for several decades now (Blofeld et al., 2003; CAAPC, 2016; Department for Health and Social Care, 2018a; Ritchie et al., 1994; NIMHE, 2003; Department for Health and Social Care, 2018b; Department of Health, 2009). Over this time, some national-level measures have been implemented to address this. However, trends indicating inequality remain steadfast with some signs of a worsening of the issue even prior to Covid-19; including increases in risk of (diagnosis of) mental health issues/distress and worsening access to support for migrants (Choucan and Nazroo, 2020; Halvorsrud et al., 2019; Kalathil et al., 2011, p.16). As a proportion of the UK's population, BAME groupings have not only grown, but are changing in demographics (Cabinet Office, 2017; Government Office for Science, 2013). For example, the last two decades have seen the arrival of sizable migrant groupings from the Middle-East (i.e. Iraq, Afghanistan) and of white racialised peoples (i.e. Polish). Additionally, traditional associations in the UK between being 'British' and being 'white' become increasingly non-sensical given the growing 2nd and 3rd generation 'migrant' population and the number of people of mixed heritage. Such trends together with recent events add both to the importance and urgency of intervening in this area of inequality at the State level. Efforts to address this issue at the national level in England currently focus only on inequalities transpiring within the mental health service system, a scope that I argue is far too narrow to effect improvement. With the current political and economic climate set to worsen this area of inequality, my thesis offers important insights that support existing calls for change.

This research therefore explores the mental health inequality reported to persistently impact people of BAME backgrounds. In particular, I consider what policymakers of future national-level strategies might learn from the lived experiences of people located at the intersection of mental health issues/distress and BAME status/backgrounds. Exploration of this topic has required a cross-disciplinary approach, engaging me in research and theory ranging from medical discourses such as epidemiology and psychiatry, to works emerging from more sociological and critical traditions (i.e. critical race theory and disability studies). Taking an cross-disciplinary approach not only deepens my own understanding, but enables me to better critique dominant discourses and understand the perspectives of participants.

Approaching this from a critical realist perspective, I recognise the multiplicity of perspectives and variety of forms of phenomena involved in this complex social issue. Further, I acknowledge that the concepts of ‘race’, ‘ethnicity’ and ‘mental health’ emerge from and operate within phenomena and systems that are in continual flux; shaping and being shaped by each other (see Appendix 1). Core to this research, then, is my endeavour to find ways that public policy might develop a cohesive strategy to address this area of inequality that allows for the diversity, complexity and fluidity inherent in the issue.

Much of the literature considering this area of inequality focuses on the experiences of people deemed to have ‘severe mental illness’ (SMI) and/or are in psychiatric wards. In this study, I therefore seek to fill a relative gap in the literature regarding the experiences of people with long-term mental health issues/distress who live in the community. Participants in this research predominantly experience mental health issues/distress classified within medical discourses as common mental disorders (CMDs). Several participants, however, reject this terminology, leading me to use ‘mental health issues/distress’ when not adopting terms specific to particular participants. In this study, I use the term ‘BAME’ due to its common usage across disciplines relevant to this topic area and its inclusion of all racialised peoples and ethnic minorities in England. The decision to include white minorities results in part from evidence indicating disproportionately increased risk of mental health issues/distress among Irish, Polish and 2nd/3rd generation migrants. I further use the term ‘grouping’ to reinforce the constructed and problematic natures of ‘race’ and ethnicity (see Appendix 1). I focus on England because this is where my study has taken place, the experiences of participants are of English services, (recognising that health policy is devolved). However, I note that much of the literature speaks to the whole of the UK. As such my own language in chapter 3 reflects this. Finally, I address gaps in the literature regarding the documenting of lived experiences that explicitly acknowledge intersectionality. Intersectionality refers to discrimination and oppression specific to people who carry multiple marginalised or stigmatised ‘identity-markers’; i.e. female, lesbian, mentally ill, disabled, black (see p.22-25 for more information). Though intersectionality theory has circulated in equality movements and scholarship around racism for some decades (Collins and Bilge, 2016), it is only now emerging in the UK BAME mental health inequality literature.

1 Why this topic for this researcher?

I came to this topic through my work prior to beginning this PhD. With a career in central government as a policy-maker, primarily in relation to disability issues, I was in regular contact with disability activists working in the civil society and charity sector. [redacted] disabled people are not a homogenous group. Treating disabled people as such therefore further marginalises many already marginalised people. [redacted] failure by policy-makers and service providers to properly address the needs of intersectional disabled people meant that many went without the support or opportunities that they should have.

My own recognition of the importance of addressing intersectional issues in this sphere grew when my role changed and I became the UK's international representative for domestic disability issues. [redacted] In 2017 I took the UK Government through its first periodic review of the UK implementation of the United Nations Convention for the Rights of Persons with Disabilities (CRPD). My interest in intersectional experiences now firmly instilled, [redacted] Where diversity was considered, this tended to be diversity of impairment type, though some exceptions did exist[1]. [redacted]

Convinced further of the need for more research of an intersectional nature, I considered issues that had been raised by the CRPD committee and those highlighted to me by stakeholders. Whilst able to identify as white British, my background is multi-cultural and includes first-hand experience of migration in both childhood and young adulthood. I was therefore particularly interested in issues impacting people with mixed or ‘minority’ cultural identities. Within the policy sphere consideration of people with cross-cultural and migratory backgrounds usually means exploring the needs of people categorised as BAME. I therefore approached Julie J Charles (a disability advocate) who highlighted the need for more research regarding the intersection of disability and BAME status/background. Her observation in 2016/7 is mirrored in one she offered me earlier this year (see Appendix 2), following the events of Covid-19 and the rise of anti-racism movements in the UK. Together with staff from her organisation, the Equalities National Council (ENC), I narrowed the focus of this research from disability generally to mental health. Not only did mental health seem to staff at the ENC to be the most pressing issue for many of their clientele, but issues pertaining to this intersection had also been raised in the CRPD examinations’ concluding observations (UN CRPD, 2017, pp.6–7). Further, I confess a highly personal interest in mental health issues/distress, particularly within the context of mixed cultural backgrounds and migration. Within this, it was felt that this work should retain a pan-minority ethnicity and pan-‘race’ approach (see p.28).

My work in the civil service had prepared me well for working in consultation and (to some degree) in collaboration with partners. However, it had also conditioned me to consider the political and economic context that work was being undertaken in at every stage; including the initial stages where the issue is defined (the ‘scoping’ stage). Though it is important to undertake such work at some point, these factors often set the parameters within which policy development takes place, as opposed to being *an* important consideration amongst several. Through this research I grew to realise that, important though these factors are, using them at the start of research to delineate the scope of the work is potentially harmful to the outcome. Particularly when the focus of work relates to marginalised peoples and groups. This is because it sets the work in contexts that make most sense to those in more dominant positions within our society. This dynamic risks reinforces existing marginalising practices by asking those marginalised to meet the subject matter from the perspective of the more dominant. Aware of the adverse psychological impact of marginalisation, and adamant that this research would not replicate such experiences, I needed to adapt my approach to prioritise understandings of phenomena emerging from those with lived experience. Only then could I consider how mainstream or dominant elements in society might be altered to meet them in their intersectional locations. Whilst my research question was developed primarily as a result of conversations with participants, my own journey through this research is reflected in its framing:

> What might policymakers addressing BAME mental health inequality learn from the lived experiences of people located at the intersection of BAME background and mental health issues/distress?

To explore this, it is worth understanding what strategies have been implemented to date in England at the national-level by the State

2 BAME mental health inequality in national strategies for England

In public health policy, consideration of health inequalities generally means reviewing two broad areas of interest:

- prevention, which considers causation, incidence and prevalence of ill-health; and
- service provision, with the focus being on service outcomes and service user/survivor experiences.

Whilst different definitions of ‘health inequality’ exist (see Appendix 3), those within UK public health policy generally take this approach. The State has employed the terminology of mental health *inequalities* in relation to disparities reported in incidence of mental health issues/distress and service outcomes for some decades now. Recognition of BAME mental health inequalities by the State took place around the late 1990’s/early 2000’s, emerging from decades of social change in relation to both racism and approaches to mental health (see Appendix 4). This period saw possibly the greatest focussed attention that the issue has ever received in the UK - with the possible exception of recent months. Not only was there a significant increase in epidemiological research as a result of improvements to data, but several inquiries into the treatment of Black people in mental health services were widely reported on. Such reports sat in the wider context of the Stephen Lawrence inquiry, which provided the State's eventual admission of institutional racism in the police and judicial systems.

In response to calls for action, the State commissioned two reports to investigate why there were persistent disparities for BAME populations in the mental health context (NIMHE, 2003; Department of Health, 2003). In 2005, the Delivering Race Equality (DRE) programme was instigated. It's remit was defined as providing 'a coherent programme of work for achieving equality of access, experience and outcomes for BME mental health service users' (Department of Health, 2005, p.3). This programme involved initiatives such as increasing engagement with BAME community groups, delivering race awareness training to staff in mental health services and improvements to data collection to better enable improvements to services. Though some interesting and insightful work took place at the community level through this programme, it had little - or no - impact on the issue at the national level (Department of Health, 2009). Ending around 2010, the DRE programme produced a document which included lessons learnt which was provided to policymakers. In this, the programme highlighted the need to recognise the diversity of this population grouping and the fact that people of BAME backgrounds have multiple aspects to their identity (ibid, p.6). (See Appendix 5 for more information).

In the last decade, there has been a move away from focused action to address BAME mental health inequalities. Instead, discussions have centred more on general increases in the demand for mental health services or on the mental health inequalities experienced by young people and older people with dementia (NHS England, 2019b; NHS England, 2019a). Furthermore, mainstreaming approaches to equality issues following the introduction of the Equality Act 2010 (EQ10) have seen issues of inequality rolled into general mental health and health strategies (Department of Health, 2011b; HM Government, 2010; NHS England, 2019b). The last national-level strategy to consider mental health inequalities among marginalised groups was 'No Health without Mental Health' (NHMH), published in 2011. This strategy included a chapter on mental health inequalities which considered 'inequality' as they effected groups defined by any of seven protected characteristics in EQ10. Though this strategy stressed that people are not defined by one aspect of their identity and can experience multiple disadvantage, it failed entirely to address the ways that these multiple disadvantages might interconnect and impact on each other. Further, issues considered relevant to BAME mental health inequalities were limited to a number of policies addressed primarily at service experiences. These consisted of improving data collection, building better relationships between mental health services and BAME community groups, and implementing a few measures specific to tackling racism and the lack of ethnic diversity among staff (see Appendix 6).

No measures were included to address the prevention of reported increased incidence of mental health issues/distress among BAME populations. This was despite the State acknowledging epidemiological trends as reflections of 'actual' illness and accepting causal explanations for mental health inequality that stem from increased exposure to wider social inequalities (Department of Health, 2011b, p.57). It should be noted that this policy was implemented simultaneously to the State's implementation of austerity measures that saw substantial decreases in real-term budgets in public services (Docherty and Thornicroft, 2015; Fernández et al., 2013; Reeves et al., 2013, p.434). Such pressures on budgets, in the context of increased demand for mental health services and wider austerity measures, have necessarily impacted on the delivery of support and the ability of many services to accommodate for the needs of a diverse population (Beresford, 2013; Mattheys, 2015; Stuckler et al., 2017, p.19; Thomas, 2016, p.459; Thomas et al., 2018, p.1).

This, together with a strategy that barely started to address the complex issues involved in BAME mental health inequality, have undoubtedly contributed to the lack of any substantial improvements to either epidemiological or service-related trends (Cabinet Office, 2017, pp.49–50; Mental Health Taskforce, 2016; Department for Health and Social Care, 2018b). Indeed, leading scholars in this field all but omit the NHMH in their analyses of State strategies to address BAME mental health inequality (Choucan and Nazroo, 2020; Fernando, 2017, c.6; Glasby and Tew, 2015, pp.176–180; Sewell, 2014; Sewell, 2018), focusing still today on the DRE programme. A recent report stated that 'Since 2010, there has been no targeted national policy aimed at improving mental health care for BME communities', adding that 'campaigning groups have expressed concern that mental health services lack a sense of strategic direction for reducing inequalities in BME mental health' (CAAPC, 2016, p.76); indicating the severe limitations of measures in the NHMH to address BAME mental health inequality.

To date there is no update to the NHMH (2011). Instead changes to mental health services are included in the NHS long-term plan (2019). Though this strategy also encompasses the State's position on health inequality, not a single mention is made in this strategy in relation to BAME mental health inequality. Rather, inequalities experienced by BAME groupings are raised in relation to specific physical health issues, such as obesity, diabetes and maternity health. However a government commissioned independent review of the Mental Health Act 1983 (MHA83) highlights several issues relating to BAME mental health inequalities within the context of mental health services and the Act (Department for Health and Social Care, 2018b, p.10). Additionally, it provided an admission of the existence of racism at the structural and institutional levels within mental health care:

> So we have to accept the painful reality of the impact of that combination of unconscious bias, structural and institutional racism, which is visible across society, also applies in mental health care. (Department for Health and Social Care, 2018b, pp.10–11)

Despite acknowledging institutional racism within policing and the judiciary, the State has yet to acknowledge this within the health and social care system (see Appendix 5), though it does accept interpersonal racism (Department of Health, 2005, p.22). I happened to be in the office of one of my gateway organisations – Nilaari - on the day that this review was published. The impact that such a statement made cannot be under-estimated; a literal roar of joy went up in the office at this declaration. However, I remain conscious that the review has also received significant criticism by leading scholars in the field (Fernando, 2018; Nazroo, 2019, p.2). For example, Nazroo writes that:

> although the review bravely raises questions of racism and discrimination, simply naming the problem doesn't lead to an effective understanding of its nature, nor identify ways to address it. Indeed, the review does nothing meaningful to consider how racism within mental health services might be addressed. (Nazroo, 2019)

It is now nearing two years since the review was published and the State is yet to publish its full response. In an email response to my enquiry on the topic, the Department of Health and Social care stated that it would publish a:

> …White Paper [in response to the review] as soon as it is possible to do so. The Government will consult publicly on its proposals and will bring forward a Bill to amend the Act when parliamentary time allows. These reforms will be supported by improvements to crisis and community mental health services through the NHS Long Term Plan and its increased investment (see Appendix 7)

In the meantime, it has accepted several recommendations pertaining to BAME mental health inequality. This includes a commitment to addressing the disproportionate numbers of people from BAME backgrounds detained under the MHA (1983) (Parkin and Powell, 2020, p.13). Further, the NHS has committed to implementing a Patient and Carer Race Equality Framework (PCREF) (NHS England, 2019c) – an initiative proposed in the review by the Mental Health Act Review African and Caribbean Group, led by Dr Dyer who is herself a Black service user/survivor. Currently being trialled in two locations, the framework is positioned as a tool to support the implementation of a 'Patient and Carer Race Equality Standards' and ongoing work to increase workforce race equality (NHS England, 2015).

Though the PCREF focuses specifically on service outcomes and experiences, one initiative does go beyond this; the development of a methodology to determine the percentage of people from particular BAME groupings 'that *should* be represented in services' (Department for Health and Social Care, 2018a, p.59) (emphasis added). This measure begins to speak to my own calls in this thesis for policy to continually critically examines assumptions used to define BAME mental health inequality. The PCREF further commits to the delivery of a 'patient and carer rated tool' to increase the voices of BAME service users/survivors in services (ibid); aligning with my own call for policymakers to take seriously and learn from lived experience. One further set of actions taken by the State, albeit not specifically to address BAME mental health inequality, has been to develop 280 workstreams across gov that will work towards improving mental health generally. Whilst by the State's own admission there is need to align these work-strands together strategically, this signals an awareness of the impact that wider State policies have on mental health issues in the population (Govconnect, 2019).

3 Enriching policy responses to BAME mental health inequality

As previously highlighted, the DRE and any actions included in the NHMH have failed to produce any lasting impact at the national level, though some important learning outcomes did fall from the DRE. Chiefly, the need for: improved disaggregated data; closer working between health care commissioners/providers and the BAME voluntary sector/community; increased diversity awareness among healthcare staff; and the need to design policies and services that accommodate for the diversity and range of needs among BAME groupings (see Appendix 5). Though the NHMH clearly used these as a basis for its own approach, it often did so poorly. Perhaps of most importance to this thesis is the way in which it adopted the ‘single equalities’ approach advocated by the DRE programme. By this I mean that it acknowledged multiple disadvantage without addressing the ways in which these interact and present. Further critiques include the persistently narrow scope of strategies specific to BAME mental health inequality, which continues to focus on service outcomes and experiences without measures to address wider social inequalities as they impact on BAME groupings. Finally, calls often centre on the need to address institutional racism in all of its forms (Nazroo et al., 2019; Williams, 2014).

In this thesis, I observe problems pertaining to the three core elements that make up public health policy: 1) defining the policy issue; 2) addressing determinants of mental health issues/distress; and 3) addressing problems within support services. I reflect on all three elements in relation to how they impact on BAME mental health inequality. Influenced by scholars from a range of disciplines[2] that emphasise the importance of lived experience and the alternative epistemologies that can arise from these, together with a critical realist perspective, this thesis focuses on what might be learnt from people from BAME backgrounds with lived experience of long-term mental health issues. In line with the advice of staff at the ENC and Nilaari, this research intended from the start to fill a gap in the research by sampling for and being attentive to intersectional experiences. Thus, whilst testimony comes from a small sample of 7 main participants, all provide important insights from different intersectional locations within the broad category of ‘BAME’.

Ultimately, this thesis demonstrates the need to engage with people with relevant lived experiences at *all* stages of policy development, including the stage at which the ‘problem’ is defined and scoped. The operationalisation of impoverished understandings at the point of scoping enables crucial areas of inequality to remain unexplored and unaddressed. Further, close examination of testimony provided from a place of lived experience at the intersection of – at a minimum - BAME backgrounds and mental health issues/distress demonstrates that consideration of multiple discriminations in an additive manner are simply inadequate to the needs of people within this grouping. I have found instead that recognising the interconnected and intersectional ways in which people from BAME backgrounds experience mental health and wider social inequalities is vital for any future strategy. As a result, I conclude this thesis by proposing two heuristics that would – if properly implemented and given the appropriate support by Ministers - support policy-makers to significantly enrich their responses to BAME mental health inequality. These are: the conceptualisation of an issue as a ‘wicked problem’, and an operationalisation of intersectionality theory.

Social issues must have several traits to be considered a ‘wicked problem’ (see Appendix 8). First, the issue must be one whereby there is no single definition of the issue, due to a multiplicity of perspectives which all have their own internally coherent understandings. The implication from a policy perspective being that if there is no one definition of the issue, it is highly unlikely that there is a single ‘solution’. Indeed, ‘wicked problems’ are understood as those for which finding a ‘solution’ is highly unlikely, shifting focus on to the development of policy ‘resolutions’ (Rittel and Webber, 1973); the term I adopt is ‘responses’. Another reason that ‘wicked problems’ are understood as not having solutions relate to their second core characteristic; that of existing within networks of ‘open’ systems. ‘Open’ systems refer to the systems that give rise to phenomena being influenced and influencing other systems and phenomena such that they cannot be fully understood in isolation from their context. In a policy context, this means that the development of any responses to ‘wicked problems’ must take an approach that considers wider determinants. The findings in this thesis support an articulation of BAME mental health inequality as a ‘wicked problem’, and give weight to my proposition of this as a heuristic that might improve policy-making in this space. My employment of intersectionality theory further supports such an articulation of this issue, demonstrating the ‘open’ nature of systems of oppression and the need to recognise and address experiences arising from this. In addition to highlighting specific experiential phenomena missed when intersectionality is ignored, I also discuss how integrating an intersectional approach into policy-making would support a richer response to BAME mental health inequality.

4 Overview of the thesis

Chapter 2 - Methodology: My methodology chapter sets out the reasons why I have adopted a critical realist perspective in this cross-disciplinary study, and how this has influenced my methodology and methods. I provide an overview of intersectionality theory, highlighting how it fits with a critical realist perspective and describing its application in this thesis. Finally, I discuss decisions made in conducting this research, with a particular focus on ethical issues encountered and the ways that I adapted approaches to meet the needs/wishes of participants.

Chapter 3 - Literature review: The structure of my literature review mirrors the key concerns in public policy regarding health inequalities. I begin with the definition of the issue, setting out the evidence suggestive of an inequality. Applying a critical lens, I explore some of the assumptions underpinning dominant interpretations of such data. I then consider issues pertaining to incidence, prevalence, and prevention by considering key aetiological hypothesis proposed in relation to BAME mental health inequality. Finally, I explore research regarding inequalities found in service provision. This provides a structure broadly paralleled through my findings and discussion chapter, as it better enables me to reflect on this area from the perspective of a policy-maker.

Chapter 4 - Findings 1: The first of my findings chapters, I here explore participants perspectives on mental health terminology and determinants. Drawing out the similarities and differences in their perspectives, I demonstrate how participants' terminological and aetiological choices are influenced by a range of lived experiences, including those of discrimination and oppression.

Chapter 5 - Findings 2: In this second findings chapter I consider testimony in relation to participants' interactions with the State and its agencies in relation to mental health issues. Whilst the focus remains on mental health and related services, experiences with other State services clearly influence participants' views of services provided. However, most influential seems to be the particular social stratification and intersectional locations of participants.

Chapter 6 - Discussion: In this chapter I explore how the literature and my own findings map across each other in relation to the three areas of consideration in health inequality policy; defining the issue; prevention; and service performance. A number of gaps in the literature are identified, and evidence grows that supports the need for: reconsideration of fundamental assumptions within mental health discourses; greater operationalisation of a conceptualisation of the issue as operating in open systems; acceptance of important role that racism, intersectionality and other forms of oppression play in BAME mental health inequality.

Chapter 7 - Conclusion: My conclusion provides a brief overview of the main themes emerging from my discussion, and how these support my proposal that State responses to BAME mental health inequality would benefit from the adoption of two heuristics; the concept of the 'wicked problem', and an intersectionality lens. I set out why it is that I believe these tools could support policy-makers to bring richer understandings to their policy-making practices. In addition, I highlight several gaps in the literature that warrant further investigation.

Chapter 2: Methodology

> *I'm going to sign any letter you want me to sign, anything. I, whatever is in my conversation today, our conversation been, and I know that you recording, eh I want them to* (.) *As much as you can, you push it as, somebody who can really listen to it and really understand what's people's problem.*
>
> Mahdi, 2018

> Peter: *…their interest is to sit there and to intellectualise things and hide behind that curtain. You know.*
>
> Stéphanie: What, academics? Do you think?
>
> Peter: *I think so, a lot of the time that's what happens you know. There's too much of that sort of thing, intellectualisation, you know, rather than just dealing with the actual thing.*
>
> Peter, 2018

My intention has always been to be led by participants in terms of the direction of this research. However, I was aware of my own particular interest in epistemological injustices experienced by marginalised peoples; these being injustices resulting from a denial of their knowledges (Dotson, 2014; Pohlhaus, 2012). Participants, however, wanted an output focused on issues of a more tangible and political nature. This is clear in the above quote from Mahdi, a young Afghan man, when he expresses that he is happy to sign anything if it means stories like his get *really* heard and *really* understood. Working with participants, I also became aware of the need to avoid too much '*intellectualisation* (.) *rather than just dealing with the actual thing*'; i.e. the 'actual' issues impacting directly on the lives of people at this intersection. These desires were echoed by the gateway organisations supporting this work: Equality National Council (London); and Nilaari (Bristol). Two ambitions emerged:

1. To elevate testimonies from the intersections of BAME status and mental health issues/distress; and

2. To have the potential to inform relevant policy.

Recognising the importance of enabling participants to influence the direction of research in studies with emancipatory aims (Brydon-Miller and Tolman, 1997, pp.806–807), I settled on the more politically focused research question and the sub questions in Box 1. This research question also capitalises on my own previous experience of working in central government as a policymaker, albeit not in public health policy. My experience provides me with insights into both the reality of policy-making processes currently and some of the different ways in which evidence is used to inform decisions. I therefore set about producing research that retains the complexity and diversity of participant's testimonies, whilst providing findings that enable the application of richer understandings to policy responses at the national level. As such I pay attention to the similarities and differences in participants' experiences, with the intention of highlighting how these might influence future policy development. My application of intersectionalality theory has been instrumental in enabling me to do this.

Box 1 – Research questions

What might policymakers addressing BAME mental health inequality learn from the lived experiences of people located in the effected population?

Sub questions:

1. What indicates that BAME mental health inequality exists in England?
2. What is the current national policy approach to this public health issue?
3. What indicates limitations or problems with the current approach?
4. What are the lived experiences and perceptions of participants regarding:
    a. mental health issues/distress, both at a personal and general level?
    b. mental health services and the policies that influence them?
5. What similarities and differences emerge from participant's testimonies?
6. What experiences emerge from participants' intersectional locations?
7. Where does the current policy approach address or fail to address issues raised in participant testimonies?

As discussed in my introduction, the nature of both policymaking and this subject area has required me to take a cross-disciplinary approach. Cross-disciplinary works and qualitative research more generally are increasingly being generated in relation to this topic. However, critical and mental health service user/survivor researchers note that there is a continued ‘failure to incorporate non-medical approaches into mental health services' policy, practice and research’; partly because ‘these distinct communities of discourse [medical and user-led research] generate distinct forms of knowledge’ (Middleton, 2013, p.11). This situation seems to remain despite calls from many academics and activists for more diversity in the evidence considered in policy-making (Beresford and Carr, 2018; Davidson et al., 2015, p.53; NICE, 2007, p.17; Papadopoulos, 2006, p.82; Sweeney et al., 2009; Sweeney, 2013; Willen et al., 2011, p.333).

In 2009/2010, the National Institute for Clinical Excellence (NICE) set up a review of their own practices around evidence-based decisions. Having for decades elevated research within positivist paradigms and positioning meta-analysis as the most effective and reliable evidence on which to base its decisions, there was increasing recognition that this came at a significant cost for public health issues of a highly social nature. The review found that ‘the evidence which derives from traditional public health seldom departs from its principal explanatory tool being pathological outcomes at the individual level.’, which was problematic because ‘the patterns of health and disease are… social facts which require a social explanation above and beyond individuals aggregated together’ (Kelly et al., 2010, p.1060). This review did much to encourage the inclusion of more non-positivist research and application of theory in public health decision-making, creating more space for cross-disciplinary works such as this to influence public health policymaking.

This methodology chapter therefore explains how I have - through my theoretical lens, methodological approach and research design - set out to address policymakers who have to work across disciplinary boundaries, without compromising on the following three principles I have adopted as a researcher with emancipatory aims to:

- remain grounded in and honour the complex and diverse lived experiences of participants;
- avoid replicating marginalisation experienced by participants elsewhere in their lives; and
- remain relevant to participants and their concerns.

Part A – Enabling research that can really listen

Designing research that speaks across discourses in a way that promotes action whilst also challenging some of the ontological and epistemological assumptions within dominant discourses is, itself a challenge. Yet retaining a critical perspective in the context of mental health discourses is vital for work of an emancipatory – or anti-oppressive (Wilson and Beresford, 2000) - nature. Since the State really began to intervene in this area of life in the mid 1800's, biological and bio-genetic models of mental health have dominated (Granshaw and Porter, 1989; Porter, 1987, p.109; Rogers and Pilgrim, 2001, p.46). This medicalised approach, governed by positivist and post-positivist paradigms, has been helpful in advancing some aims of a social justice nature. For example, by providing justifications for placing duties on the State to support people experiencing mental health issues/distress, and furthering the development of *some* treatments that help *some* people.

However, such approaches when operationalised universally and unproblematically can excerpt oppression and violence; particularly on people situated in marginalised social locations. This is particularly the case for those intersectionally located wherein mental health plays a part. First, intersectionally located people have faced historical silencing, ignored by both dominant majority groups and identity politics movements. Secondly, the unproblematised application of mental health-related concepts around the loss of mental capacity provides the only means in the UK by which people can have the entirety of their agency legally stripped away (*Mental Health Act*, 1983; *Mental Capacity Act*, 2005).

Mental health service user/survivor researchers have also highlighted how such oppressions can occur in research conducted within a strong positivist medical paradigm (Liegghio, 2013, p.123; Menzies et al., 2013, p.8; Sweeney, 2013, p.5; Telford and Faulkner, 2004, p.553). Issues include:

> individual psychiatrists, clinical researchers ask[ing] the wrong questions that lead them to wrong, irrelevant or damaging conclusions. They try scientifically to observe, but they fail to understand… (Russo, 2009, p.173)

Russo here highlights that these researchers fail to move outside of their own frames of reference, inhibiting them from understanding the perspectives of service users/survivors. Critical and user/survivor-led discourses have therefore undertaken to provide alternatives to overly-medicalised approaches born of positivist traditions; sometimes reflecting on how critical approaches from different discourses might come together (Goodley and Lawthom, 2005, c.1).

In this vein, a number of social models of mental health have developed, focusing on interactions between mental health experiences and discourses and the social world (see Appendix 9). For example, the hermeneutical model focuses on how ‘normalcy’ is pathologized, whilst the social reaction/response model explores stigma and discrimination in the context of mental health (Davidson et al., 2015, c.3; Rogers and Pilgrim, 2014, c.1). Whilst extremely valuable in critiquing mental health discourses and practices, these particular models provide relatively narrow and distinct directions for research, rendering them inappropriate for this research. In contrast, social constructionist and social realist models refer more to particular ontological and epistemological stances with broader possibilities of application regarding topic areas. The social constructionist position, broadly speaking, sits in opposition to the positivist paradigm. In its strictest form, it rejects the possibility of universal truth claims, maintaining that all knowledge is socially constructed and therefore relative. Radically challenging dominant narratives at both the ontological and epistemological levels, this has enabled the ‘unmasking’ of oppressive concepts that have been naturalised (held as existing independently of social constructs) within positivist paradigms.

However, the approach holds two limitations of importance for this research. First, its denial of any non-socially constructed phenomena reduces mental health issues/distress to nothing more than ‘a by-product of the activity of mental health professionals’ (Pilgrim and Bentall, 1999, p.261). This is potentially dangerous as it risks denying some people their lived experiences of particular forms of mental health issues/distress, thus reinforcing marginalisation experienced outside of this research. I note that many social constructionists actually hold much more nuanced views regarding the ontology of such phenomena (i.e. Hacking, 2000), views that I would argue begin to align with those held by critical realists. Secondly, the strong constructionist position leads not only to a tendency to focus on discourses rather than ‘social realities’, but also produces theories that cannot be applied in order to design practice or policy.

While social constructionism problematises concepts and illuminates the structures from which they emerge, it provides no means by which to judge alternatives for practical application. The social constructionist position insists on a relativism that provides no basis on which to make such judgements. Where scholars have tried, such efforts have often led to the privileging of one standpoint over another; i.e. that of lived experience over expertise (Cruickshank, 2012, pp.78–79). Such privileging leads to an internal incoherence that may damage the credibility of such work when considered across discourses, particularly within the politically charged context of policy. Further, an inability to make judgements regarding truth claims and to positively apply theories and knowledge uncovered is particularly problematic for research seeking to enrich and change policy approaches.

Critical realism provides an alternative that navigates ‘this false binary opposition between positivism and relativism’, which has ‘problematic implications for practice-based disciplines’, seeking instead ‘to develop a non-positivist notion of knowledge being positively applied.’ (ibid, p.71). It does this in part by stratifying phenomena with seemingly different ontologies; namely ‘actual phenomena’ existing separately to human social constructs, and that of the social world (i.e. the phenomena itself – not just the meanings attached to it – are socially constructed). Though its account of actual phenomena may at first seem a replication of positivism, there are some important differences.

First, though critical realism acknowledges that there is phenomena that exists separate to humans, it still views these as operating in multiple systems which interact, shaping and being shaped by each other (Bhaskar and Lawson, 1998, p.5; Cruickshank, 2012, p.73). Such systems are sometimes referred to as open systems; indeed, this is what I mean by the term. In contrast, positivist accounts often situate phenomena as operating in closed and universal systems. Secondly, critical realism holds that knowledge regarding phenomena is never more than a ‘theory of knowledge’; it is always ‘provisional and fallible’ (Gorski, 2013, p.659). Whilst positivist positions allow for their theories to be fallible, they do not allow for them to be provisional in the sense meant here. Here, ‘provisionality’ stems not only from possible fallibility, but also links back to the view that phenomena – even actual phenomena – operate in open systems.

A critical realist critique of positivist research is that it is too narrowly focused on ‘theories of knowledge’, leading to an oversight in building ‘theories of reality’ (Cruickshank, 2012, p.73). Reality - in the critical realist paradigm - is:

> constituted not only by experiences and the course of actual events, but also by structures, powers mechanisms and tendencies - by aspects of reality that underpin, generate and facilitate the actual phenomena that we may experience... (Bhaskar and Lawson, 1998, p.5)

Thus, theories of knowledge must inform and be informed by theories of reality; both being interlinked through the open systems in which they operate. Reality, conceived in this way, is therefore ‘both multi-dimensional and stratified and also open and differentiated...' (ibid, p.5). The stratification of phenomena provides the basis for critical realism’s epistemological relativism; i.e. recognising differences in the ontology of certain phenomena as produced and emerging from different frameworks enables greater understanding (Cruickshank, 2012; Gorski, 2013, p.659). This not only enables critique of dominant narratives, but also critical realism’s ability to hold multiple accounts of reality as of equal merit. Meanwhile, its insistence that some phenomena is not entirely socially constructed enables a resistance to judgemental relativism without jeopardising the coherence of the critical realist position. By this I mean that whilst all perspectives can be held as having some merit and speaking to some aspect of reality, there is a means by which to elevate some theories over others. This is by their coherence with the actual phenomenon in question. Thus, theories of knowledge and reality can be advanced and applied, as long as they are continually understood to be provisional and fallible.

For these reasons I adopt a critical realist approach to investigate of BAME mental health inequalities. This topic is one in which the ontological nature of the phenomena observed is still hotly contested, being potentially subject to category error/fallacy fallacies (see p.58 and 60) and containing experiences of multiple and/or mixed ontological natures (Hacking, 2000, pp.117–119). Further, it is a field in which the denial of multiple ‘realities’ propagates the inequality I seek to explore. This theoretical framework therefore enables the positive application of ‘knowledges’ that are continually problematised through critique that contributes to the development of multi-dimensional and non-static theories of reality. As Archer

(1995) suggests, critical realist approaches can inform policy reforms by providing postpositivist yet scientific accounts of how issues operate in society and institutions; scientific accounts that (importantly) avoid employing the sort of dogmatism or cultural imperialism that more positivist approaches risk (Pilgrim and Bentall, 1999). Finally, it is my view, that this position begins to support arguments made in intersectional theory for the elevation of lived experience in works constructing theories of reality on the topic of inequalities.

1 Integrating intersectionality theory

Intersectionality theory seeks to better understand experiences of discrimination and oppression that people who carry multiple marginalised identity-markers endure. Identity-markers confer status vis-à-vis those differently categorised, shaped and mediated as they are by the social, historical and (importantly) political contexts from which they emerge and operate in. Whilst identity-markers play an important role in intersectionality theory, intersectionality should not be understood as the study of identity. Rather, it is the study of power dynamics enacted on people and peoples as a result of the multiple identity-markers they may carry, and the vulnerabilities to oppression and discrimination that these enable (Southbank Centre, 2016). It elevates the lived experiences of marginalised people by giving voice to the *different* experiences arising from intersectional locations (i.e. Black woman, disabled gay man). By ‘different’, I mean that oppression experienced from specific intersectional locations manifests otherwise to how it might arise from only one marginalised identity-marker (Crenshaw, 1989; Crenshaw, 1991; Collins, 1990; Collins and Bilge, 2016). This acknowledgement of the different forms of discrimination and oppression emerging from intersectional locations is a core tenant of intersectionality theory.

Intersectionality theory puts lived experience as front and centre, acknowledging that a persons’ marginalised positionality provides insights into certain phenomena that is more hidden to people in privileged or dominant positions. Explicitly acknowledging the privileging of knowledge born of lived experience within intersectional projects, Collins (2019) addresses possible criticisms of intersectionality being constructed on anecdotes when she states that the ‘truth of each survivor can be disputed, but the truth of the pattern itself can no longer be denied.’ (Collins, 2019, p.288). This statement recognises both the value inherent in knowledges seeped in lived experiences, whilst acknowledging the need for more generalisable data to drive change; both social and at the epistemic level. Situating intersectional research as ‘resistance knowledge projects’, she describes a space in academia for intersectionality that enables the emergence of multiple perspectives that can be brought together through dialogue to critique dominant epistemic discourses and to challenge the practices that fall from them.

This type of approach has brought leading intersectional theorists to promote intersectionality as ‘an analytical tool to capture and engage contextual dynamics of power’ (Cho et al., 2013, p.788). Rejecting single-issue approaches to research (i,e. only focusing on ‘race’ or dis/ability), Cho et al. (2013) situate intersectionality as ‘a gathering place for open-ended investigations of the overlapping and conflicting dynamics of race, gender, class, sexuality, nation, and other inequalities’. Intersectionality research explicitly acknowledges that systems of oppression do not operate in silos, but rather take the form of systems of a more ‘open’ nature. One form of oppression maintains and influences the ways in which others emerge, and vice versa. Developed from examination of experiences of systemic discrimination at the individual, group and systemic levels, the:

> value of intersectionality approaches to social analysis is that they include virtually the entire social and institutional context in the problem formulation, and thus represent an important analytical resource for framing the complexity of the disproportionality problem. (Mccall and Skrtic, 2009, p.7)

This more wholistic approach to issues of ‘disproportionality’ and inequality positions intersectionality theory as a powerful heuristic for critical inquiry. However, intersectionality theorists stress that such work must remain grounded in the lived experiences of such phenomena, highlighting the symbiotic relationship between such critical inquiry and praxis in this space (Cho et al., 2013, p.786; Collins and Bilge, 2016, c.2). Praxis in intersectionality is understood as ‘rooted in the experiences and struggles of disenfranchised people’ (Collins and Bilge, 2016, p.36). Through the interplay between critical inquiry and praxis, intersectionality provides a means of considering not only how open systems operate and exert themselves on peoples according to their intersectional locations, but also how this transpires in the individual's lived experience.

The generation of new knowledge, gathered with anti-oppressive aims and an eye to the political contexts from which they emerged, holds promise for researchers and policymakers like myself, who engage in work relating to persistent social inequalities. Indeed, this potential was crystallised for me when reading several papers in the fields of disability studies and education, whereby the employment of an intersectional lens brought forth significant issues in widespread education practices (Erevelles and Minear, 2010; Liasidou, 2016; Staunaes, 2003; Wilson et al., 2006). In the last decade, several attempts have been made to translate intersectionality theory into policymaking frameworks (Coll-Planas and Solà-Morales, 2019; Hankivsky and Cormier, 2011). One of the most developed to date is the intersectionality-based policy analysis framework (IBPA), which sets out 8 principles to guide inquiry and 12 questions for policymakers to answer as part of their problem formulation and settlement development (Hankivsky et al., 2014). Though there are some practical issues with the IBPA (e.g. assuming high levels of resource and a level of political will for radical critique that is rarely present), it does demonstrate the potential that intersectionality offers by way of a framework to guide the scoping of 'wicked' problems (see Annex 8) and development of policy responses grounded in lived experience.

Within the public health context, just as the need for social theory in research and policy-making relating to health inequality was being increasingly recognised around 2010 (see p17), so too was the need for approaches capable of addressing wider social inequalities (Marmot et al., 2010; Metzl, 2012; Metzl and Hansen, 2014). Advocates of intersectional approaches today build on this (Gkiouleka et al., 2018; Hankivsky and Christoffersen, 2008; Heard et al., 2020; Iyer et al., 2008; Kapilashrami et al., 2015). For example, by emphasising the theory's ability to facilitate an 'understanding of health inequalities beyond the purely socioeconomic by addressing the multiple layers of privilege and disadvantage' (Gkiouleka et al., 2018, p.92). Further, though rooted in the lived experiences of people living the health inequality in question, intersectional approaches promote a 'focus on social dynamics rather than social categories, recognising that experiences of advantage and disadvantage reflect the exercise of power across social institutions.'

(Kapilashrami et al., 2015, p.288). Thus, analysis of the role of privilege and disadvantage within health inequality is enabled at the individual, institutional and systemic levels. This is of particular relevance to the topic of BAME mental health inequality, an area of healthcare in which systemic and institutional racism - in all of its possible intersectional guises - has been repeatedly denied at the institutional and systemic level by the State.

This research, therefore, adopts an intersectional lens which I feel enhances the theoretical framework provided by critical realism in the context of this topic. This lens has greatly influenced the methodology I have adopted, causing me to align more closely with critical ethnographic approaches that also engage in the exploration of individuals' experiences within the context of wider power dynamics. It has also influenced specific choices regarding methods; for example, my approach to sampling (see p.29-30) and a layer of data analysis specifically aimed at identifying intersectional experiences and dynamics (see p.43). This, as chapters 4 to 7 demonstrate, has enabled aspects of participants' experiences to emerge that I may otherwise have failed to recognise.

2 A critical, anti-oppressive methodology

Madison (2019, p.21) suggests that 'critical theory finds its method in critical ethnography'. In seeking to translate the critical realist position and intersectional theory into my methodology and research design, I adopt a critical ethnographic approach that seeks participant collaboration wherever possible. This is with a view to gathering rich data based on lived experiences relevant to the topic, and maximising the emergence of both congruences and challenges to dominant 'theories of knowledge' regarding BAME mental health inequalities. Critical ethnography emerged in response, Noblit (2003) claims, to two needs. First, from critical theorists' need for a methodology enabling empirical research that aligns with the philosophical premises and aims of critical theory. Secondly, to save interpretive ethnography from being 'relegated to the status of a "micro" theory' as a result of its relativist position (Noblit, 2003, p.182). As with traditional ethnography, critical ethnography focuses on the social meanings, values, structures, and activities within particular settings or 'fields' of human interaction (Brewer, 2000, p.11; Madison, 2019, p.3). In addition, critical ethnography adopting a critical realist approach provides a 'reflexive methodology where material structures and ecological systems in fact and in truth exist' (Madison, 2019, p.18). This enables the researcher to go beyond simply describing 'what is', beginning to reflect on 'what could be', with often emancipatory aims.

Critical ethnographers challenge truth claims and 'taken-for-granted' ways of thinking, whilst maintaining a practice that gives primacy to lived experiences and provides a basis for driving social change. This might 'range from modest rethinking of comfortable thoughts to more direct engagement that includes political activism' (Thomas, 1993, p.17). Thus, where conventional ethnographers may stop at providing rich descriptive data of a community, critical ethnographers seek to understand the hidden structures and power dynamics that contribute to the current state. This enables contextualised accounts of multiple lived experiences illuminated through rich descriptions. It is through such understandings that the critical ethnographer is able to consider 'what could be', developing alternative 'theories of knowledge' applicable in settings such as healthcare and related policymaking (Bransford, 2006; Cook, 2005, p.132; Oladele et al., 2012, p.17).

This does, however, necessitate that the critical ethnographer takes up a position with regards to the data they seek to represent. If a vision of 'what could be' is proposed to effect change, then the researcher cannot remain in a state of judgmental relativism. It requires developing 'theories of knowledge' that, whilst grounded in data reflective of actual phenomena, are nonetheless influenced by the positionality of the researcher as much as (or more than) the researched. As such, 'good ethnography is not limited to knowledge or information about others "out there" but expands the definition to include stories about oneself', whilst remaining careful not to inadvertently dominate over the testimonies of research participants (Tracy, 2010, p.842).

As a researcher exploring certain intersectional experiences from a critical paradigm, self-reflexivity requires more than simply reflecting on internal responses to events and people encountered. It requires consideration of my own 'location' within the social categories that impact on and marginalise participants in our society (Madison, 2019, p.44; Maynard, 2002; Sholock, 2012, p.704; Tracy, 2010, p.842; Wilson, 2006, p.205). This location impacts not only my 'worldview' and how I interpret data, but also the power dynamics between myself and participants. For example, I am white and British, exposing me to white privilege and shielding me from the racism experienced by many participants in this research. I am also, however, a second-generation migrant with experience of immigration as a child. This provides me with first hand insights regarding migration experiences and having a mixed cultural upbringing; experiences relevant to most participants in one way or another. I further recognise that these experiences influence how I engaged with participants and, therefore, the direction of some parts of our conversations. In this way I recognise how myself and participants 'mutually influence the other' (Bransford, 2006, p.179) in the production of the theories of knowledge and reality that emerge in this thesis.

Simply recognising one's own positionality, however, is not adequate. Particularly the case in research seeking to better understand how certain intersectional locations interact with mental health issues/distress, such that indicators of inequality emerge at the population level. Noblit (2003, p185) warns that:

> critical ethnographers must explicitly consider how their own acts of studying and representing people and situations are acts of domination even as critical ethnographers reveal the same in what they study.

As such, critical ethnography is called to 'turn its value orientation and epistemological understandings back on itself' (ibid, p.185). Essentially, explicit and transparent self-reflexivity is required. In the context of a critical realist approach, this involves researchers refusing to negate their existence and positionality and 'reflecting upon the data as a partial account of specific and context bond [bound] truths and realities' (Madison, 2019, p.18). This is all the more important when engaged in research that hopes to inform future policy approaches that directly impact on marginalised people.

Additional efforts to remain actively self-reflexive therefore include:

- being transparent with participants about my own positionality and relevant experiences (or lack thereof);
- consciously providing spaces to discuss how my positionality might impact my interpretations and representations of their testimonies;
- discussing findings with participants throughout the research process; and

- being candid in my writing about how my positionality has influenced decisions taken.

Additionally, Thomas (1993, p.21-22) suggests distinguishing between value-free and value-laden ‘facts’. Value-free ‘facts’ relate to ‘actual phenomena’ of Bhaskar, and would be purely descriptive in nature. Value-laden ‘facts’, in contrast, express an interpretation of phenomena. Thomas further suggests that this distinction be made explicit to the reader by only using the word ‘is’ for value-free facts and using ‘ought’ for value-laden ones. Whilst this is fairly limited in terms of self-reflexivity in writing, it provides a continual prompt for the researcher to ‘check-in’ with themselves.

3 Defining my research focus and participant sample

As alluded to in my introductory chapter, my gateway organisations significantly influenced the scope of this work. Both being BAME led organisations, with one also being a disability-user led organisation, I asked for their steers on how I might narrow down my project. Through our discussions, it became clear that they felt a pan-ethnicity and pan mental health approach would be most useful. It was hoped that this would draw out similarities across BAME groupings in the marginalising experiences that staff members felt contributed to BAME mental health issues/distress inequality. I was further encouraged by staff to consider the role of intersectional locations in participants’ experiences, with the relative dearth of intersectional studies in this field being pointed out to me. I was keen to both help fill this gap and explore how multiple systems of oppression might be congregating to create mental health inequalities amongst England’s BAME populations.

Though taking a pan-mental health approach, I did decide to focus on experiences of people living ‘in the community’. This is because there is already significant emphasis on experiences within psychiatric wards in the BAME mental health inequality space, as well as a focus predominantly on people labelled as having Severe Mental Illness (Wilson, 2006, p.198). Further, conscious of the controversy regarding mental health diagnosis and labels, I did not ask participants for the diagnoses that they had been provided. Influenced by social models of disability (Barnes et al., 2013; Davis, 1995; Roulstone et al., 2013; Shakespeare, 2017), I decided that the particulars of a mental health diagnosis were of little importance in this research. Not coming from a clinical background, I am not interested in defining the ontological basis for mental health issues, but in exploring factors in the social world that contribute to mental health *inequalities.* As such, labels that made some participants deeply uncomfortable were not enforced, with the focus turning instead to the actual experiences of such issues/distress and participant perceptions of these.

Whilst these decisions did little to narrow the scope of the research, they did align with my own preferences. I, too, had a desire to explore the differences and similarities in experiences across ethnic groupings and mental health diagnoses, rather than focus in on the way this phenomenon was unfolding in just one minority ethnic grouping. This predilection no doubt reveals my fascination in how dominant English society and the navigation of this by people of mixed and minority ethnicity impacts on mental health issues/distress; a learning borne of my own experiences of learning to navigate English culture and fuelled further by trends highlighted in my introduction.

Working through my gateway organisations to take this approach forward, I employed a two-part purposeful sampling approach. First, selecting homogenously to ensure that participants were indeed of BAME background with lived experience of mental health issues/distress. Then working through this group to apply a maximum variation sampling approach to ensure a diversity of intersectional locations represented within my target participant group (Palinkas et al., 2015, p.18). The idea being that by 'maximizing differences', I would increase the probability of 'collect[ing] different and varied data bearing on a category, while yet finding strategic similarities among the groups' (Glaser and Strauss, 1967, p.56). Whilst I wanted to ensure a sample group that enabled exploration across minority ethnic groupings, mental health diagnoses and intersectional locations, I did not want to do so at the cost of gathering rich data. I recognised the unfeasibility of seeking to chart experiences from all possible intersectional locations within the target participant group.

I also acknowledged the near impossibility of achieving theoretical saturation of the sort promoted in grounded theory; i.e. the collection of data until 'no new properties of the pattern [that form theoretical categories developed] emerge' (Glaser, 2001, p.191). As such, I limited the number of participants to between 6-8; a number that

I felt would be manageable whilst also allowing a significant range of locations and experiences (Guetterman, 2015, p.17). Ultimately, 7 people's testimonies formed the core of this study; their BAME backgrounds, experiences of mental health issues/distress and intersectional locations are outlined on p94. Supplementing for losses in the diversity of intersectional locations possible through a wider sample size, I engaged 9 staff members working within or alongside my gateway organisations in one-off 1-2-1 semi-structured interviews, and several more in team meetings. With a variety of relevant lived experiences themselves, and all being of BAME backgrounds (Appendix 13), they provided me with an invaluable backdrop. I used this not only to help me contextualise non-staff participant testimonies, but also in a number of other ways that I discuss later in this chapter.

This freed me to seek out rich, in-depth data with a small number of core participants; the sort of data often missing from evidence from positivist paradigms that is prioritised in public-health policymaking (Cruickshank, 2012, p.74; Kelly et al., 2010, p.1058; Pawson, 2006, c.3). Pawson (2006, p.43) – in highlighting the need for non-positivist, rich data to influence such policymaking – points out why a reliance on meta-analysis in particular is problematic in the context of public health issues of more social natures. Namely, that the level of simplification and aggregation involved - while producing highly replicable results – also produces findings likely to be 'artificial and misleading' (ibid, p.43). One way in which results might become misleading, for example, is the reduction of 'similarity' to 'sameness' (Fricker, 1999, p.201). By this I mean that experiences are simplified such that the congruences of experience are valued above the differences, distorting descriptions of the 'actual thing' and their social realities. Whilst replicability might be the correct approach for decisions such as choosing between drug therapies, it is less appropriate to issues situated more in the 'social' than 'natural' world.

Part B – Stepping in front of the intellectual curtain: conducting research

The above section sets out the theoretical and methodological perspectives that underpin this work, and the scope of the study itself. Throughout, I highlight how such approaches support this research to build on the body of methodologically diverse evidence required to enrich public health policy responses. I now discuss the specifics of my research design and issues that occurred when I stepped out from ‘*behind the intellectual curtain*’ and into the field, as Peter might say.

4 Finding my ethnographic ‘place’

I decided to pursue a research design using more traditional ethnographic methods; i.e. taking up opportunities to better understand participants’ social realities through ‘hanging out’ when possible, in addition to semi-structured interviews and ethnographic conversations. The idea being that ‘hanging out’ might enable me insights into the social context in which participants live. For example, meeting Satch in various locations exposed me to some of the dynamics he experiences with other people in his locality that would otherwise have been invisible to me. Or spending a little time with Samaiya in her home provided insights about how interconnected the daily lives of her extended family are.

Participants in this research do not occupy a shared ‘place’ in terms of a unified community or geographical locations in any meaningful way, however all resided in parts of large cities (London and Bristol) with high levels of minority ethnic density. Not having a tangible ‘field sites’ that would enable me to ‘enter and spend time within the grounded day-to-day, embodied actions, of a field site’ of a given social world (Madison, 2019, pp.3–4), I had to reconceptualise ‘place’. Wolcott provides interesting insight in this regard. He suggests that ‘In place of place’ (Wolcott, 1999, p.25), ethnographic works are increasingly emphasising particular problems which then provide ‘place’. In the context of BAME mental health inequality, then, ‘place’ becomes the intersectional locations that arise when people are socially stratified according to ‘race’, ethnicity and mental health. ‘Place’ is found in the intersectional locations of multiple, disparate individuals in UK society. As such, the ‘sites’ of my fieldwork were dictated by my participants and consisted of the places that were meaningful to them. Yet, even with this decided, further barriers limited my ability to engage in ‘sustained hanging around’ (Charmaz, 2013, p.35). For example, participants’ availability. Some chose not to engage with me on an ongoing basis and two participants that did were inhibited from meeting with me for extended periods due to hospitalisation. Further, I was mindful of creating dependencies on me by a small number of participants that might have proved harmful if I later could not continue to provide such support (see section 6).

When we were able to ‘hang out’ or meet, then, I invited participants to suggest the locations for our ethnographic conversations. Suggestions proved insightful. For example, Mahdi tended to choose to meet in parks. As his testimony alludes, parks are one of the few spaces in which he finds peace. Satch asked to be taken to a part of Bristol that he loves and feels a sense of belonging, but that his physical ill-health prevents him from visiting alone. There was one café/bar in particular where Satch felt very at home. On several occasions however, this location was shut and we had to find an alternative café. The hunt for an alternative café was extremely revealing to me. For whilst I was looking for places that might offer a degree of privacy, Satch was focused on finding somewhere that wasn’t ‘too white’. Satch explained his discomfort in places where he was the only or one of a few non-white people. A further consideration that only emerged later, was Satch’s discomfort in spaces that were too middle-class:

> Fieldnote with Satch: Satch started getting visible uncomfortable and energy suddenly dropped. To avoid talking about the mental health stuff, he diverted discussion to unusual stories about dancing. But I think the café was also too fancy; when we left he spoke about it not being the fault of the people there but it feeling a bit too snooty.

Observing Satch’s responses to and negotiations of place impressed on me his acute awareness of his intersectional location and how this impacts both his behaviour and his sense of wellbeing.

Another way in which I tried to access participants’ social realities was by following their recommendations for music, books and videos to watch. For Satch, music and music scenes play a pivotal role in his sense of identity and belonging. The café we would always try to go to, for example, is below a community space that hosted many a gig in which he participated. One particular album that he recommended – ‘Distant relatives’ by Damian Marley and Nas - provided me with insights into the Black diaspora and Rastafarian culture that inform his sense of belonging. This means of trying to access participants’ social realities was particularly important with regards to Peter, whom I predominantly met at the offices of one of my gateway organisations. Peter shared the titles of books and links to videos that have informed his views regarding mental health issues/distress. For example, links to a lecture by Dr. Joy DeGruy on post-traumatic slave disorder and books such as ‘The Spectrum’ by Dean Ornish M.D. These sources provided an additional platform through which to explore Peter's perspectives and informed our future ethnographic conversations.

5 Gathering data

As Thomas (1993, p.41) notes, 'Good ethnography requires flexibility'. This flexibility was required not only in relation to the sites in which data collection occurred, but also in my approach to interviews and ethnographic conversations. As previously alluded, I wanted to start from a position of openness, allowing participants to direct the research within the topic of mental health issues/distress. This was not only due to standard practices among emancipatory and participatory research, but also because:

> Being too directive poses hazards when interviewing chronically ill people. The overly-directive researcher can cut off the most interesting leads and rich data. Further, the researcher may load assumptions into the questions without being aware of doing so. (Charmaz, 1990, p.1167)

With my three guiding principles in mind, Charmaz's reflections together with an initial false-start when employing an interview script, I moved more towards the use of 'topic guides' (see Appendix 10). These enabled me to more systematically cover key issues whilst 'allowing the flexibility to pursue the detail that is salient to each individual participant' (Arthur and Nazroo, 2003, p.115) This approach proved invaluable as a range of issues did indeed emerge that may not have appeared on any interview schedule prepared from my own positionality. For example, housing issues or rivalries across and within specific communities.

Further, it allowed the flexibility required as a result of the individual needs of participants (Mirfin-Veitch et al., 2018, pp.367–368). Early in my fieldwork, I recognised that decisions to maximise variation among participants meant working with people with diverse needs and levels of knowledge and education. For example, whilst several participants were able to engage in the topic at quite a high theoretical level, others were less able or interested in doing so. Samaiya, for example, was unsure what 'marginalisation' meant whilst Mya provided an insightful summary of what 'intersectionality' means and Peter expounded notions of intergenerational racism. Additionally, there was diversity in intellectual and cognitive capabilities across participants. Satch and Andeep highlighted substance misuse or medications as impacting their cognitive abilities and Samaiya self-reports as having significant learning difficulties. Samaiya's learning difficulties are the reason why her sister is present and participates in our discussion. This is the only interview where an additional person was present and resulted from Samaiya's own request.

Several participants also highlight experiencing issues with memory and concentration as a result of health issues or distress. For example, Peter reported difficulties remembering what we had discussed in previous conversations, relating this to memory and concentration issues experienced more generally. This, however, did not significantly impact on our conversations. It just meant that I would provide a relatively detailed account of our previous conversation before we picked up again; a process I too found helpful, as our meetings were often months apart. More evident to me as a researcher were the memory and concentration issues experienced by Satch. Satch later told me that a recent neurological scan had revealed damage to nerve endings as a result of substance misuse that account for his memory issues. Satch's memory and concentration issues were, through much of this data collection period, significantly aggravated by his heightened distress which often expressed itself through an anxious state. I learnt that, with Satch, I needed to adopt a different approach than I had with other participants. Instead of long in-depth ethnographic conversations every few months, we would meet once or twice a month and speak for around 30 minutes before Satch would become tired or struggle to remain on topic. I also learnt to distinguish between the days when it was best to let him speak on whatever topic he needed to (asking permission to record when the topic discussed was relevant), and when I might inject topics into the conversations. The subsequent flexibility in approaches taken are visible in Appendix 10.

Data collection using semi-structured and ethnographic conversations was an iterative process for me. Borrowing from grounded theory methods (Glaser and Strauss, 1967; Charmaz, 2013), I considered the topics emerging from across participants - revisiting or raising these in the next round of ethnographic conversations. Issues prioritised were those emerging across multiple participants, or those that seemed of particular importance to one or two. For example, only two participants raised the issue of racism without my prompting. I then raised this with other participants, who spoke on the subject if it resonated with them. As not all participants ended up working with me on a continuous basis, I began interviews by providing an open platform. If the person then raised a topic that had been raised elsewhere, I prompted them to speak more on the issue. If certain issues raised by other participants had not been covered and the person was coming to the end of their own stream of thoughts, I would raise these. In this way, I was able to garner views on many of the topics raised across most participant and compare responses.

I was also aware that I was working in a cross-cultural setting in which I did not have an in-depth knowledge of the various cultures I would be encountering. I felt it likely that topics of importance could remain hidden as a result of my being an outsider culturally (Alim, 2004). To mitigate against this, I paid attention to what was not said as well as to what was (Tracy, 2010, p.843) and remained alert to possible misunderstandings due to cultural and intersectional differences (Maynard, 2002, p.37). For example, I was conscious that several participants had not spoken to me about the role of religion and/or spirituality, and reflected that this might be linked to assumptions about my own beliefs in this secular society. Where I felt there may be a gap like this, I raised the issues in later ethnographic conversations with core participants and interviews with staff members. Further, I arranged to present anonymised and amalgamated initial findings to staff in their team meetings. These discussions were of enormous support. On several occasions they led to helpful insights on areas of importance to several participants that had not been raised by participants themselves. For example, several staff members joined me in my surprise that cultural clashes had not featured more highly in the first round of interviews and conversations with participants. In their experience, these areas were significant factors in the difficulties that this BAME populations faces. Taking this insight into my next round of ethnographic conversations with participants, I was able to garner important information that might otherwise have remained hidden.

Conscious also of the impact that power dynamics might have on the testimonies offered, I adopted a demeanour that I hoped would encourage dialogue that welcomed ‘both difference and unity, both agreement and disagreement’ (Madison, 2019, p.17). For example, the below is an excerpt from my conversation with Mya. She had stated the importance of mental health diagnosis, and I responded by expressing my alternative view in the following way:

> Years ago, I was unwell. Definitely I feel that I was unwell. But I absolutely refused the doctor to give me a diagnosis. So, for me there's a real conflict there, of talking about it as being illness or not. So, I was just curious hearing you talk about it.

Whilst my discomfort with diagnostic practices around mental health issues/distress are clearly expressed, I did so in a manner that did not undermine Mya's own beliefs. This was no doubt helped by my openness regarding my own past experiences such that I was situated as something of an insider researcher. However, I took similar approaches to challenge views on topics on which I was clearly an outsider researcher. For example, challenging Mahdi's claim that '*because of these foreigners, this country's kind of messed up.*' This is not a view that I share and I was surprised when Mahdi expressed this being a foreigner to the UK himself. Through challenge and further discussion, Mahdi expanded that he did not apply this view universally. This discussion ultimately provided insights into the ways in which Mahdi felt migrant people were being divided into worthy and unworthy of support, and how he had internalised these views. Disagreement was thus situated as unproblematic and enabled non-threatening 'confrontations' (Kvale and Brinkmann, 2009, p.156) that, when combined with ensuring that the platform remained primarily for the participant to speak, encouraged further self-reflection on the part of the participant and researcher. It also later enabled me to provide written accounts of such views where I might state my own (contradictory) view without feeling I was committing a deep betrayal of a particular participant (Newkirk, 1996, p.7). Further, this dynamic was also a means of explicitly acknowledging the inter-subjectivity of the sorts of 'theories of knowledge' and reality being discussed (Simmons, 2017, p.7).

Useful though this dynamic was, it had its limitations. Though it facilitated checking my interpretations of statements and positions articulated, it was not helpful in validating claims themselves. As a researcher engaged in anti-oppressive work, I started from a position of giving full credibility to participants' testimonies. This does not mean I did not question the coherence of or express surprise at some of the experiences and views relayed. However, as just discussed, most of these issues were able to be resolved through dialogue without putting the participant's testimony in any doubt. This is particularly important in the mental health context due to the common experience of testimonial smothering that people labelled as ‘mentally ill’ often endure (Tate, 2019; *Mental Health Act*, 1983).

However, two participants did, on specific occasion, give me concern regarding the credibility of parts of their testimonies. In our first interview, Samantha stated quite openly that, in her interactions with mental healthcare workers, she would *‘make sarcastic comments just like I'm doing to you.’* This was a means of keeping the staff at a distance. Following a telephone conversation held months after, I noted in a fieldnote that Samantha told me that ‘she was hit on the head and knocked out and robbed going into her apartment and there’s now a hole that needs fixing somewhere… the police don’t know who did it (I think but not entirely clear)’. I was concerned, but the story was not particularly cohesive. In our following conversation, she told me that her and her friends were laughing because she had been ‘*sarcastic*’ with me. Working with Samantha over an extended period proved invaluable, for I was able to return to her with accounts that – in less playful moods – she would clarify or correct. More difficult was deciding how to treat an account of events that Satch gave shortly following a second attempt at dying during this research period. These accounts were made at a point when I was just checking in to see how he was. We later met with his support worker, a lady that Satch trusted and valued very much. When Satch went to the bathroom, I asked her about these incidents out of concern. She informed me that these events had not taken place. Given the distressing context within which these comments were made and the trust that Satch himself placed in this support worker (who he had known for around 15 years), I decided not to ask him about these again for research purposes.

6 Ethical issues: Navigating power dynamics and friendship

Considerations of an ethical nature have informed decisions I have made at every stage of this research, as I hope is evident throughout this chapter; from choices about theoretical frameworks, (whereby those chosen were done so in part due to their emancipatory potential), to approaches taken to analyse and write-up my findings (see sections 7-8). In this, I have gone beyond simply meeting the requirements of regulatory/procedural ethics set out in my ethics approval plan (see Appendix 11), immersing myself in a continual self-reflexive ‘ethics in practice’ (Guillemin and Gillam, 2004). ‘Ethics in practice’ essentially acknowledges that ethical dilemmas occur throughout qualitative research and often demand immediate responses from researchers that have not been foreseen. In this vein. I augmented an standard informed consent process (see consent forms, Appendix 12), by engaging in a 'process consent' (Ellis, 2007, p.23) approach whereby I checked at various stages of the research that participants were content for me to continue collecting and using their testimony.

I also adopted a relational ethics approach. Relational ethicists view ethical practices as necessarily requiring researchers to 'acknowledge our interpersonal bonds to others, and take responsibility for actions and their consequences' (ibid, p.3). Acknowledging that 'ethics in practice' in research with other people is inevitably 'a relational and dialogic encounter with participants' (Barker and Macleod, 2018, p.185), it accommodates for the fact that participants bring their own interpretations and expectations of what is 'ethical' behaviour. Further, it acknowledges the importance of considering context and systemic power dynamics as researchers navigate ethical dilemmas (Routledge, 2004, p.86). As such, the ways that a researcher responds to ethical dilemmas that arise through interactions with participants cannot follow a strict set of rules without risking harm in the form of ignoring the participants' own agency. Indeed, I took the position that attending to participants' views in this respect was an important means for me to ensure that I acknowledged and respected their agency within this work. This approach to ethical dilemmas proved invaluable, as issues did occur as relationships with some participants developed and evolved that required careful handling (Banks and Brydon-Miller, 2018; Mnyaka and Macleod, 2018, p.134; Stevenson and Lawthom, 2017, para.18). Not least because, just as Barker (2018) describes taking place during her own doctoral research, several participants in this study 'invited me into a relationship in which they asked me to see them, hear them, attend to them, and acknowledge them as fellow human beings', as opposed to 'research participants whose only value existed in the responses they offered' (Barker and Macleod, 2018, p.184) to my questions.

Whilst I did all I could to ensure that participants remained conscious that I was meeting with them in my capacity as a researcher, Satch, Samantha and Mahdi would refer to me as 'mate' or 'friend'. Satch also affectionately referred to me as 'kid', having children of his own that are roughly my age. Several considerations prohibited me from correcting or challenging them in these instances, though I was careful not to reciprocate such proclamations. Primarily, this seemed to me to be evidence of my success in breaking down power imbalances that elevate the researcher at the expense of participants. In efforts to create spaces that enabled 'unimpaired self-presentation by participants… characterised by mutuality of expectations rather than one-sided norms' (Crotty, 1998, p.143), I had intentionally cultivated an informal, discursive tone. I wanted participants to feel comfortable challenging incorrect assumptions or interpretations I made, whether as a result of language barriers, ignorance or of my own privileged epistemic position (Medina, 2013, pp.5–13). It is also true that none of these participants would have accepted a dynamic in which they felt there was not such a balance. An insistence on maintaining formal researcher/participant boundaries would have damaged our interactions, curtailing the richness of data collected. But most importantly, I did not want to risk behaving in ways that would reflect marginalising experiences that had occurred elsewhere.

Speaking with staff in my gateway organisations ahead of meeting participants, they highlighted to me the negative view that many of their clients have of Western notions of 'professionalism'; i.e. the distanced approaches pertaining to 'objectivity' encouraged in practices of western medicine and bureaucracy. Among their client base, this did not often connote fairness and competence, but was instead a display of disdain and a lack of humanity. Staff highlighted how this form of 'professionalism' could be quite alienating (see Appendix 13). For example, James - a Black man with prior lived experience of mental health issues/distress - described how this Eurocentric version of professionalism continues to impact negatively on him even though he is now part of the workforce:

> *I have to be a different person in my work place. …There's protocol and policies you have to follow and even a code of behaviour, so I can never go in there and start doing things I would like to do, like going 'yes mate'. You've got to hold yourself back. And / it's about professionalism, which I consider / specialists sometimes can be a middle-class white order and / got to work within these constructs.*

Views such as this impressed on me the importance of recognising that 'relationships are constructed around an abstruse framework of previous interactions with others.' (Levinson, 2010, p.195). Adopting the demeanour of a ‘distanced professional’ may have met with criteria within certain research paradigms and gained ethics approval more swiftly. However, I did not feel I could, in good conscience, risk resembling interactions that participants have had with professionals when accessing the support they needed from the State and its agencies.

In navigating the intricacies of these relationships and maintaining the ethical integrity of this research, my adoption of a relational ethics approach proved invaluable. It provided me with access to a community of researchers and their experiences as I took steps to walk the tightrope of being friendly, developing actual friendships and enabling a dependency on me that I would be unlikely to be able to sustain, whilst trying to remain flexible enough to meet the needs of participants. Such steps included being explicit about when we were doing work related to the research or not, making a show of using the dictaphone or taking notes. If issues of interest to my research came up in the margins of data collection, I would later ask permission to draw on this for the research. This was particularly important with Mahdi, Satch and Samantha due to the affection they expressed towards me. For whilst I did feel a genuine sense of connection with them all, I was conscious that – for them – this may have more to do with their intense sense of isolation than me as a person. As Charmaz (2013, p.72) notes, ‘Marginalized people, particularly those who are isolated, may want more time rather than less’. Having carefully considered the potential emotional demands that might be placed on me and my own ability to meet these (Tillmann-Healy, 2003, p.740), I did not want to exploit this situation only to later let them down.

Despite the steps I took, I was at times called upon to provide more support than was appropriate in my role as a researcher. If participants did overstep boundaries by making more demands on me than I was able to fulfil, I used these opportunities to restate the limits of what I could provide to them. However, enforcing strict boundaries was not always appropriate within the paradigm of more relational ethics approaches (Banks and Brydon-Miller, 2018, pp.16–17). For example, in a state of significant anxiety and following a suicide attempt, Satch asked me to take forward his applications for welfare and organise his medical appointments. I replied that as a student I was not best placed to do this for him, but that I would be happy to meet for a coffee the next day instead.

Another example involves Mahdi. Meeting to engage in a further ethnographic conversation, Mahdi began telling me about his current state of heartbreak before we had begun to audio record our discussion. Apologising for talking so much, he confided that he just needed to speak to a woman about his emotions; he did not feel he could speak to his male friends about such things. As his mother and aunts had been killed in war, he had turned to me. As a result, I took no audio recordings, focussing instead on providing an empathetic ear. However, on this occasion and because of the relevance of his testimony to this research, when Mahdi was more emotionally stable, I did ask his permission to draw on this conversation; a request which he agreed to. Finding that 'an (apparently innocuous) follow-up interview' has become something more akin 'a therapy session' (Miller, 2017, p.83) is a phenomenon reported by other researchers working in similar fields. Whilst not attempting to replicate counselling sessions, (for which I have no training), I was aware that the choices I made to adopt informal, dialogical approaches might encourage interactions of a therapeutic nature (Birch and Miller, 2000, p.199). Indeed, in one interview with a staff member, she spoke of a bereavement which she then admitted to not having spoken of to anyone else previously. This moment was incredibly intimate and emotional for us both. My decision to engage in some limited actions that exceeded the norms of research professionalism were further supported by the view that 'any project is actually based on a complex mosaic of interactions in which approaches towards ethical guidelines become fluid and variable.' (Levinson, 2010, p.194) I – like others before me - prioritised humanity and ethical responsibility to the participant (Barker and Macleod, 2018, p.185; Guillemin and Gillam, 2004, p.265; Newkirk, 1996, p.14) over strict, universally applied boundaries.

7 Coding and Analysis

Some might argue that the flexibility adopted throughout this research jeopardises the legitimacy of my findings. Arguably, the way in which I applied my methods leaves room for criticism regarding the systematic nature of my approach. I would argue that, though flexible, I remained systematic through the use of topic guides and by undertaking an iterative approach to data collection. This systematic handling of data is further reinforced by my approach to analysis and the steps taken to assure authenticity and credibility in the final stages of this work. It is this that I now discuss.

When I came to analyse data collected, I realised that I had amassed a sizable data set of very rich testimonies. I had not yet written my literature review chapter - though I had done some of the reading - in an effort to ensure my coding was guided primarily by participants' testimonies rather than by the themes I would organise the literature review around. Knowing that I would take a largely inductive thematic approach (Braun and Clarke, 2006, p.12), I began the process of identifying the top three topics occurring in each participant's testimony. This process was guided by most participants' desires for a focus on the more political and practical issues that inform their experiences and perceptions of mental health issues/distress. I then compared these lists of top issues across participants; 11 main issues emerged (see Appendix 14). I then consulted participants where possible and staff at the gateway organisations regarding this list. They seemed content with both the findings and where I had placed emphasis.

I found that these issues could be broadly divided into experiences and understandings of mental health, and how interactions with social structures and systems impact on people's mental health issues/distress. This provided the structure for my findings' chapters and, subsequently, my literature review chapter. By happy coincidence (or perhaps the unconscious influence of the literature I had already read), I later found that these two topic headings mapped well against the priorities of public health policy regarding inequalities; albeit with some substantial expansion of these priorities. As outlined in my introduction, policy considerations of mental health inequalities can generally be divided into 'prevention' and 'service outcomes'. Consideration of 'prevention' often involves not only trends relating to 'illness' rates, but also what triggers these; i.e. aetiological hypotheses. Research considering 'service outcomes and experiences' includes management data related to pathways to care and treatment, and research into health-seeking behaviours. Epidemiological trends and their accompanying aetiological hypotheses mapped well against participants' experiences and perceptions of mental health issues/distress. And consideration of 'service outcomes and experiences' mapped relatively well against interactions with social structures impacting mental health if expanded beyond mental health services. Codes that did not, however, map across were those relating to competition and divisions across participant groups. On reflection, I decided not to focus on these issues in depth; whilst inevitably important, I do not feel that I collected data of adequate depth to be truly insightful in this space. Further, participants' preferences for a more political focus encouraged me to pay greater attention to the role of interactions with the State. However, I recognise this as a gap worthy of greater investigation in any further research projects.

I conducted a series of final interviews with participants, and then began a more detailed round of analysis, this time implementing a two-part initial coding process (Charmaz, 2013, p.113). I rejected coding by word or line due to English not being the first language of all participants, instead coding by considering the event, process or emotion being described in segments of data. I then compiled the codes from across participants' testimonies into a spreadsheet to consider which issues were raised by the most participants. Considering frequency per participant instead of per interview counterbalanced the possible weighting issues of having conducted considerably more interviews with some participants than others. The spreadsheet enabled the development of broader themes that highlighted similarities in experience, whilst the codes underpinning them illustrated the diversity within. I undertook the same two-stage process with interviews from staff members, noting where codes matched or were in addition to those generated through participants' testimonies. This served as a means of supporting decisions I made regarding the most important points to include in this thesis, and enabled me to use staff interviews in my discussion chapter to further enrich understandings developed. This process resulted in the emergence of the themes and sub-themes presented in Table 1, which I used as a structure within NVIVO to locate and group exemplar extracts.

A third round of coding took a more deductive approach in that I explicitly drew on intersectional theory to guide me in seeking out experiences specific to participants' socially stratified and marginal locations. This included being attentive to issues that were raised/engaged with by only one or two participants as a result of the particularities of their intersectional location. For example, the ways in which Mahdi's marriage compounded the lack of State support provided to people awaiting refugee status. Whilst these would not generate themes in and of themselves, they provided diversity within themes and helped to draw out the power dynamics at play. In this way, I used intersectionality to further highlight changes required at the systemic level to drive social change (Collins, 2019, p.2).

Table 1: Themes

Master Themes	Sub-themes	Outline
Understandings of mental health from BAME/mental health intersectional locations.	• Definitions of mental health inequality.	Explores how BAME mental health inequality is defined by different parties, and how perspectives and terminology employed reflects situatedness.
	• Determinants of mental health.	Considers the place of biological and socio-cultural factors in BAME mental health inequality, and existing protective factors.
State support for mental health issues/distress for BAME populations.	• Accessing support.	Considers issues and barriers in primary care and diagnostic practices.
	• Using mental health and related support services.	Examines behaviours and practices in services, and views regarding treatment options and how they are delivered.
	• Calls for change	Proposals for how the mental health of BAME populations and relevant services can be improved.

8 Legitimacy, writing up and representation

I sought legitimacy through authenticity and credibility rather than by appealing to replicability. As such, ensuring that my representations of participant testimonies aligned with their intended meanings was crucial. To this end, I used thick description that remained close to the data, providing verbatim accounts wherever possible and avoiding high levels of inference (Silverman, 2013, p.299). As such, my interpretations ‘account for the complex specificity and circumstantiality’ (Tracy, 2010, p.843) within the data. In addition, this enabled me to present interpretations of participants’ testimonies within the context in which they were made in many instances. This was important, as it allowed greater consideration of the open systems and social structures that interact with participants’ experiences and perceptions of mental health issues/distress. It also further enabled me to tease out differences and nuances in and across testimonies. This helped me to avoid falling prey to providing a ‘singularity of voices’ (Ebbs, 1996, p.218), where in fact there is significant diversity. Thus, a picture of the interconnectedness of wider exposure to marginalisation in its various forms and mental health issues/distress emerges with all the similarities and diversity one might imagine within this varied intersectionally located participant group. Reflective of this, I present a multivocal piece of research of a dialogic nature that seeks to remain broad enough to be of use to national level policy without denying the particulars that stop research becoming ‘artificial and misleading’ (Pawson, 2006, p.43).

A further means of ensuring authenticity was sought through enabling a collaborative approach in the drafting of findings so as to seek participant or ‘respondent validation’ (Brydon-Miller and Tolman, 1997, p.806; Newkirk, 1996, pp.13–14; Papadopoulos, 2006, p.91; Silverman, 2013, p.288). This has two benefits. First, I agree with the view that ‘two (or more) people working together’ can ‘achieve greater understanding’ (Simmons and Watson, 2015, p.56). Secondly, it allows verification of my representations of participant testimonies directly. For, despite remaining ‘close’ to the data in writing up, I am aware that misinterpretation is still possible, and increasingly so when working across cultural boundaries (Alim, 2004; Wilson, 2006, p.198). Though this research has not been as participatory as I had originally hoped, I continued to see value in engaging participants as much as possible at key points in the research. As such, I again discussed with participants how they might want to engage with me during the analysis and write-up stages.

Once more, application of a uniform approach was not possible. For example, whilst Peter asked to be provided a copy of this thesis prior to finalisation, Mahdi maintained that he did not want me to reflect findings back to him. Samantha and Satch fall somewhere in-between this. Unfortunately, I have been entirely unable to verify my interpretations with Andeep, Mya and Samaiya due to a lack of contact from them subsequent to our interviews. Despite this lack of uniformity, I preferred to engage participants as and how they agreed in these final stages; not least because several participants had commented on the limits of understandings gained through research as opposed to through lived experience:

> Peter: *I do believe that the… actual sufferers in all this have to play a big role* ((in research and policymaking))*. It has, they must have* (.) *a much greater degree of input than there has been so far. Maybe even more so than the other side. Because they've had the practical experience. And unless you've had that, you will always be missing something, you know.*
>
> ------
>
> Fieldnote with Samantha: …she said that lived experience is totally different to being trained in mental health (MH). …one is telling you what they've read, and the other is talking about what they've lived. And unless you've lived it, you can't know what it's like for those who do live it.

Limited and ununiform though the reality of engagement in the final stages might have been, I feel strongly that this did enable some further enrichment of this research. I was able (to some degree) to check my interpretations and representations so as to ensure authenticity in some of the more nuanced distinctions I make.

Further, it kept the voices of participants ever present in my mind. A sort of mental safety check if you like, reminding me to remain 'faithful' (Ebbs, 1996, p.220) to participants and avoid 'stealing' stories (Pittaway et al., 2010). And a reminder of the importance of researchers being explicit about 'how we have made choices and set priorities' (Frank, 2004, p.192). Researchers have written of the temptation (conscious or not) to mis-represent testimonies out of an eagerness to demonstrate something they feel passionate about. Resisting this temptation, the researcher must remain:

> true to the data, and not move beyond in a wild orgy of verbal bloodletting in which the researcher moves from interpretations of insights to yelling "revolution" from the rooftop (Thomas, 1993, p.63).

In reading the above quote, I was reminded of another part of the conversation I had with Peter regarding how findings should be represented in this thesis (see Appendix 15). He held that I needed to be extremely careful not to claim interpretations on my part as the undisputed view of a given participant. This chimes with the writings of many researchers committed to reflexive ethical practices, in which they stress the importance of ensuring a praxis of ‘writing from our selves’, ‘a strategy that is employed to mark one’s own voice among other voices and to acknowledge that what is presented as knowledge is constructed from particular authorial positions’ (Marx and Treharne, 2018, p.335). This aligns with Thomas’ (1993) previously mentioned distinction between ‘is’ and ‘ought’ statements. Ensuring such distinctions of voice, Peter stated, was particularly important in relation to topics of which I have little or no lived experience:

> Stéphanie: ….is it then more about not making a claim to know what the experience is if you’ve not had it yourself, but rather to make the claim that this is what you’ve heard, or this is what you’ve read about? Is that the difference that you’re talking about?
>
> Peter: *Yeah. ‘This is what I’ve learnt, as a result of’. Because you’re dealing with people* (.) *with the experience. Say you’ve learnt from their experience and their explanations and so on, you see. A lot of people take these things and claim to be the expert, when all they have is one side of the coin.*

By ‘one side of the coin’, Peter was referring to an earlier statement about research only providing insights of one side of a coin; lived experience sits on the other side, unreachable through reading and learning alone. This view is shared by many scholars from a critical perspective who recognise lived experiences ‘of the oppressed’ as a ‘critical tool to undermine [oppressive] dominant discourses’ (Moodley et al., 2019, p.81), not least those working within the fields of epistemic injustice and intersectionality; areas of research that Collins (2019) situates as often being ‘resistance knowledge projects’.

I have tried as far as possible to adhere to the suggestions Peter made in the above extract in my findings chapters. Not only out of respect for his wishes, but also because such an approach enabled me to be explicit about where I was providing description and where I was using extracts illustratively to support an analytical point (Braun and Clarke, 2006, p.25); where I make ‘value-free’ and ‘value-laden’ statements. Further, it offers an additional means of ensuring that I speak *with* participants in this work, and not *for* them (Alcoff, 1991; Lugones et al., 1983). It is in this vain that I decided to present participants’ testimonies near verbatim (see Appendix 16), as opposed to providing versions with all grammatical errors and idiosyncrasies removed. Conscious of the potential for the inclusion of such ‘errors’ to reinforce a disempowering dynamic (Carter et al., 2018, pp.37–38), I ensured that I took the same approach with my own speech (to my discomfort at times). They have their own voices; they do not need me to speak for them. Rather, as I feel Mahdi intimated, they just often lack a platform from which others will *‘really listen*’. I hope that this research can, to some degree, act as just such a platform.

Finally, as an additional means of verifying the authenticity of voice and credibility in this research, I took two further precautionary measures to provide a means of ‘crystallization’ (Ellingson, 2014, p.444). Crystallization is ‘the practice of using multiple data, sources, researchers, and [theoretical] lenses’ to ‘open up a more complex, in-depth, but still thoroughly partial, understanding of the issue.’ (Tracy, 2010, pp.843–844). Tracy (2010) sets this in opposition to processes of triangulation, which she holds leads the researcher towards providing a more singular representation of phenomena. The first measure, then, was to ensure that I paid particular attention to academic and grey literature produced by people with lived experience relevant to this project in the course of developing my literature review (which I intentionally undertook post coding). This included watching several mental health service user/survivor films/documentaries that, though not mentioned in my literature review did augment my understanding (MadFilmsByMadPeople, 2012a; MadFilmsByMadPeople, 2012b; Mental Health America, 2017; NSUN, 2020). This literature provided me not only with access to a wider pool of voices speaking from a place of lived experience, but was also a means for me to honour Peter and Samantha’s views that there is no replacement for the understandings gained through lived experience.

Further, following on from the support that my two gateway organisations had provided during my data collection, I arranged to speak at staff meetings in both gateway organisations to give an account of my final findings and ask for views on specific ways of representing issues. Consulting ‘members of the community or group to be studied’ has been suggested by researchers engaged in promoting culturally competent research as one means of increasing cultural sensitivity (Papadopoulos, 2006, p.86). Whilst staff in the organisations do not match the intersectional locations of participants exactly, the diversity among them meant that they did have relevant lived experience (Banks and Brydon-Miller, 2018, p.5) as well as insights drawn from many years of working in and with minority ethnic communities in a mental health context. Unfortunately the Equalities National Council (ENC) closed in the first few months of 2020, illustrating first-hand the financial difficulties that disability charities – and BAME charities in particular – have been experiencing for years now (Fernando, 2017, p.162; McIntosh, 2019). Though Nilaari remains in operation, the staff were somewhat overwhelmed with work during the Covid-19 lockdown and were unable to engage in this research in its final months. However, Julie J Charles (founder of the ENC), kindly offered to read parts of the thesis. Being of BAME and a mental health service user/survivor herself with several decades of experience in this field, I accepted her offer with gratitude. In these ways I have endeavoured to ensure that the thesis that follows provides an authentic representation of participant voices and the issues most pertinent to BAME populations in England.

Chapter 3: Literature Review

The State's evidence-base for policy regarding BAME mental health inequality is drawn predominantly from government data/research, government commissioned independent reviews and research from psychiatric discourses, with some input from independent research bodies, other medical professional bodies and NGOs. This literature review takes a similarly cross-disciplinary approach, but with greater emphasis placed on critical, transcultural and BAME mental health service user/survivor perspectives. Policy pertaining to issues of public health inequality can be split into two parts (see Appendix 3); the first concerned with determinants of health to address incidence/prevalence of illness and consider prevention measures, and the second with healthcare outcomes and experiences. However, policy regarding BAME mental health inequality has thus far tended to address this second issue only, avoiding real engagement with the first and the controversies around it. These controversies are highlighted in parts A and B, which look at different ways of interpreting epidemiological trends and some of the epistemological issues arising from cross-cultural contexts and an awareness of systems of oppression. Part C then considers literature seeking to understand trends indicating inequality experienced within mental health services.

Part A: Defining the issue

In this section I briefly outline key trends used to define the issue within a public health policy context, providing discussion of important methodological issues that are problematic when interpreting these trends. I then provide an overview of the critical literature underpinning challenges to dominant western medical narratives.

1 Epidemiological trends

In the UK, interest in the mental health of BAME populations originated largely from a series of psychiatric epidemiological studies in the 1960-70's. Reported trends indicated significant disparities in rates of psychiatric hospital admissions between BAME and white people (Hemsi, 1967; Kiev, 1965; Rwegellera, 1977). Studies focused primarily on 'newly' settled West Indian[3] and African populations and indicated significantly elevated rates of diagnosis of psychosis. These trends persist (see Tables 2 and 3), despite research widening to consider a greater number of BAME groupings. Notably, a recent systematic review has suggested that trends in the UK demonstrate not only a broadly stagnant over-representation of African and African-Caribbean populations in diagnoses of psychoses, but also: an increasing representation among some Asian groupings; and findings of the significant over-representation of people of mixed heritage or from the white ‘other’ grouping in more recent studies (Halvorsrud et al., 2019). The focus of most epidemiological work remains on risk of diagnosis of ‘severe mental illness’ (SMI) – e.g. psychosis[4]. This is likely due to the relative ease of access to hospital admissions data, with those hospitalised tending to have (or be diagnosed as having) experienced psychosis. Increasingly, studies seek to understand trends in relation to mental health issues/distress categorised as ‘common mental disorders’ (CMD). CMD comprise of neuroses such as depression, anxiety and post-traumatic stress disorder. Although contested, some recent research suggests that CMD is somewhat over-represented among BAME groupings (see Appendix 17).

Debates regarding the reliability of the data used and how results should be interpreted are rife in this field, supported by substantial and widely acknowledged methodological problems (see Appendix 18). Examples of such issues include ethnicity not being systematically recorded on admission to hospital (Cochrane and Bal, 1988, p.364), and people with pre-existing diagnoses being recorded multiple times if they present at different hospitals (Nazroo and Iley, 2011, p.90). Data may also be biased by variation in health-seeking behaviours or pathways to care across ethnic groupings (Halvorsrud et al., 2019, p.1319; Rogers and Pilgrim, 2014, pp.56–7). These lead to difficulties regarding interpretations of data. For example, is the over-representation of the UK’s African-Caribbean population in SMI trends the result of ‘actual’ illness, or the result of unreliable hospital data, racism in diagnosis or mis-interpretations of certain experiential phenomena across cultures? Though the Royal College of Psychiatrists (RCP) now acknowledges the role of institutional racism in BAME mental health inequality (Department for Health and Social Care, 2018b, p.10), it maintains that there is ‘more consensus that this increase [of Schizophrenia rates among people of black African and Caribbean heritage] is real, and not an artefact…’ (ibid, p10), a position akin to that in the NHMH, 2011. However, numerous scholars from within the ‘psy’ disciplines (including psychiatry), medical sociology and critical mental health studies continue to present research suggesting that racism and cross-cultural issues in diagnostic practices increase incidence rates among BAME groupings (Littlewood and Lipsedge, 1981; Fernando, 2017; Fawcett and Karban, 2005, pp.45–53; Rogers and Pilgrim, 2014, p.55; Nazroo, 2015; Glasby and Tew, 2015, p.169; Bhui, 2019). Additional barriers to developing richer understandings of the phenomena identified in trends include significant gaps in the data (see Appendix 17).

Overall, the literature most consistently highlights the following key trends: high diagnosis rates of psychosis among black groupings (i.e. African and African-Caribbean); low or equal risk of diagnosis of SMI and CMD for Asian groupings comparative to the white/white British reference group; high risk of self-harm and suicide for the Irish group; high risk of diagnosis of psychosis for 1st generation migrants, which increases for 2nd generation migrants; and higher risk of neurosis or mood ‘disorders’ among people of mixed ethnicity. However, a recent systematic review of epidemiological research highlights some shifts in aspects of the trends highlighted above (Halvorsrud et al., 2019). Additionally, these trends are not always upheld when heterogeneity within ethnic categories or when the intersectional locations of people within groupings are considered (see Appendix 17).

Considerable gaps also persist. These include a dearth of studies examining: rates of CMD across BAME populations (Fryers et al., 2004, p.13; Nazroo and Iley, 2011, p.87; Weich and McManus, 2002, p.25); trends pertaining to white ‘other’, mixed ethnicity/‘race’, Arab groupings and 2nd/3rd generation migrants (Das-Munshi et al., 2012, p.17). Further, though there is a growing body of work considering diversity within particular BAME groupings, studies exploring people in intersectional locations within a particular ethnic grouping are still relatively few in comparison to the locations possible within a grouping. With this in mind, Tables 2 and 3 provide a brief overview of the trends that ‘set the scene’ for policy intervention, regarding risk of (diagnosis of) mental health issues/distress categorised as SMI and CMD. (See Appendix 17 for a more detailed overview of these trends.)

Table 2 – Severe Mental Illness (SMI)

Ethnic grouping	Diagnosis	Risk rate	Trend over time	Intersectional trends
Black African/ African-Caribbean[5] populations	Predominantly: Schizophrenia	Incidence studies show significantly elevated risk. Prevalence studies show considerably lower risk than incidence, though risk remained elevated.	Consistently high since the 1960's.	Reports based on incidence rates tend to show particularly high rates for men – especially young men and non-migrant men - in this group. However, prevalence studies indicate rates of psychosis to be equal in these subgroups as in the white population. In prevalence studies, increased rates of psychosis resulted from increased rates among young Caribbean women.
Asian/South Asian populations	Psychosis generally	Incidence studies indicate some elevation of risk for the grouping on aggregate. However studies disaggregating ethnicity within the 'Asian' grouping show significant variation across this category.	Changing over time, with newer studies indicating significantly elevated rates.	Older women in this grouping seemed at higher risk of Schizophrenia comparative to white women and the general Asian populations. One study also found Asian women under 30 experienced higher risk than women of the same age among the African-Caribbean population.
White 'other'[6] /Mixed ethnicity populations	Psychosis generally	Incidence studies indicate significantly increased risk among white migrants, (with significant variation according to country of origin) and people of mixed ethnicity.	Consistently showing elevated rates since the 1970's.	Incidence studies indicate increased risk among white migrants, and even higher among second generation migrants generally.

Table 3 – Common Mental Disorders (CMD)

Ethnic grouping	Diagnosis	Risk rate	Trend over time	Intersectional trends
Black African/ African-Caribbean[7]	Predominantly: Depression, some Anxiety	Some indication of elevated risk of both; most often this relates to depression.	Unclear and inconsistent	Several studies from the late 1990's found East African women to be particularly at risk of suicide.
Asian/South Asian populations.	Depression, Anxiety and phobias.	There is very little agreement. Most often, the grouping is collectively reported as having equal or lower risk of CMDs than white people. However, even those reporting this recognise it is untrue when disaggregated by nationality.	Inconsistency across studies making trends difficult to determine.	Reported intersectional trends include; lower rates of depression among Pakistani women whilst Pakistani men are more likely to self-report as depressed than white counterparts; high risk of suicide among 1st generation migrant Indian women; higher risk of CMDs among Asian women than white women; lower risk of CMD among Asian men than white men and significantly lower than white women.
White 'other'[8] /Mixed ethnicity populations	Predominantly: Depression and Anxiety	Elevated risk of both in the white 'other' and mixed ethnicity group	Relatively consistent, though under researched.	Women in the mixed ethnicity grouping demonstrated significantly elevated risk of CMDs, whilst men in this grouping had lower risk than white counterparts. Risk of self-harm and suicide particularly high among Irish men.

Note: Trends are comparative to the 'white British' or (for earlier studies) the 'white' ethnic grouping. This is true for Tables 2 and 3.

See Appendix 17 for references informing tables 2 and 3.

2 Indicators of inequality in mental health services and treatment

Disproportionality issues are also indicated in research and organisational management data assessing mental health service user/survivor experiences and outcomes. Box 2 provides an overview of the main issues reported. As with research regarding risk of diagnosis, research tends to focus on black populations[9] - particularly the African-Caribbean grouping. Less attention is paid to trends relating to Asian population groups, with very little research on the experiences of other minority ethnic groupings or refugees and asylum seekers. This might be partially influenced by accessibility of data issues[10]. Another reason might be the historically more sensational nature of inequalities experienced by black service users, which lends itself to receiving more media and public attention. Some argue that another reason for such attention is the way that such incidents play into stereotypes of men that are ‘big, black and dangerous’ (see p.84). The UK’s black population is also perhaps more visible to State-affiliated services than the asylum-seeking population might be, with more established voluntary organisations to raise awareness of issues experienced (see Appendix 4).

Box 2: Trends in mental health service performance

Inequalities in access to services:

- Under-representation of several BAME groupings in GP referrals to mental health services.
- Over-representation of black people (particularly working-age men) in adverse pathways to care involving police, the judiciary system and mandatory sectioning.

Inequalities in service experiences:

- Disproportionate number of black people in secondary and tertiary services
- Longer stays on in-patient psychiatric units for people of BAME backgrounds.
- Greater use of coercive treatments – i.e. disproportionate use of Community Treatment Orders (CTOs) on BAME populations.
- Increased use of psychotropic medication on in-patients from BAME backgrounds, but an under-representation of the same population group receiving medication for CMD or talking therapies.

Many of the data issues cited in relation to epidemiological trends also impact data collected regarding the experiences of BAME people accessing and using mental health services. Though definitions of the issue pertaining to service outcomes and experiences are more likely to draw from qualitative data than the above epidemiological trends, this is not always the case; e.g. where statistics are collected from hospital or juridical management data. Reliance on quantitative data here arguably fuels contestation regarding how trends found should be interpreted. Debates are frequently related to people’s position regarding whether epidemiological trends are indicative of actual mental ‘illness’ or of contestable diagnoses (Fernando, 2017; Department for Health and Social Care, 2018b). An example is seen with regards to the significantly elevated rates of pathways to care involving the judiciary reported for African and African-Caribbean (heritage) people. One explanation is that this should be expected where a given population experiences higher rates of psychosis. This clearly aligns with the position that epidemiological trends demonstrate increases in actual illness, not just diagnosis. Another explanation, however, suggests that such trends are reflective of widespread racism at the interpersonal, institutional and systemic levels. Institutional racism is here understood as involving overt and covert racist attitudes at both the individual and institutional levels (Ture and Hamilton, 1992, p.5). As Chouhan and Nazroo point out, ‘there is a convincing body of evidence suggesting that the higher admission rate of black people for severe mental illness is disproportionate and reflects the ways in which they are racialised’ (Byrne et al., 2020, p.82).

Culturally-based differences in understandings and experiences of ‘illness’ may also impact on trends observed regarding service experience and treatment outcomes. For example, fundamental differences in the ways that some cultures conceptualise ‘illness’ or the body/mind dynamic can result in distress presenting differently (Kleinman, 1977; Lin and Cheung, 1999, p.776; Rogers and Pilgrim, 2014, p.65; Bayetti and Jain, 2019, p.224). An example is the somewhat contentious Somatisation hypothesis, (see Appendix 19); contentious because of how such theories can also be applied in ways that situate racialised peoples as lacking the psychological sophistication to ‘express themselves verbally in a way that was consistent with the psychotherapeutic model’ (Moodley et al., 2019, p.82). Where people do hold different worldviews that lead to greater somatisation or alternative understandings of mental health issues/distress, this may lead them to engage in health-seeking behaviours more in keeping with their conceptualisations and experiences of such phenomena. Such differences impact some trends highlighted in Box 2. For example, leading to an under-representation of people from certain BAME groupings being referred to secondary services by GP's. This is important as such trends inform calls for mental health services to improve on their ability to accommodate multiple culturally-mediated presentations of mental health issues/distress (Lanzara et al., 2019, p.14/15). Accessibility issues (such as language barriers) are also raised as impacting on the health-seeking behaviours of minority ethnic groups subject to such experiences. These and the issues highlighted in the previous paragraph begin to articulate some of the difficulties of defining the nature of BAME mental health inequality. Adding to this are disputes regarding the soundness of some of the concepts core to the issue of BAME mental health inequality.

3 Mental health at the intersections of 'race' and ethnicity.

Debates at the epistemological level, while generally ignored in State produced policy documents, are highly relevant context to the interpretations of the above trends, to clinical practice and to my own findings (see chapters 4 and 5). Critiques of western medical models tend to focus on two points of contestation. The first relates to mental health determinants. This is viewed as of great importance due to its influence on treatments developed and offered to people. I.e. bio-deterministic determinants lead to medication. The second area concerns which experiences and behaviours should be categorised as 'illness/disorder'. Radical or critical scholarship in this field often considers these issues together, bringing a critical lens to the fundamental ontological premises and epistemological frameworks that support them.

Important critical figures within psychiatry began highlighting concerns in the 1960's. For example, Szasz and Laing raised alarms regarding continued attempts to systematically categorise psychological and physiological responses to adverse circumstances as mental illnesses/disorders. Szasz was concerned that psychiatry was falling prey to a fundamental categorical error whereby the physician's inability to distinguish ‘problems of living’ from diseases of the brain and/or body was leading to a pathologization of distress (Szasz, 1960, p.114). Not denying that some people may have symptoms impacting on the functioning of the brain and emotional regulation as a result of biological diseases or disorders, he holds that distress is not always reducible to this. Therefore, conceptualising all presentations of distress as ‘mental illness’ not only pertains to an unfounded confidence in bio-genetic aetiological hypotheses, but can lead to a medicalisation of distress that is inaccurate and potentially damaging.

Writing more recently, Szasz holds that scientific advances locating neuropathological causes for ‘mental illness’ simply confirm his hypothesis of categorical error, maintaining that the nature of the concept of mental ‘illness’ and its operationalisation is inherently political (Szasz, 2011). The ‘political’ potential to pathologize legitimate distress resulting from oppression has troubled many critical scholars in this field. Cooper - an important figure in the British anti-psychiatry movement - wrote that psychiatry ‘chooses to refract and condense on to its identified patients the subtle violence of the society it only too often represents’ (Cooper, 1967, p.xii). Mental health discourses, constructed within the parameters of the norms of the society from which it evolves, embody the discriminations and oppressions underpinning that society.

Similar concerns continue to be raised (Fernando, 1995, p.23; Goodley and Lawthom, 2005, p.4; Kutchins and Kirk, 2001; Read and Dillon, 2013; Timimi, 2019). The ‘targets of these distortions often include[ing] the relatively powerless, including women, minorities, and gay people’ (Kutchins and Kirk, 2001, pp.10–15), depoliticising negative responses to adverse situations. Powerful examples are found in the UK’s history of ‘madness’, whereby the differential treatment of ‘pauper lunatics’ compared to wealthier, gentile ‘lunatics’ was supported by eugenicist narratives (Goodwin, 1997; Jones, 1955; Porter, 1987; Porter, 2003; Scull, 2006). These critiques highlight the importance of retaining a critical eye on how mental health discourses are constructed and operationalised. This importance grows with the level of State involvement in mental health, particularly for those seeking to address inequalities experienced by marginalised social groupings (Foucault, 2001; LeFrancois et al., 2013; Middleton, 2013; Timimi, 2019, p.57).

Where mental health discourses intersect with racialisation, history unfortunately provides a rich tapestry of abuses in the pathologization of distress, where ‘difference’ has been medicalised to uphold and justify oppressive ideologies such as white supremacy. The complex interplay between the construction of racialised identities and ‘madness’, ‘deviance’ and ‘feeblemindedness’ have been well documented both internationally (Davis, 1995, pp.36–37; Erevelles, 2011, c.1; Fanon, 2001, pp.241–243; Metzl, 2011; Mills, 2019) and within the British context (Fernando et al., 1998; Fernando, 2017; Gilroy, 2013, c.3; Kalathil et al., 2011, p.30; Moodley et al., 2019). Such constructions enabled the emergence of pathologized explanations of acts of resistance or despair observed among oppressed peoples. For example:

> The cause, in the most of cases, that induces the negro to run away from service, is as much a disease of the mind as any other species of mental alienation… (Cartwright, 1851, p.707).

This ‘disease’ was coined ‘drapetomania’. Drapetomania demonstrates the ways in which distress and acts of resistance from oppressed people have been pathologized, with the effect of de-politicising their plight and silencing their voices. Though slavery had been legally abolished for some decades by the 1960’s in America, the same process of pathologization to maintain the status quo resurfaced. For example, through the development of a new diagnostic category called Protest Psychosis: ‘a condition in which the rhetoric of the Black Power movement drove “Negro men” to insanity’, with ‘black liberation movements literally caus[ing] delusions, hallucinations, and violent projections in black men.’ (Metzl, 2011, p.100). This label was used to incarcerate civil rights protestors in asylums indefinitely.

Acknowledging that progress has been made since times of legal slavery, Metzl maintains that ‘psychiatric definitions of insanity continue to police racial hierarchies, tensions, and unspoken codes’ (Metzl, 2011, p.ix), a view shared by critical scholars in the UK. For example, Fernando explains how psychiatric diagnoses are subject to racism and racial prejudice through their use of 'common sense' knowledge, which - in post-colonial settings - is imbued with racial stereotypes and prejudices:

> alienness seems to be linked to schizophrenia (as a diagnosis) and to biological (or genetic) inferiority (as a human type). It is not difficult

> to see how 'race' comes into both these concepts - alienness and biological inferiority. (Fernando and Keating, 2008, p.47).

'Common sense' images of black people as 'dangerous' and 'deviant' can bias diagnostic assessments towards an increased application of diagnostic labels also associated with dangerousness; e.g. schizophrenia. In this way, racism is recreated within and shapes specific diagnostic categories and the diagnostic processes associated with them. Such processes, some argue, are necessarily present in societies where historical and institutionalised racism exist. The danger is that medicalised approaches to mental health issues/distress have the potential to lend the credibility associated with the natural sciences in Western societies to diagnostic categories imbued with racist ideas.

The limitations and problems inherent within Western conceptualisations of mental health are further highlighted through cross-cultural research in this field. As previously mentioned, distress can be expressed in many different ways and is often culturally mediated, as are concepts of illness. Kleinman warns that attempts to (re)interpret different expressions of distress as symptoms of 'illnesses' within the Western paradigm leads to 'category fallacy' (Kleinman, 1977, p.4). 'Category fallacy' involves lifting phenomena from the cultural context it emerged from and analysing it within the parameters of a potentially incompatible epistemological framework. This can result in the misinterpretation of phenomena and pathologization of an unhelpful or harmful sort (Bennett, 2006, p.103; Littlewood and Lipsedge, 1981, p.291). Such processes might also be seen as a form of cultural imperialism, whereby Western paradigms are treated preferentially over other worldviews. An example of cultural imperialism in diagnostic practices might be that of assigning the diagnostic label of schizophrenia to people from non-Western cultures who express hearing voices and having hallucinations (see p.78-79).

Part B: Determinants of inequality in a BAME mental health context

Whilst scholars within critical factions of 'psy' disciplines highlight issues of diagnostic practices, many also accept that instances of 'actual' mental health issues/distress are likely present within BAME groupings at an elevated rate to the general population. This section, then, considers key hypotheses regarding determinants of mental health inequality for BAME groupings where 'actual' incidence/prevalence is at play. From a policy perspective, reviewing these hypotheses is important as they offer opportunities of ‘providing improved psychiatric services for these particular population groups.' (Fearon et al., 2006, p.1548) Finding responses to troubling phenomena is more likely to be successful if there is an understanding of causal influences. Whilst it is not within the scope of this research to posit any particular explanatory theories as ‘truest’, an awareness of the different explanations is important as they direct policy responses.

As discussed in my introductory chapter, the NHMH (2011) and more recent policy documents allow for multiple causal theories to explain why people of particular social groupings experience higher risk of mental health issues/distress. Within psychiatric epidemiology, most explanatory theories provided fall into ‘two classes of theory [which] are in competition: those of selection, and those of social causation.’ (Halpern, 1993, p.567). Selection theories situate the social inequalities people face as a result of (or – in instances of deprivation from childhood - heightened by) mental health (Ødegård, 1932). Social causation theories claim that mental health issues/distress are caused *by* social inequality. Whilst both categories might play a role in explaining the persistence of BAME mental health inequality, the majority of the literature focuses on hypotheses of a more social causation nature.

4 Biological predispositions and selection theories

Selection-based theories align more readily with understandings of mental health that situate biological factors as the prime contributing factor in generating the trends highlighted in Table 1. Early epidemiological studies regarding these trends did not often expend effort determining possible causes, largely due to the underlying assumption that mental health issues/distress resulted from biological and/or genetic differences in people. Biological hypotheses proposed to explain reported elevated risk among BAME groupings have included genetic predisposition, exposure to prenatal and perinatal viruses, and hereditary low IQ (Sharpley et al., 2001, pp.61–62). Another key hypothesis among selection theories is that of social drift. This seeks to explain elevated levels among migrants and people who have moved to more urban locations. Social drift posits that ‘symptomatic individuals’ (Os et al., 2001, p.667) may be drawn towards certain situations or behaviours, partly as a result of their ‘illness’. This explanation does not have some of the potentially racist implications of hypotheses of genetic predisposition. Rather, it suggests that people with shared heritage who are experiencing mental health issues/distress are more likely to find themselves in the UK as migrants or in urban locations where elevated risk is generally reported; e.g. refugees from areas of conflict. Within the social drift framework, migration or urban settings themselves are not causal factors in increased risk of diagnosis (or illness/distress). Rather people with certain symptoms are more likely to express ‘x’ behaviour, which may lead to experiences of disadvantage. Social deprivation in a selection context therefore tends to focus on downward social mobility or the inability to escape deprivation situations as a result of mental health issues/distress (Tiffin et al., 2005, p.870). As Cooper (2005) notes, there is little doubt that experiences of mental health issues/distress can have serious – sometimes catastrophic – impacts on people’s life chances.

In the context of BAME mental health inequalities, the narrative of ‘selection’ can serve to depoliticise disparities recorded and medicalise wider social inequalities experienced by people from BAME backgrounds. Acceptance of social drift as *the* explanation for – as opposed to *a contributing factor* in – the increased risk of diagnosis (or illness/distress) implies that the issue resides within BAME groupings. For policy-makers this means two things. First, disparities need not be conceived of as an indication of inequality, just difference. Policy responses based on this understanding of mental health might include ensuring greater access to treatments and programmes to improve early detection of ‘illness’. Secondly, there is a diminution of the argument that addressing mental health inequality requires attending to wider social inequalities. Within selection theory, wider society and social structures are not considered root causes of mental health inequalities. Even if a person experiences inequality as a result of illness/distress, the argument could run that prevention measures and treatments should not focus on these inequalities as they are not the cause of symptoms.

Selection and social drift theories, however, have been found inadequate in explaining epidemiological trends indicating inequalities. Perhaps motivated by a need to contest the racist implications falling from selection theories of bio-genetic or cultural inferiority among racialised peoples, research to interrogate such hypotheses was undertaken. Studies in the late 1990’s/early 2000’s demonstrated several phenomena that undermined a number of selection-based explanations. For example, regarding social drift theories relating to the likelihood of living in urban settings. Boydell et al. highlighted that the limited housing options available to people of BAME backgrounds in a socio-economically deprived part of London made it unlikely that ‘symptomatic people’ drifted towards particular geographic areas. Rather, they are more likely to have had little to no choice about where they lived. Thus social drift failed to explain increased risk of diagnosis (or illness/distress) in urban spaces for some BAME groupings (Boydell et al., 2001). Further, studies considering increased risk among migrants found:

- no elevated risk for ethnic groupings in their countries of origin[11] (Bhal, 1999, p.10; Brugha et al., 2004; Cooper, 2005; Fearon et al., 2006);
- elevated risk present across a range of migrant and ethnic groups in the UK (Halvorsrud et al., 2019; Selten et al., 2007); and
- elevated risk in 2nd generation migrants comparative to 1st generation migrants (Bhal, 1999, p.10; Das-Munshi et al., 2012, p.18; Selten and Cantor-Graae, 2005; Selten et al., 2007, p.111).

These issues did not disprove the migratory social drift theory, but they did significantly weaken hypotheses regarding genetic and cultural predisposition. Additional arguments included Halpern’s observation that social drift does not adequately account for disparities of risk within BAME groupings (Halpern, 1993, p.603) – an early nod to what might now be considered intersectional phenomena. Together, such research provided a compelling platform from which to turn attention back towards socio-cultural factors of a social causation nature.

5 Socio-cultural factors as driving mental health issues/distress

In this section, I have organised key social causation hypotheses so as to align with the categories that emerged from my own data, rather than in accordance to the ways theories might be separated in the literature. These categories are:

- Childhood/pre-migration trauma and suffering;
- Material deprivation and stressors in adulthood/post-migration; and
- Discrimination and oppression.

I retain my focus on theories specific to BAME mental health inequality, to the possible exclusion of general aetiological explanations. For example, I only include issues of childhood trauma or personal suffering if they are theorised as disproportionately impacting on BAME groupings.

5.1 Childhood/pre-migration trauma and suffering

Childhood trauma and pre-migratory trauma are not generally categorised together in the literature. However, participants in this research tend to split their early and current lives via either childhood/adulthood or pre/post-migration depending on their migration/citizenship status, a similar divide seems to take place in the literature. In the literature pertaining to BAME mental health inequality – particularly that which aimed directly at influencing national-level policy – the focus tends to be more on experiences in adulthood or post-migration. The below provides some of the overarching issues highlighted by the literature. However I do not go into detail as this was not an area of great focus for participants.

In relation to childhood trauma and BAME mental health inequality, studies highlight that social inequalities can increase exposure to childhood adversity and trauma; factors widely acknowledged as increasing risk of mental health issues/distress in adulthood. The higher risk of social inequality experienced by BAME groupings (Cabinet Office, 2017) might therefore result in increases of exposure to difficulties in childhood for children of BAME backgrounds (NIMHE, 2003, p.11). Often the childhood trauma referred to results from sexual and/or physical abuse, neglect and loss (Davidson et al., 2015, p.26). Within the context of research in the UK on BAME mental health inequality, the experience of separation from a parent during childhood has been linked with the emergence of SMI. Whilst this was seen to impact people across ethnic groupings, several studies suggested that instances of such separation occur more frequently among particular BAME groupings, among whom trends for SMI are elevated (Mallett et al., 2002, p.334; Morgan et al., 2009, p.232).

In more recent research pertaining to migrants, there is much focus on refugees and asylum seekers. A frequently highlighted factor that may contribute to higher levels of mental health issues in the UK is the higher exposure to traumatic events that people within this grouping are likely to have experienced (Fang et al., 2015, p.4; Fazel et al., 2012; Rogers and Pilgrim, 2014, p.66; Vahdaninia et al., 2020, p.12). Risk of mental health issues/distress as a result are highlighted as dependent on:

> the magnitude of the event, its personal meaning to the victim, lack of control over the event, its predictability, its impact on physical welfare, and its diversionary impact on expressed needs or normal expectations in the life course (Rogers and Pilgrim, 2014, p.66)

Such factors are important determinants in understanding mental health inequalities among UK populations where forced migration is more likely to have been experienced, leading some scholars to advocate for interventions from higher-income nations like the UK to ‘keep negative exposures to a minimum in countries of origin and countries of transit’ (Fazel et al., 2012, p.279).

5.2 Material deprivation and precarity in adulthood/post-migration

Under this heading I discuss two prominent hypotheses, both of which are significantly inter-related: urbanicity and socio-economic deprivation. Many of the issues highlighted as impacting on the mental health of migrants, particularly people forced to migrate, are reflected in these hypotheses. However this group may also experience additional barriers due to a lack of legal status providing them with the same access to social support and security regarding remaining in the UK that most other people of BAME backgrounds have (Fang et al., 2015, pp.5–6). The urbanicity theory considers socio-economic deprivation as an important variable, just as housing situations are sighted in theories of the role of socio-economic deprivation in propagating mental health inequality. Urbanicity also highlights the higher incidence of mental health issues/distress among people living in urban areas. As previously mentioned, social drift theory fails to adequately account for increases (of diagnosis) of illness/distress among people with little choice about where they reside, as well as among those born and raised in urban settings (Cooper, 2005, p.361; Mallett et al., 2002, p.333). This distinction has become progressively more important for BAME groupings who predominantly reside in inner-city locations and are increasingly British-born 2nd, 3rd and 4th generation migrants. Many BAME groupings find themselves residing in:

> a toxic urban environment characterized not only by noise, pollutants, viral infections, etc., but by unemployment, low socio-economic status and high levels of social deprivation, lone-parent

> families, poor housing conditions and exposure to an institutionally racist society (Mallett et al., 2002, p.333)

Though Mallett et al. (2002) are here referring specifically to people of African-Caribbean descent, the same is applicable to several other BAME groupings; namely Pakistani and Bangladeshi populations (Cabinet Office, 2017, p.28). However, as Appendix 17 shows, Pakistani and Bangladeshi populations do not seem to experience the same level of increased risk of diagnosis (or illness/distress) – particularly psychosis – as the African-Caribbean group. For migrants – particularly asylum seekers – 'urbanicity' might also include exposure to 'hostility from host populations in the places they flee to' (Fernando, 2010, p.92), leading to policies that situate them in 'toxic' environments from which they struggle to escape. Such environments - held as detrimental to a person's wellbeing and mental health generally – can retraumatise people who have had significant exposure to trauma and suffering in their past; e.g. asylum seekers/refugees (Watters, 2014, pp.70–71).

Socio-economic deprivation[12] is measured in a variety of ways. Most often it seems to encompass one or more of the following indicators: income and wealth[13], housing tenure, employment status and educational attainment (Rogers and Pilgrim, 2002, pp.21–22). Links between socio-economic deprivation and mental health issues are relatively well established in mental health discourses (Cooper, 2005, p.361; Coope et al., 2014; MacIntyre et al., 2018; Rogers and Pilgrim, 2002; Thomas et al., 2019; Zimmerman et al., 2004). In a social causation context, it is understood as increasing mental health issues/distress because of exposure to stressors and oppression. The impact of this factor on BAME mental health inequality is still being debated as epidemiologists try to distinguish between the impact of socio-economic deprivation and other risk factors that might arise as a direct result of their minority ethnicity; i.e. culturally-related identity dislocation (Halpern, 1993, p.603) or racism. Yet awareness of the need to understand how this factor impacts on BAME mental health inequalities is growing (Brugha et al., 2004; Das-Munshi et al., 2012, p.p19; Morgan et al., 2009; Qassem et al., 2015; Shah, 2004; Smith, 2000, p.1694). Brugha et al. (2002) note, for example, that whilst 'Subjective social support and recent life events' did not seem to increase risk of SMI among UK African-Caribbean populations, 'risk factors particularly associated with low income or poverty' did (Brugha et al., 2004, p.943).

Distinguishing between such factors is complicated by views that socio-economic deprivation is, for many BAME groupings, related to disadvantages and discriminations experience as a result of minority ethnicity. For example, unemployment. Mallett et al. (2002) suggest that unemployment tends to be a signifier of ‘financial deprivation, lack of self-esteem, stigma and powerlessness’ and reduced social networks (Mallett et al., 2002, p.333). It is also one of the factors repeatedly cited as having a strong correlation to increased risk of mental health issues/distress among certain BAME groupings (Bhugra et al., 1997, p.797; Kapadia et al., 2018, p.302; Leff, 1999, p.46; Mallett et al., 2002, p.333; Shah, 2004, p.s11). This correlation is explained in part by selection theory; e.g. unemployment results from behaviours relating to poor mental health/distress rather than in triggering it in the first place.

However, when considering this in relation to BAME populations, selection theory is inadequate for explaining the widespread inequalities in employment between ethnic groupings in the general population (Cabinet Office, 2017, p.26). By this I mean that prevalence of mental health issues does not account for the levels of inequality experienced by different BAME groupings. Several recent studies also found correlations between mental health issues/distress and groups experiencing multiple disadvantage, (e.g. low educational attainment, material deprivation), (Barr et al., 2015, pp.327–330; Coope et al., 2014, p.76). Low educational attainment is also found in some BAME groupings who also experience high unemployment (Bhopal, 2018, p.135; Cabinet Office, 2017, p.20). An argument for the existence of BAME systemic inequality that impacts on socio-economic status emerges, making distinctions between the effect of minority ethnicity status and socio-economic deprivation difficult to calculate.

5.3 Discrimination and oppression

Experiences of discrimination and oppression are widely accepted as negatively impacting on mental health. In using the term oppression in this thesis I refer to Young’s definition of oppression as having ‘five faces’ through which it manifests. These being exploitation, marginalisation, powerlessness, cultural imperialism and violence (Young and Allen, 2011, c.2). American social epidemiologist Krieger has found that ‘any random set of individuals selected from either of the groups [social categories of people], if subjected to the same adverse exposures, would have a greater likelihood of morbidity or mortality compared to individuals who are not exposed' (Krieger, 2014, p.658). Exploration of discrimination and oppression within the context of BAME mental health inequality focuses primarily on experiences of racism and racial prejudice, though more intersectional works do also highlight the role of other systems of oppression (for example, Kalathil et al., 2011, c.4). Research considering the experiences of migrants also highlight forms of discrimination and oppression specific to xenophobia, including 'name calling, stoning and/or being denied services based on how they are portrayed in the media as 'untrustworthy', 'dangerous' and 'uncivilized'' (Fang et al., 2015, p.5). Consideration of racism tends to take two main forms: the role of racism in diagnostic assessments (see section 6.3), and the role it plays in triggering 'actual' mental health issues/distress.

Research seeking to better understand how experiences of racism might act as a determinant in mental health continue to build an evidence base. This has led to a general acceptance that experiences of racism and discrimination (real and perceived) do impact people's risk of mental health issues (Bardol et al., 2020; Karlsen et al., 2005), particularly when combined with low self-esteem or self-belief (Alleyne, 2008, p.171; Cooper et al., 2008, p.189; Sharpley et al., 2001, pp.64–5). Low self-esteem or self-belief might themselves result from experiences or perceptions of racism and discrimination. A study in 2006 explored whether or not accusations of racism from people diagnosed with psychosis might result from symptomatic delusions. Contrary to the anticipated results, findings indicated that this group was more likely to perceive social disadvantages they experience as resulting from their own failings than as primarily the result of experiences of racism and discrimination. This was partly as a result of low self-esteem and self-belief, leading the authors to hypothesise that:

> It is possible that correctly identifying hostility as due to another's prejudice rather than to internal factors is protective, and that those unable to do so are more vulnerable to developing psychosis. (Cooper et al., 2008, p.189)

Where this positive psychological process does not occur, such social stressors may cause short term physiological changes impacting on health generally. Long-term exposure is suggested as leading to cognitive changes such as the development of mental health issues/distress (McKenzie, 2006, p.385).

A plethora of literature exists to consider the psychological mechanisms that lead to mental health issues/distress as a result of repeated exposure to racism. For example, work looking specifically at the impact of microaggressions finds that:

> the degree to which seemingly innocuous situations were rated as emotionally negative was associated with the degree to which a participant believed that the treatment was relevant to his or her race (Wang et al., 2011, p.5)

Coming at this topic from the perspective of a policy-maker tasked with improving national-level policy responses to BAME mental health inequality, I need to understand the main determinants but do not have the space to consider the intricacies of the psychological processes involved. Instead, I include the above to demonstrate why so many scholars, practitioners and activists concerned with BAME mental health inequality emphasise the importance of society, State and mental health professionals openly recognising the existence of racism in the UK.

Racism is acknowledged in the literature as taking many forms, all of which are thought to impact on risk of 'actual' illness/distress. These include exposure to institutional racism resulting in fear of services (see p.76-77) and the numerous ways in which structural inequality occurring as a result of systemic racism manifests. Box 2 presents an overarching view of the main ways that racism is discussed as manifesting in relation to BAME mental health inequality. Among researchers in this space, there is an acknowledgment that studying 'the direct experience of racism aetiologically to specific psychiatric illness' (McKenzie, 2002, p.89) is extremely difficult given the complex ways in which racism manifests and is interlinked with other forms of marginalisation.

This might lead one to the assumption that the interconnectivity and intersectionality of 'race'/minority ethnicity and other forms of discrimination and oppression features strongly in this area of research. Whilst the issue of multiple disadvantage does appear with descriptions of arguably intersectional experiences (see section 5.2, for example), explicit exploration of intersectional experiences is relatively new. This is the case not only in the UK, but internationally, particularly when in relation to work at the population level or in relation to health policy (Bauer, 2014; Haarmans et al., 2016; Hankivsky, 2011, c.1; Seng et al., 2012). Empirical intersectional mental health research that is inclusive of ‘race’ is found primarily in America and Canada. In the UK, such works are increasingly appearing or being advocated for. However, there is yet to be enough research of this sort collated to enable an overarching view of how intersectionality inclusive of BAME status impacts and interacts with risk of developing mental health issues/distress at the group level.

Box 3 - Manifestations of racism linked to mental health issues/distress

- *Socially inflicted racialised trauma:* These can take mental, physical or sexual form and include continual exposure to microaggressions or witnessing racially and xenophobically motivated attacks.
- *Institutional racism* – the primary focus being receipt of healthcare that is inadequate or inappropriate, or interactions with the policy and judiciary.
- *Intersectional discrimination with racialised components*.
- *Racially-related decreased opportunity for upward mobility*: i.e. lower educational attainment of racialised groups, barriers to progressing careers due to racial stereotypes, refusal of bank loans due to racial profiling;
- *Socio-economic disadvantage and racism* – i.e. due to intergenerational poverty, which might result from the barriers to upward mobility discussed above;
- *Barriers to equal access to positive aspects of social environment* – i.e. certain BAME groupings often live in poorer housing, or are subject to negative stereotyping in mainstream media.

(M. Sharpley et al., 2001; McKenzie, 2006; Nazroo et al., 2019; Naz et al., 2019, p.4)

Indeed, intersectional issues tend to be discussed either as manifestations of racism alone, or in studies of intersectionally located groups within a specific ethnic grouping but without mention of intersectionality theory. This can lead to studies focusing the experiences of intersectionally located people not adequately exploring the structural elements from which such experiences emerge. Intersectionality theory pushes researchers to consider such factors. As a result of not employing an intersectionality lens, the role of intersectionality in BAME mental health – beyond the implicit examination of the intersection of ‘race’/ethnicity and mental ill-health status - has not been significantly accounted for in a systematic way in this topic area. As advocates of intersectional research in other fields highlight, this gap risks developing understandings of ‘patterns of differences between the groups… but only at the expense of suppressing those within groups.' (Flintoff et al., 2008, p.6).

This gap aside, the wide and varying ways in which the role of racism and discrimination in the development of mental health issues/distress has been researched has led to an increasing acceptance of this as an important factor explaining the increased risk of diagnosis (and illness/distress) observed across a range of BAME groupings (Bécares et al., 2009; Bhui et al., 2018; Cantor-Graae and Selten, 2005; Karlsen et al., 2005; McKenzie, 2002; Nazroo et al., 2019; Pickett and Wilkinson, 2008; Shah, 2004; Virdee, 1997, pp.284–285; Department for Health and Social Care, 2018b, p.10). That is not to say, however, that there is not still considerable debate regarding the role of institutional racism in the phenomenon of BAME mental health inequalities. For example, some scholars and practitioners in the field hold fast that a focus on racism distracts from the role of social deprivation in accounting for BAME mental health inequality (Singh and Burns, 2006) – see p.91.

6 Protective socio-cultural factors

Finally, two main hypotheses emerge from the literature in relation to protective factors experienced by some BAME groupings where there is strong community cohesion: ‘ethnic density’ and social capital. The ‘ethnic density’ hypothesis grew in part from studies seeking to better understanding why certain BAME groupings (i.e. the UK’s Chinese population) do not seem to experience the same elevation in diagnosis (or illness/distress) as black populations, (Bécares and Nazroo, 2013; Bécares et al., 2018; Boydell et al., 2001; Halpern, 1993; Pickett and Wilkinson, 2008; Shaw et al., 2012; Schofield et al., 2011; Stafford et al., 2010). It suggests that where BAME populations reside in areas of dense population by people of the same ethnicity and where incidence of ill-health/distress is lowered, high ethnic density may be playing a role in maintaining good mental health. Essentially, living in such an area may not prevent exposure to social deprivation or racism, but a ‘buffering’ effect is created that engenders greater group understandings that demeaning experiences result from unjust prejudice (Bécares et al., 2009, p.701). Thus the maintenance of self-esteem and self-belief in the face of adversity is enabled. Additionally, living in areas of high ethnic density may be particularly helpful to migrants, protecting their mental health through a ‘minimizing of the disjunction between home and host cultures.’ (Halpern, 1993, p.603) However, ethnic density has not been found to serve as a protection against the effects of material deprivation, (Bécares et al., 2018, p.1).

Though conceptualisations of ‘social capital’ vary (Almedom, 2005, p.944), in the context of health research it generally refers to the health benefits of positive social relations and social cohesion. In areas of high ‘ethnic density’ and social cohesion, ‘minority ethnicity’ may provide a form of social capital that acts as a psychological protection. Density of other unifying characteristics, such as ‘religion, occupation or class’ (Pickett and Wilkinson, 2008, p.328) have also been found to provide a similar ‘buffering’ effect where social cohesion is present. McKenzie et al. (2002) note that social capital need not require geographic proximity to exist in a person’s life. Social capital might, for example, be elevated through belonging to diasporas or virtual communities constituted through family ties, religious beliefs or other interests a person has, as opposed to through their neighbourhood ‘community’. The role of religion as a protective factor is not often discussed in relation to BAME mental health inequality, with religion often treated – in policy circles particularly – as a separate issue. However, studies looking at specific religious communities have found faith to act as a protective factor (Lindridge, 2007, p.20; Department for Health and Social Care, 2018a, pp.280–1; Sadiq, 2019).

Part C: Interactions with mental health support services

Part A of this chapter provided an overview of trends found in relation to BAME mental health inequality in services. In this section, I take a closer look at the literature exploring these trends. In addition to academic research, this section is informed by grey literature that is highly qualitative and/or responding to specific events; i.e. inquiries into the deaths of BAME (particularly black) patients in psychiatric wards. Although such work presents testimonies of lived experience (much as my study does), only a small proportion of the grey literature is actually produced by people of BAME backgrounds who are mental health service users/survivors. Further, as the ‘Modernising the Mental Health Act’ report points out, many reports fail to provide explanations for trends, making discerning between more likely hypotheses extremely difficult – if not impossible – to determine from the literature alone (Department for Health and Social Care, 2018b, p.171). It is in this context that part C explores:

- Accessing mental health support services
- Using mental health services

These headings align both with those in my findings chapters and with the way in which policy often separates issues relating to support services. However, I note here that there is indeed something of a different focus between much of the literature and my own study (see p3).

7 Accessing support

Issues relating to accessing support are held as both illustrative of inequality and *as* inequality. In a policy context, the main issues discussed in relation to BAME groupings are disparities in primary care and adverse pathways to care. Another key area for consideration relates to issues found in the diagnostic process; as additional to, (though not distinct from), problems regarding diagnostic categories (see part A).

6.1 Accessing support through primary care

Despite an aggregate over-representation of BAME groupings in mental health services and proportionate (or high) levels of registration and consultation[14] with GP practices, it is perhaps surprising to find significant pockets of under-representation with regards to GP involvement on the grounds of mental health issues/distress among this population grouping. For example, Asian groupings have long been cited as not engaging with GP services for mental health issues (Bhal, 1999, p.13; Bhui et al., 2003, pp.112–114; NIMHE, 2003, p.12), despite an over-representation in GP consultations for general health reasons (Lloyd and Fuller, 2002, p.102). The African-Caribbean group is also under-represented in primary care services, despite significant over-representation in secondary or tertiary services[15] (Bhal, 1999; Bhui et al., 2003, pp.112–114; Rogers and Pilgrim, 2014, c.4; NIMHE, 2003, p.12; Synergi, 2017, p.3).

Contentions that such disparities are reflective of mental illness distribution across the population are no longer wholly accepted, despite the State implying they are (Department of Health, 2011b, p.59). For example, it might be expected that if the

African-Caribbean population do experience higher rates of SMI, they would also be over-represented in GP referrals to secondary or tertiary services. Yet the Care Quality Commission (2010) found referral rates were significantly lower for the black population[16], including the African-Caribbean grouping (Care Quality Commission, 2010, p.21). Additionally, indications of elevated rates of depression in community-based studies (NIMHE, 2004, p.12; Weich and McManus, 2002, p.25) are not supported by accompanying therapuetic treatment rates (NHS England and BABCP, 2019b, p.4; Connolly, 2010, p.170; Cooper et al., 2010, p.99; Hatch and Thornicroft, 2012, p.844; Nazroo and Iley, 2011).

Some scholars suggest that such trends reflect diagnostic issues within primary care settings (Glasby and Tew, 2015, p.167). For example, the State commissioned Inside Outside (2004) report suggests that ‘Black and South Asian patients are less likely to have mental health problems recognised by their GP or the nature of their presentation wrongly attributed to mental illness.’ (NIMHE, 2003). Lower recognition of mental health issues may result from the difficulties GPs experience distinguishing physical illness from somatised presentations of mental illness. Alternatively, the finding that South Asian groupings are under-represented in primary care might be consistent with findings of low or ‘proportionate’[17] representation in mental health services overall (Patel and Shaw, 2009, p.16), and therefore not indicative of inequalities requiring State-level intervention. There is, in the literature, a lack of consensus regarding the rates of ‘actual’ mental health issues/distress experienced by South Asian populations. For instance, in contrast to Patel and Shaw, Bhui et al.’s (2003) systematic review states that:

> South Asians had the highest community rates of mental disorder, were the most frequent consulters in primary care and were less likely than White people to have their mental disorder recognised (Bhui et al., 2003, p.112)

Referral rates to crisis care for certain Asian groupings have also been reported as disproportionately low (CAAPC, 2016, p.74)

The impact of cultural differences regarding attitudes to illness or issues arising from being a migrant to the UK are also explored in this context. For migrants, differences in health-seeking behaviour can be driven by relatively basic logistical issues. For example, a lack of knowledge about the range of services available is reported to contribute to the low levels of Asian women seeking support[18] (Fawcett and Karban, 2005, p.47). Linked to this is the more general role that language barriers among predominantly first generation migrants might play on people's abilities to seek support (NIMHE, 2003, p.12). Refugees and asylum seekers may also experience considerable difficulties registering with a GP, despite being entitled to healthcare (Fang et al., 2015, p.2; NIMHE, 2004, p.24). Although primarily logistical, addressing these issues is not always straight forward; cultural difference can add significant complexity that must be accounted for in policy responses. Patel and Shaw (2009) provide an example of when the 'solution' to one barrier – in this case the use of an interpreter to overcome language barriers – may give rise to yet another barrier to accessing mainstream support:

> traditional views on mental health that are commonly held by Gujaratis, makes it difficult for patients to disclose what they truly want to say as they feel that the interpreter will stigmatise them – particularly as they are likely to be from the same community. (Patel and Shaw, 2009, p.20)

Additionally, where there are both different conceptualisations of mental health and language barriers, barriers to communication between patient and healthcare staff are augmented (Thomas, 2016, p.467). An interpreter may have difficulties translating a GP's questions if the questions rely on Western conceptualisations of the mind and body, or there may be no equivalent terminology for things such as 'depression' (Patel and Shaw, 2009, p.21). As a result of such issues, some people may not seek support from mainstream services as they feel the services have inadequate awareness of these different conceptualisations and a lack of flexibility to accommodate other cultural norms. This demonstrates how solutions to barriers must always be considered in the context of wider issues. In this particular instance, conflicts in cultural norms in relation to illness and community dynamics play a significant role in the outcome of solutions that may – to a policy-maker – seem entirely logical and sufficient.

6.2 Adverse pathways to care and their impact

Key issues regarding adverse pathways into care, then, are the high rates of migrant, black and Asian populations entering mental health services by compulsory detention through use of the Mental Health Act (1983), far exceeding rates for white British people (Bhui et al., 2003; K. Bhui et al., 2015; CAAPC, 2016, p.74; Hatch and Thornicroft, 2012, p.844; NIMHE, 2003, pp.12–13; Singh et al., 2007, p.2; Department for Health and Social Care, 2018b, p.257). This might result in part from avoidance of mental health services in the early stages of mental health issues/distress. As Clement et al. (2015) note, 'delays may contribute to adverse pathways to care… the duration of untreated illness is associated with worse outcomes' (Clement et al., 2015, p.11), though the hypothesis of delays in treatment for psychosis is disputed (Morgan et al., 2006, p.246). One explanation for these delays relates to health-seeking behaviours that result in increased numbers within BAME groupings reaching an acute point with their mental health issues/distress. Another hypothesis relates to racism and racial prejudice, citing institutional and interpersonal racism in the police and judiciary services (Browne, 1997, p.21), and the possible role of 'transmitted discrimination' (Rogers and Pilgrim, 2014, p.60) as contributory factors.

Transmitted discrimination refers to instances where people call the police to report 'troubling' behaviour which is informed by racialised stereotypes. As a result, police attend to the 'public disturbance', initiating a process of transferring the discrimination felt at a community level into police action that might ultimately lead to sectioning under the MHA (Rogers and Pilgrim, 2014, p.60). Hypotheses regarding racism are supported by the high rates of primarily black people entering mental health services through police intervention or the criminal justice system (Browne, 1997; Hatch and Thornicroft, 2012, p.844; Rogers and Pilgrim, 2014, pp.59–61), and repeated findings of racism and racial prejudice in these systems (Ministry of Justice, 2017; MacPherson, 1999).

Indeed, some research has found that many BAME people found mental health services and the pathway to care to 'replicate the experiences of racism and discrimination of black people in wider society' (Keating and Robertson, 2004, p.442). This has been reported as having a significant impact on health-seeking behaviours among black populations in particular, by inciting fear of services.

‘Breaking the Circle of Fear’ (2002) describes the ‘circle of fear’ that inhibits many black people from seeking health care for mental health issues (SCMH, 2002). Researchers working on the project wrote that:

> Sources of fear include perceptions of MH services, attitudes to mental illness and diagnosis, and experiences of hospital care. The impact of fear included limited trust, limited engagement and delayed help-seeking behaviour. …these fears mar the interactions between these communities [African and African-Caribbean] and MH services, affect help-seeking behaviour adversely, and lead to restrictive and punitive interventions. (Keating and Robertson, 2004, p.439)

Black populations are more likely to have negative experiences of mental health services which include greater exposure to coercive treatments among other things. Awareness of this generates fear which is amplified by experiences of marginalisation in other aspects of life, perhaps as a result of minority ethnicity or from mental health issues/distress. Therefore, people may actively avoid seeking support for mental health in the early stages of any issues/distress (Bhugra et al., 1997, pp.793–794; Singh et al., 2007, p.3), increasing the chances of entering mental health services at the point of crisis - perhaps through involuntary detention. Often this involves the police, criminal justice system and the use of sectioning under the Mental Health Act (1983). This may then elicit more coercive treatment plans and provides the circumstances for increased violent incidences, resulting in more severe treatment conditions (Sheehan et al., 1995, p.598). Staff perceptions of black male patients have also been reported to include perceptions of increased tendencies for violence, leading to differential treatment (Browne, 1997, p.20). Singh et al. (2007) take the view that the influence of racial prejudice on staff behaviour is not a significant factor in BAME mental health inequality in a service context.

Concerns regarding inequalities continue to be raised by healthcare professionals, academics, BAME service users/survivors and their organisations. Indications that this circle of fear is still present is provided by the Mental Health Act Review African and Caribbean group’s recent report calling for mental health services to:

> build confidence [in communities] that they can adequately respond to the needs of African and Caribbean people in the right way at the right time. This should encourage people with mental health needs to present earlier and avert crisis. (Department for Health and Social Care, 2018a, p.60)

Indeed, the new PCREF (see p.10-11) – if taking the form of that recommended in the above cited report - seeks to address this issue. Such issues are not, however, limited to the black African and African-Caribbean people. For example, though the specifics involved might differ for Irish people, there is evidence to suggest that the racialised stereotyping of Irish people contributes to a tendency to seek help through Accident and Emergency services rather than through primary care services (NIMHE, 2004, p.19).

6.3 Diagnostic practices in the context of minority ethnicity

Issues pertaining to diagnostic practices specifically are difficult to separate from the racialisation involved in the construction of diagnostic categories (see section 3), with diagnostic processes problematic in:

> the way assessments are carried out, in the colour-blindness involved in ignoring ways of thinking other than those of European culture and the insights derived from 'white knowledge', and so on (Fernando, 2017, p.93)

The construction of diagnostic categories aside, issues seem to relate to two main factors: cultural difference or racialisation/racism. In relation to the impact of cultural differences, these include the difficulties previously mentioned regarding healthcare professionals' ability to detect mental health issues. Another significant issue is that phenomena considered to be within social norms in some cultures are interpreted in western medicine as deviant or abnormal. This can lead to diagnoses of mental illness that would be considered inappropriate in the person's own culture (Morgan et al., 2009, p.234; Sharpley et al., 2001, p.60). Sharpley et al. provide an example relevant to diagnoses of schizophrenia among people of black African and Caribbean heritage:

> Modern Western cultures do not assign credibility to hallucinations, and generally regard them as pathological. However, in many non-

> Western societies, hallucinatory experiences are not considered bizarre, and are considered ‘real’ as opposed to ‘as if real’ (Sharpley et al., 2001, p.60)

Because hallucinatory experiences are not accepted within the Western medical paradigm as indicative of experiencing phenomena beyond the individual, they are deemed evidence of illness.

A further issue relates to stereotyping and how this can reinforce diagnostic categories underpinned by racism and racial prejudice, with ‘cultural and racial stereotyping’ impacting on ‘the types of services and diagnosis individuals from minority backgrounds seek and receive’ (NIMHE, 2003, p.12). ‘Seek’ here refers to the health seeking behaviours that result from issues such as the ‘circle of fear’. ‘Receive’, however, refers to the ways in which mental health care and psychiatric practices are influenced by such stereotyping. This can lead to failures to diagnose or the mis-diagnosis of people, resulting in the wrong treatments being offered. Sashidharan provides the example provided of the stereotyping of Irish people as alcoholics and their over-representation in psychiatric wards with diagnoses of ‘alcohol disorders’. The contention is that the stereotype of the Irish ‘lush’ was resulting in early (mis)diagnosis of alcoholism, where diagnosis of CMD/distress might have been more appropriate. This can result in being referred to inappropriate services or treatment options. In today’s system, people misdiagnosed in this way may experience additional barriers to accessing appropriate support due to the segregation of substance misuse and mental health services and the requirements services place on people (Institute of Alcohol Studies and Centre for Mental Health, 2018). For example, many mental health services will not accept people who turn up having drunk alcohol that day.

Perhaps the most frequent example of the influence of racialised stereotypes in this area, however, is that highlighted in part A regarding black men and schizophrenia. Additionally, the literature raises issues pertaining to the relationships between predominantly white psychiatrists and people of colour being assessed. For instance:

> the relationship between professionals and Black people are adversarial from the start for various reasons, e.g., their past

> experiences with psychiatry, the police and other institutions. It is therefore difficult to take a full history in order to arrive at an accurate assessment of the situation. There is a perceived pressure to make a quick diagnosis that leaves no space or opportunity to make a tentative diagnosis. (SCMH, 2002, p.45)

Findings like this draw attention to the distrust reported in many black communities towards mental health services.

6.3 Responses to diagnostic labels

Issues such as those highlighted in the above sections are perceived as impacting on the ways in which many people from BAME backgrounds respond to diagnostic labels. For example, the female BAME mental health service user/survivor led report Recovery and Resilience (2011) presents findings that:

> Acceptance [of the biomedical model and accompanying labels] was a complicated process based on whether a given explanation and/or diagnosis made sense of their experiences, the level of self-blame, isolation and other stigmatising factors that a person experienced, and whether the bio-medical explanation and the accompanying treatment involved some kind of “therapeutic alliance” (Kalathil et al., 2011, p.30)

Essentially, acceptance of the biomedical model and diagnostic labels was dependent on how it corresponded to lived experience and the role it played in empowering or disempowering participants. The women’s intersectional locations added to the complexity of negotiations of diagnostic categories, in which stigma related to mental health and mental illness might add another layer of disempowerment. Within mental health discourses stigma is often understood as resulting from the process of labelling difference and applying negative stereotypes to these labels (Link and Phelan, 2006, p.528), impacting people’s willingness to accept diagnoses and seek (stigmatising) treatments (Clement et al., 2015, p.21). For BAME groupings in particular, alternative beliefs about the causes of mental health and intersectional location can complicate this stigma (CAAPC, 2016, p.74).

For example, widely held beliefs that mental health issues/distress result from fate or from being possessed by evil spirits among the Chinese grouping can create a form of ‘moral’ stigma that western secular societies don’t have in the same way

(NIMHE, 2004, p.18). Similar beliefs have been reported among people of African and African-Caribbean descent, as well as views expressed by religious leaders in this grouping that mental health issues/distress are indicative of a 'moral failing on the part of the individual.' (Mantovani et al., 2017, p.375) Although religious belief and communities can act as a protective factor against the development of mental health issues (see p.72), it also has the potential to augment stigma. Mental 'illness' might also be more stigmatising in societies where there is an emphasis on social harmony over individual concerns (Ryder et al., 2002, p.12).

Additionally, some cultures set a very different bar before they consider a person to be experiencing mental health issues. For example, Mantovani et al. (2017) also found that some people of African descent associated 'mental health' with 'madness' or 'insanity'. One participant explained this, stating:

> Those of us from Black background… our perception of mental illness is somebody's totally derailed and is walking the street probably naked. …and so if anyone tells you that you have a mental health issue you are ready to fight them… …because we relate mental health to insanity, a total level of insanity. (ibid, p.376)

Cultural norms that differ from those in the UK may then contribute not only to delays in seeking support, but also add to stigma around treatment by implying more severe illness/distress than the person is comfortable with. Such norms, together with understandings of mental health issues/distress linked to being 'evil' or negatively 'fated', also serve to increase 'associated' or 'familial' stigma; the stigma felt by family and friends by association. Within certain BAME groupings, there is a greater impetus to hide or a refusal to accept that a family member experiences mental health issues/distress. For example, some Asian groupings attach loss of status within the community to having family members that experience disability (of which mental health might be a form). Repercussions might include unmarried family members or the person experiencing distress having more difficulties finding a partner due to fears of hereditary 'khootum'[19] issues (Katbamna et al., 2000, p.15; Knifton et al., 2010, p.2). Concerns about family reputation and fear of contagion by association have also been reported among some black populations (Mantovani et al., 2017, p.378). Together with the issues relating to the 'circle of fear' and stigma, the perception that available treatments are ineffective or inappropriate contributes to yet another form of intersectional barriers impacting on the health-seeking behaviours of BAME groupings (Henderson et al., 2013, p.777; Knifton, 2012, p.287), including acceptance of diagnostic labels.

8 Using mental health services

Once people of BAME backgrounds have entered into mental health services, a number of further inequalities are raised in relation to their experiences using the service. Overall, BAME service user/survivor satisfaction across primary, secondary and tertiary mental health services are reported as lower than for the general population (Glasby and Tew, 2015, p.168; Lloyd and Fuller, 2002, p.101; NIMHE, 2004, p.20; NIMHE, 2003, p.12). Reasons for this are many, and alter according to ethnicity and racialisation.

7.1 Coercive procedures and approaches

Inequalities related to in-service experiences often highlight the disproportionate use of coercion and force on people of BAME backgrounds, mirroring issues relating to pathways to care. Once more, research often centres on the experiences of black populations, primarily men. However, more recently the disproportionally high number of black women detained in services involuntarily has received attention (Bansal et al., 2014; CAAPC, 2016, p.74; Department for Health and Social Care, 2018b, p.257). There is also evidence to suggest that some women fear entering mixed sex wards, particularly if they have been subject to domestic violence (Kalathil et al., 2011, p.48). Overall, key issues raised are:

- increased likelihood of treatments delivered coercively;
- increased risk of being placed in secure units;
- likelihood of enduring longer stays on wards; and
- exposure to racism and discrimination from both staff and patients.

Whilst some research contends that increased detentions, longer stays and use of secure units are likely reflective of need arising from ‘actual’ SMI (Bansal et al., 2014; Bowers et al., 2017, p.19; Singh et al., 2014, p.1003), recent qualitative research undertaken to inform a review of the MHA83 supports claims that mental health services reflect ‘discriminatory practice at the hands of the police’ (Department for Health and Social Care, 2018a, p.43). This reinforces views that racism and discrimination experienced in wider society are reflected in these services (Keating and Robertson, 2004, p.442; Adebowale, 2013, p.26). The result being that black African and African-Caribbean people are more likely to experience ‘unnecessary use of force; unjustified suspicion; lack of effort to communicate; overuse of sectioning; more restrictive care’ (Department for Health and Social Care, 2018a, p.43). ‘Restrictive care’ includes hospitalisation, deployment to secure units and use of physical restraints. An earlier review of mental health services also found BAME groupings to have experienced overt racism at the hands of staff (CAAPC, 2016, p.71). This adds to findings from reviews and inquiries that found evidence of exposure to racism from other patients, which is either dismissed or acknowledged but unaddressed by staff (Blofeld et al., 2003; Prins, 1993; Department for Health and Social Care, 2018b, p.292).

For those who are not inpatients on psychiatric wards, BAME groupings experience discrepancies in the provision of Community Mental Health Team (CMHT) support, with Asian groupings less likely to receive such support and black populations more likely (Hatch and Thornicroft, 2012, p.844). Additionally, black patients are significantly more likely to be placed on Community Treatment Orders (CTOs) (Department for Health and Social Care, 2018b, p.10). CTOs enable certain healthcare practitioners to enforce treatment on people even after they have been released to live in the community. An example might be that someone is released from hospital on the condition that they have regular doses of medication by injection by healthcare workers. They cannot simply decide to stop their medication. Thus, even when not detained, black patients are still more likely to experience coercive treatment.

Higher rates of people of BAME backgrounds in secure units and seclusion are reported (Care Quality Commission, 2010, p.21; Griffiths, 2018, p.14; NIMHE, 2004, p.12; Department for Health and Social Care, 2018b, p.10). This is explained in numerous ways, including allegations that BAME patients are involved in violent incidents more often than white British patients (Fawcett and Karban, 2005, p.45). Another explanation offered is that exposure to more coercive pathways to care provoke a (marginally) increased involvement of black patients in violent incidents recorded (Sheehan et al., 1995). Many researchers contest that more coercive practices result from ‘actual’ aggression, pointing out that there is little evidence to support this. Some even suggest that levels of aggression are actually lower among black patients (Keating and Robertson, 2004, p.445). It is stated that stereotypes of the ‘big, black and dangerous’ sort influence staff, and therefore the treatment provided (Prins, 1993; Department for Health and Social Care, 2018a, p.43).

7.2 Treatments

Here I explore trends regarding treatments provided within mental health services, (though some of these treatments are also available through primary care services). I do not make judgements regarding the efficacy or reasoning behind specific treatments, but highlight disparities specific to BAME populations. Overall, findings tend to demonstrate that ‘black communities receive the MH services they don’t want, but not the ones they do or might want.’ (Keating and Robertson, 2004, p.439).

7.2.1 Medication

I mention in section 7.1 issues pertaining to forced medication when people are placed under CTOs. Another significant issue in relation to medication is the perception that BAME groupings experience an over-reliance on medication by mental health professionals and are at greater risk of overmedication. The over-reliance on medication in mental health services is not, however, specific to BAME mental health inequality. Indeed, this highly contentious debate is conducted globally and regardless of ethnic groupings (Connolly, 2010; Hutton et al., 2013; McHugh et al., 2013; Mosher and Bola, 2013, p.373; Patel et al., 2014; Quirk et al., 2012; Tseris, 2019). More specific to BAME populations in England are claims regarding overmedication and medication provided without talking therapies to accompany them; issues repeatedly highlighted in public inquiries, independent reviews and qualitative BAME service user/survivor research (Blofeld et al., 2003, p.68; Fitzpatrick et al., 2014, p.7; Griffiths, 2018, p.14; Kalathil, 2008, p.4; Lindridge, 2007; Lloyd and Moodley, 1992; Department for Health and Social Care, 2018a; SCMH, 2002, p.11; Race Equality Foundation, 2014, p.1).

Reasons provided for an over-reliance on medication by staff in psychiatric wards when attending to BAME service users/survivors are many. A recent cross-sectional study highlighted evidence that ‘depot preparations were more likely to reduce the risk of relapse compared to oral preparations’ (Das-Munshi et al., 2018, pp.7–8), implying that this might explain higher use of injections among a population grouping with high relapse rates. More frequently highlighted, however, are the lack of time and resources available to provide alternative care and the role of stereotypes. For example, where:

> prejudice and the fear of violence influence risk assessments and decisions on treatment, responses are likely to be dominated by a heavy reliance on medication and restriction. (ibid, p6).

In line with this, some quantitative research indicates an increased risk to people of some BAME backgrounds being prescribed excessive amounts of medication, particularly psychotropic medications in psychiatric care (Blofeld et al., 2003, p.68; Keating and Robertson, 2004, p.440; Department for Health and Social Care, 2018a, p.46).

Many BAME service users/survivors express fear of medication in user-led and other qualitative grey literature. Their fear tends to centre around being over-medicated; a situation not aided by a lack of information provided, particularly in relation to side-effects (Griffiths, 2018, p.7) and the loss of power and agency in relation to professionals able to enforce prescriptions (SCMH, 2002, pp.24–25). Even among participants who expressed some positive results from medication (Kalathil et al., 2011, p.60; Race Equality Foundation, 2014, p.3; SCMH, 2002, p.37), side-effects were still a concern. Side-effects cited include people becoming like ‘zombies’, limiting one’s ability to work and provoking physical health issues (Race Equality Foundation, 2014; SCMH, 2002; Griffiths, 2018, p.37). This was sometimes accompanied by a perception that the provision of medication enabled a lack of other support to continue (Griffiths, p.41). Examples of views related to power and agency include the following extract form a BAME service user/survivor:

> They [professionals] try to succeed in their way, that is to prescribe medication, and they don’t take you seriously, so what is the point? They’re not there to help me, so why should I talk to them? (ibid, p31)

Another BAME service user/survivor led report states that where participants did accept medication as useful, they still made a ‘clear distinction between medication as a necessity for symptom control and ‘real’ recovery’ (Kalathil et al., 2011, p.10), with real recovery often involving addressing the more socio-cultural root causes.

Views that medication is administered in a way that pushes the need to address wider social issues and inequalities aside are found in much of the grey literature (Fitzpatrick et al., 2014, p.28; Race Equality Foundation, 2014, p.3). Refusal to consider wider social issues and the situatedness of some service users/survivors has also been reported as leading to some of the most marginalised people having to face difficult decisions regarding their treatment. For example, asylum seekers were highlighted as having to choose between buying medication or food at times (Griffiths, 2018, p.21).

7.2.2 Talking therapies

Issues highlighted in relation to talking therapies and BAME mental health inequality often relate to low referral rates to services such as Improving Access to Psychological Therapies (IAPT), lower completion of talking therapy treatments and lower recovery outcomes among BAME groupings (Baker, 2020, pp.18–19; NHS England and BABCP, 2019a; Das-Munshi et al., 2018; Fitzpatrick et al., 2014, p.8; Kalathil et al., 2011, p.11; Perfect et al., 2016, p.13). Logistical issues once more include language barriers (Mind, 2009, p.3). More generally, one suggested explanation for the low success rates of talking therapies is the Eurocentric nature of such therapies (Tribe, 2014, p.137). The need for greater cultural competency in therapeutic settings is emphasised by some academics/practitioners and BAME service users/survivors alike. For example:

> All you need to do is look at all the psychologist (…) they're usually White. They're usually female. None of them, studied, ya know, transcultural therapy. So they don't know what you know and then they say (…) the person's not therapeutically minded (Participant quote, Department for Health and Social Care, 2018a, p.45)

This lack of diversity is often cited as leading to a want in understanding of other cultures, of racism and highly secular approaches, resulting in offers of support that feel inappropriate for some. A report published by the BAME service user/survivor organisation Kindred Minds states that:

> On the rare occasions we are offered talking therapy, it is likely to be cognitive behavioural therapy, with no access to a broader range of approaches. … there is very little access to culturally appropriate

> and diverse treatments that we would find more helpful. (Griffiths, 2018, p.26)

Such findings support calls for greater emphasis on developing cultural competency among mental health staff and therapists (Alleyne, 2008, p.173; K.S. Bhui et al., 2015; Chowdhary et al., 2014; Department for Health and Social Care, 2018a; Department for Health and Social Care, 2018b, p.56), a need recognised in NHS England guidance to IAPT services (NHS England and BABCP, 2019b, p.5). Other improvement measures suggested in the guidance include: ensuring there is adequate consideration of literacy and language proficiency of service users, and making information available in other languages; using a range of distribution networks to spread awareness of services; being flexible around appointments and checking preferences regarding the gender and background of therapists (NHS England and BABCP, 2019a, p.7).

Fernando (2017) warns, however, that there is also reason to be cautious of cultural awareness programmes, highlighting that unless implemented with great care, there is a risk that such learning will translate into a form of cultural profiling similar in practice to stereotyping. Examples of this already exist. For instance, awareness of the importance of family in treatment and recovery among some Asian communities sometimes leads to the assumption that Asian people prefer to ‘look after their own’, or that talking therapies are not suitable due to language barriers that are more likely among certain ethnic groupings (Kapadia et al., 2018, p.304; NIMHE, 2004, p.30; Patel and Shaw, 2009, p.21). As a result, treatment options might be withheld.

Other stereotypes highlighted as impacting on referrals to psychological therapies have a more racist tone, and pertain to people of BAME backgrounds being more often perceived as not being psychologically minded, ‘unsuitable’ or ‘lacking in insight’ (Department for Health and Social Care, 2018a, p.45; SCMH, 2002, p.80); a remnant of colonial thinking (Fernando, 2017, p.105). A further barrier relating to racism is the general inability to address or the discomfort and subsequent avoidance of discussing experiences of racism by (predominantly white) therapists and psychiatrists (Bhui et al., 2012, p.196). This failure to recognise ‘the justified anger arising from racism in society… even if personal discrimination is recognised in a theoretical sort of way’ (Fernando, 1995, p.32) means that, although the link between oppression and mental health issues/distress is recognised theoretically, in practice racism is either ignored or misinterpreted as evidence of paranoia. This claim is supported by the findings of inquiries following the deaths of BAME inpatients (Blofeld et al., 2003, pp.23–25; Department for Health and Social Care, 2018a, p.43; Prins, 1993, pp.51–55).

Professional bodies (or sub-committees within them) and activists have subsequently produced and disseminated a range of race equality and cultural awareness training materials (NHS England and BABCP, 2019b; Fernando, 2017, sec.6.2; Sewell, 2009; Tribe, 2014, p.137). Indeed, race equality training was a central measure in the DRE programme (see Appendix 5). However such problems are not easily overcome (Moodley et al., 2019, pp.85–86; Sewell, 2009, p.40), and:

> fear of working with the other can result, on the one hand, in race becoming either absent or marginalised in psychotherapy… On the other hand, if race becomes the singular focus, then therapists are accused of reifying race (Moodley et al., 2019, p.83)

Moodley et al (2019) go on to advocate for therapists to acknowledge the person's multi-faceted identity; including sexuality, gender, class etc. Although few and far between, there are a number of scholars and practitioners calling for consideration of multiple and intersectional aspects of experience in therapeutic practice (Kalathil et al., 2011, p.48; Moodley et al., 2019; Newland et al., 2015, p.173). Some call on therapists to:

> step beyond the comfort of familiar, but narrow confines of our approaches which focus only at the level of the individual; …and direct our interventions also to the to the social context in which people live, suffer and survive. (Newland et al., 2015, p.182)

In this way, therapy may seem more appropriate to people in marginalised and intersectional locations.

This section has focused on one-to-one interventions due to a dearth of recent studies regarding the experiences of people from BAME backgrounds in group therapy in the UK. The research I did find tended to be based in America, with some highlighting the need for the facilitator/therapist to be aware of dynamics between ethnic groupings in mixed-ethnicity groups (Chang-Caffaro and Caffaro, 2018; Tsui and Schultz, 1988). UK studies tended instead to emphasise the need to for interventions to be ‘culturally sensitive’ (Masood et al., 2015, p.1; NICE, 2017; Vahdaninia et al., 2020, p.13).

7.2.3 Alternate treatments and cultural norms

Some research highlights that people with non-western cultural backgrounds and alternative understandings of mental health may prefer to seek out treatments outside of western medical and therapeutic options. For example, instead of turning to a GP or therapist, they may seek support from spiritual healers who might advise prayer, fasting or perform exorcisms (Arshad and Johal, 1999, p.66; Mantovani et al., 2017, p.379). Or as an alternative to western medication, they may seek herbal remedies or acupuncture (Patel and Shaw, 2009, p.19). Different cultural norms around illness also contribute to people feeling that services are not appropriate for them. For example, norms surrounding illness for some BAME groupings include the family playing a significant role in the recovery process. Yet this is not always recognised by services (Mind, 2009, p.13).

Additionally, western approaches that exclude families from the treatment process can serve to reinforce perceptions of stigma by association, due to the employment of theories that ‘delineated the family as the pathogenesis of the individual’s mental illness.’ (Gary, 2005, p.988). These understandings therefore support treatment approaches that distance the person from their family. For some minority ethnic populations, stereotyped views of either the family makeup (e.g. – the absent black father) or norms for social roles (e.g. – the subjugated Muslim woman) feed into health-seeking behaviours that avoid such stigma. Such factors can lead to greater social isolation and exclusion ‘at the level of individual, family and society’, which might then be ‘compounded by the discrimination and racism associated with membership of an ethnic minority community.’ (Knifton et al., 2010, p.2) Here we see the emergence of multiple or intersectional stigma, often referred to as ‘double’ or ‘multiple’ stigma (Gary, 2005, p.979; Henderson et al., 2013, p.777).

9 Conclusion and calls for change

In this chapter I have set out the current state of the literature in relation to BAME mental health inequality in England. In part A, I provided an overview of the trends suggestive of an area of inequality. Further, I explored some of the epistemological issues in mental health discourses that require consideration in the context of marginalised groups, 'race' and ethnicity. Parts B and C proceeded to examine the trends highlighted in further detail, dividing discussions into the determinants of mental health inequality to debate epidemiological trends, and research to explain trends found in service outcomes and experiences. Though debates regarding nearly all aspects of this subject area remain highly contentious, there is a general acceptance that an inequality is present. The challenges come when defining what these are and how they come to be. Gaps that I identified in the literature include the need for greater understandings of:

- Incidence and prevalence of mental health issues//distress classified as CMDs;
- the 'open systems' that impact on racialised people's mental health and health-seeking behaviours;
- how intersectional location impacts on mental health and support service experiences; and
- how all of the above impact on under-researched BAME groupings, particularly newer minority groups to the England, 2nd/3rd generation migrants and people of 'mixed' ethnicity and those in the white 'other' grouping who are increasingly exposed to xenophobia.

In thinking about ways forward, it is no surprise that scholars, practitioners and activists suggest an array of measures that they feel need to be implemented to drive change. These measures are generally targeted at either healthcare practitioners and therapists, or at the State. The first is one that receives wide recognition and is promoted without much opposition; ensuring that services become more culturally sensitive and for staff to develop greater cultural competence. 'Cultural competence' in healthcare includes having services and staff that are able to 'identify cross-cultural expressions of illness and health' (Metzl and Hansen, 2014, p.126) and provide services that are 'sensitive to the needs of people from diverse backgrounds' (Thomas, 2016, p.463). However, this must be implemented with care and, as Fernando (2017) and Bhui et al. (2012) note, without an avoidance of addressing racism.

Other calls for change tend to fall into two camps recognisable by their emphasis (or lack thereof) on racism. On the one hand there are those who feel that a focus on racism within mental health services is unhelpful in addressing BAME mental health inequality (Morgan and Hutchinson, 2010, p.707; Singh, 2009). They call on the State to increase investment in geographic areas of high BAME populations to enable services there to better meet the needs of BAME service user/survivors. This is underpinned by the view that higher rates of diagnosis are reflective of 'actual' illness. Singh and Burns reject accusations of institutional racism in mental health discourses and practices as a driving factor in the trends seen, though they allow that racial discrimination 'undoubtedly occurs in British society and leads to much personal suffering and possibly also to mental illnesses' (Singh et al., 2007, p.17). However, they maintain the position that a focus on racism detracts from the provision of much needed support and may lead to 'damaging consequences for the profession, ethnic minority groups, and, most crucially, for ethnic minority patients' (Singh and Burns, 2006, p.650).

In opposition to this, many scholars whose work focuses specifically on BAME mental health inequalities call for racism in mental health discourses and practice to be addressed. Scholars such as Fernando, Nazroo and Bhui insist that inequalities such as those represented by the trends cannot be resolved without a concerted focus on racism at the micro, meso and miso levels (Bhui et al., 2018; Byrne et al., 2020; Fernando, 2017; Nazroo et al., 2019). For example, Nazroo et al. write that 'racisms are fundamental causes of observed race/ethnic inequalities in risk of severe mental illness and in outcomes relating to severe mental illness'. Addressing BAME mental health inequality therefore requires examination of:

> the ways in which structural, interpersonal and institutional racisms operate and mutually constitute one another. …alongside a focus on other sources of social and economic inequality, it is crucial that the public health agenda pays close attention to issues of racism and how they shape the lives of race/ethnic minority people. (Nazroo et al., 2019, p.12)

The implication for policy is that there is need to address not only racism and racial prejudice at the interpersonal level, but at the institutional and epistemological levels also. Initiatives from such positions might include examining how stereotyping influences decisions, increasing BAME representation at all levels of staffing, re-interrogating diagnostic categories and their application, and recognising intersectional forms of racism. Instigating action to do this requires an explicit recognition by professional bodies and the State of the existence of institutional racism in mental health discourses and systems. Though the recognition of racism provided by the RCP in the MHA83 report (2018) was a step in the right direction, many feel that it does not quite go far enough. For example, Fernando highlights that it 'fails to even mention institutional racism' and 'raised false hopes in the minds and hearts of many black people' (Fernando, 2018).

In literature emerging over the recent years, I have increasingly seen discussion of the need to address intersectionality in this space (Bhui et al., 2012, p.186; Griffiths, 2018, sec.2; Mantovani et al., 2017, p.381; Nazroo et al., 2019, p.4; Department for Health and Social Care, 2018b, p.258). Historically, there has been some resistance to taking 'single equalities' approaches to address inequalities experienced by BAME groupings in England. This stems from a fear that such an approach might 'obscure the particular drivers of inequality in a specific domain' (Vige and Sewell, 2012, p.146). This perspective is understandable when we consider that the implementation of a 'single equalities' approach in the NHMH (2011) resulted in the strategy addressing BAME mental health inequality being reduced to a few short paragraphs. However, it is my view that the NHMH (2011) is simply an example of the single equality approach being poorly utilised to develop strategy. However, a single equalities approach still falls short of intersectionality as it does not necessitate consideration of how systems of oppression mutually sustain each other or emphasise the specificities of intersectional experiences. I recall Crenshaw's statement that:

> focus on the most privileged group members marginalises those who are multiply-burdened and obscures claims that cannot be understood as resulting discrete sources of discrimination. I suggest further that this focus on otherwise-privileged group members creates a distorted analysis of racism and sexism because the operative conceptions of race and sex become grounded in

> experiences that actually represent only a subset of a much more complex phenomenon. (Crenshaw, 1989, p.140)

Crenshaw insists that to truly address racism, intersectional experiences must be accounted for, a position also taken by other intersectionality theorists.

Interestingly, people emerging as supportive of intersectional approaches tend also to highlight the need for action that ‘deal[s] with the complexity of socio-economic factors or the experience of racism’ and ensures that ‘broader attention is paid to the structural and societal factors that cause ethnic inequalities in health, without which ‘progress on reducing them will be minimal’ (Byrne et al., 2020, p.320). This aligns with calls for recognition that ‘future policy to reduce racial inequality in mental health will need to locate its mission more in the realm of human and civil rights and public health’ (Sewell, 2014, p.86). By this, I take Sewell to be calling attention to the multiple and intersecting ways in which racialised people experience inequality, discrimination and oppression such that BAME mental health inequality emerges.

Such views open up space for policy-makers to recognise not only the various forms of racism that must be addressed, but also the interconnectivity of a range of oppressive experiences. I note Synergi’s recent employment of the vocabulary of ‘wicked problem’ (Bhui et al., 2018, p.576) in one of its reports. In my view, the introduction of this concept demonstrates an acknowledgement that addressing BAME mental health inequalities requires addressing not only racism, but also other ‘open systems’ that impact on the lives of people from BAME backgrounds with mental health issues/distress; albeit without losing sight of the importance of issues stemming from racism and racial prejudice. In this, scholars advocating for and against a focus on racism in psychiatric practices are joined in highlighting the need to address wider social inequalities so as to take preventative measures. Together, these calls articulate a need to consider the wide systems which produce and reproduce the array of inequalities highlighted in the body of this chapter; many of which appear in the testimonies of participants in the two chapters that follow.

Participants and their intersectional locations

Andeep: A Sikh, middle age man, Andeep indicated having previously experienced depression and difficulties with alcohol. His views about currently experiencing depression or not alternated throughout our conversation. At the time of our interviews he was unemployed, though he spoke of being a carer for his mother. Andeep expressed his aspirations of one day returning to work and a desire to undertake qualifications in computing. He is currently unmarried.

Mahdi: Mahdi is a young Afghan man in his early 20’s who received refugee status a few days before our first meeting. He described experiencing a number of psychosomatic symptoms as a result of trauma, and has made several suicide attempts. Born into a Shia Muslim family, he has now converted to Catholicism. Though married to a British woman, Mahdi and his wife separated during the course of this research, leading to his having an unstable housing situation for about a year. He has no other family, as they were murdered in the Afghan conflict; around the age of 11, Mahdi was taken prisoner by the Taliban for 7 years. He is currently unemployed and living in council housing, though he aspires to work one day. He has no formal education, but feels he has learnt much from the ‘university of life’.

Mya: Self-identifying as a white British middle-class woman, Mya is also a third-generation migrant of Jewish descent. Mya experiences anxiety and some suicidal thought, and mentioned undergoing assessments for another undisclosed diagnosis. A qualified occupational therapist, she is currently unemployed due to her mental health. Though not identifying with any one religion, she has moved from being agnostic to having a strong faith in a God in recent years. Mya is unmarried and gave no indication of living with a partner, and her family do not live nearby.

Peter: A black man in his late 50’s, Peter migrated to England with his family in his early life. Peter preferred for his country of origin not to be disclosed in this thesis. Experiencing ‘*depressive moods*’, Peter also describes experiencing some difficulties with his physical health. Having been brought up in a Baptist family, Peter now identifies as spiritual without adhering to a particular religion. Previously a business man and owning his own home, Peter did not disclose his current employment status. Peter lives alone, but indicates having family nearby, including grandchildren.

Samaiya: Samaiya is a Muslim woman of Bangladeshi descent in her mid-30’s. She experiences anxiety and depression, and describes having several physical health issues. She explains that chronic illness in childhood has significantly impacted her mental health as an adult. Samaiya also experiences learning difficulties that have led her to have low literacy and numeracy skills, though she would like to address this one day. Samaiya has never been in employment. Living with her parents and other family members, she helps in the house and with her nieces and nephews when feeling well enough. She is very close to a sister who currently lives abroad.

Samantha: In her mid-30’s, Samantha is a black woman who migrated to the UK from Swaziland in her 20’s. Samantha describes experiences of anxiety and depression and describes having hallucinations at times. She experiences difficulties with alcoholism, but became sober half-way through this research. Samantha also has a number of physical health conditions, including HIV, epilepsy and a newly acquired visual impairment. Samantha has a strong faith in God, identifying as Christian. Divorced, Samantha currently lives alone in council housing. Presently unemployed, Samantha previously worked in the hospitality sector, gaining college qualifications in his area.

Satch: A black British man in his late 50’s, Satch was born in England to an Irish mother and Puerto-Rican father, and was raised in a children’s home from the age of 5. He describes experiencing stress, anxiety and sadness, making two suicide attempts during this research. An ‘*old man addict’*, Satch has been largely sober of class A drugs for more than 15 years. Satch has numerous physical health issues limiting his mobility, such as COPD. Satch identifies as part of the ‘Dreads’ scene, holding beliefs aligning with Rastafari spiritualism, though he rejects some aspects of the religion. Previously living alone in council housing, he now lives in sheltered accommodation. Unable to work, Satch was previously a labourer and was in prison on multiple occasions. He has several children and grandchildren.

Experiences of mental health issues/distress: As previously mentioned (p.29), I do not provide details of participants’ mental health diagnoses in this thesis. However, an overview of participants’ descriptions of their mental health issues/distress is provided in Appendix 20.

Chapter 4: Mental health - understandings from BAME intersectional locations

The previous chapter provided an overview of the literature discussing BAME mental health inequality pertinent to policymaking activity, with parts A and B addressing how the issue is defined and the main aetiological theories explaining epidemiological trends indicating inequality. Here, I explore the perspectives of the seven core participants described in the previous pages. I use a range of mental health terminology throughout this and the following chapter, reflecting participants' terminological preferences. For example, I employ the term 'mental illness' when presenting testimony from Mahdi and Mya, and 'mental problems' when referring to discussions with Samantha. When making general points, I employ 'mental health issues/distress', in an attempt to encompass all perspectives.

First, then, I explore how systemic inequalities influence participants' views of mental health issues/distress as it effects social groupings of which they are members. I also consider participant choices regarding mental health terminology in more detail, examining how these are negotiated from their specific intersectional locations. In part B of this chapter, I seek to present participant views and understandings of the determinants of mental health issues/distress. I focus primarily on determinants that participants indicate as impacting people who share marginalised or stigmatised identity-makers. This is with a view to developing an understanding of their views on the determinants relevant to BAME mental health inequality, as opposed to more general contributory factors in mental health.

Part A: Defining BAME mental health inequality

Most participants did not comment specifically on trends situating people of BAME backgrounds as at increased risk of (diagnosis of) mental health issues/distress. However, several did raise issues of social inequality that disproportionately impact people from BAME backgrounds. Mahdi spoke passionately about the way that State policies regarding asylum seekers not only traumatise, but drive some people towards acts of suicide. Such acts are often perceived within western mental health discourses as symptomatic of or as a mental health issue (Bennett, 2006, pp.216–221). Thus, though Mahdi does not speak about the aetiological trends highlighted in the previous chapter, he provides an example of systemic issues that he feels result in increased risk of mental illness at the population level. Similarly, Samantha and Mya highlight – albeit briefly – issues pertaining to cultural differences and how these might provoke mental health issues/distress. For Samantha this relates to not feeling able to express herself adequately without being judged as breaking with English norms of communication. Mya's example highlights issues arising from the intersection of gender and minority ethnicity. She explains that women living in multicultural contexts have to navigate multiple and conflicting social expectations, which can negatively impact on a person's mental health where stigma and judgement is present. Both examples disproportionately impact people of BAME backgrounds, particularly migrants and their descendants.

Peter, however, does comment directly on the issue of BAME mental health inequality. He does not believe black people are predisposed to mental health issues/distress at any greater rate than others. Rather, he provides numerous alternative explanations for reported increased rates of distress among black people in the UK. These can be broadly separated into two categories: issues of misdiagnosis; and increased incidence of distress as a result of systemic injustices. Issues pertaining to misdiagnosis include the symptoms of physical health issues, such as nutritional deficiencies being misinterpreted as signs of mental health issues. An example that Peter provides relates to Vitamin D deficiencies, which he informs me occur at higher rates among black people in cold climates like the UK. Peter reports that '*it's not really a mental thing as such, in a lot of cases.'* However, a person 'presenting' in this way is diagnosed as such because the *'Medicine doctor has no interest in exploring the reasons… and sometimes it's simply due to a deficiency*'. If symptoms commonly interpreted as mental health issues/ distress are in fact the result of nutritional/vitamin deficiencies, then it seems logical to Peter that this mistake would disproportionately impact black people living in the UK. He expresses that diagnoses of mental illness in these circumstances are then propped up by racist claims that black people are more susceptible to such illnesses.

The view that racist stereotypes and racial prejudice situating black people as more predisposed (as a result of genetic or cultural factors) to mental 'illness' seems to inform Peter's deep scepticism of diagnoses involving 'paranoia' (see Appendix 20). Peter implies that people from disadvantaged backgrounds are '*treated as almost* *you're paranoid*' if they '*see certain things taking place'* that don't conform to the dominant view in society; i.e. micro-aggressions or other indirect forms of racism. The result sometimes being that experiences of oppressive systems are denied. There are traces of such experiences in Satch's testimony, an '*old man addict'* who rejects other people's attempts to diagnose him as '*mentally ill'*. For example, he speaks of being told that he has a chip on his shoulder, a comment that denies the legitimacy of any ill-feeling he might have towards others as a result of injustices experienced. Such denials, Peter indicates, can lead to a pathologization of oppression, such that '*people are being decided / people are sectioned and so on, when sometimes it's not necessary*'. Such issues, Peter seems to suggest, augment epidemiological trends already elevated due to 'actual' distress resulting from greater exposure to oppression.

Participants also perceive many inequalities in relation to mental health and related support services that might be interpreted as disproportionately impacting people with particular intersectional locations or identity-markers. These will be explored in the following chapter, where their testimonies demonstrate a view of the scope of BAME mental health inequality that I interpret as moving beyond a focus on just healthcare.

1 Determining the terms: terminological decisions

Also of relevance to this discussion is the way that participants navigate mental health terminology. Just as scholars evaluate the implications and uses of certain terminology, so too do participants. With the possible exception of Samaiya, they are not passive recipients of terminology handed to them by medical practitioners, but rather active players who navigate their way through the implications of various options available. This may not illuminate participant views on statistical trends that currently define BAME mental health inequality. However, the ways in which participants justify terminological choices provides significant insights into how they view mental health discourses and wider social inequalities (experienced as the group level) to interact and impact on the individual. As Peter points out, it is important to notice who '*determines the terms'* within a mental health context, and why they make the choices they do.

Discussions about terminology were easier with some participants than with others for a variety of reasons. For example, it was difficult to discuss mental health terminology directly with Satch. He often turned the conversation to substance misuse, even when we had agreed in advance to discuss mental health specifically. At one point however, Satch states that he considers substance misuse to be a strand of mental health. Equally, his avoidance of ‘mental health’ terminology itself is revealing. Samaiya and I did not discuss terminology around mental health and what informed the words that she prefers specifically. However, she did state that anxiety and depression ‘*can count this as a disability*’ as it can lead people to ‘*feel isolated scared and they / they've got depression they might feel bad or anxiety which is you know keeping you back not doing things*’.

I was able to have more direct conversations with other participants about their terminological preferences and their reasoning. From these conversations (and Satch’s subversions of such discussions), it seems that the main factors influencing participant relationships to certain terminology are:

- personal experiences of mental health issues/distress;
- aetiological beliefs;
- exposure to specific discourses (including different cultural understandings); and
- experiences of oppressions, at the individual and systemic level (including intersectional ones).

Whilst all four factors play some role in the adoption of particular terminology, focus on particular factors varies across participants. Whilst the below might be read as individual experiences rather than issues that speak to inequalities at a population level, many of these experiences are mediated by power dynamics that create such inequalities and social stratifications.

Mahdi seemed most focused on personal experiences, for example. Whilst he is clear that he attributes his mental illness to pre-migration trauma and present social factors, he does not seek to use the terminology of distress. Instead he comfortably speaks of ‘illness’. For example, in describing a recent incident where he became very upset and experienced psychosomatic symptoms, he states ‘*I’m not well*’. At no point in our conversations did I detect shame relating to his being ‘ill’. Prompting him to further consider the word ‘illness’ and his comfort with the term, he responded:

> *Well I’m, I’m OK I’m / I think we can’t change the truth. That’s the truth, that I’m not good. I’m not in a good place. But I hope in future I will get better. I hope, the only thing you can do is hope. And at the moment I know I’m not, I’m not a normal / sometime I’m thinking about something else, and I jump I talking about something / I don’t, I can’t really focus on something. I have problems / I have memories problem that, I, I put something at home and I forget it very soon. And I have to search for it hours.* (.) *Most of the time I feel like if I don’t have my wife or somebody to help me out at home, I don’t think so I can function very well*.

Mahdi links his being ‘ill’ to his inability to ‘*function very well*’ at present. At the time of our first interview, Mahdi’s wife supported him with everyday tasks (see Appendix 20), as he sometimes feels unable to do this alone due to his mental illness. Additionally, ‘unusual’ behaviours and ticks that other people notice (see Appendix 20) add to his sense of not being ‘*normal*’ following what the Taliban ‘*did in my brain*’ and subsequent trauma.

Though Andeep oscillates between referring to himself as having a mental illness or not, demonstrating discomfort with the terminology when applied to himself, he comments that mental health issues as ‘illness’ exist. As with Mahdi, he justifies this conclusion by drawing on the impact of mental health issues/distress on a person’s ability to ‘do things’. Indeed, he seems more comfortable with medicalised terminology when this is discussed in the context of his current inability to work; whereas his *dis*comfort intensifies when discussed in the context of medication. Mya, too, draws on functionality issues she experiences to inform her adoption of ‘illness’ terminology. However, being a trained occupational therapist, she also seems to draw on her knowledge of aetiological theories:

> *I just think that, if it stops you functioning, it is illness. It’s not just difference. You know, I’m not / you know if I’m depressed and I can’t get up in the morning and get dressed and showered, I am ill, I’m not just*

> *different, do you know what I mean? And I suppose, and even like, you know with anxiety, if I'm too anxious to engage with certain things, well then I am ill then I'm not just neuro / because I might want to, not engaging in it because I don't want to, I'm not engaging in it because it makes me feel anxious.*

Mya is keen to highlight that differences in her behaviour in relation to other people result from an 'illness' which she is afflicted with. Whilst the above statement that she is '*not just neuro*' – indicating 'neurodivergent' - initially seems to jar with a previous claim that her brain may have been predisposed to certain mental illnesses, it is in fact consistent with her articulation of illness resulting from a combination of genetic, biological and social/environment factors. Such predispositions do not mean that people are fundamentally different to others, but rather that certain aspects of their being and situatedness trigger an illness that others may be more or less susceptible to. This allows her to maintain that the difficulties she experiences meeting social expectations are not the result of a lack of willingness or an innate inability that situates her as inferior to others. She notes the usefulness of a diagnosis in helping her to recieve financial support while she is unable to work, for example, through the welfare system.

Mahdi displays similar concerns about meeting social expectations when he repeatedly informs me that he wants to '*be useful',* asserting that Afghan people are full of pride and want to support themselves. He wants to work in the future and to contribute to the economy and to society in general, but feels he is '*not stable mentally or, or whatever, I'm not stable to work at the moment*.' Mya demonstrates awareness of the stigma attached to mental health labels that attribute blame to individuals for not meeting social expectations; i.e. '*If you're depressed, they go 'Oh are you depressed or are you just lazy?*''. For Mya, as with Mahdi, it is very important to hold to a conceptualisation of mental illness that does not situate them as a fundamentally 'different' sort of human or as making a lifestyle choice that means blame can be attributed to them for the difficulties they face. For Andeep, Mahdi and Mya, 'illness' narratives seem to provide such a space as well as aligning with their personal experiences of limited '*functioning*'.

Samantha encountered western conceptualisations of ‘mental health’ after arriving in the UK in her 20’s. She is very uncomfortable with the way ‘*mental problems’* are spoken about within a health context. Though she acknowledges that the concept of ‘mental health’ provides her with a new way of thinking about her mental state prior to emigrating, she remains cautious of the term and utterly rejects ‘mental illness’: ‘*I hate saying mental illness because* (.) *because I don't believe in that word. I don't.’* The reasons she gives are twofold. First, she feels that it simply doesn’t correspond with her own personal experience:

> Samantha: *…you could just say ‘oh yeah I'm, I've got mental problems’. Or,* (.) *yeah. Something like that, or, I’m men / ment / I've gone men / mental. Like, or something like I feel like I've / I / I’m, I’m going mentally* (.) *distracted. I feel like mentally* (.) *mentally or physically mentally*
>
> Stéphanie: Distr[acted?
>
> Samantha: *distracted*] *yeah.*

Samantha seems to view what is termed ‘mental health’ or ‘mental illness’ in the UK not as health issues, but an amplification of psychological and emotional difficulties that people face as a result of things that happen to them. As such, people might end up with ‘*mental problems*’ or being ‘*mentally distracted*’. The person experiencing such issues can then choose to handle them (or not), just as they may choose to handle (or not) other ‘*problems*’ in their life.

This links to the second reason Samantha rejects illness terminology, which is that she perceives such narratives as enabling people’s agency to be removed. This removal of agency can happen as a result of internal reasoning whereby a person becomes ‘*paranoid’* that they are unable to control their own mental processes. She feels that this leads to people ‘*freaking out*’, resulting in feelings of losing control and experiencing suicidal thoughts. Thus, whilst Samantha does employ labels such as ‘depression’ or ‘stress’, she does not use them as diagnostic labels, but rather to express emotional states. For example, she states that ‘*mental condition* (.) *is* (.) *it is depression. It is depression, stress* (.) *those things, once they come together, they can make you mad.*’ These emotional states may both precipitate and be part of the experience of distress, but do not appear to be regarded by Samantha in an ‘illness’ context; she neither speaks of them as symptoms or as diagnoses of illness. Rather they are emotional and mental states that may result in a person becoming '*mad*', but still not 'ill'.

Another way in which medicalised terminology is perceived by some participants to reduce agency links to how such discourses and approaches can be used to oppress people. Specifically, Samantha feels that it encourages both people in positions of authority and people deemed to have a mental 'illness' to avoid addressing the root causes of their '*problems*'. This sense of being dismissed if one accepts mental health labels is shared by Satch and Peter. Satch, for example, speaks of mainstream support services that '*just put us in the package mental health*', where people deemed to have mental health issues can be '*pushed to one side*'. Instead he uses terminology that describes distress - such as being '*pissed off'* – rather than terminology like the 'mad' or 'crazy' that Samantha employs. This, it appears to me, stems from Satch's view that such responses would be natural for anybody forced to go around in circles in a frustrating search for the support they feel they need. This view seems to resonate with Peter, who – as I have shown – perceives multiple causes for the apparent mental health inequalities experienced by BAME populations in the UK.

This takes us to the fourth factor influencing the terminology adopted by various participants: experiences of oppression. In particular, the way that medicalised mental health discourses interact with racism to produce even more profound forms of oppression that might exist where only one marginalised identity-marker is present. I have already highlighted some of Peter's comments on this topic. Satch provides a further such example when he recounts the story of his Dad's admission to a psychiatric ward when Satch was a small child (see p.122). Witnessing his father's degradation within a medicalised mental health context, as a result in part of his father's resistance to and distress in the face of racist practices that sought to separate him from his young children, no doubt impacted on him greatly. This gave him early insight into how medicalised mental health discourses can legitimise practices that both deny people their human rights and pathologize the resultant distress. As a child onlooker, Satch perceives a disconnect between the father he knew and the man in front of him in the hospital, asking what *'they'* – the authorities, be they hospital staff or the police – had done to him. The belief that mental health labels can and are used to disempower people has been supported by Satch's experiences in subsequent years, as will be explored in the following chapter.

Both Satch and Peter, then, perceive medicalised discourses around mental health as acting to de-politicise distress by enabling practitioners and institutions to dismiss the need to address social inequalities (even when they acknowledge the causal role of such inequalities); a view also expressed by Samantha, and Mahdi to some degree. Medicalised approaches instead allow the focus and responsibility for recovery to be placed on the individual and, sometimes, the individual's community. To my understanding, Peter views this refusal to address inequalities as something deeply insidious; a pathologization of the distress that arises from oppressed and marginalised locations. This likely informs Peter's discomfort with even the term 'mental health': he is '*not keen on the term really to be honest*'.

Peter's consideration of the interplay between mental illness and oppression is not limited to just racially motivated oppressions. In addition to highlighting how such discourses impact on black people, he also speaks of how people from the '*upper echelons'* of society manipulate terminology to avoid stigma attached to mental health labels that he feels are disproportionately applied to people who are socio-economically disadvantaged. Referring to the upper class, he states that '*if you're from that level of society then you're eccentric. But if you're sort of working class, you're mad.'* Peter is clear that he does not believe people from working class backgrounds to be psychologically inferior to those residing in the upper classes such that they have a greater predisposition to being '*mad*', a term which attracts significant stigma. Instead, he views the disproportionate application of such terms to poor people historically, as a heuristic used by people in the upper class to distinguish those within their class experiencing mental health issues/distress from those in the poorer, less educated '*working class'*.

This belief also highlights Peter's awareness of the deeply problematic stigma surrounding mental health and associated terminology. He states of mental illness that '*It's just that term / that / that you're, that you've a mental problem. A lot of people may see that as being told they're mad*', implying that he believes mental 'illness' to carry the same stigma and disempowering properties that ‘madness’ did/does. Once more illustrating Peter’s point, Satch also acknowledges the role that stigma plays in his refusal of mental health labels, stating ‘*It’s a horrible, horrid stigma to it. I wouldn’t, wouldn’t even say I’ve got it. Not got anything mental health for shhh*’. Allowing oneself to be associated with terminology that has the power to disempower and stigmatise is dangerous, particularly for people who already feel disempowered as a result of other social categories into which they are placed. Though Samaiya and her sister don’t speak of stigma in relation to mental health issues that Samaiya have, they do tell me of the stigma that their brother fears. Also experiencing mental health issues, their brother recently turned down a job with people they know as he was concerned that they would notice his difficulties. Even Mya, who insists that mental illness is no different to everyday physical illnesses, is acutely aware that ‘*the stigma in itself of just saying mental health exists. Some people don’t like that.’* Here she highlights not only the stigma placed on people experiencing mental health issues/distress, but also the stigmas that influence some people to deny the existence of mental illness altogether.

Part B: Perspectives on determinants of mental health

In this section I explore participants’ views regarding the determinants of mental health resulting from both their lived experiences and understandings of mental health issues/distress. There is much diversity across participants’ perspectives. However, there is also a significant margin of agreement among them in relation to the importance of socio-cultural determinants. Once more, though discussion of this is predominantly in the context of personal experiences, social inequalities and power dynamics are highlighted that impact incidence and prevalence of mental health issues/distress at the population level.

2 The role of biology

All participants except Samaiya have interacted with mental health-related services beyond support from their GP, and all had encountered medicalised approaches and terminology of mental health issues/distress though the depths of knowledge ranged greatly. For example, Mya, having previously worked in health-care settings has perhaps the most in-depth insight into medicalised conceptualisations of mental health. In contrast, Samantha expressed her surprise at genetic hypotheses outlined in an episode of ‘Law and Order’ she had recently watched and asked me to explain more about such ideas. She explained that in Swaziland there is no such thing as mental health; people just have to get on with things. Alternatively, they are believed to be possessed by Jinn. Samantha did not feel that genetic explanations were helpful as they may lead people to think ‘*I’ll be like that’* and get ‘*paranoid’*.

Unsurprisingly, Mya’s views on the causes of mental health issues are those that most closely align with medicalised conceptualisations. In discussing the role of biological factors in the development of mental illness, Mya states that *‘as technology evolves’* and there is *‘more and more research being done in neuroscience’, ‘they’re finding lots more physical evidence.’* Mya demonstrates a belief that evidence does exist to support the claim that there are neurological – be they genetic or other biological - reasons why some people experience mental health issues and others do not. She feels it is simply a matter of time before enough physical evidence is gathered to enable a fuller understanding of how these factors cause psychosomatic and other symptoms of mental ‘illness’. It is important to note, however, that she at no point implies this as being an explanation for increased (diagnosis of) mental illness among certain population groups.

When I ask about the role of social and environmental factors, she acknowledges that these can have a significant impact on someone’s experience. However, Mya is quick to point out that social and environmental factors also play a role in numerous physical conditions: ‘*say you get migraines, well actually maybe what that’s triggered by is* (.) *…stress, or its by people talking loudly on a bus*’. Mya continues ‘*But is it a social and environmental illness, migraine? Because it’s brought on by loud noise and strip lighting created by man?*’. Drawing on her own lived experience of asthma and mental health, she positions asthma as being:

> *a bit genetic, maybe a bit environmental because I did seem to develop it when I lived in this really damp house. And mental health, maybe it was genetic factors but also environmental factors caused you know certain things to manifest, but you know certain things I think probably were / was there in my brain*

In drawing such analogies, she presents a view of mental illness as a vulnerability to certain experiences of ill-health as a result of any number of reasons, including biological ones, in the same way that a person might be predisposed to a particular physical ailment. She asks, *'why's mental health got to be treated differently to physical health?'.*

It is possible that Mahdi believes that neurological or biochemical issues play a role in mental illness, however this terminology is not familiar to him. Instead, he speaks of his brain as separate to himself in statements such as '*I can't trust my brain*', indicating elsewhere that his mental illness results in part from all that the Taliban '*did in my brain*'. The inference here is that something has been done to alter his brain such that it now behaves in ways he cannot always control. However, as becomes evident in section 3, Mahdi's views in many ways seem more aligned with social-cultural and environmental aetiological hypotheses. Taking this up with him in a later conversation he described his view as being that mental illness is biological in the way that a cut is. It might be caused by things other than your own body, but it is biological and if you keep infecting it, it won't get better. He makes the analogy between infection and stress, stating that if someone is in a continual state of stress, they can't heal and get better.

Another way in which biological factors are thought to cause or aggravate mental health issues/distress by several participants is through the role that physical health issues play in their own experiences. I have already explored these in relation to Peter in part A, p.97-98. Physical health issues play a significant role for Samaiya. She expresses a belief that her anxiety and depression are very much linked to the comas she had as a child:

> Stéphanie: Earlier you were saying as well that you were in some comas when you were younger.
>
> Samaiya: *Yeah, three times because of the problems I had.*
>
> Stéphanie: And you said that you got very anxious and you think it comes from that as well.
>
> Samaiya*: Yeah, I think depress or anxious, everything stress out.*

Samaiya and her sister believe that Samaiya's mental health issues began around the time that she started to experience significant problems with her physical health. Whilst they also believe her learning difficulties play an important role in maintaining her anxiety and depression, they do not underestimate the impact that childhood comas – and the fear that accompanied these – have had in the initial development of her mental health issues. These factors, in addition to the continuous pain Samaiya experiences, contribute to her on-going depression and anxiety.

The role of pain and exhaustion resulting from physical health issues is similarly cited by Satch and Samantha. For example, when Satch recounts the reasons that he tried to die, he mentions '*fatigue'*, which results in part from coping with physical health conditions. These include COPD, Hepatitis C and a spinal injury. Samantha describes how exhaustion and mobility issues frustrate her to the point that they aggravate feelings of depression. Samantha is currently losing her vision and is HIV positive. At the time of our first conversation, Samantha spent much of her time in bed, feeling physically exhausted. Explaining how physical conditions might impact on people psychologically, she draws on the analogy of losing a leg. Samantha, whose identity revolves around being extremely active and sporty, feels that losing a leg would be a tragedy she could not recover from:

> *You look at it and you go your life is done. It's ended. That is where / You start getting mental in your head. Because you feel like / like me, I feel like my life has ended. Because I'm not able to do the things I used to do*.

In addition, Samantha states that her HIV diagnosis leaves her feeling '*Terrified*' because of the future she believed it to bring at the time of our first conversation. This terror is augmented by having seen so many loved ones die as a result of the disease. Illustrating her fear, she explains that during one of her periods of hospitalisation, she '*even have a seizure. …I was that* (.) *stressed and, I was crying like, I was starting to remember him there.*' She remembered seeing a man who was a father-figure to her in a hospital bed as he died of HIV. The possibility that the same would happen to her triggered feelings of acute distress.

Satch highlights the ways in which physical health issues have impacted on his mental health on several occasions. For example, recounting his experience of receiving interferon treatment for Hepatitis C, he states that '*interferon pain is, is hard to explain. It's there, it's in your head… And you're emotional, you know.'* In another example, Satch highlights his frustration in relation to seeking out support to '*get me flat into, into normal, healthy, living space for me lungs.'*:

> *getting the council to give you a proper home, emm, or like I got a shit hole and, and slowly it got fitted, it's being fixed. …I mean I've got COPD, I mean the worst one / the worst lung diseases and I'm 57, and they're not* (.) *they're just ignoring it, and, you know, it's like* (.) *you could die the next day and nobody would know that these people are the / are the / hand in your death, you know.*

Here, Satch's declining physical health and reliance on social housing combine to create significant anxiety, frustration and fear. Having experienced precarious living situations throughout much of his life he seems deeply concerned that he won't be able to resolve this before his health declines further and he is unable to fight for the support he needs. At one point referring to substance misusers as '*the nameless*' in society, this concern appears further augmented by feelings that he is viewed as 'less than' by people in positions of authority; a feeling shared by Mahdi.

3 Socio-cultural factors

The following sections explore participants' views in relation to a number of possible determinants in BAME mental health inequalities.

3.1 Childhood/pre-migration trauma and suffering

Recognition that childhood and/or pre-migration trauma plays a role in people developing mental health issues/distress is one area where participants' views align; indeed the only participants not to mention such issues were Andeep and Peter. However, Peter does cite past difficulties from an unspecified period in his past as playing a significant role in his own distress when he speaks of talking therapies that '*stirred up things'* which he had '*sort of buried in my mind somewhere in the past'*. In contrast, Mya highlights having a difficult relationship with her mother and having been raised in a strict family that did not match that of others around her, with the implication being that these have impacted on her mental health in some form. As previously illustrated, Samaiya points to trauma resulting from childhood comas as playing a causal role in the development of her mental health issues. Additionally, she and her sister speak of how early negative experiences linked to having learning difficulties have lowered Samaiya's confidence. This they cite as an important factor in Samaiya's on-going depression and anxiety. Samaiya explains '*I honestly felt scared and because of my learning difficult saying I don't know I* (.) *couldn't go to teacher. I just didn't feel confident to go to, because I was scared I don't know.*' These early experiences still influence her current attitude towards education, contributing to her hesitation to take courses to improve her numeracy and literacy skills, as she desires to.

Satch also indicates an understanding of mental health issues as being informed by past trauma, including childhood trauma. Satch speaks on several occasions of extremely traumatic events in his childhood that have had lasting impacts on his ability to cope with challenges in life and with emotions. One such experience being the violence with which he was removed from his father's care when his father was committed to a psychiatric hospital. Another is being rejected by his mother's new partner due to being '*half-caste'*, which led to his being placed in a children's home where abuse prevailed:

> Satch: *A lot of the kids, when they were growing up around me, knew not to, not to make too much of a, you know, a and moan about it, cos* (.) *cos you know the staff would just, yeah, kid / they'd get sent off to a place* (.) *a place, for under, I think it was for under 18's, so they could lock 'em up and keep 'em quiet.*
>
> Stephanie: Oh what, if the kids were having too much emotional?
>
> Satch: *Umm. Umm.* ((Agreement))
>
> Stephanie: being too
>
> Satch: *If they, if they was trying to, if they thought they was tryin' to cause an, a problem, you know stir get eh fill the other others in and get them to you know, rebel and start you know, and start their behaviour up and that sort of thing. And you know, you had one or two that just wouldn't give up. They'd get beat. I mean. That. I mean. They used to roll you up in a mattress and beat the fucking hell out of you, but they can't do none of that now.*

In an earlier discussion, Satch speaks of not knowing how to handle his emotions as a result of the need to suppress emotional responses in the children's home to stay safe. The idea of letting emotion out, he states, terrifies him. Satch explicitly sites this fear of emotions as a key driver in his substance misuse. In a separate discussion, he relays that events from his childhood have led him to having difficulties coping with responsibility and accepting love. He explains that having faced rejection '*from me own Mum and Dad*' means that '*any type of rejection, I-I-I really took to heart*'. The result being that Satch fears feeling '*love, because if I felt love and then I lost them, it was more pain than* (.) *God no.*' Building and maintaining the sorts of intimate and loving relationships that constitute a close, supportive social network is difficult for Satch. Indeed, Satch states that this contributes to why he remains in the city he lives in instead of moving to cities closer to his children and grandchildren.

The two participants who speak of pre-migration trauma and suffering are Mahdi and Samantha. Mahdi draws clear links between trauma experienced in childhood, pre his migration to the UK, and his current mental illness:

> *obviously I had lots of problem from my back country all they did in my brain and everything leading up. I brought my illness here with me. It's not something that I getted here. My parents died in front of me. They got killed. I been tortured for six, seven years. My whole body is full of tortures. My head and everywhere.*

Mahdi is clear that his mental illness was initially caused by exposure to extremely traumatic events while still very young in Afghanistan. Having been born into war, around the age of 11-12 years old his family was murdered and he was taken as '*a slave*' by the Taliban, '*doing everything for them by force*.' The result is a significant impact on his '*brain'* which, aged 23-4 at the time of this research, he continues to contend with (see Appendix 20).

Samantha alludes to trauma as a child or young person contributing to her mental distraction when she states '*I know what caused me to be down.* (.) *I come from, I come from Africa and there was a lot of stuff going on innit back home.'*. However, she does not discuss what this trauma was. It is worth noting that though she here refers back to her time in Swaziland, in the rest of this discussion Samantha speaks of her mental health as having declined as a result of traumatic events that took place whilst in the UK. Only on one other occasion does Samantha reflect that difficulties she experienced psychologically in Swaziland may have been deemed mental health issues in the UK. Similarly, though Mahdi is forthcoming about some of the trauma he experienced in Afghanistan as a result of the war, the majority of his testimony focuses on experiences since arriving in the UK.

3.2 Material deprivation and precarity in adulthood/post-migration

Most participants cite aspects of their current situation or trauma experienced as an adult as playing a significant role in the development and/or aggravation of their current mental health issues/distress. One of the most commonly cited issues among participants was the stress arising from attempts to maintain stability, security and a decent standard of living. Concerns included financial precarity, housing issues and interactions with the State that heighten feelings of insecurity. Though not all issues impacted all participants, these do form a significant portion of conversations pertaining to the determinants of mental health issues/distress.

For several participants, discussions of these issues were often bundled together, with Samantha and Satch referring to these as ‘stress’. Samantha states that her feelings of depression and stress - which can lead to ‘*mental problems’* - result from *‘money problems, domestic violence, family problems. You know, like, boyfriend problems, husband problems* (.) *things like that.’* Samantha explains that her current ‘*depression started when* (.) *well, it started when* (.) *when I was doing my visa*’ and the ‘*person I came with from Swaziland, who was like almost my dad to me, he was very ill.’* She clarifies that *‘he was literally dying at that time I am doing a visa.’* She later provides a fuller picture of the context that triggered her current mental problems:

> Samantha: *then I have to go and see my husband, who used to beat me up, that's why I left. And I used to go and see a domestic violence person, and the same thing again. Uh, my mother-in-law passed away just after* ((father-figure)) *passed away. So every, everything was just happening in, you know June and July, was the hardest one I will never forget.*
>
> Stéphanie: Yeah. Everything happened at once.

> Samantha: *Everything happened at once in one go. Visa, I had to go to Newport. Had to do the funerals, and then the next day I've got hh, you know I was, I was so depressed, so stressed out, I don't even know. I was going crazy.*

It is worth noting that Samantha proudly displays her certificate of citizenship prominently on her dining room table, alongside professional certificates gained in UK colleges; or at least these were present when I visited.

Many participants' problematic interpersonal relationships, exposure to violence and grief are highlighted as are key causal factors in people developing mental health issues/distress. For example, grief also feeds into several other participants' experience of distress; i.e. Andeep losing his Dad, Satch who's youngest son died approximately seven years prior to this research, and Mahdi who lost all of his family to war as a child. Whilst participants acknowledge such events as having profound impacts on their emotional and psychological wellbeing, it seems to be these in combination with other experiences more akin to social inequalities that are held to cause mental health issues/distress. For example, interpersonal issues combined with financial issues feature in Andeep's articulation of what causes mental 'illness'. Contemplating whether mental illness exists or not, he concluded that it probably does because of issues such as wanting a spouse but not having the finances to support such a desire, or going through a divorce. Further, he notes that his own experience of being ill was precipitated by having lost a lot of money.

A combination of factors augmenting feelings of a lack of security certainly influenced actions taken by Satch that he describes as being '*mental health*', such as when he '*tried dying*'. Explaining the circumstances that led to his attempt, he states '*I been round and round and I'm sick of it.*' In a previous conversation some weeks prior, Satch had been extremely anxious about various requests he was making of the State for support; primarily in relation to welfare payments and housing. These fears were not unfounded. Following a reassessment for a welfare benefit - Satch's payments were stopped and he had to appeal to have his award reinstated. In relation to his housing, he was adamant that this was inappropriate for someone with his physical health issues, stating '*I got a shit hole'* that has only recently had its central heating fixed. An altercation with a member of staff in a charitable organisation supporting him with these claims led the organisation to ban him from their services for six weeks. Satch explains that '*I just got pissed off with all that, being banned and all that, and I thought I can't be arsed man. I'm getting nowhere fast. And, I'm getting too old.*' An accumulation of trying to obtain support and feeling that he is not getting anywhere fast, combined with the exhaustion and pain he experiences lead him to feel acute distress. As a result, he does not merely seek to engage in substance misuse, but to actually take his own life.

Most participants in this study mentioned being in receipt of welfare payments of some form. Mya, Andeep and Samantha all seem content enough with the benefits they are in receipt of, though Samantha does mention that money is tight at times. Mahdi, however, highlights the disparities in the financial support provided to asylum seekers: £35-40 per week. He reminds me that some people wait for refugee status for 10 to 20 years with only this to subsist on. Drawing comparisons to the majority population, Mahdi states:

> *you can't just torturing people with £30 a week. Uh, look at people. They're going to pub. They're going to restaurant. They / one-time dinner is more than £100. How come £35 is enough for a person for one week?*

Mahdi adds that the State '*don't give the chance to the asylum seeker to go and work.*' As such, government policy is viewed by Mahdi as not only providing inadequate financial support for asylum seekers to live as others around them do, but also as prohibiting them from seeking to elevating their position through employment. Though Mahdi does not use the language of discrimination, it is clear that he experiences this as an injustice not only to himself, but towards others in his predicament.

The psychological impact of Mahdi's financial precarity is reinforced by the insecurity of his asylum status. A large part of Mahdi's testimony in our initial discussion focuses on experiences of the asylum-seeking process, which he describes in places as a '*kind of torture*.' Using this term with regards to the asylum-seeking process shortly after having described the torture he underwent at the hands of the Taliban, Mahdi does not use this word simply for dramatic flair. Rather, it is an accurate depiction of the impact it has had on him, repeating and adding to it on multiple occasions: '*that effect my mental issue a lot that, it's kind of torture*' or that it is '*kind* *of mentally emotionally torturing me*'. Indeed, a refusal of Mahdi's asylum claim precipitated the recent suicide attempt described in Appendix 20:

> *that time when I tried to suicide it was, I got refused. I knew I'm gonna be tortured and dead. And get killed. And that's why I wanted to end it here. But at the moment as like, I got five years to stay here. And I don't think so I'm going to suicide. I might get upset at something, I do self-harm, I can do self-harm or I can be something, I can be rude or stuff, I can be upset or I can do anything but I am not going to really think about suicide at the moment.*

Mahdi directly links this action to fears of being sent back to Afghanistan, where he believes the Taliban will '*find me out, then they gonna kill me like very horrible way*.' Mahdi further notes that even if the Taliban were completely expelled from Afghanistan, the Home Office is not taking into consideration that he has converted from Islam to Christianity and has married a non-Muslim woman. He explains that his fellow compatriots '*would make my life hell the moment they see me*' praying in a Christian way. Mahdi describes how such stressors have led him to experience panic attacks, stating '*I have a record of panic attack. I / I / my body start shaking and I fall down* (.) *and I bang my head on the table, that back in the day, probably two years ago. When they wanted to send me to Hungary*.'

Reflecting on the fact that he has been given 5 years leave to remain instead of indefinite, he states '*you still put me on hold. So, my mental health doesn't get better'*. Mahdi directly links such factors as both seriously aggravating his existing mental illness, and inhibiting his ability to heal and recover. Mahdi's personal experience also informs his more generalised understandings of the causes of mental illness, made evident when he moves from stating that such processes are '*torturing me'* to claiming that '*they kind of torturing people'*. Mahdi strongly implies that asylum seekers '*suffering from depression and anxiety and other forms'* of mental illness are all likely to be significantly impacted by insecurities and lack of a sense of stable safety in the same way that he is. This, together with uncertainty regarding his Visa, lead to considerable concerns regarding his marriage. With '*all the pressure was on my wife all the time'*, Mahdi at one point suggests that it might have been better if he had not married his wife despite loving her. As an asylum seeker married to a woman who works, he was not entitled to much in the way of financial support. Mahdi was acutely aware of the negative impact this was having on her, and the subsequent impact on his dignity. When they did in fact separate, however, things did not go smoothly for Mahdi. Having been given refugee status, he was entitled to welfare and housing support. However, the housing he was provided was shared with others whom Mahdi felt very uncomfortable being around, further aggravating his mental illness.

Peter also highlights his belief of the negative role that financial instability and subsequent feelings of insecurity has on both a person's physical health and distress. Peter states that '*people are finding it very difficult to cope, struggling quite badly in some cases*' with '*the pressures of society these days*'. When I ask which 'pressures of society', he responds '*the whole work situation'*. Peter cites lowered wages and the increase of short-term contracts as creating a situation where '*there are no certaintie*s', a significant change from '*years ago*' when '*you'd be in a job that is pretty much guaranteed, so you didn't have that worry*'. The result being that nowadays:

> *people feel very insecure. You know and that creates a lot of worry, stress, tension, all the rest of it. And as we know, stress is a major contributing factor in many illnesses. And so on. And being under constant stress, and people not sleeping well and so on because they're worried and you know, all that sort of stuff, it all, you know, has a, you know, an impact on you and creates all sort of problems'*

Here Peter articulates a view that unstable access to basic material goods impacts on many people by causing physical '*illness*' and/or '*all sorts of problems*'. I interpret 'all sorts of problems' here as including experiences of distress due to difficulties coping with uncertainty and hardship: i.e. having a '*mortgage to pay and all the rest of it, you have young children, and so on, and it's a constant worry*.' Peter, like Mahdi and Satch, contextualises such problems within a broader narrative of social dynamics and inequalities. Peter proposes that employees – a proxy for people in positions lacking authority - '*don't feature much in anything, you know, you're just a number. And I think throughout society now we're pretty much being treated in that way'*. This can result in a feeling of '*constant stress'* and being devalued as a person.

There is a real sense of Peter feeling that a devaluation of individuals who occupy disempowered social positions is an important factor in why some people '*struggle quite badly'* to '*cope'*, amounting to significant distress. In fact, in a later conversation to discuss my findings, Peter adds that simply knowing that you are at *'the bottom of the ladder'* in any respect adds additional stress and pressure, which impacts on a person's ability to cope.

3.3 Discrimination and oppression

The above sections describe participants' views regarding the central role that trauma and heightened stress play in the triggering and maintaining of mental health issues/distress in many instances. Running through these narratives are inferences to the impact that discrimination and marginalisation have on people's psychological and emotional wellbeing. Many participants seemed to oscillate between feelings of disempowerment and hopelessness, and those of agency, resistance and determination. These instances often include broader social inequalities encountered as a result of being placed within particular marginalised social categories. Only Andeep did not report experiences of discrimination or oppression of any form in our conversation. However, when stating that praying helped him manage his mental health, he quickly stated that he did not want to talk about this practice. I can only speculate that this might be due to having experienced and/or anticipating negative responses to his religious beliefs.

3.3.1 Racism (including xenophobia)

Predominantly, such experiences relate to various forms of racism (including xenophobia), though issues pertaining to other forms of discrimination and marginalisation are also highlighted. Racism was primarily spoken of by participants racialised black, as opposed to other categories of racialisation. Interestingly, the women in this research spoke less about racism than the men. For example, though Samantha admits on one occasion that she has experienced racism, she does not provide details beyond confirming that it negatively impacted her mental health. Though unhesitant in confirming this, she also expresses her frustration when other migrants '*complain*' about such issues. She reports telling them *'look around, do you see your country?'*. Samantha states that the UK has a strong 'blame' culture that she finds difficult, and she perceives comments about racism from fellow migrants as evidence of this culture influencing them. Further, whilst Samantha indicates experiencing difficulties specific to black women, she is closed to discussions on the subject. Excluding Mya[20] (the only core participant able to identify as white British if she wants), only Samaiya and her sister report not having experienced racism. Samaiya's sister reflects that this might be '*because we're in a place where you know it's there's a lot of people of ethnic minorities here*', meaning that *'you just didn't feel like you stood out'*. As a result, they do not feel that racism has impacted on Samaiya's mental health issues.

Satch and Peter, however, readily provide multiple examples of racism, with Mahdi speaking openly about more xenophobic forms of discrimination that impact mental health. Speaking in more general terms about the role of racism in the creation and maintaining of distress, Peter reports that black people are in a '*constant battle'*. This results from having to satisfy mainstream culture's behavioural (and possibly other) norms *'in order to gain a degree of acceptance'*:

> *it can get difficult, because it can get you into a frame of mind where you feel constantly observed and analysed and all the rest of it. When you come across that sort of thing constantly, you're constantly being impacted by that and so on.*

Having to constantly navigate between the norms of dominant society and those of the minority communities and cultures that racialised people identify with requires a constant vigilance and attention to 'the other'. To illustrate this point, Peter speaks of a recent experience of a micro-aggression he has had when using public transport. Having just spoken of how black people are often misinterpreted as aggressive when being expressive, Peter explains that as he was catching a train there was some confusion with a ticket officer:

> Peter: *the gentleman said to me 'No, no, no, you can't you're not allowed to do that..', and I said 'yes, I know this is just to enter this end, I've got my ticket in* ( )*', and he was growing / So I said 'It's OK, I understand, I've done this before.' You know. And he said 'It was only a mistake. I was only, I was only'*
>
> Both: ((laugh))

> Peter: *So I said 'Yes I know'. He said 'I was only trying to help you, I was only trying'. I said, 'Yes I do know that.' I said 'Why are you explain.' And he said 'Oh, because you seemed as though you, you were, you were upset about'. I / I was just / I was shocked. I mean really shocked. And he was quite convinced that I was behaving in that manner. And that was so disturbing.*

Peter comments that such experiences inevitably impact on a person's wellbeing and state of mind, remarking that if white people '*were subjected to the same, it would affect anyone in the same way*.' It is interesting to note the similarities between this and Samantha's account about having to mediate her behaviour so as not to be perceived as aggressive. However, where Peter perceives such instances as emerging from racial prejudice, Samantha couches them in terms of cultural clashes (see p.164-165).

Mahdi highlights injustices he perceives as being perpetrated towards asylum seekers, often using comparative discursive techniques similar to that of Peter above. Speaking of his interactions with the Home Office, he poignantly asks '*You blood is red, my blood is not red? Do you think my veins are all water? Do you think I don't feel pain? I am not a human? Or you are much better than me?'* It is telling that Mahdi feels compelled to explicitly state '*I think asylum seekers are human beings …and they should be treated like human as well.*' In addition to his very real fear for his life if he is returned to Afghanistan, he is also fearful that his marriage will be effectively interrupted. In response to asking how he is to maintain his marriage if he is sent to Hungary, he reports being told by the Home Office that he could continue his relationship via Skype. Incredulous, Mahdi expresses his wish to ask the official who made this statement:

> *'Can you just do the same? I'm going to do this. I have problems that I'm going to get killed my / in Kabul and my country, but I'm still fine if you want me to get killed I'm going to go. But can you do the same with me? Come over with me and just keep your relation with your missus on the Skype?'*

The result of the approach of officials and policy being that both Mahdi and his wife's lives were '*kind of stopped, on our, our life*'. For Mahdi, this all amounts to being treated as a denial of human rights. He states that '*the past three years I got very bad tortured'* in the UK, going on to explain that he attempted suicide as a result of such torturous stresses. Feelings of being perceived and treated as 'lesser humans' combine with policies and practices (i.e. not allowing asylum seekers to work whilst providing insufficient finances to live on) to aggravate Mahdi's mental illness and hinder his recovery.

This view also influences his perceptions of interactions with non-State services. The morning before our first interview, Mahdi and his wife had tried to open a bank account for him as he had just received refugee status and would now be entitled to welfare payments. However, the banks refused to open accounts for him as they did not accept governmental documents as proof of address. In response to bank staff stating that it is not their fault that they cannot open an account for him, Mahdi agrees, stating '*Obviously it's not your fault because the system is not good.*'. He elaborates that '*it's government's fault that proof / your stupid policies. Why I have leave to remain. I am human being. You put me down in front of other customers there. / I was just embarrassed.'* Mahdi appears here to associate such barriers to wider State positions that discriminate against asylum seekers and refugees. After having this experience in several banks, Mahdi reports that he began to experience physical symptoms associated with his mental illness such that he and his wife had to return home.

As a result of practices such as those above, Mahdi is not only beholden to his wife who is struggling to support them both, but he also feels subject to humiliations that:

> *put down my dignity. And that tortures me in front of my own self like, I don't feel the same like other people. Eh, that is also a big effect on my trauma* (.) *and my brain that I, every day I'm like, in a very, trying to just die. Just because I am not* (.) *I can't be the same like other people. I can't have my rights you know. I can't have / I don't have nothing you know. I / I / if my wife is not there I might end up homeless*

When Mahdi speaks of being different to others, this tends to be in relation to his mental illness. Here, however, it relates specifically to not being granted the same legal rights as others. He directly links having his dignity '*put down'* and experiencing barriers to accessing his own '*rights'* to his trauma being aggravated such that he is unable to move forward. Again, this experience informs Mahdi's understanding of factors that maintain and aggravate mental health issues more generally. This is evident when he advocates for the introduction of policies that would allow asylum seekers to '*help themselves'* to live with dignity by allowing them to work. Without this, Mahdi feels that asylum seekers are being driven to '*the centre of the bridge*', where the State '*leave them to jump*'. Mahdi is effectively stating that, by denying people equal treatment and the opportunity to live with dignity, society pushes people in certain social locations towards suicidal thoughts and actions.

The intergenerational nature and impacts of racism and racial injustices are highlighted by Peter in his comment that:

> *You look at the black race, who for centuries, not one experience, but for centuries* (.) *what those children experienced. All the way through their lives to adulthood, and continue to endure. You know, you see your father just taken out to be beaten to death, or beaten to unconsciousness then he's hunged up.*

Rejecting claims that black people are '*more susceptible to this mental thing',* Peter articulates how intergenerational trauma might contribute to reportedly higher rates of psychosis experienced by black people in societies with a history of racism. I understand the inference to be that black people are not more susceptible to psychosis, but may experience post-traumatic slave syndrome (PTSS). Referring me to Dr Joy DeGruy's work (Carney, 2016), Peter notes that this legacy of slavery is not yet widely accepted within mainstream mental health discourses. Responding to sceptics, he states that '*when those things have happened for centuries, for generations* (.) *it must have had an impact*.' Peter's acceptance of this diagnostic category, however, should not be taken to mean that he suddenly accepts mental 'illness' labels. Rather I understand this as Peter welcoming research that acknowledges the psychological and cognitive impacts of intergenerational trauma and that highlights the logic that such issues therefore necessarily disproportionately impact any group within society that has experienced systemic trauma for generations. It offers the possibility of acknowledging a person's distress without implying that a population's susceptibility to psychosis is biological/genetic, but rather socio-historical in nature. A similarity might be found here between Peter's views around PTSS and how it should be understood as producing distress, and Mahdi's explanation of mental illness as a biological phenomenon when experienced, but caused and healed through social and environmental factors.

Though Peter is the only person to speak directly of intergenerational trauma, Satch shares experiences that illustrate Peter's point. He states, for example, that racist practices in 1960's Britain prohibited his Puerto-Rican 'GI' father from caring for him and his younger sister when Satch's parents' relationship broke down, stating '*back then, when a black man and a white woman made children, and they split up, the black man never got, there was rules like, the English-born parent gets the most say'.* As a result of desperate actions that his father took to keep his children in his care, Satch's Dad was incarcerated in a psychiatric institution and Satch was placed in an abusive children's home, as previously mentioned. Though Satch does not speak of specific trauma his father experienced, he hints at the oppression his father was subjected to in America, stating *'even in America blacks didn't get much'.* He recalls the impact that seeing his Dad in the psychiatric ward had on him as a small child:

> Satch: *I remember going to visit him, and he had this fucking nightie on, and when he turned round to get us a cup of tea, you could see his black bum.*
>
> Both: ((laugh))
>
> Stéphanie: Was it one of them nighties like, from the hospital? With no back?
>
> Satch: *Yeah. Yeah, and I, you know, I was crying. I thought 'What have they done to him?'*

This appears to have had a profound impact on Satch and indicates his awareness of the interconnectedness between institutionalised racism, experiences of extreme distress and being deemed 'mentally ill'. He also infers that such experiences at the age of five years had a lasting impact on his wellbeing and played an important part in his eventual substance misuse. Exploring why he might be an '*addict'* whilst others are not, he explains that though he now understands how wider issues such as racism played an important role in his separation from his parents, '*Back in the day*

I felt I'm / I don't / I been. What it is, it's like being rejected, and, from, the day I were five when me Dad and Mum rejected me'. In this way Satch's testimony begins to illustrate and evidence Peter's claim regarding the role of intergenerational trauma on the mental health of black people in the UK.

A further example of intergenerational trauma as a result of racialisation might be found in Mya's account. She explains that her grandfather was a Jewish refugee from the Second World War who, upon arrival in the UK, rejected his religion entirely. Exploring how this history and her Jewish heritage might have impacted on her own upbringing, Mya notes that her Granddad:

> *doesn't talk about* (.) *he doesn't like to talk about his family life at all because you know it wasn't very happy. And* (.) *my Mum wasn't very happy as a child, so she doesn't really like to talk, so, I don't know if it, if it's because of the cultural aspect or if it's just because of how my family was?*

Just prior to this, Mya had stated that she saw her family life and structure as aligned with '*really traditional families*' that '*mirror quite almost like, quite religious families*', as opposed to the secular family structures and behaviours dominant in the UK. Though brought up atheist, she felt she could relate to traditional religious family structures '*more than I can then relate to my like atheist and agnostic peers'*. Part of this seems to involve a certain strictness imposed by her mother, which Mya supposes could be due either to 'Jewishness' or just how her Mum and Grandad are as people. She notes '*my grandad is very black and white*', adding *'that is a lot to do with his personality, but I think it is a lot to do with* (.) *how / it's a lot to do with how he was brought up. And that probably is a lot to do with* (.) *yeah, the Jewishness.'* For Mya this seems to have created a disconnect in the way that she was raised, having to obey to a strictness not shared by her peers, but without the justificatory framework: '*if you're brought up like quite strictly but you also have religion and you, you maybe have a slightly different interpretation of religion, if you can study it and justify it'*. Having now developed a faith in God, this disconnect and that with herself and her family appears to have deepened. Whilst this part of Mya's testimony might be read as part of her past trauma - one that results from being brought up with multiple cultural reference points that do not necessarily coincide with those of the dominant culture around her – I believe it is also reflective of how intergenerational trauma can operate. Mya and her mother were not subjected to the atrocities of World War II committed towards Jewish people. However, Mya seems to recognise the possibility that this part of History – through her Grandad's undiscussed unhappy '*family life'* - has had a direct (albeit diffuse) impact on Mya and her mental health.

3.3.2 Additional and intersectional discrimination and oppression

Another aspect of identity from which oppressions disproportionately impacting people of BAME backgrounds can arise relates to encounters between cultural norms. Being of a minority culture in the UK can lead to a marginalisation of one's own mannerism, behaviours and beliefs if they are in conflict with cultural norms in the UK. For example, Samantha explains that people in England express themselves very differently and have a tendency to avoid confrontations when there in a dispute. She provided examples from both her previous marriage and employment where she had either to repress her emotional responses to situations or apologies for her behaviour when she felt she had simply sought to resolve a dispute. Continually having to do such things meant she felt unable to '*say what you want to say*', thereby '*suffocating*'. This, she explains, has a significant impact on a person's mental health and it contributed to her feelings of depression. Whilst Mahdi, as the only other participant to have migrated to the UK as an adult, also reports cultural differences as negatively impacting relationships in his personal life; namely through his marriage to a British woman. However, the difficulties he expressed do not seem to take an oppressive form. Rather they relate to differences in expectations of what a marriage should entail.

Though not addressing cultural differences directly, Mya does highlight difficulties that women with mixed cultural backgrounds may experience in relation to the numerous and sometimes contradictory social expectations placed on them. This, Mya states, can lead to a 'no-win' situation that women have to navigate. She offers the example of mothers and expectations around work; i.e. a woman who stays home to raise her children might be considered either '*judgemental of women who do go out to work'* or alternatively as '*a drain on society*'. Mya further highlights that such expectations differ across cultures, and seems to suggest that judgments are made by other women regarding such choices without adequate consideration of what the norms and expectations might be in different cultures. Navigating such expectations and judgements, Mya intimates, can put significant pressures on people that impact on their mental wellbeing.

The above and the previous section describe the ways in which difference, discrimination and oppression considered central to BAME inequalities impact on mental health inequality experienced by this population grouping. However, participants also raised a number of further social categories that also exposed them to discrimination and oppressions. Primarily, participants raised the issues that arise as a result of poverty or being considered '*lower class*'. Mya, Peter and Satch indicate people from disadvantaged socio-economic backgrounds being treated differently: as '*numbers'* or have others '*look down on'* them. In addition to creating significant pressures and stress that impact mental health issues/distress, difficulties highlighted in relation to the issues discussed in terms of how they disempower and attack people's dignity. Peter highlights social dynamics whereby '*the hierarchy system'* states that *'whatever applies to you down there* (.) *can't possibly apply to us up here*'.

Satch provides a personal example from his childhood. Explaining that children in the children's home had to tidy the home ahead of inspectors visiting, Satch describes his impressions of these visits. Namely, that the officers would look down on them whilst they put their best efforts into pleasing the inspectors. Satch comments '*What do you get out of, you know* (.) *them kind of people? To impress them, what do you get?*' Satch, like other participants, is acutely aware of the ways that various aspects of his identity and situatedness – and their combinations - disempower him in relation to others. For example, he comments that '*the nameless population'* of substance misusers are treated in ways that '*nobody deserves to be treated*'. It should be noted that Satch is not speaking of substance misusers who are able to fund their addictions, but people like himself who experienced addiction in a state of poverty. He implies that being treated with so little dignity and humanity impacts negatively on their mental health when he adds that '*what would help*' would be to get substance misusers *'into, you know, the rest of the community, you know, get you involved*'.

Other examples highlight the competition that seems to emerge between marginalised groups; be that competition for status or for support. In relation to status, Mahdi provides an example when he distinguishes between 'worthy' immigrants and those who '*exaggerate, they lie'* to receive benefits from the State in the UK:

> *we say in Afghan in our language that when a forest get burnt, there is thousand of trees. Probably they're all dry. But there are five portions of fresh trees. If 95% of the dry trees get burnt, the 5% of the fresh tree also burn with them.*

By this Mahdi expresses his view that there are many asylum seekers who are here for economic betterment or an easier lifestyle, and that it is because of this that people like himself have to endure torturous waits and immigration processes. In contrast, Satch expresses feelings of being in competition with migrants to receive support: '*it's like anything you want or you need, you've got to have a big / going in for some kind of uhh, mad competition to get*.' He expresses frustration that migrants to the UK are receiving support when he is struggling to gain what he needs.

In relation to status, Satch speaks of factions within black communities. Speaking of when he was a young adult, he recalls calling '*All the black people who come to England and started acting emm, so British* (.) *that they ended up wearing Union Jack jumpers*' the '*black petit bourgeois.*' Following just after his account of the children's home inspections, he states that '*the black petit bourgeois'* positioned themselves as above other black people having gained white-collar jobs, running to tell the authorities when someone within the black community was misbehaving. He reports similar dynamics within the 'Dreads' community, stating that '*there was a lot of back-biting. Hypocritical talking. Too much, too much lip servicing.*' He believed that this happened because some people wanted to '*feel a bit, a bit more, righteous*' and *'stroke their egos a bit.'* Though, having been the one looked down upon in this dynamic, Satch states that he can understand this need; i.e. to gain advantage from deeply marginalised positions. Nonetheless, it is evident that this was unpleasant for him. Further, he recognises that such efforts did not create equality for racialised people even if one or two were invited to the occasional dinner or party. These examples further highlight the multiple systems of oppression that can operate on oppressed groupings such that intersectionally located people within them become even further marginalised.

Additional identity-markers explored or that emerged as having impacted on participants' mental health issues/distress include gender and having a learning dis/ability. Beginning with gender, though issues were highlighted, these were few and often not elaborated on in much detail. Samantha mentioned domestic violence and acknowledged issues specific to black women but did not expand on this. Mya highlights issues surrounding social expectations of how mothers should behave. However, these tend to be spoken of more in terms of difficulties with competing social expectations than oppression per sae. Equally, though gender played a role in some incidents recounted by Satch and Peter (e.g. their being viewed intimidating or aggressive), sexism itself was not highlighted. Instead, these were presented predominantly through the lens of racism. Such incidents seem intersectional in nature, though not presented using such terminology. This is perhaps because the concept of intersectionality was either new to or unknown to most participants.

With regards to dis/ability, Samaiya and her sister indicate a belief that issues relating to having learning difficulties and physical disabilities that disrupted her education have negatively impacted Samaiya's mental health. They speak of how Samaiya '*tries to disguise'* her learning difficulties and low levels of numeracy and literacy for fear that '*Some might judge her for it'*. The impact being that she feels unable to address some of the issues that maintain her current feelings of depression. Samaiya's sister adds - and Samaiya agrees - that '*if she can deal with the basic numeracy and literacy issues, she would feel empowered she would not feel how she's feeling all the time'.* However, Samaiya does not feel confident returning to college as a result of barriers experienced in her childhood and adolescence; all of which relate to her difficulties and disabilities. For example, she states that in school:

> Stéphanie: *And do you think part of it is them taking more time to make sure that you understand it? So if they had spent more time talking to you,*
>
> Samaiya: *Yeah, that would have helped me more. There wasn't much help from them.*
>
> Stéphanie: *And did they make you feel comfortable asking questions?* (.) *Did anyone do anything to say 'do you understand this'?*

> Samaiya: *Maybe in the class, or with all the children. Do you understand* ()
>
> Sister: *Not individually, no one asked you individually?*
>
> Samaiya: *No, no not individually.*
>
> Stéphanie *And I suppose it's / you've got to be very brave to put your hand up.*
>
> Samaiya: *Yeah I was shy and you know not [confident.*
>
> Sister: *Also if you've got such] a big learning gap and then I don't know.*
>
> Samaiya: *I honestly felt scared and because of my learning difficult saying, I don't know I couldn't go to teacher. I just didn't feel confident to go to, because I was scared, I don't know.*

Stigma surrounding learning difficulties and low educational attainment prohibited Samaiya herself from seeking support as a child, leaving her needs inadequately provided for. Samaiya's sister reflects that '*when she went to college she experienced the same problem'* – referring here to not being provided '*someone who was a specialist in special needs student, who could help her*'. Her sister also recalls their family seeking support for Samaiya's education, but they were informed there was no support available. Further, they highlight that changes to college campuses mean that Samaiya's physical disabilities together with her lack of confidence are a further barrier to attending college. As such, Samaiya feels further disempowered when considering taking actions that might improve her mental health issues and confidence.

4 Protective socio-cultural factors

Participants highlighted not only how their mental health issues/distress impacts on them specifically, but also the aspects of their lives and actions taken that help them to manage such experiences. Whilst some of these were highly personal, several seemed common across participants in one form or another as well as relating to wider social issues. These were:

- Social networks and belonging
- Religion, spirituality and faith

- Self-worth

4.1 Social networks and belonging

Mahdi is the only participant living with a partner during (part of) this research, though Samaiya lives in the family home with parents, a brother and sister-in-law and their children. Andeep is his mother's care-giver, but I was unclear whether they lived together or not. Satch, Samantha and Peter live alone, though Peter has family members living nearby. Satch was moved into supported living several months after his second attempt at dying. It was unclear whether Mya had flatmates (she did not mention any). This is relevant because living with family, where mentioned, seems to offer support that helps participants manage their mental health issues/distress; support that those living alone do not have. For example, Samaiya speaks of '*playing with the children in the house'* to '*keep myself to stay happy'*, and Mahdi makes frequent statements to the effect of '*Most of the time I feel like if I don't have my wife or somebody to help me out at home, I don't think so I can function very well.'* Such statements contrast to those such as Mya's '*I feel quite isolated'*, or Samantha's self-declared tendency to keep people at a distance using sarcasm and her sense of having '*to deal with everything myself*'. Satch, was unable to travel to visit his children and grandchildren due to his health prior to his suicide attempt. Further, not wishing to concern his son, he had also disengaged from his family though it was evident that he missed them. Comments made some weeks after his suicide attempt lead me to believe that this separation added to Satch's acute despair.

Other participants also comment on the negative impact of losing or having a reduction in the support received by family. For example, Samaiya states that when her sister returns to her residence in Saudi Arabia, she feels '*isolated sometimes'*. Samaiya continues that *'it's ok, I still have to get on with life. She has her own life I have my own.*' However, this separation evidently leads to an intensification of feelings that contribute to her depression, such as isolation and feeling that she is not able to fully live her life. Equally, the importance of Mahdi's wife in staving off feelings of isolation became clear to me when we met following their separation and he confided that he missed having female figures in his life to speak to (see p.41). His wife seemed central to how he managed the emotional turmoil that accompanies his mental illness. At one point he states that he feels so alone that he has contemplated turning to drink, though he then reports that he has come through too much trauma to allow himself to do so over the breakdown of his marriage. These examples highlight the important role that close support networks and family play in enabling people to manage their mental health issues/distress.

Throughout our discussions, Satch recounts stories that recognise the importance of ‘belonging’ to his mental health/wellbeing. Often, he seems to have found this through music scenes and subcultures. For example, he recalls how being part of the Northern Soul scene as a teenager provided him with much needed respect, belonging and even love, stating that ‘*getting some love and* (.) *understanding. Ahh, it’s just mad man, it’s, you know / my music, my music taste, was also part of my family.*’ When the Northern Soul scene waned, he joined the ‘*Dreads scene*’, seeking that same sense of belonging. Speaking of music that he listens to today, Satch recommended an album called ‘Distant Relatives’. He highlighted a particular song that held great meaning for him:

> *listen to it. I swear to God. There’s one called Dispear. And it’s called This Spear. You know what I mean, we got to, we got to stop all this with this spear. We’ve got to come together. And then another one saying yeah we’re all brothers and sisters*

This song speaks to the sense of connection that Satch craves, highlighting the need for people - the black diaspora and indigenous people in particular - to come together to combat despair created through marginalisation and the current social structure (see Appendix 21). Media and cultural outlets also play an important role for Andeep in terms of feeling connected to his heritage and culture. He explains that he and his mother watch the Sikh TV channel, and that this brings them both much joy as it shows enthusiasm in keeping Sikhism alive. It also makes them feel more connected as it brings Sikh people together. Though Andeep may not be physically surrounded by other Sikh people, he is reminded that there is a community which he is part of, even if – like Satch – he forms part of the diaspora.

4.2 Religion, spirituality and faith

Religion, spirituality and faith in a higher entity are highlighted by most participants as important aspects of their inner lives and experiences. Several participants were hesitant in speaking of this. However, when they do, religion, spirituality and faith play supportive roles in participants' management of their mental health issues/distress. Though Samaiya and her sister do not speak specifically of how Samaiya's relationship to God influences her wellbeing, Islam is cited as a positive influence in their lives. For example, speaking of the potential benefit to Samaiya if she were to feel she had '*purpose in life*' - which she suggests might be found through going back into education - Samaiya's sister states '*our prophet Muhammad he said you know you should learn from your cradle to your grave.*' Mahdi, having converted from Islam to Christianity following fleeing Afghanistan, explains that '*When I get so upset, I go to church*', as '*church give me peace and I sit and I feel relaxed.*' It is unclear if this is due to Church itself being a peaceful quiet space with few people most of the time, because he feels closer to God in the space, or because he has a good relationship with the parish priest. Mahdi clearly feels a great bond with the priest, stating '*He is the first person in this country that I really respected.*' Mahdi explains that the Father '*helped me a lot and when I go there and I sit with him I feel much better. He makes me feel, he bless me and he makes me feel that life is not over.'*

Samantha, who makes a major breakthrough over the period of this research with regards to her own mental problems, speaks of reconnecting with God as an important factor in this turn around. She describes a discussion where a support worker encouraged – and ultimately prompted - her to find her way back to God. Though Samantha rejects churchgoing, she speaks of God as providing her with the strength she needs to recover. Satch also rejects churchgoing but remains very spiritual, stating that he turns to the 'higher power' in times of crisis. Having grown up in Catholic institutions, his beliefs now align more closely with Rastafari philosophy though he rejects practices that ban ingesting certain substances. Peter does not speak of how his spirituality supports him, though he indicates that it is an important feature of his lived experience and is informed by traditional African practices that have more focus on community and the interconnectedness of people.

Andeep mentions that prayer helps him with his mental health, commenting that he finds the rituals within religion particularly helpful when practising meditation.

In comparison to most participants who grew up with religion, Mya went from being agnostic in an atheist Jewish family to having a powerful spiritual experience a few years ago. This experience entailed God coming to her such that she felt she could not deny his presence. She now finds herself with a strong faith in God, but without a religion. Whilst she takes comfort in her faith, she also perceives the possible support that might accompany being part of a religious community. Shortly after reporting that she finds herself feeling isolated, she states '*I feel like the idea of having like a religious community where people are* (.) *I don't know, it tends to be more wholesome doesn't it. Like I want that.*' In referring to '*more wholesome*', Mya makes a comparison to her wider social group whom she describes as '*lovely people*', but who '*want to just go to the pub, or take drugs, things like that.*'; activities she finds difficult to engage in due to her mental illness. She seems, in fact, to be in search of the sort of support that Mahdi reports finding with his Father, aware that it holds the potential to have a positive impact on her wellbeing. Further to this, she suggests that '*religion offers you a worth* (.) *when maybe other sections of society when you've got a mental health condition kind of bin you off.*'

4.3 Self-worth

Mya, in her search for a religion that might provide a sense of worth, demonstrates an importance of feeling self-worth that is mirrored in the desires and coping mechanisms of other participants. For example, Satch speaks of gaining a sense of self-worth through employment when he was younger and from volunteering in more recent years. Though now unable to undertake volunteering work, Satch recalls that *'I would love to / I mean I used to / for them, I used to go to colleges and stuff',* explaining that he would *'talk to about, eh, 60 young, males mostly, and em just tell them about the downfalls of messing around with substances'.* He told me that he received a certificate of thanks and positive feedback, as well as a sense of pride in having helped others. He later reflects on the importance of being treated with respect and being given a sense of worth when recovering from substance abuse, which Satch perceives as a strand of mental health issues:

> *giving people a chance to* (.) *make / feel like they're, making, making they're helping to make a change. And it makes them, it makes, you're putting some / some / Something into people who've never had a job and now they're getting a bit of respect*

Satch had previously expressed that he '*was never so happy as when I was working. I felt / you were / you know, when you feel you're somebody*'. Though participants express not being able to work at this moment, knowing that they did and - for Andeep, Mahdi and Mya – hoping that they will once more work, seems extremely important to their sense of self (Mahdi) and self-worth (Andeep). It is telling that when I shared with Andeep that I had once taken medication related to mental health issues/distress - albeit for a short period – he responded by stating with some evident relief that there is hope for people with mental health issues. This conclusion was drawn from the fact that I was now sitting in front of him, working; returning to work being a strong ambition for him. For Mahdi, this seems to be intricately tied into his self-identity as a young Afghan man:

> *I know myself and I know our culture, I know Afghans. Once I'm on my feet, I will never take free money from you. I will try and help people like me. Or not people like me even Britains, the homeless Britains. Lots of homeless innit.*

Mahdi had previously stated of Afghan people that '*All our people are not bad*.', adding '*we have full of honour, we have full of pride, we have full of dignity*.', part of which is linked to the ability to provide for themselves and support others. Though Mahdi is unable to work at present, he prides himself in working towards being able to and in helping people such as myself in this research in the meantime. Mya notes that there is a lot of stigma in today's '*capitalist society'* if you are not working or furthering yourself in education, a sentiment not far removed from Peter's own that capitalist societies disempower and devalue many with a subsequent negative impact on levels of distress.

5 Conclusion

This chapter provided insights into participants' understandings of mental health issues/distress as it impacts on them and others similarly situated in society. Whilst most participants drew primarily from their own lived experiences, they also provided insights into situations they have witnessed as impacting the mental health of others in their communities or locality. Overall, most participants demonstrated understandings that stressed the role of socio-cultural issues in maintaining and aggravating mental health issue/distress. However, whilst participants are very clear that social inequalities play a significant role in their mental health issues/distress, they do not present themselves as victims lacking agency. Indeed, most went to great lengths to demonstrate how they resist narratives that threaten their agency and reinforce marginalisation. This same tendency is present in participant's testimonies regarding experiences of mental health and related support services, which is considered in the following chapter.

Chapter 5: State support for mental health - BAME intersectional perspectives

In the previous chapter, I explored participants' understandings and perceptions of mental health issues/distress. The chapter presented not only views relating to their own personal experiences, but also perceptions of how mental health issues/distress relates to a person's social stratification and experiences of marginalisation. In this chapter, I consider participants' testimonies regarding their experiences of State support for mental health issues/distress. In this way, it relates to issues of health inequalities focused on service performance. Part A, then, focuses on participants' experiences of accessing support for their mental health issues/distress. This section includes some limited discussion of perceptions of diagnostic practices, complimenting discussions in chapter 4 regarding views on diagnostic categories. Part B explores experiences of participants in using the services once they have accessed support. This include accounts of maintaining support, and views on the treatment options provided to them. Though focusing primarily on mental health and related services (i.e. primary care and substance misuse clinics), I also highlight accounts of interactions with other public services. I include such accounts as they impact on participants' actual mental health issues/distress and influence how they perceive and interact with mental health services; participants' testimonies often present such experiences as interwoven and interdependent. Whilst problematic dynamics at the interpersonal level are present in this chapter, this is not my focus. Instead, I concentrate on how systems, processes and policies are experienced and perceived.

Part A: Accessing support

Whilst Samantha is the only participant to describe how she first came into contact with mental health services, most do share experiences related to accessing support. This includes interactions with GPs and/or undergoing assessments. Descriptions often highlight a range of procedures that participants respond to differently according to the context in which they encounter them and the outcomes of engaging in these. This testimony has been organised under the following headings:

- accessing support through primary care; and

- being diagnosed and assessed.

Unlike discussion of access to support in the literature review chapter, I do not explore adverse pathways to secondary or tertiary care as participants either had not experienced these or did not share these experiences with me.

1 Accessing support through primary care

Peter appears to access support for his depressive moods through his GP practice. Though he reports positive experiences with GPs, recently Peter feels that the service he is provided has changed for the worse. This includes accessing support for distress. For example, he reports difficulties receiving the support he required following an assessment of his needs:

> *I don't know whether it's down to individuals or whether it's the actual system, but more recently, I was sent for an assessment. And, that was conducted, recommendations were made, and it just wasn't followed up on.*

Peter notes that his previous GP, with whom he had a good rapport, had recently retired. Around this time, the GP appointments system changed and *'things just wasn't quite the same.*'. Not only was the new GP more intent on medication as a treatment option, an approach Peter disagrees with, but appointments also became a strict 10 minutes slot in which patients are limited to discussing only one issue. Peter states that '*as a result of that, you find sometimes, you don't really get to say what you need to say.*' Whilst the 'one issue per appointment' policy may be adequate for people with less complex needs, Peter indicates this being impractical for people with more complex needs such as his; i.e. people with both physical health issues and, say, depression.

Similarly, Samantha highlights difficulties obtaining information and accessing her GP directly following changes to triaging services that required her to discuss very personal information with the receptionist before being allowed to make a GP appointment. Aware of the stigma surrounding a range of conditions she has (including HIV and alcoholism), Samantha is uncomfortable sharing this information with reception staff. As a result of her refusal, she was told by the GP in a telephone consultation that she had developed an '*attitude'*. Samantha is angry about this as she feels the doctor had not adequately accounted for the fact that she was awaiting very important test results and that the anxiety around this, together with her desire for privacy and concerns around stigmatisation, was impacting her ability to adhere to their new procedures. Here, procedural issues collided with interpersonal ones to create barriers to accessing services in a way that supports Samantha's wellbeing. This contrasts significantly with her account of when the hospital she attended listened to her explanation of difficulties she was having with processes around receiving medication and met her '*in the middle*' with a workable solution.

Peter also hints at the role that individuals working within GP practices can play in hindering patients' receipt of support in his account of undertaking an assessment and then not receiving support. He does not, however, expand on this to clarify whether he believes this to result from problematic interpersonal relations (including discriminatory behaviour) or incompetence. In fact, though other participants discuss the presence of discrimination in other situations, only Mya relays a specific account about seeking access to support from GP services. In a conversation about barriers to accessing services, Mya makes an interesting comparison between her experience and that of a friend who is visibly of a minority ethnic background. Of Asian heritage, her friend moved to the UK at the age of 7 but was raised '*quite separately from her community'*, by which is meant Asian communities. Mya comments that this friend has experienced significant issues accessing mental health support. At times, the role of stereotyping in this differential treatment was explicit. For example, a health worker once commented that her English was excellent, assuming that she had migrated here later in life when her friend had in fact grown up in the UK. Noting that her friend's GP practice is in a part of the city where poverty is rife and reflecting on the difference of treatment that she and her friend have received, Mya states:

> *you've got mental health problems but you've got problems with substance mis-use, got alcohol problems, and maybe there's a lot of, you know, people might see that 'Oh well you've turned away from your traditional society and you've gone down the route of drug and alcohol abuse'. And maybe it's seen as well either you're seen as part of your traditional community or you're on this path. Rather than actually, maybe you're somewhere in between, and maybe we need to not really be thinking about / you know, that stuff's irrelevant, let's treat the person in*

> *front of me, rather than thinking like / Because you know with her, I'm sure that she's almost been a bit written off before her time.*

Alive to intersectional theory and issues, Mya continues by pointing out the role that negative stereotypes of racialised people from lower socioeconomic backgrounds might play in experiences of health care. She believes that stereotypes of racialised people who have '*their expensive Nike trainers on'* and *'their hair back*' act as a barrier to accessing mental health services. Mya contrasts her friend's experience with her own. She reflects that, although a direct comparison cannot be made due to them attending different GP practices, the practice she attends serves a similar demographic. Yet the treatment she receives is very different:

> *maybe because I'm dressed, you know I've got my little thingy on* ((indicates a headband)), *you know I'm wearing a dress, it might make me look a bit more sweet, and I might go in and say very similar things, and I'm seen as a victim.*

Mya expresses the belief that white women are more likely to be considered victims of difficult circumstances than racialised women, despite statistical evidence to the contrary (Office for National Statistics, 2018).

Mya also indicates a belief that signifiers of class and education play a significant role when seeking an explanation as to why she and her friend had such different experiences accessing services: *'I think other people are seen as rough. And that's not necessarily just to do with the colour of their skin. It's class* (.) *and education as well'*. This view echoes statements made by Peter in relation to class and 'madness', and Satch and Mahdi regarding being treated disdainfully as a result of either class or 'race', or combinations of various identity-markers (see chapter 4). Whilst no other participants comment on the role of discrimination specifically in the initial stages of seeking to access mental health-related support, this issue is a significant part of the narrative provided when considering access to a broad spectrum of support.

2 Being diagnosed and assessed

Though Mya does not describe her own experience of a diagnostic assessment, she does comment that having '*a particular diagnosis over another, is helpful because it means that you get the right support.*' As discussed in chapter 4, Mya considers medicalised terminology and approaches useful; not only in terms of allowing a person to understand the psychosomatic symptoms they experience, but also in situating oneself in relation to others (i.e. not lazy, but 'ill') and to enable systems of support to be delivered more effectively. Perhaps unsurprisingly given his adoption of medicalised terminology, Mahdi also frames having been assessed and diagnosed as having a mental illness generally positively. It is worth noting that a diagnosis of mental illness provided Mahdi with a certified recognition of his trauma, which supported his claim for asylum. Mahdi had lost his case with the Home Office and was in the process of appealing the decision to deny him refuge. He recalls that a psychologist '*proved that I have problem*' and that the '*Home Office, due to that report, accept my case and give me five years visa.*' His diagnosis enabled him to jump the final hoop that gave him access to the security he required.

Samantha speaks in neutral tones about her encounter with a psychologist who '*was in tears*' when she '*told how it was going on'*. As a result of this interaction, the psychologist '*got in touch with my GP and told him that 'can you put Samantha on anti-depression tablets*'. Though Mahdi and Samantha mention having met with psychiatrists, in both instances this related to going through immigration processes rather than seeking support specifically for their mental health issues/distress. Neither comment directly about their experiences of the psychiatric assessment itself. Satch, having undertaken one between suicide attempts during this research, does describe his experience. His telling takes a somewhat different tone:

> *the other day when they sent me to this psychiatrist* (.) *and, you know, with him it was more* (.) *you just, you just getting in to telling him about your family, and then he, he'll switch it over to, like, Bristol and, you know, what I'm doing to, help meself stay off, drugs and stuff like that and you get / so you start trying to get your head into, telling him how hard it is. You can't, you know,*

Satch indicates finding the assessment extremely hard to participate in, feeling it is conducted in a way that makes engaging in a structured, cohesive manner impossible. Satch, fearful of being labelled '*mentally ill'* (see p.122), is extremely concerned with ensuring that he is perceived as presenting a biography that is comprehensible.

Whilst this does not mark his entry into mental health-related services, psychiatric assessments are part of the process for accessing further or different mental health-related support. He conveys a belief that this process assessed his mental state with little to no regard for his own perspectives. He describes his biographical accounts being unceremoniously dismissed before he had finished telling them, stating that the psychiatrist was '*changing his way of talking',* (i.e. *'going on about me family,'* and then switching suddenly to *'why I went to prison, so many times*'). Otherwise, Satch reports he would be '*throwing a tennis ball at you and asking you to peel an orange*'. This contrasts significantly in tone to the brief mentions of interactions with psychologists that Mahdi and Samantha make, which both convey – if not gratitude, then a positive impact from having their distress recognised by someone in a position to help them. Instead, Satch describes feeling unheard whilst being expected to speak of traumatic memories that invoke emotions he struggles to cope with. It is worth noting that Satch's account of this then flows into an account of his time in a substance misuse clinic that used degradation as a means of promoting recovery which then also led to descriptions of life in prison. Stories from all three settings having in common the sense of others trying to degrade, undermine and exert control over him.

Diagnostic assessments by a psychiatrist are just one form of assessment that participants describe in relation to accessing mental health services. Despite the neutral tone she takes in relation to her psychiatric assessment, Samantha does not speak positively of the repeated mental health-related assessments she has been exposed to since then. Describing an assessment process later undertaken to access support from a substance misuse clinic, Samantha emphasises frustrations resulting from all of the '*paperwork*' that accompanied it. Samantha emphatically states '*they assessed you, which is the most annoying thing. Might as well be mental by the time, by the time they finish*'. Asked what she found so annoying, she continues '*It's the paperwork. I hate it. It's just all writing, writing, writing, writing, writing, writing, writing, writing, writing, writing, writing.'*, later using profanities to convey the extent of her feeling.

This frustration does not stem exclusively from physical barriers to completing forms as a result of visual impairment, as she explains that in this instance the person assessing her was *'asking questions, writing down'* her answers. Rather it was the need to answer so many questions that she feels are simply for the purposes of the service that *‘was annoying me’*, seeing little return for herself in this exchange. Samantha finds talking ‘*very hard*’. By talking she risks providing personal information to people who – armed with such knowledge - ‘*know how to break me*’. Thus, opening up in an assessment means putting oneself in a vulnerable position in a space where the ‘reward’ of support is neither immediate or guaranteed. Additionally, Samantha confirms in a later discussion that dealing with paperwork brings back traumatic memories of going through the UK immigration process. As with Mahdi, the process of acquiring a Visa was traumatic, involving multiple applications and vast amounts of paperwork. Samantha describes the ‘*paperwork and that, in dealing with it*’ as having taken ‘*the life out of me.*’

Like Satch with his psychiatric assessment, Samantha must place herself in what feels like a vulnerable position and relive old trauma in an attempt to gain increased support for her mental problems. One difference, however, is that while Samantha focuses purely on the procedural issues that ‘*annoyed*’ her, it is less clear from Satch’s account whether his abhorrence results from the specific psychiatrist who assessed him, the assessment format or a mix of both. Regardless, it is evident that - like Samantha – the process forces the confiding of deeply personal information for assessment rather than therapeutic purposes. For Satch – and to some extent Samantha – this frustration is likely further aggravated by their scepticism of diagnoses (see chapter 4) and dominant treatments. Further, this process is conducted by people perceived by participants to be in positions of greater power; a power that is then augmented by the acquisition of such intimate knowledge (Tate, 2019).

Whilst Satch is generally more comfortable talking about past experiences than Samantha, having spoken to school children on multiple occasions about the realities of being an ‘*addict*’ and being in prison, this is different. Speaking in schools provided Satch with a sense of being valued for sharing his stories. In contrast, this ‘*switching*’ of topics just as he is ‘*getting into talking about*’ difficult subjects, reinforces feelings of disempowerment and not being heard properly. For both, engaging in processes that require making oneself vulnerable and evokes past trauma in an attempt to gain additional support triggers feelings of anger, irritation and frustration. Particularly when there is no guarantee that adequate or appropriate support will be provided afterwards; a point that Peter also makes in relation to an assessment undertaken on the request of his GP.

2.1 Responses to diagnostic labels

Influencing such experiences is the need to navigate diagnostic labels. This issue includes specific difficulties for participants who challenge medicalised approaches and/or have long histories of marginalisation. Participants have complex negotiations to make when considering accepting mental health or mental illness labels (see chapter 4, part A). This includes a tension between the possible disempowerment and stigma that such labels can bring, and their desire for support. Though each have different responses to such labels, Mya, Samantha and Peter all explicitly recognise that it is very difficult to find the right support without being able to articulate what the issue is. For example, Samantha states that mental health professionals '*will help you through that when they* <u>*know*</u> *exactly what is going on.*' Where these participants' views differ is that whilst Peter and Samantha feel it is the causes of distress that must be understood to be properly addressed, Mya seems more comfortable with the symptoms of a diagnosis remaining the focus of treatment plans. Not only do diagnostic labels help to ensure the 'correct' medical treatment is provided, but she also accepts its necessity in accessing other forms of support: '*I need to claim benefits and* stuff', noting that '*if I'm out of work because I'm ill, I'm entitled to a lot more.*' Diagnosis not only serves to direct treatment, but – as Mya and Mahdi point out - is also a passport to a plethora of support.

For many participants, as highlighted in the previous chapter, accepting a diagnosis is a fraught process that risks amplifying their marginality relative to the organisations and professionals they interact with. For example, Samantha equates accepting having a 'mental illness' diagnosis with handing '*power over that*' to people with the potential to '*break*' her. Satch, who together with Peter are arguably the most resistant to accepting mental health labels, makes this issue apparent when he states that people are '*forever trying to label me mentally ill and it makes me feel bad'*. Though in the same meeting Satch states that he just wants more support - even if it takes a suicide attempt to get it (see Appendix 20) - he is still resistant to being associated with any mental illnesses beyond addiction. Recalling the story Satch tells of his Dad's time in a psychiatric ward (see p.122) and the consequences of this for him as a child, this is perhaps unsurprising. Peter comments on the problematic – even prohibitive - nature of mental health-related labels, stating that '*a lot of people fail to seek, help. Because they don't want to be labelled. They don't want, you know, to be associated with that stigma.*' I found evidence of this phenomenon while interviewing people. For example, Samaiya's brother's hesitancy to admit to other people that he experiences mental health issues for fear of being stigmatised.

As suggested above, Peter, Samantha and Satch express the sentiment that mental health labels enable a dismissal by services to address the causes of the issue/distress. In one discussion Satch states: '*I feel like, you know, just pushed to one side*' by mainstream support services as '*they just put us in the package mental health*.' Being placed in the mental health '*package*' equates, in Satch's view, to receiving a lesser service. Peter highlights that this dismissal of causes includes a refusal to address structural inequalities experienced in daily life or nutritional deficiencies. Labels are, for Peter in particular, inherently political:

> *I just think things are labelled these days, for specific reasons, and they're not favourable to those* (.) *involved, those who co / you know, those who are suffering from these conditions and so on. And I think these, some of these labels are unnecessary.*

The implication seems to be that the application of stigmatising labels is not necessary to the provision of support to people. Peter is – as I understand it – stating that whilst he acknowledges the role that such labels play in the provision of support, this would not be necessary if services really listened to what people actually needed. This is presented as an alternative to relying on medical authority in the form of diagnostic labels. In his view it seems that service provision is not an adequate justification for diagnostic labelling to perpetuate. Rather it is a useful device for those in more powerful positions, i.e. service providers, justifying their existence and supporting their practices even when these are '*not favourable*' to those living with the 'illnesses'.

Part B: Using mental health and support services

In the above I begin to demonstrate the dynamics that many participants perceive between themselves, the systems they are navigating and the professionals working within them. Considering participants' testimonies of being in receipt of support, two key themes emerge. First is the sense of continually having to adopt and take actions that serve the interests of service providers and not themselves. Participants describe this as often being at a cost to their own wellbeing and mental health. Second is the overwhelming view of being provided inappropriate or inadequate support. Usually this refers to encountering services that are unable to meet the needs of participants due to systemic or organisational reasons, as opposed to interpersonal issues. Here we therefore see the introduction of broader structural issues that go beyond influencing or maintaining problematic procedures. They include the implementation of problematic policies at national (and international) levels, leading to the delivery of practices - such as treatment options – that most participants feel do not meet their needs. For example, most participants express the view that there is either an inability or unwillingness of support services to address the issues they perceive as causing or aggravating their mental health issues.

3 Service needs vs the needs of BAME service user/survivors

Many participants spoke of feeling that mental health services and related support (i.e. substance misuse clinics) were more concerned with ensuring that procedures were complied with and boxes ticked than with meeting the needs of the people accessing the service. For example, Peter speaks of healthcare staff running around '*making sure all the boxes are ticked*' so as to pass inspections, rather than ensuring that good practice is in place all year round. In a later interview Peter reiterates this view, stating that policy is created but that '*it's not being done but paperwork is in place to say yes it's being done*.', satisfying the authorities who have oversight of service delivery without needing to invest time and resources in actually delivering the initiative effectively. Also drawing on the analogy of 'ticking boxes', Satch speaks of *'ticking pocket doctors'* who have '*the minimum knowledge of ….mental health where drugs are concerned*' being sent to provide him care, indicating that they have just enough knowledge to tick a box but not enough to actually help him. Recalling Satch's comment that he is always provided '*the cheapest kind of understanding*', it is evident throughout his testimony that he does not feel that services really understand his needs, or that they genuinely seek to. Instead, he indicates believing that they provide what they want to provide, sometimes expecting him to act as their '*guinea pig'* for new treatments with no regard to the after effects on him.

A similar sentiment is present in Mahdi's testimony when he explains his healthcare navigator's expectation for him to report to him once a week to show him that '*I'm not gonna kill myself*':

> *they are not helping me. I think it's just a business. To just 'Oh yeah yeah, I had a client today. Mahdi. Job done' No, no no. Get another client. Leave me be in peace. I want to be in peace. I want to relax. I just got my five years visa. I want, I'm trying to focus on my life*.

Mahdi, like Peter and Satch does not believe that his wellbeing is driving the forms of support being offered. They feel instead that 'business' concerns, such as meeting targets and delivering support for the least possible cost, are being prioritised over delivering what people with mental health issues/distress actually require. Whilst Mahdi recognises that the NHS is '*too crowded'* due to its being free, and is therefore '*under pressure*', he is not willing to submit himself to practices that serve only to tick the box of the service provider and are of no benefit to him. Particularly if it requires him to denigrate himself in some way; e.g. asking his wife for money for the bus.

The view that business interests take precedence over the needs of individuals using the services is shared by many participants. They perceive mental health-related support as being provided more as a commodity in a business setting than as healthcare with the wellbeing of the person as its priority. Following comments regarding the healthcare system's reliance on medication, Satch observes that '*all this money they say they're spending, I can't see it. All this money they're spending, they're just making up 'oh this and that''*. He continues:

> *I mean of course people need work, but get them to be doing / If it's this kind of work where they're working with another human being, mental health or not, you know, nobody deserves to be treated like that*

Satch demonstrates his awareness of government announcements that more money is being put into mental health-related care, however he does not see evidence of this at the ground level. Further, he highlights the role that a demand and supply model might have in influencing policy within a ‘business’ setting. People make their livelihoods by providing care and treatments to people with mental health issues, hence ‘*people need work’*. While he accepts this, he does not feel that the way services are delivered meets the needs of people accessing them; an issue that he indicates is reflected in the way staff treat service users/survivors.

Several participants express similar views, implying that this business focus is at times reinforced by interpersonal interactions with healthcare professionals. Overall, the main themes to emerge with regards to participants’ views of their interactions with individuals working within the mental health support context were:

- feelings that staff lack real understanding of their experiences and needs, which sometimes translates into or includes discriminatory behaviour;
- not feeling heard or believed; and
- an acute awareness of power dynamics - often this involves participants feeling that staff were behaving coercively, augmenting the coercion inherent in the system.

These issues seem to contribute to participants’ needs to conduct acts of resistance. Where resistance does not appear to occur, participants acted to hide aspects of themselves or altered their behaviour/appearance. As the rest of this chapter highlights, participants instead feel that they have to take significant steps – often to their own detriment – to meet the needs of service providers so as to access the support they require. This, it seems to me, is further augmented by the particular intersectional locations that some participants occupy.

3.1 Meeting services’ expectations to gain support

Participants highlighted specific ways in which they have had to put the needs of support services before their own wellbeing, so as to access much needed support. Whilst not all of the support discussed is strictly provided by mental health services, it was required by participants in part to enable them to maintain their wellbeing; i.e. substance misuse clinics. In my first encounter with Satch, he quickly introduced me to his sense of continually having to ‘*jump through loops’* to receive the support he needs. Within the first minute of turning my Dictaphone on, he states that support services '*want the ideal, substance abuser who'll just come skipping in and say all the right things and everything*.' Shortly after, Satch reports:

> Satch: *I'm trying, always having to jump through loops as well, you know. I feel like, you know. You get* (.) *you know, offers for help and then you've got to end up / you find yourself, uh yeah, jumping through loops man.*
>
> Stéphanie: What sort of hoops? Like what sort of things?
>
> Satch: *You know. Find a, a daily group. I don't want a group. Do you know what I mean, I've bee / I've done all that. You know, I've been 15 years in recovery, you know.*

Satch explains that '*everything seems to be a fear thing.'* In another example he states that threats included being told that *'you will be removed from this home or house, and will be moved away from your friends'* if people do not abide by rules regarding sexual relations with other service users/survivors. Satch explains that abiding by these rules was difficult when in substance misuse rehabilitation, because once sober *'all the feelings'd come back and the feeling of being a normal man or women. It's natural.'* He expresses the view that service providers set rules that may make sense from a service delivery perspective, but that deny recognition of service users as having the same natural desires and needs as other human beings and enforced severe penalties for people who act on such needs. Satch described being forced to engage in a process of trading-off between basic needs and other aspects of their identity.

Satch perceives this as an example of '*mad rules and regulations'* that *'come and go'* – implemented by service providers to manage their services and those that use them, but that are harmful and dehumanising while in place. It is not that Satch believes services should not have any rules or expectations of service users, but rather that they should not be '*as rigid'* and strictly applied, as trying to conform to these to ensure continued support is '*just tiring'*. Failure to adapt to the criteria or expectations of the services, even when they require a person to disavow important parts of themselves, can be perceived as a refusal to behave appropriately such that services disengage (Harvey, 2019). Aware of this but exhausted by attempting to meet their expectations, Satch would sometimes struggle to contain his frustration.

This is often perceived as aggression and has led to Satch losing support, sometimes with disastrous consequences (see p.113-114).

Satch also describes counselling sessions using similar techniques of fear:

> *the counsellor could, kinda pl.. / you know, like the, the donkey on a stick kind of thing. You know, 'Do this. Do tha.', or 'We was expecting, you know, some more from you'. You know stuff like that when you was, when you're in the rehab. Well in, in the* (.) *what'd you call it* (.) *care thing. Yeah, or you got your accommodation / you get, you're worried about losing that. You're worried about, you know, it's all fear.*

It is unclear if this counselling was undertaken in the context of mental health services or substance misuse services. However, this testimony reveals the ways in which people located at the intersection of poverty, substance abuse and mental health issues might experience coercion in the context of mental health treatments. As with Samantha and requirements to complete paperwork, engaging in such groups may actually be detrimental to Satch. The expectation placed on Satch to engage in activities that he does not find beneficial, and may in fact cause harm, so as to maintain support or be granted access to additional help epitomises shared perceptions of continually jumping through hoops. This power dynamic arguably also sheds light on Mahdi's willingness to submit to medication he does not believe is effective so as to receive welfare payments, despite his usually assertive demeanour. Mahdi recognises the link to accepting the treatments staff want him to undertake and receipt of a wider range of support that he requires, such as welfare payments due to his relative poverty.

Another example of engaging in practices felt to be harmful is again found in Samantha's testimony. I have previously highlighted Samantha's disdain for paperwork. Requirements to complete paperwork continued in counselling sessions where she was expected to respond to a wellbeing questionnaire each time she attended[21]. Given that the counselling was being provided at a substance misuse clinic as a result of excess drinking, it is concerning that engaging in this activity led her to feel that '*by the time I get out of there I just wanted to go to the bar and get a whiskey'*. She states that the paperwork was '*a lot of rubbish'*, later adding that completing these questionnaires is '*enough to make you crazy.*' As previously discussed, completing copious paperwork reminds Samantha of a particularly traumatic period of her life. Additionally, though she did receive help completing the forms, the process forces her to confront loss relating to her deteriorating eyesight. Samantha feels that this activity serves no benefit to her, stating that '*I didn't come here to do, for you to do paperwork.*' Further, cultural differences may also influence her view of paperwork as '*a lot of rubbish*', as she seems to consider it as being in opposition to taking 'action'. Samantha stipulates 'action' as being how things, including dealing with distress, are dealt with in Swaziland. The insistence of services that she complete wellbeing questionnaires in her counselling sessions forces Samantha to engage in a process that does not align with her views of what is helpful to recovery, and forces her to confront past and present points of distress in her life, intensifying her desire to drink[22]. That this is to satisfy the requirements of a process tailored, Samantha implies, to the needs of the service provider rather than her own is '*annoying*' at the very least. Yet engaging in this is presented as a mandatory part of receiving therapy.

Peter highlights the marginalisation that can occur when practices implemented do not allow for multiple understandings of mental health issues, and the additional effort then required to maintain support. Peter's testimony suggests friction between himself and a new GP, resulting largely from them having different beliefs about how Peter should manage his '*depressive mood*'. He recounts an exchange with his GP where he explained that he did not want to take the medication offered because it had not previously worked. In response he '*was told that if I don't take it, I'm not helping myself.*' Peter clarified that he felt compelled to take the medication against his better judgement, to stop himself being categorised as someone unwilling to help himself. Such a categorisation might lead to further hesitancy on the part of the GP to provide other forms of support. Given GP's roles as gatekeepers to other forms of support, it is understandable that Peter might have felt compelled to take the medication once more, if only to demonstrate that it was not effective on him. Yet, Peter believes this medication to be not only ineffective but harmful, causing him '*Gastroenteritis, and all the rest of it.*' Thus, like Satch and Samantha, he was forced to jump hoops that are potentially detrimental to his wellbeing simply to assure continued or future support from service providers and gateway services.

Like Peter, Satch and Samantha also highlight ways in which the services' demands were borne out through interactions with mental health practitioners. Stating that she's '*got to do it my own way*', Samantha outlines disagreements with staff members telling her what they believed she should do to get onto the path of recovery from both her substance misuse and her mental problems. Samantha continues '*I keep explaining it to the mental team*', telling them that she '*can't step in other people's shoes*'; by which she means doing what others do and having the same result. This belief that what worked for others is not helpful for her may be partly informed by the cultural differences regarding treatments, (see p.164) However, it is also influenced by Samantha's openly admitted tendency to follow the path that opposes that which she is told she *must* follow; it is an act of defiance and/or resistance.

Another factor also seems to be that Samantha believes most staff do not understand what she is going through because they lack lived experience of mental problems. She feels that there is a very real disconnect between what is taught in textbooks and how such issues/distress are experienced. As such, Samantha is unwilling to accept people lacking lived experience as 'expert', and herself as 'less expert'. Satch demonstrates a similar view when describing an unsuccessful therapy session with a councillor. Unable to engage with the therapy the way expected of him - stating '*I couldn't do it, couldn't do it'* – Satch observed the councillor becoming '*irritated by that*.' Satch holds that this demonstrates a lack of understanding, stating '*if you can't understand* (.) *past your nose like uh, you can't understand, you know, he's in the wrong job like.*' For both Samantha and Satch, a perceived lack of relevant lived experience undermines not only the authority with which they feel staff conduct themselves, but also their expertise. Through these conversations, they emphasise the need for staff to realise their limitations of knowledge and adjust their approaches accordingly.

3.2 Altering behaviour and appearance

Finally, several participants speak of people having to alter their appearance or behaviour so as to 'fit' within service provider criteria/expectations. Some of these accounts are relatively subtle, with the connections to wider systemic issues (such as prejudice and cultural incompetence) not being explicitly stated. For example, Samantha highlights instances where her behaviour led to her removal from therapeutic settings[23] or prevented her from gaining the support she actually needed[24]. In the previous chapter I highlighted how difficult Samantha finds continually mediating her behaviour and way of expressing herself. Samantha does not bring these things together in her testimony, but I note the similarities and possible crossover. In contrast, Mya explicitly highlights how signifiers of marginalised identity-markers might impact on people's experiences of health and mental health services in her account of the different way she and her friend were treated in GP practices. Satch provides first hand examples from within a mental health-related context of how his intersectional location creates additional hoops to jump to maintain access to or receipt of additional support. I have already provided one example in his having to ignore sexual desired to retain his accommodation. A further example relates to altering his appearance to avoid stereotyping and discriminatory treatment.

Accompanying Satch to a meeting with one of his support workers, I learnt that he has previously cut all of his dreadlocks off in preparation for entering a substance misuse clinic. His support worker recalled asking him why he had done this; she states that he said he didn't want any trouble. She adds that she felt he was often perceived as threatening due to his being a black man with dreadlocks. She later provides an example of Satch being banned from using mental health-related services on the premise of having intimidated a member of staff when he looked into the facility through the window. When she challenged this, she was informed that intimidation is subjective. Satch validates her account and in other discussions provides further similar stories of how his appearance and particular intersectional location as a black man with dreadlocks have impacted on the way he has been treated in services; no doubt further augmented by his history of both substance misuse and spells in prison.

Some participants also described engaging in a protective silence about aspects of themselves that they feel put them at further risk of losing credibility and becoming even more disempowered. Examples of this include Satch's unwillingness to be open about his initial suicide attempt with support services and Samantha's use of sarcasm to avoid revealing anything too personal. Another example can be drawn from Mya's testimony regarding her spiritual experience several years ago that awakened a strong faith in God, though she remains unaffiliated to any specific religion. When I ask if she has spoken to anyone within mental health services about her spiritual awakening, she responds that she has been too frightened to do so. Part of the reason for this is based on something she witnessed when working as an occupational therapist in a psychiatric ward:

> *before I got ill / well I / before I got more ill, and, when I was doing one of my placements in mental health / wasn't based in, on a psychiatric ward but I did spend a couple of days there / and there was this one lady and she / her, her delusion was very much about, God and* (.) *I mean what she was saying didn't make any sense, but I think that, maybe, is an extra thing that scares me.*

Mya observed the way that staff responded to this woman's testimony regarding her spiritual or religious beliefs and witnessed these being understood by healthcare staff as evidence of delusions. Fearful that a similar thing could happen to her if she reveals her own spiritual experience, she researched the subject. Mya found information from the Royal College of Psychiatrists '*saying how hard it was to, you know to have this sort of, to identify which is which*'; 'which is which' meaning that it is hard to determine what results from religious belief which is considered to reside within 'normal' psychopathy, and what is the result of 'delusion'. As a result of this ambiguity and her previous agnostic position, Mya feels safer keeping her experience to herself - even within her counselling session – despite the fact that it occupied an important place in her life and is causing her considerable inner conflict.

However, this is not everyone's experience. Meeting Samantha at a time when she felt *'life is getting greater'*, she speaks of the positive impact of reigniting her relationship with God in her recovery. She explains that a mental health worker from one of my BAME-led gateway organisations encouraged her to revisit her faith as a means of finding the strength to move forward. I also asked if she had felt comfortable expressing her faith when receiving mainstream healthcare. Samantha informs me that she had, and that while in hospital she was in, she regularly visited the chapel. Thus, whilst religious beliefs can and are accommodated within some healthcare services, they also hold the potential – particularly in a mental health context – to further discredit people. This power differential creates obvious and logical motivations to consider hiding aspects of the self, even at the cost of the effectiveness of treatments such as talking therapies.

4 Treatments

In the previous section I consider examples of service provider expectations of service users that must be met if people wish to access or continue receiving support, regardless of the implications for individual participants. I also highlight testimonies where services adjusted their processes or practices to better suit the needs of a particular participant and the positive impacts this has. In this section I consider participants' views of the appropriateness and adequacy of support received to help manage or recover from their mental health issues/distress; exploring views on specific treatment options provided. I focus, as participants do, on medication and talking therapies.

4.1 Medication

I begin by stating that most participants express an overriding sense that there is, among healthcare workers, a limited ability to or interest in seeking to understand and address the causes of people's mental health issues/distress. Peter is particularly articulate on this point, stating:

> *I just think, the current approach isn't, isn't right at all because there are reasons as to why people find themselves in those situations and if you're not dealing with the root cause, it's pointless. What you're doing basically is masking the symptoms, and that makes no sense to me.*

For Peter and several other participants, this belief that healthcare services lack the interest or ability to address 'root causes' is closely aligned with a perception of an overreliance on medication:

> Samantha: *the mental group when I was in* [Hospital A]*, they came and see me. They talk to me. They asked me how I'm feeling and la la la la la la. After that they just went and upped my dose, and then that was it.*
>
> -----
>
> Peter: *Medicine doctor has no interest in exploring the reasons as to why, and sometimes it's simply due to a deficiency*[25]*, or certain deficiencies. And that is not explored. You're given a medication to mask the*

> *symptoms. The cause is not taken into consideration. And there is this whole mental thing going on. Which is a symptom. And that's where all the focus is.*
>
> -----
>
> Mahdi: *I'm getting 150 Sertraline every day, and 15 ml* ( ) *night time, so* (.) *I don't think so 150 is low dose, it's very strong dose for anti-depression tablets …So, so, if I am having that already, that's not helping me. Because you're not trying to help me. Why didn't you give me leave to remain forever?*

These extracts demonstrate a strong belief that mainstream approaches aimed at supporting people to manage or recover from their mental health issues/distress are too limited. Instead of seeking to address the '*root causes'* that trigger, maintain or aggravate the issues/distress (see chapter 4), participants feel that mainstream healthcare tends to address or *'mask'* the symptoms by simply prescribing medication. Present traumas tend to be understood as arising from social factors, such as socioeconomic position, exposure to discrimination, disempowerment, violence etc. When participants speak of services not addressing the root causes, I suggest that this should be understood primarily as not addressing ongoing experiences of trauma, stress and systemic marginalisation and discrimination.

For example, Mahdi views insecurity around his rights to remain in the UK as a significant factor aggravating his mental illness. Having expressed frustration at being granted only a 5-year Visa, he reflects '*I'm secured I feel OK. I'm safe. I'm not gonna die. Not today.',* adding *'So at least there's one switch is off in my brain OK. I'm relax.'.* He continues:

> *I think, I need to be more relax more than medications. Because as much I take these chemicals, even 3, 3 tablets, 4, 4 tablets, every day, but I'm not good here, I'm not relax. I am not stable. I am not safe.*

For Mahdi, being given medication is simply '*not helping*' him. It does not address the 'root causes' triggering his present ongoing trauma and does not adequately '*mask the symptoms'*. What he needs is to know that he is safe not just for '*today*', but that he can start to build a new life for himself in the UK that he won't be uprooted from in the future. For Peter, root causes include biological factors, such as vitamin deficiencies. This, he suggests, might be remedied by greater exposure to the sun, changes of diet or the taking of vitamin and mineral supplements. Peter explains however, that alternatives to medication are '*not explored'*. Andeep, who explains at the start of our conversation that talking to someone means that you probably won't develop mental health issues, is also deeply sceptical of medication. He describes a cycle with medication that is unhelpful to recovery. He states that you become depressed, and so you are put on medication. But these medications make it difficult to communicate because of the impact they have, and this is a problem because communicating difficulties is – in Andeep's view – integral to recovery.

Medication received not just the greatest attention when discussing support available, but also elicited some of the strongest emotional responses. Most participants consider this practice problematic for two main reasons:

1. Applying a *'one cap fits all'* approach ignores the person's individual situation – this approach insists that medications should be assumed to work and be a positive step for everyone; and
2. It's depoliticising and disempowering effect – several participants consider medication's sedative effect as a means for support services to avoid addressing more complex 'root causes'.

Peter is most explicit about feeling there is a '*one cap fits all*' approach: '*The other problem is, this one cap fits all situation. Medication does not work for everyone*', later stating *'it clearly doesn't work for me, but their approach is to keep trying another and another and another and another, and so on. And that doesn't make sense to me.*' Similar experiences are evident in both Mahdi and Samantha's testimonies in the extracts at the start of this section, with healthcare professionals not openly acknowledging that medication does not work for everyone. Samantha describes her medication dose being '*just upped*' despite explaining the issues troubling her. This clearly frustrates her as, like Peter, she considers this practice somewhat pointless. In fact, it informs her rejection of medicalised terminology:

> *if you say that to them 'Oh I've got a mental health / a mental illness', they will bring the mental team. They will assess you.* (.) *And then, they give you a pill.*

Elsewhere stating:

> *they give you citalopram, and, and then if they don't work, they change it and they give you something else.*

The implication being that, when medication does not have the desired impact, healthcare providers simply up the dose or switch to different tablets. When it comes to '*depression tablets'*, Samantha has '*done them all! Been there, done it.*' She states that she '*started on Citalopram, and all it does is, it takes away your moods. And it makes you happy.*' Though she here recognises that the medication had a positive impact on her emotional state, she is not satisfied that it should be the extent of support offered to her; it does not address the other issues in her life.

This reliance on medication is not only concerning to participants because of its avoidance of social and environmental factors, but also because of the potential side-effects. Peter speaks of developing gastroenteritis and other maladies as a result of taking such medication, highlighting that others in his social network have had similar experiences. Speaking of his sister, he states that whenever she '*hit a really bad patch',* her medication was changed. Additionally, the number of medications prescribed are '*continually going up. Because as one side-effect kicks in, you're given another, in order to combat that. And on and on it goes.'* Peter feels that the negative impacts of mental health medication are not generally given adequate consideration. Peter also expresses the view that medications affect black people differently to white people due to '*a difference in the genetic makeup of a Caucasian person and a black person'.* He states that there are '*no clinical trials done on the, on the black race*.' He asks the rhetorical question:

> *if none of that is taken into consideration, no data is collected, no trials are being done and so on, how can those medications work effectively for a group that was never taken into consideration at all?*

Another side-effect is highlighted by Andeep, Peter and Satch; the '*Zombie'* effect. Satch gives the following description of men residing in his locality:

> Satch: *it's easier to just shut them up with / you see a lot of them who ain't, who ain't as outspoken, and they just walk around. Every day I see*

> *some of them walking around the streets and they've got nothing to do, nowhere to go, and* [*they jus*
>
> Stéphanie: What, the] doctors?
>
> Satch: *and they all, there's a Jamaican one who [shouts] and he drinks, and he's walking around 'eiyayaeiya', you know and, the poor guy's like that because they're just feeding him full of fucking* (.) *shit.*
>
> Stéphanie: Like what?
>
> Satch: *You know like, liquid cosh we used to call it in jail. It's like* (.) *it / it / keeps like a loud patient a bit* ((mimics 'spaced out' look))
>
> Stéphanie: Aww, like it sedates them?
>
> Satch: *Yeah. And they're just walking around like a, like a Zombie you know.*

A direct link is made here between the medications being provided to people and their '*zombie*'-like state. Peter speaks of '*a lot of people walking around like Zombies'* as a direct result of medication. When I met Andeep, he was at that time using medication though he stated that he didn't like them as they make his mind '*boggle*'. I observed that he did seem in something of a sedated state, speaking very slowly and eyelids heavy. I cannot compare this behaviour to when he is not medicated, but my observation fits with his own comments. Peter suggests that '*in some cases depending on, you know, the practitioner you're dealing with',* there are instances whereby '*black people may be more / there'll be more of an urgency to medicate'*.

Peter suggests that '*one of the things that, presents a problem is* (.) *expressions'*, continuing that '*you might find some black people very expressive'.* However, '*if you're assertive, you're seen as aggressive'* by staff, which '*is a major problem'* for many black people seeking support. Whilst Satch does not make this exact claim, he does use the above story to illustrate his view that medication is used as a means to stop people making too many demands or causing problems for support services. He believes that services find it easier to supply medications to '*shut them up*' than to listen and address the social and environmental issues causing people to seek support in the first place. This implies an active choice on the part of service providers or ‘the system’ to disempower and depoliticise people who are struggling. As a result, people who ‘*ain’t as outspoken*’ as himself are likely to be transformed into a passive ‘*Zombie*’ who ‘*just walk around*’ with ‘*nothing to do’*. The implication is that to avoid being ‘*fobbed off to medication*’ or being told to ‘*just take the medication and carry on*’ – as Peter puts it – people must be willing to be ‘*outspoken*’. However, this comes with its own difficulties as Satch notes.

Self-confessing to being ‘*hard to work with*’ – or at least to having been hard to work with in the past - Satch knows that his willingness to be *‘outspoken’* and demand what he feels he needs earns him such a badge. Indeed, supporting him to receive medication during the Covid-19 lockdown by going to the pharmacy to pick it up, I found that the pharmacy workers knew him by name and his reputation as ‘difficult’ was evident. Yet, speaking with his support worker, she explained that he only behaves this way when he feels unheard or frustrated that he is not being given the support that he needs. Stating that she doesn’t find him hard to work with, she adds that she feels people view him this way because of a combination of his behaviour (i.e. being demanding and ‘mouthy’) when upset and the stereotypes of black men – particularly those with dreadlocks – being dangerous. She adds that if you understand his history and the barriers he has faced, his behaviour is entirely understandable. This seems to echo Satch’s own view when he recounts being told *‘you’ve got a chip on your shoulder’* by a member of staff at a prison he served at, to which he responds ‘*So?! You would if you lived*’ his life. Seen in the context of his past experiences, his responses to certain situations are, in his and his support worker’s view, entirely logical.

It is notable, perhaps, that Mahdi also mentions his wife’s statement that he can be ‘*a very difficult person*’ at times. Though he later explains that is partly due behaviours towards her that result from his mental illness and being very *‘sensitive’*, he also links this to not allowing professionals to refuse his needs. He recounts exchanges with his solicitor where he asks: ‘*Are you playing with me? Like, you can’t play with me. I know everything. Come on! Move on! Don’t / don’t / stop hide and seek. Do your job.*’ Yet, in response to medication, Mahdi, uses submissive language when he declares his willingness to ‘*lay down like this, have Sertraline*’ in return for receiving financial support. Just as a diagnosis label supported his claim for asylum, so too does he feel that taking medication supports his claims for financial - and later housing - support. Such accounts begin to demonstrate why participants feel the need to embark in acts of resistance against mental health treatment practices offered by the NHS, whilst others accept them even if they do not agree that they are helpful.

Peter expresses a further view that many people accept medication as a result of '*conditioning*'. He states that many people would:

> *rather pop a pill and get the quick fix and that is never going to solve your problem. And I think we've also / we're so conditioned now that we don't focus on a permanent solution to the problem. So, we accept what's on offer, and, in my opinion it's not a cure. It's just a suppression of the symptoms.*

Accepting medication without challenge is not, for Peter, evidence that people believe it effective. Rather, it is evidence of an unwillingness or inability to fight for what they feel is really needed for recovery or effective management of their mental health. Peter holds that an important factor in this conditioning is the authority given to medical practitioners and medical discourses in society. Whilst he states that service users seek a '*quick fix'*, he does not attribute this to people's natural dispositions or a lack of interest in alternatives. Rather he suggests such behaviour as the result of having been '*conditioned*' to '*accept what's on offer*' and placing trust in medical practitioners. Peter maintains that *'the medical profession is a trusted source. By the majority'*, stating that people are more likely to trust the advice of medical doctors than holistic practitioners. As such, Peter does not blame individuals for accepting inappropriate or inadequate support in the form of medication, but the system that has conditioned them to accept it. He states that *'the pressures of society*' mean that '*people are finding it very difficult to cope, struggling quite badly in some cases'* such that '*things spiral out of control'.* Therefore, when *'in comes the quick fix'*, it is understandable that people who have '*struggled*' might seek the path of least resistance with the promise of a '*quick*' turnaround. In contrast, Peter describes actively fighting the dominance of medicalised approaches by seeking out alternative treatments that he feels better address his symptoms. This involves seeking out and trying alternative approaches, such as addressing nutritional deficiencies or finding '*some homeopathic things'* which he feels *'works quite well'*.

4.2 Talking therapies

Though participants who discuss treatments they undertook focus mostly on medication, several also speak of experiences with talking therapies. Whether participants feel these are helpful or not depends on many factors and acts of resistance are certainly present here also. Once more, negative experiences are raised more often than positive ones. A common theme is feeling pushed or coerced to attend group therapy sessions which many participants feel are not helpful to them. I highlighted earlier that Satch perceives having to '*find a daily group'* to access other support as just another hoop to jump through. Peter also finds attending group therapy sessions unhelpful, stating '*I don't fare well in groups',* elaborating that '*I just don't feel comfortable with it. Because some people are good at speaking in a group and opening up and so on and I'm not.'* Yet Peter explains feeling compelled to attend as he was unaware that he should have had a choice in the sort of therapy he undertook:

> Peter: *They put this in place, and everyone has to fit into that. It's for instance like the group therapies. You see. It's not for everyone. I'm sure that's known. And yet, it's been implemented in such a ways as to say this works for everybody. That's one cap fit all situation. And, even when you're being interviewed, you're being pushed in that direction, you know and so. And I didn't know I had a choice.*
>
> Stéphanie: Oh really!
>
> Peter: *No, it wasn't until* (.) *I had a call for some feedback, and I was asked, as to whether I was um happy with my choice. And I said 'Choice? I didn't have a choice.' And then there was a pause* (.) *and I asked the question 'Was there a choice?' And they became a bit awkward and eventually I got the answer well, you know. I realised that there was a choice but, you know.*

Peter expresses knowing himself well enough prior to attending the sessions to judge that he was unlikely to '*fare well'*, as he would not '*feel comfortable'* '*opening up'* in that setting. Therefore, had he been aware that there was a choice of attending one-to-one therapy sessions, he has no doubt he would have done so. Peter communicates that this obscuring of the choices is intentional, at both the systemic level and at the level of individual interactions; i.e. the person he spoke to who ‘*pushed´* him in a particular ‘*direction’*, who is part of a system that creates a ‘*one cap fits all situation’* which ‘*everyone has to fit into’*. Satch expresses a similar belief, stating that this is problematic as ‘*out of ten, maybe two people will be / will be / will get something from that, but the rest, they’re just going round in circles*’. Recall that Satch’s attendance of such groups is sometimes a requirement of receiving other support that he actually desires.

Samantha provides examples from her own experiences of unhelpful group therapy sessions, describing attending one where she was eventually asked to leave by the session leader. This was a group for people experiencing mental health issues/distress. Samantha describes the experience as ‘*frustrating’*, stating ‘*I don’t get it.’* She also struggled to connect with other people’s outlooks, stating ‘*me, I don't like people talking bullshit sometimes.’* She later informs me of being paid to attend a group therapy session for people living with HIV. To ensure that mobility issues or finances are not a barrier, transport to and from the session was paid for and an additional £10 provided as an incentive to attend. Samantha explains that she attended because she *‘just had to do it to shut you up*’; ‘you’ being her support worker. However, she left early as she found the group was bringing her down. Though the situation differs from Peter and Satch in that receipt of support wasn’t dependent on attending sessions, Samantha’s description contains elements of feeling pressured into attending a form of support she does not feel suited to.

Samantha discusses her experiences with group therapy in detail. Two key issues are also reflected in Peter and Satch’s testimonies:

1. Difficulties connecting with others in the group and/or navigating group dynamics; and
2. Impact of being brought up to deal with issues in particular ways.

I draw on the example of Samantha’s mental-health group to explore the first issue. Samantha refers to people talking *‘bullshit’.* By this she means either that they talk about ‘mental illness’ as something they have no control over, or complain about the government not adequately supporting them. Just as Samantha found genetic explanations of mental problems unhelpful, (see p.105), so too does she seem to find these discussions to be self-disempowering experiences that are unhelpful to be exposed to. She also describes group dynamics that position her and two other '*girls*' as being overpowered by another woman in the group who spoke more openly about her experiences and views. Samantha refers to this lady as '*Lady Gaga',* stating:

> *She just couldn't give anybody a chance to speak. There was this girl, she was sitting next to me, I kept on pushing her saying 'say something'. And that, I could tell that that is dep / she is depressed, and I could fee / I could relate to that and I could see that to her, on her. And I kept on pushing her to speak. But oh no! Lady Gaga over there* (.)

Adding when I asked if she managed to speak:

> *No. Yeah.* (.) *Well if what everything I tried I speak, she would speak Lady Gaga over there, and speak over you.*

Though Samantha focuses on the other '*girl*' being silenced by Lady Gaga, it seems that Samantha feels that the group dynamic was also not convivial to her opening up. Though the reasons that Samantha finds the two groups she attended unhelpful differ, there is a common thread about finding the dynamics in the group and content discussed challenging, thus she experiences them as negative. Peter, too, indicates issues with managing group dynamics in his declaration that he does not '*fare well in groups'*.

Satch's accounts of group therapy sessions in substance misuse clinics and prison also raise this issue, however this is framed more as dynamics which are inherently problematic rather than as difficulties he has personally. Satch's descriptions provide insight into how identity-markers and the power dynamics surrounding them impact on experiences of and behaviour in group therapy. Describing the format many such sessions took, he explains that you first had to write a statement which you then read out to the group:

> Satch: *And then* (.) *everyone gives you a 'eyyyyyy' and that and said that was, that was* (.) *potted history* (.) *And you've got / and you go 'how I got here today'. And you know, you know, mostly you just say yourself 'I want to make amends to my family' and all this, that and the other. Like you hear some of them like, they talk like they, they'd never dream of it,*

> *something like that, if they hadn't have / come to Bristol or met, met the people they did meet when they got here. It's like they act like you know the, the middle-class people really. It's just that* (.)
>
> Stéphanie: What they were middle class, or they're acting like they were? Oh, they were. ((Responding to nods))
>
> Satch: *Yeah, they thought that, they thought they were and, and they acted like / it was / they would act like* (.) *'I' you know, 'I', 'I put shame on my family and broke my mother's heart' and all that, and it was all so fake.*

It is unclear whether Satch feels people were being fake because they didn't actually care about '*putting shame*' on their family, or whether he meant they were attempting to fake their social status prior to becoming addicts to meet the expectations of service providers or situate themselves in a particular way within the group. However, he makes clear that markers of social status, stigma and social divides such as those explored in the previous chapter are not left at the door of group therapy sessions, but impact on the group dynamics and how people behave within them. Additionally, in certain contexts it is important to note that people brought together to participate in such group sessions may already know each other from their wider community or past encounters. As Satch highlights when talking about experiences within prison settings, '*a lot would kind of know each other in the wire'*. This aligns with a later comment by Peter that he was uncomfortable discussing deeply personal information with people from his locality who he is likely to encounter in the street, and with whom he has not built a trusting relationship. A group setting, then, is one in which harmful power dynamics in the outside world can be brought into the intended therapeutic space.

Linked to this perhaps, is the impact of being brought up to respond to adversity and distress in particular ways that do not necessarily match with the group therapy format. For example, Satch – like most other participants - experienced trauma and marginalisation throughout his life. Chapter 4 presents Satch's account of learning not to express emotion or discontent in public in the children's home he was placed in. Children who did express emotion were '*sent off*' '*so they could lock 'em up and keep 'em quiet*', or staff would *'roll you up in a mattress and beat the fucking hell out of you*'. This exposure to organisational cultures of 'shutting up and putting up' over a sustained period in childhood has been compounded by exposure to similar cultures within prison systems and marginalising experiences in wider society. The effect being that opening up in group settings at times when he feels vulnerable is more difficult than it might be for those who have not been immersed in such environments.

Samantha attributes her difficulties '*get*(ting) *it*' as resulting partly from a cultural clash. This clash impacts not only on her experience of group therapy, but all talking therapies:

> *Sometimes talking, yeah. But action, is what I do. That's because I grew up in Africa where we're always acting. We didn't have talk. That is why for me it's difficult for me to just sit down and talk.*'

Samantha explains that in Africa, her Grandmother woke her and her siblings up at around 5 or 6am to do chores such as '*go and fetch water in the river. We had to clean the house, we had to go and fetch firewood. We had to go to the field*'. There just was not time, nor was it customary, to talk about how one was feeling: '*for me it's a different culture, like sort of thing like how I grew up. It was always fast, fast, fast, fast, fast. It was always action*.', adding '*That's why I find it difficult me, to sit down and just talk.*' Aware that alternative approaches to therapy are available in the form of gardening, craft-based therapies etc, I ask if she has been offered such alternatives. Her response is '*I ain't doing frigging gardening! Forget it',* adding *'I like action stuff. Like active stuff. Not bloody scooping things. I think I find that enough back home.*' 'Active stuff' being '*Zumba.* (.) *And I like to go to the gym. Me and my friend used to finish work and go to the gym.* (.) *I liked to play tennis.* (.) *Like all the fun stuff.'* Samantha's physical health limits her ability to engage in her usual coping mechanism of 'action', yet less intense activities hold no appeal, as they do not match her preferences or identity, stating that she is '*not a patient person*': '*I fidget all the time. Got to do something.'*

Yet, I have observed that Samantha does enjoy talking, whether with myself or members of staff in the gateway organisation, regularly calling for a chat. In a more recent discussion Samantha states that it is not that she does not want to engage in talking therapies, but that it is a case of two cultures clashing. She states that she does not agree with the way things are done in the UK in relation to mental problems and ‘we’ do not agree with how things are done in her culture. She continues that in such situations, unless a middle ground is found, there is no way forward. This aspect of Samantha’s experience does not appear generalisable to all participants, even those who are also immigrants to the UK. For example, though Peter indicates not receiving any benefits from group therapy sessions, he does not cite cultural issues as part of this. Peter does speak of cultural clashes. However, he is speaking at a more fundamental level about clashes between western individualistic approaches and more communitarian approaches from Africa. He expresses that conversations about cultural clashes always remain at a very surface level, where actually these more fundamental issues require attention. Mahdi does not speak of talking therapies at all. However, he does state that he does not feel that cultural differences have been problematic for him within mental health services, though they are in interpersonal relationships in his private life.

Interestingly, towards the end of this research Samantha called me to tell me about a different group session she attended which she found a more positive experience, largely because conversations were interspersed or interwoven with activities; a session was run by one of the BAME-led gateway organisations supporting this research. Andeep, though not referring specifically to talking therapy, states that having someone to speak to means that you probably will not have mental issues as half of the burden is gone once shared. Peter also speaks of his experience of receiving one-to-one therapy sessions through the NHS. This differed significantly from that of group sessions in that he ‘*was beginning to see some benefits from it’*. However, just as benefits were emerging, ‘*it finished’* and:

> *I ended up with more questions than answers. Yeah, you know it stirred up things and, some of which some I wasn’t aware of, some which I’d sort of buried in my mind somewhere in the past, I’d sort of shelved things and some of those things were* ( ) *and were resurfaced and so on. And there wasn’t sufficient time to deal with them.*

Peter indicates that though he found the one-to-one therapy beneficial, this took time and NHS provision does not allow such support on a long-term basis. He continues that his therapist ‘*was quite concerned’* about stopping the sessions at that point, stating that *‘she couldn’t leave me like that, and then she tried to get me some more* *sessions, but she could only get me two.'* Despite healthcare professionals recognising both the potential benefit to his mental health/distress and the risk of acute distress if therapy sessions are discontinued, staff reported being constrained in what they could provide. Peter feels that '*that sort of, made things even more difficult than when I started. Eventually it sort of, went into a bit of a dive*.' Though recognising Peter's need for one-to-one therapy, '*the doctor wasn't sure whether it was wise to put me through that again because the sessions were limited and there was nothing they could do, it wasn't in their control.*' As a result, Peter '*just sort of struggled, struggled along'*. He relays that '*things would get worse. I would, you know, dig in and try to, fight back',* reflecting that *'I would sometimes make a headway and sometimes not, and so on, and it was just sort of pretty much up and down*.'

Before I move to the next section, I want to quickly highlight some additional views expressed in relation to treatments that reinforce comments earlier highlighted regarding service provider needs being put before those of service users/survivors. Many participants state or imply that medication is a low-cost means of enabling people to tread water while the real issues are ignored. Indeed, Peter seems to feel that such cuts in funding are driving the 'one cap fits all' approach discussed earlier, as well as determining the particular forms of 'support' most readily available to them:

> *Well I think decisions are made, more in line with, available funding and other interests and so on. Sometimes I don't think they, individuals' needs are put first. You know. And so on. That, that's what I've noticed.*

Adding that people's needs are:

> *not taken as seriously as it should. And it's trivialised and, 'regardless to what's needed, this is what we are prepared to do', or 'this is what we are allowed to do', or 'this is what we can do, as a result of the available finance we have'.*

Peter continues, stating that achieving better support is possible, but that it requires '*enough finance'* and for the '*right people'* and '*policies'* to be implemented. He implies that the '*right policies'* would have to enable enough flexibility in the system for it to be able to meet people's individual needs, rather than expecting people who are already struggling to meet the system's needs. At present '*the person absolutely* *needs to shape to fit to whatever policies are laid down'*, regardless of their appropriateness for the individuals the policies are intended to support. '*It's for instance like the, the group therapies'*, he continues, elsewhere stating '*group therapy is much cheaper to run,* (.) *and that's the reason I believe for, creating all these new policies and programmes*'. The implication, I believe, is that Peter regards the support made most readily available is that perceived by policymakers as the most cost efficient rather than the most effective for the recipient.

4.3 Additional considerations when intersectionally located

A number of logistical issues also present hoops to jump to recieve support. These issues further frustrate participants, causing additional and different difficulties for those already struggling to meet service expectations – often as a result of their specific intersectional locations. For example, Mahdi comments that '*my wife have to do for me. Even my medication, we have to buy every two months, every one month.*' Any aspect of Mahdi's treatment that requires spending money means asking his wife for additional financial support. Mahdi's particular intersectional location – an asylum seeker married to a woman who earns a wage - means that his prescriptions are payable:

> *My anti-depression tablets and <u>everything</u>. From food-wise to clothes to everything and being dependent. And that put down my dignity. And that tortures me in front of my own self like. I don't feel the same like other people. That is also a big effect on my trauma*

Mahdi was unable to claim normal employment benefits or work legally as an asylum-seeker due to legislation. As discussed in chapter 4, his mental illness further prohibited his ability to seek out work. Further, his being married to a salaried woman meant that he was not eligible for some of the few benefits he may otherwise have been granted. Mahdi is forced to be financially dependent on his wife. He describes his '*dignity'* as being negatively impacted such that it '*tortures'* him and aggravates his '*trauma'*.

Elsewhere Mahdi speaks of the cost of transportation to attend weekly check-ups with his NHS care navigator as a result of previous suicide attempts. Having now been provided with leave to remain in the UK for five years, Mahdi feels he is no longer at risk of attempting suicide. As such, he feels that the check-ups are '*kind of* *waste for me for going like every week, every two week to the* [health centre] *for just sitting, just to enquire.'* Reiterating that he is not in receipt of welfare benefits, Mahdi states that '*most of the time I have to walk to* ((the Centre)) *and come back walking. I feel embarrassed asking my wife for bus ticket. It affects my dignity, I'm Afghan man.'* This contrasts with Satch's experience. The cost of transport would hinder Satch's ability to attend healthcare (albeit not mental health-related) appointments. To overcome this, a support worker from a charitable organisation put in place arrangements for Satch to receive free transport to and from appointments[26]. Whilst Satch's significant mobility issues may account for the difference in support available here, the fact remains that whilst a solution is found for Satch, supportive measures for Mahdi - such as the check-ups - fail to recognise the additional financial burden they create for people with no recourse to financial support. For Mahdi, there is also a failure to recognise the role of cultural difference that, here, increases the potential harm to Mahdi's wellbeing caused by the loss of '*dignity*' at having to ask his wife for additional financial support.

As the above shows, some participants did provide evidence of support being provided to overcome logistical barriers (or hoops) to provision. A further example is provided by Samantha. Both Samantha and Satch have significant mobility issues at various points in this research and highlight difficulties retrieving medication from the chemists as a result of their physical health. Such issues caused significant frustration for both participants. As with Mahdi, it forces them to confront an aspect of their present situation that they find difficult to cope with in order to receive the treatments they required in the way mainstream services want to deliver them. Following an extended period of significant decline in her physical health and increased '*mental distraction'*, Samantha was asked by hospital staff '*How can we make things less complicated for you?*'. Explaining the difficulties she has collecting and correctly self-administering her many medications due to her sight loss, the hospital agreed to collate all her medications into one monthly delivery straight to her home. Packaging them such that the pills are separated into those she needs to take in the morning, afternoon and evening. Samantha states that this adjustment to standard practices '*eases things up a bit because that way I'm on top of it*', additionally helping her manage her mental problems as she feels more able to cope.

5 Calls for change

At the time of collecting data, political rhetoric was still insisting on a need for austerity measures with regards spending on public services[27], while government also claimed to be putting more money into mental health services. In line with Satch's earlier statement, several other participants indicate not being able to '*see it'*, speaking instead of diminishing services. For example, Peter's account of changes to GP practices that result in 10-minute consultations where only one issue is discussed. Over the course of this research Samantha and Satch also comment on difficulties getting adequate time with their GPs. Peter speaks of his discharge from specialist support in a homeopathic hospital occurring '*at a point when they weren't funding that anymore'*; hence no possibility of re-referral. Both Satch and Samantha express concern that entire services are shutting down, indicating their belief that this will have serious impacts on people needing support; including leading to criminal acts or deaths. Satch explains:

> Satch: *now all the money's going in from the, city council,* ((City)) *council, they can hardly run these places anymore. There's not a lot of 'em left now, 'cos a lot, a lot keep closing down. They, I mean*
>
> Stéphanie: Just 'cos the funding's gone?
>
> Satch: *Umm* ((in agreement))*. I mean, even the funding for / I mean, there's only the* ((substance misuse service)) *and em, em,* (.) *and the little, little organisations like* ((gateway charity)) *and where* ((support worker)) *is now, that one at* ((location of support organisation))*. I mean, they've always been there, support places, and probably always will be. When the government starts taking them away, that's when there will be trouble,* [*because*
>
> Stéphanie: What sort of] trouble do you think there'd be?
>
> Satch: *Because, well there's be no-one, nothing, nothing at all.*
>
> Stéphanie: So, what do you recon [will happen?
>
> Satch: *So people'll just have*] *a, a / it'll be like*
>
> Stéphanie: Do you think it'll be like crime or deaths or (.)?

> Satch: <u>Yeaahhh</u>*, they, I mean, God there'd be no-one around to help, to look ou / you know, to try and, be and make a difference. I mean, it feel, it feels like that already. It feels like everyone's given in already.*

Satch already feels that smaller local support services are struggling to cope with demand due to funding shortages, and that a number of services have already shut. The result for him personally is that he finds himself '*running round'* more to receive the array of support that he needs. I asked about crime or deaths here because I recalled a previous discussion wherein Satch described '*losing all, all sense and common* (.) *you know, decency and thinking of going out and koshing someone*.' His thought to '*bop someone over the head*' resulted from extreme frustration getting the support he requires, including difficulties receiving his medications. Instead, he had attempted to take his own life. Following this incident, he half joked about making himself homeless if the support worker he turned to for support did not step up.

Samantha, also frustrated by her attempts to get adequate support from her doctor and difficulties accessing medications, states that she feels like going out onto the street and '*clobbering*' someone. Whilst this is not stated with any real intent behind it, it does indicate a high level of frustration and anger. Samantha directly links the issues she is experiencing with government cuts in funding. This surprised me as Samantha had previously expressed frustration when people in group therapy sessions repeatedly made comments such as '*the government is not looking after*' them adequately (see p.162). Whilst Samantha retains a position that people should not blame 'government' as much as some around her do, as this research progressed, she gradually expressed concerns at receiving increasingly inadequate health-related support as a result of process changes and cuts to services. Samantha and Satch's views align also with Mahdi's observations that the way asylum seekers are treated by the State in the UK drives people to commit suicide (see chapter 4, section 3) or towards stealing: *'you want me to do? Go steal? To go jail? Or go kill myself? You're trying to make the situation very tight for asylum seeker so they do something stupid.'* Though not speaking here about funding being pulled from services, Mahdi too highlights what a lack of support might drive people to do.

Some participants did make a few comments regarding improvements they felt should be made to services provided. Regarding having the '*right people' and* *‘policies’* in place and delivering services with adequate flexibility to meet the needs of a diverse population, Peter also calls for:

- BAME people to be employed in mental health services;
- user-led involvement from people with mental health issues/distress; and
- the need for more black people to be involved in medical trials.

Satch explicitly comments on the need for more black people working within support services. This view relates to a belief in the need for a greater diversity of lived experience among support staff to tackle racism and racial prejudice. Satch’s comment follows testimony about specific experiences of racism/racial prejudice within the context of mental health related support. He recounts the story of a staff member in a substance misuse clinics who continually accused him of dealing drugs to the other inhabitants though he could provide no proof. Satch insists that he was doing nothing of the sort and is adamant that such treatment results from his being a black man with dreadlocks. Such experiences led Satch to alter his appearance prior to returning to such clinics, (i.e. cutting off his dreadlocks to look less intimidating). Satch implies that if there were more staff from a BAME background, some of the stereotypes driving discriminatory behaviours he has been subjected to might be countered. Overall, this points to a call for the voices and expertise of people with relevant lived experience to be prioritised. This aligns also with comments made by Samantha regarding her needing staff members to meet her half-way regarding how her treatment is delivered.

A further plea is also made that people using support services also be treated with greater dignity. Mahdi and Satch highlight the need for this in a range of services, highlighting to me the need for consideration of all State-led support services when seeking to address mental health issues. Mahdi, for example, speaks of this issue particularly in relation to asylum seekers not being ‘*treated like human’* in the UK, in the context of immigration processes and welfare payments.

6 Conclusion

This chapter demonstrates that, just as the negotiations made regarding understandings of mental health are complex and shaped by participants’ intersectional locations, so too are their negotiations of State support services. Their experiences and perceptions of support cannot be separated out from the wider context in which they experience them. It is this, for example, that leads to perceptions of support as inappropriate or inadequate to their needs. Indeed, participants express that engaging in treatments or engaging with support providers can aggravate their mental health issues/distress because it ignores their living circumstances, triggers past trauma or exposes them to situations that reinforce their marginalised positions. In the following chapter, I discuss my own interpretations of what the findings in this and chapter 4 mean for policy-makers working in this field. I do this in the context of the literature, highlighting where it supports or contradicts participants' testimonies as presented here. Overall, I find three core lessons for policy-makers to draw from this in-depth exploration of the testimony of participants in this study.

Chapter 6: Discussion

In both my literature review and across my findings chapters I consider issues in relation to the three key areas of public health policy regarding health inequalities; definitions of the issue, prevention, and service performance. This structure will now support me in considering what policymakers might learn from those with lived experience at the intersections of BAME status/backgrounds and mental health issues/distress. I therefore begin this chapter by considering how BAME mental health inequality is defined by various parties as an issue requiring attention and intervention. As mentioned in chapters 4 and 5, most participants did not hypothesise at a group level about why people from BAME groupings might experience (diagnosis of) mental health issues/distress at disparate rates to white British people, making direct comparison between the literature review and my own data more difficult. However, participants' choices of terminology often highlight important negotiations they make in relation to mental health and other experiences resulting from how they are stratified and situated in society. Close examination of these navigations and responses to diagnostic categories therefore provide insights into how power dynamics at the population level are understood to manifest through mental health discourses and practices. Consequently, these conversations open up opportunities to explore whether ontological and epistemological issues highlighted in the critical literature are reflected in participants' own perspectives.

In part B, I move to discuss the determinants of mental health issues/distress highlighted by participants and in the literature. Having focused primarily on those determinants that say something of participants' particular social stratification and intersectional locations in chapter 4, I offer an analysis across hypotheses focused at the group level in the context of views of determinants at the individual level. The results of this analysis are then considered in the context of national strategies to address BAME mental health inequality to determine what might be learnt by policymakers. Part C undertakes the same process, but with a focus on experiences of State-led support services; primarily mental health and related support services. Once more, a direct comparison between my findings and the literature is not straight forward. This is primarily due to this study intentionally seeking to fill a relative gap in the literature regarding the experiences of people from BAME backgrounds diagnosed with CMD and living in the community, (as opposed to being in a psychiatric ward). Throughout these sections, I include testimony from staff members at my gateway organisation that I interviewed. These are inserted primarily where their positions offer a unique or significant insight into a given issue raised by participants. Finally, I examine calls for change in the literature in the context of participants' views on what needs to change and how. Ultimately, this chapter seeks to highlight several changes that policymakers might bring to their approach of the issue to be better placed to develop any future national strategies addressing the issue. I begin, then, with and examination of how the issue is defined.

Part A: Defining the issue

In Appendix 6, I suggest that aspects of the State's definition of BAME mental health inequality in the NHMH (2011) are problematic. The State now explicitly recognises trends highlighted in epidemiological research and service outcome/experiences data as evidence of inequality, not just disparity. This shift by the State is likely linked to a shift within 'psy' disciplines dominant within the NHS. Whilst practices in the NHS remain largely adherent to bio-medical models, they have increasingly moved away from bio-genetic explanatory hypotheses of a selectionist nature to explain BAME mental health inequalities, focusing more on the role of social factors. This shift is welcomed by many scholars, practitioners and activists in this area. However, significant debates persist regarding how this issue should be defined (see chapter 3), and what this means for interventions implemented to address it. Often these debates concern the role of racism and cultural imperialism in mental health discourses and practices, and how these impact interpretations of epidemiological and service-performance trends.

Though dominant discourses, grounded in western medicalised models of mental health, maintain that epidemiological trends are indicative of 'actual' illness, they are increasingly open to hypotheses that service performance trends reflect the influence of racism and racial prejudice (Cox, 2001, p.248; Department for Health and Social Care, 2018b, p.10). Yet, these explanations also insist that differences in service outcomes recorded are most often the result of disparities in need; e.g. the increased medication and longer stays in psychiatric wards experienced by black people are primarily the result of increased need, not racial prejudice in mental health systems. Scholars and practitioners writing from a critical or transcultural position do not dismiss that increased need may be at play. However, some highlight that the continued dominance of the western medical tradition within mental healthcare in the UK likely increases both perceptions of and ‘actual’ BAME mental health inequality. The State currently adopts the dominant narrative regarding how BAME mental health inequality ought to be defined (see Appendix 6). This undoubtably fuels focus on mental health services, while evading taking action to address the socio-cultural factors contributing to increased ‘actual’ mental health issues/distress as they impact on BAME populations.

Whilst the need for ‘cultural competence’ – which seeks to address issues such as those arising from culturally-mediated differences in understandings of mental health - is widely accepted in services (see chapter 3, part C), this tends to be at a relatively surface level and does not disturb the epistemological framework of western medicine. Further, there is no real examination of how systemic and institutionalised racism functions in this space. I note once more that whilst the State has accepted the presence of interpersonal racism in mental health services, it has yet to accept institutional racism. The unquestioning adoption of the dominant medical narrative, while understandable as the State and its policymakers (often) are not experts in the field, is to the detriment of scholarship from trans-cultural and critical standpoints. This omission is of great importance as such scholarship presents research that better encompasses the experiences of racialised and minority ethnic peoples. Indeed, I have found that the testimonies of participants in this research are most aligned with such scholarship. The PCREF currently being trialled was formulated primarily by people with lived experience of the BAME/mental health intersection. Although this framework falls short of a national strategy to address BAME mental health inequality overall due to its focus on mental health services, I do feel that the added value of lived experience is visible. This is because of a measure that pushes at the boundaries of epistemic assumptions regarding diagnosis through its recommendation to revisit how many BAME people should be expected to experience actual mental health issues/distress (see p.10).

1 Interpreting trends from the margins

Exploring the main challenges to more medicalised interpretations of trends and how these might provide too narrow a scope for an impactful national-level strategy, I find in the literature a strong focus on the ways that racism and cultural imperialism is translated into diagnostic categories and assessment practices, and the practices that fall from these. Primarily, the transcultural and critical literature deconstructs the emergence and development of specific mental health labels and how they have been influenced by racist narratives. Most participants do not hold this specialist knowledge. However, several express beliefs and/or provide examples that demonstrate points made in the literature regarding racism. For example, Peter's observation of the historic perception of black people as '*more susceptible*' to mental health issues/distress than white people. This perception – which is a form of racial prejudice when applied in a blanket manner that does not account for group-level oppression and trauma - can discourage medical practitioners from exploring alternative explanations when a black person presents with physical symptoms. Peter's suggestion that these 'symptoms' are sometimes symptomatic of physical health issues is reminiscent of both: Szasz's (2011) warnings regarding 'categorical error' in diagnosis, where physical health issues are categorised as mental health as a result of the limitations of diagnostic tools and concepts; and of cautions regarding the blanket application of theories of somatisation among people of BAME backgrounds (see Appendix 19).

Whilst no other core participant highlights this issue, a staff member interviewed also reported similar experiences. Ruth, previously a senior NHS mental health nurse herself, spoke of a time when both she and her son were diagnosed as having mental health issues/distress as a result of physical health symptoms they described. Working in the field herself, Ruth was adamant that the problems they were experiencing were not related to mental health issues/distress. Insisting that they be seen by specialists, she was eventually diagnosed with *'severe obstructive sleep apnoea'* and vitamin D deficiency among other things. Her son received a diagnosis of hypermobility (see Appendix 22). Cautions in the literature regarding the possible mis-application of somatisation theory (see Appendix 19) speak exactly to that which Peter and Ruth describe; the assumption of somatisation among people of BAME backgrounds. More commonly reported in the literature, however, is the opposite; e.g. the mis-diagnosis of mental health issues/distress as physical ailments among many BAME groupings (see chapter 3, section 7.1).

Fears of misdiagnosis are present in the testimony of other participants also. For example, when Satch speaks of professionals '*forever trying to label me mentally ill'* (see p.142), or when Mya explains her reticence at speaking of her spiritual revelation some years prior (see p.151-152). Though no other participants expressed fear in relation to spirituality and misdiagnosis, Ruth also highlights instances she witnessed when spirituality that did not conform to the major religions of the UK were misinterpreted as symptoms of psychosis (see Appendix 22). She provides an account of a lady sectioned under the MHA83 with religious delusions who faced a diagnosis of schizophrenia, remarking that:

> *it was a blessing that this particular consultant* [who undertook the final assessment] *understood the culture. He knew of that religious sect. It's dominant in certain parts of Africa.*

Had it not been for the consultant psychiatrist assessing the lady being both able to speak pigeon English and aware of a religious sect prominent in Africa, this lady would likely have been sectioned and placed on psychotropic medication. Such issues are precisely the reason why Mya feared speaking to therapists about her spiritual experience, and are arguably of greater importance among BAME groupings than for the white British population. Many people of BAME backgrounds are more likely to be affiliated to religious groups that are less well understood in the UK, and to view religious belief and affiliation as core to their identity generally (Burton et al., 2008, pp.17–18; Government Office for Science, 2013, p.17). Yet previous strategies to address BAME mental health inequality have not addressed this.

Though the role of differences in religious/spiritual beliefs and cultural norms in misdiagnosis is discussed in the literature, more commonly debated in relation to diagnostic labels and practices in the critical literature are the ways in which mental health discourses pathologize responses to oppression. Dominant discourses widely accept prolonged exposure to discrimination and oppression as a significant risk factor for mental health issues/distress. This acceptance is mirrored in the State's strategies regarding mental health inequalities. For example, the NHMH (2011) includes an Annex with actions across government departments that the State claims supports its equality agenda; e.g. reforms to welfare payments, and the introduction of 'pupil premiums' to increase support to disadvantaged children (Department of Health, 2011b, pp.79–85). As I demonstrate in my findings chapters and discuss in part B of this chapter, participants also recognise the role that distress from and resistance to oppression plays in their own mental health issues/distress. Indeed, many participants *emphasise* the role such experiences play in triggering mental health issues/distress among people of similar ‘race’, ethnicity, or migrant status to themselves (see chapter 4).

A more controversial claim is that mental health discourses and practices serve at times to reinforce such oppressions. One form being the pathologization of outrage, suffering and resistance arising from experiences of discrimination and oppression. In my literature review, I provide examples of such diagnostic categories; for instance, Drapetomania and protest psychosis (see p.59). This study provides testimony in support of this hypothesis. For instance, Satch’s refusal of any mental health label other than *‘addict’* is inextricably linked to the disempowering and dehumanising effects of such labels. For Satch, the difficulties he has with addiction and emotions result from very real experiences of discrimination and oppression faced throughout his life, and likely those experienced by his father. Comments denying him a right to anger in relation to such experiences (e.g. ‘*you’ve got a chip on your shoulder’*) only reinforce his determination to reject being labelled such that his resistance to oppression can be pathologized.

Another example is found in Peter’s problematisation of ‘paranoia’ in the context of exposure to racism and racially-motivated micro-aggressions. Peter appears to imply that mental health discourses are not able to appropriately differentiate between responses to actual incidents of racism and irrational paranoia. This claim is interesting when married with the writings of scholars such as Fernando, Bhui and Nazroo who argue that racism is not adequately or appropriately accounted for within mental health practices (Fernando, 2017; Nazroo et al., 2019), leading often to a focus on the individual instead of systemic inequality and oppression. The danger of such pathologization at the individual level, is that protests against injustices are interpreted as evidence of pathologies, lending an illegitimacy to claims made by those deemed ill as opposed to being viewed as legitimising evidence of injustice. Several participants express such concerns; for example, in addition to Peter’s concerns above, Mahdi, Samantha and Satch highlight how medication is used to dismiss the need to address the ‘root causes’ of, or aggravating factors in, their distress when these pertain to wider social inequalities.

Their voices are depoliticised and/or silenced. Not only might this be a contributing factor in the repeated findings that people of BAME backgrounds are less satisfied with their experiences of mental health services, but it may also explain why some disengage or refuse to seek out support from services in the first place. It is perhaps not a coincidence that the participants who were most resistant to medicalised terminology are those carrying the identity-marker ‘black’.

At the level of national policy, strict medicalised and depoliticised interpretations provide a basis on which the State can moderate the degree to which it addresses discrimination, oppression and inequality in society. Medicalised discourses acknowledge that racism and discrimination contribute significantly to mental health inequality, thus such issues must be recognised and addressed. However, the same discourse also posits that claims of discrimination and oppression are delusions or paranoia resulting *from* mental ‘illness’, not factors external to the person. The State retains room to manoeuvre regarding the extent to which it seeks to address such issues, leading to the development of strategies that (largely) avoid taking preventative measures to reduce incidence/prevalence of ‘actual’ mental health issues/distress among BAME populations. Thus, a strict adherence to dominant narratives in mental health discourses renders the scope of national-level strategies to address BAME mental health inequality inadequate.

Additionally, such approaches enable the continued failure to consider the ways in which England’s racist and colonial past has infused itself in mental health discourses and practices, and manifest in the present day. It fails to question how systems around mental health reinforce racism and colonial narratives that denigrate other worldviews. Given the role of such phenomena in ‘actual’ instances of mental health issues/distress, in possible misdiagnoses and in diagnostic practices, this is a significant gap in any policy aimed at addressing BAME mental health inequality. The failure to challenge such assumptions or to address the ways in which racist and colonialist narratives still permeate our society results in phenomena core to shaping BAME mental health inequalities remaining out of scope of policy responses. This is of particular importance when considering national-level strategies, as local policies have a more limited ability to address the ways that high-level systemic issues pervade England’s national institutions.

2 Navigating medicalised terminology of mental health

Thus far, my own research seems to align well with the literature specifically concerned with BAME mental health inequality, particularly that of a transcultural standpoint with its particular focus on racialisation and cultural imperialism. Where it diverges, however, is the primacy given to racism as *the* form of oppression requiring attention in this area of inequality. Whilst experiences of racism are present in my findings, more widely found was the impact of oppression experienced as a result of a wide range of identity-markers. It is these in both additive form and in combination that seem to impact most on participants' navigations of mental health discourses and practices. This becomes evident when paying close attention to individual participants' specific experiences of oppression and how these intertwine with their discussions of mental health terminology (see chapter 4, part A).

It is telling that those participants who do accept medicalised terminology for mental health tend to do so in part because it somehow helps them to overcome various forms of stigma or oppression. The medical model of mental health has legitimised claims for specific support for some participants - e.g Mahdi and his asylum claim, and Mya regarding access to welfare benefits (see p.101) - and provides a socially accepted reason for not meeting social expectations - e.g Andeep, Mahdi and Mya regarding expectations to work (see p.101-102). Indeed, an examination of participants' testimonies to explore the role of illness narratives for people in marginalised intersectional location would undoubtably provide interesting insights. However, this would go beyond the scope of this thesis. Instead, I note that part A of chapter 4 demonstrates that aetiological beliefs were not the most significant factor in participants' choice of terminology. Rather, people's experiences of marginalisation and the forms of discrimination and oppression they are subject to does. This explains, perhaps, why two participants who accept medicalised terminology (to varying degrees) do not accept medical treatments as sufficient support for mental health issues/distress (see Table 5).

As discussed in chapter 4, Andeep remains continually cautious about labelling himself as experiencing mental health issues, often shifting between ascribing to being ill or not, with his discontent with medication driving evasions of medicalised terminology to describe his own experiences. In contrast, Mahdi fully adopts the language of 'mental illness'. Yet, like Andeep, he is deeply critical of the current reliance on medicalised approaches to mental health treatments. Something else is at play for Mahdi, and it does not appear to be that his aetiological beliefs are inclusive of biological factors. Instead, his reasons seem more linked to how different discourses situate him in relation to his identity and oppressions experienced. For instance, how his mental illness impacts his interactions with people (see Appendix 20) or his ability to be in employment. A further consideration supporting Mahdi's adoption of mental 'illness' terminology might also be the role that a diagnosis has played in his obtaining refugee status in the UK. He recalls that a psychologist '*proved that I have problem*' and that the '*Home Office, due to that report, accept my case and give me five years visa.*'

Table 5: Accord between terminology and views on treatment

Participant	Accepts medicalised terminology (incl. mental health)?	Accepts mainstream medicalised support as appropriate?	Terminology align with views on support?
Andeep	Yes	No	No
Mya	Yes	Yes	Yes
Mahdi	Yes	No	No
Peter	No	No	Yes
Samaiya	Yes	Unknown	Unknown
Satch	Mostly no	No	Yes
Samantha	No	No	Yes

Other forms of discrimination and oppression that seem to mediate the terminological choices of participants include those relating to class, disability and experiences of a more intersectional nature. For example, Peter speaks eloquently about how poverty or being '*working class'* means that a person is more likely to be labelled as '*mad'* (see p.104). Juxtaposed with his views that stress resulting from financial difficulties and worries about housing result in many people '*not coping'*, this leads me to believe that he perceives the distress of poverty to be too often pathologized. In this way, the issue is turned into one of the individual, rather than remaining focused on inequalities in UK society. This sort of rationale seems to drive several participants' to reject medicalised terminology to describe their distress (see chapter 4, part A). One reason that Peter seems more amenable to the diagnostic category of post-traumatic slave syndrome (PTSS) is that the experience of oppression – specifically, intergenerational trauma - is a founding block of this category. These negotiations, though not a significant feature of qualitative research into BAME mental health inequality, are reflective of findings in the BAME mental health service user/survivor led report Recovery and Resilience (2011, p27).

For Samantha this rationale seems to augment any disposition against medicalised understandings that might arise from a discord between such narratives and the alternative understandings she has brought from Swaziland. Though understandings of mental health issues/distress from Swaziland do seem to influence Samantha's views, her rejection of medicalised narratives seem more often to stem from the way that such terminology encourages submission. For example, she states that the mental health team '*just went and upped my dose, and then that was it'*, dismissing what she actually wanted or needed. A woman who has experienced domestic violence, who is continually told to express herself differently and who has experienced racism and intersectional oppression as a black migrant woman, she is unwilling to expose herself to discourses that further silence her. Evidence of the pathologizing of distress from marginalised locations was presented to me by staff members. Perhaps the most shocking example pertains to a lady living in council housing. Marcia explained that a lady she had worked with had been falsely diagnosed as delusional following her reports to a housing association that '*seeing blood coming through the wall*' of her apartment. Deciding to investigate further, Marcia found that the lady's neighbour '*would actually self-harm'* such that blood seeped through the wall into her apartment. Marcia provides three such examples of people's living conditions being ignored and a diagnosis of mental health illness being given instead (see Appendix 22).

This study therefore suggests that oppression in its many forms is key to understanding BAME mental health inequality. Scholars of a critical standpoint within mental health discourses do highlight how marginalisation of all forms can be reinforced within mental health discourses. Whilst it is natural that scholarship specific to the experiences of BAME populations might focus primarily on racism and cultural imperialism, this practice tends to be at the expense of recognition of multiple and intersectional experiences of discrimination and oppression. As I highlight in my literature review, this gap in the literature is increasingly being recognised with some starting to call for policy responses to address intersectional issues (see p.92). There has, however, been no national-level strategy to address BAME mental health inequality since such calls have emerged from prominent figures in the field. Just as Fernando (1998) comments that the impact of racism is understood at the theoretical but not the practical level, I feel that this point too is understood at the theoretical level to some degree but not at the practical level in policy circles. By this I mean that both the DRE evaluation document and the NHMH (2011) went to great lengths to emphasise that no person is entirely defined by one facet of their identity and many people experience multiple disadvantage. However, this did not translate into a scoping of the issue of BAME mental health inequality that adequately emphasised the need to consider interconnecting issues arising from multiple disadvantage. Where such issues were included in the scope, they were *only* of an additive nature; with the intersectional nature of many forms of multiple disadvantage neglected entirely.

Summary

In considering how BAME mental health inequality is defined in national-level policy, setting the scope for any potential strategies to address the issues, I find the following. First, the dominant narrative that the State draws from is not representative of the views and lived experience of many within the target population. In designing and implementing a policy response that meets the needs of BAME people experiencing mental health issues/distress – a health issue that is often intimately linked with experiences of marginalisation - definitions of the issue must seek to incorporate, (not marginalise), the diversity of voices of that group and the research that most aligns with them. Whilst there is still a place for dominant narratives, this must not be to the cost of alternative perspectives. Accepting definitions that are not reflective of the diversity of perspectives within the target population, strategies:

- fail to address an array of issues not accepted by dominant conceptualisations; and
- risk reinforcing oppressions that contribute to BAME mental health inequalities.

Using dominant western medicalised perspectives to limit - or ‘tame’ (see Appendix 8) – the scope of policy responses, leads such responses to become both *more* manageable for policymakers and *less relevant* to the problem as it is experienced by those impacted. It is perhaps in part due to this that responses thus far have failed to have the impact desired. Changing the approach taken to scope policy, so that the process becomes more inclusive of diverse perspectives and more representative of lived experience of the inequality in question, might lead to greater emphasis being placed on structural and systemic issues. This includes the influence of racism and racial prejudice on psychiatric epistemologies and practices, and the way that mental health discourses navigate oppression and the networks of systems of oppression that uphold it.

Part B: Determinants of mental health/distress in the context of ‘inequality’

Running parallel to the largely epistemological challenges set out in part A is the acceptance by many that aetiological trends are predominantly reflective of inequalities in ‘actual’ mental health issues/distress. This position does not contradict the above challenges, but rather highlights the complexity of BAME mental health inequality as a social issue. The co-existence of these explanations of trends seems supported by consideration of the testimonies of participants in this research. For, even those participants most averse to the use of medicalised terminology spoke of determinants that might reasonably be considered to disproportionately impact people of BAME backgrounds in the UK in triggering or aggravating ‘actual’ mental health issues/distress. Exploration of determinants is important in a policy context as aetiological hypotheses direct the actions taken to address increased risk of incidence/prevalence.

3 Pre-disposition and biology in BAME mental health inequality

Overall, the body of research examining epidemiological trends supports policy approaches that prioritise consideration of wider social inequalities, though it does not entirely rule out explanations of a bio-genetic basis at the individual level, and selection basis at the group level. Though bio-genetic understandings of a selection-basis are present among participants, understandings of determinants align predominantly with the literature of a more social causation approach. The exemption being perhaps in relation to the theory of social drift. Though participants do not express awareness of this theory, both Mahdi and Samantha report experiencing psychological/emotional difficulties prior to migration (see chapter 4, section 3), indicating that this played a role in their decisions to leave their countries of origin. For Mahdi, this was the need to escape torture at the hands of the Taliban. Samantha is less explicit. However, she seems to suggest that difficulties experienced in Swaziland contributed to her decision to follow her then British boyfriend to England. She further recognises that some of her difficulties might be considered mental health issues in the UK. In this way, Mahdi and Samantha describe motivations for migration that align with the proposition that ‘symptomatic individuals’ might be drawn to migrate in disproportionate levels to ‘non-symptomatic’ people (Os et al., 2001). A similar process is expressed in relation to urban spaces to explain increased levels of mental health inequality in cities. Satch describes migrations across cities in his adult life as being intricately linked to seeking support for his substance misuse or to follow music scenes; music being one of the key ways that Satch develops a sense of belonging that mitigates some of his distress.

More generally however, participants’ understandings of mental health determinants seem partly influenced by both their lived experiences and judgements regarding whether hypotheses empower or disempower. This seems to mimic the rationale employed when making terminological choices. It is perhaps unsurprising then that very few participants accept bio-genetic explanations of a selection-basis. Such explanations are often situated in the critical literature as disempowering to people of BAME backgrounds due to historic links between these claims and racist views regarding the biological inferiority of racialised people. Bio-genetic explanations proposed in relation to BAME mental health inequality included suggestions of black people as more prone to low IQ (Sharpley et al., 2001). Though there is evidence of links between low IQ and mental health (Aylward et al., 1984; Koenen et al., 2009; Melby et al., 2020; Sheitman et al., 2000), and of low educational attainment among African-Caribbean people in the UK (Rhamie and Hallam, 2002, pp.151–152), putting these two factors together in a simplistic manner misses the significant impact of systemic racism and cultural imperialism in the education system on educational attainment among BAME pupils. Narratives that position BAME groupings as genetically or culturally predisposed to mental health issues/distress have been largely disproved (see p.62-63). Several participants express awareness of how such narratives reinforce oppressions they experience, e.g. Peter on paranoia and susceptibility (see p.98). Indeed, the only participant to express an acceptance of bio-genetic predisposition to mental illness via their acceptance of neurological determinants is Mya; the one participant in this research who can evade racialisation.

Interestingly, though Mahdi is the other participant most comfortable with medicalised terminology, he is clear that mental illness remains the result of external factors that then impact a person in ways that can manifest as biological. This understanding is best conveyed through his analogy of a cut (see p.107). Socio-cultural factors are inextricably linked to the biological aspect of mental illness in that they direct whether the '*cut*' heals or becomes increasingly infected. The biological 'cut' interacts and reacts with socio-cultural and environmental issues. This interaction recognises that mental illness is not isolated within the body/mind of the individual, but rather that it functions among open systems that influence its journey. In this way, Mahdi accepts medicalised models of mental health, whilst also maintaining a view of determinants that is firmly situated within explanations of a social causation nature. In this way, Mahdi navigates the potentially disempowering aspects of biological explanations of mental health issues/distress in a process very similar to that described in the Recovery and Resilience report (2011, p30-31).

A similarity might be seen here with Peter's navigation of acknowledging inequalities of 'actual' mental health issues/distress experienced by black people without accepting medicalised narratives that depoliticise or reinforce aetiological hypotheses imbued with racism. The similarity being that acceptance of the existence of 'actual' mental health issues/distress is predicated only on theories most aligned with social causation approaches. For instance, PTSS is accepted because acknowledgement of social inequality as the cause of distress is inherent in the category, not bio-genetic or cultural inferiority. Thus, its manifestation in a group is evidence of exposure to inequality, not susceptibility due to racial inferiority. I note also that whilst Mya accepted genetic explanations for mental illness in some people, she at no point indicates a belief that this explains mental health *inequalities*. Additionally, whilst Mya allows that mental illnesses might be bio-genetically determined in some instances, she too speaks of the relationship between biological and environmental factors in mental health. I simply wanted to highlight her acceptance of bio-genetic predisposition as contrasting significantly with views expressed by other participants who have been exposed to oppressions that include racialisation.

A second way in which biological factors present among participants' testimonies in a 'social causation' manner relates to the psychological and emotional impact that experiences of physical ill-health and disability can have on an individual. Samaiya, Samantha and Satch report that their physical impairments directly impact on their mental health/distress when they describe feelings of exhaustion and physical pain (see p.107-109). Other statements relate to the additional psychological impact of disabling experiences associated with physical impairments (see p.127-128). For instance, Samaiya's sentiment that she '*wanted to do things which I haven't achieved'*, due to difficulties experienced in an education system that did not adequately accommodate for her learning needs or the needs arising from her chronic illness (see Appendix 20).

Far from bringing participants' views closer to bio-genetic explanations that posit mental illness as 'prior to' experiences of inequality (see chapter 3, section 4), my findings demonstrate the extent to which participants' view mental health issues/distress as *caused by* social factors. Even where participants highlight biological issues that precede mental health issues/distress, this is often intricately linked with experiences of disablement, which I understand as issues of social inequality. In more recent decades, research has tended to prioritise exploration of socio-cultural and environmental factors. This aligns well with the determinants that participants in this study prioritise. However, I suggest that the increasing absence of consideration of biological issues might have inadvertently led to a gap in the literature regarding experiences at intersections inclusive of chronic illness/physical impairment, disability, race/minority ethnicity and mental health. Whilst consideration of the intersection of physical and mental health and disability does take place within Disability Studies (Beresford et al., 2010; Erevelles, 2011; Goodley and Lawthom, 2005; Price, 2017), it is ominously absent in studies on BAME mental health inequality.

Within the context of national-level policy, the NHS long-term plan (2019) implies an approach to addressing physical and mental health inequalities for BAME groupings that is informed by an additive approach. This looks at both physical and mental health, but not the intersection of both such that it impacts on BAME mental health inequality. Similarly, the NHMH (2011) addressed disability and BAME mental health inequalities entirely separately as a result of its ‘multi-strand’ approach (see Appendix 6). As such, the State misses the ways that these issues intersect and co-construct each other. With physical health issues and disability experienced at higher rates among BAME groupings (Byrne et al., 2020; PHE, 2018) – an issue made more visible during this pandemic period - I suggest that this area could be fruitful in better understanding some of the complex ways in which BAME mental health inequality arises.

Despite this identified gap, I acknowledge that public health policy circles do increasingly recognise the importance of socio-cultural and environmental issues, and the interconnectedness of the body and mind, in matters of health (Department for Health and Social Care, 1998; Department of Health, 1980; Department of Health, 2011b; Marmot et al., 2010; NHS England, 2019b). Indeed, my evaluation of the NHMH (2011) demonstrates that the State included the rhetoric of both selection and social causation in their definition of mental health inequality (see Appendix 6), with some very limited action to address social inequality. Influencing policies addressing mental health inequalities, reports such as those highlighted above should encourage greater consideration of the role of socio-cultural and environmental factors when seeking to implement preventative measures in public health, particularly when addressing health inequalities.

4 Socio-cultural factors: open systems and intersectionality

Many of the key socio-cultural determinants found within the literature are present in the testimonies of participants in this study. For example, issues raised regarding childhood and pre-migratory trauma and suffering are present in all but Andeep’s testimony. With regards to childhood trauma, Satch’s account correlates strongly with research that points to the trauma inflicted through separation from a parent (Mallett et al., 2002, p.334; Morgan et al., 2009, p.232). The literature on this matter recognised that such events in any child’s life would likely increase risk of mental health issues/distress in adulthood. However, scholars here acknowledge this as an issue of particular importance for BAME mental health inequality because wider social inequalities experienced by many BAME groupings increase incidents of separation. The role of social inequalities specific to racialised people in Satch's separation from his parents is absolutely clear. First, racism at the interpersonal level led to his mother's decision not to keep raising him and his younger sister. Secondly, Satch reports that racism at a more systemic level influenced social work practices such that his father was not permitted to care for his children as a single-parent black man. Thus, whilst separation from parents is a determinant of mental health across social categories, it has a particular relationship to the inequalities experienced by BAME groupings that renders it of particular importance to BAME mental health inequality.

Though an area of relevance to increased rates of 'actual' mental health issues/distress, much of the literature in this space does not focus on childhood experiences of hardship and trauma specifically. Rather, it tends to be implied in discussions of exposure to socio-economic deprivation and racism; including intergenerational forms. In considering how participants viewed mental health determinants in this sub-theme, I note that most acknowledge childhood and pre-migratory trauma as being *the* or *an* instigator of mental health issues/distress. However, they tended not to view these as the issues that this research should focus on. Perhaps because some consider these to be the result of personal circumstances, not inequality – a view that I might challenge. For example, Samaiya expressed that her physical health and learning difficulties as a child have had a significant impact on her mental health, but does not necessarily situate difficulties faced as resulting from an ablest society when others might. Another reason for not wanting to focus on these issues might be that they feel that these issues go beyond the scope of what the State and society in England can reasonably be held responsible for; for example, in relation to pre-migratory experiences such as Mahdi's and Samantha's. For these reasons, I highlight such issues as important for future epidemiological research and national strategies to address when considering BAME mental health inequality, despite a lack of detailed exploration in this thesis. A final reason why participants seemed not to want to focus on such issues was that they conveyed feeling able to heal or manage the issues/distress arising from childhood/pre-migratory trauma if not continually exposed to stressors and oppression that aggravate their mental health. Focusing on issues more pressing and relevant to their adult/post-migratory experiences, participants often spoke of issues created or sustained by the State through its policies and services, or inequalities perceived as within its scope of responsibility, e.g. socio-economic deprivation, systemic racism etc.

Material deprivation is situated as a key determinant within both the literature and the testimonies of participants. Even Peter, who owns his own home and ran a business for many years, holds issues related to material deprivation as significant in the distress that many people experience. The literature highlights several hypotheses relating to different aspects of material deprivation; I focused on urbanicity and socio-economic disadvantage. Encapsulated within these are the material experiences of inadequate and unstable housing, unemployment, low educational attainment, and the increased risk of exposure to low social status. All of the above factors are found in some form in participants' testimonies. For example, housing. This was generally raised by those participants living in council housing and pertained to the unsuitability of the property for their needs, though Peter did pass comment in the margins between our conversations about the negative impact of people in cities not having a garden. Like Mahdi, who often seeks refuge in parks (see Appendix 20), he was all too aware of the positive impact of the outdoors and of nature on people's wellbeing. Housing issues constituted a considerable part of Satch's anxiety at the start of this research and was cited by him as contributing to his suicide attempt. Equally, inappropriate housing aggravated Mahdi's mental illness following his separation from his wife, as he did not feel safe with the residents in the apartment he was placed in.

Perhaps, however, the factor most widely raised across participants in relation to material deprivation and stressors is that of financial difficulties; an issue that also features significantly in the literature. These are situated by participants and scholars alike as an important aggravating factor for mental health, with Peter citing it as a cause for people '*finding it very difficult to cope'*. Indeed, only two participants did not indicate any difficulties of this sort: Mya, who positions herself as middle class; and Samaiya, whose family have always provided for her and who (from observation) seem well enough situated financially. The stress caused by such precarity and the exposure to other difficulties as a result is evident throughout participants' accounts. Instability of finances is highlighted as limiting what participants can achieve, e.g. Andeep is unable to consider marriage (see p.113); Mahdi and his wife could not move forward and build a life together in part due to financial constraints (see p.116). For others, it creates anxiety about maintaining a decent standard of living and security; for instance, Satch's fears of being left without heating (see Appendix 20); Peter's linking financial concerns to being able to pay the mortgage (see p.116); Mahdi's struggle to afford medication (see p.167). This is also something commented on by staff members interviewed (see Appendix 23). John O explains that people he is supporting with welfare claims on the basis of physical disabilities are:

> *afraid of / 'oh my benefit is being stopped' / they are very unsure that they couldn't get money. …They tend to now become so severe, anxiously severe and depressed because of those difficulties. Maybe because of the financial aspect of it. ...So all of this coupled together to give them mental problems.*

This extract is supportive of the literature regarding the links between poverty and mental health issues/distress, situating people who experience poverty as exposed to more stressors and as at increased risk of mental health issues/distress (see chapter 3, section 5.2). Specific to BAME mental health inequality, the literature tends to explore how oppressive social dynamics situate people of BAME backgrounds as more likely to experience socio-economic disadvantage. Interestingly, only Mahdi provided me with comments that explicitly bring his BAME status and financial situation together when he highlights that the Home Office is '*torturing people with £30 a week'*. Though much more implicit, Satch's account of the '*black petit bourgeois'* also demonstrates an awareness of an interconnectedness between 'Blackness', socio-economic deprivation and class. In describing this he acknowledges that some black people arriving to the UK in the 1960/70's perceived it necessary to reject their own cultural norms, and assimilate into British society to gain 'white collar' jobs that might lift them from socio-economic disadvantage and elivate their social standing.

This racial aspect of the disproportionate poverty experienced by BAME groupings, whilst acknowledged as an area of inequality by the State remains unattended to in its policy to address BAME mental health inequality. For example, the DRE clearly states that ‘Financial insecurity, unemployment and a poor built environment also have a negative impact on mental health and all disproportionately affect BME groups’ (Department of Health, 2005, p.60). Yet its only action in relation to financial insecurity was to make ‘modifications to state financial assistance so that patients do not leave residential hospital care in order to obtain adequate financial assistance from the state’ (Department of Health, 2005, p.32). Whilst undoubtably important to those leaving psychiatric wards, this recourse addresses only a problem in mental health support provision rules and nothing to respond to financial insecurity as a determinant of BAME mental health inequality. In the NHMH (2011), disproportionate levels of socioeconomic disadvantage among BAME populations were once more recognised as a determinant of importance. However, the measures set out to address poverty were generalised and in no way addressed this racialised intersection of disadvantage (Department of Health, 2011b, pp.79–85). It certainly does not contain any measures that might address inequalities described by Mahdi regarding providing adequate financial support for asylum seekers. These omissions are reflective not only of political discourses that problematise migrants, but also of a more general ambivalence and avoidance regarding intersectionality in State policy.

A further gap in policy, and an issue that seems less stressed in the literature, relates to how interactions with the State can heighten feelings of precarity and retraumatise people. Whilst policy and the literature in this space tend to focus on State-led mental health services and pathways to care involving the police and judiciary, interactions relating to other support systems (e.g. welfare and housing) seem to feature less. This is despite government reports highlighting inequalities in such services for BAME populations (Department for Work and Pensions, 2010). Whilst the asylum-seeking process does receive some attention in the literature, broader experiences with visa applications tend not to. As the above paragraph suggests, a lack of the State’s consideration of the interaction between socio-economic disadvantage and BAME status is reflected in a lack of consideration of how processes for seeking support such as welfare and housing might disproportionately disadvantage people at the intersection of BAME status and mental health issues. This disadvantage increases further when people at this intersection also have lower levels of education or intellectual disabilities (both of which are reported as impacting some BAME groupings at increased levels, see p.67 and p.61 respectively). As a staff member – Zara - explains '*if you don't speak a certain language*' (i.e. technocratic), then people are likely to '*be left out of society on your own*' without the support that they should be entitled to (see Appendix 23).

Thus, issues such as those exemplified by Mahdi and Satch, which disproportionately impact BAME groupings due to their increased exposure to poverty as a result of systemic injustices, remain largely unaddressed. Instead policies to address access of support to the majority feature in strategies under the auspices of tackling issues for marginalised groups (Department of Health, 2011b, pp.79–85). The retraumatising impact of the asylum and visa processes on migrant people within the BAME population are not addressed in any of the most recent national-level strategies addressing health or BAME mental health inequality (Department of Health, 2005; Department of Health, 2011b; NHS England, 2019), although it has been highlighted in the literature as an important area for policy to address (Fazel et al., 2012, p.266). Instead the DRE (2005) and NHMH (2011) simply acknowledge a disparity in mental health diagnoses among migrants and their children or in their ability to access and influence service design (Department of Health, 2005, p68; Department of Health, 2011b, p.59). Yet it is clear from Mahdi and Samantha that going through these processes was traumatic as a result of the system in place, contributing to mental health issues/distress. As with Satch and his interactions with multiple agencies regarding welfare and housing, these interactions with the State re-traumatised Mahdi and ultimately prompted a suicide attempt. As I showed in chapter 5, such experiences not only contribute to participants' ability to recover or manage their mental health issues/distress, but also have a significant impact on how they engage with mental health services. I explore this further in part C.

5 Discrimination, oppression and their networks

This leads neatly to a discussion of discrimination and oppression as important determinants in BAME mental health inequality. Of all of the various forms of discrimination and oppression, an aggregate of participants' testimonies highlights racism as one of the most common forms experienced or witnessed; sitting alongside issues pertaining to socio-economic disadvantage. As such, findings in this study reflect the primary focus given to issues of racism in the literature. However, it is important to note that it was not a majority of participants who spoke of racism, but rather those racialised black (as opposed to racialised people more generally). If discrimination pertaining to migrants, or a certain ‘class’ of migrants is included due to the racialisation involved in such discrimination, then a majority of participants can be said to have spoken of personal experiences of discrimination and oppression of a racial nature. Racism in the literature is described as impacting BAME mental health inequality in a number of ways, and of operating at the interpersonal, institutional and systemic level. Further, a range of manifestations of racism are highlighted; overt racial abuse, microaggressions, intergenerational inequality and trauma resulting from systemic racism, and more recently intersectional experiences. Most of the manifestations of racism highlighted in the literature are also present in participant accounts of the experiences that have impacted on their mental health or that of racialised peoples’ more generally.

For example, the literature highlights how racism operating both systemically and at the interpersonal level in social interactions can be psychologically harmful for racialised people exposed to such abuse and prejudice. The literature explores the intricacies of the psychological processes that trigger mental health issues/distress resulting from such experiences (see chapter 3, section 5.3). Peter and Samantha both cite exposure to racism as causing or aggravating mental health issues/distress. Similarly, Mahdi repeatedly states in very explicit terms that discrimination and oppression experienced as a result of his status as an asylum seeker significantly aggravate his mental illness, likening such experiences to ‘*torturing’* (see p.114-115). Peter highlights the cognitive dissonance created through constant exposure to micro-aggressions and having one’s own cultural and culturally-mediated behaviours marginalised (see p. 98 and p.118-119). Peter also highlights the impact of exposure to micro-aggressions which are often then denied by perpetrators. As Cooper et al (2008) intimate, Peter’s testimony appears to support suggestions that the denial of such experiences resulting from a racialised system of oppression is psychologically harmful to the oppressed racialised person. Satch does not explicitly speak of such instances outside of the context of mental health-related support services. However, comments made between recorded conversations indicate the extent to which racism and microaggressions impact his daily life (see p.32).

Combining experiences resulting from racism with those of oppression issued from being a migrant, I find further evidence in my own findings that support the literature's claims in relation to the existence of many forms of racism and their impact on BAME mental health inequality. Mahdi articulates the importance of retaining his '*dignity'* on many occasions, a dignity that is intertwined with his ability to meet the social expectations placed on men in Afghan society and in the UK. This includes financial expectations, such as providing for his wife and himself. Yet, he describes multiple ways in which his status as an asylum seeker prohibits this, placing him in a position of poverty from which he cannot escape. This causes him great distress additional to that he brought from Afghanistan. One final example comes from Samantha, who is continually being interpreted as aggressive when expressing herself. This acted as a barrier to her achieving what she wanted in a variety of ways, for instance in work or in her interactions with her GP's practice. For both Mahdi and Samantha, these barriers reinforced their marginal positions and gave concrete form to their oppression, significantly impacting on their mental health issues/distress.

Thus, for the State to address BAME mental health inequality with any level of success, it must understand this social issue as having a particular ontology. Racism (inclusive of xenophobia) must be understood not as an isolated belief system operating like a coloured lens on a camera, for example, an overlay to an image that can easily be separated from both the camera and the image. Rather, it is an open system that shapes and is shaped by everything that it comes into contact with. In part A of my literature review and this chapter, I explored how racism and mental health discourses are interconnected such that they can be mutually constitutive. This understanding of racism as a dynamic open system must be carried into conceptualisations of the determinants in BAME mental health inequality by policy-makers, the ramifications of which are a recognition of the need to tackle racism of all forms and at all levels: interpersonal, institutional and systemic. To date, any focus on this in relation to BAME mental health inequality has been to address (some aspects of) racism within mental health services without an admission of the existence of institutional racism by the State (see Appendix 5). In the NHMH, it is notable that all actions to address stigma in relation to mental health pertained to stigma and discrimination specific to ‘mental illness’.

The analysis presented in this section supports calls for the State to better address racism in all of its forms as part of any response to BAME mental health inequality in the UK. However, it also draws attention to the need to do so in a way that looks beyond the ways in which racism impacts mental health discourses and manifests in related services. It must include consideration of how it manifests in society and as wider social inequalities. Importantly, it must examine the ways that the State itself acts as a conduit for a variety of forms of racism through its own policies and practices, including how it produces and maintains institutional racism across the services it provides. For example, no State strategy for BAME mental health inequality has highlighted the need to address racism in the [redacted] system at either the interpersonal or systemic levels. As both this literature and my participants demonstrate, this issue is pervasive, impacting multiple areas of life that limit a persons’ ability to thrive. Additionally, I have yet to see evidence that the State has actively considered the impact of visa and asylum-seeking processes on the mental health of migrants to the UK. First generation migrants form a significant portion of the BAME population in the UK, albeit decreasingly so as demographics change. However, the majority of the literature in this space does not highlight migration processes as an important factor requiring urgent attention in the context of BAME mental health inequality unless the research is specifically focused on the experiences of refugees and asylum seekers.

Further, this study supports the view that racism operates as part of a network of systems of oppression that interact and maintain each other in one form or another. It is in this ‘network’ that intersectional experiences emerge. Crenshaw highlights that a focus on the ‘most privileged group members marginalises those who are multiply-burdened’, providing ‘a distorted analysis of racism and sexism’ (Crenshaw, 1989, p.140), or any other relevant system of oppression. Thus, intersectional forms of racism must be addressed if policy responses to mental health inequality of a racialised nature are to have any success. A lack of such an approach would continue to leave unaddressed experiences of discrimination and oppression that impact on people of BAME backgrounds, increasing exposure to recognised risk factors in mental health. For example, experiences at the intersection of race, cultural difference, migrant status and gender – for example, Samantha's being continually perceived as aggressive and unprofessional such that her career stagnates and wellbeing is negatively impacted.

Awareness of these issues are of particular importance when we observe that the State's inability, resistance or evasion of addressing intersectional issues then results in policies and practices that further exasperate BAME mental health inequality by placing certain BAME groupings into extremely oppressive positions. For example, in addition to experiencing the discrimination and oppressions that often accompany racialisation, asylum status and experiences of long-term mental health issues, Mahdi is also forced into a position of poverty by State policies and legislation. Given the significant links drawn between mental health and socio-economic deprivation - particularly when paired with racialisation and migration - such oversights would seriously limit policy responses seeking to lower incidence/prevalence of mental health issues among certain BAME groupings.

Intersectional locations may also impact peoples' abilities to benefit from protective factors such as ethnic density or social capital. All participants in this research have experienced mental health issues/distress of some form, and thus have not been protected from developing such issues as a result of these factors. However, it is clear through most participants' testimonies that protective factors such as those highlighted in my literature review (ethnic density and social capital) do play a supportive role in participants' lives. For example, Samaiya's sister comments that they have never really experienced difficulties as a result of racism, suggesting that this might be due to living in an area with high ethnic diversity. Andeep expresses that feeling connected to his Sikh community is very important for him and his wellbeing. In contrast, Mya describes the negative impact on her mental health of not belonging to a religious group that might better understand her background and align with her beliefs. Belonging is equally important to Mahdi and Satch. However, taking an intersectional eye to their testimony it becomes clear that their intersectional locations act as a barrier to benefiting from these to the extent that other people of BAME background might. For example, Mahdi is conscious that having converted to Christianity means that people in Afghanistan '*would make my life hell the moment they see me*'. Indeed, he confided that he is rejected by some Afghan refugees in the UK as a result of his conversion. Equally, Satch's being of ‘lower class’, an ex-offender and substance misuser, places him in an intersectional location that has led him to experience ostracization by certain people in black communities and sub-cultures.

Reflecting on my findings more generally, I also find that female participants were much less likely than their male counterparts to highlight systems of oppression as impacting on their wellbeing. For example, Samantha gets frustrated when she feels there is too much focus on racism, preferring to speak in terms of cultural difference; Mya speaks of competing social expectations for women more as cultural issues than oppressions experienced by women; Samaiya and her sister did not necessarily frame the barriers Samaiya experienced in education in terms of ableism, at least not initially. Given findings that suggest the protective value of recognising adversities faced as resulting from systems of oppression as opposed to personal failures (Cooper et al., 2008, p.200), such findings from gendered intersectional locations may be important to address; not least given the indications in some epidemiological studies of increased risk of mental health among women in some BAME populations (see Appendix 17), and in the UK population generally (Mental Health Foundation, 2015). A focus on intersectionality, however, should not be to the detriment of a focus on racism. Rather, I have situated it as necessary to addressing racism in a way not distorted by the adoption of a limited understanding of the problem (see Crenshaw, p.92-93). Similarly, I would highlight the need to also consider other forms of discrimination and oppression experienced additionally too (and not intersectionally) by people of BAME backgrounds. Non-racially motivated forms of oppression significantly impact the mental health of participants in this study, for example, Samaiya’s disability. Whilst not linked to racism in Samaiya’s case, links between disability and mental health issues/distress warrant attention from policymakers addressing BAME mental health inequality. This is because disability disproportionately impacts certain BAME groupings (Cabinet Office, 2017, p.25; ENC and SCOPE, 2012, pp.13–14).

Summary

Overall, I found a great deal of overlap between the determinants highlighted in the research as of prime concern to BAME mental health inequality though there were a few gaps. These generally pertained to issues that are most often understood as being of concern for people grouped together under a different identity-marker in research taking a ‘single issue’ approach; e.g. disability is dealt with in research focused on/with disabled people, while BAME research focuses on racialisation, racism and cultural difference. Additionally, in paying attention to *how* participants discussed these determinants, I have highlighted two aspects of their experiences that are less pronounced in the literature. These relate to the interconnectedness of determinants and the presence of intersectional experiences. Consideration of the interconnectedness of determinants are present even in the testimonies of participants most aligned with biological aetiological beliefs. Responding to such an understanding of determinants would require policy-makers to break out of the restrictions imposed by the somewhat arbitrary and artificial policy silos currently in place, with all (or most) of government working more fluidly to reflect the complex and open systems that they seek to influence.

Further, reviewing how intersectional experiences contribute to mental health issues/distress and related inequality, I also began to discuss why intersectionality is vital to building richer understandings of key determinants in BAME mental health inequality. Examination of intersectionality reveals how open systems of oppression might combine differently for people of BAME backgrounds, sustaining disadvantages and oppressions experienced. For instance, knowing that socio-economic deprivation and precarity significantly impact mental health, policy makers drawing on intersectionality might consider how these combine with fears of being refused refuge to retraumatise asylum seekers with pre-existing mental health issues. Understanding this it may not prevent incidence/prevalence of mental health issues/distress, but may support the prevention of people requiring acute services as a result of suicide attempts or the triggering of psychosis.

Part C: Experiences of State-led support services

Improvements to policies preventing increased risk of ‘actual’ mental health issues/distress among BAME groupings satisfy one element of health inequality policymaking. The other area requiring attention is that of improving service provision and its efficacy and appropriateness for BAME groupings. I argue that in countries where welfare, health and social care systems (including mental health services) are State-led, this must include consideration of how State services contribute to BAME mental health inequality. As previously mentioned, despite a disparity between the focus and sample groups in much of the literature and my own study, there are significant parallels in some of the overarching themes that emerge.

6 Accessing support from services

Issues pertaining to health seeking behaviours, interactions with primary care services and diagnostic assessments were present in both the literature and the testimonies of participants. What comes to the fore in the literature are a range of problems that relate either to cultural difference or racialisation. These are highlighted as leading people of BAME backgrounds to be unable to access support, not want to access the support offered or be forced to engage in services against their will. Not being able to access support is often reported as stemming from logistical issues such as language barriers or from cultural differences that mean GP's and patients experience miscommunications. The lack of such issues emerging from my own findings is likely reflective only of my small sample group which did not include people with very low levels of English language skills[28].

The literature speaks of people not wanting to access the support available as a result of two main issues. First, as a result of culturally-mediated differences in ideas of what 'mental health' is and how it should be addressed. Examples of such disagreements within the context of interactions with GPs are present in my study. For example, Peter explicitly states that he wants to use alternative treatments for his distress as he indicates a belief that some of his issues stem from nutritional and digestive problems, not psychological difficulties. Whilst Peter's position might not result from cultural differences regarding health issues and illness, it places him in a position of epistemic difference from western medicine similar to that created by cultural difference. Samantha's testimony provides evidence of very different, culturally mediated understandings of mental health. As with the African participants in Mantovani et al. (2017)'s study, Samantha also seems to associate mental health issues with a 'a total level of insanity' (Mantovani et al., 2017, p.376) that might be perceived as SMI in the UK. Though Samantha did engage with the GP and mental health services, this seems not to have resulted from her own decision to seek help from medical professionals, but from the actions of a psychologist met during the process of seeking residency in the UK.

People of BAME backgrounds may also resist accessing mental health services as a result of ‘circles of fear’ (see p.77). This links closely to people being forced into services against their will. This finding of the role of fear is reflected in my own findings, perhaps most strikingly in the testimony of Satch. Satch avoids any mental health labels beyond ‘*addict’* and does not want to be placed in ‘*the package mental health*’. Both Peter and Satch demonstrate awareness of the particular issues that black people face within mental health services, knowledge that seems to augment their resistance to medicalised approaches to mental health (including diagnosis). As ‘Breaking the circles of fear’ (2002) and Satch and Peter’s testimonies demonstrate, awareness of inequalities in mental health services for black people are widely known in black ‘communities’. Further parallels between the literature and my own findings pertain to the ways in which practices and procedures when accessing services reinforce and ‘replicate the experiences of racism and discrimination’ (Keating and Robertson, 2004, p.442) endured in other settings. Such experiences are recognised in both the literature and this study as manifesting through interpersonal interactions. An example from this study is Mya’s account of her friend’s experience. I also note Peter and Samantha’s remarks regarding being perceived as aggressive instead of assertive and Ruth’s account of the near misdiagnosis of a religious lady, and how such stereotyping can lead to and reflect issues such as ‘transmitted discrimination’ (see p.76) and intersectional experiences.

In the literature, the reinforcement of discrimination and racism at institutional levels often entail coercive practices of a more explicit and physically violent nature than in my own findings. More nuanced experiences tend not to be exposed to the same degree; likely due to a focus primarily on people diagnosed with SMI or on adverse pathways to tertiary services (e.g. psychiatric wards). Yet, such experiences often set the tone for engagements with services once access has been gained and undoubtably contribute to issues such as the ‘circle of fear’ (Keating and Robertson, 2004). The insistence by some services that BAME service users/survivors comply with practices rooted in dominant understandings marginalise those for whom these narratives are foreign. In some instances, this can result in participants engaging in processes that are experienced by them as harmful. For instance, Peter’s feeling obliged to take medication so that he was not labelled as ‘*not helping myself’* (see p.149). Engaging in certain processes to access support can also rekindle distress by demanding that participants engage in activities that remind them of painful and/or traumatic experiences. For example, Samantha's account of needing to engage with *'paperwork'* in order to receive counselling sessions. Something she stated was '*enough to make you crazy*' partly because it recalled to mind a particularly distressing period of her life (see p.148-149). Given that people from BAME backgrounds are more likely to have previously engaged with such processes in difficult circumstances, such issues are important considerations for services seeking to minimise re-traumatisation or similar experiences.

A further disparity between the literature and my own research is the literature's prime focus on racism (inclusive of xenophobia). Whilst this focus was reflected in conversations of determinants, it is not replicated in this study in relation to accessing support. Instead, participant accounts tend to highlight ways that their disempowered and marginalised positions *in general* are reinforced. A prime example of this is found in Satch's account of his diagnostic assessment, whereby he felt that he was being forced into providing an account of his life that was incohesive as a result of the techniques used in the assessment. Reflective of findings in the 'Breaking circles of fear' report (2002) that highlighted issues of trust and psychiatrists failing to take full histories, Satch feels that he is being manipulated in such a way that positions him as 'diagnosable', which he openly resents. His resistance to diagnosis, however, does not seem to arise solely from experiences of racism, but from exposure to a range of oppressions – including intersectional ones. I observe, for example, that Satch's account of this assessment quickly merges into accounts of substance misuse clinics and prison, and degradations experienced there. Interestingly, the times when participants speak positively of their experiences arise when they serve to empower them in some way, for instance, Mahdi's account of his diagnostic assessment and how this enabled him to gain refugee status (see p.139).

Applying a lens that recognises multiple and intersectional oppression also highlights how simple procedural changes to services acting as gateways to mental health services might contribute to BAME mental health inequality. For instance, Peter's testimony regarding the inadequacy of 10-minute GP consultations, which disadvantages people with multiple or complex needs. This is partly because '*you* *don’t really get to say what you need to say’*, (see p.136), and GPs ignore the interconnectivity of matters of health. Whilst the under-representation of BAME groupings receiving GP support for mental health issues is a trend that pre-dates the widespread introduction of the practice that Peter is referring to (and is not therefore an explanation for those trends), it does demonstrate that seemingly simple changes can have significant impacts on marginalised groups. This is particularly so when the impact on a diverse range of people are not considered. A lack of consideration of such impacts can contribute to health inequalities experienced by social groupings with disproportionately high rates of complex needs. For instance, disabled people, people experiencing communication barriers, and people whose intersectional location puts them at greater risk of experiencing co-morbidity.

7 Using services

Whilst participants in this research did not experience or speak of experiences of CTO’s and psychiatric wards, several parallels still emerge from their testimonies regarding receiving support for mental health issues/distress. These include: perceptions that support delivery methods are not conducive to recovery/coping; caution and distrust in relationships with staff; and disagreements about the appropriateness and efficacy of treatments provided. Further, issues of cultural difference, discrimination and racism are present in both. Interwoven through these findings I find a continuation of the themes I highlight as important for policy-makers in previous sections of this chapter. Namely, the interconnectedness of phenomena as they are experienced and lived, and the need to recognise the role of intersectionality. Indeed, it is arguably in relation to experiences of services that issues of intersectionality crystallise most strongly into concrete examples in this study.

In relation to service delivery, participants in this study do not speak of the more violent coercion and restraint most present in the literature. However, as with comments regarding access to support, their views of using services certainly do encompass feelings of being forced to engage in practices and treatments that are not beneficial to them. Additionally, participants also sometimes describe having to engage with mental health treatments so as to retain access to other wider support. For instance, Satch reports being told he must engage with counselling or he will not be allowed to retain his accommodation (see p.147-148); or Mahdi, who perceives taking medication for his mental health as linked to being in receipt of welfare payments and related support (see p.158). In these examples, participants' locations at the intersection of mental health and socio-economic disadvantage combine to create an experience of these systems that is coercive.

In the literature, reasons for the disproportional use of coercive practices in mental health systems are not always elaborated on. A common hypothesis is of increased rates of SMI manifesting in a state of crisis due to the avoidance of services in the early stages of 'illness'. The most common explanation provided is racial stereotyping. Racial stereotyping is highlighted in this study as impacting on some participants' experiences of mental health and related services. Notably, Satch provides accounts of several occasions where he was treated with increased suspicion and denied access to support as a result of being perceived as intimidating. This is a claim that his own social worker Lisa firmly believes resulted from his being black, male and having dreadlocks when she states that this results from '*how he's looked, and, and people get scared easily by him*', despite his having '*never been huge, he's never been kind of bulky or anything'* (see Appendix 24). The impact on Satch being that he felt compelled to alter his appearance when next attending a clinic so as not to invite *'problems'*. However, stereotyping is not highlighted in this study in relation to coercive practices.

Two additional factors are highlighted as contributing to the coercion that participants perceive in their interactions with mental health services. The first relates to multiple disadvantage and intersectionality. Attending to people's intersectional locations in this study has revealed why some participants perceive certain processes as coercive when others service users might not. For example, were it not for Samantha's intersectional location as physically disabled and a migrant, she might not have been exposed to difficulties that – when told she must engage in certain activities to receive support – amount to an experience that feels coercive. Coercive because she feels forced to engage in something that she knows to be harmful to herself. Similarly, Satch and Mahdi imply that they had no real option other than to engage in treatments they did not care for due to their need for housing and financial support. This demonstrates the need for policymakers considering future strategies to address BAME mental health inequality to consider more than oppressions of a purely racial nature. As found in relation to determinants (part B), the intersectional forms that racism can take and the other forms of oppression that people of BAME backgrounds are at increased risk of experiencing also require significant consideration. Additionally, my study illustrates the need for policymakers to consider how negative and fear-provoking interactions with the State in other systems (e.g. housing, welfare, visas) are transferred into experiences of mental health services. Whilst this has been explored repeatedly in relation to policing and the judiciary, and to some extent in relation to education, it is less explored in relation to support services related to socio-economic disadvantage/urbanicity.

The second factor is the impact of austerity and the approach taken to cuts in public services in its wake. Interestingly, this is not an issue that I have seen raised in the literature pertaining to BAME mental health inequalities. Whilst the issue of service cuts has been highlighted as having a detrimental impact on mental health services generally (see p.8), its link to more coercive methods impacting people with BAME status is not generally made. This is perhaps because this literature on austerity tends to focus on practices that are coercive, regardless of any identity-markers unrelated to socio-economic positions. This study, however, reveals that a number of practices are experienced as coercive as a result of participants' social stratification and intersectionality. The impact of austerity was to significantly and systematically cut public expenditure from 2009/10, (including to mental health services), and to augment efficiency drives already in place. [redacted]

The impact of this on services' abilities to deliver support flexibly to a diverse set of people's needs is reflected in most participants' accounts of using services, contributing considerably to feelings of being coerced. Participants make clear their view that services are focused on meeting their own targets, even if this is to the detriment of clients who diverge from the mainstream (see chapter 5, section 3). Samantha's account of the GP's receptionist trying to force her to use a newly implemented triaging service (see p.136-137) for example, demonstrates an important consequence of efficiency projects; namely, that these often take as their starting point the experience of an aggregate ‘majority’. Around this, processes are designed and implemented. Then where possible or where consideration is given, adjustments are made for marginalised groups or people with differing needs. In this instance, little regard seems to have been given to the impact of this process change on someone with ‘*mental problems’* who is awaiting important test results linked to a number of stigmatising health issues, and whose cultural differences manifest in part through how they express themselves. Add to this the increased workloads of staff and the margin for flexibility to accommodate different needs closes in; often on those for whom the system is not primarily designed for.

[redacted] For example, John M works in a project spanning multiple services to improve the experiences of people with complex needs including mental health issues/distress. He explained that he gets *‘so pissed off with it’*, referring to the lack of flexibility in systems when just a little ‘*flex’* could create the *‘perfect storm*’ for people he is working with to get their lives back on track. He elaborates that *‘the situation can be really overcome if we are just using / these terms now the system flex / flex in the system, just a tad, you know, we're not asking for much’*. Yet, he reports often being met with resistance from within services, particularly from psychiatrists. This resistance is something that he anticipates worsening with the increased centralisation of services such as prisons. Ruth provides a moving account of the frustration that she and many of her colleagues experienced as their workloads were increased and they were told they could no longer provide the type of care that they felt was most humane. The impact of this was that ‘*Some of the social workers / very experienced, and they are saying ‘No! This is not right.’ You know. All of us left with (.) broken. Broken. Really. Broken’*. This account is mirrored by Marcia’s own misgivings about remaining in the mental health profession, stating ‘*Being part of that machine, do I want to be part of it?’*. (See Appendix 25 for full accounts).

For others, this inattention to people outside of the mainstream leads not only to poor services, but a total lack of support in relation to mental health for certain BAME populations. Kamilla, a therapist and fellow PhD researcher, speaks on this topic in relation to the money being spent by the State and large charitable organisations to raise awareness of mental health. The main purposes of raising awareness being to tackle stigma and increase awareness that support exists. Kamilla explains that:

> *in like mainstream society, I can see that a lot is being done, but then if I look at / my culture, for example, so I'm Pakistani, so if I think about the Pakistani community, there's not really much done or I don't feel like there's being much done.* (.) *I know somebody here who / like whose, whose Mum has schizophrenia but she, she's home all the time and he looks after her and he doesn't really have anyone to talk to about how difficult it is …which is very sad, because obviously then people are dealing with this stuff in isolation*

This is arguably reflective of Satch's comment that '*All this money they're spending, they're just making up'*, followed by a discussion of the services that are closing due to lack of funding. Satch states that there will '*be no-one around to help'*. Though the context is different, both Kamilla and Satch highlight how a focus on the 'mainstream' in expenditure leaves marginalised parts of the population '*isolated'* and without support. The result here being that some of the most marginalised people in our society feel pushed to '*Go steal? To go jail? Or go kill myself?*', compelled to '*clobber'* or *'bop someone over the head*' or to intentionally put themselves in situations of crisis (see chapter 5, section 5), just to have their right to an 'adequate standard of living and social protection' (UN General Assembly, 2007, sec.28) fulfilled. Thus, marginalisation in the wider society is reinforced once more as people are provided '*the cheapest kind of understanding'* under the pretext of 'austerity' and/or 'value for money' in public services.

8 Treatments

This sense of being provided the cheapest support available, with little regard for people's situatedness or preferences - cultural or other - continues into discussions of specific treatment options provided. This is true in both the literature and the testimonies of participants in this research (with the exception of Mya and Samaiya). Indeed, though the setting and conditions in which participants in this research receive treatments may vary from those predominant in the literature, many key themes again align. This is true even in relation to talking therapies, despite participants speaking primarily of group therapies whilst the literature focuses almost exclusively on one-to-one forms of therapy. In relation to medication, only two participants (Mya and Samaiya) seemed neutral to its use. All other participants expressed concern at its position as the prime form of support provided.

The literature highlights three main issues in relation to medication and BAME mental health inequalities. The first relates to the role of racism and racial stereotypes in causing certain BAME groupings to experience higher overall levels of medication. Whilst it is impossible for this study to determine if such claims are true, I do note the perception among some participants that there is an '*urgency to medicate'* black people and anyone whom services perceive as making too many demands (see p.157). The second issue relates to problematic side-effects, and the fear and lack of information around these. These issues are found primarily in qualitative research, particularly that committed to giving primacy to the voices of BAME mental health service users/survivors. Problematic side-effects include serious negative impacts on physical health such as those mentioned by Peter in relation to himself and his sister. Both Griffiths (2018) and Peter report that people are not often provided with information regarding the side-effects of medication for mental health issues – physical or other. More often raised in both the literature and this study, however, was the impact that medication has on people's abilities to communicate and function as per *their* 'normal'. Findings in the 'Breaking circles of fear' report (2002) mirrored wording used by three participants in this research: that people were being medicated to the point of becoming 'zombies'.

Participants express resistance, irritation and anger, resulting from a sense of disempowerment and marginalisation that accompanies the insistence on medication. This disempowerment and marginalisation constitute the third issue highlighted in the literature. Indeed, the parallels between participants' testimony in the BAME service user/survivor-led report 'A call for social justice' (2018) is striking. The report highlights one particular quote where a participant states that in pushing people to take medication, mental health professionals refuse to 'take you seriously', adding that 'They're not there to help me' (Griffiths, 2018, p.31). Such sentiments are reflected in extracts presented in chapter 5, where multiple participants describe being *'fobbed off to medication'* whilst their actual desires for support are dismissed or ignored. It is for this reason that Satch feels he must remain '*outspoken'***,** that Peter has taken his care into his own hands and researched alternative approaches, and that Samantha, Mahdi and Andeep express frustration when medication continues to be the support offered. There is a shared sense that medication is used as a means of enabling the State to avoid having to deal with the actual causes of mental health issues which, for participants, are primarily socio-cultural factors. This view is one shared in the grey literature and some academic works.

Reliance on medication by mental health services and professionals therefore serves two functions that are likely to increase poor experiences of mental health services for BAME groupings. The first is that, even if it does not reinforce racism per sae - though I do not deny that it does in some instances - such practices do reinforce the oppressions that people of BAME backgrounds experience outside of the mental health system. In this, marginalisation in particular is enforced as people's own views and knowledge born of lived experiences are denied in favour of medical perspectives and practices. Indeed, such practices undoubtably contribute to the widespread distrust between BAME groupings and mental health professionals highlighted in both the literature and this study. Further, for those participants who are socio-economically disadvantaged, medication acts as the mechanism by which their requests for support to address poverty – a key determinant in BAME mental health inequality – can be denied or put to the side. I recall to mind Marcia's account of the lady with bleeding walls in her council apartment, (see p.182). Socio-economic disadvantage was both explicitly and implicitly linked by both participants and staff interviewed as being used to coerce people to adhere to the treatments prescribed. For example, Ruth states that:

> *I did take the medications when they threatened me… with if you don't take it, we will discharge you from the services, and.. When they just discharge me from the services what happens then is that PIP I'm getting and everything will stop. Because they will say 'You refused treatment.' This is the letter. Oh yeah, that's what happens. It has knock on effects*

This testimony brings to my mind Mahdi's linking '*lay down like this, have Sertraline*' to receiving welfare payments. Poverty, in such circumstances, is used to coerce people to take medications that they do not want or feel are helping very much.

Interactions with services of this sort carry through, at times, into talking therapies offered. For example, experiences of feeling coerced to engage with various forms of talking therapies are present in Peter, Samantha and Satch's testimony. Another issue raised is the sense that not all staff in services have the best interests of BAME service users/survivors at heart. For instance, Satch speaks of a councillor whom he felt had little understanding or empathy for his situation (see p.148). Yet, he reports not being able to disengage due to the '*the donkey on a stick'* (e.g. carrot and stick) approach employed whereby he would lose his accommodation by not attending. Peter also highlights that, even when staff did want to ensure that he got the support he needed, sometimes the system would not allow them to provide it (see p.166). This particular issue is one not limited to BAME groupings in the literature, but highlighted in relation to anyone with more complex needs (Perfect et al., 2016). However, people of BAME backgrounds are among those most likely to have such complex needs due to their exposure to racism and a variety of additional social inequalities.

Contrary to trends reported in the literature regarding a lack of access to talking therapies, the majority of participants in this study were provided access to talking therapies, (whether they desired them or not). I cannot say that my findings contradict those of the literature as this might very well be an anomaly within this very small sample of people, most of whom were being supported by BAME-led organisations. Further, I am aware that those participants who are more likely to be deemed 'unsuitable' or 'lacking in insight' did not speak to me about engaging with talking therapies. I am thinking here of Andeep and Samaiya. Andeep appeared heavily medicated and, though he spoke of the benefits of talking through emotional and psychological difficulties, he did so in relation to sharing these with loved ones rather than in a therapeutic setting. Samaiya, whose mental health issues were frequently overlooked when younger due to her physical health conditions and learning difficulties was not in receipt of talking therapies. Reasons for this were not, however, discussed.

The main reasons provided in the literature regarding lower outcomes in relation to talking therapies relate to the cultural inappropriateness and insensitiveness of therapeutic practices, and the evasion of racism due to therapists' discomfort or inabilities to speak of this (see p.87-88). Whilst issues of cultural appropriateness are present in Samantha's account when she speaks of finding it difficult to '*sit down and just talk*' (see p.164), the only therapy that Samantha spoke well of was one organised by a BAME-led organisation where discussion was mediated by activity. In contrast, Mahdi reports experiencing no cultural barriers in relation to support received for his mental health. Issues pertaining to therapists' abilities to address issues of racism or other forms of oppression were not highlighted, a possible exception being Satch's account of the councillor who wouldn't '*understand* (.) *past your nose*'[30]. However, I believe Satch to be referring more generally to oppressive experiences in his past, pointing towards a need highlighted by both Moodley et al. (2019) and Newland et al. (2015); primarily, the need for therapists to consider the ways in which people are multiply and intersectionally located and how this might impact on the treatments they need. Support for this is further provided by this study through discussions of group therapy.

Though group therapy is provided through State-funded IAPT services (Perfect et al., 2016, p.4), it barely features in the literature pertaining to BAME mental health inequality. Yet, it was a primary focus for the three participants who spoke at length about talking therapies. Peter, Samantha and Satch, all highlighted similar concerns. The first concern being the coercion/significant pressure they felt under to attend group therapy, despite each being eloquent about why they did not feel this support was most appropriate for them. Perhaps most significant to this thesis was the way in which their individual intersectional locations and past experiences made them uncomfortable in group settings of this sort. The distrust of others that people at certain intersectional locations or residing within communities with different dynamics do not seem to be taken into consideration. Core participants were not the only people to provide narratives as to why group situations might be more problematic in the context of BAME mental health inequality. Some staff also highlighted such issues Jean, a staff member interviewed, explained that within her community:

> *it's not tight knit as in unity stand together. It's a very much a what's he doing, or oh if he can do that, then my daughter can do that. …we all often describe ourselves as crabs in a bucket. If you put some crabs in a bucket they will stand on each other's head to get out and actually that's pretty much it. We tend to be looking around, we trust no one*

James also reported that within certain black communities there was a tendency to feel that:

> *amongst our race people is when / I think / 'you're probably thinking negative of me', 'you're probably doing this and that', because we're so used of the discrimination or people thinking ill of us*

Similar issues were also highlighted by Satch, albeit from a very different setting. Speaking of group therapy sessions in a prison context, Satch highlights that many in the group would already *'know each other in the wire'*, a situation not conducive to making oneself vulnerable. Indeed, Satch provides the most explicit discussion of how social hierarchies and systems of oppression influence the dynamics of group therapy in ways that, once more, bring such issues into therapeutic spaces (see p.162-163). These social dynamics and histories of oppression are not left at the therapists' door, just as they are not left at the door of mental health services more generally.

Peter and Satch both express the view that group therapy is being increasingly provided as a result of cuts to services, with Peter stating that this is '*much cheaper to run'* than one-to-one therapy. I could not find documentation to confirm the actual delivery rates of group therapy comparative to one-to-one interventions; group therapy within IAPT is clustered into 'CBT' treatments which also include one-to-one sessions (Perfect et al., 2016). However, if this is the case, it opens up particular issues for people of BAME backgrounds and in intersectional locations that policymakers must be aware of, particularly if they wish to decrease BAME mental health inequalities in service performance data. As the literature highlights, therapeutic spaces are often not neutral spaces. Just as racism is highlighted as present in interactions between people in psychiatric wards, so too can it and other forms of oppression manifest in group therapy sessions. Being alert to the marginalised and intersectional locations that many people in BAME groupings inhabit is therefore vital to policymakers if considering increasing reliance on such therapeutic methods. Even if such considerations do not change the ultimate direction of the policy, an intersectionally-sensitive approach would provoke consideration of how different social groupings might respond to this, and what adaptions beyond cultural sensitivity might be necessary.

Summary

Overall, the experiences of participants of mental health services reflected the literature in that they were felt predominantly to be inadequate or inappropriate, despite some positive experiences. Interestingly, the positive experiences recounted by participants emerged where care was taken on the part of service providers/staff to attend to participants' specific needs[31]. Indeed, the causes of many of the problems highlighted above can be viewed as resulting from the application of the '*cheapest kind of understanding'* at the interpersonal, institutional and systemic levels. Newland et al (2015) calls for therapists to direct interventions to address issues in the wider social context in which people reside. Supporting this, my thesis points to the need for policymakers engaged in addressing BAME mental health inequality to do the same. A tight focus on mental health services, whilst important, is inadequate, just as a focus on wider social inequalities that does not account for their interactions with racism and intersectionality is.

9 Calls for change

My literature review highlighted a number of calls for change in relation mental health discourses, service practices and policy made at State levels. These generally fell into the following categories: increased resources to expand service capacity and improve delivery; increased cultural competency among mental health service staff and practices; a focus on racism and the ways it manifests in mental health discourses and practices; and an increased need to build understanding of and address intersectional experiences within BAME groupings. Staff members interviewed by myself advocated for many of the same improvements. For them, however, there was not the same division between those calling for more resources and those advocating a focus on racism. Most staff highlighted both as absolutely necessary, along with greater cultural competence.

Some participants also spoke of what they think is needed to improve mental health and experiences of services for people similarly 'located'. Where discussed explicitly, improvements generally related to service provision. Highlighted by the largest number of participants was the need for more resources to be directed towards marginalised groups. Aligning with the critical literature, the need to address racism was also raised. Additionally, participants drew attention to the need for increased lived experience of both BAME status/background and mental health issues/distress in decision-making and service delivery. Indeed, it is in this call for increased lived experience that we see a possible point of coming together between people advocating for action in relation to BAME mental health inequalities, and movements such as the Disability, Mad or mental health service user/survivor movements, and anti-racism movements. Interestingly, participants did not seem as focused on cultural differences as needing addressing as the literature or staff members.

Finally, a note in relation to calls for greater consideration of intersectionality and action that recognises the impact of wider inequalities at play in relation to BAME mental health inequality. Calls from participants regarding their desires that services stop focusing on prescribing medication and actually address issues like material deprivations or migrant status aligns strongly with advocates in the literature that draw attention to the need to consider wider social issues to address BAME mental health issues. In the literature this increasingly includes issues labelled ‘intersectional’. Whilst most participants in this study do not have the language of intersectionality, they do provide examples of intersectional experiences that impact on their mental health and experiences of services. In this way, their testimonies support calls for wider social issues and intersectional experiences to take a more central role in any future BAME mental health inequality strategy, whilst also emphasising the need to address racism and cultural difference.

10 Conclusion

These findings have important consequences for policy-makers adopting a conceptualisation of this social issue as emerging from and operating within open systems. They reinforce the need to consider the *network* of State-led support services more holistically to improve experiences of mental health services by this population group, rather than mental health services in isolation. This need arises not only from participants bringing a variety of past experiences into how they respond to treatments and the delivery of services. It is also borne of the increased likelihood that people of BAME backgrounds are intersectionally located and will be (or have been) exposed to a range of systems of oppression. In the next, and final chapter, I bring this discussion into sharper focus. Primarily, I demonstrate how the above support my proposal that any future strategy to address BAME mental health inequality would benefit not only from greater inclusion of people with lived experience of both BAME status and mental health issues/distress (including ‘CMDs’), but also from employing two heuristics, the first being that of the ‘wicked problem’, and the second being ‘intersectionality’.

Chapter 7: Conclusion

> Comrades, let us flee from this motionless movement where gradually dialectic is changing into the logic of equilibrium. Let us reconsider the question of mankind. Let us reconsider the question of cerebral reality and of the cerebral mass of all humanity, whose connexions must be increased, whose channels must be diversified and whose messages must be rehumanized.
>
> (Fanon, 2001, p.252)

The arrival of the Covid-19 pandemic in the last 12 months has sent shockwaves across the globe, altering much about the way we in the west and elsewhere live. Not only has it raised questions regarding what we as a society truly value, it has also brought the fault lines in our social structures to the fore. For example, the way that people working in care are underpaid and un-recognised, or the educational inequalities experienced by children from socio-economically deprived backgrounds who do not have ready access to computers and the internet. Whilst this period has been more than trying for many, it is often in such times that opportunities for change arise. Already, we have seen the rise of anti-racism movements that state that enough is enough. Though the killing of George Floyd was the final catalyst, the context of stark health and morbidity inequalities highlighted through the pandemic cannot be ignored. It, too, provided vital fuel by highlighting how the inequalities experienced by BAME populations across many wealthy western nations translate into matters of life and death (Booth, 2020; The Movement for Black Lives, 2020). This was exemplified in a child’s powerful poem, which circulated on social media supporting anti-racism movements in my home town of Bristol (see Appendix 27).

Sitting at my desk writing up my thesis, I found many of the things I was writing about now being heatedly debated everywhere I turned. The morning news, social media outlets, notices from my university, friends and neighbours. Still in contact with a few participants in this research, I saw first-hand that this pandemic was not ‘the great leveller’ claimed by some in the spring. Rather, it was a magnifier of the social inequalities that participants had spoken to me about in the years preceding the pandemic outbreak. It brought home to me the relevance of this work in today’s social and political climate, demonstrating the role that policy-makers have in augmenting or mitigating against health inequalities. Participants had been right. This thesis does need to be about policy and change. It does need to put forward participant's perspectives such that readers better '*understand what's people's problem'* (Mahdi, 2018). And it does need to address policies that provide marginalised people with *'the cheapest kind of understanding'* (Satch, 2018). As I set out in my introduction, past strategies have been impoverished in several ways, not least due to their continued narrow focus on inequalities within mental health and related support services. Nowhere do these strategies seek to address wider social inequalities recognised within 'psy' disciplines as a significant causal factor in the increased risk of (diagnosis of) mental health issues/distress among BAME groupings. This impoverished approach has led to nation-level policies addressing BAME mental health inequalities to fail to have any significant impact on epidemiological or service performance trends.

Taking a predominantly inductive approach, I discovered much about what policy-makers of future strategies addressing this policy issue might learn from the lived experiences of people at various intersections that include BAME status/background and mental health issues/distress. Considering these findings within the context of why previous strategies might have failed to improve trends, I found the following main lessons. These are the need for policy-makers to:

1. widen the policy scope to reflect diverse definitions of BAME mental health inequality, which includes addressing the '*root causes'*;
2. base policy design on the ontological understanding that phenomena and systems in this space operate and are experienced as interconnected; and
3. recognise intersectional experiences and design policies that both address needs arising from this and do not reinforce such forms of marginalisation.

Reflecting on my own journey from policy-maker to researcher, I recognised how central particular epistemological frames and theoretical lenses have been to my own ability to *'really listen'* (Mahdi, 2018) and enrich my understanding. Thinking about how these might be translated into a policy context whereby most policy-makers simply do not have the luxury of interrogating the more philosophical aspects of epistemological and methodological choices, I happened across two things. First was the notion of complex social issues as 'wicked problems'. The second was the emerging work being done to translate intersectional theory into workable tools for policy-makers, often stemming from the work of those developing intersectional research methods.

1 Wicked problem: scope and ontological considerations

The concept of the ‘wicked problem’ addresses the first two issues, which speak more to epistemic and ontological issues within policy-making practices that are particularly problematic when responding to issues of inequality. Outlined briefly on p.12-13 and expanded on in Appendix 8, the concept of the ‘wicked problem’ essentially stipulates an ontological and epistemological frame that situates social issues as complex, interconnected, and involving a multiplicity of knowledges which each play a role in building richer theories of reality. It situates ‘wicked’ social issues as having no single definition and operating within complex networks of open systems; open systems being systems that are shaped and shape other systems, particularly in the social world. The concept of a wicked problem is not, therefore, applicable to all policy issues, but I feel that it encompasses something core to the issue of BAME mental health inequality.

As demonstrated by both the literature and my own analysis of data from this study, this area of inequality is one in which definitions are multiple and it is nearly impossible to delineate the start or the end. This is because epistemological and ontological issues are highlighted as fundamental to some of the manifestations of inequality (see chapter 3, section 3). As previously alluded in this thesis, the State in its strategies has relied on definitions provided by scholars and professional bodies applying understandings firmly within western medical discourses. These discourses now allow for understandings that move beyond bio-genetic aetiologies. However, they leave unproblematised issues pertaining to diagnostic categories and the possible ways in which such categories pathologize difference and distress arising from experiences of oppression. Yet, this understanding is far from the only one available to policy-makers. Even from within ‘psy’ disciplines, there are those calling for such pathologization to be problematised within mental health practices and related policies. Focusing in on the findings of this study and other research where testimonies of lived experience are given primacy, this call intensifies. Similarly, interpretations of trends and explanatory theories most commonly put forward by dominant medical narratives are not those that best align with scholarship focussing specifically on the experiences and understandings of BAME groupings or participants in this research (see chapter 6, part A).

Adopting a conceptualisation of BAME mental health inequality as a ‘wicked problem’ would require policy-makers to actively seek a diversity of perspectives that represent all parties with an (significant) interest in the area *prior to* defining the issue and scoping the strategy. This moves beyond current practices of consultation or collaboration, whereby interested parties are invited to provide their views on the main issues within a topic area or – as is more common – to provide answers to a series of questions set by policy-makers and Ministers. Regardless of the approach taken, however, policy-makers come already armed with significant limits to the scope of any potential policy or strategy. These result primarily from assessments of political will, financial and resource considerations, and barriers arising from governmental and governance structures. Interested parties are then encouraged to respond within these parameters, situating current structures - moulded in the shape of dominant discourses and practices - as unable to be altered in any fundamental way.

Certainly, this seems to be the process at play in relation to BAME mental health issues, where no strategy has ever moved beyond addressing inequalities related to the provision of support for mental health issues/distress. Though wider social inequalities are accepted by the State as an important risk factor in the development of mental health issues/distress within a health inequality context, no strategy has set about trying to systematically addressing these causes. Looking closely at the testimonies of participants in this research and issues highlighted in the literature in relation to this topic, I find this to be a serious limitation. Indeed, this policy position is arguably mirrored in the overreliance on medicalised treatment practices whereby people are given medication with little or no attention being paid to *‘the root cause’*; an approach highlighted by several participants as ‘*pointless’* (Peter, 2018). I would argue that maintaining such approaches is not only detrimental to the ultimate strategy or policy designed, but is actually a means by which experiences of oppression are perpetuated. The State becomes no different to the medical practices that ignore alternative perspectives. As alluded in my introduction, the inability of the State – and by proxy, its policy-makers – to truly bring all interested parties into dialogue prior to setting parameters forces people in marginalised positions to ‘fit in’ with those in more privileged and dominant positions. In this way, policymaking practices pursued in the name of addressing BAME mental health inequality risk replicating the very experiences of marginalisation cited as a key factor in generating this inequality.

In contrast, an approach informed by the concept of a wicked problem necessarily accepts complexity and multiplicity as critical to understanding how an issue manifests and operates in the social world. Therefore, consultation, collaboration and co-production at the scoping stage, informed by this way of thinking, should actively seek out diverse perspectives which are then treated with equal legitimacy. This, I suggest, supports policy-makers defining BAME mental health inequality to mitigate against engaging in ways that replicate oppression and cultural imperialism and provides a non-partisan means of shifting dynamics of power. In addition to supporting State policy-makers to avoid replicating the inequality they seek to address, actions to broaden the perspectives feeding into definitions of the issue should result in richer ‘theories of reality’. Richer in that they are truer to the ‘actual’ phenomena as they are experienced by multiple parties involved.

However, there is an important limitation within the concept worth recognising, particularly in relation to BAME mental health inequality and other issues of inequality. ‘Inequality’ as a phenomenon is not only made up of concrete issues divorced from a person’s internal processes. Aspects of this phenomenon are in fact located within the lived experiences of people subject to a given inequality. This gives people with lived experience of a particular issue access to ‘theories of knowledge’ more directly in contact with the ‘actual phenomenon’ being examined. They are therefore likely to be coherent with the ‘actual phenomenon’ in a way that decreases with every level of abstraction that is inserted. This provides a basis for such knowledges to be prioritised above other more abstracted forms. As Fricker states:

> When our practice is uninformed by the experience of people in a given social position, we are collectively in a position fully to understand neither the experiences in question, nor any other areas of the social world to which they have interpretive relevance. (Fricker, 1999, p.208)

This, together with any emancipatory or anti-oppression aims of future BAME mental health inequality strategy, provide strong arguments for people with lived experience of the intersection of BAME status/background and mental health issues/distress to have their testimonies prioritised in policy-making without designating other perspectives as obsolete.

The need for an awareness of competing knowledges in the articulation of an issue all bring different aspects of a phenomena to light, building richer understandings that enable policy-makers to take more wholistic approaches. Without this, policymaking processes are unable to produce responses able to attend to a given issue in anything remotely resembling a wholistic way. This is deeply problematic where an issue is identified as having the characteristics of ‘wickedness’, as such issues not only have no single, conclusive definition, but also have an ontology whereby no aspect of the problem can be isolated without impacting on other aspects. Changes in one area, even if treated as an isolated issue by those implementing the change, will most likely have a ripple effect as the systems involved are open in nature. Certainly, the issue of BAME mental health inequality does seem to be one in which the systems core to its emergence are ‘open’ in nature, interconnecting to shape and be shaped by each other. Though there was evidence of this in the literature, an in-depth examination of testimonies of participants in this study revealed that this interconnectedness was not only happening at the level of structuring the phenomena itself, but also at the level of experience of such phenomena.

Evidence that the State’s understandings of health inequalities as purely an issue for medical practices is disappearing, influenced by repeated reports (Department of Health, 1980; Department for Health and Social Care, 1998; Marmot et al., 2010) that emphasise the interconnected nature of social inequalities and health issues. For example, the increasing implementation of ‘social prescribing’. Though remaining within medicalised models that focus attention on interventions for implementation by an individual, this intervention does begin to operationalise recognition of the role of the social world in health. Whilst such approaches still evade the issue of dealing with the structural causes of inequality, it begins to build a culture that situates consideration of wider social factors as integral to addressing issues previously ‘tamed’ as pertaining to the body only. This evasion of structural inequality, however, is problematic for policy issues such as BAME mental health inequality, whereby systems of oppression are fundamental elements of the network of open systems giving rise to the issue. A true embracing of the issue as a 'wicked' problem would not be able to make such an evasion. One reason being that it is highly unlikely that those involved in defining the issue and scope, (i.e. people with lived experience of the inequality), would accept such an approach. Another being that where an ontology whereby all relevant systems involved are open in nature is truly embraced, consideration would have to be given to how the mechanisms and manifestations of structural inequalities shape the systems that focus is being turned to. This position might strengthen arguments for issues such as the need to recognise institutional racism, providing a stronger basis on which to counter politically-based arguments against this. Further, it would necessarily require the development of a national-level strategy that, for the first-time in England's history, addressed the causes of BAME mental health inequalities in relation to service provision *and* incidence/prevalence of mental health issues/distress. This would be due to a recognition that experiences leading to the development of mental health issues and/or in diagnostic practices are deeply interconnected with those forms of inequality manifesting within service outcomes and experiences.

The concept of the 'wicked problem' provides the policy-maker with a tool that situates them as non-partisan, whilst enabling them to argue for recognition of formulations of an issue uncomfortable to those in positions of privilege. The policy-maker can provide an argument for a particular conceptualisation of the issue whilst distancing their arguments from those that might be otherwise understood as politically-charged and partisan. Thus, the concept holds two main benefits that I propose position it as a potentially useful heuristic for State policy-makers working in this policy area. First, it distils complex epistemological and ontological arguments into an easily understandable tool that promotes approaches to enrich understandings of issues requiring policy responses. And secondly, it provides a means by which to argue for the scope of strategies to be expanded in the non-partisan way so integral to the a-political position that State policy-makers must present themselves. In making this statement, I am not however doing so naively. An acceptance of non-political arguments for taking one course of action over another requires a will to prioritise the implementation of a strategy fit for purpose over and above considerations of a more partisan nature. This requires a level of humility and introspection that State parties are not always willing to demonstrate, as evidenced by repeated refusals to recognise institutional racism in England’s health and care systems (see Appendix 5). However, I maintain that the non-partisan nature of the ‘wicked problem’ still provides a helpful basis on which State policy-makers can push for changes in policy-making practices in this and similar policy areas and start working towards organisational cultural change.

2 Incorporating an intersectional lens

Intersectionality, as I point out in chapter 2, was originally developed to address a gap in the American legal system that was unable to account for particular experiences. This led to an equalities legal framework that was unable to safeguard intersectionally located people from forms of discrimination and oppression that deviated from those allowed for within a framework based on single-issue approaches. A similar issue is at play in national-level policy responses to BAME mental health inequality in England, as was in fact pointed out in the DRE’s evaluation report (see Appendix 5). Department of Health (2010) highlights that BAME populations are complex and diverse, and that any future strategy must recognise this and act accordingly. The implication being that homogenising approaches to BAME mental health inequality were simply inadequate. For Wilson, this led to a need for a ‘single equalities’ approach that saw discrimination and oppression resulting from any of the 9 protected characteristics in the Equality Act 2010 as relevant.

My own research concurs with views that situate any form of discrimination and oppression experienced within BAME groupings as relevant to the issue of BAME mental health inequality. As chapters 4-6 demonstrate, the role of discrimination and oppression resulting from classism and ableism in relation to physical and learning impairments seem of particular relevance to this area of inequality. These, and other stigmatising identity-markers played instrumental parts in both the development and aggravation of mental health issues/distress and inequalities experiences within support services. However, such issues are not always presented as of relevance to this issue and receive little attention in the literature. As a result, whilst I align with those advocating for greater focus on racism and racial prejudice in policy responses to BAME mental health inequality, I suggest this must be done alongside an attention to both multiple discrimination of an additive sort and to intersectional experiences. Intersectionality is increasingly recognised within activist circles and slowly being introduced into British academic research in this area of inequality. However, it still comes up against significant opposition from within and outside of government and seems still relatively unknown among many people living in the intersection of BAME status/background and mental health issues/distress.

[redacted] learning about intersectional theory was a turning point in my understandings of inequality, discrimination and oppression. In relation to this research, without the understanding gained of how prejudicial power dynamics can function together to create 'different' expressions of oppression, I am certain that I would have missed some of the nuances of participants' experiences. For example, it is my grounding in intersectionality theory that drew my attention to the interconnected and interdependent ways in which power dynamics and systems of oppression experiences past and present were impacting on how participants responded to processes involved in accessing support. Further, it is this intersectional lens that enabled me to identify commonalities of experience without losing the richness of difference and diversity among participants. By this I am referring to the commonality of experiences of discrimination and oppression, though the specific forms of these differed across participants. Taking an intersectional lens enabled me not only to identify experiences of intersectionality, but also those gaps in the literature that relate to experiences more aligned with multiple discrimination.

[redacted] I realised that one of the reservations around employing this lens is the perception that intersectionality in policymaking would require consideration to be given to a never-ending number of sub-groups of marginalised people. In the world of policy, this is simply unfeasible much of the time. Whilst intersectionality theory does highlight that people in an indefinite number of intersectional locations have differing needs that require attention, it does not do so by advocating and considering each intersectional location individually until each is addressed. Instead, in keeping with the ontological premises of wicked problems, intersectionality theory highlights the need to understand the open nature of multiple systems of oppression in operation in our society and what happens when these interact. Whilst these do manifest in a multitude of different experiences at the individual and group levels, this way of thinking about intersectionality provides policy-makers with a more manageable approach that is inclusive of and open to issues of an intersectional nature. Indeed, this sort of interpretation seems to be that which has underpinned more recent attempts to translate intersectional theory into policy approaches (Coll-Planas and Solà-Morales, 2019; Hankivsky, 2012; Heard et al., 2020).

A second obstacle to the implementation of intersectional approaches, still related to people's perceptions of intersectional theory, is that it would diminish focuses on the system of oppression particular to a given social group. For example, Sewell (2012) seems to suggest that approaches to BAME mental health inequality that take either a 'single equalities' or intersectional approach might lead to a lesser focus on racism. This reservation is understandable in the context of a State that continues to refute the existence of institutional racism as a significant factor in the inequalities BAME groupings experience within mental health services. However, I tend to agree more with Crenshaw's position when she states that a refusal to acknowledge and explore intersectional experiences leads to a distortion in our understandings of systems of oppression, such that we are ill-equipped to truly tackle them (Crenshaw, 1989). Indeed, this is a position increasingly held by organisations such as the UN, whose CRPD committee recently published a general comment advocating consideration of intersectionally located disabled people in equalities policies (UN CRPD, 2018). As my own study and other research conducted with an intersectional lens highlight, a lack of attention to such experiences leads to significant gaps in understandings of the issue at hand. Gaps that I hold produce precisely the 'cheapest kind of understanding' that deepens the inequalities and marginalisation experienced by people such as participants in this study; the impacts of which include higher risk of development or a worsening of mental health issues/distress.

3 Limitations and implications following from this research

In chapter 2, I highlighted several limitations to this research in relation to the width of diversity within my sample. I recognise that participants in this research are not necessarily representative of the BAME population or of the population at the intersection of BAME status/background and mental health issues/distress. Experiences pertaining to important systems of oppression such as those relating to sexual orientation and sex are absent from this study, as are the experiences of people from within many minority ethnic groupings, older people and children and wealthier people within this population group. Had this research been seeking to identify a series of pointed policy recommendations, these limitations would be significant. Certainly, any future policy-making work in this area should ensure that experiences pertaining to all of the key systems of oppression and a wider range of intersectional locations are represented. Though my findings did highlight specific areas requiring action, (i.e. meeting financial and housing needs, over-reliance on medication), this was not the ultimate aim of my research. Instead, I was taking a more overarching look to identify if there was something in the overall approach that policy-makers bring to this area of inequality that might benefit from changing. In this I feel I was successful, drawing from participants' testimonies to identify several reasons why the overall approaches taken by previous policies were inadequate to the aims they espoused.

I therefore suggest that this thesis holds much of significance for any future work on a national-level strategy to address BAME mental health inequality. Though based specifically on people located at spaces within one particular intersectional location, I do feel that the recommendations I deduced from this study hold potential relevance for policy being developed in other areas of inequality. Though the political climate at present may be a difficult one in which to introduce a 'wicked problem' approach to this topic and intersectionality, I feel that it is time to start introducing policy-makers to such concepts more widely than is done at present. In this time of significant change in England, and the UK more widely, there is opportunity for change. Not just in what we do, but hopefully in *how* we do it. The value of lived experience and recognition of intersectionality is increasing in civil society, and the State must keep up.

There are also implications for academic research, though these are more specific to the area of BAME mental health inequality. As highlighted earlier in this chapter, chapter 6 revealed several gaps in the literature that the field would benefit from investigating further. First, I feel that much can be learnt from examining the experiences of people deemed by medical discourses to have CMD forms of mental health issues/distress. There is a tendency in research to focus on those deemed to experience SMI who use/survive tertiary services. Indeed, even much of the research pertaining to aetiological theories for this area of inequality focus primarily on risk factors for SMI. This focus mirrors that in State policy, which fails to address with any real purpose the risk factors for increased rates of 'actual' mental health issues/distress among BAME populations. Yet, participants in this research demonstrated themselves to have an acute awareness of the issues involved in triggering, maintaining and aggravating their mental health issues/distress. More research of this sort is necessary to any future strategy considering prevention measures; measures that address the wider network of open systems giving rise to this inequality.

Primarily, however, chapter 6 highlighted the need for more research considering the role of intersectionality and intersectional experiences in perpetuating BAME mental health inequality. An intersection of particular relevance for which there is a dearth of research is the intersection of BAME status/background, mental health issues/distress and other forms of disability and chronic illness. Whilst the need to consider the above is pressing, I also recognised a need to examine the role of other systems of oppression as they act on BAME groupings in more additive ways. Emphasis on intersectionality, then, must be situated not as replacing 'single-issue' or 'multiple discrimination' approaches, but rather as providing another lens by which to augment understandings of inequalities as they are experienced by all in a marginalised social grouping. I emphasise the need for the UK to catch up with countries such as America, Canada and Australia to develop workable intersectionally informed policy-making models if it wishes to maintain its international reputation as a world leader in equalities issues. More importantly, it must do so if we wish to see a 'rehumanized' society emerge from these turbulent times that is richer in the understandings and treatment provided to all.

Endnotes

Chapter 1

1 For example, in sexual-health related policy, the needs of disabled women were stated to have been considered. [redacted]

2 Primarily: disability studies, Black feminism, medical sociology and philosophy of epistemology.

Chapter 3

3 This Windrush generation migrated in answer to the British government's request for citizens of the British Empire to help rebuild the UK following the destruction caused during the second world war.

4 Whilst definitions can differ (Ruggeri et al., 2000, p.149), SMI generally refers to psychosis and CMD to neurosis (Rogers and Pilgrim, 2014, p.55).

5 Occasionally studies also included black British people. Sometimes it is unclear if the black African and African-Caribbean population considered include black British people who are 2nd/3rd generation.

6 This group is usually assumed to comprise predominantly of Irish-born people and people from central and eastern Europe. Such studies often do not include, or fail to distinguish between, 1st and 2nd generation migrants.

7 Footnote 3 applies

8 Footnote 4 applies.

9 On close inspection, this often includes the experiences of black people of mixed heritage and second generation black migrants.

10 It is easier to research groups that are over-represented in services rather than those who are under-represented.

11 Bhugra et al. state that 'A genetic cause is unlikely because two epidemiological studies in Jamaica (Hickling & Rodgers-Johnson, 1995) and Trinidad (Bhugra et al. 1996) have not found the incidence of schizophrenia to be raised.' (Bhugra et al., 1997, p.797)

12 This is sometimes also referred to as 'social deprivation', 'social disadvantage' or 'socio-economic disadvantage' – this terminology appears to be largely inter-

changeable with differences mirroring variety of measures used within specific terminology.

13 Often measured by ownership of a car, which may in fact be a culturally or geographically inappropriate measure. I.e. – high numbers of BAME groups reside in London where ownership is rarer.

14 Lloyd and Fuller also add that age was a significant factor in likelihood to consult a doctor, with older people from South Asian and African-Caribbean backgrounds. There was also variation in consultation rates in relation to gender across ethnic groupings. For the Asian grouping, migration after the age of 12 also impacted on likelihood to consult a doctor (Lloyd and Fuller, 2002, p.102).

15 Secondary services include community care; acute, crisis and rehabilitation services; and many services provided through the ‘Improving Access to Psychological Therapies’ (IAPT) programme. Tertiary services include secure mental health wards and forensic psychiatry services; inpatient ‘Child and Adult mental health services’ (CAMHS); and prison health care.

16 The report states that ‘Rates [of GP referrals] were 8% higher than average among the White British group. They were lower than average among the Other White, black Caribbean, black African and White/black Caribbean Mixed groups by 28% to 72%.’ (Care Quality Commission, 2010, p.21)

17 By which I mean equal to levels found in the comparison population, be that white or white British.

18 More recent research challenges the assertion that Asian women in the UK don’t know where to seek support, pointing out that Asian people have high use of GP services for physical health issues. (Kapadia et al., 2018, p.304).

19 Khootum refers to ‘kinship network united by common blood-line’, (Katbamna et al., 2000, p.15)

Chapter 4

20 Mya is seen as qualifying as being of minority ethnicity within this research as a result of her Jewish heritage. However, this is not visible and as such Mya is generally perceived as being white British. She is indeed able, and does, self-

identify as white British, though she believes her Jewish heritage to have impacted on her upbringing.

Chapter 5

21 These forms ask people to mark how they are feeling that day against a range of measures, generally by providing a number of a scale.

22 Samantha confirmed this in a later discussion. My field notes state the following: ‘I asked why she hated the paperwork in MH so much, and without me prompting she said straight away because it reminds her of the Visa process.’ – Samantha: Field notes 190808.

23 She was removed from the group therapy session she cites for the way she was speaking to and about other people in the group.

24 Deflecting questions from healthcare practitioners with sarcastic remarks and refusing to speak about her issues.

25 Here Peter is referring to mineral or vitamin based deficiencies, such as a lack of Vitamin D3 due to lack of exposure to sun.

26 Satch would also become confused and anxious about his appointment times and who he was supposed to see, for what and when. As a result, Satch expressed needing a support worker to book the transport and keep him on track with appointments. Without this support, he became quickly overwhelmed.

27 Most experiences and interviews were conducted prior to the September 2019 Budget announcement where the Chancellor of the Exchequer announced the formal end of austerity measures. All were concluded prior to Covid-19 measures.

Chapter 6

28 That said, having begun to interview a lady who did not speak English and her daughter, I am in no doubt that such barriers are a very real issue for some people.

29 [redacted]

[redacted]

30 The lack of such findings regarding racism I recognise once more as possibly the consequence of a limitation of this study as opposed to a lack of participants perceiving this gap. I simply did not enter into conversations about the content of therapeutic sessions with participants unless they volunteered such information, acknowledging the limits of my own skills and not wanting to risk causing harm.

31 For example, the hospital organising Samantha’s medicines into daily tubs to help her keep track and accommodate for her decreasing eyesight. Or Peter’s previous GP who took notice of his past negative experiences with medication and valued his views on treatments enough to refer him to a homeopathic hospital. Or Satch’s attachment to a particular social worker who did not stick to rigid ideas of how people ‘should’ behave, but took the time to understand why Satch might be getting upset and frustrated.

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Appendix 1: ‘Race’, ethnicity and BAME - problematic concepts / terminology

In this thesis, I am tentative in my use of certain terminology, often adopting more unusual wording such as ethnic ‘groupings’ or adding ‘distress’ to the customary ‘mental health issues’. Where I have used more medicalised terminology, I have tried to indicate a level of scepticism. This is not because I disavow of all medicalised interpretations and understandings of psychological phenomena, but rather to emphases the ‘provisional and fallible’ (Gorski, 2013, p.659) nature of such knowledge. This, I feel is important given the certainty with which such concepts are often treated within more positivist sciences, including much of western medicine. Whilst this is linguistically cumbersome at times, it is the result of taking a critical approach in this research and acknowledging the fundamentally problematic nature of concepts core to this topic. I.e. ‘race’, ‘ethnicity’, ‘mental illness/disorder’ and ‘mental health’. Debates on the conceptual soundness of these notions centre largely on ontological disputes or arise from a plurality of epistemological positions. I address some of the issues pertaining to mental health in Chapter 3. However, within the topic of BAME mental health inequality, consideration of such issues around ‘race’ and ‘ethnicity’ are also important though I am unable to include this in the body of this thesis.

‘Race’ was held for many years to be a legitimate means by which to categorise differences between people and peoples. This was based on the idea that specific features of a person, (predominantly physical), indicate not only a difference in heritage, but in ‘type’ of human. Today, some scholars still consider classifications of ‘race’ as legitimate. However, many dispute this, positing it instead as a social construction (Hacking, 2000, pp.16–18), often emerging from a desire to differentiate between ‘them’ and ‘us’. This latter conceptualisation, does not deny differences in skin tone, hair or facial structure. Rather, it disputes that these features constitute a different ‘type’ of human, being instead diversity within the category of ‘human’. Such scholars are also likely to state that whilst ‘race’ is a social construct without a solid basis, ‘racism’ remains ontologically sound.

Whist racial boundaries are sometimes used in this field to delineate between population groups, today ethnicity is more commonly applied. However, ethnicity is also problematic. Emerging in the 1970's, the term is conceptualised differently across the globe. Distinct societies, for example, place a lesser or greater emphasis on racialisation in constituting certain people as having minority ethnicity (Fenton, 2010, c.2). At the most basic level, 'ethnic collectively and belongingness (i.e. ethnic phenomena)' are generally conceptualised 'using notions of common origin or destiny.' (Anthias, 1992, p.421). These categories become problematic when they are deployed as though fixed and a naturally occurring phenomena, rather than as constructions that fit current social and political needs (Anthias, 1992, p.425; Cole, 1993, p.671; Fenton, 2010, p.4; Moodley et al., 2019). Fixed groupings of this sort are inconsistent with the reality of homogeneity within geographic areas and the fluidity and flux of borders. Furthermore, they ignore the homogeneity emerging as a result of people's social stratification and other aspects of identity (Bhatti, 2011, p.84). Thus 'ethnicity', whilst it might provide some indication of a person's cultural heritage, provides *only* that; an *indication* of *possible* cultural and religious heritage. Employing ethnic groupings too simplistically poses significant issues for research:

> ethnicity is not a sound epidemiological variable because of problems of definition, problems of heterogeneity in the population and ethnocentricity among researchers, among other factors. (Bhugra and Bahl, 1999, p.3).

The employment of crude categories can lead to misrepresentations and misunderstandings of what is happening at the community level. For example, in the 1990's, ethnicity data did not disaggregate population groups originating from South Asia. It was not until studies began separating out the experiences of people of Pakistani, Bangladeshi and Indian backgrounds that it was found that the groupings differed significantly in their experiences (see Appendix 17). However, when investigating inequalities that seem to emerge when population data is disaggregated by ethnicity, it becomes necessary to employ such concepts, albeit whilst recognising their problematic natures (Maynard, 2002, p.35; Sewell, 2018). Thus, I refer to categories of ethnicity as 'groupings', maintaining awareness of their fluidity and socially constructed nature and the heterogeneity within them.

Primarily, however, the terminology I employ is that of 'BAME'. In policy and statistics the terms most commonly used across the time period most relevant to this research 2000-present are BAME, later expanded to BAME. However, the term

‘BAME’ remains controversial (Adebisi, 2019; Bhui et al., 2012, p.196), with debates around this reasserting themselves in light of Covid-19 health inequalities and the global anti-racism resurgence (Fawcett Society, 2020). I decided to continue using this term for several reasons. First it is one commonly used in mental health discourses, policy circles and by many user-led organisations and activists. Furthermore, there is a lack of another term that encompasses both ‘race’ and ethnicity, and allows for consideration of white minorities also. I considered using ‘racialised people’. However this places ‘racism’ specifically at the core of this research, which was not the intention of this research nor reflective of many participants’ testimonies. This is not a study focused on ‘race’, racialisation and racism, but originally of the experiences of people with mixed cultural backgrounds. Rather issues of ‘race’ form an important part of this work because it is one of the main focuses within the literature speaking to policy, and because it was raised by several participants. It would have been disingenuous for me to leave this topic out of the research and tantamount to a white-washing of participants’ testimonies. As such, I do not feel that ‘minority ethnicity’ on its own would be adequate; I need a term inclusive of racialisation, including among white people. This is because my sample includes one participant who does not presently experience racialisation though she might in certain circumstances. Mya, who identifies predominantly as white British would have been racialised ‘Jewish’ in Nazi Germany.

Appendix 2: Julie J Charles statement 01/07/20

People of colour and of different ethnic backgrounds are known widely as BAME... BLACK ASIAN and MINORITY ETHNIC. Not everyone relates to this term as it can be quite stigmatising and more people are relating to being black British, south Asian, African and Caribbean etc.

When we then cross paths with having lived experience of mental health this can be quite soul destroying as it somewhat overlaps with some of the descriptions or categories we are put in. Such as being a women who is unmarried, bisexual, has lived experience of living with bipolar and is also living with long term physical health difficulties.

The Equality Act states 9 strands of which a person can be categorised into: age, disability, gender, marital status, maternity, race, religion/belief, sex and sexual orientation. However even with these in place as human beings we experience widespread sectionalism as many of us cross over more than one strand. This is called intersectionality. Intersectionality is real and it’s vital that policy recognises this so services at a grass roots level are meeting the needs of all communities instead of putting us in tick boxes.

As a black British disabled women I experience the constant lack of services to meet my needs as they are not at formed on the basis of intersectionality but on just whatever can be met, whether a service meets your needs or not or I continue to experience discrimination which feels like racism and sometimes is racism so to end.

I STRONGLY recommend that there be a new framework of the EHRC categories which in fact does not define a person but actually does not hold to account most policies which many are not meeting the needs of those of us who intricately are intersectional people.

Appendix 3: Definitions of health inequalities

Though the State has intervened at a national level in mental health issues in one form or another since 1774 (*Act for Regulating Private Madhouses*, 1774), a focused interest in BAME mental health inequalities did not emerge until the late 1990's/early 2000's. In fact, despite the Department of Health and Social Care's publication of a report into health inequalities generally in the UK in 1980 (Department of Health, 1980), Marmot states that it was not until the newly elected Labour government came to power that the State committed to addressing health inequalities (Marmot, 2004, p.262). Research was commissioned, resulting in the Acheson (1998) report. This report highlighted the significant role of social and environmental factors in health inequalities. It not only upheld findings from the earlier 'Black report' (1980)[1], but pointed to the persistent nature of health inequalities[2] and the need to address issues extending far beyond medical care[3]. Additionally, it demonstrated the link between the disproportionate experience of wider social inequalities and presentations of health inequalities amongst BAME communities[4] (Department for Health and Social Care, 1998, p.79).

The Acheson report adopted a socioeconomic model to explore and understand health inequalities. This essentially meant that disparities in health would be explored in relation to social and economic factors widely understood to impact on health outcomes. Additionally, instead of considering health policy in a silo – as more medicalised approaches might tend towards - the inter-linked nature of policies

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[1] Possibly one of (or 'the') first government sanctioned reports considering health inequalities in the context of government policy globally (Department for Health and Social Care, 1998, p.10)

[2] These health inequalities had in fact been reported prior to the Acheson report to be widening (Smith et al., 1990, p.373), adding to the need for government to begin addressing such issues.

[3] It is notable that less than 10% of the 39 recommendations provided were directly about medical care. In fact, the opening general recommendation explicitly sets out the need to address structural and systemic inequality across society in order to address health inequality: 'We RECOMMEND that as part of health impact assessment, all policies likely to have a direct or indirect effect on health should be evaluated in terms of their impact on health inequalities, and should be formulated in such a way that by favouring the less well off they will, wherever possible, reduce such inequalities.', (Department for Health and Social Care, 1998, p.75)

[4] As a result, the report specifically recommended 1) that the needs of BAME groups be given particular attention in the development and implementation of policies designed to address socioeconomic disadvantage; 2) develop health services more sensitive to the needs of BAME communities and promote awareness of health risk among BAME groups; and 3) to ensure that the needs of BAME groups are given specific consideration with regards to 'needs assessment, resource allocation, health care planning and provision', which would entail better collection of data disaggregated by ethnicity (Department for Health and Social Care, 1998, p.79).

was explicitly acknowledged (Department for Health and Social Care, 1998, pp.10–13). Though mental health services in the UK are still widely felt to operate on a bio-medical model [insert refs], remnants of Acheson's socioeconomic model resonate in the State's current 'health inequality' definition. At the time of writing, the Public Health England (PHE) website defined 'health inequality' as:

> the preventable, unfair and unjust differences in health status between groups, populations or individuals that arise from the unequal distribution of social, environmental and economic conditions within societies, which determine the risk of people getting ill, their ability to prevent sickness, or opportunities to take action and access treatment when ill health occurs. (PHE, n.d)

This definition explicitly acknowledges the impact of social, economic and environmental factors in the causation and maintenance of health inequalities across England's population. As such, health inequalities are defined as disparities in incidence or prevalence of ill-health in a given population (or disproportionality issues), occurring as a result of inequalities experienced in wider society. It is this attribution of systemic issues – as opposed to biogenetic factors or non-systemic-related trauma - to the causation of ill-health that positions disparities in health as 'inequality', not 'difference'. The final sentence of the above definition also delineates the current focus for public health policy with regards to health inequalities: prevention and service/treatment performance of ill health.

Interestingly, the definition provided regarding BAME populations differs slightly. Whilst continuing to recognise the 'unfair' nature of health inequalities, the PHE also highlights the role of historical inequalities when it acknowledges the role of 'current and past disparities in wealth, power and resources for health and differential exposure to health damaging environments and risks.' (PHE, 2018, p.8). Reference to the historicity of such issues seems to recognise that many BAME populations in the UK have been exposed to intergenerational marginalisation, which might lead to being impacted by adverse circumstances differently to social groupings who don't experience similar historical inequalities. This framing aligns with the following statement by the Royal College of Psychiatrists (RCP):

> We are all affected by our culture… We all have racial characteristic. However, what is often forgotten is a history of colonialism and neo-colonialism, which can still condition present-day discriminatory attitudes. (Cox, 2001, p.248)

Here, the RCP explicitly acknowledges the relevance of colonialism and neo-colonialism on the present existence of BAME mental health issues; a step not made by the PHE. For, whilst it hints at systemic injustices, the PHE instead uses the language of ‘disparities’ in ‘wealth’ and ‘power’ distribution. Yet, the PHE definition does insinuate recognition of marginalisation. Marginalisation is here understood as entailing both issues of distributive justice and existence of cultural and institutional conditions that deprive people of ‘exercising capacities in a context of recognition and interaction’ (Young and Allen, 2011, p.55). This omission is perhaps reflective of the fact that the State is yet to accept charges of institutionalised racism within the healthcare context. Avoidance of this is aided by disputes within psychiatry, psychology and psychoanalysis regarding how to conceive of BAME mental health inequality and the circumstances giving rise to them. More recent definitions in State strategies addressing mental health inequalities do not make reference to the role of colonialism and racism, even when responding to BAME mental health inequality (Department of Health, 2011b).

Appendix 4: Socio-political circumstances that drove State intervention

This annex provides a very broad overview of what is a rich history of social change that encouraged State intervention in BAME mental health inequality in the late 1990's/early 2000's. In addition to growing concern with widening health inequalities despite the introduction of the National Health Service (NHS) and the welfare state in the 1940's, the 1960's through to the 90's saw significant social change. Commenting on challenges to the dominance of traditional forms of psychiatry in Britain from the 1960's onward, Crossley notes that '…social movements introduce plurality, dynamism and the potential for change' (Crossley, 1998, p.877). Identity politics and civil rights movements across minority groups were emerging more strongly than previously and society was in a state of radical change, overtly critiquing traditional authorities. Of central importance to BAME mental health inequalities are the anti-racism movement and the mental health service user's movement (MHUM).

First, from the 1960's through to the 80's, the British anti-racism movement continued to gain momentum, partly in response to growing neo-fascist movements in the 1970's (Gilroy, 2013; Virdee, 1997, p.259). It is in this period that the Race Relations Act (1976) was implemented. This Act prohibited both direct and indirect racism and placed a duty on local government to eliminate unlawful racism and promote equality of opportunities (*Race Relations Act*, 1976, p.71). Direct and indirect discrimination can be seen as aligning to the distinctions Gilroy makes when he speaks of racism and racial prejudice. Additionally, whilst the Act was welcomed in many spaces, some working within health services highlighted the difficulties this Act might cause in terms of addressing BAME health inequalities. However, racism continued to be a considerable issue, both in society at large and within the context of the State. Gilroy (1987) points to the racialisation of events such as the Brixton riot of 1981, reflecting that the State commissioned report investigating the causes of the riots did not help to calm racial tensions. He notes that 'Scarman's clumsy denial that 'institutional racism' exists in Britain[5], however plausible within his own definitions, fuelled the anti-racist fervour of his critics' (Gilroy, 2013, p.178). The term 'institutional racism' comes originally from the seminal text 'Black Power: The politics

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[5] The conclusion of the report stated: 'institutional racism does not exist in Britain: but racial disadvantage and its nasty associate racial discrimination have not yet been eliminated', (Scarman, 1981, p.135)

of liberation' (1967). In this text, Ture and Hamilton posit that institutional racism involves both overt and covert racist attitudes at both the individual and institutional levels (Ture and Hamilton, 1992, p.5). Thus, admission of interpersonal incidents and direct racism alone will not adequately address issues stemming from racism in societies where institutional racism is present.

Then, in the early to mid-1990's, a new neo-fascist nationalist party emerged in the form of the British National Party (BNP). The BNP won a number of seats on local councils and stirred racial hatred in their localities. BAME communities responded in several ways. First, community representatives put pressure on authorities such as government and the police to take action to prohibit and punish racially-motivated violence. Secondly, there was a growth in anti-racism groups seeking to support victims of racial hatred. Thirdly, was the emergence of 'self-defence groups for the first time since the 1970's' (Virdee, 1997, p.260). From a position of opposition in parliament, Labour-held councils in London who had significant anti-racist factions within them, mounted anti-racism campaigns which included the slogan 'Stamp out institutional racism now' (Gilroy, 2013, p.183).

Indeed, on coming into power once more in 1997, Labour made an amendment to the Race Relations Act in 2000 which extended the duties of local government to a greater number of 'specified public authorities to work towards the elimination of unlawful discrimination and promote equality of opportunity and good relations between persons of different racial groups;' (*Explanatory Notes to Race Relations (Amendment) Act*, 2000, para.8). Labour's arrival to power also saw the eventual opening of the Stephen Lawrence inquiry in 1997. This inquiry culminated in the MacPherson report which cited institutional racism in policing as a significant factor in Mr. Lawrence's death in 1993. Though there is controversy regarding the definition of 'institutional racism' provided in the Macpherson report[6], a watershed moment occurred when the State accepted this claim of institutional racism. Whilst racism and racial discrimination occurring at the personal level had previously been acknowledged in State commissioned reports (Scarman, 1981, p.135; Department

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[6] Significant space within the report is given to debating what is meant by the term 'institutional racism'. The definition provided in the MacPherson report has received criticism as it implies that racism at the individual level is 'unwitting' (MacPherson, 1999, para.6.34), thus denying overt racism at the individual level as being part of institutional racism in Britain.

of Health, 1992, p.26), this was the first time that government accepted the existence of racism at an institutional, and therefore structural and systemic, level.

A second area of social change relevant to this thesis was the increasing recognition of psychiatric patients' movements in Britain in the 1980's, which became known more generally as the MHUM[7] (Rogers and Pilgrim, 1991). This movement began to elevate the previously silenced voices and rights of people experiencing mental health issues/distress[8]. The MHUM comprised of numerous smaller organisations across Britain. Actions taken by the movement included:

- co-ordinated lobbying of MPs;
- actions to remove prominent posters depicting psychiatric patients as 'frenzied' and 'dangerous' (i.e. those published by the charity SANE) from public spaces[9]; and
- opposing the RCPs' actions to amend the Mental Health Act 1983 such that it included Community Treatment Orders (CTOs) (Rogers and Pilgrim, 1991, pp.13–132).

Catching up with mental health service user movements abroad, the MHUM continued to promote the importance and value of knowledge gained through lived experience to increasingly wider audiences. Though there have been many divisions in the movement (Crossley, 2004), action continues today. An example is through movements such as the UK's mental health service user/survivor movement

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[7] Though organisations aimed at elevating the voices and rights of people using mental health services existed in the early 1970's (Crossley, 2004, p.164), they struggled to receive recognition and to stay operational. However, some did re-emerge later to join the MHUM (Rogers and Pilgrim, 1991, p.131).

[8] Movements claiming to advocate for psychiatric patients prior to recent decades had tended to be led by people who lacked lived experience of either mental health issues/distress or mental health treatments. For example, key figures in Reform movement of the 1800's were primarily members of parliament, of aristocratic background and/or highly educated; thus, not representative of the majority of people incarcerated in asylums of the time who were predominantly 'pauper lunaticks'. Whilst reformist Lord Ashley and commissioners working with him 'broke with tradition in listening to the patients' grievances' (Jones, 1955, p.170) in the course of their work, it would not be until the MHUM that mental health service users themselves would take a prominent part in activist work regarding mental health.

[9] These posters were launched by the organisation 'Schizophrenia A National Emergency' (SANE). This organisation was concerned by the systematic closure of mental health hospitals from the mid 1950's onward. Their depictions of psychiatric patients as 'frenzied' and 'dangerous' maintained prejudicial attitudes and stereotypes. Efforts to challenge such stereotypes included filming a powerful documentary called 'We're not mad, we're angry', where people with lived experience of psychiatric treatment spoke of their experiences (MadFilmsByMadPeople, 2012b).

and the more global Mad Pride movement (Beresford, 2012; Menzies et al., 2013; Sweeney et al., 2009).

CTOs provide doctors with the legal powers to enforce compulsory treatment to people experiencing mental health issues/distress living in the community (*Mental Health Act*, 1983, sec.17). Activists such as those in the MHUM felt that CTOs fundamentally undermine efforts to emancipate people who had previously been psychiatric patients. From the State perspective, CTOs were seen as an alternative to inpatient psychiatric care in order to provide the least restrictive care possible, and as a means of balancing deinstitutionalisation agenda with the need to provide care. This view must be seen in the context of decades of inadequate community care provision following the rapid acceleration of mental health hospital closures in the 1970's/80's in the UK[10] (Scull, 1984, p.77; Goodwin, 1997; Rogers and Pilgrim, 2001, p.62).

At the time, promises for the delivery of community care did not materialise to any adequate degree (Davidson et al., 2015, p.42). Whilst a white paper (1975) on the subject stated that improvements to psychiatric care had been made and out-patient clinics expanded, it acknowledged that 'these improvements are not getting at the core of the problem. What we have to do is to get to grips with shifting the emphasis to community care.' (Department of Health, 1975, para.6). Lack of adequate funding, attributed by some to the UK's economic downturn in the 1970's, is often cited as the reason for the failure to implement provisions set out in the White paper. Instead, by the late 1980's, there was a relative crisis in the system whereby people did not seem to be receiving the support that they required (Glasby and Tew, 2015, p.35)[11].

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[10] Inpatient numbers in hospitals in the UK peaked in 1954, Mental health hospital closures were part of successive governments' plans to implement 'decarceration' or 'deinstitutionalisation' policies. Scull suggests that drivers for this include 'the advent of psychoactive drugs; and a realization, fuelled by a mass of modern social scientific research, that mental hospitals are fundamentally antitherapeutic institutions…' (Scull, 1984, p.77). Scull, together with several other leading scholars in this field, does not seem to believe the introduction of psychoactive drugs to have driven hospital closures so much as the growing evidence of hospitals not succeeding in providing appropriate therapeutic environments for mental health issues (Goodwin, 1997, pp.35–37; Rogers and Pilgrim, 2001, p.62). The last remaining 'asylum' in the UK was closed in the 1990's. Scull (1884) later also points to the rocketing costs of mental health hospitals pre-1960's. These closures, well intentioned or not, failed to be accompanied by the community care promised by government.

[11] Growing pressure to review community care provision across both physical and mental health led to an investigation which culminated in a report called 'Making a reality of community care' (Audit Commission, 1986). The report highlighted the need to reform community care as it stood due to 'a lack of joined-up working between health and social care', and 'growing concerns about the essentially unpaid and significant

By the late 1990's, reforms of the NHS contemplated by a new government would have to include reforms to the mental health system. CTOs were brought in to legislation through the 2007 amendments to the Mental Health Act (Lawton-Smith, 2008, pp.4–5).

Within the mental health space, the 1960's/70's also saw serious critique of traditional clinical and forensic psychiatry and psychiatric practices from within its own discipline. In my Introduction chapter I outlined the theory of 'wicked problems' and highlighted the emergence of the anti-psychiatry movement led by Laing in the UK in the mid 1960's. The arrival of the MHUM was likely aided not only by a general social context of increasing civil rights and psychiatric patient movements globally[12], but also by discourses from psychiatric dissenters - such as Laing and Cooper - who highlighted the 'violence' of traditional psychiatric practices[13]. Though some feel that the 1980's/90's saw a retrenchment of biomedical models of mental health (Menzies et al., 2013, p.6), there is also evidence of continued efforts from within psychiatry to push against its traditional practices and limited epistemological position.

In the UK, one movement of particular importance to this research was the work undertaken by affiliates of the Transcultural Psychiatry Society (TCPS). Although concerned with both issues of 'race' and cultural insensitivities within the mental health system, the mid 1980's saw a specific focus on tackling racism following research with BAME people with lived experience of services (Fernando, 2017, pp.114–115). Unfortunately, the transcultural psychiatry movement lost much of its ability to incite change by the early 1990's[14] due to a misappropriation of core ideas:

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contribution that informal, often family, carers were increasingly being expected to provide, harking back to the pre-Victorian, pre-asylum era of mental health care' (Glasby and Tew, 2015, p.35). As a result, an Independent review was commissioned by government. This reaffirmed the claim that insufficient resources and confusion around responsibility within governance structures meant that community care was failing, leaving people with inadequate support for both physical and mental health issues. This finally resulted in the instigation of the National Health Service and Community Care Act (*National Health Service and Community Care Act*, 1990).

[12] Rogers and Pilgrim note that the UK was somewhat late to have an active metal health service user movement in comparison to the US and the rest of Europe (Rogers and Pilgrim, 1991).

[13] Cooper writes that '…I have been concerned with the question of violence in psychiatry and have concluded that perhaps the most striking form of violence in psychiatry is nothing less than the violence of psychiatry in so far as this discipline chooses to refract and condense on to its identified patients the subtle violence of the society it only too often represents to and against these patients.', (Cooper, 1967, p.xii)

[14] Fernando writes 'Gradually many consultants and other senior staff in areas with relatively high number of ethnic minority people began to claim an interest in 'transcultural psychiatry', some of them claiming to actually practice 'transcultural psychiatry'… The notion was circulated in the NHS that all psychiatrists

> Gradually many consultants and other senior staff in areas with relatively high number of ethnic minority people began to claim an interest in 'transcultural psychiatry', some of them claiming to actually practice 'transcultural psychiatry'… The notion was circulated in the NHS that all psychiatrists should be 'transcultural' and some health authorities claimed that the psychiatrists in their region were… By the early 1990's, the term 'transcultural psychiatry' was demeaned in practice as merely meaning a voicing of sensitivity to 'culture', usually… by using interpreters when the clients concerned were not proficient in the English. (Fernando, 2017, p.116)

Arguably, however, such misappropriation of the term might indicate growing awareness of BAME mental health inequalities within public health services at the time, if not a genuine interest in addressing such issues. Determined to force genuine change, members of the TCPS continued to seek opportunities to highlight issues relating to institutional racism. This led to the building of a significant body of evidence in government commissioned independent reports and inquiries highlighting a range of inequalities experienced by BAME groups. Successive reports provided to Parliament by the Mental Health Act Commission (MHAC) from the late 1980s to the mid-1990s reported inequalities where racism and racial prejudice were evident.

With regards to inquiries, the 1990s saw the emergence of several shocking incidents involving black psychiatric patients. The Blackwood inquiry investigated the deaths of three black men in the Broadmoor mental health hospital (Prins, 1993); and the Clunis inquiry followed a murder committed by a black former-psychiatric patient (Ritchie et al., 1994). The Blackwood report's title, 'Big, Black and Dangerous' acknowledged the racialised stereotyping prevalent in public discourse at that time; stereotypes not helped by sanist propaganda such as that mentioned earlier promoted by SANE. Despite the wider context of multiple MHAC reports highlighting racism within the mental health system, the government of the time

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should be 'transcultural' and some health authorities claimed that the psychiatrists in their region were… By the early 1990's, the term 'transcultural psychiatry' was demeaned in practice as merely meaning a voicing of sensitivity to 'culture', usually… by using interpreters when the clients concerned were not proficient in the English.' (Fernando, 2017, p.116) refused to accept the Blackwood inquiry's finding of racism as a significant factor in the three deaths. The report's summary anticipates this denial, stating:

> Because of the deep-seated defensive (but to a degree understandable) reactions that arise in response to the type of criticisms we are making, we're concerned that our recommendations may not be implemented… (Prins, 1993, p.77)

As with the Black report in 1980, government was not yet prepared to act on evidence of structural and systemic inequalities impacting on minority or marginalised groups[15].

It is interesting, perhaps then, that the Clunis report one year later did not report findings of institutional racism. Investigating the circumstances that led long-term psychiatric patient Christopher Clunis to murder a man he did not know, the only mention of racism (despite claims to 'keep a close eye' on 'suggestion of racial prejudice') are statements to the effect of:

> we have not come across any prejudice or discrimination in relation to Christopher Clunis, save a willingness to accept too readily that he had abused drugs. (Ritchie et al., 1994, p.129).

Investigating the issue of substance misuse, the inquiry found no evidence of sustained misuse beyond Clunis' own accounts while in states of distress (Ritchie et al., 1994, p.7). Acknowledging reports of the over-representation of black people in detention and elevated rates of Schizophrenia diagnosis, the report cautions that staff be less willing to accept such claims unquestioningly from patients, including black people, without supporting evidence (Ritchie et al., 1994, p.129). Instead of issues of 'race', the report focused on the lack of adequate community care available. Interestingly, the wife of the man murdered, a manger within mental health services herself, states her concern for Clunis given the 'apparent lack of care that he received'. She continued that:

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[15] Fernando reports that 'The Chairman of the inquiry team, Professor Herschel Prins, told me that he was told informally that once he left the MHUM, he would be barred from visiting Broadmoor hospital.' (Fernando, 2017, p.122). Such was the denial of institutional racism and racial prejudice at the time.

> her aim is not to ensure that dangerous or potentially dangerous mentally ill people are locked up.', but that 'her husband will not have died in vain if mentally ill patients proper care… (Ritchie et al., 1994, pp.5–6).

Through her grief, she acknowledged that the serious system-wide lack of mental health care provision - not Clunis' 'race' or individual presentation of mental health issues/distress – was a key factor in her husband's murder.

Though pressure was mounting to address this area, commentators noted that a change of government was likely necessary for action to take place. Gilroy commented in 1987 that, due to the Conservative administration having 'played the race card as part of its own populist electoral strategy', anti-racism 'acquired a party political connotation' (Gilroy, 2013, p.177). Whilst it is true that the previous government had shown some interest in addressing issues of such inequalities[16], this was very limited, sporadic and piecemeal. Change of political party was crucial to the inception of State interest in BAME mental health inequalities at a national and strategic level. The new government quickly commissioned and accepted the findings of both the Acheson report on health inequalities, and the MacPherson report which highlighted institutional racism in Britain.

There was now also scope – politically - for action to be taken on the sorts of BAME mental health inequalities that had previously been established in the MHAC papers and the inquiries previously mentioned. And action was indeed emerging from a number of areas. As is evident from Appendix 17, the late 1990s/early 2000s saw a significant increase in research in this subject. Two national-level research project exploring disparities in diagnosis rates emerged (the AESOP and EMPIRIC projects). Also from this period was the ground breaking report 'Breaking the circles of fear' (SCMH, 2002) report cited in my literature review; this is just one example

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[16] At the national level, the NHS mental health task force published the results of a consultation – also referred to as the 'regional race programme' - regarding the experiences of BAME groups in mental health services, seeking out 'what works well for them [BAME mental health service users] and what does not.' (Mental Health Taskforce, 1994, p.1). Earlier, the Home Office had undertaken a review of the support provided for offenders with mental health issues/distress. Volume 6 of the report considered issues of 'race' and gender, and examined support provided in both the criminal justice system and psychiatric services (Department of Health, 1992). With regards to addressing racism specifically, Fernando states that the MHAC reports leading the then Conservative government providing funding for the Ipamo project; a project to provide mental health services to black people in South London, including Brixton (Fernando, 2017, pp.119 and 126-127.). This was not, however, expanded beyond London to my knowledge.

of research emerging from the voluntary field at this time. Sashidharan – a senior RCP member of BAME background - noted that:

> There is now a sense of urgency in tackling racism within public bodies such as the NHS, if the pronouncement from the government and many public bodies following the MacPherson report are anything to go by. For the first time in many years it would appear that there exists a political climate that allows us to acknowledge the existence of racism not just at the personal level but also as an institutional problem. (Sashidharan, 2001, p.244)

However, despite opening his article with the above sense of opportunity, the remaining passages highlight serious concerns that no real change would in fact take place. Writing two years after the MacPherson publication, he noted that ‘perhaps predictably, the College and other professional bodies in mental health have so far avoided any serious discussion’ on racism in British psychiatry’ (Sashidharan, 2001, p.244). Shortly after this article, the president of the RCP acknowledged Sashidharan’s comments and put forward the RCP’s strategy to address racism. An Ethnic Issue Committee was set up to implement a series of recommendations, including commissioning an independent review of racism in British psychiatry; providing training in cultural sensitivity and competency; increasing awareness of possible discrimination and abuse in the application of metal health legislation; ensuring equal access to services; and ‘continuing dialogue with all relevant user groups, including Black and other ethnic minority user groups’ (Cox, 2001, p.249).

Appendix 5: Delivering Race Equality

The following consists of two sections. First, I provide an overview of work undertaken to underpin the Delivering Race Equality (DRE) strategy/programme, and the controversies that surrounded the State's actions in regards to this. I then outline the content of the strategy and issues encountered in its delivery. I include information taken from the State's own evaluation of the programme upon its closing in 2009/10.

1 Setting out to address BAME mental health issues at the national level

Annex 3 sets out a very brief and broad overview of the social, political and economic context from which the UK's first and only nationwide strategy focused specifically on addressing BAME inequalities in mental health to emerge; Delivering Race Equality (DRE) (2005). The State demonstrated considerable interest in this area of inequality between 1999-2001. First, setting the scene for this work was the National Service Framework for Mental Health, a national strategy to address the crisis in mental health care. It went beyond just acknowledging the existence of disparities for BAME groupings, such as diagnosis rates and pathways to care, by setting out changes to service provision to address such inequalities. These included ensuring greater input from people with lived experience in the design and implementation of services, addressing racial discrimination, the need to recruit more BAME staff and the inclusion of the experiences of 'service users and carers, including those from black and minority ethnic communities' in performance assessments (Department of Health, 1999, p.74). However, it was felt by some that the actions articulated regarding BAME mental health inequalities were vague (Fitzpatrick et al., 2014, p.10), and that further work was required.

In 2001, the State commissioned a new report to inform strategy specifically addressing BAME mental health inequalities. Sashidharan was appointed to lead the research; the appointment of BAME psychiatrist to lead this work was very welcomed by many activists in this field. The Inside Outside report (2003) highlighted a series of structural and systemic changes required within statutory services. Additionally, it emphasised the need to empower BAME communities and their voluntary sector to ensure their involvement in changes to statutory services. The report was also explicit about the existence of institutional racism within mental health services, adopting MacPherson’s definition. The report highlighted the possible role that the new Race Relations Act (2000) could play in addressing this:

> If all mental health organisations meet their statutory obligations as set out in the Race Relations (Amendment) Act (2000), and are consistent with the guidelines provided by the Commission for Racial Equality, this will go a long way towards creating the culture and circumstances that will allow significant progress in dealing with institutional racism within mental health services. (NIMHE, 2003, p.18)

Controversially, instead of acting upon the recommendations of the Inside Outside report to develop this, the State commissioned a different academic to devise a consultation document to inform the Delivering Race Equality (DRE) strategy whilst the Inside Outside report was still being finalised. Also published in 2003, the consultation document was seriously critiqued for inadequate input of BAME service users and lack of consultation with expert practitioners in this specialism (Fernando, 2017, p.122). The not only reinforced the disempowerment of BAME people in mental health contexts, (an issue that this strategy was purportedly intended to address), but also constituted an evasion of what many BAME experts in the field felt were the real issues requiring attention. Fernando explains that though ‘couched in similar terminology to that used in *Inside Outside*’, different conclusions and recommendations were proposed:

> The emphasis on changing statutory services so that they would be in line with what BME communities wanted (and empower them to voice their views) was shifted into an emphasis on collecting information.’ (Fernando, 2017, p.123).

Important details were also altered. For example, the need for ‘community development’ articulated in Inside Outside (2003) became ‘community engagement’; one being far less resource intensive and easier to implement than the other. Most importantly, however, was the total omission of institutional racism. In fact, racism itself was only mentioned twice, both instances occurring within the same sentence. Given the prominence of allegations of racism (if not institutional racism) in research and previous reports/inquiries, I find it hard to believe this omission to be unintentional. The proposed strategy simply did not address the issues resulting in inequalities in any meaningful way. Needless to say, the consultation did not meet with the warmest reception[17] (Fernando et al., 2008, p.54).

Compounding this was the publication in 2003 of an inquiry into the death of David 'Rocky' Bennett – a young black man - whilst detained in a psychiatric ward in 1998. Amongst the areas investigated were practices such as diagnostic processes, the use of secure wards, medication and restraint. Its findings supported those in previous reports and inquiries (Blofeld et al., 2003, pt.2). Also adopting MacPherson's definition, it – like the Inside Outside report - unequivocally highlighted the existence of institutional racism in Britain's mental health system[18], citing this as a significant factor in the death of Mr. Bennett (Blofeld et al., 2003, p.25). As such, recommendations included mandatory training for staff in cultural awareness and sensitivity, and on multiple forms of racism; and acknowledgement of institutional racism in mental health services at the Ministerial level (Blofeld et al., 2003, pp.67–68). The State's response to the three documents mentioned above was published together in one report in 2005. This report also included the finalised DRE action plan (or strategy).

2 The final DRE programme and its content

In 2005, the State finally published its 5-year national strategy for addressing BAME mental health inequalities. This publication incorporated the government response to the Bennett inquiry and cited both the Inside Outside report and DRE (2003) as key resource in its development. Despite its problematic start, publication of DRE (2005) did, as Lord Adebowale notes, mark 'a sea change' in State approaches to this topic, 'in that it served notice that maintaining the status quo was no longer a viable option.' (Department of Health, 2009, p.3). The aim of DRE was summarised by the then Secretary of State for Health as 'equality of access, equality of

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[17] A list of 'critical responses' to DRE (2003) was published as an Annex in the DRE (2005) document. For an account of how it was received by leading professionals in the field, see Fernando (2017), p122-124.

[18] The report states that '…we concluded that there was evidence of incidents of institutional racism from time to time in the lengthy period that David Bennett was suffering from mental health problems. …They indicate that institutional racism has been present in the mental health services, both NHS and private, for many years.' (Blofeld et al., 2003, p.25)

experience and equality of outcome' (Department of Health, 2005, p.7), believed achievable by focus on three core 'building blocks':

1. developing mental health services that were more appropriate and responsive to the needs of specific minority or marginalised groups;
2. greater community engagement in planning processes, supported by newly recruited Community Development Workers (CDW); and
3. improvements to information collection and dissemination, including enhancing the systematic collection of data disaggregated by ethnicity and of good practice[19].

In addition to these 'building blocks', 12 specific areas requiring change were identified and held as the 'characteristics' of success, (see Box 4). These sought to integrate the NHS Chief Executive's, (Sir Crisp), newly launched 10-point race equality action plan (2004) with plans to address issues highlighted in the reports mentioned before.

Whilst the characteristics in Box 4 demonstrate attention to some of the issues long highlighted by research and reports regarding inequalities, it is notable that the language used is relatively neutral, referring to 'disproportionate' rather than inequal. This signals a desire to remain impartial regarding the nature of the causes of specific issues, even where there was a will to refer to the totality of the issues as one of inequality. Having worked as a policy maker in central government, it seems probable to me that this be a means of balancing the concerns of multiple key stakeholders in an attempt to keep them all engaged in the agenda. Though I disagree with the approach taken, this same thinking may also explain the State's response to the Bennett inquiry recommendation for ministerial acknowledgement of institutional racism in the mental health system:

> It is possible to hide behind the label of institutional racism – to confuse the act of recognising it with real action to reform services. If services are discriminatory, then ultimately the responsibility for solving the problem lies with everyone involved in planning,

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[19] For a comprehensive summary of all action points, see pages 54-58, 63-64 and 70-71 of the report.

> managing and providing the services. (Department of Health, 2005, p.22)

It ends its response:

> What matters most is implementing DRE and delivering its goals of equal access, equal experience and equal outcomes for BME patients. That is what the Government is committed to and what it, and the NHS, should be judged on. (Department of Health, 2005, p.23)

This, for all intents and purposes, amounts to a refusal to acknowledge institutional racism within the mental health system. Such a refusal seems somewhat out of kilter given that this comes from the same government that accepted charges of institutional racism in the MacPherson report and undertook work to generate the UK's first focused strategy in this area; the State's knowledge of the extensive research and inquiries cataloguing issues resulting from a range of forms of racism; and the social and political context provided in above sections.

However, Fernando (2017) points to a shift in public discourses regarding racism in the lead up and aftermath of the 9/11 incident in 2001 that seriously impacted government's willingness to address issues of racism and racial inequalities[20]. Prior to 9/11 in 2001, a series of riots, dubbed 'race riots' broke out in the north of England. Fernando posits that though tensions were clearly already present, 9/11 acted as a watershed moment that provided far-right groups a platform on which to regain a foothold on the public stage. The 7/7 London bombings of 2005 further inflamed rising xenophobia, racism, and what is now recognised as Islamophobic rhetoric in public discourses. Given that 7/7 took place only months prior to the publication of DRE (2005), it is perhaps less surprising that the document falls short of laying charges of institutional racism at the door of the NHS, despite the mass of evidence. Instead, the Ministerial address states that 'Racism or discrimination in any form have no place in modern society, and they certainly have no place in modern health

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[20] Fernando supports this view by providing an account of a meeting he had with the then Director of Social Services in 2001, following 9/11. Introducing himself as a psychiatrist, he spoke of the difficulties that NGO's providing mental health support for black people were having receiving funding. The 'spontaneous response was that it was 'very difficult' in light of 9/11 to provide funds for such projects.' (Fernando, 2017, p.162)

or social care' (Department of Health, 2005, p.7). This omission and a lack of focus on racism itself was disappointing to many service users, practitioners, carers and campaigners (Sewell, 2018, p.207).

Box 4: DRE action plan

The 12 'Characteristics' of the DRE action plan:

1. less fear of mental health care and services among BAME communities and BAME service users;
2. increased satisfaction with services;
3. a reduction in the disproportionate rate of admission of people from BAME communities to psychiatric inpatient units;
4. a reduction in the disproportionate rates of compulsory detention of BAME users in inpatient units;
5. fewer violent incidents that are secondary to inadequate treatment of mental illness;
6. a reduction in the use of seclusion in BAME groups;
7. preventing deaths in services following physical intervention;
8. an increase in the proportion of BAME service users who feel they have recovered from their illness;
9. a reduction in the proportion of prisoners from BAME communities;
10. a more balanced range of effective therapies such as peer support services, psychotherapeutic and counselling treatments, and culturally appropriate pharmacological interventions that are and effective;
11. a more active role for BAME communities and BAME service users in the training of professionals, in the development of mental health policy, and in the planning and provision of services; and
12. a workforce and organisation capable of delivering appropriate and responsive mental health services to BAME communities.

(Department of Health 2005, p19)

The DRE strategy, however, still included a number of actions that held the promise of some improvements at the systemic level. Unfortunately, the DRE programme implementing the strategy failed to deliver a system characterised by the 12 points in Box 4 within the 5-year target; or in fact signs of any significant progress at the national systemic level, (see Box 5). The State's evaluation documents cited overly ambitious aims and the wrong 'starting point' as significant factors in this outcome. A number of assumptions were highlighted as contributing to this:

- the complexity and heterogeneity of BAME groupings had been misunderstood;

- inappropriate data collected for monitoring processes;
- the intractability of problematic attitudes both within and external to the mental health system underestimated; and
- the importance of addressing discrimination and marginalisation experienced across the life-course and in all aspects of life misjudged (Department of Health, 2009, p.7; Department of Health, 2010, p.46).

This last point was also made by the founder of the DRE ambassador project, Julie J Charles, quoted in the interim review as stating:

> It's not just about the interface of mental health services and supporting people to access those services. People don't have mental health problems in isolation, we need to look at factors like housing, employment and education. (Department of Health, 2009, pp.17–18)

Julie is also the founder of one of the gateway organisations involved in this research. Whilst she had no involvement in the interviews I undertook with participants or the subsequent analysis[21], her view is supported not only by the author of this report but by my own findings discussed in later chapters. Critics and supporters of the programme alike also cited under-resourcing as a significant challenge of implementation.

Despite the failure to instigate any significant systemic improvements for BAME mental health service users, the evaluation reports highlight useful learning achieved through the programme. Considering the DRE programme to have taken a 'formative approach' in delivery (Clark, 2009, p.482), the review articulated 4 key lessons for future action. These would provide the different 'starting point' alluded to in the 2010 evaluation report. The first was to utilise the learning from the DRE programme in future initiatives; one key area being the development of appropriate data gathering for monitoring and improvement purposes. Though there was widespread recognition of significant methodological issues with many of the data points identified for collection to monitor progress (Aspinall, 2006), many of which

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[21] Though Julie did comment on my findings, this took place post my own analysis and served simply to confirm or challenge my conclusions. In this instance she commented that my findings aligned with her own observations and experiences. For more information regarding ways of working with gateway organisations, see Chapter 2.

had been known for decades (see Appendix 18) policy-makers proceeded with incorrect assumptions. The result being that the Count me in Census was generally regarded as inadequate and data collection for monitoring remained an area for significant improvement. Another learning point was to build on the work of the DRE programme with the voluntary sector, service users and carers to have meaningful involvement in the development of services, policies and strategies. In so doing, the hope was to encourage a 'more equitable relationship (in systemic terms) with users, carers, communities.' (Department of Health, 2010, p.47).

A third lesson was to re-think the scope of staff training required to instigate cultural change at the organisational level. Whilst race equality training was still considered important, the report found that more was required to build a workforce that actively embraced diversity and was open to new and/or different approaches. One suggested means of doing this was to encourage an ‘explanatory model’ in the delivery of mental health services. This, it was hoped, would address power imbalances between the BAME service users and carers and the medical and support staff, enabling better interpersonal interaction and thus outcomes. Whilst this suggestion was no doubt welcome, it fails to convey some of the barriers experienced by those delivering race equality training in their roles as DRE community development workers (CDW). Primarily, the difficulty of delivering race equality training in a context where institutional or systemic racism was effectively denied. Sewell, writing from his experience working within the programme, reflects that:

> This meant that implementation focused largely on what could be done to help racialised communities, with little emphasis on what the system had to do to change itself (apart from the nationally endorsed training module, which was targeted at frontline staff). (Sewell, 2018, p.207)

This is arguably reflective of a State that is unwilling to recognise the presence of institutional racism, focusing instead on interpersonal racism.

Box 5: Performance of DRE programme

Performance against the 12 Characteristics:

1. *Reduction of fear of mental health services* – A survey into levels of satisfaction with services showed results equal to those of the white British population. However, evidence from community groups indicates fear is still present in some BAME groupings.
2. *Increased satisfaction with services* - see above.
3. *Reduction in disproportionate admission rates* - Little to no change observed.
4. *Reduction in compulsory detention rates* - No change observed. However, the caveat is given that 'higher rates of mental illness in some BAME groups means that compulsory detention rates alone are not a good indicator of quality in mental health services'.
5. *Reduction in violent incidents* – No evidence found of a disparity between BAME and white British inpatients regarding incidents of physical assault, accidents and self-harm, or of a link between ethnicity and the use of coercion reported by inpatients.
6. *Reduction in use of seclusion* - No consistent trend of disparities between in the use of seclusion between BAME and white British inpatients, except for the 'other black' grouping.
7. *Prevention of deaths in mental health services* – Numbers of deaths per year were too small to demonstrate trends over a 5-year period.
8. *Increased self-reported recovery rates* - Research demonstrates no disparity between BAME and white British patients.
9. *Reduction of BAME prisoners* - The proportion of the BAME population increased.
10. *Greater range of therapies and medication made available* - BAME people were still less likely to gain access to therapies, even among those requesting them. Barriers to access cited are: mistrust of services; worries about confidentiality; poor information; and language barriers.
11. *A more active role for BAME communities in training, policy development, service planning and delivery* - No comment on the success of initiatives overall, but examples provided.
12. *Improving workforce capability* – Evaluation demonstrated variable impact of initiatives.

(Summary of findings, Department of Health, 2009 and 2010)

Lastly, and of particular relevance to this thesis, was the recommendation that a ‘single equalities’ approach be taken. By this was meant that future strategies should not focus solely on issues arising from ‘race’ or minority ethnicity alone, as this is not reflective of many people’s lived experiences. Whilst it doesn’t use the language of intersectionality, the report alludes to the importance of addressing issues arising from being intersectionally located, stating that ‘a single equalities approach promotes… a socially inclusive and human rights approach to mental health.’ (Department of Health, 2010, p.47). The link between a ‘single equalities’ approach and intersectionality was also noted by Sewell, when he cautions against ‘racism’ being forgotten as a result of this combined approach (Sewell, 2018, p.207).

The evaluation report signalled the ending of the DRE programme. Instead, the lessons learnt would be incorporated into the new general strategy for mental health: New Horizons. As a strategy intended to mainstream mental health delivery, it also claimed to adopt the ‘single equalities’ approach by mainstreaming discrimination issues. Though the strategy was never implemented due to a change in government, it had intended to implement the ‘single equalities’ approach in line with the new Equality Act (2010). Further, it sought – at least in rhetoric – to integrate a more social model approach into mental health strategy (Tew, 2011, p.1)

The Equality Act was enacted, replacing legislation such as the Race Relations Act (2000) and the Disability Discrimination Act (1995). This Act brought multiple pieces of legislation relating to discrimination together into a ‘single equality’ approach[22]. It also includes the Public Sector Equality Duty (PSED), which places a legal duty on the public sector to assure against direct and indirect discrimination as a result of their policies and practices. A further duty placed on the State and public services is to conduct an Equality Impact Assessment (EIA) at the point of policy development to evaluate the impact that policy might have on people with ‘protected characteristics’ such as race and disability. However, intersectionality was not in fact legislated for in the introduction of the Equality Act (2010). Whilst the Act includes provisions for dual discrimination of the additive sort[23], it does not provide for

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[22] Though here I highlight that in all but name, this report highlights the importance of considering people’s intersectional locations, intersectionality is not something that government at the time was willing to legislate for. Whilst the Equality Act includes provisions for multiple discrimination of the additive sort, it does not provide for intersectional experiences of discrimination.

[23] The legislation states that ‘…B cannot establish a contravention of this Act… [if] A shows that A's treatment of B is not direct discrimination because of either or both of the characteristics in the combination.’ Essentially, ‘B’ must demonstrate direct discrimination specific to at least one of the protected characteristics in their intersectional experience. If this can not be done, as in the case highlighted by Crenshaw of the black American women seeking employment (Crenshaw, 1989), then the court can legally dismiss the case. Interestingly, in practice different courts take different views on this in the UK.

intersectional experiences (*Equality Act*, 2010, sec.14). Given that it is also in the Equality Act (2010) that the Public Sector Equality Duty (PSED) and the duty to conduct equality impact assessments (EIAs) is found, this omission arguably undermines future undertakings in policy making to take ‘single equalities’ approaches that ‘address all aspects of people’s lived lives’ (Department of Health, 2010, p.47).

Appendix 6: No Health without Mental Health (2011)

The No Health without Mental Health is the last strategy in the UK which includes a strategy to address mental health inequalities, including those experienced by people of BAME backgrounds. Here I examine how the issue of BAME mental health inequality is defined in the NHMH, some of the assumptions made and approaches taken to the issue, and finally provide a brief overview of the actions listed for implementation. The NHMH strategy set out primarily to engender '*parity of esteem between mental and physical health services*' (Department of Health, 2011b, p.2). It does, however, include a chapter specifically devoted to inequalities found in mental health as they pertain to people protected by the Equality Act 2010 (EA10). Here the strategy sets out the three ways in which mental health inequality is conceptualised within a policy context (Department of Health, 2011b, p.57): inequalities that lead to mental health issues/distress; inequalities that result from experiencing mental health issues/distress; and inequalities experienced in service provision. Highlighting how inequalities can lead to mental health issues/distress, the strategy draws on the experiences of many BAME groupings:

> Aspects of people's identity and experiences of inequality interact with each other. For example, people from black and minority ethnic (BME) groups are more likely to live in deprived areas and have negative experiences, both as a result of their ethnic identity and because of their socio-economic status and living environment. (Department of Health, 2011b, p.56)

The strategy takes a multi-stranded equalities approach that mirrors the EA10, meaning that there is a section within the chapter for issues pertaining specifically to each of the EA10 protected characteristics, including 'race' and religion. Indicators of BAME mental health inequality cited to delineate the scope of the issue as it pertains to 'race' are:

- 3x admission rates to psychiatric wards among some black groups;
- increased rate of mental health issues/distress among some migrant groups, including the children of migrants, asylum seekers and refugees;
- over-representation of African-Caribbean people subject to compulsory treatment under the Mental Health Act (MHA); and

- the receipt of poor and untimely support by South East Asian women.

In relation to religion, there is recognition that there is a need for mental health services to better address needs arising from being religious; this is recognised as disproportionately impacting BAME groupings, as they are more likely to consider themselves religious.

These indicators provide a sample of inequalities faced by people of BAME backgrounds within the context of mental health, and demonstrate consideration of both incidence and service outcomes. The NHMH concedes that evidence indicating increased incidence of mental health issues/distress is extremely complex, highlighting the range of mental health issues/distress experienced among BAME groupings and the various ways in which they can present. It also alludes to debates regarding data on mental health incidence and prevalence, such as those I outline in Chapter 3, though it later brushes such issues aside. For example, stating that higher levels of admissions to psychiatric wards among some BAME groupings is supported by ‘some research indicating that this is an illustration of need.’ (Department of Health, 2011b, p.59) Thus, evidence such as that indicating increased risk of severe mental health issues among certain BAME groupings is taken ‘as is’, forming the basis for policy decisions to be made.

The strategy further recognises complexities arising from the diversity of ‘cultural backgrounds, socio-economic status and experiences in wider society’ (Department of Health, 2011b, p.59) that comprise BAME groupings. Following from the recommendations of the DRE programme that any further work to address this area of inequality must make provisions for such complexity, the strategy states on multiple occasions the importance of taking a multi-stranded approach and recognising that people can experience numerous forms of inequality that impact on their mental health. Despite this – and despite highlighting the plight of multiply disadvantaged (or intersectionally located) South Asian women - none of the proposed actions actually address issues of multiple disadvantage. Instead the strategy deals with each protected characteristic in turn without really addressing issues as they manifest for people who are multiply disadvantaged or intersectionally located. Indeed, there is no mention of intersectionality anywhere in the document or its accompanying Equality Impact assessment (EIA). As with the

EA10, this term is auspiciously absent, reflecting debates in identity politics about whether intersectional theory is a helpful tool in promoting equality for BAME and racialised peoples or not. As I examine further in my discussion chapter, this is deeply problematic and enables significant gaps in policy responses to remain.

With regards to the actions set out in the strategy, very few relate specifically to addressing BAME mental health inequality. Those that were specified in the NHMH and its accompanying EIA focused primarily on better collection of data on service outcomes, disaggregated by ethnicity, for monitoring purposes; the reinforcement of new statutory requirements for public services to comply with the Public Sector Equality Duty (PSED); and to establish mechanisms by which to engage with local service user groups (Department of Health, 2011b, pp.59–60; Department of Health, 2011a) (see Table 5). Responsibility for these falls primarily to NHS and local commissioning boards, GP consortia and service providers. One further specific action was to ensure that all NHS Trusts offered a chaplaincy service. The only policy targeted at central government specifically in relation to BAME inequality was the commitment for the then Department of Health to ‘make best use of research in developing effective approaches for reducing race equality in mental health’ (Department of Health, 2011b, p.60).

It is notable that all issues not directly pertaining to mental health service delivery is simply not addressed in the context of BAME inequality. Whilst there are actions across government to address issues in the welfare system, housing etc – demonstrating a recognition of these wider determinants in mental health, there is nothing addressing these issues as they impact on BAME groupings. Thus the role of racism, intergenerational impacts of colonialism, cultural and linguistic barriers, xenophobia etc, in generating and exacerbating wider social inequalities that negatively impact on people’s mental health remain acknowledged, but unchecked in this strategy.

Table 5 – Policies and actions to address BAME mental health inequality

Document	Action for whom?	Proposed action
NHMH, Ch6, p60.	Local commissioners and services providers.	Increase/improve local collection and monitoring of data on ethnicity and culture, and use to inform commissioning and provision of health and social care.
		Focus on outcomes that work for both individuals and communities.
		Improve monitoring and evaluate the effectiveness of service delivery around equality needs.
		Establish mechanisms enabling and empowering local user groups to engage with providers and commissioners effectively.
	NHS commissioning board and GP consortia	New statutory responsibilities for: NHS commissioning Board and GP consortia
	Department for Health	Use research to develop effective approaches for reducing 'race inequality' in mental health
NHMH EIA, p36.	NHS commissioning board	Monitor use of MHA and CTOs across ethnic groupings
	Local commissioners and services providers.	Monitor the impact of 'cultural competency' initiatives in services, and in work with community and voluntary organisations
	Care Quality Commission, HealthWatch England and local branches	Monitor numbers of people accessing independent mental health advocacy services and seeking support from 'second opinion appointed doctors'.
	IAPT programme	Increase the data collected in relation to BAME communities.
	Local HealthWatch NHS information centre	Ensure that all mental health trusts have a Chaplaincy service and a Spirituality Strategy.

Appendix 7: Correspondence from Department of Health and Social Care

Department of Health and Social Care [redacted]
To: "Harvey, Stephanie" [redacted]

11 August 2020
at 09:46

Our ref: [redacted]

Dear Miss Harvey,

Thank you for your correspondence of 3 June about the Independent Review of the Mental Health Act. I have been asked to reply and I apologise for the delayed response.

The Government is committed to treating mental health with the same urgency as physical health. The Government also recognises the need to modernise the Mental Health Act 1983 to ensure it is used in a fair and just way and that patients are not detained any more than is absolutely necessary.

That is why the Department asked Sir Simon Wessely to carry out his Independent Review of the Mental Health Act. The Department has welcomed his report and has already accepted a number of its recommendations.

The Government plans for reform will make sure that people subject to the Act receive better care, that they have a much greater say in that care, and that they are treated with the dignity and respect they deserve.

The Government also wants to make it easier for people with learning disabilities and autism to be discharged from hospital, and to improve how they are treated in law.

The Government committed to publishing a White Paper which will set out the Government's response to Sir Simon's Review and pave the way for reform of the Mental Health Act 1983.

The Government will publish its White Paper as soon as it is possible to do so. The Government will consult publicly on its proposals and will bring forward a Bill to amend the Act when parliamentary time allows.

These reforms will be supported by improvements to crisis and community mental health services through the NHS Long Term Plan and its increased investment of at least a further £2.3billion a year by 2023/24.

I hope this reply is helpful.

Yours sincerely,

[redacted]
Ministerial Correspondence and Public Enquiries
Department of Health and Social Care

Appendix 8: The concept of the ‘wicked problem’

A recent paper of the Synergi project[24] suggests that policymakers conceptualise BAME mental health inequality as a ‘wicked’ problem (Bhui et al., 2018, p.10). Though not developed further in the paper, I too feel that the concept of ‘wicked’ problems might aid policymakers to enrich future policy responses at the national level. Used as a heuristic, this concept might enable a means of defining the issue that better fits the diversity of perspectives and lived experiences of the population group being considered, aligning not only with the needs of the State’s stakeholders but also with a critical realist perspective. Stemming from a place that recognises the interconnectedness, interdependence and multiplicity of realities in the social world, ‘wickedness’ promotes an acceptance of complexity and epistemological diversity. In this way it can be viewed as a tool with which to counter more reductionist approaches, such as might be found in strict bio-genetic medical perspectives; perspectives that several participants in this research might argue produce the ‘*cheapest kind of understanding’*.

Developed in the 1970’s to address non-linear, complex social issues in public policymaking, ‘wicked problems’ enabled a clear distinction to be made between policy issues arising from the natural sciences and those of a more social nature. Issues of the natural sciences were labelled ‘tame’ problems. Tame problems operate in ‘closed’ systems (systems without interdependencies), are easily defined and have solutions that are easily verifiable as correct or incorrect. In contrast, wicked problems operate in ‘large and interconnected networks of systems’, whereby ‘outputs from one become inputs to others’ (Rittel and Webber, 1973, p.159): open systems. As a result, wicked problems are difficult to define, have multiple ways of being conceptualised, are subject to changes in its manifestation, and lack a ‘correct’ solution (see Box 2). Indeed, they are almost always unresolvable issues. Policymakers dealing with wicked problems must know that:

- residing in networks of open systems means that ‘solutions’ will have unintended consequences and impacts beyond the issue itself; and

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[24] Synergi is an interdisciplinary research project seeking to influence policy and practice regarding BAME inequality relating to SMI lead by Professors Nazroo and Bhui.

- multiple differently situated interested parties will have their own legitimate conceptualisations of the issue, and accompanying ‘solutions’ (Roberts, 2000, pp.1–2).

The un-resolvability of such issues lead Rittel and Webber (1973) to speak of ‘(re)solutions’, reflecting the iterative process of solution making in this context and the constant evolution of wicked problems. The original conceptualisation of wicked problems has been - correctly, in my view - critiqued for its over-simplification of issues in the natural sciences, creating a false dichotomy between these and those in the social sphere (Turnbull and Hoppe, 2019, p.318). However, I feel that the concept remains useful when applied as a heuristic that advocates a particular ontological position rather than as a means to distinguish between domains of ‘realities’. A position that drives collaborative approaches to policy-making (Innes and Booher, 2018, c.1), that honours and values different perspectives.

Box 6: Characteristics of wicked problems and seeking their (re)solution

1. No single definition of the problem exists, due to a lack of consensus regarding what ‘the problem’ actually is; *interested parties compete to frame the issue in ways that align best with their views and preferred solution.*
2. The problem operates in and is shaped by networks of open systems; thus every wicked problem can be conceived of as a symptom of another similarly wicked problem.

As a result:

3. Problem solving is non-linear, with solutions being open ended, with ‘*better/worse’* options (as opposed to ‘correct/incorrect’).
4. There being no point at which the policymaker can be sure they have resolved the problem*; otherwise known as the ‘no stopping rule’.*
5. Solutions implemented will have impacts beyond the problem, due to operating in networks of open systems; this may lead to the nature of the problem itself altering.

Additionally:

6. The process of finding solutions is further complicated by constraints in the policymaking world; *i.e. limited resources, political will and ramifications.*
7. The context within which policymakers and the problem operate continually changes, altering the nature of the problem and rendering solutions impossible; *instead (re)solutions must be sought.*

(List uses: Rittel and Webber, 1973, pp.161–166; Roberts, 2000, p.1)

Appendix 9: Social models of mental health

Social models in mental health generally refer to the various ways in which social processes are explored within the context of mental health. Often this involves applying sociological approaches, usually with the aim of challenging assumptions made in the traditional ‘psy’ disciplines; psychiatry, psychoanalysis and psychology. Key social approaches (or models) are:

- *Social causation* – seeks to uncover the relationship between social disadvantage and mental health issues/distress;
- *Hermeneutical* – often highly conceptual, this approach tends to focus on how ‘normalcy’ is pathologized;
- *Societal reaction (or response)* – focuses on sigma and discrimination in the context of mental health;
- *Social constructionism* – holds at its core that reality is produced by human activity. As such, it tends to focus on the ways in which ontological beliefs regarding mental health are constructed (as opposed to discovered).
- *Social realism* – takes an ontological stance that aspects of reality are independent of human activity though much of it is not. It aligns with multi-level theories of causation, perceiving mental health issues as emerging from and operating within ‘open systems’.

With the exception of social causation and models, these approaches are not focused on demonstrating the role of social factors in the aetiology of mental health. Rather, they are more concerned with how experiences and/or understandings of mental health are constructed or mediated by social and cultural factors. Indeed, a weakness within the social causation approach for scholars adhering to social models of mental health, is that it can in fact serve to uphold the medical model by adhering to diagnostic categories of mental illness and the medicalised assumptions that underpin them (Rogers and Pilgrim, 2014, p.9). For example, many such studies use diagnostic categories to choose their sample base. As such, though it does entail investigation of the role of social processes in mental health, which might challenge bio-determinism within medical approaches, it often leaves the phenomenon of mental ‘illness’ and diagnostic categories unproblematised.

The works of scholars such as Beresford and Tew have sought to take social approaches in mental health a step further by proposing specific social models that might enable concrete changes in practices. Tew suggests two social models that might be helpful in transforming mental health care practices that are otherwise based on bio-medical understandings and their accompanying models of illness and sick roles. The first aligns with the social causation model above, and the second with the societal reaction model (Tew, 2011, c.7). Using these models, Tew seeks to provide a 'clearer theoretical understanding of the mechanisms whereby adverse social experiences may provoke journeys into mental distress' (ibid, p.169), building a bridge between social and psychological theories to enable social theories to influence and change practice. In this way, Tew might be seen as attempting to address McKenzie's request for a social model of the development of mental health issues/distress and their aetiologies.

Beresford's focus is slightly different in that, although he seeks to move away from the dominance of the medical model in mental health, his proposals seem more focused on increasing mental health service user/survivor agency and rights than on challenging aetiological beliefs. As such, he proposes the adoption of the disability social model or the creation of a social model of madness and distress based on the principles of the disability model. The disability social model distinguishes between a person's impairment (including chronic illness and mental health) and the disability they experience as a result of disabling factors in the social sphere. Disabling factors might include societal reactions to impairments or the way that ableist societies privileges 'average' body/mind types. This model has proved invaluable in driving forward disabled people's rights and challenging ableist discrimination. However, as Beresford himself acknowledges, many people experiencing mental health issues/distress reject the idea of using the social model of disability as they do not consider themselves disabled and/or fear becoming subject to additional stigma as a result of positioning themselves thus (Beresford et al., 2010; Beresford, 2012), a view supported by Tew (Tew, 2011, pp.103–104).

Yet, this or a similar tool might enable people experiencing mental health issues/distress to fight against the loss of rights and agency that often accompanies becoming a mental health service user/survivor. Indeed Goodley and Lawthom (2005) remark on how the agendas of disability studies and critical psychology might support each other to advance the rights of people with mental health issues/distress. Areas in which they might support each other include: aiding the adoption of different understandings that challenge ‘existing professional discourses on impairment’ (Goodley and Lawthom, 2005, p.188), primarily ‘tragedy’ models of impairment; recognise disabled people as having complex identities, and empowering these (ibid, 191-192); and supporting an approach to mental health that promotes activism and views people with mental health issues/distress as agents capable of resistance (ibid, 192-193).

Appendix 10: Topic guides and interview schedule

Topic guides, initial interviews: Core participant

Intro

- Introduce self, thank them, and explain purpose of research
- Why they've been invited to be interviewed – time/experience valued
- Explain how the interview will work and topics – OK to record?
- Collect consent form, and discuss confidentiality and withdrawal

Initiate conversation

- Tell me a bit about yourself.
- Where would you like to start a discussion about mental health?

Mental health

- How do you understanding mental health?
    - What do you think it is?
    - How does it affect you/people you know?
- What impacts on your mental health/distress? How?

Later interviews:

- Different understandings of mental health?
- Attitudes to mental health?

Intersectionality: BAME, mental health, plus X

- What other parts of your/a persons' identity or situation impacts on your/their mental health?

Later interviews:

- Racism / Socio-economic / Class / Religion?
- Cultural differences?

Services

- What are your experiences of mental health services?
    - What was good? Why?
    - What was not good? Why?
- What could be done to improve services?

Later interviews:

- Discrimination?
- Cultural clashes?

Disability and Mental Health (used in earlier interviews)

- What do you understand disability to be?
    - How do you think mental health issues fit with this (or not)?

Closing

- Anything else you'd like to add?
- A transcription/see summary or interpretation? Contact re clarifications?

Topic guides, initial interviews: Staff interviews

Intro

- Introduce self, thank them, and explain purpose of research
- Why they've been invited to be interviewed – time/experience valued
- Explain how the interview will work and topics – OK to record?
- Collect consent form, and discuss confidentiality and withdrawal

Initiate conversation

- Tell me a bit about your role here.
- What brought you to work in a mental health setting?

Mental health

- You must hear a lot of people's experiences of mental health issues
    - What sorts of issues to people tend to come with?
- Do you see any issues that are specific to your BAME clients?
- What do you think people's understandings of mental health is?
    - Are there differences across ethnic groupings?

Later interviews:

- What attitudes to mental health are prevalent in X community? Why?

Intersectionality: BAME, mental health, plus X

- How does (identity-marker/social category mentioned by interviewee) together with mental health issues impact people?

Later interviews:

- Socio-economic / Class / Religion / Gender?

Services

- How are services appropriate/inappropriate for the needs of your BAME clients?
    - And for clients with complex needs/multiple disadvantage?
- How do you provide services differently to meet the needs of your clients?

Later interviews:

- Cultural clashes?
- Diagnosis issues?

Disability and Mental Health (used in earlier interviews)

- How do your BAME clients understand disability?
    - In relation to mental health issues?
- Do your clients identify with 'disability' and why?
- Is the social model of disability helpful?

Closing

- Anything else you'd like to add?
- A transcription/see summary or interpretation? Contact re clarifications?

Interview schedule: Core participants

Date	Participant	Conversation length	Location	Purpose
05 Jan 2018	Samaiya	01:35:00 audio recording	Her home	Data gather
21 Aug 2018	Samantha	01:09:00 audio recording	Her home	Data gather
23 Aug 2018	Satch	00:45:00 audio recording	Gateway organisation	Data gather
30 Aug 2018	Peter	00:47:00 audio recording	Gateway organisation	Data gather
25 Sept 2018	Satch	00:54:00 audio recording	Café	Data gather
27 Sept 2018	Satch	00:35:00 audio recording	Café – after spending non-research time together: duty of care	Data gather and duty of care
01 Oct 2018	Peter	01:50:00 audio recording	Gateway organisation	Data gather and reflect on findings
02 Oct 2018	Misc – not used	00:9:00 audio recording	Gateway organisation	Not used due to ethical reasons

18 Oct 2018	Peter	N/A	Email and text	Sharing resources
23 Oct 2018	Satch	00:30:00 audio recording	Café	Data gather
24 Oct 2018	Samantha	30min-1hour. No audio recording	Phone call – unable to meet in person due to health (in hospital)	Participant called to discuss
31 Oct 2018	Satch	1-2hours. No audio recording	Café	Data gather and reflect on findings
07 Nov 2018	Mya	01:40:00	Gateway organisation	Data gather
07 Nov 2018	Mahdi	01:20:00	Gateway organisation	Data gather
12 Nov 2018	Misc – not used	01:40:00	Her home	Not used due to ethical reasons
29 Nov 2018	Andeep	~ 40min. No audio recording	Gateway organisation	Data gather
17 Dec 2018	Samantha	~0.5-1hour. No audio recording	Phone call – participant's choice due to health	Participant called to discuss
04 Feb 2019	Mahdi	~1-2hours	Park	Data gather and duty of care
~10 Feb 2019	Mahdi	~20min. No audio recording	Phone call	Participant called to discuss
14 March 2019	Satch	00:12:00	Café	Data gather and duty of care
08 May 2019	Mahdi	~1-2hours. No audio recording	Park	Data gather and duty of care
05 Aug 2019	Satch	~1-2hours. No audio recording	Cafe	Duty of care
21 June 2019	Samantha	~0.5-1hour. No audio recording	Phone call – participant's choice due to health	Participant called to discuss
09 July 2019	Samantha	~0.5-1hour. No audio recording	Phone call – participant's choice due to health	Participant called to discuss
08 July 2019	Samantha	~1-2hours. No audio recording	Her home.	Data gather and reflect on findings
01 Oct 2019	Mahdi	~40min. No audio recording	Park	Data gather and reflect on findings

18 Oct 2019	Peter	~1-2hours. No audio recording	Library cafe	Data gather and reflect on findings

To note: additional text messages and short phone calls were also had, however I only included these if they informed data gathered for analysis in the thesis.

Interview schedule: Staff participants

Date	**Participant**	**Conversation length**	**Location**	**Purpose**
17 Oct 2017	Staff team – London	N/A	Gateway organisation	Refine research
02 May 2018	Staff team – Bristol	N/A	Gateway organisation	Introduce and gather tips on approach
13 July 2018	Zara	02:00:00	Gateway organisation	Data gather
13 July 2018	James	01:37:00	Gateway organisation	Data gather
19 July 2018	Kamilla	01:28:00	Gateway organisation	Data gather
24 July 2018	Ruth	00:32:00	Gateway organisation	Data gather
24 July 2018	John O	01:29:00	Gateway organisation	Data gather
31 July 2018	Jean	01:20:00	Gateway organisation	Data gather
01 Aug 2018	Ruth	02:23:00	Gateway organisation	Data gather
07 Aug 2018	Marcia	01:13:00	Gateway organisation	Data gather
21 Aug 2018	John M	01:58:00	Gateway organisation	Data gather
26 Aug 2018	Lisa	01:25:00	Cafe	Data gather
06 March	Julie - London	N/A	Her home (organisation closed)	Reflect on findings
13 March 2019	Staff team - Bristol	N/A	Gateway organisation	Reflect on findings
31 Aug 2020	Julie - London	N/A	Email and phone	Reflect on findings and drafting

To note: Informal discussions were also had with staff when I spent days working from their organisations. Emerging themes were sometimes discussed.

Appendix 11: Ethics approval

Bath Spa University Research Ethics Approval Form

Student/Staff name	Stephanie Harvey
Programme and/or module	Disability and Cultural Studies – Research PhD
Title of the proposed research project:	‘Meeting in the margins’: being disabled, minority ethnic and more
Number and type of proposed participants	This project seeks to investigate the process of exclusion and marginalisation for adults from minority ethnic backgrounds with long-term mental health conditions. It will use a combination of one-to-one interviews, creative-practices and group discussion. Participants here can be broadly put into three groups: • Core participants; • Representatives of support organisations; • Community members. Core participants 6-8 adults with long-term mental health conditions from a range of minority ethnicities residing in either London (Newham) or Bristol. I will work with these core participants on a one-to-one basis to explore interesting findings in depth. Where language barriers may be involved I will seek interpretation support for languages other than English and French. My research methodology however, in attempting to bridge possible hermeneutical gaps resulting from multiple minority statuses, should also support people with limited English (where as a result

	of disability or ethnic/migrant status) – see methods section. These participants will be chosen on the basis of: • mutual commitment to work closely together to explore issues relevant to the research question, • ability to explore some of the themes in more depth (where the participant desires support from a carer/trusted person, I will seek commitment from the person providing support as well as the core participant). Participants will be made aware of their right to withdraw at any stage of the data collection, and information will be provided using clear and simple language to ensure informed consent. (Information sheets will be reviewed by my gateway organisations for clarity and ease of understanding). Where appropriate, this information can also be provided to family members/support workers/carers. <u>Support Organisations</u> Representatives of organisations supporting adults from minority ethnic backgrounds with long-term mental health issues will have a working knowledge of the issues that the people they work with experience. They may additionally keep logs with data of the sort of issues that are reported to them. I will seek to interview staff/volunteers working in these organisations, and investigate any other sources of relevant data they may have that they are allowed to share with me. <u>Community members</u> This research may engage with people within my core participants' communities to more fully understand sources of exclusion/marginalisation and inclusion processes. This will only be done with the agreement of my participants, and will take the form of open discussions (possibly using artefacts from my work with participants as a starting point). Though the format of this engagement cannot be pre-determined, (due to the need to co-construct this with my core participants), ensuring that community members engaging in such discussions are informed of the purpose of the research and how their input will be used will be central to my preparations.
How is permission being sought from the participants and/or their	**Mental Health conditions – the right to choose** This research acknowledges that 'long-term mental health condition' is extremely broad and allows for severe to mild mental health conditions. This work is emancipatory in nature, seeking to give voice to a group of people who are otherwise marginalised. As such, it is important not to exclude those who may have more 'severe' mental health conditions on the basis of a concern for their well-being that denies their own wishes. In line with the UN

parents/carers?	Convention on the Rights of Persons with Disabilities, disability activism and scholarship, I hold that participants (as long as they have capacity for informed consent) have the right to decide themselves whether or not they wish to participate. Approaches that have not been condition specific have been taken in other qualitative research in the disability and chronic illness fields - i.e. Ahmad, a leading academic in the disability/ethnic minority field in the UK, discusses cultural differences in understandings of disability - including issues of stigma – without excluding those with ‘severe’ conditions. However I recognise that I may need to amend my practices according to the needs of individual participants; discussion of reasonable adjustments and support needs will be had in the initial discussion. If I require further advice regarding adjustments, there are a number of mental health helplines and I can also refer to my supervisors and gateway organisations. Additionally, those with more ‘severe’ mental health conditions may already have support networks in place – I will always offer to liaise with this network should the participant wish. **Awareness of personal nature of discussions** This work will require discussion of issues of a personal nature, and will require working with participants who may be considered to be vulnerable adults. All participants will be provided with an information sheet and consent form. They will be provided with an opportunity to discuss the project and any issues regarding participation with me; two copies per participant will be provided to sign – one for me to keep and one for them. (See information sheets/consent forms in Annex A). The consent form includes confirmation of this conversation. In line with ESRC guidelines – which provide specific guidance on consent from vulnerable participants - participants will be invited to bring someone they trust with them and/or to discuss the information in private with them prior to signing the consent form. This project will not include participants considered to lack capacity to give informed consent. Representatives of organisations and community members wishing to engage in the later stages of this project will be provided with information sheets. They will also be provided with my email address in case they have further questions. **Additional support available to participants** The Equalities National Council (ENC) will act as a gateway organisation for this research in Newham; I am still in the process of arranging a gateway organisation in Bristol. The ENC have

	agreed to provide support throughout the project to both myself and participants. This may include being present when the project and consent/data issues are being explained. Based in the Newham itself, the ENC is well known by residents for providing support to disabled people from a range of ethnic backgrounds. They have a record of previously working with others (i.e. the disability charity, SCOPE) to undertake research. Importantly they are also a user-led organisation. I will endeavour to work with a user-led organisation in Bristol also, as this aligns with the participatory approach I will take in my research. In line with ESRC guidelines around coercion – which are more detailed than the AHRC and RCUK information - I will ensure that: • I am known to be/introduced as independent of the ENC though they are supporting the project, • decisions not to take part or withdrawal to/from participation won't impact on support they may receive from the ENC or any other organisations involved – this will be made clear in the information sheet and re-affirmed in discussion.
How is participants' anonymity to be preserved?	In considering the handling of data I have tried to balance the need to present research honestly, transparently and to demonstrate rigour (as per the Universities UK Concordat for research integrity – as pointed to on the AHRC website), with the need to respect the privacy of my participants (as set out in the Bath Spa University Code of Good Practice). Data presented in written work (for academic purposes) will be anonymised to the greatest extent possible (i.e. – using pseudonyms*) without harming the integrity of the work itself, unless the participant expressly asks for their real name to be used. Engagement with wider communities where there is any risk to anonymity (where anonymity has been requested) will only take place with the express permission of my participants. I cannot guarantee that people close to participants would not be able to identify the origins of comments referred to within the research if they were to look up my thesis (or related papers), due to their existing knowledge of individuals. For this reason, I will take the following steps: 1. Information and consent sheets will explicitly highlight this aspect of involvement at the point at which I approach someone to become a core participant - sheets to other participants will highlight my intended use of the information they provide. 2. Where possible/appropriate, I will invite participants to review the findings, and I will include an email address in

	the information sheet provided to all participants so that they can contact me at any point with concerns. 3. All core participants (and if necessary or requested, an appointed/trusted person) will be engaged to review findings and input on the design of data collection throughout the research process. 4. The personal details of participants will not be shared with others unless I am expressly (and in writing) asked to do so by the participant themselves. During the data collection process and for the period that it is held, I will follow the below processes to ensure data protection in line with the Data Protection Act 1998: • Pseudonyms will be used throughout the data collected, unless the participant expressly (and in writing) requests otherwise. • Data of a potentially sensitive nature will be held in encrypted documents, with password protection. • All printed material will be kept locked in a locked filing cabinet accessible only to the researcher. • Emails containing sensitive information will be labelled accordingly, i.e – Confidential, and will be stored in encrypted files upon termination of an exchange; email will only be used with consent from the participant. The wider D4D project anticipates holding exhibitions, and some materials from my own research project may be relevant to these. If this occurs, permission will be sought from participants. *Pseudonyms will be used in all the data management, including transcriptions, visual and research documents, due to the likely sensitive nature of some of the information; unless the participant has requested their real name to be used.
Describe the research methods proposed (e.g. interviews, classroom observations)	I have chosen methodologies and methods that allow for increased levels of participant involvement, seeking to empower the participants through this process whilst also enhancing my own understanding of the participants and their experiences. Central to this project will be a coproduction approach, allowing participants to be not just ‘research subjects’, but also to guide the research itself; i.e. – they will have opportunities to be involved in decisions on the tools we use to explore themes and gather information. This project, by its very nature, is exploring the ways that norms and social structures shape the experiences of my participants and how they are understood by others. It explicitly acknowledges

hermeneutical difficulties that people with ‘marginal’ experiences may face and seeks to find means of overcoming some of these to more accurately communicate their perspectives/experiences. Therefore, it is key that participants are not only involved in reviewing my interpretations of the data collected, but that the collection of data is itself informed by them.

My chosen methodologies support this:

- A grounded theory approach allows a hypothesis to emerge from the initial data and subsequently evolve (without need of assumptions that risk being based in perspectives governed by norms that marginalise my participants).
- Critical ethnography, using methods like in-depth interviews, enables co-production, a life history approach (which enables insight into how identities and beliefs are constructed) and acknowledges the positionality of both the researcher and the participant (particularly important acknowledgements to uphold the integrity of this work specifically).
- Participatory Action Research (PAR) – this research seeks not only to be participatory, but also emancipatory in nature. Through creative practice it will seek to overcome some of the hermeneutical difficulties minority groups may experience when communicating their own positionality.
- Intersectionality, used as both a theoretical framework and a tool for critical praxis, will inform both my approach in data collection and the way information is analysed; used properly, it should complement a critical ethnography approach and serve to empower marginalised voices (Collins and Bilge, 2016).

Methods:
The specifics regarding data collection methods will be co-produced with participants. However, I will make significant use of unstructured and semi-structured interviews in Stage 1 of data collection. These will be conducted in such a way as to allow participants to contribute in ways that they are comfortable, ensuring that they are not put under any strain.

In this early stage questions I will investigate in order to answer the central thesis question (what are the processes of exclusion and marginalization for my participants) include:

- How do my participants feel this happens?
- How do organisations working with BAME disabled people feel this happens?
- What particular experiences of exclusion/marginalisation do my participants feel results from disability, mental ill-health, ethnicity, or a combination of these (and any other factors)?
- Are there different cultural beliefs or norms that impact on

	exclusion/marginalisation? – how do both my participants and organisations navigate these? • How do participants and organisations envisage pathways to inclusion being? – what would they entail? In Stage 2 I will work with core participants after the interviews to explore themes raised in more creative ways. I will use creative practice to explore the central themes with participants; this might include photo-elicitation and the creation of storyboards/graphic books (the methods employed need to be culturally appropriate and co-decided with participants). This recognises hermeneutical limitations for minority groups, and tries to help move past this by introducing visual/other elements into meaning-making and communication. In stage 3, the artefacts created will be used to begin group discussions with other participants. If participants are comfortable, I will explore using the artefacts to hold discussions with people in the wider community. I will use a semi or unstructured interview approach in these discussions, building on themes that have come through from the research leading up to this. This will allow me to explore the intersubjective elements of my research more. The semi and unstructured approach will allow participants to remain able to influence the research direction in this late stage. It also supports creating a level of intimacy necessary to enable greater depth of understanding (whilst maintaining researcher integrity and abiding to both the Universities UK Concordat and Bath Spa University's own Code of Good Practice). **Review and revise:** In the spirit of true co-production, in line with BERA ethical guidelines 2011 paragraph 24, and to further ensure the integrity of this research by explicitly addressing my own situatedness (i.e. white, middle-class, hidden disability) in relation to that of my participants (i.e. minority ethnicity, working-class, disabled) - I will take the following steps: 1. Regular review and revise points with core participants: review data collection methods and findings relating to a particular participant with them and revising where appropriate. This will also provide participants with opportunities to input into how they are represented or to discuss how they represent themselves in stages 2 and 3. 2. Group discussions: where participants agree to be contacted in the future to discuss my findings as I write them up, they will be invited to do so. These measures should help me to mitigate possible mis-interpretations resulting from my situatedness in relation to the people I'm working with.

	*Mindful of the Research Council UK (RCUK) guidelines - the guidelines that the AHRC adhere to - regarding joint working, the agreement between myself and the gateway organisation will clearly define our roles, and stipulate my ownership (and final editing rights) of the research. It will also clearly state that they will not have access to any personal data without anonymization or consent from the participant/s, as per the Data Protection Act 1998. **Withdrawal from the field** I will be working with a small number of core participants over a period of time, and acknowledge that attachments may form. In recognition of this, I will need to be mindful of withdrawal processes. I will ensure that de-briefing sessions explore representations of my findings, as well how participants feel about their participation in the project and how they feel no longer being involved may impact on them. If concerns are raised then I will discuss with the participant where they might seek support on a more on-going basis. However, this research seeks to enable participants to explore their own marginalisation in a way that is emancipatory and empower – if they have been involved in stages 2 and 3, they will come away with additional skills to continue expressing and exploring such issues themselves. If problems do occur, I will seek advice from my supervisors. Where appropriate, and with the participants' permission, I would approach support workers they may have.
List the ethical issues and potential risks associated with the research methods outlined above (e.g. confidentiality) and how you propose to deal with each of these.	**Project relationship to D4D** This project is linked to the AHRC funded D4D project, led by Professor Levinson who is also my Director of Studies. The D4D project has a number of work strands exploring various aspects of disability and community, which explore issues of exclusion and inclusion to some degree. My project will complement the work of the wider D4D project by looking at this central theme of exclusion/inclusion/marginalization from an intersectional perspective. All of the work strands take participatory and emancipatory positions in all of its work, and allows room for creative methodologies. Though my research is a standalone piece, it complements the D4D project by considering one of the main themes from an intersectional perspective and by using methodologies and methods that reflect D4D work strands. One of the work streams is specifically dedicated to ethics in disability-related research, led by Professor Brydon-Miller (who is an international leader in Covenantal Ethics). The D4D project must itself receive ethics approval from all of the universities it is linked to, including Bath Spa. As an AHRC project, it must also

adhere to RCUK guidelines – I refer to these guidelines in the above sections. All involved in the project meet at regular intervals; during these meetings time is set aside to discuss any ethical issues arising from our various projects. This support network will re-enforce the support provided by my supervisors.

Potential Risks
I have considered the below issues and risks that may result from the methods listed above.

1. **Perceived imbalance of power between researcher and participant:** I am aware that labelling myself a researcher, attached to an establishment that carries credibility (a university) and with the support of a local support charity, there is a possibility that the participant may perceive a power imbalance. Though I try to mitigate against this by using co-production wherever possible and clearly explaining participants' rights (including to withdraw) in the information sheet, I will have to be mindful of this. Where I perceive that the participant seems dis-empowered by the process, I will reassess my approach with them. I will also ensure that they are aware of the independent support they can receive from the gateway organisation.

2. **Disagreement regarding findings:** Key to my approach is ensuring that I don't simply re-enforce 'white, middle-class, ableist' systems and perspectives in my research. However, I will be using the findings and relating them to other research and theories in the relevant fields, and will be the only person with detailed knowledge of all of the data gathered. I recognise the potential for disagreements with the interpretations of participants. These instances will require careful and sensitive handling on my part, consideration of what is leading to the disagreement, and my accessing the expertise of supervisors (see bottom of section for relevant experience). Where an agreement cannot be made, I will consider highlighting the difference in perspectives, or include the information such that the participant's perspective is clear (but distinct from my own).

3. **Risk of participant withdrawal:** Core participants will be made aware of their right to withdraw from the project up until the final writing-up stage begins (anticipated Dec 2018). Due to the possible sensitive nature of this research, withdrawal is a very real possibility, though the PAR approach seeks to limit this by empowering participants. However, due to this, I hope to work closely with about 6-8 core participants, with a view to having a minimum of 4 life stories that I can use. Should participants do not wish me to

use the data or artefacts collected from them after submission of my thesis, I will respect such requests; there will be no time limit on such decisions and a means of contacting me beyond my doctoral period will be provided.

With regards to information already published – intentions to publish works that include data collected from participants during the project period will always be discussed with participants. They will have opportunities to engage/review with the works I propose to publish prior to my doing so if they refer to specifics in the data gathered from them. This will also be the case for any works I seek to publish/produce with gateway or third-party organisations. Organisations I work with will be made aware of the possibility that participants withdrawing permission to use data collected from them.

4. **Anonymity and Confidentiality:** In addition to that mentioned in the ‘participant anonymity’ section:
    - All group discussions will begin with the signing of a consent form that includes an agreements of mutual respect and confidentiality towards all in the group.
    - Anonymity will be optional for participants with regards to their own engagement in the project, though any write-ups I produce for academic purposes will be anonymised (unless a request is made in writing for otherwise).
    - If work derived from or created during this project is used for purposes such as a community exhibition, permission will be sought from participants – separate consent forms would collected for such activity.
    - Findings will be anonymised and held as such. This includes any visual or audio data collected.

Data will be held in line with RCUK guidelines and advice will also be sought from the D4D data manager, who has responsibility for ensuring that D4D workstreams adhere to the latest recommended practice.

5. **Protecting participants from risk of exposure to harm:** In discussing the purpose of the research with participants, I will ensure awareness that engaging in this research may mean discussing sensitive and personal topics. I will emphasise that if any conversation makes them uneasy they can ask to move to a different topic, and re-iterate that if they still feel uncomfortable with being involved in the research they can withdraw at any point up until the final write-up stage of the PhD. If they wish to withdraw after this

point, I will discuss this with my Director of Studies – certainly data collected from them would not be used in any further work other than the thesis.

I will also reiterate steps I can take to protect their anonymity. The consent form will include confirmation that this conversation has been had. The co-productive approach and regular ‘review and revise’ process should empower the participant to express and change practices or language that they find harmful. Finally, the gateway organisation will provide support and advice to any participants wanting to speak to someone from within the community in confidence about issues raised.

With regards to limiting the people I work with on the basis of mental health diagnosis due to perceived possible harm: Excluding people on the basis of medical advice, rather than including people and then ensuring that my practices are adjusted to meet their needs, runs counter to accepted practices within disability realms. Such referral to medical diagnosis would be seen to uphold the medical model of disability and is arguably unethical within this subject area.

6. **Risk of exposing myself to harm:** Initially I will work from the gateway organisation and I will take their advice with regards to safe areas to work and meeting places. I will ensure that I meet with participants in public places, at least in initial stages. I will also take the precautionary step of getting a phone specifically for use with participants, and will inform family/friends of my location/s. Again, the gateway organisation can provide me with a support network within the community should issues of safety or harm arise. I have a good network within the disability sector in London should I need advice with regards to issues arising due to mental health (my own or that of participants).

   Additionally, in my previous career I received training and hands on experience working with vulnerable adults. I was the manager of a frontline service in charge of security, customer service and MAPPA cases (cases where the person’s rights to work are restricted due to convictions). I was trained in handling difficult situations/discussions and received practical experience, such as calming someone threatening to commit suicide, supporting women escaping pimps in our office and having one-to-one conversations with people with serious convictions about their conduct. I have also line-managed multiple people over the years with mental health conditions, complex needs and/or difficult

	home lives. Lastly, I have further experience relating to mental health in my own private life.	
Describe how your findings will be reported or disseminated	1. Doctoral thesis. 2. The D4D website (D4D is the research project that my studentship is attached to, led by Prof. Martin Levinson), and potentially through the D4D final publication. I will also aim to share findings though: 3. Publication of articles in relevant journals, chapters or blogs. 4. Presenting papers on my research at conferences or workshops. 5. Discussing my research in any teaching I may undertake, or in spaces provided by the Graduate College (i.e. Bath Spa research roundtables). 6. Pre-agreed presentations of my work with the Office for Disability Issues. Additionally, opportunities to further share this work may include: 7. Publications co-authored with the gateway organisation and other disability lobbyists to influence policy (this only a possibility – no formal agreement has yet been made.) 8. A public creative event, depending on the methods used to gather data and the wishes of participants.	
Funding – Detail the funding and projected costs of your project	My place as a PhD student is AHRC funded, and it is attached to the D4D project. The costs of the research as currently designed will be minimal. I may seek some funding available through the BSU researcher office for materials when doing the art-based practice.	
RSA – State the amount of RSA time to be allocated to your project	Currently I don’t anticipate any.	
I have read the Universit		

y’s Process and Procedure for the Approval of Research Activity (please sign and date)		

Ethical Review of Research Projects – Checklist

Supervising Tutor/ Director of Studies Approval level required (Y/N)			
a)	proposals using human participants for research	Y	
b)	proposals for research that intends to use undergraduate students as participants		N
School Ethics Sub-Committee approval required			
c)	procedures involving any risk to a participant’s health (for example intrusive physiological or psychological procedures)		N
d)	research involving the donation of bodily material, organs and the recently deceased		N
e)	proposals which involve financial payments or payments in kind to participants above reimbursement of expenses		N
f)	proposals wishing to use children under the age of 16 or those over 16 who are unable to give informed consent (e.g. people with learning disabilities; see Mental Capacity Act 2005) as participants	Y	
g)	research proposals to be carried out by persons unconnected with the University, but wishing to use staff and/or students as participants		N
h)	proposals which investigate existing working or professional practices at the researcher’s own place of work (including staff surveys)		N
i)	research where the safety of the researcher may be in question;		N

j)	proposals which require participants to take part in the study without their knowledge and consent at the time		N
k)	research involving prisoners and young offenders	Y	
University Ethics Sub-Committee approval required			
l)	research involving access to records of personal or sensitive confidential information, including genetic or other biological information, concerning identifiable individuals		N
m)	surveys, questionnaires and any research, the nature of which might be offensive, distressing or deeply personal for the particular target group	Y	

Document checklist for submission

I have completed and include the following documents with this form	√
Information Sheet	x
Consent Form	x
Debriefing	x
Research design documentation e.g. interview schedule; questionnaire	x

Supervising Tutor/Director of Studies/Director of Research use only:

Comments on the ethical issues raised by the proposed research:	All research with vulnerable groups requires very careful consideration, going beyond the standard guidelines. Key questions are whether the research will be of genuine value to the potential participants and their communities, and whether the research proposed has predicted potential difficulties, considered strategies to address those difficulties, and done all	

	possible to protect those involved. The candidate has gone to great lengths to address the above. She will be supported by the experienced D4D research team, many of whom have carried out extensive research with disabled people. There is a danger, as noted in the 2011 Specialist Research Ethics Guidance Paper Sheffield University, (‘DOING RESEARCH WITH PEOPLE WITH LEARNING DISABILITIES’) that important research, of potential value to participants, will not be carried out due to apprehensions about risk. As noted by Barnes (2009), it is crucial to include the participants as far as possible in co-constructing the research environment, and I feel that the candidate has demonstrated awareness and sensitivity in that regard.	
Either:	I am satisfied that the ethical issues raised by the proposed research project have been addressed and give approval for the project to go ahead	
Or:		
Signature and Date:	[redacted] 13.10.17	

A copy of this form should be sent to the Director of Research in the School

School Ethics Sub-Committee Use Only:

Comments on the ethical issues raised by the proposed research and how well they have been addressed		
PASS	I am satisfied that the ethical issues raised by the proposed research project have been addressed and give approval for the project to go ahead	
CONDITIONAL PASS	The ethical issues raised by the proposed research project have not been adequately addressed and require re-submission to the IfE Ethics Sub-Committee. The following adjustments need to be made:	
REFERRAL	The ethical issues raised by the proposed research project require referral to the University Ethics Sub-Committee.	The ethical issues require referral to the University Ethics Sub-Committee
Signature and Date: (Chair of School level committee)	[redacted] 16th December 2017	
Signature and Date: (Dean of School)	[redacted] 5th January 2017	

A copy of this form should be retained by the Director of Research in the School

University Ethics Sub-Committee Use Only:

Comments on the ethical issues raised by the proposed research and how well they have been addressed		
Either:	I am satisfied that the ethical issues raised by the proposed research project have been addressed and give approval for the project to go ahead	X
Or:	The ethical issues raised by the proposed research project have not been adequately addressed and require re-submission to the committee.	
Signature and Date: (Chair of University Ethics Sub-Committee)	[redacted] Note: This sign-off is to confirm the audit trail that shows sign-off was achieved on the 18th June 2018 under the previous Ethical Review processes in the School of Education. This is because signed documentation from reviewers was not received and they have now left BSU.	

A copy of this form should be retained by the Vice-Provost, Research & Enterprise

Appendix 12: Sample consent forms

Sample information sheet

‘Meeting in the margins’: exploring differences between lived experience, policy and theory.

Why have I been contacted?

You have been contacted as a family member or friend of a person living with a long-term mental health condition, who is also from a minority ethnic background. You are invited to take part in a research project called ‘Meeting in the margins’, which is exploring how people can become excluded or marginalized. This would involve being interviewed by a researcher.

If you wish to continue being involved in the project, you may be invited to participate in the second stage of the research. This second stage will involve using more creative methods to explore some of the themes we discussed in the interview.

Who is doing this research?

I, Stephanie Harvey, am a PhD student in Disability and Cultural Studies at Bath Spa university. My PhD research is a stand-alone project with links to a larger research project called D4D, funded by the Arts and Humanities Research Council. For more information about D4D, see http://d4d.org.uk/.

What is the purpose of this research?

‘Meeting in the margins’ looks at how people with long-term mental health conditions from different minority cultural backgrounds can become marginalized. This research will consider differences between life experiences and the ways that mental health, disability and other things are talked about.

The aim is to find ways of building understanding across different sections of society about people’s experiences of marginalization, by better understanding how differences between lived experience, policy and theory contribute to the process of marginalization. This could help policy-makers, service providers, community leaders and others to improve inclusion.

How will we do the research and how long will it take?

This research will be a Participatory Action Research project. This means that the research looks to have a positive impact and that participants will play an active role in how the research moves forward. Participants will work with me (the researcher) to decide on how I gather information and will have a say in how this information is interpreted. It may also take a Critical Ethnographic approach, which means that it would consider how people's experiences are impacted by social structures.

I will start this research by having one-to-one interviews. These will take between 1-2 hours, depending on your availability. If you then wish to continue working with me, we will discuss the next stage and what your availability will be. The project will stop collecting information around summer 2019, however you do not need to remain involved for this period if you do not wish to.

What is the commitment if I become a participant?

If you decide to become a participant in this research, you are agreeing to exploring your experiences of inclusion and exclusion and how particular elements of your identity play a part in these experiences. You are also agreeing to have your anonymised information used in my PhD research write-up and associated academic papers/presentations. Though I cannot guarantee your anonymity if people close to you read publications I make, you will have the opportunity to review papers I wish to publish before I submit them until my PhD is complete.

If you have any questions about participating in this research, staff at the Equalities National Council (ENC) will offer independent advice or information about working with me. This organisation is helping me with my research because they think the topic is important, but I do not work for the ENC. If you decide not to participate in this research, your decision will **not** impact on the support you get from the ENC or any other organisation.

What are the potential benefits and harms of taking part in this research?

This research hopes to use your experiences to challenge the ways that policy and theory thinks about 'mental health' and 'disability'. It will take your experiences as the starting point, so as to produce research that makes the voices of participants heard. I hope that this research will be an empowering experience where you have the opportunity to explore what has contributed to your experiences of marginalisation and to have your voice heard.

Please note that we may discuss very personal topics. The researcher may encourage exploration of these issues, but will never force you to disclose more than you are comfortable with. If you wish to be anonymised in this research, the researcher will do all they can to maintain this. However, extracts of discussions will be included in the research produced. There is a risk that people who know you well could identify you if they read the research papers.

To ensure that you are comfortable with what I include in the research, you will be invited to review what is written about the information you have provided. If you wish, the researcher will work with you to ensure that you are happy with how information you have given is interpreted. If you do request your real name to be used in this research, we will carefully consider the extracts used in the research if they include information about people you are close to, and only use them if important to reflecting on the point you are making.

If I agree to be involved, can I change my mind?

You will be able to withdraw at any point during the data collection phase of the research. Once I begin to write-up the findings, you will be invited to review the information related to you and comment if you have provided your email address in the consent form allowing me to contact you.

If you later decide that you do not want me to use data collected from yourself in any papers, then you have the right to request that I do not use your data in any work after completion of the PhD. You can also request that your information is only used for specific parts of the research. Such requests should be made to [redacted].

How will the data be recorded?

I will take written notes and, with your permission, make audio recordings of some discussions. If photos are taken, this will always be with your permission. Additionally, we may use a range of other creative ways of exploring themes. All personal details will be anonymised, unless you specifically opt to be named. You also have the right to be provided with copies of the information I gather from you should you wish. If you feel that some of the information is incorrect, you can ask the researcher for it to be corrected.

How will I handle, store and protect the data I collect?

Any information you provide to me as part of the research would be in complete confidence. I am legally and ethically obliged to comply with the Data Protection Act 2018:

- The data I collect through the course of my research will be anonymised - this means that your name or any personal identifiers will not be attached to the data we collect and store, <u>unless</u> you have requested to be named. You may prefer to choose a pseudonym – i.e. you make up a name for this project to protect your identity.
- The data we collect will be stored safely in a locked filing cabinet or password protected files on a password protected computer by Stephanie Harvey. This information will be retained for the duration of the PhD and in an anonymised form following this (unless you have specifically requested your data to be deleted).
- You will not be identified personally in any reports or other written outputs, <u>unless</u> you have requested to be named.
- You can withdraw from the research at any time before the writing up stages, (likely to begin May 2019) with no need to explain why.

Interview tapes, photographs, transcripts or other forms of note-taking, will be held in confidence. They will not be used other than for the purposes described above and third parties will not be allowed access to them (except as may be required by the law). However, if you request it, you will be supplied with a copy of your interview transcript so *that you can comment on and edit it as you see fit (please give your email below so that I am able to contact you at a later date).Your data will be held in accordance with the Data Protection Act.*

Will my confidentiality always be maintained?

The information that we collect will be held confidentially by myself, as outlined above. I may discuss the information you provide with my supervisors, but this will be done with respect for confidentiality. However, if you tell me information related to your immediate safety or the safety of another person, I may need to discuss this with relevant parties. I will always seek to first discuss this with yourself and come to a mutual agreement about how we will proceed.

What will happen to the results of the research?

This research will inform my PhD thesis and be used in academic papers and presentations. I will share my final findings with other researchers in the D4D project, on the D4D website and possibly in a D4D book. I will also share the final research outcomes with disability charities and activists, government policy-makers and in universities to try to influence their work. In all these situations the information provided will be anonymised and pseudonyms used, unless requested otherwise by yourself.

I do not want restrict this work to written outputs, and intend to use some of the findings for more creative practices. This will depend on how you, as a participant, and I decide to explore this topic and the way in which you are comfortable with me using the information you provide.

What do I do if I want to take part?

If you wish to take part please contact:
Stephanie Harvey and fill in the consent form below. The consent form can either be emailed to the address below or printed and brought with you at your next meeting with me.

Email: [redacted]

If you do not wish to take part, you do not need to do anything.
Thank you for your time.

FINAL NOTE

The researcher, Stephanie Harvey, will respect the RCUK (Research Councils UK) guidelines for transparency of data and will follow ethical guidelines as proposed by the AHRC (Arts and Humanities Research Council). All research has to be approved by an independent research ethics committee.

This research has been approved by the Bath Spa University Research Ethics Committee for the Institute for Education. For more information about expected ethical standards, see:

https://www.bathspa.ac.uk/research-and-enterprise/research-strategy/integrity-and-ethics/

If you have any complaints:
In the first instance you may wish to raise any complaints with the researcher to seek resolution, or with any relevant support organisations.

If you have any concerns about the conduct of Stephanie Harvey, or other details you do not wish to discuss with her or the Equalities National Council, please contact:
Complaints Officer, Bath Spa University, Newton St Loe, Bath, BA2 9BN.
Tel: [redacted]

Core participant consent form

I have been fully informed about the aims and purposes of the project, and that I have had an opportunity to raise any questions or concerns with the researcher.

I understand that:

- there is no compulsion for me to participate in this research project and, if I do choose to participate, I may withdraw at any stage;
- I have the right to refuse permission for the publication of any information about me until the final write-up stage of the PhD thesis or of any related papers;
- After the PhD is complete, I have the right to request that my information is not used in further papers, or for my information to be deleted;
- any information which I give will be used for this research project and for academic purposes, which may include publications or conference or seminar presentations;
- some of the information I provide may be shared (in an anonymized form) with the researcher's supervisors and researchers working in the D4D project;
- all information I give will be treated as confidential;
- the researcher(s) will make every effort to preserve my anonymity, if that is my preference.

I also understand that, by signing this I am legally agreeing to keep the identities of all other participants and any comments they make confidential, unless given permission to do otherwise by the other participant.

..........................………………..……..
……….............................……………..
(Signature of participant) (Date)

………………………………………………
...…………………………………..……
(Printed name of participant) (Email address of participant if they have requested further information)

………………………………………………
……………………………………..……
(Printed name of appointee, if appropriate) (Date)

..........................………………….. ....…………………..
(Signature of researcher) (Printed name of researcher)

One copy of this form will be kept by the participant; a second copy will be kept by the researcher(s).

Staff consent forms

I have been fully informed about the aims and purposes of the project, and that I have had an opportunity to raise any questions or concerns with the researcher.

I understand that:

- there is no compulsion for me to participate in this research project and, if I do choose to participate, I may withdraw at any stage;
- I have the right to refuse permission for the publication of any information about me until the final write-up stage of the PhD thesis or of any related papers;
- After the PhD is complete, I have the right to request that my information is not used in further papers, or for my information to be deleted;
- any information which I give will be used for this research project and for academic purposes, which may include publications or conference or seminar presentations;
- some of the information I provide may be shared (in an anonymized form) with the researcher's supervisors and researchers working in the D4D project;
- all information I give will be treated as confidential;
- the researcher(s) will make every effort to preserve my anonymity, if that is my preference.

I also understand that, by signing this I am legally agreeing to keep the identities of all other participants and any comments they make confidential, unless given permission to do otherwise by the other participant.

..........................……………..……..
…………..............................……………..
(Signature of participant) (Date)

………………………………………………
...…………………………………..……
(Printed name of participant) (Email address of participant if they have requested further information)

..........................………………..
(Signature of researcher)

..........................………………..
(Printed name of researcher)

One copy of this form will be kept by the participant; a second copy will be kept by the researcher(s).

Gateway organisations: roles and responsibilities agreement

Role of the Gateway organization

During data collection

Gateway organizations will support the researcher in recruiting participants. This might include approaching people they support who they think might be interested in participating, or allowing the researcher to publicize the work through their networks. All participants will be made aware that this research is separate from the gateway organization, and that they will not have support from the organization taken away from them if they do not wish to participate in the research any longer.

If the gateway organization is able to support the research by providing a safe space to conduct interviews, then this will form part of the agreement between them and the researcher. The researcher does NOT expect costs of this research to be met by the gateway organization.

Staff from gateway organizations will also be invited to participate in the research by being interviewed. This will be voluntary and with approval from the correct level within the organization.

During write-ups

In the final stage of the project, or if the researcher writes papers for publication during the course of the project, the gateway organization will be invited to review the documents. However, involvement in this will be at the discretion of the organization individually in recognition of workloads.

Responsibilities

The gateway organization will:

- Come to an agreement with the researcher regarding the level of support they will provide, and ensure that this agreement is respected.
- Ensure that they do not breach confidentiality regarding participants involved in the research, even if they helped to recruit them.
- Ensure that their conduct with regards to this research is aligned with the governing principles of co-production with participants and an emancipatory approach.
- They speak directly to the researcher if they have any concerns they have with the research (without breaching their own responsibility for confidentiality towards participants) in the first instance, with a view to resolving potential difficulties.

Role of the researcher

The researcher will conduct this research in accordance with best practice in research, adhering to AHRC, University UK and Research Council UK guidelines. The researcher will conduct the research via interviews in the first instance, and then using more creative methods co-produced with participants. The researcher will conduct analysis of the data collected, and keep participants and organisations informed on the work. The researcher will also seek to meet any costs occurring as a result of the work and undertake the administrative and logistical tasks involved, unless the gateway organisation offers otherwise.

The researcher will hold all the data collected during this research securely. Data collected will be owned by the researcher and the participant it was collected from; the gateway organisation will not have rights over this data due to confidentiality between the researcher and the participant.

Responsibilities
The researcher will:

- Come to an agreement with the organization regarding the level of support they will provide, and ensure that she does not place additional support requests on them without first agreeing these.
- Ensure that she does not breach confidentiality regarding participants involved in the research and the data collected from them, including that of the staff at the organization.
- Ensure that her conduct with regards to this research is aligned with the governing principles of co-production with participants and an emancipatory approach, and that she behaves in a way that respects the ethos of the gateway organization.
- She speaks directly to an appointed person within the organization if she has any concerns with regards the organization's involvement in the research in the first instance, with a view to resolving potential difficulties.
- Ensure that she is mindful of the potential impact of this work on participants and behaves so as to produce no harmful impacts on those involved in the research.

Agreement of Gateway organizations

I have been fully informed about the aims and purposes of the project, and the role and responsibilities involved. I also confirm that I have had an opportunity to raise any questions or concerns with the researcher.

I understand that:

- I may withdraw from the research at any stage should I wish;
- I will maintain the confidentiality of participants and the researcher; and
- I will conduct my role in the research with integrity, supporting the overall integrity of the research itself.

……………………………………………
……………………………………………

(Signature) (Date)

……………………………………………
……………………………………………

(Printed name of staff member) (Name of and title within organization)

……………………………………………
……………………………………………

(Signature of researcher) (Printed name of researcher)

Appendix 13: Staff demographics and extended extract on 'professionalism'

Table 6: Demographics of staff interviewed

Name	Role	Ethnicity/Migrant status	Religion	MH declared	Gender
Zara	Admin and advocate in BAME-led organisation	British, black / 2nd-3rd generation	N/A	No	Female
James	NHS care co-ordinator	British, black Caribbean / 2nd generation	Christian	Yes – Depression	Male
Kamila	Therapist	British, Pakistani / 2nd generation	Muslim	No	Female
Ruth	Former NHS senior mental health nurse	Ghanaian / 1st generation	Christian	No - Misdiagnosed	Female
John O	Advocate/Social worker	Nigerian / 1st generation	Christian	No	Male
Jean	Nurse/Founder of BAME-led organisation	British, black Caribbean / 2nd-3rd generation	N/A	No	Female
Marcia	Therapist	black West Indian / unsure	Christian	No	Female
John M	Care co-ordinator	British, Irish / 2nd generation	Roman Catholic	No	Male
Lisa	NHS senior health link worker	British, black / 2nd-3rd generation	N/A	No	Female

James: Professionalism

Extract 1

Stéphanie: I remember when we were at one of the team meetings, umm, N. is very passionate about this actually isn't she, because she feels that people get misdiagnosed umm when actually part of it is cultural differences.

James: *Yeah.*

Stéphanie: Is that something [that you /

James: *Most definitely.*

Stéphanie: think plays] in?

James: *I have to be a different person in my work place. Most of the people in my NHS, nothing against the NHS, I love It to bits, umm, but when you work in a particular sort of assessment, you have to become the norm, there's protocol and policies you have to follow and even a code of behaviour, so I can never go in there and start doing things I would like to do, like going yes mate / you've got to hold yourself back.*

Stéphanie: Yes.

James: *And / it's about professionalism, which I consider / specialists sometimes can be a middle class white order and / got to work within these constructs, umm, and again with mental health as well. I've seen some people of a BME description come across and it's almost like it's being attributed to satisfy their definition and to fit in to a construct or an idea they have of a particular social group. And it's wrong. It's wrong because you know some people / I'm not saying all, but some clients, are not necessarily diagnosed correctly, but at the same time, you have to take on board that some are, because they are not medicated and they need particular medication to help them cope in life, so I don't do on-way traffic, I do two-way traffic. I look at some of the issues which we face as people and some of the faults and barriers that we present to other people as well. I think you have to be fair as well. So it's a combination of a lot of things, yes.*

Extract 2

James: *But what I'm saying at the end of the day is that sometimes people take other people's culture and then they beat you up with it, if you do not conform to something which you don't always understand, or you don't always particularly want to be a part of. It doesn't mean you are a bad person, umm / I've / I have to be very careful with my mouth, with my particular views, I have to like / I have to think 100 times before I open my mouth, because if I say something like that, I know what the consequences would be. Where if I represent myself like this, I know what the consequences would be and I think what's happened now we get a lot of umm BME group in particular they try and form they own sub-culture, not to do anything untoward, but they want to feel comfortable talking and expressing who they are and having their own values and belief systems.*

Stéphanie: Without having to do that mediation

James: *Oh, yeah, and because there's always a consequence, consequence, always a consequence. You / what happens then you will get more BME people working in a mainstream organisation, be more professional, than their white counterparts, because they know there will be basically consequences, it will just say something, do something, which is not of the norm. It, it, it's /*

Stéphanie: Do you think people are more on the lookout and less willing to excuse it as just a sort of interesting part of that person?

James: *If it's BME people / there's a report called a Snowy Peaks Report, you have to read it, Snowy Peaks.*

Appendix 14: Top themes from round 1

Table 7: Top themes from round 1 of analysis

#	Themes from Top 3 exercise	Participant	Interview	Present, but not top theme.	Notes
1	Difficulties meeting expectations & requirements (socially and service provision)	1	1.180705;	2.180821; 3.180823; 7.181107	
2	Appropriateness & Adequacy of services/support	1, 2, 3, 4, 7	1.180705;2.180821; 3.180823;4.180830; 7.181107		This may in part be due to how I'm accessing my participants
3	Psychological & Behavioural responses to difficulties meeting expectations & requirements	1	1.180705	2.180821;3.180823;4.180830; 7.181107	
4	Beliefs of causes of and what MH is	2	2.180821;	4.180830; 7.181107	
5	Problems caused by term 'Mental Illness'	2	2.180821	4.180830;	7.181107 seems to accept it.
6	Role of power dynamics in disempowerment	3	3.1800823	4.180830; 7.181107	
7	Difficulties in relationships between professional/support staff and participant	3	3.180823	1.180705;4.180830;	4.180830 also had positive comments.
8	Sustaining the system/status quo over people's wellbeing	4	4.18083	3.180823;7.181107;	Might fit 11, but is more about 'efficiency' over effectiveness.

9	Use of medication	4	4.18083	2.180821;7.181107;	This could also fit into 2 and 7.
10	Insecurity of support retraumatises	7	7.181107	3.180823;	
11	High level politics creating dehumanising mechanisms	7	7.181107	3.180823; 4.180830	

Appendix 15: Extended extract with Peter

Context: The researcher is a young white woman of mixed cultural background, but a British accent. The participant is an older black man who migrated to the UK in childhood. Both have some experience of mental health issues/distress.

The topic of the research they are engaged in is the experiences of mental health issues/distress of people from BAME backgrounds. They are speaking of the nature of research in marginalised context, and what can be learnt through reading and what has to be lived.

Peter: *I think there is a place for both. Because it creates a balance. Umm, because with the best intentions in the world you know, we can… the subliminal factor kicks in.*

Stéphanie: Yep.

Peter: *And you can find* (.) *Oh what was I thinking of? But / But people going to lean towards what's more beneficial to themselves.*

Stéphanie: Oh is this consensus bias? Is that the word you were looking for?

Peter: *Pardon me?*

Stéphanie: Consensus?

Peter: *No* (.) *not quite, no* (.)

Stéphanie: Sorry.

Peter: *That's alright. Um, yes so I think both working alongside each other creates a balance, but I do believe that the* (.) *actual sufferers in all this have to play a big role.*

Stéphanie: Stéphanie: Hmm. ((Reflective))

Peter: *It has, they must have a much greater degree of input than there has been so far. Maybe even more so than the other side. Because they've had the practical experience. And unless you've had that, you will always be missing something, you know.*

Stéphanie: Um. ((Agreement))

Peter: *It becomes theory.*

Stéphanie: Uhum. Uhum. ((Agreement))

Peter: *It's as opposed to maybe around the actual thing. The factual side of it. And, I think there isn't enough of that.*

Stéphanie: Yeah. ((Encouraging to continue))

Peter: *This is what I mean about people sort of going off intellectualising. And they feel they - as a result of their research or, trials or whatever - they have the full picture.* (.) *But, excluding those with the actual knowledge and experience and so on and whatever, is a big mistake.*

Stéphanie: Do you think people, em, you'll never know what it is to be, exactly to be someone else right. We can't do that.

Peter: *Um. Um.* ((Agreement))

Stéphanie: But, do you not feel that (.) through speaking to other people who have had these experiences or doing a lot of reading that is coming directly from people with these experiences, you can gain some of that knowledge? Or is it still (.) or is that knowledge only valid if you are the person who has directly experienced it?

Peter: *You can only gain a percentage of that. You cannot gain the full of it. You're experience* (.) *is completely different to you gaining the knowledge and listening to someone talking about it. Or watching someone going through it or whatever.*

Stéphanie: Uhum, uhum. ((Encouraging to continue))

Peter: *It's like a man trying to tell a woman he fully understands childbirth. You know the process*

Stéphanie: Um hum, you've heard the screams.

Peter: *Exactly! OK.*

Both: ((laugh))

Peter: *And you've seen all the effects of it and so on, but the actual experience* (.) *you do not have and you cannot have. And that is the difference. There is too much* *of this thing where people believe they can just ‘research’, and observe, and whatever and so on and they’ve got the full package.* (.) *It is impossible.*

Stéphanie: Yep.

Peter: *The experience, is the key.*

Stéphanie: Yeah.

Peter: *Because, um* (.) *there’s many things in this world that some people will get a full understanding of, as a result of actually experiencing and some won’t. And it’s the same nonsense that’s been used where women are concerned. Developing various things for women. Men sit there and think, OK, we know it all. And they’ll do a bit of research amongst the women and so on and they’ll take the lead and* (.) *Why not let the women do it?*

Stéphanie: Uhum, uhum. ((Reflective))

Peter: *They’re going to be the end users. They’re the ones it’s for. They’re the ones with the need. So they should take a lead role. The men could come on board with whatever else they have to contribute, but the women should take the lead role in such a matter. And in anything out there, that’s my opinion, the people with the actual experience should take the lead role.*

Stéphanie: It’s a really interesting one. I sort of want to ask you a d-d-difficult question.

Peter: *OK.*

Stéphanie: How do you feel about me doing this research topic then?

Peter: *The same applies. The same applies. Umm, the research can take you so far.*

Stéphanie: Hmm.

Peter: *And you can gain a lot of knowledge.*

Stéphanie: Yep.

Peter: *But the experience* (.) *is another.*

Stéphanie: No I / I absolutely agree with you actually. Not even contending that. Um. But I'm asking this, partly uh, partly just because I'm interested. And also because, actually it's interesting for me in writing up the ethics part of what I've got to do. Umm I think I said to you that I do want my project to be as collaborative as I can make it, em, which is why I've tried to do things like ask you where you wanted to start, but there's still this, at the end of the day I'm still sort of directing things, and, umm, I can't think of words! Brain freeze!

Both: ((laugh))

Stéphanie: And so I guess I wondered whether you had an opinion about me just even conducting this research. Whether I've got legitimacy in doing it or not. So I've had experience of mental health services, and my Mum's French, but I'm still, you know, a White European person. And although for me I know that my interest is in cross-cultural things, some of the aspects of my research very clearly are going to be around, minority ethnicity. And racism comes into it, you know.

Peter: *Ummm. Um.* ((Encouraging to continue))

Stéphanie: Do you think then, that I just shouldn't be exploring those issues? Or / and I'm not going to take anything personally. I literally just find this interesting / Or do you think it's about <u>how</u> I then write about it that's important?

Peter: *Ummm, yeah, I think the way you write about it is extremely important. Umm, because I was talking about the human factor before.*

Stéphanie: Yeah.

Peter: *And / It applies to all of us. Even if we are not aware that it's present.*

Stéphanie: Yeah.

Peter: *And those human factors are the little things sometimes that are not thought about or looked at. And that can kick in at any point and can prejudice an outcome and so on. Umm, but that's a human thing. It's very difficult I think for most people to sort of, remain objective in certain situations. Not that it isn't possible, but it can be I believe quite difficult, and it very much depends on the individual.*

Stéphanie: And I suppose it's about / this is my view, but I wonder if you hold it / is it then more about not making a claim to know what the experience is if you've not had it yourself, but rather to make the claim that this is what you've heard, or this is what you've read about? Is <u>that</u> the difference that you're talking about?

Peter: *Yeah. 'This is what I've learnt, as a result of'. Because you're dealing with people, with the experience. Say you've learnt from their experience and their explanations and so on, you see. A lot of people take these things and claim to be the expert, when all they have is one side of the coin.*

Stéphanie: But then again I suppose they're an expert of that side of the coin.

Peter: *But if you haven't got the both sides, then you haven't got the full picture.*

Stéphanie: Does anyone really ever have every side of everything?

Peter: *Possibly not, but what I'm getting at is, it comes back to what I was saying with women.*

Stéphanie: Uhum ((Encouraging to continue))

Peter: *Women know their bodies. They know their needs. And, if something is to be designed for a specific need of the female, and the female gets involved because they know precisely what they're looking for and what would be the best fit for, then obviously you're going to get something much better suited to satisfy that need than if I, a man, were to come and talk to you and investigate it, and try to create that thing. I could do a very good job! But at the end of the day, there may be something missing.*

Appendix 16: Transcription formatting

Adapted from (Atkinson and Heritage, 1999)

[ ]	Placed around speech, this indicates overlapping talk
(.)	Pause longer than expected at the end of a sentence or for a coma, sometimes taking place mid-sentence.
_	Underlining where emphasis was placed on a word or phrase
.hh	An expressive inhale
hh	An expressive exhale
(word)	Uncertainty on the transcriber/researcher’s part of the word spoken
( )	Something said, but not understood by transcriber/researcher
(())	Researcher’s description of events, or alternative name to protect confidentiality
/	Change in the construct of direction of a sentence
…	Section omitted

Appendix 17: Exploring epidemiological trends in more detail

In the following section, I do not attempt to provide any form of meta-analysis of quantitative data or precise figures but focus instead on general trends observed over the previous 25 years[25]. As Leff so aptly put it, 'The rate of illness is quite simply a vulgar fraction' (Leff, 1999, p.41), and this thesis does not require such problematic quantification of general trends. It is also worth noting from the outset the dearth of information regarding rates of CMD across BAME populations[26] (Fryers et al., 2004, p.s13; Weich and McManus, 2002, p.25). This is perhaps due to the more problematic nature of collecting data, as people experiencing CMD are less likely to encounter mental health services that people experiencing psychosis. Many people experiencing mild to moderate CMD may only encounter their general practitioner (GP) with regards to such issues, making traditional sources of data (such as hospital admissions) inappropriate for such studies. Caveats concluded, the secondary literature provides a complex picture with significant heterogeneity across ethnic groups and their risk rates across diagnostic categories (Bhugra and Bahl, 1999; Fernando et al., 1998; Lester and Glasby, 2006, p.188; Nazroo and Iley, 2011; Rogers and Pilgrim, 2014, p.56; Synergi, 2017). Key trends, observed over several decades are highlighted on p.52. The following provides a more detailed overview of these trends and those signalled in Tables 2 and 3.

Undoubtably the most researched trend is the significantly elevated risk of diagnosis of psychosis – particularly Schizophrenia – among the UK's black population, with the highest number of studies focusing on the UK's African-Caribbean population. Secondary literature often quotes risk levels of 3 to 5 times above that of the white/white British reference population. Though an influential study in the 1970's placed diagnosis rates as higher than most studies conducted subsequently (Rwegellera, 1977), research concerning black African and African-Caribbean groups have consistently supported this trend since the early to mid-1960's (Bhugra

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[25] It is in the late 1990's that studies in this area appear using improved, though still flawed, population and ethnicity data from national surveys such as the Census. It is also around the early 2000's that research from two major studies – EMPIRIC and AESOP, both looking at rates of mental health issues/distress among BAME people – began to publish their findings.

[26] Having conducted a population-based study to determine CMD trends across BAME population groups, Shah states that 'The common mental disorders in ethnic minority populations in the UK have been subject to very little study.' (Fryers et al., 2004, p.s13)

et al., 1997; Cooper, 2005; Fearon et al., 2006; Harrison et al., 1988; Halvorsrud et al., 2019; Hemsi, 1967; Littlewood and Lipsedge, 1981; McKenzie and Murray, 1999; Morgan et al., 2009; Qassem et al., 2015; Wessely et al., 1991). Men – especially young men – are often reported as at particular risk of diagnosis (Cabinet Office, 2017; Fearon et al., 2006; Nazroo and Iley, 2011, p.83). Qassem et al. (2015, 1060) noted that black people under the age of 45 were at significantly higher risk of diagnosis than white people of the same age. Several papers also demonstrate significantly higher risk for those who are British-born (Cantor-Graae and Selten, 2005; Harrison et al., 1988, p.643)[27].

Studies considering prevalence[28] have shown considerably lower risk of diagnosis rates for this population group than the studies highlighted above. Using the three community-based prevalence studies available to them, Qassem et al. (2015, 1062) found that though Black populations were still found to have increased risk of diagnosis psychosis in comparison to the white population, all three studies showed a significant reduction in the disparity when compared to risk calculated using incidence data. Whilst risk of diagnosis of psychosis in several prevalence studies remain statistically significantly elevated in comparison to the reference group (King et al., 2005; Qassem et al., 2015), the substantial discrepancy between rates in incidence and prevalence studies does pose some interesting questions. Some scholars view this as supportive of hypothesis suggesting that inequalities relating racism, cross-cultural issues in diagnostic practices and pathways into mental health services are inflating risk of diagnosis for this population grouping. This is further supported by trends found in prevalence studies when considering intersectionally located sub-groups. For example, Nazroo and Iley (2011) suggest that risk of diagnosis of psychosis for 'men; young men; and non-migrant men; was no greater than that for equivalent white people', adding later that 'the higher rate found for Caribbean people in the community surveys was entirely driven by the higher rate found for Caribbean women' (Nazroo and Iley, 2011, p.83). An earlier study suggests that elevated risk rates for African-Caribbean women is predominantly experienced among those women under the age of 30 (Bhugra et al., 1997, p.796).

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[27] Studies concerned with this issue often focus on the African-Caribbean population more than on the Black population over-all.

[28] Particularly community-based studies considering prevalence.

With regards to risk of CMD, drawing from the little commentary available, some elevation in risk rates of depression among Black populations[29] is reported (Cabinet Office, 2017, p.49; Rogers and Pilgrim, 2014, p.55; Shah, 2004). However, research is far from providing a clear and consistent picture. In the 1990's, Fernando highlighted the under-representation of Black people in hospital admissions once admissions on the basis of psychosis had been excluded (Fernando et al., 1998, p.121). This might be interpreted as either under-diagnosis or lesser risk of CMD. Rogers and Pilgrim (2014) report lower risk of diagnosis of anxiety among African-Caribbean people compared to white reference groups. This view is supported by studies such as that conducted in by Lloyd and St Louis in 1999, which found experiences of poor concentration, forgetfulness and anxiety[30] to be less frequently reported by black people (Lloyd and St Louis, 1999, p.65), and findings from a large-scale study conducted as part of the wider national-level EMPIRIC research project (Weich et al., 2004). However, a review of population-based studies in 2004 also found prevalence of CMD to be higher among black people[31], with a particular emphasis on increased risk of depression (Fryers et al., 2004, p.s12). A recent government-led report found black women to be at a higher risk of both depression and anxiety than all other ethnic groups (Cabinet Office, 2017, p.49). An NHS document also reported that increasing suicide rates among young African-Caribbean people, warning that 'self-harm should be of more concern than the perceived danger to others from people with schizophrenia' (NIMHE, 2004, p.12). Further, several older studies suggest that East African women are at a particularly high risk of suicide (Bhal, 1999, p.11; Soni Raleigh, 1996, p.55).

Historically the Asian[32] grouping have not been found to demonstrate the significantly increased risk of diagnosis for psychosis that Black populations have (Fearon et al., 2006; Halpern, 1993, p.602; Leff, 1999; Nazroo and Iley, 2011, p.83; Selten et al., 2007). This perhaps contributes to a lesser focus on this group within SMI-related diagnostic categories, which Bhugra et al. (1997) suggests is a missed opportunity in terms of better determining possible aetiological explanations for

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[29] With the primary focus of sources being once more on African-Caribbean populations.

[30] Within the context of this study, these were among a range of 'symptoms' that might indicate the presence of some form of CMD.

[31] Specifically African-Caribbean and African groups.

[32] Older studies tend to refer to 'Asian'. Studies from the late 1990's refer more often to South Asian, separating this out into Indian, Bangladeshi and Pakistani where possible.

disparities across ethnic groups. Noting substantial differences in the cultures and religious practices of the ethnic groups implicated, they nevertheless suggest that these results are somewhat unexpected given that both groups migrated to the UK around the same time and experience widespread racism. There is also suggestion of differences across national groups within the Asian category. King et al. placed Pakistani and Indian populations at high risk of psychosis, whilst the UK's Bangladeshi populations demonstrated low risk in the EMPIRIC study (King et al., 2005, p.377). This contrasts with more recent findings from the Synergi project[33] which, though suggestive of increased risk of diagnosis of Schizophrenia for the Asian grouping generally, highlights particularly high risk rates among the Bangladeshi population (Synergi, 2017, p.2).

In 2019, Halvorsrud et al. found that risk of diagnosis of Schizophrenia for the South Asian grouping was approximately equal to the white/white British population until the inclusion of two more recent studies. These studies increased risk rates such that they were statistically significantly elevated in comparison to the reference group, with the exception of risk among the UK's Chinese population whose risk level remained low. This systematic review also found the South Asian grouping experienced statistically significantly increased risk of affective psychosis. Looking at intersectional locations within this population group, older Asian women seem to experience an elevated risk of Schizophrenia comparative to white women and Asian people differently located. Though risk of diagnosis for the Asian grouping overall was lower than for the African-Caribbean population, this trend reversed when looking only at women over 30 in each population group (Bhugra et al., 1997, p.796).

Studies focusing on CMD diagnoses among Asian populations suggest significant heterogeneity within this ethnic category, which perhaps contributes to a lack of consistency in findings across studies. Rogers and Pilgrim (2014) report diagnosed levels of anxiety in this group to be overall equal to white reference populations. However, as they acknowledge, when disaggregated by nationality levels of diagnosed depression tend to be as follows: Pakistani population experiencing equal levels to the reference population, with the Indian population experiencing

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[33] A multi-disciplinary project aimed at influencing policy and raising the voices of BAME people experiencing SMI.

lower rates and the Bangladeshi community experiencing much lower rates (Weich and McManus, 2002, p.25). In contrast, Shah (2004) holds that there is no indication of lower risk for any BAME group, including the Asian grouping, reporting instead high risk rates for phobias among Asian groups (Fryers et al., 2004, p.s12). Within this ethnicity grouping, there is once more indications of higher risk of distress among certain intersectionally located women. Whilst Weich and McManus (2002) report lower rates of depression among Pakistani women[34], Bhal highlights high rates of suicide among Indian women; particularly young first-generation migrant women (Bhal, 1999, p.11). Interestingly, particularly given Bhal's findings and trends regarding psychosis and older Asian women, the recent Race Disparity Audit found the Asian grouping to experience significantly higher rates of CMD diagnosis among Asian women compared to white British women. In contrast, rates among men were slightly lower than white British men and significantly lower than white British women (Cabinet Office, 2017, p.49).

Relatively little attention has been paid to white 'other' and 'mixed ethnicity' groups. Studies considering the experiences of migrants sometimes highlights issues among the white 'other' group, particularly those of Irish-born people. However, such studies often do not include or fail to distinguish between 1st and 2nd generation migrants, thus missing opportunities potentially to examine risk rates and experiences of a wider pool of people fitting either the white 'other' or mixed ethnicity category. Studies considering risk of psychosis among migrants generally report increased levels across migrant groups and migrant generations (Brugha et al., 2004; Cantor-Graae and Selten, 2005; Cooper, 2005; Fawcett and Karban, 2005; Selten et al., 2007). With regards to white migrants, Nazroo and Iley report that risk of diagnosis of psychosis among white people was historically found to be significantly higher among those who were not British born (Nazroo and Iley, 2011, p.84). This is consistent with more recent findings that those in the white 'other' group have a statistically significantly elevated risk of diagnosis of psychosis (Fearon et al., 2006; Halvorsrud et al., 2019) and earlier findings of Irish-born men experiencing high risk of Schizophrenia diagnosis (Cochrane and Bal, 1988). Though there is evidence of continued elevated levels for Irish-born people, recent

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[34] In contrast, Pakistani men were found to be more likely to self-report as experiencing depression than white counterparts.

findings from the Synergi project suggest that risk of diagnosis of Schizophrenia might be significantly higher among the Polish population than either the Irish or white ‘other’ categories (Synergi, 2017, p.2). Research on second generation migrants tends to focus on 2nd generation African-Caribbean people as opposed to white ‘other’ or people of mixed heritage, (though such studies may indeed include a significant number of people of mixed ethnicity). As previously noted, significantly higher risk rates of psychosis have been reported with regards to 2nd generation migrants (Cantor-Graae and Selten, 2005; Nazroo and Iley, 2011, p.83). If these studies do indeed include people of mixed ethnicity, such findings are consistent with more recent studies highlighting statistically significantly elevated levels of psychosis found in the chronically under-researched mixed ethnicity group (Halvorsrud et al., 2019; Synergi, 2017, p.2).

With regards to CMD, Weich et al. reported finding the highest rates of depression and anxiety among non-British white people (Weich et al., 2004); in particular Irish participants (Weich and McManus, 2002, p.25). This is somewhat inconsistent with the findings of both the Synergi project and the Race Disparity Audit. The Synergi (2017) report suggested that the highest risk of mood disorder diagnosis sat with people of mixed heritage, though levels were also elevated for people in the white ‘other’ category. This is broadly consistent with an early paper from the AESOP research project which found high risk of diagnosis of bipolar affective disorder among people of mixed heritage (Lloyd et al., 2005). Breaking results down by gender, the Race Disparity Audit found men and women identifying as white ‘other’ to experience less CMD than their white British counterparts. In contrast, women in the ‘mixed’ category were found to experience significantly elevated rates of CMD diagnosis compared to their white counterparts, whilst ‘mixed’ ethnicity men demonstrated lower risk rates (Cabinet Office, 2017, p.49). Other studies indicate specific issues for the Irish group. Shah highlights higher rates of anxiety among Irish-born people (Fryers et al., 2004, p.s12), whilst Peate notes studies indicating elevated levels of depression, self-harm and suicide in Irish men comparative to British men (Peate, 2012, p.84).

Appendix 18: Methodological issues in epidemiological research

The issues described below relate primarily to epidemiological studies considering risk of diagnosis (and illness/distress), though some also impact on research regarding experiences of mental health services. Historically, research regarding BAME mental health inequalities focused on quantifying differences of incidence or prevalence[35] of particular mental health issues/distress across ethnic groupings prevalent in the UK population. Issues inhibiting the building of an accurate and comprehensive picture include:

- data is often problematic to gather and can include significant inaccuracies;
- data lacks sufficient detail to highlight heterogeneity in broad ethnic groupings; and
- reliance on quantitative data combined with the two previous issues, plus the problematic nature of core concepts, makes the causal relations between aetiological factors difficult to determine.

Difficulties gathering data of sufficient reliability and accuracy arguably biased the field, particularly in the early days of research, forcing the use of incidence rates as a proxy for 'illness'. Incidence is usually calculated using hospital admissions data. An alternative is to calculate prevalence, which requires wider sources of information so as to include people living in the community. Whilst admissions data is more readily accessible than population data, it is not unproblematic. Issues include ethnicity not being systematically recorded (Cochrane and Bal, 1988, p.364), and people with pre-existing diagnoses being recorded multiple times if they present at different hospitals (Nazroo and Iley, 2011, p.90). Such data may also be biased by variation in health-seeking behaviours or pathways to care across ethnic groupings (Halvorsrud et al., 2019, p.1319; Rogers and Pilgrim, 2014, pp.56–7).

The significance of such issues were brought to the fore in a paper contrasting the results of three community-based studies estimating prevalence of psychosis to an aggregate of results found using incidence rates. It found that, though both types of study found increased risk of psychosis amongst black African and African-Caribbean populations in comparison to the white population, all three prevalence

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[35] Incidence generally refers to the number of first-time diagnoses made in a given time period, whereas prevalence counts the total number of people with a given diagnosis at a given point or time period.

studies showed a significant reduction in the disparity when compared to risk calculated using incidence data (Qassem et al., 2015, p.1062). Some scholars view this finding as supportive of hypotheses suggesting that inequalities resulting from racism, cross-cultural issues in diagnostic practices and pathways into mental health services are inflating risk of diagnosis for particular BAME groupings. Nazroo, for example, points to this 'inconsistency in estimates of risk between clinical incidence studies and community survey studies' (Nazroo, 2015, p.1065) as highlighting the potential for misleading results in studies that do not adequately problematise the use of hospital admissions (or similar) data as a proxy to data on actual diagnosis or presentations of mental health issues/distress. This is further supported by trends found in prevalence studies when considering intersectionally located sub-groups (see Appendix 17). Improvements in data collection have been made. For example:

> more informed epidemiological work has displaced some old assumptions[36]… We are now faced with a more complex picture in relation to the relative impact of racism and social exclusion, with socioeconomic factors predominating the latter. (Rogers and Pilgrim, 2014, p.53)

One such improvement has been the greater disaggregation of population data by ethnicity[37], enabling exploration of variations in trends occurring within or across broad ethnic groupings. For example, studies using Census data prior to 1991 often actually calculated trends among migrant groups; British-born people of minority ethnicity would be missed as previous Census' asked for country of origin, not ethnicity (Census, 2015). Additionally, heterogeneity within broad groupings – i.e. 'South Asian' – are increasingly reported. Yet such data still often struggles to provide the intersectional detail that might lead to the sorts of granular understandings required to really grasp important 'within group' trends.

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[36] I take 'old assumptions' to refer to a reliance on bio-genetic explanations.

[37] E.g the 1991 Census introduced questions regarding people's ethnicity and health for the first time. Subsequent Census' have increased the number of options available for people to tick regarding their ethnicity (Census, 2015). This enabled more detailed consideration of health and minority ethnicity status to be explored (Modood et al., 1997, c.7). Another example is the 'ethnic boost' in the 1999 Health Survey for England.

Appendix 19: Alternative understandings - somatisation

Western medicine has a very particular way of conceptualising mental health that is not shared by all cultures across the globe, despite the Global Mental Health agenda. Some of the easiest differences in understandings of mental health result from alternative beliefs in the causes of mental health issues/distress. For example, the belief among some cultures that 'madness' is caused by spirit or demon possession. Within western societies exists the concept of spirits and demons, even if the idea of demon possession is shunned by western medical practices. More complex to translate across cultures are the different ways in which cultures conceptualise disease, illness and/or distress. This is particularly so when the cultures across which translation is being sought have fundamentally different worldviews, particularly around the idea of the 'self' or the body/mind/spirit.

Such differences may even make consideration of different aetiological beliefs difficult if the person seeking to understand does not have a sense of the worldview from which such beliefs stem. For example, a person brought up and educated in western traditions may struggle to understand Traditional Chinese Medicine's (TCM) practice of identifying a 'pattern of disharmony' (Kaptchuk, 2000, p.4) within a person when seeking to heal an individual presenting with certain symptoms. This is because illness in this TCM's 'worldview' is perceived of as reflecting disharmony of or imbalance within the whole body. The body here should be understood as including the mind, as the body and mind are generally understood as one, not dichotomously as in western biomedicine. This differs significantly from the way we conceive of mental health in the traditional western approaches significantly. Arguably, in cultures where the mind and body are not conceived of independently, the concept of 'mental health' itself may seem nonsensical. For the person brought up in western approaches, it may seem illogical to treat the whole body for an illness they believe to be firmly located within the mind. As Kleinman notes, whilst disease is *often* influenced by culture (i.e. – impacting the aetiology or course of disease), illness is *always* culturally mediated[38]. Kleinman demonstrates this idea through an

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[38] Kleinman writes that 'Disease can be thought of as malfunctioning or maladaptation of biological or psychological processes. Illness is the personal, interpersonal, and cultural reaction to disease. Although social and cultural factors may or may not influence the aetiology, pathophysiology, and course of disease, they *always* influence illness.' (Kleinman, 1977, p.9)

exploration of theories of somatisation. A still contentious area, I too will spend some time on this phenomena as it provides a useful illustrations of some of the difficulties in working cross-culturally with regards to mental health issues/distress.

Somatisation, then, generally refers to the presentation and experience of mental health issues/distress through physical symptoms. This phenomenon is usually associated with people originating from Asia (Patel and Shaw, 2009, p.19). Examples of somatisation include that which might be categorised as ‘depression’ in Western psychiatry being experienced and expressed as physical pressure on the heart and chest area, a ‘falling’ of the heart or ‘thinking-too-much-in the heart’ (Kleinman, 1977; Fenton and Sadiq-Sangster, 1996, pp.71–77). It has been noted that though people presenting with pressure on the heart might point to social and familial stressors as causal factors, they insist that they experience physical ailments and that it is there that requires treatment rather than any emotional issues. Such presentations have been observed in numerous diasporic Asian communities in the UK (Arshad and Johal, 1999; Patel and Shaw, 2009; Fenton and Sadiq-Sangster, 1996; Bhatt et al., 1989).

Controversy, however, surrounds theories of somatisation. Disputes might arise from the multiple ways in which the phenomenon referred to as somatisation is interpreted. For example, it might be regarded as any of the suggestions below:

> (a) a non-recognition of mental illness, so that ailments are always presented as somatic, (b) a non-recognition of the link between physical ailments and emotional states, (c) a presentation of ailments as somatic despite some recognition of mental distress, and (d) simply a non-presentation of mental symptoms to bio-medical doctors. (Fenton and Sadiq-Sangster, 1996, p.71)

Different theories lend themselves more or less to universalism or relativism regarding disease and illness categories. Disputes between causal theories become controversial in this context due to concerns of ‘cultural imperialism’ and generally involve scholars disagreeing over the degree to which mental health can be understood as universal or culturally relative (Ryder et al., 2002, pp.3–5). For example, interpreting certain phenomenon experienced within specific cultures as simply a different presentation of the same ‘disease’, involves applying a universalism that denies ontological difference though it allows for epistemic difference. The inherent danger, for ‘relativists’, is that such translations lead to a form of cultural imperialism that favours one epistemological framework (here, Western psychiatry) over others. Alternative frameworks might include different understandings of the mind-body relationship, where they are understood as ‘one’ rather than in a dichotomous relationship, enabling more embodied experiences of emotional and psychological distress (Fenton and Sadiq-Sangster, 1996, p.69; Ryder et al., 2002, p.11). Another example might be understandings of the self that are more relational than the individualistic approaches to the self-provided in Western ‘psy’ disciplines. Fenton and Sadiq-Sangster (1996) suggest that such differences might explain why Punjabi women in Bristol experiencing ‘thinking-too-much-illness’, sleeplessness and sorrow (symptoms often linked with depression in Western societies) were less likely to express ‘statements of low self-regard’ – a symptom common to British people with diagnoses of depression.

Fears of such cultural imperialism in global mental health research expressed by scholars today stem perhaps from the approaches taken by scholars working in Asia in the 1950’s/60’s. They observed that patients tended to speak of physical ailments whilst displaying symptoms of distress or relaying causal factors that would lead to diagnoses of mental health illness in Western medicine. As such, an explanatory model was developed that posited such behaviours as the somatisation of emotional and mental distress. This generally took a deficit model approach, suggesting that ‘Asians’ relative lack of psychological mindedness and a putative deficiency of psychological descriptive terms in Asian languages.’ (Lin and Cheung, 1999, p.776). There is indeed a lack of comparative terms across some languages when it comes to mental health. For example, there is no direct translation for ‘anxiety’ or ‘depression’ in multiple Asian languages. However, it should be noted that terminology such as ‘depression’ did not always exist in the Anglo-Saxon and Latin-based languages of Western societies either (Rogers and Pilgrim, 2014, p.65). Rather, it emerged from the advancement of highly culturally-mediated disciplines concerned with mental health issues/distress. In this way, Rogers and Pilgrim (2014) suggest that such disparities may in fact highlight weaknesses within Western epistemologies rather than deficits in other cultural understandings.

Additionally, research also indicates that Asian people are indeed very aware of their emotional or psychological states. However, these states might not be interpreted as mental illness (or madness) in themselves, even if they are acknowledged as a form of illness (i.e. ‘thinking-illness’), as linked to physical ailments, and as causal factors in the development of mental illness (Fenton and Sadiq-Sangster, 1996, p.76). This might result from the existence of beliefs about non-medical illness that are not present in British culture, or indicate a cultural difference between some Asian cultures and Western psychiatry with regards to the point at which distress is pathologized. Alternatively – or additionally - cultural norms might lead people from some Asian groupings to be more reticent in sharing such experiences (particularly in healthcare settings) than people from Western societies might be. For example, stigma regarding mental illness or public displays of emotion might encourage a reticence to discuss emotional states (Lin and Cheung, 1999, p.776).

Leading the way for such challenges to the early formulation of the somatisation thesis was the work of Kleinman. Whilst acknowledging the presence of somatised experiences of emotional and mental distress, he positions this not as resulting from epistemological deficit but as ontological difference resulting from cultural difference. He suggests that earlier explanations failed to adequately account for the fundamental way in which culture mediates the ‘form and meaning’ of sicknesses; in particular chronic sicknesses where concepts of illness form and inform experiences of ‘disease’ (Kleinman, 1977, p.9). Illustrating how somatisation presents, he writes that:

> Patients frequently use physical complaints as a legitimated metaphor to indirectly express personal and interpersonal problems. Such terms… link popular beliefs about body states and illness with psychosocial experiences and social relations. (Kleinman, 1977, p.6)

Somatised presentations of distress in a culture that does not segregate the mind from the body should be understood not as a denial of emotional and mental distress (which would be to promote ‘category fallacy’, see p60), but a different experience of it as a result of cultural mediations. Additionally, it enables a distancing from highly stigmatised views of mental illness. Thus, somatised presentations of distress might provide ‘culturally sanctioned ‘idioms of distress’’ (Lin and Cheung, 1999, p.776). In this way, they enable people to take up a ‘medical sick role’ without attracting significant stigma. Akin to the Parsonian sick role[39] hypothesised in Western societies, this ‘releases patients from responsibilities and obligations… and affords them care’ without tarring them and their families with the stigma and serious consequences that can arise from admission of mental health issues/distress (Kleinman, 1977, p.6).

Fernando (2010), in providing a broad overarching view of the ways that different worldviews impact on the resulting variety in understandings of mental health issues/distress and illness globally, highlights one major dividing factor between ‘western’ and many non-western approaches. These relate to whether or not the culture holds to holistic or non-holistic understandings of the individual or not. Situating western approaches to mental health as non-holistic, Fernando highlights that ‘holism instils an ideology that enables people to experience external and internal experiences as *one and the same*; subjective *and* objective at the same time.’ (Fernando, 2010, pp.41–42) Thus, traditionally western non-holistic approaches that understand ill health as resulting from an external or internal cause may not align with the experience of distress people from more holistic traditions have. Additionally, Fernando highlights that cultures with more holistic conceptualisations of illness and distress generally promote:

> a sense of health as a harmonious balance between various forces in the person and the social context as opposed to seeing health as individualised sense of wellbeing. (Fernando, 2010, p.42)

Unfortunately, I am unable to explore in this thesis the numerous different ways in which mental health issues/distress and illness are conceptualised globally in different cultures. However an awareness that these different beliefs exist, that they

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[39] The Parsonian ‘sick role’ articulates a conceptualisation of the role that capitalist societies, such as the UK and USA, expects people deemed ‘ill’ to play during their period of illness. This role consists broadly of several rights and their accompanying duties for the ill person. The rights consist of an exemption from holding blame for their present ‘incapacitated’ state, an exemption from ‘ordinary daily obligations and expectations’ (Parsons, 1975, p.262) and a right to be provided with access to healthcare (Varul, 2010, pp.76–77). Accompanying duties, then, consist of a duty to recognise the undesirability of this ‘incapacitated’ illness state. This gives rise to obligations regarding retreating from everyday life (Varul, 2010, p.77) and seeking to get well; wherein lies the duty which consists, ‘if the case is sufficiently severe, of seeking help from some kind of institutionalized health service agency.' (Parsons, 1975, p.262).

must be understood within the context of the cultures from which they emerge and hold integrity within that context is important when considering possible issues contributing to BAME mental health inequalities in the UK. Additionally, it is important when considering the understandings that some of participants in this research articulate. Whilst differences in approaches to this topic might be particularly evident amongst the beliefs of those who migrated to the UK, all participants have been exposed to multiple cultures in one form or another such that their worldviews stretch beyond simply traditional western perspectives. It is for reasons such as this that scholars from transcultural and critical mental health perspectives caution against a blanket approach in the implementation of the Global Mental Health agenda (Jayawickrama and Rose, 2019; Kirmayer and Pedersen, 2014)

Appendix 20: Testimonies of lived experiences of mental health issues/distress

This section of the chapter explores both the accounts that participants gave of their own lived experiences of mental health issues/distress. I then continue by exploring various supportive factors in participants' lives or actions that help them to manage and cope these experiences. It is perhaps in this section that we see in greatest clarity the moments of helplessness and disempowerment that appear at times in most participants' testimonies. However, these are also indications of resilience, the importance of maintaining agency and the will to resist – aspects of most participants' accounts that resonate often.

1 Lived accounts of experiencing mental health issues/distress

Not all participants speak in detail about their personal experiences of mental health issues/distress. Mya and Peter tend to focus more often on generalised beliefs than providing detailed personal experiences. However, with regards to personal experiences, Peter indicates that having a '*depressive mood'* while Mya speaks of her '*diagnosis of anxiety*'. Though Mya indicates '*having some symptoms that aren't* (.) *you know, are not anxiety symptoms*' and might '*lead me to be getting a different diagnosis*', she does not expand on this. Both express having internal battles to cope with past or present phenomenon. For example, Peter speaks of times when he '*just sort of struggled, struggled along'*, where he had to '*dig in and try to, fight back',* sometimes making *'headway and sometimes not'.* Mya's battle is expressed more in terms of feeling '*this huge pressure to fit yourself into the box of 'normal'.'* Both also highlight difficulties dealing with everyday tasks that they would be able to undertake were it not for their mental health issues/distress. For example, Peter indicates being unable to work at present and having difficulties with concentration. For example, when I originally asked if he'd like to read my write-up of our discussions, he stated that '*it's a bit of a challenge when it comes to, sort of reading length of things because, currently I'm experiencing mental* (.)'. Mya's description focuses more on her inability to work at present, stating '*I am unwell at the moment and I can't cope with work*'. This is set within the context that she thinks most people, including herself, desire to have purpose, employment and to be helpful in society.

Therefore, deviation from this is one way that she experiences her mental health as impacting on her life.

Samaiya - who seems to experience milder mental health issues than several other participants - often speaks of the relationship between her physical health, learning disabilities and mental health issues. In describing the challenges Samaiya faces, her sister explains that '*some days you know her hip is hurting a lot so she will find it harder, or she's mentally not there or she's feeling depressed she doesn't feel like doing anything.'*. Samaiya agrees, stating *'Yeah, I feel like sometimes just lying down and not doing anything. I just feel like that'*. The combination of her mental and physical health issues, together with challenges related to her learning difficulties, leave her feeling tired and in need of *'resting'*. Whilst she talks of immersing herself in family life to lift her spirits, '*showing'* that she is okay, she confides that '*Inside I take everything'*, adding:

> *Sometimes I feel like I'm not gaining things in my life. What I wanted to do things which I haven't achieved and now I see people studying and doing things, I think to myself I wish I was* (.) *you know going back to that, my studies and doing again, you know, but you will never come back. That's it.*

A sense of helplessness imbues her descriptions of her current situation and situatedness. By this I mean that her intersectional location at the axis of mental and physical health and learning difficulties appears to fuel a sense of helplessness regarding her own capabilities and ability to realise her aspirations. This seems to both trigger her depression and is a large part of her actual experience of mental health issues.

Andeep reports having had depression many years ago following the death of his father. When speaking of his present mental health, Andeep contradicts himself regularly, stating one moment that he does not have depression and the next that he might. This made discussion of his present experiences with mental health issues/distress difficult. However he explained that in the past he also experienced nervousness such that his hands would tremble. He also spoke of having drunk a lot in the past, inferring alcohol dependency. Unfortunately, Andeep provided no further detail as he states that it was too difficult to think about that time.

Satch, Samantha and Mahdi report experiences that indicate more acute mental health issues/distress than other participants though only Mahdi readily accepts a diagnostic label (which is of PTSD). However, all three have made multiple suicide attempts. In fact, Satch '*tried dying'* twice over the period of this research and alluded to one attempt previous in his life. The first time during this research was only 5 days prior to our second meeting. Satch states '*That's twice I've tried dying. You see that is mental health'*, continuing '*You know, when you're pissed off and you just wanna go to sleep and not wake up.*' In the same discussion Satch describes other experiential phenomena, such as it being '*hard for me to even, keep me, what I'm saying, I keep getting mixed up and, I'm so fatigued.'* A second attempt at dying took place only a few months later, leading to hospitalisation.

Samantha reports having attempted suicide three times previously. Mahdi does not stipulate the number of attempts he has made, but shows me a scar on his neck having '*recently had, this suicide attempt attack. I cutted my neck.'* Though he does not feel suicidal at the time of our first interview, Mahdi is conscious that such action could be easily triggered again, reporting still having self-harming tendencies. He states '*When I'm upset I'm up so, anger and I feel like it's better I die*'. In a later discussion he describes having suicidal thoughts following his wife recently leaving him, deciding however that he has been through too much else in his life to let this trigger another suicide attempt. Though Mya mentioned having had suicidal thoughts, she expressed feeling that acting on these would be a sin, quickly clarifying that she does not, however, think that people who take their own life are bad people.

Both Mahdi and Samantha describe experiencing hallucinations. Samantha was hospitalised on a number of occasions during this research and reports having been put in induced comas as part of her treatment[40]. One hallucination during

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[40] While Samantha was in hospital we had several phone calls where she mentioned having been put in induced comas. When we finally met in person for the second time she explained that at least one of the induced comas she had was the result of a serious bowel infection and being pumped full of anti-biotics. Samantha: Field notes 190808.

hospitalisation involved an extremely emaciated person was walking towards her. This person was soon joined by more and more extremely gaunt people until a whole crowd was coming towards her. She also describes hallucinations experienced while at home, a common one being that someone is lurking behind her. She states that these are scary for her. Mahdi's experiences seem to be an ongoing part of his mental illness, encompassing both visual and auditory hallucinations. As the participant who described psychosomatic experiences in the greatest detail, he explains that '*even at home I have problem in my head. Like, I see it, I hear noises sometimes like* (.) *uh, screams*.' Mahdi speaks of these often in the context of panicking and paranoia, where accounts of hallucinations blend with experiences where he '*got paranoid'* or has vivid nightmares. Recounting a particular incident whereby he thought his neighbours were colluding to have him deported – he was still awaiting the outcome of his asylum claim - Mahdi states that upon hearing ambulance sirens:

> *I was panicking. I was like / I was seeing people who died before, ghost, kind of ghosts. Or maybe it's all in my brain. I was thinking that somebody went just inside the kitchen, and I would have get up and check, but there is no-one. And I used to go to the toilet the same, and* (.) *and sometime when I / well I have most of the time nightmares. The nightmare is only the, the only thing I can remember is the, the, the night my parents killed, got killed and that blood and, the things that I have there*

Though other participants do not speak of nightmares as Mahdi does, several do speak of difficulties sleeping such that it either impacted on their ability to cope or is something they actively had to manage. For example, Satch smokes marijuana at night to aid his sleeping, watching nature or history documentaries when he wakes early in the morning due to physical pain. Peter mentions listening to a radio broadcast over the phone from people he respects, such as '*a proper qualified doctor'* who is also a *'holistic practitioner and he's moved away from the pharmaceutical stuff because he / it didn't make any sense to him*.' Peter does not mention what causes his sleep issues.

Fear, also, is present in several participants' testimonies. Both Mahdi and Samantha speak of feeling that people are behind or around them in a menacing way, such that they feel '*paranoid'* in their day-to-day lives:

> Samantha: *I've got anxiety. I don't like someone walking behind me. It freaks me out. I need a person to be in front of me so I can see them.*
>
> Stephanie: Yeah, yeah. (.) You can see if they're [turning towards you
>
> Samantha: *You can see, if they're coming] towards me. But sometimes you find me going like that* ((flinching)). *When I went into a shared house, I'd be* (.) *I'd be in the kitchen, and I'm looking that way and I can sense that there's someone behind me and I'm going like that* ((flinching)).
>
> ----
>
> Mahdi: *I'm not really good with the crowded places. The crowded places make me paranoid and I feel like someone is going to attack me, or everybody is staring at me. I feel uncomfortable and I start / for example, when I walk in the street and a* ((footfall)) *somewhere I* (.) *keep turning my back. I am scared. I keep turning and, it's a bit weird and society and the public that somebody / just sometime it does affect me that why / and two minutes this guy's watching a couple of times back.*
>
> Stephanie: Yeah, they're wondering why you're so
>
> Mahdi: *Yeah, yeah, why I'm looking back, back like, while I'm walking. But I, I'm kind of scared all the time like someone's going to attack me from back or something.*

In Mahdi's testimony, fear present and explicit in the way that he describes experiences of mental health. These fears often linked to being refused asylum in the UK and being sent back to Afghanistan where he had been tortured for 7 years by the Taliban, and are lived on a daily basis. Samantha does not tell me the triggers for these experiences, though she separately mentions experiencing domestic violence at the hands of her ex-husband. Both Samantha and Mahdi interpret such experiences as linked to internalised fears rather than the presence of any real external threat being present. Hence Mahdi's description of being '*paranoid'* and Samantha's linking such behaviour to '*anxiety*'. As such, they are aware that their behaviour in these situations are likely to be interpreted by '*society and the public'* as '*weird*'. Mya also alludes to anxiety-driven fear of strangers when she states that '*partly cos of my mental health position I don't like really going out in the evenings and things like that, I don't feel safe.*'

Whilst he does not speak of hallucinations, Peter does speak of paranoia, though very differently to Mahdi. Peter is deeply sceptical of mental health labels that result from people being deemed '*paranoid'*. He implies that often people from disadvantaged backgrounds are '*treated as almost you're paranoid*' if they '*see certain things taking place'* that don't conform to the dominant view in society. He continues that '*It's as though you should just accept, conform and get on with it*', otherwise you risk being seen as buying into '*Conspiracy theory'* and/or being '*paranoid'*. This can lead to '*some people, people are being decided, people are sectioned and so on, when sometimes it's not necessary*'. Though Peter does not specify having personally been accused of being paranoid, such experiences are implied when he situates himself as a non-conformist and, in later discussions, describes noticing racist microaggressions directed at him that others (particularly non-racialised people) do not perceive. Giving an example of a micro-aggression he has experienced, he states that '*this is where I think a lot of people, are accused of being paranoid*.' Peter feels that reports of micro-aggressions are often viewed by those not experiencing it as 'paranoia'. This is particularly the case where the racism is not overt, such as with many micro-aggressions motivated by racial prejudice rather than racism.

Whilst all participants mention being anxious and/or describe situations where anxious feelings and behaviours surface, none give such detail about the psychological (including psychosomatic) impact of this on their everyday life as Mahdi. For example, in addition to the above exert about walking in the street, Mahdi describes physical responses to distress, stating '*when I get very* (.) *very upset, my body shakes, and my, my, all of my body shakes and I start sweating, my heart beats gets short* (.) *so fast, and I start like, my teeth, grinding my teeth.'* Mahdi later explains that '*I don't notice sometime but some, some people who knows me, they say they do some, they say 'you do sometimes weird things', like* (.) *like, doing my fingers* ((flicking)) *or just staying like this, like this, like this* ((rigid ticks))'. These descriptions are generally provided in a matter of fact way. Additionally, like Satch and Peter[41], Mahdi also describes concentration issues:

> *sometime I'm thinking about something else, and I jump I talking about something / I don't, I can't really focus on something. I have problems / I have memories problem that, I, I put something at home and I forget it very soon. And I have to search for it hours.*

He later explains '*all my brain I can feel noise like very bad like for one hour, two hour'*. This leads him to feel that he is *'not very stable mentally'* at the moment, experiencing a '*mood problem that I have on off on off'*. Mahdi also speaks of his need for his wife to help him with tasks at home, later evidencing this claim with examples such as *'my nails are too long, mostly I don't go to haircut and this stuff. This is all my wife. It's not / This person you're looking is made by my wife.'* After separating with his wife, Mahdi comments that he does try to push himself to have productive days, but admits that at times it has taken a friend to tell him to get his hair cut before he tends to himself.

Satch does not speak of his behaviours and responses to difficult situations in the context of psychosomatic experiences or symptoms. However, he does display signs of significant anxiety over the period that he is acutely distressed - continually returning to subjects he is concerned about, being visibly frustrated and at one point asking me for help with paperwork for various appointments as he feels overwhelmed. Satch is aware that his behaviour is sometimes different to other people's, reporting that he can become '*feral*' when he does not receive the support he requires. Use of the word feral connotes, to me, an awareness by Satch that he can sometimes stray beyond sanctioned ways of behaving in our society. However, this does not translate into a view that such responses are 'symptoms' of a health issue. Rather he views it as a natural response in the context of repeatedly facing

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[41] Though Peter only alluded to concentration issues.

adversity and not having been equipped as a child with the skills required to handle such situations.

2 Individualised coping mechanisms

2.1 Taking action

Other coping mechanisms discussed are highly specific to the participants identities, preferences and hobbies. For example, Mahdi speaks on a number of occasions of going on walks in parks: ‘*At the evening time I go to the park because it’s not crowded this park. I go walk. So, I walk a lot at the night so I’m tired, I can go to bed*.’ Walking in quiet places helps to dispel some of his energy. In later discussions Mahdi cites the significant positive impact that being surrounded by nature has on him. Satch refers to a range of mechanisms he employs to cope with the anxiety he feels around the security of his housing and financial situation. For example, it is extremely important to him that he ‘*put all me / as much spare money as I can be in a month ahead in water bills, £30 in the electric and £30 in the gas*’. Satch expresses that at one point he ‘*was behind on bills and everything, and that all worries me’.* Satch is aware of the additional strain that being without electricity and gas would cause him, and does all in his power to avoid such a situation from occurring. Peter speaks of proactively seeking alternative approaches to medicine to manage the health issues and distress that he experiences. This includes researching alternative medicines and understanding the role of nutrition and deficiencies in health issues.

In contrast, Andeep, Samantha and Samaiya speak of finding ways to distract themselves. Samaiya speaks of looking after her nieces and nephews as helping her. For Andeep, distractions include keeping his living space clean and doing the cooking. He remarked that if he stopped to think about everything, he would quickly feel overwhelmed. He noted that physical work helps him to manage his nerves, later adding that he wants to work outside or his home as he doesn’t want to get lazy. Getting lazier, he states, makes a person become more ill and turns them into Zombies. However, whilst recognising this and his desire for a job, he is also conscious that there is a balance to be struck, noting that he is unsure he has the stamina to work and care for his mother at the moment. Work was a central coping mechanism for Samantha, who speaks of having immersed herself in work before her physical health declined: '*Work was a distraction. I would just leave all my problems at home'.* She reflects that it was *'the only way, like, for me* (.) *to try and reduce all of this stuff, I put myself into work.'*; '*all of this stuff'* being the stress and depression she felt. She describes ensuring she was trained on all areas of her job to ensure she would always be busy. Staying busy for Samantha means '*my brain is not working, its concentrating on that*' - meaning work - instead of the things causing her distress. Drawing a comparison with the situation she found herself in at the time of our first discussion, she states '*I'm literally mental right now. Because I'm not doing anything*.' Feeling that '*my body is controlling me. I can't control it.*', her declining physical health does not allow her to engage in the coping mechanisms she has previously turned to, such as high-energy exercise like Zumba or tennis.

2.2 Mechanisms harmful to the self

Some coping mechanisms employed are more harmful to the self and might be perceived also as evidence of their mental health issues/distress. Andeep, Satch and Samantha experience(d) significant substance misuse issues. Whilst Andeep only mentions this in passing, stating that he used to talk a lot when he was drinking – inferring alcohol abuse, if not dependency. Satch and Samantha provide more detail, speaking of this primarily as a coping mechanism rather than as part of their experience of distress itself. For example, Samantha states that she '*started drinking very heavily* (.) *just to lock everything else*', expanding that '*I'd lock myself in. Then alcohol and cigarettes.*' She explains that she does not drink every day, but that when she does, she drinks until all the available alcohol is finished or she passes out. Speaking to Samantha nearly a year later at a time when she has been sober for roughly 4 or 5 weeks, she states '*I don't know if I've stopped or not, all I know is life is getting greater.*' She explains that, though she is pleased not to be drinking at present, she has not made an active decision to stop. Rather, there has been a '*fight between Samantha and Samantha's body*' whereby her body – which rejects the alcohol and the harm it is causing – is winning as it will not allow her to swallow any alcohol. Samantha also cautions that it is wrong to think of people who drink excessively as having 'given up' on life. She explains that in part she drank to be how others wanted her to be, i.e. '*happier*'. Drinking served a double role; first, it helped her to find oblivion at times when she needed to '*lock everything'* away from the world. Secondly, it helped her to meet the expectations of those around her to behave a particular way when she did socialise.

Though Satch's introduction to drugs began in his teen years and are intricately linked to becoming involved in a particular subculture (the Northern Soul music scene), he links addiction and drug-use in his later adult years to coping with distress. For example, Satch speaks of times when '*you feel sorry for yourself really bad*' and '*instead of being angry, I was just sad*.', stating '*that's why, you know, I smoke chemicals.*' In a separate discussion, Satch reflects '*I think I did it a lot, to try and, soothe me mind at certain times, certain dates.'*, giving the example *'Christmas, is a horrible time for me*.' Satch reports having been an addict for 35 years, using drugs ranging from smoking marijuana to injecting heroine. He has now been in recovery for approximately 15 years, describing himself as *'an old man and still an addict, but I'm not using needles anymore, or buying heroin and crack. I just, I ain't got the time for that anymore*.' Instead he primarily uses prescription methadone and smokes marijuana. Whether or not Satch views substance misuse as simply a coping mechanism, or as a presentation of mental health in itself, fluctuates. In one discussion he angrily declares '*They're forever trying to label me mentally ill and it makes me feel bad*.', being more comfortable with the label '*addict'*. However, on a separate occasion he states that he views addiction as one of three strands of mental health. Interestingly, the first statement was made shortly after his first attempt at dying, whilst the second came at a time when he felt more settled and secure. I have not included Mahdi's self-harming here, as Mahdi frames this only as a symptom of his mental illness, not as a means of coping when overwhelmed.

Appendix 21: Lyrics: ‘Dispear’

[redacted]

[redacted]

[redacted]

[redacted]

[redacted]

[redacted]

[redacted]

(Marley and Jones, 2010)

[Lyrics redacted from the digital version of this thesis for copyright reasons]

Appendix 22: Staff extended extracts - issues of diagnosis

There are four extracts included here:

1. Ruth: Misdiagnosis of self
2. Ruth: Misdiagnosis of son
3. Ruth: Religious woman
4. Marcia

1 Ruth: Misdiagnosis of self

Ruth: *And my own experience was like, with something that I would never wish on anybody. I was talking, seeing a neurologist and I'm saying to her that 'listen, I'm not'. She wouldn't, she didn't even have time to take my history. Because she had patients waiting, and I could see she was getting frustrated and anxious and she wanted to go straight to the back. And she was telling me 'but I can't see anything on the screen', she went in 'I can't see in the records' she was very sharp with me and I thought 'Oh my god,' I was getting flashbacks from all the patients I have treated, you know, what happened to them. And so in the end, her conclusion is 'I think you need to go men.. be referred to the mental health team, and you'll be put on medications, and observed and' yeah, she, she, she actually*

Stéphanie: Woah

Ruth: *'I'm going to recommend this to your GP, because I think you are mentally, you have some mental definitely / it's nothing to do with, um, neurology. It's nothing to do with'. So she did refer me. She couldn't refer me directly, she would have done that. So I went to my GP. Um, cos I was initially dealing with one GP, and I went to a second GP and I said to him / the second one was more understanding, though he also didn't really understand what was happening to me. Guess what. To cut a long story short, I had a fall from a ladder a few years back... nasty fall, and I also suffer from carpal tunnel syndrome I don't know if you know, as well as Raynaud's disease.*

Stéphanie: I don't know Reynolds

Ruth: *Reynaud's disease my fingers go into spasms and turns colour, especially when the weather is cold. and it's so painful because no circulation. And I was typing volumes of work with that condition, and I have bi / bilateral carpal tunnel. I had, with* *the fall I had surgery cos I had, I've been operated. I went back to work only to find a pile of work waiting for me, like I said. And recommendations made by occupational health, the trust would not adhere to it because it was too many, they can't accommodate. So they said to me ' sorry'. So I was working under very unhealthy conditions, and getting home at midnight.*

Stéphanie: Ohhh!

Ruth: *So, unknowingly I was causing more nerve damage.*

Stéphanie: Yeah.

Ruth: *So, basically, finally, after fighting and pushing I refused, they were giving me medications to completely knock me off. And to knock me in my sleep completely. And my heart, what happens in my sleep, when I tell you the symptoms, when I know I said 'no I'm going to die, I'm dying in my sleep'. I think when I mentioned that phrase, 'oh she's, some is wrong with her', cos I'm saying my heart is beating, pounding, so fast. And, and so this 'oh she is agitated, very anxiety depressed', and then, they're saying, it's like 'you have a depressive disorder, and anxiety disorder. All sorts of things'. I was right all the time, guess what? It was only through continuous persistency* (.) *I spoke to some of my colleagues, I said ' this is what is happening. I can't believe that they were saying ' Fight it Ruth. You've got to believe that if you were that ill we would have known'. But then I was getting depressed, because of / not, not even so much because of the illness, but nobody believes you everybody. So*

Stéphanie: Have a low credibility, targeted

Ruth: *Exactly. It's only when I had um, in neuro / I met a neuro physicist who, to carry out nerve damage test and he says 'oh my goodness, you seem to um, you must have had nerve damage for a very long time because it's really worse. I had to have surgery, but they couldn't correct all the nerve damage. When you look at my hands, my fingers are all / I couldn't straighten. It's not straight.*

Stéphanie: Oh, yeah (.)

Ruth: *And it comes from the, the surgery was, it wasn't very successful. So I had to live with, when the nerve pain comes its incredible. To be told 'no, it's not / until they* *saw the results from the neuro / and he was an NHS, he was a top specialist. He wrote his report. Suddenly it turns out that I had severe obstructive sleep apnoea. If you read up about it, it's frightening. To have severe* (.) *So when I finally, they agreed to have a sleep test carried out, I think they thought it was going to come out 'ok, let's just give her a sleep test'. They were shocked by the results. I was stopping breathing every few seconds, continuously. And what was happening is umm, I was making sounds like someone guts spin like in the* (.) *you know when people are about to die there is a kind of noise*

Stéphanie: Yeah

Ruth: *Actually my son, he was only young, he recorded my, my breathing. It's frightening when you hear it. And, there was no oxygen. They carried out oxygen test, oxygen wasn't getting to my brain, so I was confused. That was the confusion. I didn't know where I was*

Stéphanie: That is actually part of starting to die

Ruth: *God*

Stéphanie: So your description [was correct

Ruth: *I could have had*] *a stroke. Easily a stroke. Everything I was describing, because she said to me 'you can't have sleep apnoea and be conscious of it'. No, you can. I knew because I wake up with panting as if* ( )*, I could wake up so many times I was telling her. she said 'no, it's anxiety'. Oh, god.*

Stéphanie: But why do you think (.)?

Ruth: *I had / because she just wouldn't, she was tired. When I, when she saw me it was around 1:30. I think she, she hadn't had a break, I don't know. And I could see she had so many patients. She appeared already restless* (.) *with, and, and I was sort of challenging. She was / all she wanted was to tell me ' No, I think that, I can see the results blah blah blah. The blood test you've had is normal'. They didn't carry out vitamin D. It turns out that I was severely vitamin D deficiency. That also causes confusion, easily.*

Stéphanie: That's quite a basic test to do as well.

Ruth: *And I was complaining of my limbs. And I have, I've always had, I don't know if you know about hypermobility?*

Stéphanie: Ummm, a little bit.

Ruth: *Hyper / hypermobility, that's a syndrome. Hypermobility people, you have extra* ((indicating flexibility))*. Some / do not come with pains and problems, but others do. Like mine, from childhood I was very sporty, a tomboy. But each time I engaged in sports I'm in so much pain and I bruise easily. All these factors, I, uh, and yet nobody, you know and I'm telling them ' Doctor, doctor, do you want to hear. it's a* (.)*', look I'll tell you again, I wouldn't wish it on my worst enemy.*

Stéphanie: I just wonder why (.)?

Ruth: *What happened, I / I've never / I know it happens to people, but I never thought. I thought, ok, I'm a nurse, and seeking help from the NHS from doctors, I'm thinking they would give me at least some*

Stéphanie: Credib[ility

Ruth: *You know*]*, exactly. But, oh my god*

Stéphanie: Why do you think it was that they didn't give you credibility?

Ruth: *I, other, other doctors did, because I saw in the end, in the end I saw so many other specialists. But, the most insulting part, I, I also met others who couldn't be bothered. All that they want, she / she had um, this particular neurologist, I think she comes from / I'm not sure what part of Eastern Europe but she had a strong accent as well, and she seemed to think she knows me. And I actually told her 'But you are not listening', and I think she got angry. Cos it's like ' why are you* ( )*'. She seems to know / uhh, I don't know. Again, thinking everything is mental health if, if this person has confusion, if they are even forgetting their door / um, their keys outside, leaving food / I was burning food cooking and I can't remember I was cooking. So those are acute confusion mast, should have raised warning signals that this person 'Why are they so acutely confused?'. But then she said anxiety, severe anxiety and depression can also cause, you know, confusion. It's true. Cos when someone is severely depressed they can't be bothered, they, they can't* (.) *you know*

Stéphanie: Yeah, yeah.

Ruth: *And I'm saying ‘I'm not that clinically depressed’. And she rolled up, I’m telling you / I, I just / it's, it's a horrific. I had to fight continuously. And then they diagnosed me with fibromyalgia, they said fibromyalgia.*

2 Ruth: Misdiagnosis of son

Ruth: *Umm, another bad experience I had, my son, and I didn't know I had a genetic condition in terms of hypermobility, cos my son was experiencing similar ones. And we went to, uh, I would take him to be assessed because of all the pain he was talking about. Took him to another, uh, we were referred to another NHS hospital. He met with the physio. The physio concludes that he may have mental health. Why? Because in the course of the assessment, I said I had I mentioned about fibromyalgia. Fibromyalgia is another* [*thing*

Stéphanie: Yup, I know] [it

Ruth: *which if*] *you mention it* (.)

Stéphanie: Very contentious

Ruth: *Ahh, it's all in the, yeah, very contentious in the head. I mentioned that I had that, and she suddenly ‘Oh, I think your son needs to be seen by the mental health team’. What, and I said ‘what’, I said ‘I'm a* (.)*’, I said ‘No. He doesn't have a mental health problem’. I said ‘I'm a mental health nurse’, and she said ‘ Yes but,* (.)*’, she didn't believe* ( )*. She has <u>no clue</u> about hypermobility joint, the joint disorder. Because, there are people with hypermobility joint who can do things. When I was little I was called rubber skin, because my skin could stretch*

Stéphanie: [Really ((laugh))

Ruth: *the other part.*] *And I thought it was fun. And then I always used to have <u>pain</u>, excruciating pain, when, you know. But I didn't understand, I didn't connect. In those days I was told I had rheumatism. Rheumatism is what / ok, I have rheumatism. I didn't think much of it. And my son is very sporty, so you can imagine. and we go and the physio, she tried to refer without thinking ‘well I think he's at high risk’. so he, maybe my son was imagining. I said ‘this is a boy who is very sporty. I just need him to have a proper’. So in the end she tried to refer us to a mental health team, you wouldn't believe it! And she couldn't because it has to go via the GP. Cos now,* *you have to, because I don't, it's a hospital outside of the catchment* (.) *you know referrals normally. So basically what happened is, um, she then, what she did was um referred me to see, referred myself to see a rheumatologist. Reluctantly, because I insisted on it. And when I met with the rheumatologist, who thank goodness, oh my god, he looked at the physiotherapists report and she was there in the consultancy room. This was a few months after. And he looked at me, looked at my husband and everything. He said 'this boy doesn't need* (.)*'. I'm telling you! He said ' What he needs is A, B and C and D. Yes the parents, the mother has, this is, ah, is a genetic disorder, sort of.' But it's more to do, every, cos when, when, you could easily, he also falls because of this. And he used to run, used to play football, play matches all over. He was involved in, you can imagine. And she thinks he's talking about pain and everything because, it's all in his head. The mum has fibromyalgia.*

Stéphanie: So it must be in the head.

Ruth: *So it must be in the head. And I can just imagine the number of people, you know, who are, if you can't express yourself, what you can't assert yourself. Now imagine when I was very confused. …I couldn't* (.) *Oh. I would still be on very strong medications. Because I did take the medications when they threatened me* (.) *with if you don't take it, we will discharge you from the services, and / When they just discharge me from the services what happens then is that PIP I'm getting and everything will stop. Because they will say 'You* <u>*refused*</u> *treatment.' This is the letter. Oh yeah, that's what happens. It has knock on effects*

3 Ruth: Religious woman

Ruth: *I worked, um, years ago with, in a different hospital with um, a psychiatrist who very experienced. and he, a black psychiatrist, and* (.) *we had a ward round um. And the ward run, this particular ward run involved a new patient who had been admitted over the weekend, brought in by the police and apparently she was, she was threatening people in the marketplace, shouting hell and brimstone. She wasn't wearing any shoes. No, nothing, barefoot. Wearing a long gown, and she wasn't taking any* ( ) *because people around 'oh, there's something wrong with her'. The police came saw it. 'Ahhhhhh, she may be mentally ill, someone having a relapse'. She was arrested, taken to A&E, initially to be assessed initially. 'Ah, nah nah nah.*

She has to be, go under mental health ( )*', because she was fighting and saying ' I'm not mental. I'm not* (.)*', you know, because she was resisting back. she was a Nigerian, a black um sort of woman in her early 40s. So then everybody assumed 'Wow, this is someone probably with schizophrenia or something'. And she's shouting hell, and was mentioning hell and* ( ) *burning fire and things. So when this specialist consultant in the ward round, the woman was brought in. He was into her ward round; she was put under his care as one of his patients cos we work by catchment areas. So the area where she lived, the address* ( ) *with this particular consultant. And thank god it was him. In the ward round medical interview, the* *<u>woman</u>, and she was*

((External interruption))

And then he began interviewing her, and she was speaking pigeon English. She couldn't speak / I don't know if you know pigeon English ( )*. And he understands, he speaks pigeon English fluently, he can speak anything. he turned to us and said ' this woman is not mental'. He said 'what happens is she belongs to a particular um religious sect who, they wear, they believe, they wear white gowns. I don't know if you've ever seen*

Stéphanie: [No

Ruth: *normally* (.) *And*] ( ) *on their sabbath* ( )*, they don't wear shoes. They believe in, I don't know if you know the story of 'Moses and the burning bush' where Moses was asked to take off his daily* ( )*, interpret that. So they believe if you are doing anything for God or going before God's presents, you need to remove your sandals or shoes.*

Stéphanie: Oh ok.

Ruth: *So <u>she</u> was supposedly prophetess in the sect.*

Stéphanie: Yeah.

Ruth: *And she believes the world is coming to an end so she needs to warn everybody. Doing her bit for God, by going to the market place as the best place to draw everyone's attention and to warn them that the world is coming to an end. there was a complete, 'Hellfire' and 'you'll die', and she was preaching in pigeon.*

Both: ((laugh))

Stéphanie: So it might not have been the best conversion plan ever, but it certainly wasn't mental [health

Ruth: *but she couldn't*], *she in English*

Both: ((laugh))

Stéphanie: Probably didn't do her much good.

Ruth: *So, when the police were called, she began fighting every 'You will go to hell', you know, so the* ( ) *was complete. And the more, the police were arguing with her, the more she was insisting, telling them 'God will* (.) *give you* (.) *you know, you would, for fighting against, you want to destroy his prophet warning you of the danger to come'. Gosh. So,* ((laugh)), *she*

((External interruption.))

Ruth: *Now, it was a blessing that this particular consultant understood the culture. He* <u>*knew*</u> *of that religious sect, it's dominant in certain parts of Africa. And he was also a consultant who believes in um spirituality and mental health.*

4 Marcia

Stéphanie: Do you think that sort of / some of these negatives from imperialism and classism are reflected in the way that we approach mental health diagnosis?

Marcia: *Yes. Straight.*

Stéphanie: No question.

Marcia: *No, no question, definitely. Umm I know and therefore there's not that exchange listening because it really is quite interesting and with that there was a client who was complaining that umm she could actually hear voices and she was from a different culture at certain times and she was regarded as being delusional but when you broke it down you discovered that the neighbours would come in at a certain time and they will start making a lot of noise and also there's another client in terms of what has been as seeing blood coming through the wall and she was regarded as being delusional, well, there was, because umm someone would actually self-harm and /*

Stéphanie: Oh my gosh!

Marcia: *Yes and it was coming through the wall when they self-harm in the bathroom, it was eventually*

Stéphanie: Yes, seeping through.

Marcia: *Yes. So the Council had to go in and do something because / to the building because it's health and safety, yes.*

Stéphanie: Yes, but why did these people end up in mental health services then if the / how did that happen?

Marcia: *Well it's hard to understand but when the individual would go and complain it was just seen as oh you know how could this possibly happen without it being investigated, so whereas you would spend more time to kind of break it down and possibly go and visit, but as a support worker, you arrange / you have that communication with the support worker and the investigation and come back / and do you know, this really is taking place, she's not going mad. I was working with again an Iranian individual and he had been given the diagnosis of OCD but the condition he was living in in terms of he was living over a chicken shop, you know, takeaway shop, there was rats, he couldn't sleep in his bed at night, because he was saying he couldn't sleep. He would be washing frequently and then when I really kind of broke it all down, because the building was infested with vermin and he was washing regular, he wouldn't eat anything in the building, he would have to clean and / I would do that, also.*

Stéphanie: Yes, it's hygiene.

Marcia: *That's right so you have to sort that out, it's like a social umm support, and then look at is this OCD, is the problem still there.*

Stéphanie: Why do you think people are so quick to jump to a mental health diagnosis?

Marcia: *Possibly because umm being able to describe fully what was going on or using the same terminology and lack of patience.*

Appendix 23: Staff extended extracts - engaging with State support services

There are four extracts included here:

1. John
2. Zara

1 John O

I've got people with severe osteoarthritis. I've got people with / There's a woman that has got a skin problem and because of that problem she kind of has to come out, to come be with people. So she's anxious as wherever she is going, she is so concerned about what people are saying and that put her into a depression and you can see that now, it is the depression that is the main. It's taken it from the physical now to the mental. So because people who are afraid of / 'oh my benefit is being stopped' / They are very unsure that they couldn't get money. So even though they have that physical disability that is actually the primary focus of the illness. They tend to now become so severe, anxiously severe and depressed because of those difficulties. Maybe because of the financial aspect of it. Maybe because of the worry that I don't know if this will get better. So all of this coupled together to give them mental problems.

2 Zara

Zara: *Yes. It's basically / if you / there's certain umm / obviously he's on ESA, but to get support you have to be on PIP, if you don't have the care element from PIP, there's certain things that people won't do. In the /*

Stéphanie: In the so[cial care

Zara: *the social care] / because that's where the funding comes from.*

Stéphanie: No, that is / but I didn't realise because / I didn't realise they were that linked because /

Zara: *Yes, basically it's like say for example if umm regarding to home help, we can get in contact with the Council to do the home help, but some of the elements of stuff that he needs help with, they won't assist, if it makes sense, in a way where umm they want someone that they / you to help them, they like lower / how can I put* *it / like links, like in a case of (25:39) a way where if you are not high level of support, then they will jump in. If you want a lower help of support then they will signpost you to / alright, say, for example, for him, they would be like yes you need to get meals on wheels, you can't afford meals on wheels, he's not on enough income to get meals on wheels, which would be beneficial for him to have, but he can't afford to pay that out of the money that he's on, that's got to last him for two weeks.*

Stéphanie: And it's just not taken in to account peoples sort of socio-economic /

Zara: *No, they are not taken in to account. Everything at the moment I find within the settings, since I've got back here, is everything is about money. If you don't have it there's nothing that no one can do for you and it is hard to watch because there's only a certain amount of hours, same as what I have, to help and support someone. I'm based here so I don't do home visits, like for example, J or C, they do home visits, I don't do home visits. Everyone has to come to me here because this is where I'm based.*

Stéphanie: Yes.

Zara: *So it's hard to see like umm / there's only a certain amount you can do, there's only a certain amount of funding you can get for someone and that funding also sadly comes to an end, so what do you do with that person, again, but then not step over boundaries, sometimes you get in to a place where it was like /*

Stéphanie: Dependency.

Zara: *It's like / but then you will find that now what the problem is is that you've now enabled someone to get dependent on one organisation as where we're meant to be multi-organisations working together as one, but now you've made this person become dependent on one organisation, which for me sometimes is very very stressful or straining or frustrating at times, yes, very frustrating, due to the fact that there's only limited powers I have as well if someone maybe from AWP or something else got more involved, sometimes that little title scares the DWP, just maybe a little bit more for them to move and do a little bit /*

Stéphanie: Do something.

Zara: *Do something a little bit more. So I think those are definitely reasons in behind why people can marginalise and basically scapegoat as well in a way where, if you don't have the right umm / if you don't speak a certain language, if you don't have a certain power behind you, you can be left out of society on your own, because a lot of the people I work with, as well, they get frustrated with say for example DWP, they get frustrated and they start hitting them with fire, but then they never what they want and then they get banned from services and all that kind of stuff because of they are coming across aggressive. But they are aggressive because they are frustrated. No one's speaking to them. It's even down to umm / umm / a guy that I was working with, the same guy I was working with, he phoned DWP and wanted to know why his money has been cut. They spoke to him in a certain language, he didn't understand what are you even saying, so it then got to me that I had to then phone, then I explained to him the reason behind and all it was down to was a miscommunication in the way where he was asked questions he didn't really understand.*

Stéphanie: So it's also there's an assumption that people have a certain level of /

Zara: *Understanding /*

Stéphanie: And education?

Zara: *Education level, definitely, educational level, but also there's an expectation that when you come there you are supposed to immediately know exactly the system and know exactly what it is that you need to do, as where, some of the questions I find that they do ask, someone / a lot of men, as well, it's true, a lot of men, their pride will overcome and they are asking simple questions as can you bathe yourself, just because of the pride of them not saying / they don't want to say / they don't want to say yes, no, I can't bathe myself, they will say yes, but by saying a certain answer to a certain question, you are giving them that your level of support is less and I think that's what a lot of / say, for example, a lot of questions that DWP do ask I think they are talking to as complete strangers, not someone / that support worker that kind of knows them or they feel comfortable with it, this is a total stranger that they are meeting for the first time.*

Appendix 24: Staff extended extracts - Satch’s ban from services

Lisa

Stéphanie: ‘cos you mentioned as well, when we were in X, that someone that you worked with had, they were into, I think they were going into rehab services, and they felt the need to alter the way that they looked.

Lisa: That was Satch, that was Satch.

Stéphanie: Yeah…

Lisa: That was Satch, he (.) twice he did that. I’ve seen him, I’ve been with him when he’s gone into rehab twice so the first time he was going to a unit, and he cut his hair, and uh I said ‘Why’d you do that?’ He said ‘I don’t want any problems.’ he said ((laugh)) ‘I just want this to go smoothly, I don’t want to get into any confrontations with anybody. It’s going to look less scary.’ You know. And he did it again when he went, second time when he went and um, when I was supporting him he went and did it again. So he’s very conscious of, how he, looks and also, I think all of that’s based on his experiences as well. ‘Cos he’s somebody that’s been banned from a lot of services a lot of times.

Stéphanie: Yeah, he was saying, he was saying to me that he, he used to be hard to work with is what he would say.

Lisa: I don’t think he was. I would never find him hard to work with. I was, me and him were laughing in the week, I was reminiscing and saying ‘Satch do you remember that time you went into BDP and uh you got banned for looking through the window because one of the workers felt intimidated?’ [laugh] Wasn’t even doing anything.

Both: ((laugh))

Lisa: He looking in through the (window)

Stéphanie: Seriously (.)?

Lisa: Yeah ((laughing)), and they banned him because one of the workers felt intimidated.

Stéphanie: That’s ridiculous.

Lisa: And (.) and I had to go with him to a meeting. Made a complaint and I went with him to the meeting with the manager, and one of the managers was saying ‘well, you know, it’s people’s perceptions isn’t it, and if she felt intimidated then that is valid.’ So I said, ‘well what is that based on? What is that / What is that’

Stéphanie: I’m mean that’s essentially saying that people’s unconscious biases are valid.

Lisa: Yeah. Yeah. Yeah. So yeah, we (.) we challenged it. We didn’t get anywhere, he was still banned. But interestingly, even though he was deemed to be dangerous at the time, one of the other workers from the organisation was meeting him on a park bench to do sessions with him. ((laugh)) On their own.

Both: ((laugh))

Lisa: So

Stéphanie: Yeah that’s not

Lisa: Yeah.

Stéphanie: consistent.

Lisa: Yeah, so (.) yeah he’s been, he’s had lots of issues because um, it’s not because he’s difficult to work with. It’s because of how he’s looked, and, and people get scared easily by him. Yeah.

Stéphanie: I just, I don’t whether it’s, you know, I know he’s been very ill and so he’s lost a lot of weight and all of this / it surprises me that / but,

Lisa: No he’s never been huge, he’s never been kind of bulky or anything. He’s always been slim. But people have always felt intimidated, that he’s dangerous.

Stéphanie: ‘Cos he doesn’t walk around in a / aggressive way

Lisa: No, he doesn’t. He doesn’t.

Stéphanie: Yeah.

Lisa: Yeah. I mean he can be quite mouthy when he’s upset. When he’s upset he can be quite, um, he can shout at people. But (.) you kind of know his history, you kind of know that, that means he’s distressed about something, you know. And it’s usually, if he feels that, you’re trying to avoid helping him, you know

Stéphanie: Yeah.

Lisa: Yeah, and now that he’s older, and he’s finding things even more difficult, he is going to find things even more difficult, to get services.

((section of conversation omitted))

Stéphanie: And do you feel that there’s something there as well that plays in with the whole race aspect as well?

Lisa: Yeah definitely, definitely. I think it just makes people think ‘oh this, this person could, you know, be dangerous because he’s black’ ((laugh))

Stéphanie: Yeah, yeah.

Lisa: Yeah, being black and agitated and being white and agitated is two different things isn’t it.

Appendix 25: Staff extended extracts - problematic service delivery

There are four extracts included here:

1. Ruth
2. John M
3. Marcia
4. Kamilla

1 Ruth

Extract 1

Ruth: *I remember one Christmas day, um, umm I went to visit a patient because she had nobody. and I'm saying 'It's Christmas, I can't leave her' and I cooked a meal and everything and went to / And then, at that time there weren't strong restrictions on professional, you know, these boundaries we've got to keep. So you can go to visit a patient and, yeah, I took her all those meals. And later on I was told 'Oh no you can't do that. You've got to keep boundaries* (.)*' And she was a little old lady, she died soon after. And I said* ((sigh)) *'What's wrong with being kind? or generous to someone?' I was always having problems anyway in my work.*

Stéphanie: What was the reasoning that was given to you, for not, not being allowed to do these things?

Ruth: *Oh, I have, we were told that we've got to keep very strict professional boundaries. So for* instance. / Exactly. *Because* time *was one of the factors. And two, there is no time to get, to stay, no! Keep them, if they've got family, let the family do that kind of thing. And I said 'Well, what about the cases were there's no family?' 'Then refer them to, to organisations. refer them to that organizations, refer', cos we had organisations who had befriended. But now they're befriending list became 6 months.*

Extract 2

Ruth: *my conscience won't let me rest. I'm thinking 'Oh, but I could have done this to help this person. I could have done that. I could have done that.' And then I'm told 'You are not the* (.) *leave. Get out of it'* ((bangs table)) *You know and things like that. I would* (.) *oh gosh.*

Stéphanie: Goes against, your own

Ruth: *But it did.. I wa / I leave, I would have an / And then I'm told 'You should learn to detach. You get too much involved, emotionally.' You know, you understand. Because sometimes, sometimes I'd be fighting in meetings about someone, an individual, 'You are too sensitive to that. you can't do this, we don't have resources.' You know, you kept being told such things. Constantly.*

Stéphanie: But did you find it, because, I'm sure there was the argument from some of the management that they are trying to protect you for getting emotionally drained.

Ruth: *They did. They did. They did say.*

Stéphanie: But did you find it more emotionally draining.

Ruth: *It is.*

Stéphanie: To try to be [detached than to

Ruth: *It is. Gosh. It is. It is.*]

Stéphanie: try to behave the way that you did?

Ruth: *I have cried. I've gone to, even funerals for patients I'm seeing, but I want to go. But I'm see / I had patients who are so attached to, you know, there is a, but I'm saying 'There is no-one to do his shopping.' ' You are not healthcare. You are a nurse for goodness sake, don't do* (.)*'* ((animated))*. I said 'But I'm going in my break hour to shop. What's* (.)*!' You know, so I was having / it's not just me. I had a few colleagues who were like that. and all of us who were like that, we ended up leaving with trauma. Because we weren't*

Stéphanie: For not being able to do that?

Ruth: *Yes. We were just broken. So broken. All the, oh gosh. Some of the social workers, very experienced and they are saying 'No! This is not right.' You know. All of us left with / broken. Broken. Really. Broken.*

2 John M

[John works in a project specifically focused on bringing services together to work better for people with complex needs who are involved with multiple services]

Extract 1

John M: *I just get so pissed off with it, so there isn't any other words that I'm going to use about it, the obviousness of the situation can be really overcome if we are just using these terms now the system flex, flex in the system, just a tad, you know, we're not asking for much, you can see the treatment's there, everyone's in agreement the treatment / everyone says the treatment is going to be fine, but we can't start it until we leave prison and back in to the community and that's happened to quite a few of me guys. Yes, another one as well, had exactly the same thing, umm, wanted to be prescribed umm pre-cabs* ( ) *for his mental health because this is what he believes to work and it helps him you know be abstinent from you know heroin while he's out as well, we'll do two jobs in one, but because pre-cabs are quite a commodity in prison, wouldn't do it, had to wait until on the out, again, I mean, I suppose it's weighing up the balances, anyway, I don't know /*

Stéphanie: But I guess that's the difficulty isn't it when you've got a system that is, for want of a better word, churning so many people through it's not able then to be responsive to any one single person's needs, unless they are very uncomplicated /

John M: *Yes. I mean I think people do get / like a blasé approach to it really / it's him again, or it's her again, or you know we've tried this, or we've done that, or not responsive, what's the point, or / Whatever / it's just like / and then the guys pick it up really quite quickly, they are no mugs, they just like well if you can't be bothered, I ain't, what do you want me to do you know and then we just fulfil the circle and then we just kick these people out, just to return maybe six weeks, maybe less, its been half hour the quickest one, again.*

Stéphanie: Half an hour?

John M: *Didn't get down the road, no.*

Stéphanie: What happened?

John M: *Well he got his release money, went in to the Off Licence, got extremely drunk, and he said I can't remember what happened, but he got re-arrested, so broke his licence agreement, was back in.*

<u>Extract 2</u>

John M: *You know it's just like what we want to do is you know is build bigger prisons. There's one in Cardiff, was it / was it / 1,000 people, 2,000 in mates that they want to provide support for.*

Stéphanie: But they are shutting down a lot of / well / women's prisons they are shutting down aren't they?

John M: *Super prisons that they want.*

Stéphanie: Oh brilliant.

John M: *Oh, what joy, yes. That's going /*

Stéphanie: Centralise everything.

John M: *It's going to make life so much nicer for every inmate isn't it.*

Stéphanie: Uh-huh and further distance the families to come and visit.

John M: *Yes, and all the rest of it, and then / it's just / the economics of it are not great in for people coming home, maybe G4's going to earn a few bob out of it, I'm sure they will, but yes, it's not / it's not conducive to / and I go back to you know the social side of it and our civic responsibility, it's just not there, not there.*

Stéphanie: It's not the driving force.

John M: *No, not at all, you know, we don't want cohesive societies because that means that we have a collective voice which they / which is quite dangerous isn't it.*

Stéphanie: Yes. Yes, yes, yes.

John M: *If we have a collective voice / we should do what the French do, swear, you know what I mean.*

((Section of conversation omitted))

John M: *It is just / just money-based capitalism, it's / it works for the elite, nobody else. Yes. I'm waiting for this sort of like what is it / like / umm / drop down economy where it sort of filters down from the top down, yes, I'm looking like / it's like pennies from heaven, shall I tip my umbrella up, stand and wait for this to happen, it's just like /*

Stéphanie: Ain't happening.

John M: *Course it ain't happening. No interest in you know filtering this shit down to us at all.*

3 Marcia

Marcia: *I've been over the years it may be a lot of cynicism, which makes me question my longevity within mental health.*

Stéphanie: Really?

Marcia: *Yes, yes, yes.*

Stéphanie: Cynicism for what specifically?

Marcia: *In, in, in terms of well / how much good am I doing any longer, umm, is there too much cynicism in terms of what I'm wanting for clients and the ability to deliver that service, because it's constantly changing and like I was saying, in terms of the prescription 12 session, six session,*

Stéphanie: It’s inadequate.

Marcia: *It's inadequate, yes.*

Stéphanie: Yes. I very much agree with you on that.

Marcia: *Being part of that machine, do I want to be part of it?*

Stéphanie: Does it play on your conscience?

Marcia: *Umm it does, it really does, it does and sometimes my / because you're under that pressure to deliver within a certain space of time, am I now adapting certain behaviours in let’s get this treatment done and dusted and /*

Stéphanie: And not holding true to /

Marcia: *Yes.*

Stéphanie: to you?

Marcia: *That values that you started out with.*

Stéphanie: Like the person / looking at the person as a whole? and giving them the time and /

Marcia: *Yes, that's right. What's needed here? What's needed there? Umm. Is it just the therapy or is there more practical things that need to be interventions that need to be in place before you could even deliver the therapy?*

Stéphanie: Do you end up supporting them with some of that or /

Marcia: *In the past I used to, umm, because I suppose the service / umm / that I used to work for, but also the changes within the requirement of different funding streams, yes. So if I / I was based as a / I used to deliver therapy within a client's home, so that gave me more flexibility to see them as a whole, what is it they were needing and even when I used to put in to place because of a multi-disciplinary team, a much larger team than X so you are able to say to someone that's sat next to you, oh, I had this client, blah de blah, oh, try this, try that, when you feed back in to the larger service they / she's done everything, so what's left for me to do, so /*

Stéphanie: Were they grateful for that or?

Marcia: *Umm / I think eventually they could actually see that it was helpful because that person's not coming back within the service. But umm I suppose that when they come to do their review, when they are looking at well what do they / someone's work / I've encroached on someone else's*

Stéphanie: Oh.

Marcia: *Yes.*

Stéphanie: So they weren't really looking at what was best for the person, so much as you're messing with our system?

Marcia: *That's it, but that's how the system kind of developed. There is / it's all become very fragmented.*

Stéphanie: Yes.

Marcia: *How the funding is*

4 Kamilla

Kamilla: *Yes. I definitely feel like there's a gap, so like where you say a lot is being done, where is it being done? Because I guess in like mainstream society, I can see that a lot is being done, but then if I look at / my culture, for example, so I'm Pakistani, so if I think about the Pakistani community, there's not really much done or I don't feel like there's being much done. And yes / even somebody / like I know somebody here who umm / like whose, whose Mum has schizophrenia but she, she's home all the time and he looks after her and he doesn't really have anyone to talk to about how difficult it is and things like that, so yes, which is very sad, because obviously then people are dealing with this stuff in isolation, yes.*

Stéphanie: So if you were aware that there's stuff going on in the mainstream to sort of raise awareness, how is it that that isn't getting through to the communities, because / I suppose the people that are trying to do the awareness raising campaigns and things are using mainstream distribution networks.

Kamilla: *Yes, yes. Yes. I think the / it would mean just reaching people, I don't know, it's maybe / it comes from both directions actually so obviously the people who are doing the awareness raising obviously speak a particular language, using particular resources and stuff, that are targeting certain people, or getting through to certain people, but not to everyone. There's a large community that maybe they see these things, like a poster in the window or something, like something on the side of a bus or something, but it probably just goes over their head because they don't associate it with themselves and with their culture.*

Appendix 26: Staff extended extracts - distrust in communities

There are four extracts included here:

1. Jean
2. James

1 Jean

Stéphanie: And in the Caribbean community then you were saying that everyone's worried about other people knowing and talking about their business.

Jean: *Yes.*

Stéphanie: Is that because there is a tighter community feel or /

Jean: *It's incestuous, alright, but it's not tight, so it's not / it's very / the Caribbean community, like I say, I'm Caribbean, we've got very much / it's umm / I can only talk about the* ((name omitted)) *Caribbean community, it's umm / it's not a tight knit as in unity stand together, it's a very much a what's he doing, or oh if he can do that, then my daughter can do that, so it's a bit of this old crab in a bucket, we all often describe ourselves as crabs in a bucket. If you put some crabs in a bucket they will stand on each other's head to get out and actually that's pretty much it. We tend to be looking around, we trust no one, we trust no one.*

Stéphanie: Where does that come from?

Jean: *It's / I think it's / there is something. We are not driven, like some other minority groups, in terms of I expect you to be a doctor or a lawyer. We are more driven in that keep the negative away from our family, so don't want to be linked with crime, don't want to be linked with mental health and if there is it has to be kept because it would be seen as embarrassing and all of that. So, yes, we're very different in how we / when I say "we", Caribbean's, yes, we're not / and you know I can talk about some communities that you know I know that from a child as young, within their head, they're talking being a doctor and a lawyer and that's what's expected of them, etc., and I don't / and I think that's good, you know, they've got a great / but it's not on the whole what you / especially in the days, back in the days, you used to find with the Caribbean community work, work, you know, our aspirations weren't like that, it was you get a job, you work and just stay out of jail.*

Stéphanie: Do you think that's linked to sort of colonial history?

Jean: *Yes, I do, absolutely, absolutely. Yes, definitely, and I think that umm you know my, my parents, both are still alive, and it was the / your head down, and you just worked, you just worked.*

2 James

James: *because within Caribbean / this is based on my experience again, mistrust, umm, you / there will be things like from a colloquial language side, ‘you go and chat my business’, umm, ‘you'll have a vendetta against me’, ‘you're talking to that person’, that person ‘I don't trust you, suspicious’. A lot of mental health issues is based on what the professionals would class as paranoia and often paranoia I think can be stressed as a basis of being let down and how you think someone is reading you, that's a big issue we have, I think, amongst our race people is when / I think / ‘you're probably thinking negative of me’, ‘you're probably doing this and that’, because we're so used of the discrimination or people thinking ill of us and it's all the same thing.*

Appendix 27: Poem by Tiana McLean, June 2020

Written by a nine year old girl and shared online by her Grandmother, this poem calls for racial equality (Booth, 2020). I found it posted on Bristol’s Black Lives Matter Bristol Facebook page, a page bringing people together to take action against racism.

“Untitled”

[redacted]

[redacted]

[redacted]

[redacted]

[redacted]

[redacted]

[redacted]

[redacted]

[redacted]

[redacted]

[redacted]

[redacted]

[redacted]

[redacted]

[redacted]

[Lyrics redacted from the digital version of this thesis for copyright reasons]

Full content uploaded on Youtube under the title 'Tiana's "Black Lives Matter" poem' at:

https://youtu.be/SM3ddXvEJTQ

Appendix 28: Published conference abstract

NNDR 2019 Symposium

Exclusionary Aspects of Claiming Disability Rights

Alex James Miller Tate, Stephanie Harvey, Adi Goldiner

In post-industrial welfare states, legislation protecting the rights of disabled people is normally perceived as enabling inclusion and reinforcing equal citizenship. Thus, laws prohibiting discrimination based on disability, securing access to public accommodations, raising disability benefits, or funding healthcare services have been typically supported by the disability community and its allies. The UNCRPD has further augmented efforts to protect disability rights in national laws. However, the potential embedded in legislation to provide such inclusion and equality is often missed.

Importantly, the manner in which rights provisions are delivered may not support the actualization of rights for all. For example, claiming disability rights involves identifying as disabled, a process which in actuality may require subjecting oneself to procedures, interventions and stigma that people would like to avoid.

This symposium explores possible deterrents to claiming rights as a disabled person, resulting from exclusionary features characterizing the process of claiming these rights. Specifically, all three papers will consider deterrents for specific groups of people who, by the UNCRPD definition of disability, are entitled to claim disability rights but have particular reasons to be cautious in doing so. Firstly, Dr. Alex Miller Tate critically explores practices that arguably bring about the 'testimonial smothering' of mental health service users in the UK. Next, Ms. Stephanie Harvey considers how a person’s intersectional location can create barriers to claiming disability rights and what this might mean for public policy approaches. Finally, Ms. Adi Goldiner discusses the interrelationship between popular perceptions of disability and the possibility of claiming disability rights; specifically, the effect that perceiving disability as a 'personal tragedy' may have on people's willingness to claim disability rights.

Speakers bring with them expertise from a range of disciplines and prior careers both in the UK and in Israel to inform the discussion. The symposium should be of interest to those working to improve the efficacy of statutes and practices aimed at increasing disabled people's ability to actualize their rights.

De facto Detention and Testimonial Smothering in Psychiatry

Alex James Miller Tate

Teaching Associate and Research Assistant

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[redacted]

De facto detention in mental health (MH) services involves a range of practices. One example is that of clinicians overtly or covertly threatening service users with involuntary detention should they fail to 'voluntarily' proceed with an in-patient stay. Another is of 'voluntary' in-patients being restrained or held behind locked doors, despite their strict right to discharge themselves from the service. There is evidence that the practice is relatively widespread across UK MH services, despite it clearly bypassing service users' formal legal protections (CQC 2014; 2016). This is in addition to the fact that in all forms it clearly constitutes an especially morally objectionable form of coerced cooperation; the service user's autonomy is violated and their cooperation forced by threatening a stigmatising and possibly violent outcome should they fail to cooperate. All of this proceeds without the service user gaining any benefit of the additional (though flimsy) legal protections being held under section can confer.

I further argue that we can expect this practice (in addition to other morally and clinically undesirable effects) to bring about the *testimonial smothering* of service users; roughly, the unjust suppression of their testimony (Dotson 2011). This means that not only the immediate victims of *de facto* detention are harmed by it. Rather, it creates an environment where all or many service users are justifiably concerned about the enormous risk to their person associated with disclosing certain information. This not only unduly suppresses their ability to safely speak of their experiences, but also impoverishes clinical knowledge of service users' needs. I argue that this injustice is sufficient to warrant the significant weakening of the clinical power in UK MH services that gives rise to these abuses.

'The cheapest kind of understanding': intersectional marginalisation in disability rights?

Stephanie Harvey

PhD candidate with the D4D research project and Associate Lecturer, Bath Spa University

[redacted]

Introduction to the research question: Taking findings from a wider research project, this paper considers barriers to claiming disability rights for people located at the intersections or disability and minority ethnicity in the UK. It explores this with a view to what public policy approaches may need to consider if the UK is to provide substantive equality for a diverse disabled population.

I consider the difficulties encountered by one particular participant. Focusing on conversations immediately surrounding an attempted suicide, the participant's testimony illustrates barriers to claiming disability rights experienced and articulated to me by many other participants in my research. In seeking to understand why factors such as a short-term ban from a support organisation contributed so significantly to this participant's acute distress, I draw from intersectional theory (Crenshaw 1991, Collins and Bilge 2011).

Methods: A case study approach explores the experiences of a man with physical disabilities who experiences long-term mental distress, is from a mixed heritage background and intersects multiple other marginalised groups in UK society. During a series of in-depth ethnographic conversations, he recounted his experiences of securing the support he requires. His testimony is further contextualised using interviews with staff working for organisations supporting him, many of whom are of minority ethnicity themselves.

Results: The man provided both narrative descriptions of previous experiences accessing services and shared current difficulties and anxieties. Overriding themes emerged regarding:

1. *difficulties meeting the expectations/requirements of mainstream services; and*
2. *disparities between service provision and his needs.*

Whilst these themes hold relevance for many disabled people, the particulars highlight barriers resulting specifically from certain intersectional experiences in the UK.

Brief discussion and implications: Disabled people with intersectional experiences, whether due to ‘race’/ethnicity or other identity markers, face additional barriers to claiming disability rights in the UK. Discussing his experiences of the healthcare system, the participant stated ‘I've always been offered the... you know, the, the cheapest kind of... understanding.’ This sentence encompasses feelings of being provided with inadequate services, a lack of understanding on multiple levels from service providers and a sense of being devalued.

These themes appear repeatedly in the researcher’s wider study and in existing academic and grey literature (Bécares and Nazroo, 2013; Jivraj and Nazroo, 2014; Ahmad and Bradby, 2008; ENC and SCOPE, 2012; EHRC, 2017; Griffiths, 2018). I argue that sufficient cause for concern exists to require (re)consideration of the systemic issues at play and posits that addressing such issues in the UK would require revisions to policy approaches.

Claiming Disability Rights with a Sense of Dignity and Pride

Adi Goldiner

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[redacted]

People perceive the nature of disability and the grounding of disability rights in different ways. Some think of disability as 'harm', and thus believe that disability rights are based on disabled people's interest in being compensated for their 'loss and suffering'. Call this the 'personal tragedy' grounding of disability rights. Others view disability as 'mere-difference', namely a trait with no inherent implications about a person's well-being, and thus believe that disability rights are grounded on disabled people's interest in being free from discrimination, oppression and social expectations to (at least aspire to) be 'normal'. Call this the 'affirmative' grounding of disability rights.

Although disability rights may be based on either grounding, practically, people's perception of the concept of disability and the grounding of disability rights can have significant implications on them claiming their legal rights as disabled people. In particular, those who embrace the 'personal tragedy' grounding of disability rights are less likely to claim such rights. Firstly, disabled people who do not conceive their impairments as tragic may plausibly find identifying as disabled as degrading, for the latter is closely connected with the view that disabled people deserve pity. Secondly, disabled people who conceive their impairments as tragic may also be less cautious in identifying as such, but they are not likely to gain the benefit of empowerment that claiming rights typically confers on right holders.

By contrast, people who embrace the 'affirmative' grounding of disability rights are more likely to claim disability rights. This grounding allows disabled people to self-identify in any way they like, even when their self-perception defies certain social expectations about how disabled people should act and feel. Moreover, the 'affirmative' grounding allows people to claim rights with a sense of dignity and pride, thereby right holders gain the additional benefit of empowerment embedded in claiming rights.

Enacting disability rights is typically deemed as a means to fighting stigma and prejudice against disabled people. But this paper shows that the full realization of the potential embedded within those rights is contingent upon people's views about disability. If people's views are aligned with the tragedy grounding of disability rights, they are less likely to claim disability rights. By contrast, the affirmative grounding of disability rights enables claiming of disability rights with a sense of dignity and pride. This paper concludes that promoting affirmative grounding of disability rights is vital for encouraging disabled people to claim their legal rights.
