Centre for
Mental Health
Commission for Equality

Commission for Equality in Mental Health

BRIEFING 3: Inequalities of experience and outcomes

Centre for Mental Health, October 2020

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SUMMARY

People with the poorest mental health too often find the help they are offered the least effective, the least relevant and, for some, the most coercive. This briefing explores why, and what can be done to bring about more equal outcomes and experiences from mental health support.

Poorer outcomes from mental health services are most dramatically evident for people from Black communities in the UK. They experience higher levels of coercion and poorer long-term outcomes. There is now some recognition that this is linked to systemic racism and discrimination, not just within the NHS but across society and public services nationwide.

Inequalities in experience and outcomes are evident on a number of other dimensions that often intersect with each other – including income and wealth, gender, specific ethnicity (for instance, Gypsy, Roma and Traveller communities), age, sexual and gender identity – and for groups of people with a range of experiences, including those with learning and neurodevelopmental disabilities, those diagnosed with 'personality disorders' and those with co-occurring conditions including alcohol misuse.

An inclusive mental health service creates a safe space for everyone, in which past discrimination and inequality can be redressed as support is offered.

The NHS in England has embarked on a major new initiative, Advancing Mental Health Equalities. It has also begun to implement the Patient and Carer Race Equality Framework – a major recommendation from the Independent Mental Health Act Review. Fully implemented and adequately resourced, these two initiatives could help to bring about system change that will improve people's experiences of mental health care nationwide.

In a system designed for equality of outcomes and experience, we would expect to see:

An enhanced community sector role in mental health support: Voluntary, community and user-led organisations can make a significant contribution to addressing inequalities in outcomes and experiences. Partnerships with state services can scale up the approaches that are rooted in community and user defined experience and outcomes.

Coproduction at every level and in every service: Lived experience needs to be valued in all aspects of mental health support. Peer-led services can provide invaluable support, especially for marginalised, disadvantaged and oppressed communities.

Culturally competent and trauma-informed approaches: Culturally appropriate care is vital to help services to address racism and discrimination, and trauma-informed approaches can create a sense of safety and reduce the risk to people who have already experienced physical and psychological harm in their lives.

A commitment to meet all needs: Adopting a system that ensures people who seek help get help at the right level, right place and right time, where necessary adjusted and adapted to meet their needs appropriately.

A whole system approach: Working with housing services, schools and colleges, the police and employers to improve experiences and outcomes across a range of domains.

Accountability and transparency: Mental health services should be able to account for the outcomes they achieve for a range of communities and groups and demonstrate actions to reduce inequalities.

INEQUALITIES IN OUTCOMES AND EXPERIENCES

While quantitative evidence about inequalities in outcomes from mental health care and treatment is patchy, two areas of the system provide compelling data about a range of unequal experiences: talking therapy services and the use of the Mental Health Act.

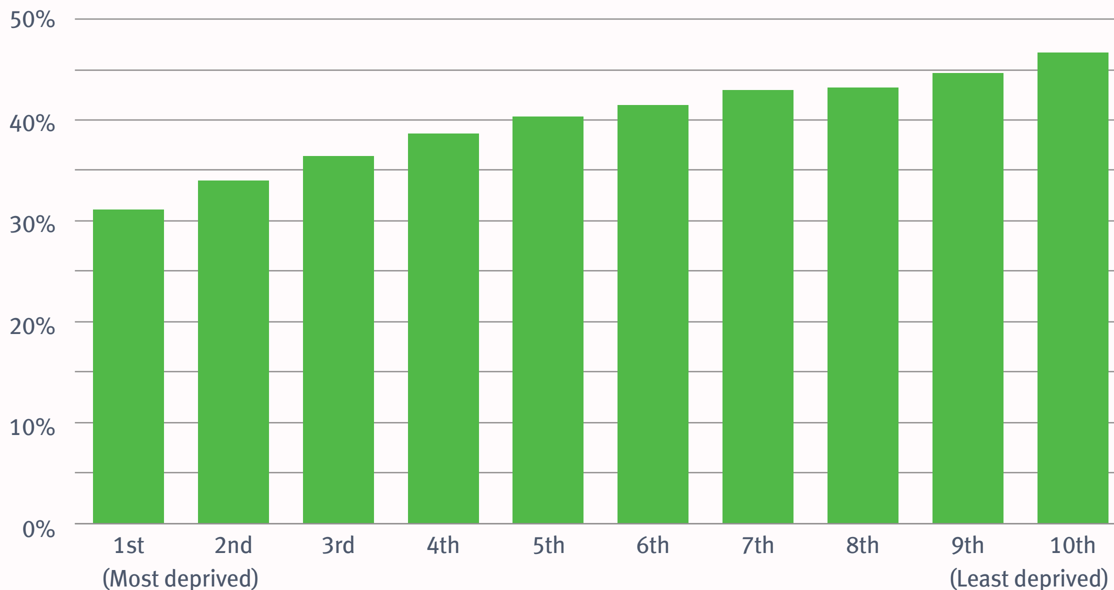
Talking therapy services

Treatment entry, completion and recovery rates in Improving Access to Psychological Therapies (IAPT) services are significantly lower in more deprived areas of the country even though referral rates are twice as high (Baker, 2020). An analysis by the Health Foundation found that the proportion of people referred to IAPT who completed treatment reduced for every decile of deprivation in different areas of the country (The Health Foundation, 2020: see Figure 1).

Further, analysis from the Nuffield Trust and Health Foundation (Quality Watch, 2020) also found that the recovery rate among those who completed treatment in the most deprived 10% of local areas was 43% in 2018/19 compared with 58% in the least deprived. The pattern is the same for the proportion who achieve a ‘reliable improvement’ (Figure 2). At every stage of the pathway, people from more deprived areas are disadvantaged compared with their peers in wealthier areas.

A similar pattern is seen with regard to ethnicity: both completion and recovery rates are consistently lower for people from Black, Asian and other minority ethnic communities than for white people (Baker, 2020). Recovery rates are also lower for disabled people than non-disabled, but there are no significant differences in outcomes by gender (ibid).

Figure 1: Percentage of IAPT referrals who receive treatment, by deprivation decile



Adapted from The Health Foundation (2020)

Source: NHS Digital https://digital.nhs.uk/data-and-information/publications/statistical/psychological-therapies-annual-reports-on-the-use-of-iapt-services

Mental Health Act use

Outcome and experience measures for secondary (specialist) mental health services are more complex and contested, with widely varying interpretations of what 'good' outcomes are and how they should be measured. One widely used measure, however, is use of the Mental Health Act. While not an 'outcome' in itself, the use of coercion is a marker of extreme distress, it is frequently a traumatic experience, and it is an indicator that non-coercive approaches have either been unsuccessful or untried.

Rates of detention under the Mental Health Act vary widely between ethnic groups. In England, the rate of detention among white British people is about 70 per 100,000 population. By comparison, white Irish people have a rate of 75 and among 'any other' white people, which may include people from Gypsy, Roma and Traveller communities, the rate is doubled, at 141. Among Asian communities, the rate for Indian people is 71 but it is 118 for Pakistani people and 142 for Bangladeshi people. Detention rates among Black African people, meanwhile, are far higher still, at 222, and for Black Caribbean people it is 277 detentions per 100,000 of the population. For 'any other' Black people the rate reaches 728.

Black British people are eight times more likely than White British people to be given a community treatment order (CTO) after being treated in hospital under the Mental Health Act. Within the former group, Black Caribbean people are substantially more likely than Black African people to be given a CTO (NHS Digital, 2019). This means that the use of coercive powers lasts longer for Black people, often for months and years following a hospital admission.

There is very limited evidence on the outcomes people from Black communities experience from mental health services longer term. The AESOP follow up study (Morgan *et al.*, 2017) provides some evidence for Black African and Caribbean communities and it finds that outcomes are typically poorer. Specifically, for both Black African and Black Caribbean people, it finds that 'hospital admissions were more frequent, longer and more often involved the police and compulsion' than for white British people. It finds that on average hospital admissions occurred every three years for Black people compared with every four for their white counterparts. It finds that 60% of Black patients had police involvement in at least one admission compared with 37% for white patients. Use of the Mental Health Act was also far higher: some 84% of African and 79% of Caribbean patients had at least one compulsory admission compared with 58% of white patients. The study found that rates of self-harm were lower among Black patients, there were no differences in 'diagnostic stability', but rates of employment were considerably lower. The authors observed 'near ubiquitous and persistent social disadvantage and isolation' among Black patients and concluded that psychosis and social disadvantage were 'mutually reinforcing...in a vicious cycle' for this group (Morgan *et al.*, 2017).

WHAT DRIVES INEQUALITIES IN OUTCOME AND EXPERIENCE?

It is important to understand what causes these and other inequalities in experience and outcomes from mental health support. Evidence points to a number of different factors that are likely to be implicated in this process.

Unequal access and the use of coercion

Unequal access to mental health support has a significant bearing on inequalities in later experiences and outcomes. The point at which a person begins to receive help for their mental health and the quality of the contact they have at that time have a major bearing on their outcomes longer term. In some cases, a bad start to a person's relationship with health and care services – battling unsuccessfully to get help followed by a coercive response when they become very unwell – has a prolonged impact on their experience of care, leading to compulsory hospital admissions and long periods in institutional settings far from home (CQC, 2019).

There is significant evidence of ethnic disparities in access to early help. GPs, for example, are much less likely to be involved in the care of Black people leading up to a first episode of psychosis than they are with white patients (Singh *et al.*, 2013). By contrast, Black people are far more likely to experience police involvement in their first contact with mental health services (Bignall *et al.*, 2019). Experiencing help via the police can feel frightening and punitive – at its worst it can damage a person's relationship with the institutions which are ultimately meant to protect their mental health (Stubbs *et al.*, 2017; Reder & Fredman, 1996) and is a major factor in the 'circles of fear' that exist between Black communities and mental health services (Keating *et al.*, 2002).

This phenomenon has been described many times, yet as recent evidence reviews (e.g. Barnett *et al.*, 2019) have indicated, few have looked beyond stereotypes, 'untested hypotheses' or homogenised categorisations to explore why Black people's experiences of mental health support are so much poorer in the UK (for example using catch-all terms such as 'BAME' to include a wide range of groups and experiences). The existence of racism is all too often explained away by seeking other reasons for unequal outcomes of mental health care rather than looking at how it intertwines with experiences Black people have had throughout their lives. As Bhui *et al.* (2018) have noted, however, an absence of evidence of "individual level, conscious and prejudicial attitudes of clinicians" does not mean that systemic racism can be ruled out, as:

"*…racism is not obvious nor easily detected in everyday life…[but] behaviours and communications may be seemingly innocuous, yet can signal prejudicial attitudes, a lack of trust, fear or avoidance.*"

These 'microaggressions' are crucial to the negative experiences of Black people in which it is impossible (and indeed unhelpful) to try to separate out experiences within mental health services and those outside.

For some groups of people, the overshadowing of mental health needs is a major block to accessing help that could reduce the risk of later poor outcomes. This has been noted in relation to people with learning disabilities (Lavis *et al.*, 2019) and those living with physical illnesses (e.g. Centre for Mental Health and Kidney Research UK, 2020). Young autistic people, meanwhile, report being told that mental health services are not equipped to meet their needs, despite having higher suicide rates than average (Harper *et al.*, 2019a). This points to the importance of making 'reasonable adjustments' to mental health services to ensure they meet the needs of autistic people (Harper *et al.*, 2019b) and others requiring adaptations to offer an equal outcome.

Traumatic experiences

The more adversity a person has experienced in their lifetime, the easier it is for feelings of powerlessness and isolation to trigger trauma for them in the present, including when that person is in receipt of care (Brewin *et al.*, 2000; Briere *et al.*, 2016; Matheson *et al.*, 2019; Wilton, 2020a). Restrictive interventions can be experienced as traumatic, especially when a person is already in distress and for people who have had similar traumatic experiences in the past. People who have been sectioned under police powers (Section 135 and 136 of the Mental Health Act) often describe the process as traumatic, especially when they have felt coerced or been subject to physical restraint (Durcan & Harris, 2018; Durcan, 2014). The introduction of a new trauma, at the point where someone's mental health is often already at crisis point, can exacerbate that person's distress.

During consultations with people who have been sectioned, Black respondents more commonly report the use of force than white people, and say that physical restraint occurs earlier in their journey. Experiences of the police during mental health crises also appear to be more negative, and Black people consistently describe being perceived as aggressive and posing a risk to others (Durcan, 2014). This echoes research which found that stereotypical views of Black people, racism, cultural ignorance, prejudice and fear of violence can combine to undermine the way in which mental health services assess and respond to the needs of Black African and Caribbean communities (Keating *et al.*, 2002).

Trauma can be further magnified by inequality. Traumatic events are more frequently experienced by people from marginalised groups including people with low socioeconomic status, autistic and disabled people and people from some ethnic minority communities (Hatch & Dohrenwend, 2007). Moreover, the perception that institutions – police, health care, government – have unjustly failed to provide adequate protection and support to a community can put members of that community at higher risk of psychological harm from a traumatic event (Rhodes & Tran, 2012; Smith & Freyd, 2014). Thus, the very existence of marginalisation contributes to poorer outcomes and poorer experiences of support amongst some groups. This has been magnified considerably during Covid-19: a major traumatic event that has disproportionately affected the most marginalised and disadvantaged, laying bare the systemic racism and discrimination they have experienced throughout life.

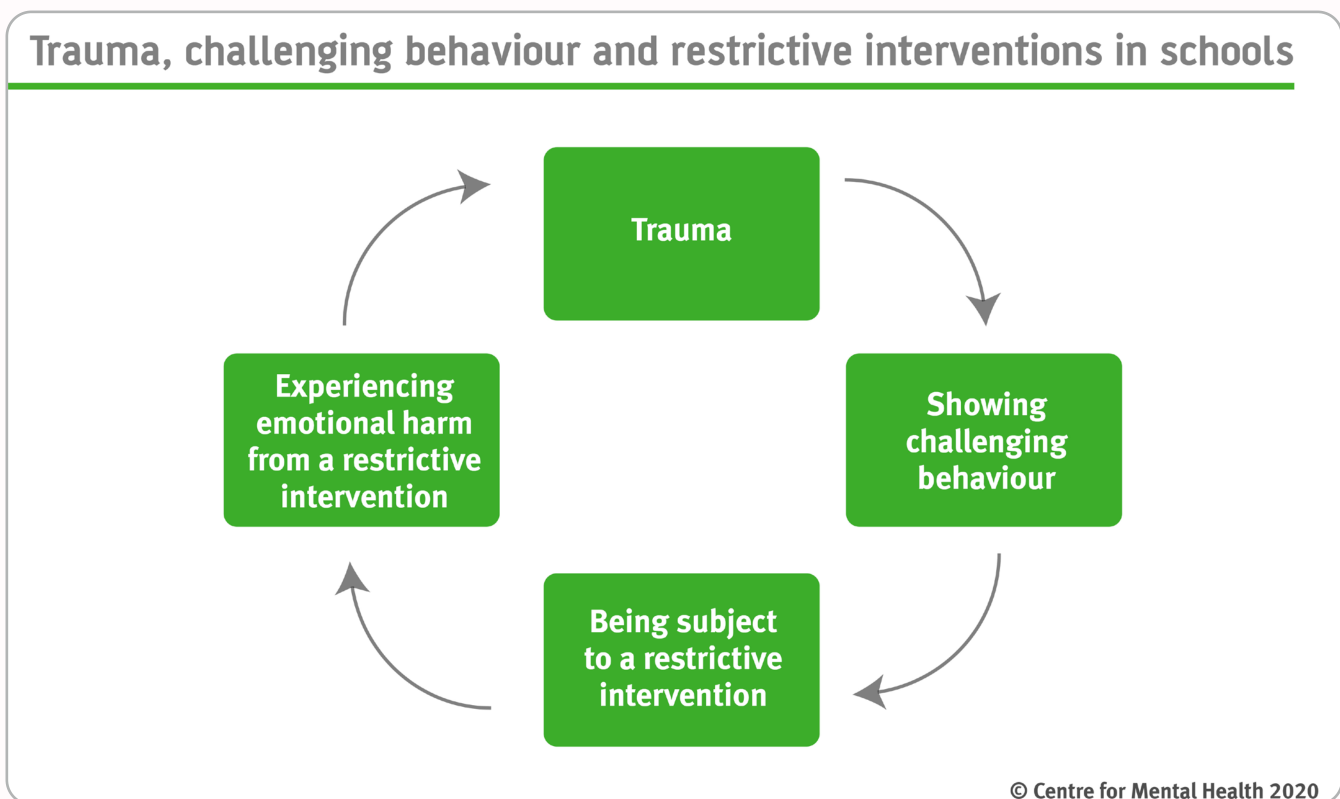
Mental health problems can be connected to experiences of violence, coercion and abuse, especially for women. Yet a recent review found that an understanding of trauma has been absent from policy, service design and delivery, particularly where women's needs are concerned (DHSC, 2018). This means that experiences of mental health treatment are for many a cause of further trauma, reinforcing the painful feelings associated with the original trauma rather than mitigating them (Wilton and Williams, 2019).

Recent research with LGBT+ people who have experienced multiple disadvantage (for example abuse, homelessness and poverty) found that support from mental health services can be poor (LGBT Foundation, 2020). They reported that mental health professionals often failed to understand their experiences and, as a result, were unsupportive or less likely to meet their needs. Trans people commonly reported that they would be less likely to access mental health services again, in part due to the lack of awareness that staff had of Gender Identity Services. Knowledge of these complex pathways and the specific issues that trans people might encounter was seen as an important, often missing, requirement for offering the right mental health support at the right time; understanding the specific needs of a trans person, rather than providing generic services which don't take these needs into account.

Children who have been exposed to trauma, abuse or neglect are much more likely to exhibit challenging behaviour to communicate distress. Where this is severe and persistent, it is linked with higher risk for almost every mental illness later in life. Despite the evidence, few children with these symptoms receive early support; the average wait for help after the first signs of mental health problems emerge in children is ten years (Khan, 2016). Instead, behavioural difficulties are often met outside of health services with restrictive interventions in schools, including seclusion and exclusion. In turn, these interventions

can echo traumatic experiences and put children at risk of further psychological harm – a potentially vicious cycle which can lead to more challenging behaviour (Wilton, 2020b).

The dynamic has a cross-cutting relationship with inequalities. Children from some ethnic minority communities, from poor and socially disadvantaged backgrounds, who are LGBT+, who have impairments or health conditions, and who are from minority religious groups are already at greater risk of traumatic experiences (Wilton, 2020b). Evidence demonstrates that restrictive interventions are imposed disproportionately on children with the same characteristics. The Timpson Review of School Exclusion found that both permanent and temporary exclusions are highest among Black Caribbean and Gypsy, Roma and Traveller pupils. It reported that 78% of permanent exclusions from secondary school affected pupils who either had special educational needs, were classified as 'in need' or were eligible for free school meals – 11% of these exclusions were for pupils with all three characteristics (DfE, 2019).



Poor responses to multiple and complex needs

There is evidence of poorer outcomes where mental health needs co-occur with other difficulties. People with severe mental illness are known to live for 15-20 fewer years due a range of avoidable health complications: challenges maintaining healthy weight, a lack of support to give up smoking, poorer and slower access to cancer screening and treatment, and poor management of diabetes and cardiac risk. Where the priority is perceived to be mental health treatment, other needs can be overlooked and poor physical health is taken for granted.

This is bidirectional: having physical health or social challenges can mean a person has poorer experiences of mental health care. For example, around 86% of people in alcohol treatment services have a co-occurring mental health difficulty; while the proportion of community mental health service users thought to have a drug use or alcohol problem is around 44% (Public Health England, 2016). Despite this high overlap in need, which is well known, a survey of professionals working in both mental health and alcohol treatment services found that alcohol use was a major barrier to getting any mental health support. Patients can be rejected by services or not provided with treatment which

accounts for both needs, and the poorest care of all was thought to be experienced by those who are also homeless (Institute of Alcohol Studies & Centre for Mental Health, 2018).

For some people with complex needs, the diagnosis they are given can be problematic in itself. The diagnosis of 'personality disorder', for example, can be ascribed to a person living with persistent and enduring distress, emotional problems and social difficulties. This is a controversial label. While advocates may view the diagnosis as a 'passport to effective help' where limited alternatives are available, service users and mental health professionals alike warn that is it stigmatising, misleading, and likely to mask the problems faced by people with complex mental health difficulties (Anna Freud Centre *et al.*, 2017).

Men and women who have 'personality disorder' are known to also be at higher risk of isolation, other mental health problems, harm from drug or alcohol use, poorer physical health and, ultimately, much shorter lives (Fok, 2012). Complex challenges and vulnerability are often experienced from early in life. Many people given the diagnosis will have experienced trauma and difficult interactions with services and systems which have repeatedly failed to meet their needs. This is despite the evidence that interventions such as Mentalization Based Therapy, for example (Bateman & Fonagy, 2013) can be effective.

Prisons and criminal justice

Many of those with the greatest mental health need live in environments which are known to put mental health at risk. An estimated 90% of people in the prison system experience a mental health or substance misuse problem. Prison populations show high instances of suicide and self-harm as well as extremely high prevalence of psychosis and diagnoses of personality disorder compared to the general population (Ministry of Justice, 2018; Durcan, 2016). A review by the Prisons and Probation Ombudsman (2016) found that, of prisoners who died in custody between 2012 and 2014, the majority had received mental health care from a health professional (one fifth had received no care).

The prison environment in itself is not conducive to good mental health care, and this can be exacerbated by the use of remand and short custodial sentences (long enough to damage relationships, too short to offer meaningful support), 'churn' between prisons, and difficulty in identifying people's needs when they enter an establishment (Durcan, 2016). For people needing a hospital admission, lengthy waits in prison for a hospital transfer can lead to long periods in segregation or health care facilities while they are acutely unwell, waiting for a bed in a secure hospital.

Release from prison can also be a period of great instability where support is limited and people with mental health problems face challenging situations financially and socially, often with nowhere to live and no money to live on. Yet continuity of care is a rarity, even for people who have been treated by prison mental health services, and thus have marked needs (Durcan *et al.*, 2018).

Again, ethnic differences emerge in this picture. Black people are overrepresented in the criminal justice system (The Lammy Review, 2017) and even more so in secure mental health services. The impact of societal and systemic racism cannot be ignored here; nor can it simply be ascribed to one sector or service without seeing how it seeps into multiple aspects of people's experiences. As young people we spoke to from MAC-UK made clear, negative experiences from one public service reflect on others: experiencing discrimination in school, from the police or in health services is highly damaging and reduces trust in all of them.

CURRENT POLICIES AND INITIATIVES TO IMPROVE OUTCOMES AND EXPERIENCES

The NHS Long Term Plan and the Independent Mental Health Act Review have both brought with them a renewed focus on inequalities in people's experiences of mental health support.

The Mental Health Act Review (Wessely *et al.*, 2018) set out plans for a Patient and Carer Race Equality Framework. At the time of writing, this is at a pilot stage in two local areas in England (Birmingham and South London). The Review made a number of major recommendations for changes both to the Mental Health Act and the wider system that could, if fully implemented, address racial and other inequalities in the use of the Act. These included the development and wider availability of culturally appropriate advocacy.

As part of the Long Term Plan's implementation, meanwhile, NHS England set up the Advancing Mental Health Equalities Taskforce, chaired by Jacqui Dyer. The taskforce is bringing equality into the mainstream of implementing the Long Term Plan's mental health ambitions – for example by seeking to improve data about equalities in mental health services and taking steps to improve equality and competency within the NHS mental health workforce.

To support commissioners and providers of mental health services to prioritise equality, NHS England published an Advancing Mental Health Equality resource (NCCMH, 2019). More recently, NHS England's Community Mental Health Framework set out a vision of 'whole population, whole person' primary and community mental health services which would ensure no one's needs remained unmet.

These initiatives will all take commitment, money and time to be successful. Unlike most previous mental health policies and strategies, these have equality as their main purpose, not as an afterthought. They have clear leadership and the support of national executive agencies. To be successful, they will require a concerted and sustained effort from government, national public bodies and local organisations across the country. Health policy is often subject to sudden changes in direction and reorganisations. Strategies that need time and stability to take effect are all too easily swept up in these short-term changes and energies are dissipated by organisational disruption or replaced by new priorities before the work is complete. Advancing Mental Health Equalities and the Patient and Carer Race Equality Framework are too important for this to be left to chance as we enter a period of possible flux and reorganisation in the health system in England.

REDUCING INEQUALITIES IN OUTCOMES AND EXPERIENCES

The UK's health care system is one of the most equitable in the world. Even so, it does not routinely achieve equity when it comes to meeting people's mental health needs. As this and previous briefings have demonstrated, entrenched inequalities undermine people's wellbeing and hinder public services in addressing them successfully. In a system designed for equality, we would expect to see:

An enhanced community sector role in mental health support: Voluntary, community and user-led organisations can make a significant contribution to addressing inequalities in outcomes and experiences. Organisations that emerge from within communities are uniquely able to harness the collective strengths of their community to provide a distinctive approach. Sadly, very few such organisations are able to demonstrate their long-term value, as funding (where it is available at all) tends to be short-lived and does not extend to evaluation or research. There is a pressing need for partnerships that enable approaches rooted in community and user-led experience and outcomes to be scaled up – to become the system, rather than an add-on.

Coproduction at every level and in every service: Lived experience needs to be valued in all aspects of mental health support, including in the design and development of services. Peer-led services can provide invaluable support, especially for marginalised, disadvantaged and oppressed communities. Statutory services and charities can work alongside experts by experience to change the nature of what they offer to better meet people's needs.

Culturally competent and trauma-informed approaches: All mental health services should seek to become culturally competent and adopt trauma-informed approaches. Culturally appropriate advocacy is a critical component of the former, and vital to help services to accept and address racism and discrimination. Trauma-informed approaches, meanwhile, can create a sense of safety and reduce the risk to people who have already experienced physical and psychological harm in their lives. And the two are interlinked: being trauma-informed also means understanding gender, race and other inequalities and how they intertwine to determine people's experiences and outcomes.

A commitment to meet all needs: In an equitable health and care system, no one's mental health needs should be met with no response. 'Inappropriate referrals', exclusion criteria and repeated assessments from multiple services leave people without support, often when they need it most. Adopting a system that ensures people who seek help get help (at the right level, right place and right time) will ultimately cost less as well as meeting needs more effectively. This will need to include making reasonable adjustments to mental health services for groups requiring support to be delivered differently – for example disabled people, including autistic people.

A whole system approach: Mental health support is less effective where the broader reasons why a person is experiencing distress or difficulty are not addressed. These can include debt, poverty, unemployment, housing, racial discrimination and physical health problems. Organisations responsible for planning local health systems should therefore collaborate with a very broad range of partners and seek to influence widely. Locally, this may mean working with housing services, schools and colleges (see box), the police and employers to ensure people with mental health needs are given a fair deal. And at the national level, this means bringing mental health equality into policies relating to education, social security, criminal justice and housing.

Community Learning Mental Health research project

The Community Learning Mental Health research project took place in 2016-17. Adult learning services delivered short courses for people with common mental health problems such as anxiety and depression. Engagement with the course – some focused on managing mental health and others on a wider range of topics – was found to be associated with improved wellbeing and wider benefits. The courses were more likely than IAPT services to reach people who were unemployed and from minority ethnic communities (Lawson et al., 2018).

Accountability and transparency: Data about the outcomes most mental health services achieve for people from different communities and social groups is poor. This makes it difficult to hold services to account for reducing inequalities in outcomes. Improved data collection is a key element of the Advancing Mental Health Equalities programme for the NHS in England. This should create the foundation for improved accountability within local systems for reducing inequalities. Integrated Care Systems should be in a position to assess how far they truly meet the needs of all communities and to bring about improvements where outcomes are currently poor.

ABOUT THE COMMISSION

The Commission for Equality in Mental Health was set up by Centre for Mental Health in 2018 with an 18-month mission to investigate inequalities in mental health in the UK and produce policy and practice proposals to tackle them.

The Commission is chaired by Liz Sayce and includes members with personal and professional knowledge and expertise about mental health inequalities. It issued a call for evidence at the start of 2019 and has received about 100 responses from across the country. The Commission sought evidence from as wide a range of people and places as possible, from published academic papers to narratives from groups and individuals. We particularly welcomed evidence from people and communities that experienced mental health inequalities first hand.

The Commission is seeking to understand why and how inequalities in mental health happen, the ways they manifest, and most importantly what can be done to prevent or mitigate them. Our call for evidence sought evidence about inequalities in the determinants of mental health (the factors that have an influence on how good or poor our mental health is during our lives), in access to help (of all kinds) for our mental health, and in the outcomes that people get when they receive support.

The Commission has particularly sought solutions to mental health inequalities. It is interested in solutions at every level: from community-led initiatives that seek to challenge power or resource imbalances locally to national policies that could help to make mental health more equitable.

The Commission's ultimate aim is to bring about a significant and sustained reduction in mental health inequalities. This is the final of three briefing papers from the Commission. We will publish a final report later this year that will set out our recommendations for what a system designed for equality should look like.

The Commission was generously funded by the Elliott Simmons Memorial Trust. We are grateful for their support in enabling us to carry out this important piece of work.

Members of the Commission

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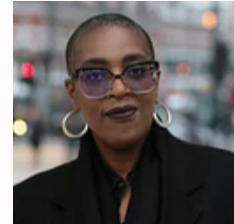
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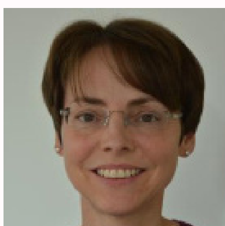
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Commission for Equality in Mental Health

Briefing 3: Inequalities of experience and outcomes

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