

What Londoners with Lived Experience Said

the impact of intersectional stigma on
mental well-being
and examples of how to reduce mental
health inequality in London



For Thrive LDN and the
London Health Board
by HEAR Equality and
Human Rights Network
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HEAR Coordinator's Introduction

HEAR is submitting this piece of supplementary research at a timely juncture, when both the mental health support needs of Londoners with intersecting identities are so pressing and there are so many opportunities for working together in finding solutions. This response demonstrates this desire to work together across sectors:

We support the ambition to achieve a world class mental health service... [and] welcome the commitment for mental health services to grow at a faster rate than the overall NHS budget... None of this is possible without us expanding the mental health workforce, including that of the voluntary and community sector... And, of course, in order to truly transform the experience of people with mental health problems, we need a cross-government approach so that problems people face in accessing support from other public services including public health, social care, housing and the benefits system are effectively tackled

Mental Health Policy Group responds to NHS long term plan', Prof. W. Burn, Royal College of Psychiatrists, S. Duggan, Mental Health Network, P. Farmer, Mind, S. Hughes, Centre for Mental Health, M. Rowland, Mental Health Foundation, M. Winstanley, Rethink Mental Illness, Jan 2019

This approach much links with the commitments made in the Mayor's Diversity and Inclusion Strategy, where the commitment is made to "develop stronger relationships with disadvantaged and excluded communities in London, so that we can develop policy and projects that are better informed by the lived experience of Londoners" (Greater London Authority 2018b, 155). Working together across sectors, commitments to lived experience are also to be found in the Strategy for Social Integration and across many other Mayoral and GLA statements and publications.

In the report that follows, guided by its members' priorities, HEAR has made a number of recommendations for action and commitment by statutory partners. HEAR for its part also makes commitments to work with these statutory partners and other stakeholders to realise these recommendations and there are already a number of opportunities available.

HEAR's members have between them a wealth of lived experience and expertise, including on the social model, and so are well placed to support, with the appropriate resources, our recommendations on 'expert by experience' representation and championing the social model. HEAR and some of its members are already working to improve understanding, collection and use of equalities data, working with colleagues at the GLA and London Plus amongst others. HEAR is committed to supporting intersectional work against hate crime across London, including through the Charities Challenging Hate Crime network, funded by Trust for London. HEAR is already championing the use of the 4Pi Involvement Standard, and the Way Ahead Systems Change Group has incorporated its dissemination and promotion into their Ambitions Framework.

We are also excited to work with partners across sectors on developing ideas about London as a Human Rights City. Members already have experience gleaned from other cities and we will be taking this work forward over the coming months.

So overall there are many opportunities for working together to reduce stigma and discrimination and help make London a healthier and happier city.

Christine Goodall
Network Coordinator

About the HEAR Network

HEAR Equality and Human Rights Network was formed as the London network of equalities organisations in late 2003 and existed as a hosted and unconstituted network until 2016, when it became an independent Charitable Incorporated Organisation (CIO). Prior to independent status, HEAR was hosted by Race on the Agenda, Women's Resource Centre, London Voluntary Service Council and Refugees in Effective and Active Partnership.

HEAR acts as a strong pan-equalities voice and source of practical knowledge on human rights and intersectionality in London. HEAR connects and supports equalities specialists across all 'protected characteristics' ('Equality Act' 2010) to make the most of their capacity and expertise, and raise expert voices to influence policy and the environment within which people work for equality for all.

HEAR is committed to user-led services, and all its work is based on the principle that people with direct experience of discrimination are in the best position to develop strategies to achieve equality; 'Nothing About Us Without Us'.

HEAR has over 800 Voluntary and Community Sector (VCS) and individual members. Our members cover all 'protected characteristics', user-led organisations, Experts by Experience (EbE), as well as those working with other marginalised communities for example people living with addiction, homelessness, survivors of Domestic Abuse/Gendered Violence, torture and persecution as well as generic VCS that work with marginalised communities like local, pan-London and national Healthwatches, advice providers, law centres and Victim Supports.

As a broad and diverse network HEAR does not seek consensus. We represent the diversity of London's communities. We do, however, present pan-equality learning, examples of good practice and cross-equality opportunities to reduce discrimination, improve rights and access, and aid policy makers and commissioners to meet statutory duties and strategic aspirations.

Our Trustees are Dr Sarah Crowther (Chair), Moud Goba, Aya Bdaiwi, Lisa Redding, Koldo Casla and Andy Gregg.

The HEAR Network is supported by an active Steering Group, whose members are Age UK London, Ashiana Network, Bexley and Bromley Accessible Transport, British Institute of Human Rights, deafPLUS, Faiths Forum for London, Inclusion London, Micro Rainbow International, Race on the Agenda and Refugees in Effective and Active Partnership.

Background to Paper and Methodology

Mental Health equality is an area of interest and expertise for many HEAR members. The causal links between exclusion, discrimination, isolation and poor mental well-being are well documented (Wallace, Nazroo, and Bécarea 2016; Linton and Rianna 2018; Bracken et al. 2012) and described in detail later.

Organisations run by and working with marginalised, including intersectional, Londoners have, therefore, extensive knowledge of the discrimination and barriers experienced by those with Mental Health Support Needs (MHSN) and have developed practical, efficient ways of overcoming them.

The communities covered in *What Londoners with Lived Experience Said* are based on our members' expert knowledge of intersectional communities with unmet MHSN that are of significant interest to London policy makers.

HEAR's research accompanies and adds value to, but is not part of, Thrive LDN's Right to Thrive, the 'Londoners Said' report or previous work commissioned from Revealing Reality.

This paper is based on HEAR members' publications and suggested reading as well as HEAR's own and commissioned research, and expertise and examples compiled from recent HEAR events and consultation submissions.

What Londoners with Lived Experience Said contains examples of intersectional discrimination, exclusion and stigma impacting on mental well-being, projects that improve mental health and well-being in intersectional communities in London, as well as how structural discrimination excludes intersectional people from accessing services and opportunities to influence policy and commissioning.

The literature review draws out practical recommendations that once adopted by Thrive LDN, London Health Board (LHB) members and the broader public sector in London will enable them to work more closely with equalities VCS and user-led mental health organisations to reduce mental health inequality and improve the mental well-being of intersectional Londoners. The paper also includes examples of communities that are at particular risk of intersectional discrimination and stigma impacting on mental health, that require further outreach and research.

Examples in *What Londoners with Lived Experience Said* have been selected to shed light on concerns raised across VCS organisations, different 'protected characteristics' and numerous intersections. Research cited is illustrative not exhaustive. This report will be available in Easy Read. Mhairi McGhee, the author of this report, is an Expert by Experience.

Political and Policy Landscape

The London Health Board (LHB) is a non-statutory group, however all members, including the Mayor, elected leaders and accountable officers do have statutory responsibilities (or represent organisations with public legal duties).

LHB is a prime opportunity to mobilise political engagement through pan-London initiatives and participation from all sectors and sections of society to work together to drive improvements and make London the 'healthiest global city' (Khan 2018).

LHB ensuring members' statutory purposes (to reduce mental health, health and care inequalities and prevention) are at the centre of all they do, whilst propelling the devolution agenda is vital. Other statutory duties to 'show due regard', held within Public Sector Equality Duty, and the duty to consult must be used to ensure structural inequalities and discrimination are not replicated or exacerbated, but instead challenged in this new landscape for London health and care (HEAR Equality and Human Rights Network 2019).

Opportunities

Mental well-being has never been discussed so openly so it is a golden opportunity for LHB members to challenge the stigma and discrimination experienced by people with MHSN needs, and educate Londoners that bullying, exclusion, hate crime and hate speech impact on mental well-being.

Throughout Mayoral policies, from the Equality, Diversity and Inclusion, Social Integration and Health Inequalities Strategies to the London Plan, and the work of Thrive LDN and Mayors Office for Policing and Crime (MOPAC) (Greater London Authority 2018a , 2018b, 2018c), run the 'golden threads' of reducing stigma and hate and improving mental well-being.

Creating parity of esteem is supported by all political parties, has been highlighted as a priority by the Prime Minister and Princes William and Harry, and has broad support from the third sector and clinical professionals... Clare Murdoch, NHS England's National Mental Health Director, ordered Clinical Commissioning Groups (CCGs) to increase their spending on services for people with mental health support needs or face sanctions
Race on the Agenda et al.,
'Mental Health Equality - Open letter to all newly elected Councillors',
23rd April 2018

2019's NHS Long Term plan begins with a commitment to "more NHS action on prevention and health inequalities" (Department of Health 2019) and dovetails with the 'The Five Year Forward View For Mental Health' (2016) and the 'No Health without Mental Health' guiding principles that services must help people with MHSN 'identify and achieve the outcomes **that matter to them**, including a suitable and stable place to live, educational opportunities, jobs and social contact ...' (Department of Health 2011, sec. 2.3, emphasis added)

In the Equality Act people with Mental Health Support Needs (MHSN) are Disabled People. This means we have additional protections and entitlements, for example the right to 'reasonable adjustments'.

The research shows wide distrust of the medical/ clinical model as applied to people with MHSN and increasing support of the Social Model of Disability (HEAR Equality and Human Rights Network 2017c). “The social model implies that with the right help and support and reasonable adjustments on the part of others people with any disability can flourish in society. And more specifically as applied to mental health it implies that the person should be treated as a whole rather than simply medicated” (Beresford et al. 2016, 30)

Some EbE have concerns about adopting the Social Model of Disability, due largely to societal stigma relating to disability, and poor explanations of the term. HEAR explains that with the Social Model of Disability we are disabled by barriers, both physical and societal, not our ‘conditions’ or ‘impairments’ per se.

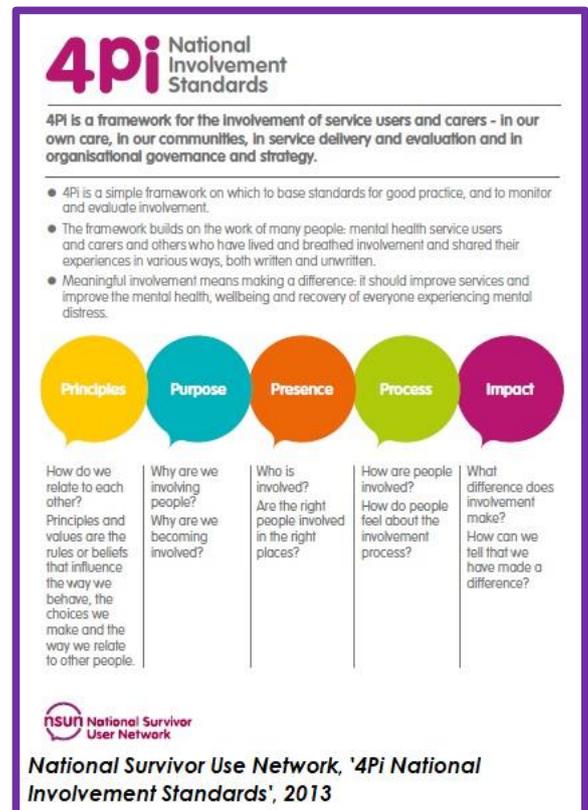
There is support from the wider health and rights sectors to adopting the less stigmatising, user-led model “Our work and research (Medicine, Conflict and Survival, Volume 23, Issue 3, August 2007) highlight a need to shift from a medical model of the causes and effects of ill-health to a social model, which assesses the needs of the individuals from a holistic perspective”(Migrant and Refugee Communities Forum (MRCF) 2014, 1)

Some with MHSN are entitled to assessment, with independent advocacy, and support under the Care Act ('Care Act' 2014), and other holistic, person-centred schemes like Personal Health budgets, so they can manage their own well-being. Using holistic health and social care appropriately is a preventative health measure.

Joint Strategic Needs Assessments, Health and Well-being Boards, NHS Equality Objectives and Equality Delivery Systems and other strategic health and care planning mechanisms should aid Local Authorities (LAs), Clinical Commissioning Groups (CCGs) to target budgets, commission for the demography that they serve and reduce health inequalities.

Without meaningful involvement throughout these processes, however, they cannot and will not aid statutory services in meeting their statutory duties or strategic aims (Think Local Act Personal and National Voices 2014, 29 examples)

Values based Commissioning (VbC), its principles and benefits, are evidenced by the Joint Commissioning Panel for Mental Health, Association of Directors of Adult Social Services, Department of Health – mental health and commissioning teams, Local Government Association, The Royal College of General Practitioners, Royal College of Psychiatrists and VCS partners



Values-based commissioning will support the delivery of the strategy No Health Without Mental Health (2011) and its implementation framework...

VbC emphasises universal strategies for whole populations and targeted interventions for at-risk groups by capturing the viewpoints of local communities and people, and focuses on commissioning for public mental health and well being...

VbC gives equal status to service user and carer input, clinical expertise and formal evidence and should lead to services that better reflect people's needs and therefore are more likely to help them recover...

More people with mental health problems will have good physical health... More people will have a positive experience of care and support... Fewer people will suffer avoidable harm... better services out of hospital... Fewer people will experience stigma and discrimination...

Involving service users as equal partners with valid expertise will also dispel myths and stigma that commissioners or health professionals may hold

Elizabeth England et al., from Joint Commissioning Panel for Mental Health, 'Guidance for Implementing Values-Based Commissioning in Mental Health', 2013, p: 20.

like NSUN, Rethink and MIND(Whitelock and Perry 2014; Perry, Barber, and Elizabeth 2013; Bennett, Appleton, and Jackson 2011) as an excellent person-centred approach to meet statutory duties.

VbC would also support strategic aspirations in Sustainability and Transformation Plans (STPs) and devolution and make the most of London's complex and changing health and care delivery and commissioning landscape.

Challenges

Equalities and human rights, and their practical implications, are not sufficiently embedded in London's statutory services (HEAR Equality and Human Rights Network 2019).

In relation to those with MHSN a pertinent example led to this research being commissioned. HEAR members told Thrive LDN that Right to Thrive/Revealing Reality's portal excluded and stigmatised intersectional people with MHSN and had a negative impact on well-being and potentially safety. 'Reasonable adjustments', an anticipatory statutory duty, requested on behalf of HEAR members, were not made.

Thrive LDN commissioning this research is a great first step towards involving EbE and expert VCS as recommended by the London Assembly Health Committee's 'Supporting mental health for all' (January 2018). HEAR members look forward to working with Thrive LDN and members of the LHB to roll-out the recommendations in this paper, designed to help embed statutory duties, overcome discrimination and reduce health inequalities, over the coming months and years,

Digital exclusion is of serious concern to all HEAR members and, as a result, is a policy priority for HEAR in 2019-2020. The egalitarian potentials for access, information, targeted and online support of new technology are clear. A 'digitally enabled' NHS is a key priority in the 'Long Term Plan' (2019) and there is a movement within statutory providers towards 'digital by default' when providing information, delivering consultations, engagement and support. Without 'due regard' ('Equality Act' 2010), having 'in real life' (IRL) alternatives and 'reasonable adjustments' easily accessible, discriminatory structures are being replicated.

The complicated commissioning and delivery landscape in London has meant mental health, already severely under-resourced, has slipped through the gaps. NHS mental health providers do not fit neatly with borough based CCGs or Local

Authorities. Changes to public health and social care have added to difficulties and the plethora of 'involvement' structures is confusing and largely not fit for purpose. Collaborations of CCGs and pan-London mechanisms like LHB must be mobilised to overcome these difficulties by providing strategic direction and modelling good practice and taking practical steps to use collaboration to meet their statutory duties.

Austerity is of serious concern to HEAR members and a major challenge to the aspiration of London becoming a 'Zero Suicide City'. London's VCS was always over-capacity, intersectional and user-led VCS even more so, and 'austerity' has disproportionately impacted on intersectional and marginalised people and the organisations that work for them.

"In 2016, an inquiry by the UN Committee on the Rights of Persons with Disabilities found that austerity policies introduced by the UK government had met "the threshold of grave or systematic violations of the rights of persons with disabilities." The Committee found high levels of poverty as a direct result of welfare and benefit cuts, social isolation, reduced standards of living, segregation in schools of children, lack of support for independent living and a host of other violations. The situation has had a direct impact on people's mental health with rates of suicide attempts doubling" (National Survivor User Network (NSUN) 2018c)

The broader contemporary context in which LGBT service users and providers operate is characterised by scarce resourcing. Public and/or statutory funding cuts over the recent past, commonly known as 'austerity', have had a demonstrably negative impact upon minority groups... (Colgan, Hunter & McKearney, 2014; McQuaid, Egdeell & Hollywood, 2010; Mitchell, Beninger, Rahim & Arthur, 2013). Service providers report, among many things, experiencing increased difficulty in delivering against their mission... It is unsurprising, therefore, that service users have reported...being unable to access... mental health, as well as social support, services. Increased feelings of marginalisation and invisibility often ensue (Mitchell et al., 2013). Minority communities... people in need and/or poverty are, in particular, being disproportionately affected by recent changes to service provision (Mitchell et al., 2013).

Daragh McDermott and Russell Luyt, 'Still Out There: An Exploration of LGBT Londoners' Unmet Needs', (Cambridge: Anglia Ruskin, June 2016), p:13

London's diversity is one of our strengths but also creates unique challenges. The policies of the 'hostile environment', described across the literature, impact on very many intersectional Londoners with MHSN, and in light of Brexit and Windrush, these policies are likely to affect even more. International discourses of hate and division put London communities at increased risk of psychological and physical harm.

LHB's aims, to drive improvements in London's health and care and reduce health inequalities and wider issues that affect health in London by championing public participation in health, support accountability in health and care services, can be realised if LHB members and the organisations they represent, take advantage of the opportunities and recommendations in this paper to overcome the challenges outlined above.

Recommendations

Expert by Experience representation on the London Health Board and at all levels of Thrive LDN

Thrive LDN commits to EbE involvement throughout its work and publishing the current user-led expertise on their Advisory Panel. The London Health Board commit to an immediate skills and expertise audit to enable EbE representation, in line with commitments to participation, following the evidence and recommendations of the London Assembly Health Committee. 'Concerns' about EbE attendance at 'high-level' or 'strategic' meetings or 'complex' legal or medical terminology say more about unconscious bias and structural discrimination than the competence of user-led organisations and EbE. The literature explains that there "needs to be political willingness all round to relinquish power, an acceptance that the best methods of involving & empowering people might not be understood until the process starts and an appreciation that good co-production takes time and resources to get it right but is worth it in the end!" (Coproduction Working Group for The Way Ahead, 2017, 15)

Thrive LDN and the London Health Board champions the Social Model across London's services

Thrive LDN and LHB commits to increased use and better understanding of the Social Model of Disability in relation to people with Mental Health Support Needs across London's health and social care services. Thrive LDN and LHB will model good practice by commissioning user-led Disability Equality training and committing to using non-stigmatising language.

Letter to the system

To you I'm probably a statistic. You probably feel sorry for me, but rub your hands in glee at someone new for a change. You've probably seen it all before, but here's someone new for you to poke and prod for a while. In the beginning I wondered if you enjoyed this, in the beginning I wondered if you judged me? Does seeing me so low and seeing me cry help you work on your game face? When you look at me, you look at your chart first. When you speak to me, I know you don't listen to me because your ears are attuned to a diagnosis.

***When you speak to me,
I know you don't listen
to me because your
ears are attuned to a
diagnosis***

***I do have hopes and
dreams, it's not all
about dark visions
and echoing voices***

To you my admission day was just another day in the office. When you went home that evening, having signed off on my form, I bet you didn't realise a little piece of my soul broke. Thanks to your prescription, you probably thought I'd be too knocked out to care. To you I'm probably just another statistic, another casualty of society. I do have hopes and dreams, it's not all about dark visions and echoing voices. I do have a place and a right to live in this society. Just like you. I do have a purpose and a goal. Just like you.

By Lavender (Danube Ward)

The Advocacy Project, 'Speakeasy', February 2016, p:10

Values-based Commissioning is rolled out across London health and social care

"The NHS is under pressure to make savings and commissioners need to make sure that the services they are purchasing from providers are actually meeting people's needs. If they don't help people to recover or manage their mental health, then they are not good value for money at a time when NHS budgets are tight. Providing the right services at the right time can also mean people are supported to live at home, rather than needing hospital care [which is]...more costly for the NHS... This expertise is really valuable." (Whitelock and Perry 2014, 6)

Intersectionality

Professor Kimberlé Crenshaw theorised intersectionality in 1989 to help communities of privilege (Training for Change 2014) understand discrimination:

“Black women can experience discrimination in any number of ways and... [challenges] assumptions that their claims of exclusion must be unidirectional... Black women can experience discrimination in ways that are both similar to and different from those experienced by white women and Black men... Yet often they experience double-discrimination-the combined effects of practices which discriminate on the basis of race, and on the basis of sex... sometimes, they experience discrimination as Black women-not the sum of race and sex discrimination, but as Black women. Black women's experiences are much broader than the general categories that discrimination discourse provides” (Crenshaw 1989, 149)

Intersectionality has since been expanded to other 'protected characteristics' and marginalised communities. (Centred 2014, 1)

Intersectionality helps people to describe additional experiences of discrimination

“Janet – a 43 year old black Afro-Caribbean bisexual person from Newham – described... the effects of facing multiple forms of prejudice. In particular, she largely attributes her diagnosis of depression to the prejudice that she experiences... [and] describes experiencing ableism, biphobia and sexism from both within LGB communities as well as from society at large.” (McDermott and Luyt 2016, 21)

Whilst there is some debate in the literature about whether intersectionality exists in 'layers' of identity, following Crenshaw's analogy of being in a road traffic incident at an intersection, a more nuanced model is largely accepted.

The HEAR Network explains the two approaches to intersectionality by imagining a cake, rather than a trifle. In a cake the individual ingredients of identity are mixed, combined, potentially changed and hard to separate. In a trifle the layers are visible, and could be scooped out, but are usually (and best?) consumed together. In reality intersectionality works in many and changing ways depending on context.

Intersectionality holds that, for instance, one is not a lesbian and disabled, rather one is the combination of these at the same time... one's identity as a lesbian is formed by one's identity as disabled, and vice versa; the elements of identity cannot be separated, are not lived or experienced as separate. From this perspective it can be unhelpful to make comparisons between different 'equality groups'... or to imagine 'hierarchies' of equality, e.g. between race and sexuality, because when doing so the existence/experiences of trans lesbians, and Black, Asian and ethnic minority (BAME) LGBT people, are marginalised or misrepresented. It can also be unhelpful to think in terms of 'multiple identities', or 'multiple discrimination' (though this is how it is conceptualised legally), as identities and experiences are not layered on top of one another

Centred, 'Intersectionality - a Literature Review' (London: HEAR, 2014), p. 1

Intersectionality illuminates inter and intra 'equality strand' ('Equality Act' 2010) discrimination. There is “an image that you can only be either LGBT or Christian and never the twain shall meet.... The reality is that some LGBT people are people

of faith and some people of faith are LGBT" (Lesbian and Gay Christian Movement (LGCM) 2014, 1). As well as around faith intra-LGBTQI discrimination is experienced by women, bisexuals, trans people, people of colour (PoC) including Gypsy, Roma, Traveller (GRT) and disabled Londoners. (Galop 2014; McDermott and Luyt 2016; Micro Rainbow International 2014)

Intersectionality highlights diversity within 'protected characteristics' like 'race', and even within seemingly more homogenous communities like Irish (Irish in Britain 2019) or Somali (Hussein 2013), for example "It is almost impossible to provide an agreed... overview of Somali terminologies regarding mental illness... Somali terminologies for mental illness include xanuunka madaxa ama maskaxda, which translated means 'head illness or brain illness'... cuduradda dhimirka or cudurka dhimirka to express that someone has 'mental illnesses or mental illness'... waali that in its most severe meaning indicates madness/craziness that cannot be reversed or cured" (Council of Somali Organisations 2017, 13)

Some Londoners exist in more than one section of an intersection, for example, bisexual intersex people and refugees of colour. This intersectional diversity is reflected across the literature. (Faiths Forum for London 2014; Fassil and Burnett 2015)

Intersectionality also can help those in positions of privilege to avoid stereotyping communities. "Hove (2011-2012) and Kaydamare (2011-2012) emphasise how a lack of intersectional focus, particularly including socioeconomic factors, contribute to further deprivation in the Zimbabwean community in London... 'othering' works to silence the Zimbabwean communities' needs beyond HIV/AIDS and asylum difficulties (Hove 2011-2012) and the specific needs of young people living with difficult family relationships and unemployment in the face of unresolved immigration status and dispersion programmes (Kaydamare 2011-2012)... active engagement with rhetoric and 'othering' discourses lies not only in addressing the specific needs of marginalised groups, but also in creating the space for voluntary and community organisations to differently engage with intersectional identities and needs perhaps more appropriately and widely than often times the current political and economic climate allows (Larasi 2011)" (Centred 2014, 3)

People with MHSN are disabled people, so are all intersectional. Many people do not disclose their MHSN or identify as disabled due to prejudicial attitudes and stigma (some internalised), compounded by a lack of knowledge, understanding and confidence in front-line services to ask these difficult questions. Equalities data is also sorely lacking on other protected characteristics and intersections engaging with health, mental health and social care services.



Thirty years ago Crenshaw explained the social and legal impacts of ignoring intersectionality (in the US legal context DeGraffenreid, Moore and Travenol (Crenshaw 1989, 150)). In 2019 across some intersections, for example “the concept of “faith and sexuality [are seen] as opposing forces and since the Equality Act (2010) this has become even more entrenched with the protected strands of faith or belief and sexuality being fought out in the courts, including the European Court of Human Rights (EHRC)” (Lesbian and Gay Christian Movement (LGCM) 2014, 1)

“In the UK intersectionality on the whole ‘has not been integrated into legal remedies, policy making or appropriate data collection’...The Public Sector Equality Duty... says public bodies, when carrying out their functions, must have due regard to the need to... advance equality of opportunity” (Babouri 2014, 3). To do this public bodies need better data about the intersectional communities that they serve.

Recommendations

London Health Board and Thrive LDN support statutory staff collect equalities data

Without knowing the communities they serve Local Authorities, the NHS and GLA are unable to commission and deliver services that will reduce health inequalities and meet their statutory duties, including showing ‘due regard’. Statutory workers including Thrive LDN staff must be trained on how and why to collect equalities data and that there is more information held in someone stating they ‘prefer not to say’ than a blank space on a form (Centre for Armenian Information and Advice 2014; Roma Support Group 2014). LHB members and Thrive LDN should commission user-led and peer researchers to support this work (National Survivor User Network (NSUN) 2018a; Billsborough et al. 2017)

London’s Health and Social Care providers, policy makers and Thrive LDN improve cultural understanding of staff

Thrive LDN and LHB immediately audit teams to know what EbE and cultural expertise is present and commission user-led training on different cultures (including disability culture) in London fill gaps in cultural understanding. Thrive LDN use this model of good practice to improve cultural understanding throughout NHS and LAs teams that support those with MHSN, and champion policies and procedures that develop and recruit staff from communities under-represented in clinical/management/commissioning positions by valuing expertise, gained through experience, as ‘desirable’ to roles. (London Assembly Health Committee 2018).

Despite our progress... we still have significant inequalities and substantial differences in outcomes in the performance of the health service. We know the downstream consequences of ill health can more effectively be tackled if the NHS took a more activist role... [and] we will make the NHS pound go further if we ensure much of the avoidable illness burden is tackled at source and we can only do that with our partners and that is what the NHS is committed to do

Simon Stevens, Chief Executive of NHS England, ‘presentation at London Health Board Conference,’ 25th October 2018

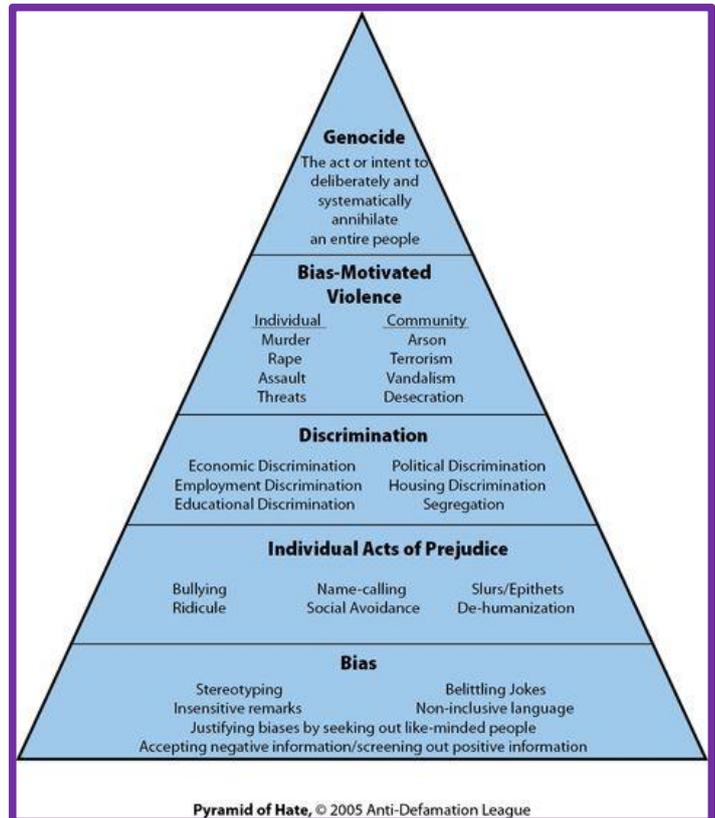
Impacts of discrimination, exclusion and stigma on mental well-being

Concepts and laws about human rights and discrimination grew out of lessons learned from the Second World War. People with Mental Health Support Needs and other Disabled People were the first targets of extermination in Aktion T4, but protests led to it becoming the only genocidal policy in Nazi Germany to be 'officially' stopped.

People with MHSN are some of the most stigmatised members of our community. Our diagnosis, conditions, impairments and symptoms are still used as slur terms.

The pyramid of hate can be a useful tool to consider the experiences of stigmatised and marginalised people.

"Experiencing prejudice is widely acknowledged by both academic and public policy reports to have detrimental impact on individuals' mental and physical health; at times precipitating individuals engaging in destructive or self-injurious behaviours (c.f. Woodhead, Gazard, Hotopf, Rahman, Rimes, & Hatch, 2015)" (McDermott and Luyt 2016)



Recent increases in hate crime and targeted violence are well documented whilst media and social media are full of 'banter' and 'debates' about hate speech versus free speech. Narratives and acts, particularly if perpetrated or accepted by the state, have significant traumatic effects. Bias, discrimination and acts of hate cross pollinate, reinforce one another and trickle up and down the pyramid. (Paterson, Walters, and Brown 2015; Walters et al. 2018; Inclusion London 2019)

*To have someone call me a sloth looking ***** who should be shipped down the sea, and shot and killed, for wanting to create life. It's just wrong*
Changing Faces,
'Steve's experiences of hate crime #VisibleHate video', 17th April 2018

Some Londoners currently live at the top of the pyramid with "act[s] and intent[s] to deliberately and systematically annihilate" them. Intersex and disabled people experience coercive 'corrective' interventions, implying their birth is a mistake. Disabled people have eugenics discussed and enacted with selective abortion, embryo selection and euthanasia.

Some Londoners' 'real' and right to exist and reproduce are 'debated' including Trans, Bi, Roma, and disabled people. Still more are abstractly annihilated in discussions about whether they are a 'proper', 'good' or 'real' Gypsy/Muslim/Refugee/Woman (HEAR Equality and Human Rights Network 2018; Roma Support Group 2014; Harrow Equalities Centre 2014).

Intersectional discrimination itself can add to MHSN “LGBT people of faith and especially those who are struggling with either identity, this causes serious conflict and psychological trauma... Throughout my work representing the LGBT community at faith-based meetings and the faith community at LGBT meetings I am very aware of the hostility in both camps towards the other. As a gender queer lesbian ordained minister I have been told in no uncertain terms that I was not welcome in as many gay bars as I have churches...” (Lesbian and Gay Christian Movement (LGCM) 2014, 2–3)

Additionally the “literature holds that [intersectionality] can create additional disadvantage, i.e. experiences of discrimination, oppression and exploitation are heightened at certain points of intersection. This was particularly highlighted by the Refugee Council (2002; 2005)”, as well as at intersections of age, disability (HEAR Equality and Human Rights Network 2018) and faith. “They take advantage of me – doing the house chores and you have to do the cleaning and shopping and sometimes you are tired but you just have to go because you are at their mercy. You just can’t let them down” (Patel and Sen 2010, 45).

Experiences of violence and hate crime

“Racism and discrimination in the UK have been linked to an increase in (what the biomedical model calls) psychosis, and research indicates that they can lead to increased physical ill health, including hypertension and cardiovascular diseases (Karlsen and Nazroo, 2002; McKenzie, 2003; Rees and Wohland, 2008; Williams, 2008; Nazroo, 2009)” (Griffiths 2018, 13–14)

Members of ‘protected characteristics’ are more at risk of experiencing hate crime and targeted violence, including domestic abuse. Communities that live with hate crime and targeted violence, whether they have been a ‘victim’ or not, experience psychological impacts and alter their behaviour, becoming more isolated. (Paterson, Walters, and Brown 2015; HEAR Equality and Human Rights Network 2018)

Intersectional people are at further risk, for example, disabled women are at least twice as likely to experience domestic abuse, and incidents are likely to last for longer, be more regular and severe. (Hague, Thiara, and Mullender 2011)

The ability to stay and feel safe is a concern across the literature. “For 55% of trans respondents and 41% of LGB respondents, experiencing verbal or physical abuse from strangers is deemed a frequent or daily concern... 29% of public survey respondents feel that they are unable to maintain their physical safety and approximately 40% of respondents, who report having experienced either homophobia and/or transphobia, do so frequently or somewhat frequently” (McDermott and Luyt 2016, 19)

Communities higher up the pyramid have less positive experiences when reporting hate incidents and discrimination. They are often not believed or seen as poor witnesses, to blame or troublemakers (Inclusion London 2019; Walters et al. 2018).

This is particularly true for people with MHSN, who should be protected by disability hate crime legislation, but violent crime against people with MHSN rarely is recorded as such even when clearly “motivated by hostility or prejudice based on” (Crown Prosecution Service 2017, 3) their Mental Health Support Needs.

Hate crime and Domestic Abuse/Gendered Violence research and legislation recognises the cumulative nature of incidents and that they tend to increase in regularity, expansiveness and violence (Hague, Thiara, and Mullender 2011; Walters et al. 2018). This echoes the pyramid of hate but is rarely seen in statutory responses to targeted abuse experienced by Disabled People.

It is well documented that survivors of hate crime and domestic abuse often do not report incidents at all. When survivors of hate crime do report the ‘justice gap’ means few get full legal redress (Walters, M, Owusu-Bempah, A and Wiedlitzka, S (2018) Hate crime and the “justice gap”: the case for law reform. Criminal Law Review, 12. pp. 961-986)

HEAR Equality and Human Rights Network, ‘Members’ Input into Opinion Research Services ‘MOPAC: Improving Victims Outcomes’ Survey’, 2018, p. 2

Pan-equality learning (expanding and transposing good practice in Local Authorities, police, public health etc., practice around responses to domestic abuse to other communities that experience targeted violence) could help build a fuller picture of hate incidents experienced by intersectional Londoners and aid the criminal justice system in gaining convictions and uplifts in sentencing. This in turn will make communities feel safer, and improve mental well-being (HEAR Equality and Human Rights Network 2018; Walters et al. 2018; Paterson, Walters, and Brown 2015; Roma Support Group 2014; Harrow Equalities Centre 2014).

Structural discrimination and unconscious bias

Discrimination and unconscious bias means some communities or behaviours are seen as threatening and others considered ‘normal for them’.

This “is concerning and can result in further mental distress for BAME patients, deterring them from seeking professional help... [their mental health] goes untreated and deteriorates” (Community Links 2018, 7)

The Sainsbury Centre for Mental Health calls this the ‘circle of fear’. “Stereotypical views... cultural ignorance, and the stigma and anxiety associated with mental illness often combine... influence risk assessments and decisions on treatment, responses are likely to be dominated by a heavy reliance on medication and restriction. Service users... become reluctant to seek... or to comply with treatment, increasing the likelihood of a personal crisis...In turn, prejudices are reinforced and provoke even more coercive responses... resulting in a downward spiral, which we call ‘circles of fear’” (Sainsbury Centre for Mental Health 2002, 8)

The Metropolitan Police Service in the McPherson Report (McPherson 1999) and the NHS in the inquiry into the death of David Bennett were found to be institutionally racist (Islam, Rabiee, and Singh 2015; Griffiths 2018). Unconscious bias plays out at other intersections as well, including GRT and Irish people (assumptions about drink), LGBTQI women and women of colour (assumptions about promiscuity), and faith (assumptions about ‘healing, witchcraft, gender/familial relations, traditions

have led to statutory failings and serious case reviews).

A number of reports describe a similar cycle of fear in school exclusions of intersectional young people and incarceration in mental health, criminal justice and immigration detention (Micro Rainbow International 2014; Chirape 2018; Roma Support Group 2014).

Black people are four times more likely than White people to be detained under the Mental Health Act... people from south Asian countries as a whole also have higher than average detention rates... Diagnosis of psychotic disorders is almost three times higher for Black people than for White people. A staggering ten times higher for Black men than for White men

Race Disparity Audit, Cabinet Office, 2017 in NSUN 'A Call for Social Justice', 2018

Exclusion, invisibility and isolation

Across the literature intersectional communities describe being excluded and isolated. Hate crime leads to behaviours that isolate people. Isolation itself has well documented impacts on mental well-being, general health and resilience. Older people describe being invisible to services as well as family (Age UK London and HEAR Equality and Human Rights Network 2017; Irish in Britain 2019) "There is general concern that loneliness and social isolation are major problems for members of the Elders Wellbeing project.. there is a prevailing notion that minority ethnic communities have strong family bonds and social networks, which help reduce loneliness and isolation. However, they argued that there are many adult children who 'do not have time for the elderly', and dismissed the idea of minority ethnic communities looking after their older people as a myth, which did not reflect the reality of many people" (Age UK London 2014, 1)

Much of the research describes communities feeling invisible in policy (Micro Rainbow International 2014), debates, the media and, most importantly, to services (Harrow Equalities Centre 2014) "many people, particularly lesbians and bisexual women, this social alienation partly emanates from a sense of social invisibility and isolation... "To be honest, invisibility, isolation, just not knowing, just having zero places to go" (McDermott and Luyt 2016, 23). The experience of invisibility and exclusion is confirmed when people ask for help and find it is not available.

Communities are described as 'hard to reach' when no attempts have been made to find them. In fact it is not communities, but services that are 'hard to reach' (Race on the Agenda 2018a). As previously invisibility in data (Irish in Britain 2019)) creates a cycle of exclusion from discussions, consultations and commissioning leading to further exclusion and isolation.

" Unlike other refugee populations, Armenians are largely invisible and ignored by the media, decision makers, statutory services, voluntary organisations and even the general public. This is because Armenians have arrived from troubled parts of the Middle East and former USSR and are often classified as Arabs, Iranians, Russians or 'White Other'" (Centre for Armenian Information and Advice 2014, 2)

Recommendations

Thrive LDN and political leaders in London commit to always challenge stigma and hate

At a time where police are over-stretched, it may be understandable for Commander Cressida Dick to minimise hate crime experienced by some Londoners, but it is not acceptable (Inclusion London 2019). Following the evidence presented in this paper and a greater understanding the impact of stigma and hate on mental well-being Thrive LDN and political leaders must commit to always challenge stigma and hate experienced by people with Mental Health Support Needs.

If there is an inaccurate or abusive item about schizophrenia in the press, a radio talk show or a TV, don't get depressed, get active. Write a letter, e-mail them, phone them up and tell them where they are wrong. It works!

Royal College of Psychiatrists, 'Schizophrenia leaflet', 2015

Thrive LDN Champions programme developed to focus on under-heard Experts by Experience

Thrive LDN Champions should be developed to focus on the communities most at risk of poor mental health, and should acknowledge the distinct expertise and roles of EbE as champions and the difference between an ally and a champion. Year 1: focus on intersectional communities laid out in this research. Year 2: could focus on other under-heard communities at risk for example 'looked after children', survivors of abuse and torture. Holding Thrive LDN champions up as experts by experience will start to shift the stigma. Thrive LDN could consider supporting/co-opting mentees, health connectors, befrienders from similar projects in the VCS to aid outreach (Mobility Help 2014; Carthy et al. 2016; Billsborough et al. 2017).

"Hindu temples, a Mosque and a Bangladeshi community centre were used to conduct health checks targeting this population in London... By working in religious and community venues, there was a high recruitment of the target population including individuals who had not registered with a doctor, an opportunity to educate whole families, and a feeling of mutual support in the community. Some attendees noted that the community centre leant itself to a patient-centred rather than 'GP-centred' consultation... Many of the community and religious leaders added to the programme in a number of ways. The healthcare team highlighted the importance of community volunteers and 'champions', who assisted with the administration of the programme and inspired community participation. In the temple communities, prior to the visit, health education programmes were used to 'prime' the target population. They also organised health promotion activities (for example, healthy cooking classes), which created a community spirit and motivation to enact and maintain lifestyle changes after" (Thomas 2016, 65)

Structural discrimination and barriers to access

Statutory bodies, including outsourced providers, have duties to provide services to all and to commission on the basis of reducing health inequalities. If intersectional Londoners with MHSN access prevention and early intervention services this will reduce hospital admissions, crisis, risks and costs as well as reduce health inequalities and improve mental well-being. The examples of barriers below reflect concerns raised by HEAR members at events and throughout the literature across many 'protected characteristics' and 'intersections'.

Source: Workshop discussions, HRCN 10/12/13: Refugee Children and Young People and Access

'Stage' of Access		Relevance to Young Refugees
'Pre-gate'	When people are not even aware that a service exists or that they might be entitled to it.	Unfamiliar with British systems, opportunities, local provision. Low connection with local information channels eg. libraries, peer networks.
Gate	The point at which a person first comes into contact with an agency (eg. Reception), and has to show they are entitled to be considered for the service	Language, documentation, credibility. Receptionist's perceptions of the refugee child – hostility, ignorance or confusion, erring to safety, Labelling? 'We don't do...'
Queue	Waiting to be considered; often includes persuading the agency to give you priority over others, eg. Waiting list.	Assuming young people will be supported by others of same ethnicity. Need to define selves in terms the agency recognises as urgent. Difficulty or failure to manage ongoing communications, letters etc.
Encounter	Face to face interaction with decision makers who decide whether and what service you will get, and when. The 'encounter' is often another kind of 'gate'.	Ability to articulate, understand what is required, different cultural background in face to face interaction. Knowing the right questions.

REAP, 'Refugee Children and Young People (Lessons from Hillingdon)', 2014, p. 6.

Inaccessible language

Across the literature poor communication between statutory services and intersectional communities is described as a major barrier to access. They include severe lack of appropriate interpreting and translations, inaccessible information, few plain English communications and poor understanding and delivery of 'reasonable adjustments'. Statutory providers use VCS to provide language and communication skills and sometimes rely on family members, including children, to interpret in confidential, traumatic and other inappropriate circumstances (Tamil Community Centre 2013; Nellums et al. 2018a; Age UK 2012) .

"Obstacles related to language and communication were identified by all interviewees... indicating the language barrier to be the most pervasive obstacle to accessing effective services. 61.76%... experienced obstacles to accessing a service because there was no interpreter available...Language obstacles were acknowledged... as making it difficult to receive an effective service: "I've been to the GP alone but there was really bad communication between us he didn't understand me at all. "(WQ). In particular, without access to an interpreter or Farsi-speaking professional, mental health treatment through talking therapies and counselling services was felt to be ineffective" (Mind in Harrow 2017, 15)

Lack of cultural understanding

Much of the literature presents statutory providers lack of understanding of the cultures and intersections in London are as a serious barrier to overcoming mental health inequality. A number of reports show that services are not aware of basic differences in cultural conceptions of mental health and illness. This means people may not know that an intervention applies to their experience, public health messages will have little traction and workers can inadvertently discriminate or cause offence. User-led VCS organisations act as advocates for their communities and anthropologists to providers (Galop 2014; Age UK London 2014; Keynejad 2008).

“Western health practitioners often encounter many challenges when providing assistance to Somali migrants and refugees with mental illness or psychosocial problems due to poor understanding of Somalis’ distinct cultural and religious conceptualisations... (Cavallera, et al. 2016)... Causes of mental illness in the cultural context of Somalia... include God's will, poor practice of religion, evil eye, evil spirit, and sorcery. Traditional treatments... [include] ritualistic dancing. Ziyara (visiting) local shrines or a living wali (a friend of God)” (Race on the Agenda 2018b, 5–6). Another example of Londoners’ different ideas about mental health include is ‘Padatam’ the Tamil concept of “a whole bodily process rather than something located only in the brain... experienced from ‘head-to-toe’” (Tamil Community Centre 2013, 3–4).

Lack of understanding of eligibility to public services

This is most clearly demonstrated in difficulties with GP registration (Nellums et al. 2018a; Roma Support Group 2014) experienced by refugees and people wrongly perceived as not being ‘ordinarily resident’ like GRT and homeless people. Disabled people pan-impairment, are also regularly wrongly deemed to be ineligible to support, demonstrated by high numbers of successful appeals across all disabled people’s entitlements. ‘Gatekeepers’ appear to presume ineligibility post-austerity and with the ‘hostile environment’. Poor understanding of eligibility to reasonable adjustments, privacy and other basic human rights impacts on all people with MHSN.

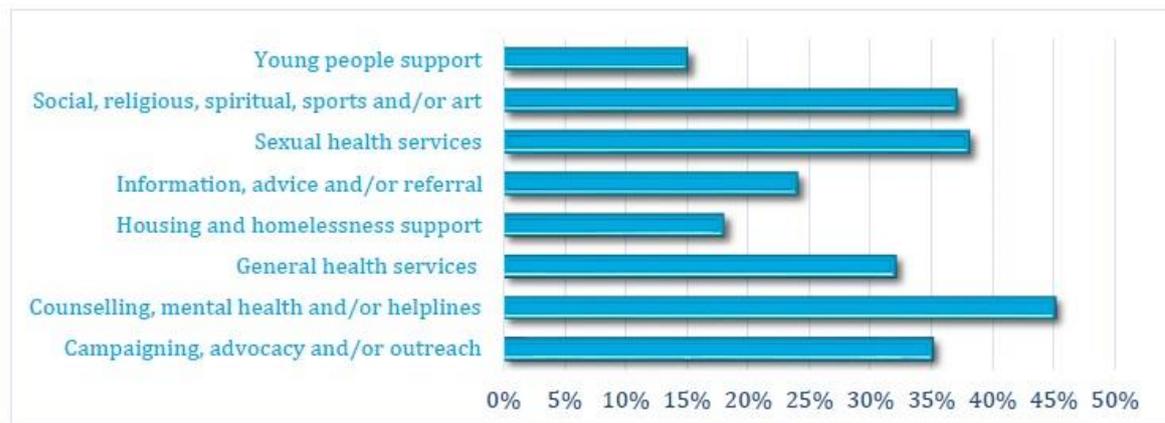
“As far as health and social care services are concerned we are constant witnesses of inadequate services due to lack of professionals’ knowledge, often causing a denial in housing and benefits refugees are legally entitled to... Home office employees asked one of our clients to show his documents to prove that he had refugee status during his ESOL class at the local adult education college. They also disclosed to his class that he was in detention for a long time. He felt really distressed about the experience and as a consequence of it left college” (Migrant and Refugee Communities Forum (MRCF) 2014)

Limited appropriate services

Limited intersectional and specialist services, further impacted by ‘austerity’ are a major barrier “respondents highlighted that despite having previously been receiving various supports and accessing services, they are now no longer doing so [as]... The service is no longer available due to closure and/or cutbacks [or] they are no longer eligible for such supports, for example, due to more restrictive

eligibility criteria" (McDermott and Luyt 2016). The literature, including the Marmot review's explanation of the 'Social Determinants of Health' (The Marmot review (périodique) 2010), describes that holistic support is necessary for mental well-being. Holistic services are severely lacking in London and without housing, parenting etc., people are unable to prioritise their mental health or build the trust needed to disclose stigmatised needs.

Figure 5. Proportion of respondents who would access LGBT services, if available (n = 78)



Daragh McDermott and Russell Luyt, 'Still Out There: An Exploration of LGBT Londoners' Unmet Needs', 2016, p: 28

Lack of trust

Linked to all the above there is a distinct lack of trust in statutory services described across the research. Trust is vital to enable marginalised people to disclose and seek support for stigmatised needs.

"Many women considered... treatment for perinatal mental health to be inadequate. Barriers to disclosure included stigma, fear of social services involvement, the absence of established relationships with trusted health professionals and the expectation of poor treatment.

- Many women who had experienced infant death, stillbirth or late miscarriage had received inadequate emotional/mental health support, as well as inadequate or inaccessible information.
- VCSE approaches to support included: practical and emotional support during and shortly after birth... mother and baby groups or parenting programmes. Perinatal mental health - 'They don't ask how you are'" (Maternity Action 2018, 19)

Recommendations

Providers in London pay user-led VCS for all statutory services provided

Health and Social Care providers in London rely on VCS to provide interpreting, independent advocacy, cultural expertise, social prescribing, expert consultancy and intelligence, furnish consultations and disseminate public health messages. London public services must commit to paying the VCS for the statutory services they provide. If public services struggle to pay the VCS for their services then they must ensure VCS are not 'out of pocket' for filling gaps for statutory providers. NHS, LAs can ensure VCS are adequately resourced by providing a venue, catering, facilitators, note takers, reasonable adjustments, helping with publicity, dissemination of findings. Statutory must always acknowledge expert contributions and consultancy from VCS and EbE. (HEAR Equality and Human Rights Network 2017a, 2017b, 2017c) Thrive LDN should model and encourage this good practice.

"The third sector cannot and should not be expected to fill the gaps left by inadequate investment in statutory service... Voluntary and community sector organisations, especially those which are peer-led, can help to bridge the gap between authorities and individuals with complex needs. These organisations play a pivotal role in supporting people who have been marginalised from mainstream services, and in educating others on how to best work with these groups. But worryingly, much of this expertise is in danger of being lost from London" (London Assembly Health Committee 2018, 24)

A Thrive LDN grants programme for user-led projects that reduce barriers experienced by intersectional people with Mental Health Support Needs

Thrive LDN should co-design a programme of grants for innovative projects that reduce barriers experienced by intersectional people with Mental Health Support Needs. Evaluation and monitoring of projects must be designed and delivered by peer researchers (National Survivor User Network (NSUN) 2018a) with parameters that will enable successful work and good practice to be upscaled and commissioned sustainably by statutory providers.

London Health Board members commit to promoting rights and entitlements

'Gatekeepers' have been led to believe that they are saving public money by denying people access to entitlements. LHB members should commit to highlighting rights and guidance. For example everyone can and should, register with a GP (Nellums et al. 2018b; Roma Support Group 2014) or disabled people can have 'reasonable adjustments'. Narratives of scroungers and the undeserving poor (entirely prejudicial tropes) interact with cultural concepts about charity, meaning some are refused services whilst others think they do not deserve support. Leaders in London can challenge stigma by promoting facts about rights and entitlements.

"In the group discussion, it was said that one of the barriers was the mind-set that the services are 'favours'... they have worked and contributed to the economy through tax and national insurance contributions. They are not conscious of how they have paid" (Ojinnaka and Nigerian Organisation of Women 2014, 5)

Structural discrimination and barriers to influencing

Statutory bodies across health and social care and the Greater London Authority (GLA) have statutory obligations to involve and consult. They also must 'show due regard' to eliminate unlawful discrimination, harassment and victimisation when considering policy and service changes, the Public Sector Equality Duty (PSED) ('Equality Act' 2010).

Across the literature are descriptions of involvement and consultation feeling 'tokenistic' or 'tick box exercises'. Unrealistic deadlines, poor or no outreach, 'involvement' being the 'usual suspects' or being the only EbE or VCS representative invited, add to the feeling that decisions to cut services or change policies having already been made despite statutory obligations (Race on the Agenda 2018a; HEAR Equality and Human Rights Network 2017c).

*The PSED involves a duty of inquiry, a public authority must be properly informed before taking a decision. If the relevant material is not available, there is a duty to acquire it, frequently through consultation with relevant groups...
vi. When there are large numbers of vulnerable people, very many of whom fall within one or more of the protected groups, the due regard necessary to discharge the duty is "very high"*
**HEAR Equality and Human Rights Network,
'Additional Submission from on Matter 2 (M2)... on the new London Plan (NLP)', February 2019**

Statutory providers across London, at all levels, are regularly informed by HEAR members that 'digital by default' and online consultation and engagement, without meaningful accessible, 'IRL' alternatives, discriminates against marginalised communities including intersectional people and those with MHSN.

Compounding inaccessible language and poor outreach is the experience that even when consultation events and submissions are arranged by VCS for statutory providers, their expert evidence is rarely reflected in strategies, policies or decision-making following consultations. For example HEAR members are disappointed that, despite many responses to consultations and other input, stigmatising terms such as mental health 'issues' and 'problems' still appear in GLA documents.

Concerns raised by HEAR members about the appropriateness and impact of Time to Change (Smith 2013), Mental Health First Aid (HEAR Equality and Human Rights Network 2017c, 2017b) and Restorative Justice (HEAR Equality and Human Rights Network 2018) resulted in no adaptations or mitigations in policies. HEAR members who started a Mental Health Equality campaign, #HardlyHardToReach, have still not been provided with details of eight CCG Equality Objectives despite asking for details for over a year.

"Users of mental health services tend to be unenthusiastic about the prospect and the experience of receiving acute care, preferring interventions to help them recover, reintegrate with society, and achieve their personal goals. However, a large proportion of the scarce mental health resources in the UK and elsewhere are committed to inpatient and other acute care" (Johnson et al. 2018, 409)

Recommendations

Statutory services in London, including Thrive LDN and LHB members, sign-up to and support the 4Pi involvement standards

“Developed by people with lived experience as part of the National Involvement Partnership (NIP) project, the 4Pi National Standards ensure effective co-production, thus really improving experiences of services and support.

4Pi was the result of an NSUN hosted project, the National Involvement Partnership (NIP), which was funded by the Department of Health (Innovation, Excellence, Strategic Development) voluntary sector funding. The aim of the three year project was to strengthen and 'hard-wire' involvement in to the planning, delivery and evaluation of the services and support we use for our mental health and wellbeing needs. This framework established some basic principles to encourage people to think of involvement in terms of ***principles, purpose, presence, process and impact***” (National Survivor User Network (NSUN), February 2019)

Thrive LDN and the London Health Board should immediately sign up to 4Pi to model good practice, monitor the extensive benefits of EbE involvement and encourage further adoption in London.

Organisations with statutory duties to consult and engage, including Thrive LDN and LHB members, communicate in plain English and do appropriate and timely outreach

With its strategic political lead the London Health Board and Thrive LDN's central role in improving mental well-being, they can model and promote good practice. Proper consultations and engagement can make London a city where there is 'nothing about us without us' and all Londoners are involved in making this the 'healthiest global city'. Consultation and engagement in PSED, EDS, JSNA and patient participation and involvement mechanisms etc., benefit the consulting body when done well. When done poorly they frustrate, upset, exhaust EbE and VCS and destroy trust in public services.

“The Joint Commissioning Panel's Guidance for implementing values-based commissioning in mental health ...

- Set up a VbC panel, bringing together NHS, public health and social care commissioners, statutory and non-statutory providers, to develop patient and service user involvement in commissioning
- Establish a patient, service user and carer advisory panel, including people from different backgrounds, with experience of different mental health problems and services. The panel will need to use other means to engage a broader group, to prevent it becoming unrepresentative or insular” (Whitelock and Perry 2014, 17)

Examples of projects that improve intersectional Londoners' mental well-being

The examples in this section are indicative of the good practice evidenced across the literature review. The case-study examples provided by HEAR members in the bibliography employ a suite, often all, these good practices in their work.

Holistic

"TCC was seen as a valuable and more importantly safe point of entry to receive direct support and to be referred to other services. The services provided by TCC to support a person's mental health condition are not intentionally designed around any psychiatric, sociological or psychological methodology. However in many circumstances the effectiveness of TCC's work is seemingly positive with regards to self perceived outcomes...The importance of functional social dialogue more generally was thought to be of high importance as was dialogue around specific issues such as domestic violence and community needs. Additionally, the patchwork of activities where people, in particular women, could interact meaningfully was thought to be integral to wellbeing. This includes Family Group sessions, English language, Yoga, PC training, sewing, benefit support and alternative therapies (meditation, massage). "I have two people, one facing suicide but eventually[sic] found work with support from TCC and another individual who felt they were suffering from depression was support by a GP via TCC""I find TCC helpful for support... getting a walking stick... Translation support to Ealing hospital and TCC's understanding of my background is my need."... TCC was viewed as a place where the 'mind can relax' being able to talk to somebody who understands what has taken place hitherto. The notion of understanding and trust is one that came across overwhelming strong and was articulated as the basis of many of the users attending TCC"(Tamil Community Centre 2013, 7)

Cross-equality learning and pan-equality partnerships

"Solace has 40 years' experience of providing excellent support for women and children experiencing domestic and sexual violence... Solace is the lead agency for the Ascent advice and counselling... This pan-London collaboration provides specialist counselling and advice services to women and girls affected by gender-based violence. Services include 1 to 1 counselling; individual advice; and group work.... As a partnership we used our monitoring data to identify gaps for certain protected characteristics groups and specifically deaf and disabled users and trans women....

We created an important space to express fears and to have a safe space to discuss issues in a non-judgemental way...

All partners trained around how to create more accessible services for deaf and disabled users...

We have developed a London service directory of disability organisations
We're now reaching more service users" (Solace Women's Aid 2017, 1-3)

Cross-sector partnerships

“The ‘Tree of Life’ group run with young men under the age of 25 years in Hackney...is a joint venture between City & Hackney BME Access service (East London Foundation Trust), City and Hackney Mind and Hackney Council for Voluntary Service (HCVS) Young Black Men’s Project...participants were asked about whether services could improve the way they offer talking therapies... Awareness campaigns should be peer led... Therapy should be offered in familiar community spaces that feel safe in order to increase access and reduce stigma [and] Community outreach work in the form of mental health awareness and psycho-education groups with a focus on early prevention and skills training to be done in community centres and schools

... Talking about the difficulties... appeared to have a de-stigmatising effect on the young men’s perceptions of their own difficulties and those of others.

‘Yeah it made me realise I shouldn’t judge crazy people I see on the street, people go through different things and it has different impacts on them’” (Carthy et al. 2016, 1 and 15–16)

Independent domestic abuse advocacy and hate crime case work

“HEC commissioned an independent survey in September 2013 which revealed that 81 per cent of clients claimed that their personal situation improved as a result of casework advice they received and 8 out of 10 clients reported increased self-esteem, confidence, a reduction in stress levels and anxiety, as well as improved wellbeing... Individual Casestudy... In his first meeting with the hate crime caseworker Ravi said he was anxious about the perpetrators coming back and intimidating him, and the effect it could have on his mental health. He said that on a scale of one to ten, with ten being the most severe, he felt very depressed and suicidal. He also felt that because of his disability, the police were not responding swiftly enough or taking him seriously because of his disability. The caseworker agreed an action plan with Ravi and discussed the options available to him... The hate crime caseworker raised the seriousness of the Shah’s case at a multi-agency panel where the police and council officers were present. As a result, regular police patrols were made in the neighbourhood, arrests were made, and the Shah’s were considered an urgent case for management transfer from their property to another” (Harrow Equalities Centre 2014, 2–4)

Language and cultural interpreting

“The barriers that Arabic speaking women face combined with the silence in the Arabic community around GBV hinders the ability of the women we support to make safer choices for themselves and their families. Al-Aman’s Women Support Services tackle the intersectionality between gender, culture and religion head-on and its culturally sensitive programme works around these hurdles to effectively deliver emotional, advocacy and practical support services to increase the safety of Arabic women and empower them for the future” (Domestic Violence Intervention Project 2014, 3)

Peer-led

"I felt like a failure being diagnosed as mentally ill and on benefits when I came out of hospital, and I realised how isolated and lonely I had become. I went to CAPE, the Recovery College, MIND events ... I felt heartened that someone with lived experience of mental illness co-facilitated the course, to show it was possible to progress from being stuck in mental illness. Also, I was relieved to be with people who, like me, suffered from mental illness and wanted to get better... I found the 'Telling Your Story' course helpful as a means of communicating how I felt, especially about my mental illness in a 'safe' environment, with others who had mental health problems and someone who had recovered...I learnt and enrolled in dramatherapy for a period to help overcome some of my reticence and anxiety. Therefore, my recovery has been made not just by medication" (MIND in Ealing and Hounslow 2018, 9)

Recommendations

Commissioners in London, including Thrive LDN and LHB, prioritise peer-led work

"There are important lessons for commissioners and organisations supporting peer support initiatives here. Our evaluation suggests that peer support works best where commissioners, provider organisations and communities work together to develop a range of approaches to peer support, reflecting the needs and aspirations of the full diversity of communities locally, and where people are enabled to take control of how and when they engage with the peer support that works best for them" (Billsborough et al. 2017, xi)

"Given their migrant or refugee backgrounds, the mentoring programme can be understood as supporting survivors of adversity to make positive changes, so that they are better able to cope with life and its challenges. Positive results are demonstrated also by the fact that, after taking part in the Project, 40% of mentees engaged more and better with social and healthcare services; 80% of mentees and ex-mentees have established links outside of the home and joined activities of interest to them; and finally, 20% of the participants have started other volunteering or education programmes. One of the ways through which many mentees decide to be active and put in place their new skills in the community, is by deciding to become mentors and give time and share personal experiences to support and encourage new mentees" (Migrant and Refugee Communities Forum (MRCF) 2014, 2)

Thrive LDN and the London Health Board members should prioritise the commissioning of peer-led work, following the evidence, at all levels, from projects, service delivery and evaluation and encourage their statutory colleagues to do the same.

London communities at risk of Mental Health inequality requiring further outreach

Londoners at risk of exploitation

A theme across the literature is that intersectional people with MHSN are at increased risk of exploitation. 'Looked after children', homeless people, female/LGBTQI refugees are at increased risk of sexual exploitation, disabled and older people at risk of 'cuckooing' ('mate hate'), intersectional young people are at risk of being exploited by criminal gangs to transport drugs and weapons and groom new members, people with MHSN of faith (in a religion, nationalism or other ideology) are at risk to being groomed to radicalism and potentially terrorism. Many experience a number or all forms of the exploitation above.

"School dropout, gangs and radicalisation are [all] signs of mental illness caused by many factors including family condition, racism and so on (A social worker participant)" (Council of Somali Organisations 2017, 37)

Faith

The literature describes how stigmatising attitudes both from and about faith communities impact on the mental well-being of many Londoners (Faiths Forum for London 2014; McDermott and Luyt 2016; Micro Rainbow International 2014). HEAR members' research also presents how, for people of faith, their beliefs, practices and communities aid mental well-being. Many faith organisations in London provide support to individuals and families with MHSN, but most do not necessarily describe these services in this way. Faith communities could be better connected to other VCS and mental well-being work (Age UK London and HEAR Equality and Human Rights Network 2017), mobilised in a more systematic way, and are an important stakeholder in challenging hate crime and radicalisation.

"Receiving support from an organization that recognizes their sexual orientation/gender identity as a gift from God provides opportunities for healing and wholeness" (Lesbian and Gay Christian Movement (LGCM) 2014, 2–3)

BAMER

Race inequality in mental health has been evidenced time and again, and the frustration and anger from HEAR members is notable in the literature (Irish in Britain 2019; Roma Support Group 2014; Linton and Rianna 2018; Bracken et al. 2012).

"Racism is a political issue. Inequality is a political issue. Mental health is a political issue. We should hold politicians to account" (National Survivor User Network (NSUN) 2018b, 5) "There's a modern day Bermuda Triangle for black men, which is located between the 3 points of; Education (the entry point), Criminal Justice and Mental Health. Thousands will pass through, but a disproportionately high number will quite literally disappear within this black man's Bermuda triangle." (Griffiths 2018, 12)

Final Recommendations

London becomes a Human Rights City and a City of Sanctuary

HEAR members have told us that they want London to lead the world on civil liberties, equality and diversity by becoming the second UK Human Rights City (Hunt 2017; HEAR Equality and Human Rights Network 2017c) as well as the benefits of the Human Rights approach for people with Mental Health Support Needs (British Institute of Human Rights 2018)

“What is a Human Rights City? A Human Rights City is city... where people of good will, in government, in organizations and in institutions... let a human rights framework guide the development of the life of the community. Equality and nondiscrimination are basic values. Efforts are made to promote an holistic vision of human rights to overcome fear and impoverishment... A Human Rights city is a practical viable model that demonstrates that learning about human rights and applying this insight can improve society...

Become a beacon of light for communities all around the world to illustrate how the application of the human rights framework can make every citizen a creative partner of society” (Peoples Movement for Human Rights Learning 2007, 3–4)

Additionally London has always been a refuge for the persecuted and as “refugees and asylum seekers... considered to be the most likely group to suffer from mental ill-being. Lacking socio-economic conditions are one of the major causes that negatively affect the mental health of migrant communities. Legal status and other resettlement stresses, such as poor and short term housing, loss of status, inability to work, difficult access to education or denied engagement in the community (Pudelek, 2013) are known to further impact mental health of asylum seekers and refugees”. London has many communities with ‘insecure’/’unclear’ immigrations status (and potentially more soon) so HEAR urges the Mayor to make London a City of Sanctuary.

The United Nations has described ‘austerity’ as “a commitment to achieving radical social re-engineering... [and] great misery has... been inflicted unnecessarily, especially on the working poor, on single mothers... on people with disabilities who are already marginalized, and on millions of children who are being locked into a cycle of poverty from which most will have great difficulty escaping” (Alston 2018, 2).

What is required from London’s leaders is a radical vision, combined with brave practical steps, to reduce health inequalities in our City, and make London the ‘healthiest global city’. Thrive LDN and the London Health Board can take a central role in championing London becoming a Human Rights City and City of Sanctuary by highlighting how it would benefit some of London’s most stigmatised communities; Londoners with Mental Health Support Needs.

We must remind one another every day that:
 Health is a Human Right
 Human Rights are For All
 We should all live Free from Fear.

Summary of Recommendations in *What Londoners with Lived Experience Said*

- **Expert by Experience representation on the London Health Board and at all levels of Thrive LDN**
- **Thrive LDN and the London Health Board champions the Social Model across London's services**
- **Values-based Commissioning is rolled out across London health and social care**
- **London Health Board and Thrive LDN support statutory staff collect equalities data**
- **London's Health and Social Care providers, policy makers and Thrive LDN improve cultural understanding of staff**
- **Thrive LDN and political leaders in London commit to always challenge stigma and hate**
- **The Thrive LDN Champions programme developed focus on under-heard Experts by Experience**
- **Providers in London pay user-led VCS for all statutory services provided**
- **A Thrive LDN grants programme for user-led projects that reduce barriers experienced by intersectional people with Mental Health Support Needs**
- **Statutory services in London, including Thrive LDN and LHB members, sign-up to and support the 4Pi involvement standards**
- **Organisations with statutory duties to consult and engage, including Thrive LDN and LHB members, communicate in plain English and do appropriate and timely outreach**
- **Commissioners in London prioritise peer-led work**
- **London becomes a Human Rights City and a City of Sanctuary**

Acronym glossary

BAMER – Black, Asian, Minority Ethnic and Refugee
 CCGs – Clinical Commissioning Groups
 EbE -Experts by Experience
 EDS – Equality Delivery System
 GLA - Greater London Authority
 GRT – Gypsy, Roma and Traveller
 IRL – In real life
 JSNA – Joint Strategic Needs Assessment
 LA – Local Authorities
 LGBTQI+ - Lesbian, Gay, Bisexual, Trans, Queer/Questioning, Intersex and other non-heterosexual and non-cis people
 LHB – London Health Board
 MHSN – Mental Health Support Needs
 NHS – National Health Service
 PoC – People of Colour
 PSED – Public Sector Equality Duty
 STPs - Sustainability and Transformation Plans
 VbC – Values-based Commissioning
 VCS – Voluntary and Community Sector

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If you need this paper in a different format please get in touch

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