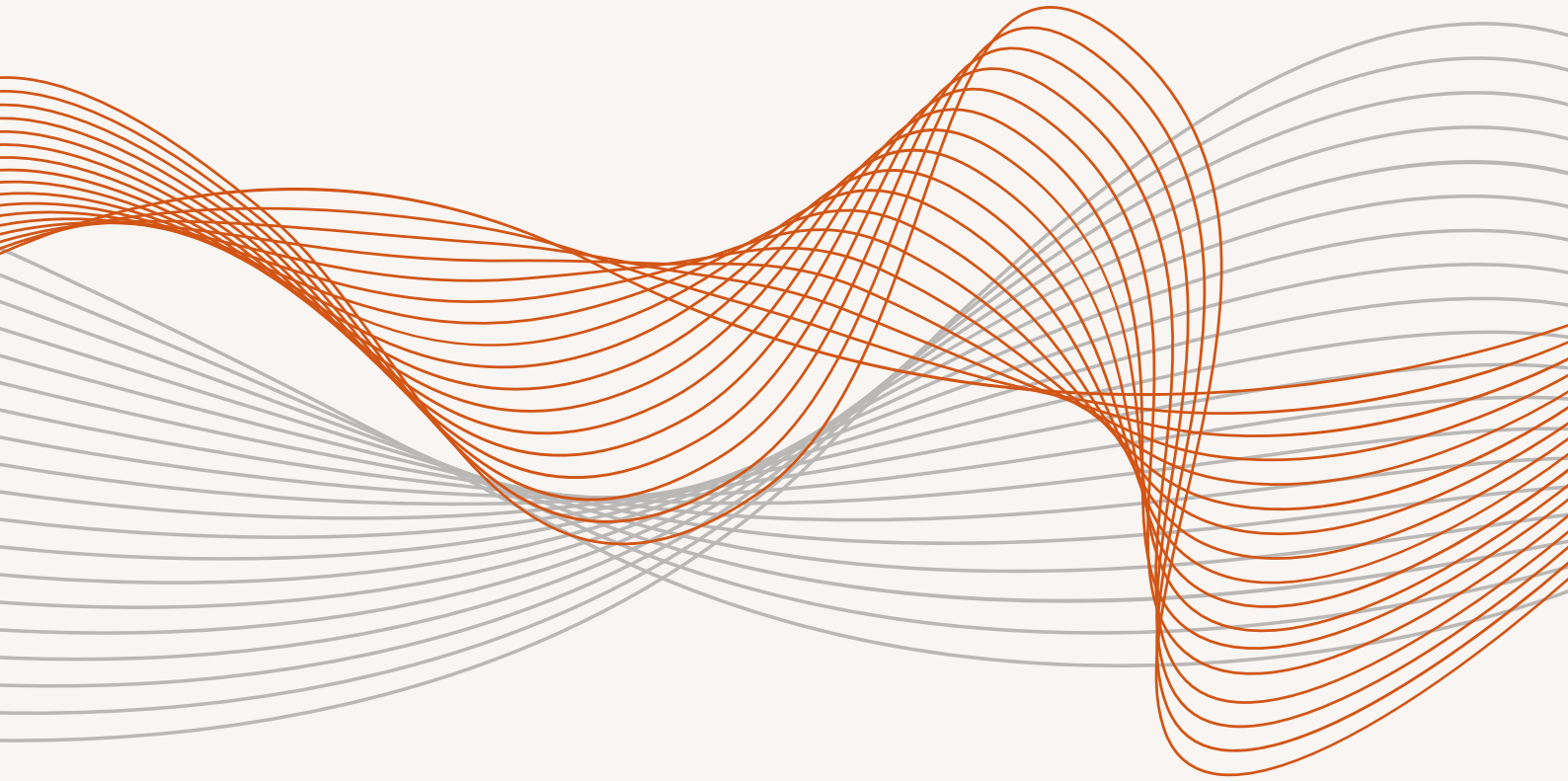
Race Equality Foundation

Association of Mental Health Providers



# Tackling inequalities faced by minority groups in mental health through the Personalised Care Programme

Association of Mental Health Providers
and the
Race Equality Foundation

# INTRODUCTION

Personalised care delivers improved health and wellbeing outcomes for people of all ages with a range of healthcare needs, based on what matters to them as individuals. Personalised Care & Support Planning (PCSP), which is to succeed the Care Programme Approach, enables a 'what matters to me' conversation and a Personal Health Budget (PHB) relies on the information and outcomes identified in the PCSP process and ultimate plan.

Personal health budgets (PHB) aim to give people greater choice, flexibility and control over the healthcare and support they access and further embed the support that matters to them. The NHS Long Term Plan committed that 200,000 people will benefit from a personal health budget by 2023/24, an objective emphasised by the previous government's Integration White Paper.

However, people from Black, Asian and Minority Ethnic communities with poor mental health (the term used throughout this report to refer to people living with mental illness or experiencing mental distress), are less likely to be able to access the personalised mental health care and support, including PHBs, that keeps them safe and enables them to live a better life. This is despite evidence suggesting that, when done well, PHBs contribute to better addressing what matters to Black, Asian and Minority Ethnic people with poor mental health and is more likely to address health inequalities.

The report by the NHS Race and Health Observatory shows unacceptable levels of racial inequalities across the provision of health and care and recommends partnership working with ethnic minority-led Voluntary, Community and Social Enterprise (VCSE) organisations to improve mental health services. The VCSE mental health sector's essential role in the transformation of mental health and allied services, premised on the principles of co-produced, personalised care, has been evidenced in Race Equality Foundation's review on personal health budgets.

As part of NHS England and NHS Improvement's Advancing mental health equalities strategy – overseen by the Advancing Mental Health Equalities Taskforce which includes the NHS Race and Health Observatory and other VCSE stakeholders – the Patient and Carer Race Equality Framework (PCREF) is one of several initiatives that aims to improve experiences of care for ethnic minorities across all mental health services. PCREF is currently being piloted in four areas in partnership with ethnic minority communities.

# SUMMARY OF LEARNING

Lessons Learned: 1 Leadership and Culture (System Leadership)

- Strong leadership and accountability are essential for delivering personalised care.
- Delivering mental health support that is personalised and implements effective personal health budgets, requires a radical shift in the culture and values of health and care leadership.
- Leadership needs cross-system working to identify inter-dependencies. It looks at the 'whole' person from all perspectives and acknowledges the need to relinquish power and control.
- Communities value personal and social support networks for mental and physical health.

Lessons Learned: 2 The Relationship Between Lead Commissioners and Operations

- 'Joined up' thinking and working among commissioners and senior leaders is crucial.
- Addressing tensions in rolling out PHBs requires collaboration and understanding of local populations.
- Connecting organisations and clarity of roles and responsibilities is essential.

Lessons Learned: 3 The Role and Impact on Clinical Staff

- Collaboration among the health and social care (NHS, LA & VCSE mental health sector) workforce is vital for implementing effective PHBs.
- Giving staff the space, and time to build the confidence to be creative in the successful delivery of PHBs
- PHBs enable a different conversation with service users, supporting recovery goals and enabling people with poor mental health to live well.

Lessons Learned: 4 Specific Funding Allocated to PHBs

- Availability of specific funding is crucial for the delivery of PHBs and enables swift delivery of support.
- Consideration of the initial setup cost and administration recognising that, ultimately, PHBs tend to require small sums of money.

# SUMMARY OF LEARNING

Lessons Learned: 5 Addressing Inequalities

- Effective engagement with individuals and groups who are excluded from or encounter difficulties in accessing services, is a fundamental perquisite for promoting equality and effective PHBs.
- Integrated and joint working between small grassroots VCSE organisation is essential for addressing inequalities. This requires investment and support from commissioners.
- Understanding local populations, intersectionalities, and working with a focus on specific communities is crucial.

Lessons Learned: 6 Engaging Small Voluntary and Community Organisations

- Collaboration with those who need support and those who provide support is important.
- Small voluntary and community organisations with deep knowledge of local communities are often better able to ensure those needing support can access and benefit from PHBs – this is particularly true of organisations that are led by the communities they are supporting.
- Commissioning processes must support and invest in the participation and development of grassroots organisations.

Lessons Learned: 7 The Right to Have a Personal Health Budget

- Confirmation of entitlement to PHBs for people with poor mental health is essential.
- It is clear that people value being meaningfully involved in the planning of their care, being able to make choices and personalise their support, so it best meets their needs.
- Failure to provide personalised aftercare services can lead to a deterioration in mental health.
- Marginalised people and groups, often facing disadvantage at multiple levels, describe PHBs as “life-changing”.
- Awareness and promotion of PHBs is necessary among Black, Asian and minority ethnic communities, to help bridge the inequalities gap.

# SUMMARY OF LEARNING

Lessons Learned: 8 Data, demographics health and care system reporting requirements and metrics.

- Comprehensive and good quality data is essential for providing the insights that can drive improvements in tackling inequalities in health and care.
- The testing of data with people's lived experience enables a better understanding between what the data shows and reasons behind it e.g. societal, cultural, economic etc.
- Careful analysis of data can expose systematic inequalities that are having a significant impact on certain communities.

Lessons Learned: 9 The need for a biopsychosocial approach to mental health.

- This includes moving away from a 'what's wrong', deficit model of health and care and to a 'strengths-based' assessment.
- Fundamentally, it means a focus on a human-centred approach, which puts people at the core of everything we do-and could be done-to improve mental health outcomes.

# BACKGROUND

From mid-2021, the Tackling Inequalities in Mental Health through Personalised Care Development Programme has brought together a partnership between Association of Mental Health Providers and the Race Equality Foundation, This partnership has sought to help build the capacity and drive the collective action required for improving access to personalised care for people from Black, Asian and minority ethnic communities, in two local mental health systems.

This programme has also endeavoured to identify the tangible actions that local health and care systems can and should take to help facilitate continuous system-wide improvement. It illustrates the transformative potential of personalised care in tackling inequalities in mental health services.

The programme has had a particular focus on identifying the capacity and development support required for VCSE mental health provider organisations, in recognition of their importance in and to local health and care systems. It has been informed and guided by the learning from NHS England and NHS Improvement's Personalised Care programme; the implementation of the community mental health framework for adults and older adults; and the recommendations of the Mental Health and Wellbeing Advisory group to the Department of Health and Social Care COVID-19 Social Care Task Force.

This paper summarises some of the lessons that have been learnt from the development and deployment of PHB offers to people with poor mental health in the two regions participating in this programme, the Northwest and the Northeast and Yorkshire. The intention is that the learning from this work helps to inform the development of a replicable model of personalised care in mental health services.

It is also hoped that this will in turn facilitate a culture of continuous system-wide improvement in the delivery of personalised care and personal health budgets for people with poor mental health and their unpaid carers. Principles for good implementation of PHBs in general apply in this context as well, notably beginning from the starting point of the individual, their strengths and recovery goals. However, there also needs to be a specific focus on implementation to address inequalities. As such, the learning will be of value to Integrated Care Systems (ICSs) and their Boards (ICBs) and should guide their development and priorities. ICBs are the key strategic and leadership vehicles for embedding the principles of personalised care, in the drive to address racial inequalities in access to mental health services, support and outcomes.

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# LEADERSHIP AND CULTURE (SYSTEM LEADERSHIP)

A fundamental building block for the delivery of personalised care is accountability, which comes from strong leadership and oversight. It is apparent from this work that in many areas there still needs to be a radical shift in leadership for mental health support that is personalised and implements effective PHBs.

This programme has highlighted that leaders need to work across systems, surpassing virtual boundaries created by those very systems in which we operate. The shift from a deficit model of health, care, and support to one that recognises people should be able to access services as active citizens within their local communities. These communities value everyone and seek to enable them to contribute as equal citizens and as such, recognise personal and social support networks are vital to people's mental and physical health.

# THE RELATIONSHIP BETWEEN LEAD COMMISSIONERS AND OPERATIONS

The Programme has highlighted the positive impact where there was 'joined-up' thinking and working (as distinct from integrated systems) amongst commissioners and other senior leaders. This joined-up working was needed across different aspects of health and care (mental health, learning disability and/or autism) as well as personalised care and PHBs to address inequalities.

These behaviours were also crucial in addressing some of the tensions in rolling out PHBs, such as the role of small versus large voluntary sector organisations and how easily these organisations could participate. Larger VCSE organisations often exert more influence both within the VCSE sector and the wider health and social care system. This poses the risk of obscuring the important role smaller grassroots VCSE organisations play in the health and care system and in addressing inequalities.

There is a need to take a systematic approach to harnessing the flexibility and adaptability demonstrated by smaller organisations in order to achieve the responsiveness that is required for PHBs.

Commissioners are key to resolving the complexity of health and care provision, where localities do not always match or where the PHB pathway covers a large geographical area or focuses on a small identifiable geographical area like a town or a district.

The success of the project was also determined by commissioners who understood:

- how PHBs helped deliver personalisation
- micro-commissioning
- local populations (as well as the benefits) were often instrumental in ensuring that other actors (VCSE organisations, local authorities, and other parts of the NHS) came on board too.

Commissioners who are efficacious in this space connect organisations, groups, and other aligned initiatives to PHBs (including the wider personalised care agenda), build a coherent sense of the programme, and clarity of roles, responsibilities, and of the PHB pathway. They also facilitate the evolution and sustainability of local systems and support offers.

# THE ROLE AND IMPACT OF THE WORKFORCE

An effective PHB offer was reliant on the health and social care workforce collaborating to help people who experience poor mental health identify what matters to them and then helping achieve this. Often the role of clinical staff was identified in successful implementation.

There was some initial reluctance noted from staff but this was turned around as PHBs began to be seen as enabling a different conversation with ‘people who use services’. Staff became welcoming of the flexibility / creativity/ responsiveness of the PHB offer and it was seen as a way of people effectively achieving their recovery goals.

# SPECIFIC FUNDING ALLOCATED TO PHBS

Making available a specific, ring-fenced pot to fund PHBs was seen as crucial in itself, and also because it aided other useful features such as speedy release of funds to enable people to achieve their identified goals.

Experience suggests that the budget to fund PHBs is comparatively small as the PHBs offered tend to require small sums of money too. Initially the larger costs are in set-up and administration, which may be defrayed in areas where there are already administration systems for direct payments, Individual Service Funds and personal budgets.

# ADDRESSING INEQUALITIES

To ensure that PHBs addressed the inequalities faced by some people who experience poor mental health, it was clear that there needed to be effective engagement with individuals and groups that were sometimes described as 'hard to reach'. Smaller VCSE organisations find that these individuals and communities are not 'hard to reach' but more likely to be 'poorly served' because of failures in engagement. Consideration needs to be given, therefore, to an inclusive and well-established engagement structure which aims to develop meaningful, diverse and continuous forms of engagement.

It was clear, however, that a key solution was to work better with and integrate small 'grassroots' organisations in the PHB offer. This involved ensuring participation of these organisations and the people they support, in development of the PHB pathway at the same time as ensuring the costs incurred by these organisations were met.

This had to be accompanied with understanding of local populations, who needed support and which VCSE organisations were working with groups experiencing inequalities. This could mean identifying organisations from several locations and/or organisations who specialised in working with specific communities.

A theme throughout this work has been that removing the barriers in access to PHBs to address the inequalities experienced by Black, Asian and minority ethnic communities, often requires actions and solutions that could also address inequalities experienced by other individuals and groups. In addition, colleagues ought to avoid seeing any one population category as homogenous. There is diversity within as well as between community groups. Explicitly considering the intersectionality of people's characteristics can help to consciously avoid seeing everyone in one particular social group as all the same. Explicitly considering the intersectionality of people's characteristics can help to consciously avoid seeing everyone in one particular social group as sharing the same needs and aspirations,

# ENGAGING SMALL VOLUNTARY AND COMMUNITY ORGANISATIONS

To address inequalities, it was important to work with those who needed support and those who were currently most likely to be providing support. These organisations will have a deeper knowledge of the local community in terms of the people and communities who live there and what personalised care could mean to them, as well as the organisations which are configured to support the community.

Often small voluntary and community organisations were identified as key, particularly in work with small communities or migrant communities. However, these organisations tended to have limited knowledge of PHBs and PHB pathways. Furthermore, these organisations tended not to have some of the infrastructure that would allow them to participate in PHBs, such as an information system that allowed the recording, analysis, and presentation of who their users were and what outcomes were achieved.

Commissioners and the commissioning process needed to take account of these 'development' needs to ensure that trusted small organisations could play a part in PHBs. Where this works particularly well is where there is a shift from competition and towards collaboration between organisations, such as sharing local knowledge and contacts, and larger VCSE organisations mentoring and supporting smaller organisations.

Additionally, the Programme has heard from some VCSE participants of the relative absence of take up of (and awareness of entitlement to) PHBs in some localities and of their concern to help up-skill the health and social care workforce (including social workers) in statutory services, to enhance their understanding of the value of PHBs for people with poor mental health.

As anticipated, the work has confirmed that the VCSE mental health provider sector has a key role in supporting and enhancing the ability of statutory social work and social care to understand and embrace personalised care in mental health and related services.

For example, in one locality participating in the Programme, where the relative lack of take up of (and awareness of entitlement to) PHBs was reported, it was noted that the local VCSE mental health service provider has been concerned to help upskill social workers in statutory services on the rights of people with poor mental health to a PHB. This example also reinforces the need to recognise the strategic (and not just the 'commissioned service provider') value of the VCSE sector in mental health system transformation narratives and investment priorities, - particularly in relation to workforce learning and development.

# THE RIGHT TO HAVE A PERSONAL HEALTH BUDGET

In 2022, a decision by the Health and Local Government and Social Care Ombudsman confirmed the importance of entitlement to Personal Health Budgets for people with mental ill-health detained under the Mental Health Act.

In doing so, it underlines the imperative for the drive for community mental health transformation to meaningfully embrace personalised care and support and specifically promote and raise awareness of PHBs -amongst health, care, and support services and professionals, and both existing and prospective users of services and their unpaid carers.

In the case in question, the Ombudsman found both Croydon Council and local health services at fault, for failing to provide the young woman in question with Mental Health Act 1983 aftercare services that led to a delayed Personal Independence Payment (PIP) claim and a deterioration in her mental health. Vulnerable South London woman failed by organisations that should have helped.

The Ombudsman's investigation identified numerous failings in how the local council and NHS bodies arranged this young woman's legal entitlement to aftercare, including:

- flawed planning and provision under Section 117 that included a failure to properly consider the complainant's need for help and information about her welfare rights, 'depriving her of the opportunity to apply for PIP at the earliest opportunity;
- failing to provide relevant information and share important documents;
- inadequate action in response to a possible risk of harm to the complainant and her parents; and
- inadequate support for the complainant's parents as her carers.

Significantly, the Ombudsman highlighted the failure of local services to ensure Personal Health Budgets (and information about them) are available to people eligible for Section 117 aftercare, despite this being a legal requirement since 2019. As such, this decision also illustrates the imperative for action to ensure that, given the value PHBs evidently hold in improving mental health outcomes for people from Black, Asian and Minority Ethnic communities, they are fully supported in accessing entitlements to them.

# DATA, METRICS, AND HEALTH AND CARE SYSTEM REPORTING REQUIREMENT

Targeted use of personalised care and PHBs has a unique role in addressing mental health inequalities and can be used as 'change agents' in the transformation required of community mental health systems.

However, the learning from this programme suggests there is a lack of clear information regarding the identification of needs at a demographic level and those in receipt of personalised care. Information on the people supported by services, the nature of those services and those not currently engaged with or by services is not currently available.

NHS England's Advancing mental health equalities strategy highlights three key workstreams:

- supporting local systems to advance equalities
- improving the quality and use of data
- workforce.

The Patient and Carer Race Equalities Framework (PCREF), developed to support the strategy, is an organisational competency framework to help services provide culturally-appropriate care to those already known to mental health services. It recommends "mental health services working more closely with racialised and ethnically and culturally diverse communities, leaders and other organisations beyond the NHS, such as religious groups, ethnic-led VCSE organisations, social care and others."

It also strongly supports the collection of relevant data by ethnicity for example: "reporting detentions, restraints, physical health checks for Serious Mental Illness (SMI) and Children and Young People (CYP) access data by ethnicity"

This kind of rigorous and systematic collation of meaningful demographic data from all relevant partners working with people with mental health needs in the community - NHS, local government, and the VCSE sector - will help to ensure targeted personalised care and PHBs improve outcomes. and that data is visible and widely accessible for this purpose.

# THE ADVANTAGES OF A BIOPSYCHOSOCIAL MODEL OF MENTAL HEALTH

An increased focus on and recognition of the importance of the adoption of a biopsychosocial model for mental health services is needed to ensure the needs of Black, Asian and Minority Ethnic people and communities are met - and indeed those from the wider community who are unable or unwilling to access current mental health provision.

Personalisation and PHBs are demonstrably effective tools in helping to facilitate that access, framed by 'what matters to you' conversations and dialogue, recognising the economic, material, and societal determinants of poor mental health experienced by people from Black, Asian and Minority Ethnic Communities.

# CONCLUSION

The work of this programme has been possible as a result of the engagement of a wide range of colleagues and partners in the VCSE and statutory mental health sectors, who have generously shared their knowledge and demonstrated a principled commitment to improving mental health services and support for people from Black, Asian and Minority Ethnic communities. The Association of Mental Health Providers and the Race Equality Foundation are very grateful to those colleagues and partners.

The programme has amplified the existing evidence base that demonstrates the importance of PHBs and personalised care in facilitating better mental health outcomes for some of the most marginalised and excluded people and communities. In identifying some actions required to mainstream the accessibility of both, the Association and the Foundation hope the learning from this Programme will be adopted by all local mental health systems and (as their strategic sponsors) Integrated Care Boards.

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