

THE END OF DELIVERING RACE EQUALITY?

PERSPECTIVES OF FRONTLINE WORKERS AND
SERVICE-USERS FROM RACIALISED GROUPS

Compiled by

RAWOrg
Rights and Wellbeing
of Racialised Groups

Who are we?

A collection of service users, campaigners, professionals and academics dedicated to ending racial inequality throughout the mental health system. We do this by facilitating understanding of the various factors that drive and maintain such inequality. We also support practical action genuinely geared towards ending this longstanding form of injustice.

Our position statement

Statement on Better Mental Health Services for people from racialised groups in the UK: A vision for change from RawOrg

Compiled by RawOrg members, 2010

The long-standing and serious failure by mental health services and other statutory agencies to appropriately deal with 'racial inequalities' is well established (Department of Health, 2003). The most recent attempt to bring about change (Department of Health, 2005) was not sufficiently resourced or sustained by government and other agencies. We consider that one of the main reasons for this is the location of the problem within people from so-called 'black and minority ethnic (BME) groups', rather than on the problems within systems and agencies that have reinforced inequalities. We believe this focus must change. We have decided to create a think tank to analyse systemic problems that need correcting and consider mental health services for people from 'racialised groups' in our society.

Essentially, the term 'racialised groups' recognises the dynamic and complex process by which racial categories are socially produced by dominant groups in ways that entrench social inequalities and marginalisation.

We reject the notion that 'mental illness' is created within groups who have been racialised because of their 'inferior' cultures, genetic predispositions or

inherent behaviours; assumptions that these play a part tend to fuel racism by blaming racialised groups for what are in fact systemic social problems, and thereby reinforce social injustice.

We maintain that the main causative factors for racial differentials within the mental health system include:

- institutional racism in society and services
- ineffective therapies and inappropriate help available for people from racialised groups in distress
- research and practice that has stereotyped and disempowered groups who have been racialised
- lack of practice development and training opportunities for frontline staff to help them deliver anti-discriminatory services
- systems that are not designed to promote equality
- leadership that has failed to drive an empowering culture in services for both service users and staff
- failure to acknowledge service user/survivor leadership in driving organisational change
- opposition from some (but not all) professionals, and a lack of commitment from government to deliver on promises made to policy consultees about tackling racial inequalities
- suspicion that addressing race inequality will overlook other forms of inequality.

We contend that long-term improvements in mental health services can only be achieved by a transformation in the culture of services through committed and capable leadership to tackle the challenge of institutional racism and other forms of discrimination. This transformation must include a 'social model' approach to mental health rather than relying solely on a diagnosis-driven approach to service delivery. Tackling discrimination on the basis of 'race' and culture is inherent to good practice and should be a part of a holistic approach to promoting equality for all groups vulnerable to oppression. There are similarities between different forms of oppression in society, but there are differences that must be taken into consideration in any strategy that claims to promote equality. No service can claim to be engaging in 'good

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practice' if it fails to tackle all forms of institutional discrimination, or does not weave together specific and focused strategies to target the different forms of discrimination and promote equality in a holistic way.

Most importantly, we feel that the way forward has to be found through leadership that places service users, their families, carers and racialised groups at the heart of policy change and the design and delivery of mental health services. We must move towards providing a wider range of cultural choice and new options in service provision and not be restricted exclusively to models of mental health originating from/located within a Western European frame of reference. We strongly support the development of service user/survivor-led services and robust ways of checking the quality of services based on standards set by service users/survivors, as well as service user-led audit.

Acknowledgements

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Members of RawOrg

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FOREWORDS

The Delivering Race Equality (DRE) programme started off with an acknowledgement of institutional racism in mental health services and a promise to work towards combating it. Yet, the official reports of the DRE programme hardly discuss whether, and how, it has succeeded in addressing this issue. Indeed, the language and rhetoric around 'racism' itself has changed in its lifetime. There is even a denial of its existence in some quarters.

Regardless of the rhetoric, racism is a reality for many people accessing mental health services. As evidenced in the *Count Me In Census* reports from 2005 to 2009, there has been little change in the way people from many racialised communities are cared for within the mental health services. That said, it is also clear that the programme has been instrumental in making much progress locally in understanding, acknowledging and acting on the needs of diverse ethnic communities.

It is understandable that a programme as complex and ambitious as the DRE will generate a range of opinions about its successes and failures. It is imperative that we learn from the programme and continue working towards race equality in mental health services. Even as some of the old challenges persist, we also have to deal with a new set of challenges, including wide-ranging funding cuts, policy shifts and the overhaul of NHS itself. This report will add to these reflections and actions for the future.

The death of David Rocky Bennett in 1998 was one of the key driving forces behind the Delivering Race Equality programme. As we reflect on the programme's legacy, I would like us to remember two other black men who died in 2010 while in the care of mental health services, whose deaths passed us by without much discussion or attention: 23-year-old Olaseni Lewis and 52-year-old Colin Holt. Let us hope that whatever is built from the legacy of the DRE programme will work towards creating safer services for all.

Jayasree Kalathil
Independent researcher and ex-user of mental health services, Survivor Research

There is no denying that Delivering Race Equality was a complex and multilayered programme of work that was set up with high ambitions. Looking back at two key events in the wider cultural climate of both law and order and healthcare in England (and the UK) in the preceding decade, it's clear that there was a pressing need for change – 1993, the racist murder of Stephen Lawrence in South London; 1998 the death of Rocky Bennett in a medium-secure mental health facility in the east of England – both delivering hard-hitting independent inquiries that pointed to systemic decay in the delivery systems under scrutiny.

The programme of work set out, not just to provide solutions for the lack of investment in the mental healthcare system that delivered a one-size-fits-all model, regardless of cultural need. It was a full-throttle response to the charges of institutional racism levelled at the mental healthcare system – a concept well captured by the Macpherson Report. With such scale of ambition, a degree of measurable success was expected, and unfortunately a degree of failure was also anticipated. Certainly the full quota of Community Development Workers (CDWs) needed to have been in post earlier. They also needed greater leverage at the top of the decision-making chain.

However, it's what we've learnt from five years of work that will perhaps be DRE's strongest legacy; including the CDW programme, Focused Implementation Sites and DRE-funded research led by academics, community researchers, service users and service providers. In order to drive forward the legacy of the DRE programme, it is crucial to make these lessons count. In doing so, the nebulous ambitions that underpinned DRE may yet be realised.

The value of this report from RawOrg is that it kicks off that much wider process of reflection post-DRE, through the lens of examining the experiences of CDWs – linchpins in the community engagement strand of the DRE work. Crucially, it also begins the process of seeking feedback on DRE from service users from racialised groups – the ultimate stakeholders in all of this. Across health

and social care, it allows us to begin to ask how we can collectively sustain the aims of the DRE programme. What worked, what didn't – and why. Such questions are critical as we move into a new era of policy development, where issues of race, culture and ethnicity are collapsed into the generic category of Equality. Sustaining these aims is the next challenge.

Onyemaechi Imonioro

Stakeholder Engagement and Equalities
Manager, Mental Health Providers Forum

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“Racism in mental health institutions and the wider society is no longer seen as an issue. Any such problems that persist are about maladaptive individuals, destructive norms and practices within racialised communities themselves.” Such understandings of ethnic inequality now in the ascendancy are in fact a rerun of an old, established position that never really went away. This is reflected in the latest cross-governmental strategy from the coalition Government, No Health Without Mental Health. This builds on some of the vision and aspirations of New Horizons. However, the new strategy still fails to address key issues around race and mental health.

The strategy makes no reference to Delivering Race Equality, implying that DRE has been relegated to the annals of failed race equality projects. DRE now becomes a historical document, which engages with the furore around the unfortunate death of David (Rocky) Bennett and the outcome of the subsequent inquiry. This led to the birth and now the demise of the only national programme in the NHS with a clear remit to tackle ethnic inequality through bringing together commissioners, providers and local communities.

We can hark back to the days of the introduction of Community Development Workers and the target of 500 being appointed, but only reaching a peak of 450 in 2010 as the DRE strategy drew to a close. By the time this report is published they will have been slashed to fewer than 200. We should celebrate and acknowledge the role of Community Development Workers' efforts in pressing for change in the functioning of mainstream services, championing more productive relations with service users, carers and the broader BME community.

This report clearly demonstrates the importance of these roles, but also how they need to be refocused in a new approach around commissioning, outcomes framework and patient-involvement strategies which are being implemented under the

auspices of cuts, public sector reform and the mantra of 'the Big Society'.

Patrick Vernon

CEO, The Afiya Trust

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DRE was a success in that it led to widespread strategic change. Its impact was felt by service providers, commissioners and planners alike. Although this report focuses on the successes of DRE measured against the anticipated 12 outcomes (Appendix 1), the issues which emerge reflect the more general experiences and disappointments of those positively contributing to the delivery of the programme.

Communication between different leaders for various aspects of delivery appears to have been a problem. Local leaders seemed not always committed to the vision captured in the 12 anticipated outcomes. The absence of an agreed national system of implementation, together with a failure to resource the work adequately, sealed the emergence of multiple and divergent narratives of what DRE represented, for whom it would deliver and for whom it was inconvenient. This was in part a consequence of the devolution of responsibilities to local implementation, with a lack of central guidance, knowledge and resources to match the scale of the task.

There was poor conceptualisation of roles and necessary actions, a lack of understanding about the significant need for investment in developing the requisite skills and information systems to deliver the vision, and an underestimation of the depth of work required. This led to rapid, 'easy-fix' local service actions, often commissioned without adequate scrutiny of sustainability and often without reference to existing knowledge. A failure to make use of existing knowledge and skills, build on these and tackle both positive and negative attitudes towards delivery of DRE seemed to set up those with good intentions for conflict, poor support and little authority to deliver or overcome challenges and threats. Those not sympathetic to prioritising race equality issues (surprisingly, this sentiment is not hard to identify before, during and indeed after the programme) were in a position to silently overlook, derail, or even subvert the programme's original vision.

Despite the magnitude of DRE in both degree of investment and impact, its legacies are hard to find in new health policy. Yet again service users and charities are drawing attention to the silence on race equality, a familiar and regrettable position. Significant research has taken place on suicide,

self-harm, pathways to and through care, community engagement and development, and care experiences in acute psychiatry. All of this has advanced our knowledge, while confirming what we already knew about improving clinical practice and systems of change – leadership, tenacity, clarity, commitment and courage are essential.

As a cornerstone of quality therapy, what's needed is greater prioritisation of human rights, dignity and safety in care. This report should therefore be

understood within a broader focus as reflecting challenges that both preceded and were endemic to DRE. At a time of financial hardship in services, it is likely that equality streams, which are a cornerstone of quality in public health, will come under attack. Within this 'new reality', how will the political classes, health commissioners, indeed society at large, prioritise race equality? The answer to this question will ultimately determine the DRE legacy.

Professor Kamaldeep Bhui



INTRODUCTION

Delivering Race Equality (DRE) was a five-year strategy with ambitious goals around addressing ethnic inequalities in the mental health system. Community Development Workers (CDWs) were key players in the delivery of these goals; working on the ground with communities to help develop effective community-based responses to mental health issues. This community focus was to link with developments within statutory services, commissioning and procurement processes championed by a network of Race Equality Leads.

The vision of DRE is captured in its 12 Service Characteristics (DoH, 2005), which describe what

mental health services should look like at the close of DRE. During the winding-down phase of the strategy, official reports reflected on its impact and legacy (DoH, 2009). The report by the University of Central Lancashire explores the impact of the community engagement programme (UCLAN, 2010). As the programme drew to a close, RawOrg sought to gather the thoughts and views of key players involved in its implementation, reflecting on achievements and shortfalls. This report summarises these reflections by gathering the views of CDWs and service users from racialised groups.

METHODOLOGY

A different approach was used for the CDW and service user consultations. For the service user component, we aimed for a relatively broad coverage. This meant using a questionnaire that people filled in themselves. Given our resources, this seemed the best way to get a representative snapshot of opinion on DRE. For the CDW component, we used a more in-depth, semi-structured interview. Due to the relative accessibility of most CDWs, this was possible with our available resources. It also reduced the possibility of receiving stock, 'party-line' responses that may well have resulted from a written questionnaire. In the future it would be useful to conduct an interview-based study with service users from racialised groups and other mental health stakeholders into how much mental healthcare provision has changed over the past five years, and into how much of this can be attributed to DRE.

CDW component

Given the numbers of responses on which the reflections below are based, the opinions and experiences expressed are simply a snapshot of the impact of DRE. Twelve CDWs were interviewed about their experience of working at the frontline. They were also asked for general thoughts on the programme as a whole. From this, we identified

both common and divergent themes and were able to construct a fairly comprehensive impression of the extent to which DRE realised its original vision in practice.

The interviews were semi-structured, and were conducted over the telephone or in person (see Appendix 2). The questions were based primarily on the job description of the CDW role – what they were expected to achieve and the aims of DRE as laid out in the strategy document. Although the majority of respondents were based in London, we sought to incorporate the views of those further afield. Given that most did not wish to be identified by name or through specific examples, we amalgamated their responses to provide the basis for broader points made in this report.

Service user component

We conducted a small-scale survey of service users from BME communities who had been in contact with mental health services during the last five years (or were a carer or family member to someone that had). The survey is reproduced in Appendix 3. The questions were based around certain aspects of the 12 DRE Characteristics that it was hoped would describe mental health services for BME communities by the end of the five years of the programme (ie, by 2010).

COMMUNITY DEVELOPMENT WORKER INTERVIEWS

Fulfilling the job description

How the role is perceived

When asked to describe their understanding of the role, Community Development Workers (CDWs) predominantly referred first to the headline functions as laid out in their job descriptions:

- to work as an agent of change
- identifying and addressing gaps in services for BME communities
- attempting to reduce the barriers that prevent people from these communities accessing services
- looking to form bridges between the community and mental health services.

There were however differences in how the role was described – how these headline functions were understood and put into practice. This difference of interpretation can be seen as an example of ambiguity within the CDW role, and/or within DRE as a whole. It has implications for how the CDW role and DRE more broadly are understood by those responsible for its implementation.

Responses from some of the CDWs focused on ideas of ‘advocating’ on behalf of BME communities, or altering services so they better serve these communities. Others also focused on ‘empowering’ communities to demand and create changes for themselves. There wasn’t a clear divide between these two positions, with most CDWs emphasising both approaches. However, the distinction is relevant, particularly as some CDWs pointed out that the distinction mirrored substantial differences in the interpretation and application of the role between those based within mental health services and those based in the community/voluntary sector.

Bridging gaps and facilitating communication

The consensus around the role of CDWs led to questions which assess the success of CDWs. Questions focused on anticipated achievements, including bridging the gaps between BME communities and health and social care services,

and facilitating better communication between community services and statutory services.

On ‘bridging gaps’, the overwhelming response from CDWs was that progress had been made but there was a huge amount more to do. Where there had been success, it had come in different forms such as:

- linking up with community and faith leaders to facilitate their engagement with mental health services
- surveying BME service users and feeding this information back to primary care trusts (PCTs), mental health trusts (MHTs) and commissioners
- getting BME service users directly involved in consultations on the types of services to develop
- providing mental health information to communities and signposting for individuals.

However, the vast majority of respondents suggested that this success was limited. The following are some of the reasons cited:

- CDWs were just getting underway in the role. More time was needed to turn the information gathered and the lessons learned into real changes on the ground. This was in part a consequence of delays in CDW recruitment.
- Although the necessary changes had been highlighted, implementation was the responsibility of higher-level decision-makers.
- Because of cultural or religious norms, some communities were harder to reach, and some resisted the input and involvement of CDWs.
- It was difficult to keep communities engaged with a consultation process when the outcomes took a long time to materialise.
- There was a lack of commitment by PCTs and MHTs to changing working practices.
- Tackling the deeper structural and systematic issues would take more time and effort than the programme allowed for.

In terms of influencing success in this area, the most common challenge cited was the difference in how the CDW role itself was defined and understood, in particular whether it was located within statutory

mental health services or within the voluntary sector. Some CDWs believed that being close to decision-makers (eg, being employed directly by a PCT) was a significant advantage, in that information from the community could be fed directly to those with the power to make use of it in shaping services. Others emphasised the importance of being closer to the community (ie, being part of a community-based voluntary organisation), which enabled meaningful engagement with the people they were seeking to empower. Interestingly, this variation in perspectives did not fall along clear lines: some working within PCTs saw their location as a limitation, while others saw it as an advantage. This reflected differences of opinion among those working in the voluntary sector.

There was broad consensus that both locations had their advantages and drawbacks, and that there should be a balance between submersion in 'community' and keeping effective lines of communication to decision-makers. That said, this distinction chimes with a prevailing view among stakeholders connected with RawOrg who have followed DRE over the years, that the impact of CDWs was to some extent moderated by the environment in which they were located. In general, CDWs based in voluntary and community settings tended more towards service delivery and less towards strategic influence on the form and function of local mental health services. CDWs located within PCTs did seem to have a greater opportunity for strategic impact. However, their reach was curtailed by the insufficient seniority of the role, and inadequate organisational support to achieve the change anticipated by the 12 service characteristics.

Questions on facilitating communication yielded similar responses. The first asked about working with the 'community' in general, while the second focused on 'community services'. The overlap in responses can be interpreted in different ways. On the one hand, the principal means of engaging with communities was via existing services and/or community groups, which were to a degree seen as one and the same. On the other, there may not be clear distinctions between what constitute 'community services' and 'community groups' in the same way as there seems to be between these categories and 'statutory services'. The latter are often perceived as somehow removed from communities. As such, there wasn't a clear distinction to be made between engagement with 'community services' and engagement with 'the community'.

The impression gleaned from the interviews is that both these explanations are valid to varying

degrees, in different areas and within different communities. However, it is important to consider the permeability between 'community' and 'community service' when considering how appropriate the CDW role description was, and the implications resulting from how the role was interpreted by individuals in different contexts. The following are examples of initiatives tailored to specific communities and/or community groups:

- Providing information to community groups and services on changes in legislation or availability of statutory services.
- Assisting groups and services to attend relevant events (involving statutory services) or contribute to consultations, or organising such events collaboratively.
- Creating panels, networks or teams where community services could communicate directly with statutory services.
- Facilitating the sharing of staff and resources between statutory and community services.

There were also a number of specific issues that made this type of work more difficult:

- There was a lack of clarity in CDW action plans about what sort of changes needed to be delivered.
- Statutory services were looking for a 'quick fix' to the problem rather than a long-term engagement strategy.
- The communication was reliant on the CDW and may not continue in their absence; ie, it was not embedded and was therefore unsustainable.
- There was a divide between statutory and community services (eg, in terms of their ability to communicate ideas and contribute to formal processes) that made effective communication difficult.
- Communications seemed to only go one way (from the community services to statutory services) and there was a lack of feedback.

An emergent theme was that CDWs had a clear understanding of the headline features of the role, although at the same time there was significant variation in how these features were interpreted. The response of CDWs to their particular circumstances was both influenced, and in part determined, by these interpretations. There was also a subtle difference in tone within and between some responses in terms of whether advocacy and working on people's behalf were emphasised, or if the focus was more on empowerment of communities to take self-directed action. The larger

variation, however, lay in how effective the CDW model was seen to be in relation to the area and institution in which the CDW was located.

In relation to CDWs achieving success in bridging gaps between the community and services, and facilitating communication between services in the statutory and voluntary sectors, most of the respondents were able to cite clear examples of progress. But a number of factors were identified as obstacles; internal factors related to the design of the role and the support available, and the external conditions in terms of organisational structures and commissioning processes.

Four aspects of the CDW role

Describing their role, most of the CDWs referred to four key aspects; 'change agent', 'service developer', 'access facilitator' and 'capacity builder'. We asked the CDWs how successful they thought they had been in each of these areas.

Change agent

Despite the enthusiasm about their work in this area, there was a general consensus that efforts had often not led to substantial change for those using services. A few respondents spoke of how they had overseen a comprehensive process that ranged from working with communities to identify where issues were concerns, through to working with commissioners to implement changes in services. Many more suggested that while productive, this process had not translated into lasting reforms.

The reasons for this lack of output tended to fall into two camps: either the services and commissioners had not been receptive to the input of CDWs, or they had seemed receptive but the information and opinions passed on seemed not to have influenced decision-making. Regarding the former explanation, there were reports of key service staff, such as GPs, being particularly sceptical towards innovative ideas, such as providing their staff with Race Equality and Cultural Capability (RECC) training. Where the latter explanation was given, CDWs spoke of how commissioners and services responded well to their input, but that real change was very slow both in terms of improving the means for communities to provide feedback and developing the services available.

Despite these challenges, there was a general sense that the lines of communication and interaction in this area had been enhanced. There was also

further mention of the consequence of the CDW being located closer to services, or closer to communities.

Service developer

For many CDWs there was a degree of overlap between how the roles of 'service developer' and 'change agent' were interpreted. Many also referred to the effective collection and passing of information to decision-makers, although they were unclear about what real difference this was making. That said, there were specific examples of how this engagement with communities and groups is taking place:

- Networks of service users from particular ethnic groups were being facilitated and helped to feed into the commissioning process and influence practice.
- Training within the community facilitating the creation and improvement of community-based services.
- Collaborative projects in the community involving both community groups and mental health services staff.
- Offering advice to community members, groups and workshops on issues such as stigma.
- Producing reports on the areas of service that need improving to better serve BME communities.

Access facilitator

The aspects of the CDW role cited above were focused on the need to change services. However, the majority of the responses in this area emphasised the need to make changes within communities themselves, ensuring more people access services when they need them. Once again, the general message seemed to be one of "a lot has been done, but there is so much more still to do." A number of successful areas of work were referred to:

- The use of films and workshops focusing on increasing awareness of mental health issues and reducing stigma within BME communities.
- Engaging with community and faith leaders to encourage a positive drive on awareness-raising and stigma-reduction.
- Working with groups that are often seen as 'hard to reach', and helping with issues such as the language barrier.
- Providing information to help signpost people towards effective support.

- Acting as a 'go-to point' for people who have fallen between the remit of primary and secondary care.
- Targeting specific locations to effectively reach people (eg, barbershops).

A number of common challenges that restricted success were also identified:

- The magnitude of deeply held stigma about mental health.
- Lack of funding necessary for focused work on reducing internal barriers to access.
- Inadequate services that reinforce stigma towards mental health issues.
- The reasons for the disengagement of BME communities include social and economic factors beyond the control of CDWs.

As in other areas, there was a general sense that this work is beginning to gain momentum and that more time and support are needed to have the type of impact described in the original goals for DRE.

Capacity builder

Part of the CDW role was the development of community organisations and community leadership. There was a general sense that CDWs had been quite successful in this regard. A number of positive examples were cited:

- Training in leadership, RECC, Mental Health First Aid (MHFA) provided to community groups and leaders, with some able to pass on the training themselves.
- Groups assisted in accessing funding, attending events and contributing to consultations and service design.
- Events, forums and networks established to allow groups to work collaboratively to share ideas and practice.
- Helping to establish specific community-based services for different ethnic groups, with a focus on providing language/translation support.

However, there were also a number of limiting factors cited, as well as concerns about the work carried out in this area:

- Funding for community groups and services is limited, especially in the current economic climate. Efforts in this area need adequate resources.
- It can be hard to keep people engaged with groups and projects.
- There is the possibility that the work is too centred on CDW efforts. When the CDW moves on from the project the underlying issues that necessitated the project may re-emerge.
- Now that the role may be coming to an end, some CDWs believe that a focus on sustainability is critical.

The work undertaken in this area was viewed more positively than that in any of the other aspects of the CDW role we asked about. CDWs seemed particularly suited to this aspect of their work.

Analysis

The 'change agent' and 'service developer' aspects seemed to focus on how the services responded to BME communities, while the 'access facilitator' and 'capacity builder' aspects related more to how BME communities sought to interact with services. Despite this apparent distinction, the amount of overlap between these functions was striking. While one may expect different areas of work to complement each other, as with the 'change agent' and 'service developer' elements, there was a lack of clarity about how these areas differed and interacted. Also, the emphasis of the responses was as much about reasons for difficulties in fulfilling the role as about what had been achieved. There was a clear sense that efforts were only just starting to bear fruit, that goals had been hugely ambitious, and that the challenges had been underestimated.

Realising the role

Successes

When asked about overall success of the role, most CDWs referred to features that were particularly effective:

- It had a clear impact in raising awareness of both mental health issues and the services available, as well as in reducing stigma.
- Regardless of whether CDWs were located within services or the community, their approaches tended to be focused on 'grass-roots' rather than 'top-down' methods.
- The presence of the CDWs raised the profile of mental health issues among those communities they engaged with.
- It enabled community voices to influence service development.
- The role delivered a model of community development, engagement and empowerment.
- It brought people from outside the mental health profession into the field, providing new energy, enthusiasm and ideas.
- CDWs put on events and helped to organise forums and networks.
- It supported community groups to expand, develop and raise funds.

There seemed to be a consensus that the CDW role was exciting, dynamic and fulfilling. This was reflected by the general enthusiasm for discussing the positive impacts that had been made. This contrasts with concerns expressed when responding to questions about fulfilment of pre-set goals.

Challenges

When asked about the challenges they faced in carrying out their role, the CDWs were all able to point to a number of factors, both internal and external, that had made things difficult for them. Although many related to each CDW's personal experience, a number of common themes emerged:

- Lack of support and understanding of what the role involved and required from a number of sources: line managers, senior management, PCTs and MHTs, other local organisations and authorities.
- Lack of structure and clarity to the role meant CDWs often felt like they were working their remit out as they went along. This was exacerbated by lack of networking and sharing of practice.
- Lack of monitoring and oversight of activities and the difficulties involved in gauging the impact of their work.
- The delay in recruiting CDWs means some have been in post for only a couple of years (out of the five years during which they should have been in post). This has left many CDWs without the anticipated support.
- The resistance of some services and institutions and the slow pace of change.
- Lack of funding and resources to really implement required changes.

These responses show that most of the CDWs interviewed felt the external environment had not been conducive to achieving the change they were looking to bring about and that the internal support was often insufficient to help them overcome these barriers.

Training

When questioned about training, many of the CDWs began by describing how their background, be it clinical or voluntary/community, had led to them applying for the role. Although there were some instances where CDWs reported that they had received little or no formal training, the majority were able to give examples of the courses they had been given access to:

- Many had received RECC and MHFA training and had become trainers themselves so that they could deliver the programmes to communities and groups.
- Some received general inductions or community development training.
- A few received project management training.

There was also consensus that where such training had been given, it had been helpful, particularly where it provided ideas and programmes that they could disseminate throughout communities.

Many respondents spoke of how the networks, forums and events were helpful in terms of sharing ideas and seeing how others carried out the role. Some also mentioned that as the programme continued this networking activity had tailed off.

A number of issues were raised regarding the training received or desired:

- There were suggestions that CDWs could have benefited from more specific training relating to their role, including 'managing projects' and 'engaging with communities and service users'.
- Some viewed the lack of training discussed above as a consequence of limited resources, or a lack of commitment from management.
- It was also pointed out that it was hard to know what sort of training was needed until one was embedded in the role.

Analysis

When asked to discuss the successes of CDWs, the pride, passion, commitment and enthusiasm for the role was evident from responses. It was also clear from their responses to questions about the challenges they faced, and the training they received, that better management would have allowed them to do an even better job. However, when looked at in the context of answers to previous questions, it does not seem that such scope for potential improvement would have been anywhere near sufficient to allow CDWs to effectively overhaul the social and economic factors that contribute to

ethnic inequalities in mental health, or comprehensively address the cultural issues within both services and communities that restrict effective delivery of care to those who need it.

Wider perspectives on DRE

Improvements in services

As an introduction to the broader questions on the success of DRE, respondents were asked: "After five years of work by the DRE programme, would you say that mental health services for black and minority ethnic communities in your area have improved, got worse, remained the same or that you don't know."

While a majority of the CDWs thought that things had improved, a third were not sure if progress had been made, or thought things had stayed the same. Even among those who stated that things were better, the responses tended to be tempered by caveats and a sense that things were only just starting to get under way.

The type of changes that were cited as constituting an improvement included:

- The general profile of BME mental health moving up the agenda and the increased aptitude for change within services.
- Improved signposting to suitable services.
- Increased awareness of mental health issues within BME communities.
- Some improvement in the flow of information from communities to services.

From the reasons given by those who didn't know whether things had improved (or thought they had remained the same) and the limitations of the success described by those who thought things had improved, a number of common opinions emerged:

- That success is very hard to measure, in part because the goals of DRE and the CDW role were quite vague.
- That the blame for lack of primary service use is often laid at the doors of the BME communities themselves.
- That the understanding of exactly what needed to be done was only now becoming clear after a few years of work.
- That efforts in this area need to be part of the mainstream, not just an add-on.

Despite the differing responses, there was a clear consensus that any improvements had been

modest, that it was hard to gauge change, and that more time was needed for initiatives to make a real difference.

Achieving DRE's goals

Respondents were then asked to look back over DRE generally, as a five-year programme, and assess whether it had achieved its goals. The answer was an almost unanimous: "No". There was some variation in the strength of this conclusion, some arguing that the goals had only been partially realised, others emphasising that the programme had struggled to even get enough CDWs into post, thus curtailing the possibility of addressing the issues. There was, however, a clear consensus that the goals were hugely ambitious and that the DRE programme and CDWs specifically had not been given enough time to tackle the substantial problems the strategy sought to address. Other more sceptical respondents suggested that given the scope and approach of DRE, its goals were virtually unachievable.

Areas for improvement

In response to the apparent lack of achievement of DRE, respondents were asked whether things could have been done differently. A large number of respondents repeated the concerns previously mentioned – that the programme was too short (especially when many CDWs weren't recruited until a couple of years in), and that the goals were too vague. However, many did suggest possible improvements:

- The role of CDWs needs to be clearer and more co-ordinated with other CDWs and the DRE strategy as a whole.
- Need for greater local buy-in from relevant organisations and institutions.
- Need for more training and improved career development.

Even with these potential improvements, there was a clear sense that CDWs were fighting an impossible battle in terms of securing comprehensive, system-wide changes in such a short space of time.

Future plans

The final question put to the CDWs was about plans in their area to continue working on race equality in mental health now that DRE had come to an end. Responses tended to fall into two camps: those that were unsure of their future and those that had clear plans in place. There was, however, a

general sense that in the short term at least the work of CDWs would continue. Responses to this question developed into a discussion about how race equality work will be incorporated into new mental health policy.

For those whose work seemed set to continue, this was generally thanks to favourable local conditions such as a sympathetic PCT or equality and diversity lead who saw value in the role. There was some suggestion that this view prevailed in areas with high BME populations, where matters of 'race' and ethnicity were particularly salient. Where the future was less certain the issues tended to be around local services and commissioners struggling to fit the work of CDWs into their broader work plans, in light of uncertainty caused by the changes in government policy and the current economic climate.

As mentioned above there was a more general debate over how the type of work carried out by CDWs would sit in the context of a single Equalities Bill and the direction of travel in mental health signalled by the previous Government's New Horizons programme. A couple of respondents claimed that the move towards a more general focus on equality and diversity would be helpful, as people were often pigeon-holed because of their ethnic background. However, the vast majority of respondents had concerns about this cultural shift, suggesting that it might dilute the focus on race within mental health, while it is just beginning to bear fruit; and the momentum built up in this area would be lost. Those who could see the benefits of a more general approach to inequality affirmed that in relation to mental health, one of the clearest manifestations of inequality relates to race and ethnicity.

Analysis

Many respondents held a firm belief that over the life of DRE, there had been no substantial improvements in mental health services. However, this should be seen in context of earlier responses about how the work was only just getting going, things were moving in the right direction. Therefore in terms of achieving the goals of DRE, it seemed to be the case that the end of the programme had simply come around too soon for substantial progress to have been made.

Most of the CDWs reported that work would continue in a similar vein for the short term at least, and there was a sense of optimism that their efforts would begin to show more tangible improvements as time went on. However, there was also significant concern that, rather than building on DRE and focusing on the areas where it came closest to success, the direction of travel in mental



health policy was away from a focus on race equality. The majority of the respondents agreed that the shift towards a 'wellbeing' and 'single equalities' approach would stunt rather than augment the progress that has been made by CDWs and DRE.

Conclusions

It was fascinating to talk to CDWs about their role and their perspectives on DRE and mental health for BME communities in general. They are clearly a group of dedicated professionals with a great passion for the work they do. Their achievements over the last five years (given that many were recruited well into the life of the strategy) are particularly impressive in the context of a challenging external environment and insufficient strategic co-ordination outlined above. Many remain optimistic that given more time, resources and support, their work will achieve the impact originally envisaged in DRE.

It is also useful to take a step back from the important work CDWs are doing and look at their

role within the wider political and socio-economic context. Although they are only one of the elements of DRE, they were clearly expected to be the linchpin in achieving its goals. However, many also acknowledged that CDWs alone were not able to resolve the myriad issues that contribute to ethnic inequalities in mental health. They were clearly capable of playing a vital role in this process, but there also needs to be a culture shift within services, the opening of communities, fundamental improvements in socio-economic conditions, and greater political conviction and force behind their efforts.

Although there were some positive comments about the apparent shift in focus towards wellbeing and equality, and diversity in general within mental health policy, there was also a broad consensus that there needs to be a continued focus on directly and explicitly addressing 'race' as a driver of inequality in mental health. If anything, the lesson from much of what CDWs reported from their work was that there needs to be a greater effort, rather than a weakening of focus, to tackle these inequalities head on in order to complete the crucial work they have begun.

VIEWS OF SERVICE USERS AND CARERS FROM RACIALISED GROUPS

Introduction

As the survey was web based, we expected to receive a fairly modest yield of completed surveys. In the end, we had a total of 28 responses. It is therefore important to start out by making clear the limitations of the data we collected in terms of drawing broad conclusions about DRE or mental health services in general. However, the information is still useful as a snapshot of service user perspectives and experiences, and by analysing the data in context, it should be possible to extract some interesting findings.

In this vein, it is worth bearing in mind the make-up of the respondents. Through the manner of dissemination (networks of user groups and visitors to the Mind website), the inference is that we reached a relatively narrow group of people; ie, those that fitted our original criteria but are also relatively engaged in mental health issues and who have access to the internet. Although there is always a tendency for only those with gripes about an issue to respond to relevant questionnaires, it's fair to say this group would be both fairly knowledgeable about mental health issues and relatively proactive in how they approach their treatment. It is possible that this counterbalanced the tendency towards receiving disproportionately negative responses.

It is also reasonable to suggest that, although there is no previous dataset to compare against, responses that suggest services are particularly good or particularly bad do have some weight. The DRE programme sought to bring about fundamental improvements which should have touched upon the generality of BME service users' experience of mental health services.

Views on DRE

The first question asked to respondents was simply whether they are aware of the Delivering Race Equality programme. This was important both in terms of gauging the public impact the programme had achieved, but also for interpreting subsequent answers that the respondents gave.

The majority of the respondents (17 out of 28) were not aware of the programme. From the point of view of DRE gaining public recognition, this is not a particularly encouraging result, particularly as those responding are assumed to be relatively engaged in mental health issues (see Introduction). Clearly, it is more important for the impact of DRE to be felt rather than recognised by service users and carers. But one might have expected more awareness among the most directly affected group.

However, from the point of view of gaining a balanced perspective on progress in this area, this outcome may be a positive one. A sample that was overwhelmingly made up of individuals aware of DRE may suggest that knowledge of the programme is widespread, but it may also suggest that our sample was skewed towards people particularly engaged in this area. If the latter were the case, it may be that respondents either have a particularly negative view of DRE (if they had heard of it through criticism) or particularly positive views due to more knowledge about the work being done. In the case of our sample, it seems to be the latter; there was generally a more positive response to the subsequent statements among those respondents who were aware of DRE. On the other hand, if none of the respondents had heard of DRE, then subsequent responses could be dismissed as coming from people who were not aware enough of services and improvements to them to offer insightful responses.

Of the 11 respondents who were aware of DRE, seven had direct experience of the programme through having been involved in training or a focus group, or as a result of contact with the programme through their work. The other four had simply heard about the programme through their contact with services. This group of 11 were also asked what impact they thought DRE had made. Although a couple of respondents who'd had relatively formal roles within DRE reported specific successes, the general perception was that the programme had struggled to achieve substantial impact and that the issues that had led to its formulation are still prevalent.

Access to services

As figure 1 shows, the vast majority of respondents (all but three) had been in contact with mental health services as a community patient. Nearly a third had also been inpatients and about a quarter had been carers or family members to a service user (hence there was clearly an overlap where some had been both carers and patients). This mixture of experiences ensured responses that reflected a variety of perspectives.

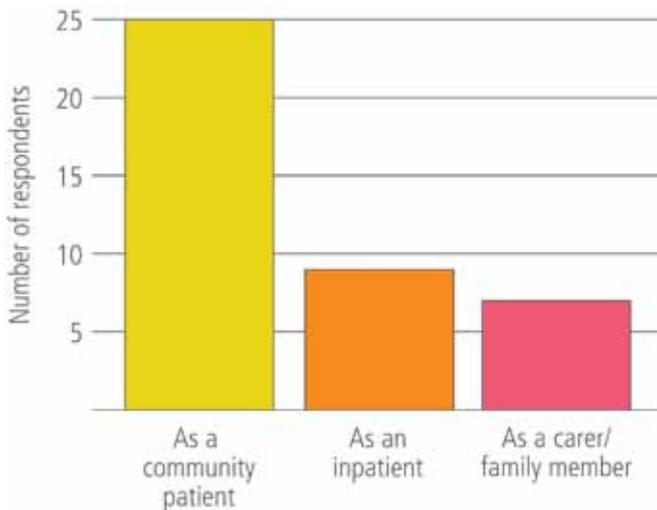


Fig 1. What contact have you had with mental health services in the last five years?

One of the key issues with BME mental health is that people tend to access services late, once their condition has become severe, rather than at an early stage when a crisis might be avoided. Failure to access services is often seen as a result of communities treating mental health as a taboo subject. It was an aim of DRE to address this stigma as well as improving services so that people were more willing to access them. Our question on this issue focused on whether people were *able* to access support at an early stage, effectively putting the onus of responsibility on services (fig. 2).

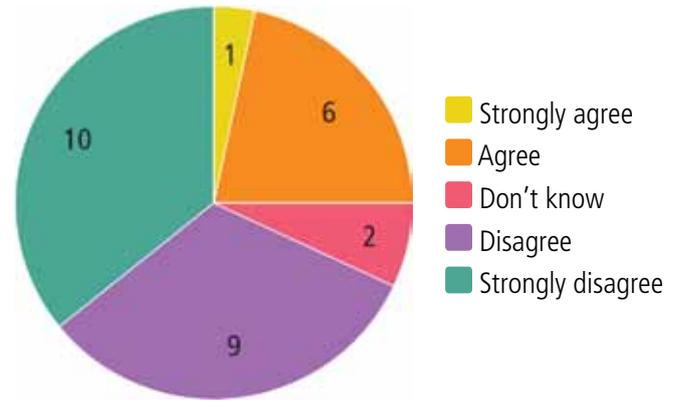


Fig 2. You were able to access the support you needed as soon as concerns around your mental health began.

The responses to this question are therefore fairly disparaging of these services – over two-thirds of respondents felt they were unable to access the support they needed at an early stage. The fact that the most common response was to strongly disagree gives an insight into the strength of feeling in this area. Although there are no comparable data that can be used to assess whether the situation has improved, the scale of discontent suggests there has been no dramatic shift in opinion.

Once they (or the person they cared for/were related to) had accessed services it was important to know what sort of treatments were made available to them. DRE had called for “a more balanced range of effective therapies such as peer-support services, psychotherapeutic and counselling treatments, as well as pharmacological interventions that are culturally appropriate and effective.” The issue of cultural appropriateness and effectiveness will be addressed in the following section, but respondents were first asked what treatments they had been offered (fig. 3).

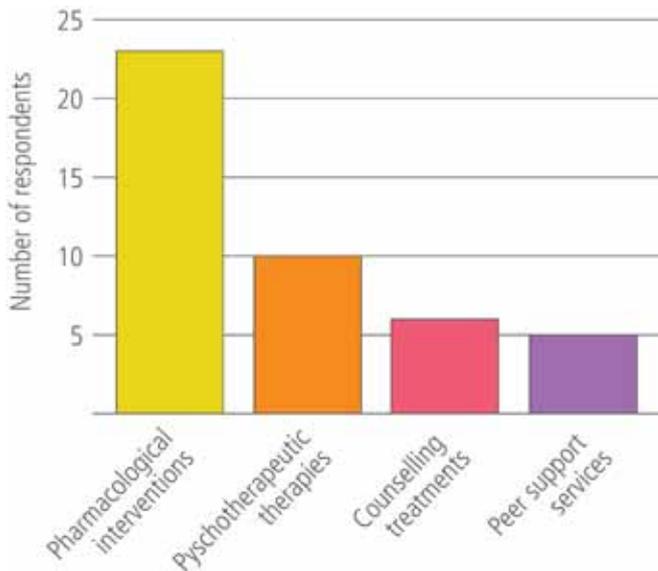


Fig 3. Which of the following treatments/therapies were made available to you?

The responses suggest that, although some people had accessed a range of services, the predominant treatment was still pharmacological intervention. There was also space for describing other treatments offered, and a few respondents spoke of complementary therapies such as massage or relaxation. Although a substantial number of respondents had been offered treatments beyond pharmacological interventions, again there is no pre-existing dataset to compare against, making it impossible to say whether this represents a clear improvement. However, it would seem that the primary line of treatment is still via medication. To some extent, this is a display of the inherent bias described in the introduction, in that it would take an overwhelmingly positive response (with most respondents accessing a wide variety of treatments) to reliably suggest improvement in this area.

Suitability of services

One reason often cited for the poor outcomes experienced by people from BME communities when using mental health services is that the services are not culturally sensitive or appropriate to the needs of these individuals. With this in mind, respondents were asked about the suitability of the treatments made available to them (fig. 4).

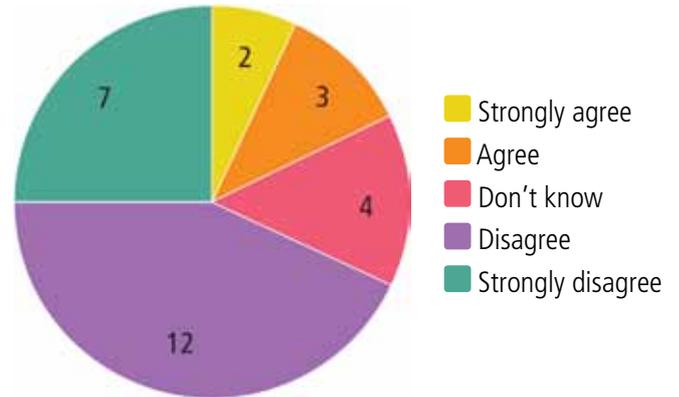


Fig 4. The treatments made available to you were built around your needs, taking into account your lifestyle and culture.

As with the question about accessing support early on, 19 of the 28 respondents disagreed with the statement they were presented with. The balance was slightly more towards 'disagree' rather than 'strongly disagree' but it is nonetheless a firm rebuttal to the idea that this aspect of services has been substantially improved. Only five of the 28 agreed or strongly agreed with the proposition.

A key element of individuals feeling that they have received appropriate care is the way they are treated by staff. Furthermore, it was a key aim of DRE to increase the proportion of staff from a BME background, which would presumably help to improve perceptions of cultural relevance. On this basis, respondents were asked directly about their experience of mental health staff (fig. 5).

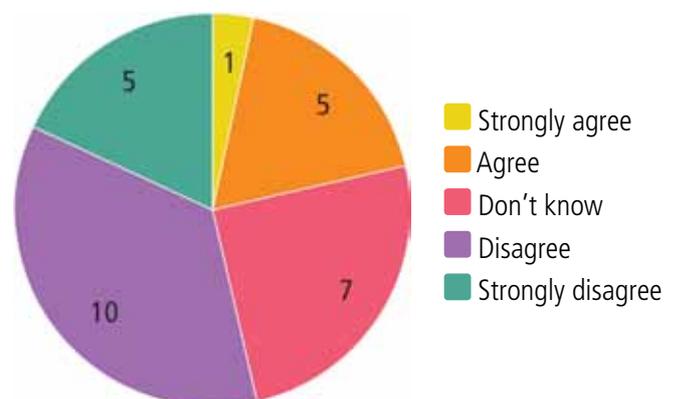


Fig 5. The staff you encountered were sensitive to, and considerate of, your lifestyle and culture.

Although the rejection of this statement was less strong than in the previous question, those responding with a 'disagree' or 'strongly disagree' made up more than half. Furthermore, the major shift was towards uncertainty rather than a positive response, with only one more 'agree' or 'strongly agree' than in the previous question. The large number of respondents who did not know how they felt about this statement perhaps reflects the fact that the cultural sensitivity of staff is quite an abstract concept, only usually distinct in a negative context. However, it is again clear that DRE has not led to the sort of revolution in terms of service user's perceptions and experiences in this area that it seemed to call for.

Another key goal of DRE was "an increase in the proportion of BME service users who feel they have recovered from their illness." We asked our respondents directly about whether they felt this was something that they had achieved based on their treatment (fig. 6).

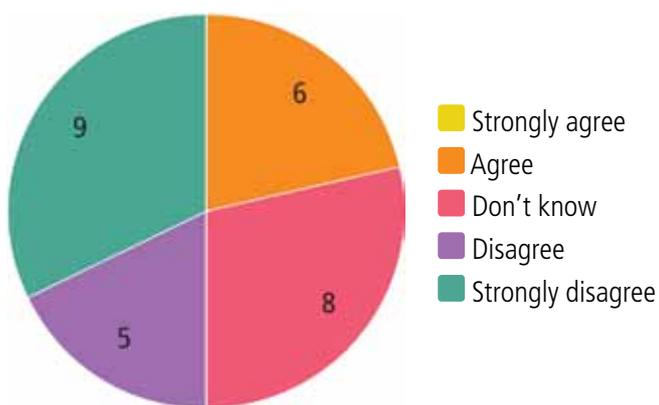


Fig 6. As a result of the services you received you were able to start to recover from your mental health issues.

Again, this was an area where the only definitive response would be a strong rejection of the proposition. The outcome was reasonably positive – only half of the respondents disagreed or strongly disagreed. However, only six respondents (just over a fifth) agreed with the statement. While this is not a ringing endorsement of attempts to make improvements in this area, neither is it a clear statement that no progress has been made.

The fact that so many people were not sure whether they agreed with the statement suggests that this may have been a vague and complex goal to achieve in any case. Although the idea of a 'recovery model' of treatment for mental health is gaining traction, with a focus on people moving on from a period of mental distress rather than trying to return to how they felt before, it is still common

for people to feel that their issues are ongoing, even if they are not currently in distress.

Improvements to services

It was hoped that, as a result of DRE, dramatic improvements to services for BME communities would come about. A key element in this process would be increased opportunities for BME service users to influence how these services operated. We asked our respondents whether they had had the opportunity to offer their input (fig. 7).

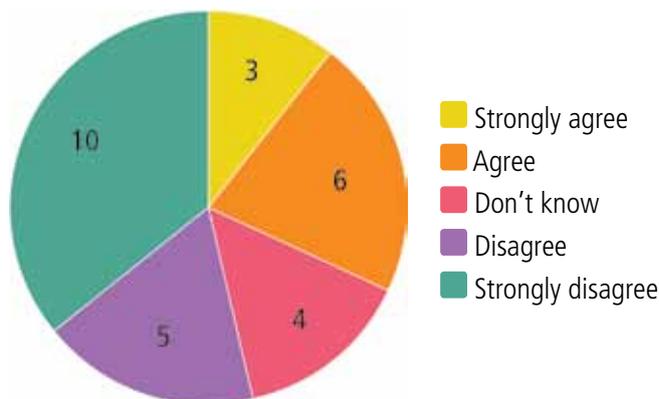


Fig 7. You were given the opportunity to contribute towards/influence how mental health services are run.

This is one of the few areas where even a small number of positive responses may constitute a reasonably successful outcome. Although we cannot clearly say that the nine affirmative answers represent an improvement in this area, due to the lack of comparable data, the fact that almost a third of a varied sample feel that they have been able to contribute to or influence services is quite encouraging. Of course, it could be suggested that this is an area where the nature of our sample may skew things, due to the likelihood of high levels of engagement among respondents (although those who felt they had been able to input were not simply those who had heard of DRE). It could also be pointed out that 19 of the 28 respondents did not clearly feel that they had been able to influence things. However, considering the relative dissatisfaction in other areas, it can be maintained that there may well be emerging lines of engagement with service development for BME service users based on this response.

However, when we looked at the subsequent descriptions given by some respondents of how they were able to contribute, the focus tended to be on self-initiated efforts through service-user groups or simply through complaining to the

primary care trust or mental health trust. Although it is obviously positive that individuals felt sufficiently empowered to take these measures, it says little about the impact of DRE on their ability to do so. There were a couple of examples where there had been formal engagement with services, but these were isolated and very much against the trend.

As well as helping those who use services to influence how they are run, DRE called for services to make more active efforts to actively engage with communities in order to rebuild trust and connections with the community. The CDW role was also designed specifically to help with this bridging process. We asked our respondents about whether they were aware of these types of efforts in this area (fig. 8).

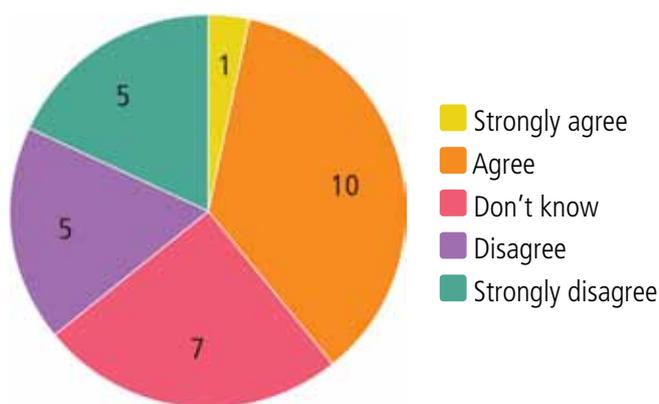


Fig 8. There have been efforts in your area to engage diverse ethnic groups with mental health services in the last five years.

Of all the statements, this one prompted the highest level of agreement and was the only one where more people agreed than disagreed. As with the previous question, it is interesting to note that those who were aware of efforts didn't simply correlate to those who were aware of DRE in general. It should not be ignored that seven respondents didn't know if there had been efforts of this sort and 10 disagreed that there had been. This would suggest that DRE hasn't been entirely successful in raising widespread awareness (or perhaps it hasn't publicised the efforts it has made well enough). However, the fact that well over a third of a varied sample of service users and carers believe that efforts in this area have been made during the last five years is fairly encouraging.

The real test of DRE, however, is whether it actually improved services in the eyes of the diverse communities it was hoping to better cater for. With this in mind, our penultimate question to respondents was whether they had noticed any such improvements (fig. 9).

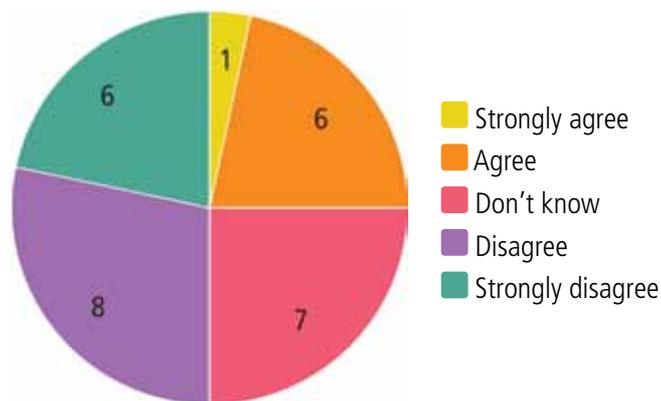


Fig 9. Mental health services in your area have noticeably improved in the last five years.

The results of this question saw a return to the disappointing levels of agreement that characterised the earlier questions. Only seven respondents, a quarter of the total, had noticed improvements while half the respondents disagreed or strongly disagreed that services had improved. Once again, a large number of respondents didn't know whether they agreed with the statement or not. For around three-quarters of respondents not to have noticed improvements is an extremely disappointing outcome for a programme that aimed for such radical progress on this stubborn issue.

Finally, the respondents were asked what they believed to be specific issues with mental health services for diverse ethnic communities and what might be done to address them. A wide range of interesting suggestions emerged:

- Many people suggested that mental health staff needed training to be more culturally aware and sensitive, with a few respondents referencing Race Equality and Cultural Capability training.
- This cultural sensitivity was mentioned in a number of contexts: from better translation services, to more ethnically diverse staff or culturally appropriate meals in hospital.
- A number of respondents suggested that there remains a serious lack of awareness of mental health issues within BME communities and a significant stigma attached to experiencing mental distress.
- Some respondents called for greater support for community groups and empowerment of service users and survivors to both influence and provide services.
- Faith groups and leaders were viewed as a good point of access in terms of disseminating information about mental health issues and services.

- A number of people simply asked for greater efforts to listen to the service user and to take more account of their perspective and wishes when providing treatment.

It was striking that many of the suggestions raised are exactly the sort of things that were supposed to have come out of DRE, suggesting that the programme itself was focusing on the right areas but simply failed to deliver substantively on these goals.

Conclusions

It was made clear at the start of this report that the conclusions that could be drawn from the survey results were severely restricted by the small sample size. However, the fact that it seems to be a varied sample does mean that the views expressed provide a plausible snapshot of opinions on the topics covered and that some rough indications of the state of BME mental health services can be extracted.

First of all, it is clear that DRE has not had a widespread impact in terms of publicity and recognition of any changes it has brought about.

Since DRE was intended to be about changing perspectives on mental health services as well as changing services themselves, the fact that most respondents hadn't heard of DRE or been aware of noticeable improvements in services locally is a very negative outcome.

In terms of experiences of services, most respondents reported that their treatment had largely consisted of drugs; had not been built around their needs/culture; was delivered by staff who were not particularly culturally aware/sensitive; and had not clearly led to recovery. Despite the limitations of the sample, these are not the type of characteristics that it was hoped would describe the experience of BME service users in 2010.

Finally, there was little agreement with the idea that services had noticeably improved locally over the DRE period. The issues identified and suggested improvements for mental health services for BME communities were largely the same as those discussed at the start of DRE five years ago. Although the survey had limited capacity to identify the broad successes of DRE, it was clearly able to recognise that there haven't been the sort of improvements that DRE aimed to deliver.

REPORT CONCLUSIONS

There is widespread agreement that the 12 characteristics it was hoped would describe BME mental health services in 2010 were laudable goals. However, from the explicit views of the CDWs and the implications of the experiences of service users, it seems clear that we are a long way off achieving these goals. There are a number of possible explanations for this, arising from the views expressed in both strands of our survey.

An optimistic interpretation might be that the characteristics were simply too vague and difficult to measure. As such, given the lack of clear indicators, it is hard to declare success or otherwise. The proportion of service users who responded with 'don't know' to statements that implicitly referred to characteristics DRE was aiming to achieve implies that the characteristics may have been rather abstract and intangible. However, even if it is hard to assess progress towards the characteristics in DRE in some instances, there seemed to be little conviction among CDWs or service users that there had been the sort of dramatic improvements DRE sought to achieve.

The set of characteristics described in DRE should, in principle, be attainable since they seek to address a situation deemed unacceptable to policy makers, campaigners and service users alike. However, while it is clear that these characteristics *should* be achieved, it is far less clear if they *could* be achieved within the timescale and methodology of DRE. The suggestion is therefore that DRE did not sufficiently engage with all the areas it needed to in order to address the underlying causes of the issues it was hoping to resolve.

It is apparent that the success of DRE rested heavily on the work of CDWs. However, clearly there is discordance between the aims of DRE and the methods it employed to achieve them. The possible over-reliance on CDWs may also help to explain why there seemed to be a lack of awareness of DRE among service users, since only those in direct contact with the work of CDWs were likely to have knowledge of the broader programme. As such, although CDWs carried out some remarkable work, the massive emphasis on their efforts as a means to achieving DRE's goals may be both a symptom and a cause of where the programme went wrong.

Another agreement among responses was about the disparity between the efforts put into achieving change in this area by CDWs and the actual changes that occurred. Many CDWs spoke of how their efforts to change services were either met with reticence, or responded to with enthusiasm which didn't materialise into substantial progress in terms of improved services. The views of service users mirrored this experience to some extent, with more people recognising efforts to engage diverse communities with services than recognising genuine local improvements in services. These indicators seem to support the previous suggestion that too much was expected from CDWs and, while they were doing their best to fulfil the role, not enough was done to make the circumstances in the external environment more conducive to pushing through substantial change.

Many of the CDWs were the first to admit that the work had only really just got going and that it would take a while longer for real results to be seen. In addition, many CDWs have only been in post for a couple of years because of delays and recruitment issues. It inevitably takes a long time for schemes and processes to become embedded and for communities to become convinced by, and involved in, such programmes. With this in mind, it is perhaps no surprise that, in general, the service users had neither perceived substantial progress nor reported the type of improved experience of services that DRE had called for. Even with all the limitations of the role in terms of achieving DRE's goals, it seems that a significant amount more could have been achieved by CDWs given the right support and more time, and that this may well have resulted in improved experiences for BME service users, even if not on the scale DRE envisaged.

It should not be concluded that all these points are original ideas, derived solely from the limited data we've collected. There are existing critiques of DRE that suggest similar problems to those raised here: the limitations of the CDW role, the lack of focus on institutional reform, the restrictive time and resources committed to the cause. Despite the challenges of the role, CDWs have carried out remarkable work. However, as a key part of DRE, they have not been facilitated and augmented by the rest of the programme. This calls for a serious



REFERENCES

consideration of how the positive and negative elements of both DRE and CDWs can be used to develop the next stage of efforts to address racial/ethnic inequality throughout the mental health system.

Department of Health (2003), *Inside Outside Improving Mental Health Services for Black and Minority Ethnic Communities in England*, London

Department of Health (2005), *Delivering race equality in mental health care: an action plan for reform inside and outside services*. www.dh.gov.uk

Department of Health and the National Mental Health Development Unit (2009), *Delivering Race Equality in Mental Health Care: a review*. www.nmhdu.org.uk

Evison F. and Glove G. (2010), *Use of mental health services by minority ethnic groups in England*, NEPHO

UCLAN (2010), *Delivering race equality in mental health care: report on the findings and outcomes of the community engagement programme 2005–2008*. www.uclan.ac.uk

APPENDICES

Appendix 1 The 12 DRE Characteristics

In 2005, the DRE action plan identified 12 characteristics which it was hoped would describe mental health services in 2010

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

Appendix 2 Views on the Delivering Race Equality (DRE) programme

Interview questionnaire for community development workers

1. What is your understanding of the CDW role?
2. Would you say CDWs have been successful in:
 - a) bridging the gap between black and minority ethnic communities and health and social care services
 - b) facilitating better communication between community services and statutory services
 - c) changing the way services were commissioned and delivered to reflect this in terms of:
 - i) identifying gaps in services (change agent)
 - ii) informing on effective mental health service development for BME communities (service developer)
 - iii) removing barriers to accessing services (access facilitator)
 - iv) assisting in the development of community organisations and community leadership (capacity builder)?
3. What in your opinion were some of the specific successes of the CDW aspect of the DRE programme?
4. What were some of the problems, challenges you faced as a CDW?
5.
 - a) Please detail some of the training and support that was available to you as a CDW.
 - b) How well did it enable you to fulfil the objectives of your role?

6. After five years of work by the DRE programme, would you say that mental health services for black and minority ethnic communities in your area have:

- improved
- remained the same
- become worse
- don't know

Please tell us why you think this.

7. a) Looking back generally over the DRE programme, do you think that it achieved its goals?

b) What do you think the DRE could have done better?

8. As the programme comes to an end in April 2010, what plans are in place in your local area to continue focusing on race equality in mental health services?

Appendix 3

Service user/carer questionnaire: BME mental health services

'Delivering Race Equality', a five-year government programme to improve the way that individuals from diverse ethnic groups experience mental health services, is coming to an end. We are interested in hearing from service users and carers about their experiences of mental health services over this period and their perceptions of changes in services.

We would be grateful if you could answer the following questions, with a focus wherever possible on your experiences in the last five years. We will use this information to inform Diverse Mind's position on how continuing efforts to improve mental health services for BME communities should proceed. Any information you provide will remain anonymous. Thank you.

1. **Are you aware of the Delivering Race Equality (DRE) programme?**

- Yes (go to question 2)
- No (go to question 3)

2. a) **Please outline what you know about the programme, including any direct involvement you may have had (for example, as a DRE ambassador or through a community engagement programme etc):**

b) **How effective do you think DRE has been in engaging with local communities and delivering more appropriate and responsive services to specific groups?**

3. What contact have you had with mental health services in the last five years? Tick one or more of the following:

- as community patient (receiving treatment at clinics/day centres/at home)
- as an inpatient (staying in hospital/secure units to receive treatments)
- as a carer/family member of someone receiving treatment

Please try to answer the following questions on behalf of the person you care for.

4. You were able to access the support you needed as soon as concerns around your mental health began. Tick the most relevant response:

- strongly agree agree not sure
- disagree strongly disagree

5. Which of the following treatments/therapies were made available to you? Tick one or more of the following:

- peer-support services (meeting with other service users)
- psychotherapeutic therapies (talking through mental health problems)
- counselling treatments (talking through social/personal problems)
- pharmacological interventions (drugs to control symptoms)
- others (please specify):

none

6. The treatments made available to you were built around your needs, taking into account your lifestyle and culture. Tick the most relevant response:

- strongly agree agree not sure
- disagree strongly disagree

7. The staff you encountered were sensitive to, and considerate of, your lifestyle and culture. Tick the most relevant response:

- strongly agree agree not sure
- disagree strongly disagree

8. As a result of the services you received you were able to start to recover from your mental health issues. Tick the most relevant response:

- strongly agree agree not sure
- disagree strongly disagree

9. You were given the opportunity to contribute towards/influence how mental health services are run. Tick the most relevant response:

- strongly agree agree not sure
- disagree strongly disagree

Please provide details of any specific examples:

10. There have been efforts in your area to engage diverse ethnic groups with mental health services in the last five years. Tick the most relevant response:

- strongly agree agree not sure
- disagree strongly disagree

11. Mental health services in your area have noticeably improved in the last five years. Tick the most relevant response:

- strongly agree agree not sure
- disagree strongly disagree

12. Are there any specific issues with mental health services in regard to serving diverse ethnic groups that you feel need addressing, and what measures might help with this?

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