

Together we will change – Community development, mental health and diversity

Learning from challenge and achievement at Sharing Voices (Bradford)

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Community development is central to the government's drive to improve mental health support for people from Black and minority ethnic groups. There is passion but little consensus about how this can be achieved. This publication profiles an example of good practice, the Sharing Voices project in Bradford, which works with a community where many people share a South Asian, Muslim heritage. It shows how self-help approaches can enable local people to find their own solutions to mental distress and engage in active lives in their communities, moving onto education and employment. It draws out lessons of wider relevance.

The following is an extract from this publication which includes:

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About this book

This book aims to help those commissioning or delivering community development initiatives focused on people with mental health needs from Black and minority ethnic (BME) groups. We hope it will contribute to the debate about how to improve the experiences of people with mental health problems from these communities. We also hope the book will be of interest to community development workers based in areas of cultural and ethnic diversity.

The book therefore caters for a wide audience, so readers may find some topics more familiar than others. For easy guidance, there is a summary of key points at the start of each chapter.

What it is about

The book combines research, policy and practice, and is focused on a community development project, Sharing Voices (Bradford) and the learning gained through the action research that took place there. Sharing Voices is funded by Bradford City Teaching Primary Care Trust, and aims to help people from BME communities understand their mental health needs and develop the solutions that they want. Although the project is located within a unique context, much of what happens there has wider relevance across the UK.

Part 1 describes the economic, social and spiritual context that impacts upon BME communities and the broad issues within mental health, community development and government policy. Part 2 describes the Sharing Voices project, and outlines the action research process that took place there. Part 3 explores the wider implications for policy and practice, with reference to the learning gained from Sharing Voices and the national and local context. The book ends with conclusions and recommendations.

Action research, referred to here, is an approach to evaluation and learning which enables those involved in the project to learn through a democratic, cumulative process. It is grounded in the perspectives of local people, the staff, their management group and representatives from local organisations. Action research is complementary to community development, which brings people together to identify and create the solutions that *they* want and that work for them. The use of action research to evaluate and enhance community development is discussed in Part 3 of this book.

Personal quotes describing the experiences of local people and participants at Sharing Voices are shown throughout this book.

Executive summary

Community development and government policy

Community development is a key element in the Government's action plan to tackle discrimination and inequality in mental health services (*Delivering Race Equality*, DH, 2005a). It is well documented that the treatment of BME service users often exacerbates their fear of mental health services and increases the likelihood of poor outcomes. Significant change is needed, but there is a lack of consensus about how community development can contribute towards achieving this.

This study explores the challenges and achievements at Sharing Voices (Bradford) and puts this in the context of a literature review on mental health, community development and diversity. This enables wider implications to be drawn which, it is hoped, will contribute to the debate on how to achieve the changes anticipated by *Delivering Race Equality*.

Sharing Voices (Bradford) and the research programme

Sharing Voices (Bradford) is a community development project which works primarily with people from South Asian, African Caribbean and African communities. It is funded by Bradford City Teaching Primary Care Trust to deliver the community development element of *Delivering Race Equality*. The project aims:

1. To liaise with statutory service providers and to work together to improve the range and quality of mental health services.
2. To stimulate voluntary sector activity in the area of mental health and well-being, by developing capacity within communities and supporting the development of self-help/support groups and networks.
3. To stimulate a wider debate locally about the nature of mental health. To contribute to debates nationally/internationally about the nature of mental health, diverse perspectives and ethnicity.

An action research programme took place from October 2004 to June 2005 with three aims:

- ❖ to describe Sharing Voices;
- ❖ to evaluate the project, taking a critical and developmental approach;
- ❖ to disseminate the learning of wider relevance both locally and across the UK.

Grassroots involvement and mutual aid

The description of the project shows that it has a strong commitment to mutual aid. Seven self-help/mutual aid groups are set up with and by people with direct experience of distress and individuals with direct experience of distress take an active role in the community development activities. Almost all group members, volunteers or individual participants used primary care or specialist mental health

services, often for many years, and others were carers. They described their experiences with the project as empowering, and many moved on to training, study or paid work.

Local staff in the statutory and voluntary sectors argued that the involvement of people at this grassroots level was essential for successful community development. Research suggests that people with direct experience of distress make more impact than others in reducing stigma and changing attitudes when working as trainers, spokespeople and colleagues (Crepaz Keay *et al.*, 2004).

Networks and partnerships promote social inclusion and social capital

Other important features of the project include the networks, partnerships and ‘safe spaces’ which enable people to build trusting relationships with others of different ethnicity, faith and gender in a way that is not easy in an area of inter-communal tensions. Participants and staff expressed a strong desire to make these connections.

Networks and partnerships also link the project and other mental health workers with groups outside the mental health sector, drawing in participants to ordinary social activities (sports, music and arts) and building upon the skills within all sectors to welcome, respect and support people with mental health needs from BME communities.

Through these features, the project promotes social inclusion, social capital and community cohesion in a city described as ‘fragmented’, where Muslim communities are particularly under pressure at this time.

The Community Development Workers for Black and Minority Ethnic Communities: Interim Guidance (DH, 2004a)

From its firm foundation within the BME community sector, the project fulfils the functions set out in the Interim Guidance for community development (DH, 2004a) to increase the skills of the NHS and voluntary sector workforce, promote participation in the design and delivery of services, and to build capacity within the BME community sector.

The Interim Guidance adopts a functional approach to community development, and does not promote grassroots involvement, self determination and mutual aid or cross sector networks of the kind facilitated at Sharing Voices. This functional approach has been used before by public authorities where there is short-term funding and a focus on specific policy implementation and outcomes.

Professional standards and values in community development

The functional approach can be contrasted with approaches taken at other times by public authorities, which match more closely the occupational standards of the professional community development bodies (Community Development Exchange, 2001; Federation for Community Development Learning, 2003).

These professional bodies promote the involvement of local people at grassroots level, to design and deliver the services that *they* want. They promote participation in public services which gives local people the opportunity to contribute to the agenda and share influence in the decision making process. This broader approach implies a sharing of power that does not take place in many consultation processes. Community-led collective action is thought to promote social change that is long term and sustainable while a more functional approach is said to be less effective (Henderson, 2005).

The challenge of delivering greater equality

The overall aim of *Delivering Race Equality* is ambitious, as its name suggests.

Inequality stems not only from the well documented racism within our institutions but also from the fact that the Western approach to mental health care, which shapes the NHS, does not cater well for many people from non-Western cultures. Many from BME communities argue mainstream services do not take account of the context of their lives or their understanding of the world around them.

To achieve equality there is a need for better NHS resources and also for alternative options which are shaped and delivered by local people. Mental health practitioners and commissioners need to ensure BME mental health projects are supported rather than constrained by service level agreements. Organisational problems in the BME voluntary sector are caused primarily by insecure funding and were evident within Sharing Voices. Greater equity and dialogue between funder and provider is required to bring about a partnership for shared objectives.

Community development which draws on the expertise of local people and facilitates the statutory sector in sharing and devolving power can help to bring about the kind of radical changes suggested within the overall aims of *Delivering Race Equality*.

Recommendation

This report has one recommendation. It is that:

- ❖ PCTs should give community development workers (commissioned under *Delivering Race Equality*) a role and funding corresponding to that set out by the professional bodies of community development (Community Development Exchange, Federation for Community Development Learning and Community Development Foundation). Where possible, workers should be in teams rather than operating individually.

This model of community development requires the active involvement of local people in identifying the problems to be addressed and determining the solutions *they* want.

A number of action points (see p106-7) support the implementation of this model in the BME mental health economy.

1

Bradford's economy and people

KEY POINTS:

- ❖ There are high levels of deprivation in the City tPCT area where this book is based, but district wide the economy is improving.
- ❖ Within communities there is a complex and evolving diversity of culture and faith.
- ❖ Islamophobia and racism create tensions, divisions and reduce job prospects.
- ❖ The '2020 Vision' Delivery Plan for Bradford supports a range of initiatives for a better future.

Bradford's economy and employment

A century ago, Bradford was a world leader in the textile industry, but from 1914 prosperity declined with mill and factory closures finally coming to an end in the 1970s. Decades of high unemployment followed the loss of traditional employment, but in recent years the number out of work has moved closer to national levels (City of Bradford Metropolitan District Council, 2005). More households are interested in starting a business here than elsewhere in the country (Yorkshire Forward, 2004). Most businesses (82%) across the city are small, employing ten or fewer people, and a quarter of the city's workforce (25%) is in the distribution, hotel and restaurant sector, where family networks provide financial support and international connections for some highly successful South Asian businesses. About a fifth of workers (18%) persevere in manufacturing, often self-employed. The public sector is the largest employer, and nearly a third of the workforce (28%) is in the city's public administration, education and health sector (City of Bradford Metropolitan District Council, 2005).

Unemployment is disproportionately experienced by Pakistani, Bangladeshi, African Caribbean and African people. The Home Office reports evidence of racism and racial discrimination in Bradford's labour market including the public sector (Home Office, 2002), where a number of schemes report some slow progress.

Table 1: Bradford Metropolitan Borough Council 2001 Census

Unemployment rate (as a % of the economically active population)							
Total	Pakistani	Bangladeshi	Black African	Black Caribbean	Indian	White Irish	White British
8%	23%	22%	16%	12%	9%	8%	6%

Bradford's population and the City Teaching Primary Care Trust (tPCT) area

Bradford has a history of people coming from across the world to support its industry or to escape unrest at home. Many South Asian and African Caribbean people responded to Government encouragement to work in the textile industry and in public services such as the NHS and transport. Over time others have come from Europe, Asia, Africa and the Middle East. Bradford now has 92 different ethnic groups. It has been described as a fragmented city, where community groups are deeply polarised (Cantle, 2001).

The population of 468,000 people includes 14.5% Pakistani, 2.7% Indian, and 1.1% Bangladeshi (Bradford Metropolitan Borough Council 2001 Census). Just over 16% of the population is Muslim, the fourth highest proportion in the UK. The Irish population is relatively low at 0.74%, the Black Caribbean and Black African even lower, at 0.65% and 0.21% respectively.

Most of this diversity is to be found within four local authority wards, Manningham, City, Little Horton and Bowling and Barkerend which are broadly coterminous with the City Teaching Primary Care Trust (City tPCT). Approximately 55% of the population here is from Black and minority ethnic (BME) communities, of which the largest group is Pakistani (approx. 51,000) (2001 Census) with smaller numbers of Indian and Bangladeshi people. This is where *Sharing Voices*, the focus of this book, is based.

Some largely white estates on the periphery of Bradford experience persistently high levels of unemployment and deprivation, but the most difficult living conditions are to be found in the City tPCT area. The Department of Health provides measures of deprivation within each PCT across the seven domains of: income; employment; health and disability; education, skills and training; housing; crime and the living environment. Bradford City tPCT is assessed as having the fifth most deprived population in the country using a multiple index of these domains (National PCT Database, 2005). Nationally, social mobility is low and declining as the income gap between rich and poor is increasing (Blanden *et al.*, 2005). The City tPCT area offers little hope for young people, especially those facing discrimination on account of their mental health, ethnicity or faith.

It is beyond the remit of this book to describe all of Bradford's BME groups. The following sections focus particularly (but not only) on the majority Muslim heritage. They are the largest minority group in the city, under a great deal of pressure across the UK since the beginning of the 'war on terror', and there has been more information in the mental health field about experiences of African Caribbean groups (notably SCMH, 2002) than about Muslims in recent years.

Muslim communities

Most Pakistani and Bangladeshi people identify themselves as Muslim. Their faith and culture, and how these are interpreted by the wider white population, are of central importance to their well-being.

There are important regional differences in language and culture amongst the Muslim population. A large proportion of Pakistanis in Bradford came from the Mirpur region, but there are significant numbers from the Punjab and the North West Frontier Province. The distinctive culture of the Pathaan, including a tradition of *purdah* for women, continues here. A small well-educated group of Kashmiris maintain their nationalist interests. The Bangladeshi people are predominately from Sylhet, while Indian Muslims are more likely to be business people from the Gujerat.

Extended family, caste or kinship ties, the ‘biraderi’, remain an important influence and source of support in work, domestic and social domains. Based in Pakistan, Bangladesh or India, many biraderi now stretch across the world. Travel between one family home or business and another is a regular way of life for some people.

“Walking around Mirpur, hearing Urdu spoken with Bradford accents, meeting people who have lived on Toller Lane for 30 years, is a humbling experience. Like it or not, multiculturalism is an inescapable fact of modern British identity, all our lives are tied together by histories and living spaces that are shared.”

(Philip Thomas describing his travel in Pakistan)

There are different sectarian groups, such as the Barelwi and Deobandi, within the Muslim population which, like the biraderi, have a major impact on where and how people live. Each mosque has its own management committee and Imams. Some remain dominated by first generation elders and Imams from ‘back home’ while others have a younger influence within them which is keen to see the mosque as a centre of learning for all the community; their approach to issues such as gender and education differ accordingly. Whilst some are static in their leadership, others change. This process of change is likely to be accelerated under pressure following the London bombings.

“If I were to open a mosque now I would be encouraging Pakistani, Gujerati, all different people to come and join my management committee ... Give it another ten years ... we’ll probably be the Imams. That’s when we can make change.”

(Young Islamic Scholar in Bradford, December 2004)

Labyrinthine alliances criss-cross the different Muslim communities in the city, based on the various ties that bind (Lewis, 1994). However, many people have little close social contact with Muslims outside their own community. There is, for instance, little contact between the Bangladeshi communities in neighbouring areas of Bradford (postal codes BD1 and BD3).

Muslim culture, faith and change

Regional, family and sectarian differences are further complicated by the need to distinguish culture from faith. The patriarchal culture of the Mirpur region, for instance, has had a disproportionate impact on the public image of Muslim women as suppressed and oppressed. Many argue this is a feature of a regional culture and misrepresents Islamic guidance: the Qur’an promotes equality of gender, good education and work opportunities for both sexes and free choice in marriage. Muslim women in the UK today tend to choose for themselves whether or not they will wear the hijab or shalwar qamiz. Many opt to choose their own partners, while others opt for guidance in marriage. Culture is a dynamic phenomenon, and within one family siblings and adults may draw upon different strands to shape their lifestyle.

“We’ve got a large Pathaan community and we want to attract the women so we’re going to be having women only training sessions ... There might be other Pakistani women who will be fairly okay with mixed sessions ... that’s another view of Islam.”

(Pakistani Community Worker, Bradford)

Young Muslims may – or may not – be devout in the frequency of their daily prayers, but Islam remains a central force in their cultural, ethnic and personal identity. Two music groups, the Naseeb and Fun-da-mental, explore key issues of Islamic faith for young people, shocking those elders who remain wedded to sectarian traditions. Similarly other forms of media (radio, papers and magazines) stretch

the boundaries of faith beyond traditional limits. Despite differences of religion and culture, the importance of faith, however interpreted, remains constant across generations of Muslims.

Now, more than ever before, young people and their parents, are engaged in a debate about what the Islamic faith and Muslim identity means to them. Many people, especially the young, draw on multiple identities, which enable them to fit in comfortably and on their own terms within the family, school, workplace, or mosque. Allegiance to their peers and the country of their birth sits alongside allegiance to their faith.

“ Yes me, I’m a British Muslim Asian Pakistani. ”

(Nadia B. in Hamdard, 2005)

Islamophobia

The Muslim communities in Bradford have attracted notoriety in the national press since the 1980s, when they took part in a number of public protests. In 1989 the burning of Salman Rushdie’s book, *The Satanic Verses*, in the city and the support of the Iranian Fatwa caused national outcry. Bradford became the centre of what was termed ‘fundamentalism’, and with local support for Iraq in the Gulf crisis, mutual suspicion developed between local communities, the national media and public institutions from government to the police. The city riots of 2001 exacerbated inter-communal tensions.

Racism has been identified as a primary cause of tension in our communities and mental health services (Parekh, 2000; Blofeld, 2003). The focus of racist harassment has gradually shifted towards Muslims. In 2002, Islamophobia was regarded as prevalent in Bradford’s schools and communities (Ouseley, 2002). Today, young people report they are frequently asked to explain their stance on ‘fundamentalism’, terrorism and the position of women, an additional pressure for young men already struggling to fulfil family expectations in an area of scarce opportunity.

“ Muslims became ever more demonised, and fear and mistrust grew rapidly within the general public. Whilst the shift from race to religion clearly has its roots prior to 9/11, it was Ground Zero that provided the catalytic impetus to its quasi-justification. ”

(Allen, 2005)

Islamophobia increased across the UK following the London bombings in July 2005. Muslims *en masse* have been portrayed in the national press as potential enemies, subject to focused stop and search activities by the police. Newspaper and verbal reports suggest Muslim women have been subjected to spitting, abuse and having their hijab torn from them.

The impact of 9/11, the situation in Iraq, Afghanistan and Palestine, the abuse and killing of Muslim prisoners by US and UK troops, and the London bombings all contribute to heightened tension and misunderstandings between Muslim and other people. Global and local events have created a sense of injustice and feelings of anger and hurt across communities in Bradford and across the UK.

African and African Caribbean communities in Bradford

There are many smaller Black groups in Bradford from different Caribbean islands and African countries. They speak many different languages and enjoy different cultures and faiths.

Some African people came to work here many years ago but most came more recently as refugees, severely traumatised at home by conflict and then in the UK by Home Office procedures and the inhospitable environment. Most are dispersed across Bradford.

There are a number of self-help and networking initiatives, for instance amongst French speaking African refugees, and an African network (A-Net), both heavily reliant on voluntary support.

African Caribbean community groups are larger and more established with a history of employment in Bradford's textile industry and public services. They enjoy more community resources and funded networks. On the whole, these are organised independently of the African groups, which have distinctly different cultures and traditions. African Caribbean people have thriving businesses, many providing for their own cultural needs, and a small but vocal population.

Many African and African Caribbean groups enjoy strong church groups which provide community support such as youth work, care services and social activities. These are often but not always a valued source of support for people with mental health problems. African groups, it is sometimes said, have fewer resources or less power than African Caribbeans, and both complain of poor funding in comparison to South Asian communities, suggesting they perceive a 'hierarchy of oppression' which leaves local people divided (Baksi *et al.*, 1995).

“ The same sort of treatment that we suffer as a result of being cast under this BME cloak, I think the African communities suffer that under the African Caribbean community. Everyone just bundles us together but there are diverse needs within both communities. ”

(African Caribbean Project Manager, Bradford)

The local response

The local picture would be incomplete if it did not mention some of the many efforts being made to address local tensions. The city council had a strong history of community development until financial cuts in 2005. Bradford Vision, as the Local Strategic Partnership, and Bradford Council have four streams of work which focus on equity, participation, community relations and safety, benefiting from regeneration funding to fulfil a '2020 Vision' Delivery Plan for the city. This is a collaborative action plan between the statutory and voluntary sectors in Bradford to encourage people to respect and celebrate differences in sex, race, culture and religion. Many large and small initiatives receive funding and support.

Bradford University has a number of initiatives within the Department of Peace Studies. This has a commitment to working with disenfranchised groups, particularly those involved in the 2001 riots, to ensure underlying tensions are eased by greater social justice in the city. Voluntary efforts within Muslim and other faith communities are also significant.

2

Diverse communities and new thinking in mental health

KEY POINTS:

- ❖ BME service users and carers fear mental health services and fear mental distress: they find services are oppressive and fail to understand or meet their needs.
- ❖ A critical perspective in mental health asks professionals to explore the way service users from non-Western cultures think about the world and the tensions in their life.
- ❖ There is more recognition of the expertise gained by using mental health services.
- ❖ The importance of alternative ways of helping people, including employment, is gaining recognition.

Fear of mental health services and mental ill-health

Mental health services in the UK have been consistently and persistently reminded that their care of people from BME groups ranges from inadequate to seriously neglectful (Walls & Sashidharan, 2003). Improvements are needed for all who experience mental health problems, but the experiences of people from BME groups are harsher and qualitatively different from their fellow service users, on account of their community histories and their current situation within the UK (SCMH, 2002).

The circles of fear which trap both mental health professionals and BME service users in a spiral of physical restraint, degradation, excessive medication and inadequate aftercare are well-documented and difficult to break (SCMH, 2002). The system which is meant to help is perceived to be alienating, replicating the racism and discrimination experienced within the wider society.

Consequently, access to services is often a last resort, in a time of crisis, leaving little scope for negotiation about treatment. Both staff and BME service users fear and anticipate violence, particularly for the disproportionate numbers of Black men who come onto the wards via the police, the courts or detained under the Mental Health Act. Greater language resources are needed for people whose language skills fade in a crisis (Walls & Sashidharan, 2003).

Many people from BME groups not only fear mental health services, they also lack information about the nature of mental health problems which are deeply stigmatising in their communities. People are afraid to acknowledge problems lest it results in ostracism within their support networks. These fears can leave individuals and their carers afraid to ask for help and knowing little about what options are available (SCMH, 2002).

The individual is not understood and the treatment is not valued

Those who do access mental health services often feel unsafe, and are reluctant to speak openly. Professionals, working under pressure, have little scope to identify underlying problems and often rely heavily on medication. High levels of medication are feared and resented, both for the immediate impact of ‘zombie’ behaviour and for the long-term side effects (Mind, 2001).

“ *Lost in the wilderness,
All hope is gone,
Voices lingering and pushing me down,
Pumped with medication,
Stripped of my identity,
Zombified to the eyeball, I don’t know me.
I daren’t mention the thoughts that run through my head,
In case they take me and I end up dead.* ”

(Sarwar, 2005a)

Challenging decisions of diagnosis or treatment is extremely difficult. BME medical staff may adopt the establishment view for their own survival, and feel torn by their inability to support individuals who disagree with their (Western) treatment (SCMH, 2002). BME staff and service users alike can feel undermined and treated with disrespect in an environment perceived as oppressive (Walls & Sashidharan, 2003).

Assumptions based on stereotypical views of ethnicity, gender and faith prevail widely inside (as outside) mental health services. Staff may make assumptions about South Asian family networks and treatment of women without exploring the individual differences described in Chapter 1. Family, culture and faith may be perceived by the service user as the primary source of strength, but many BME service users report their views on family involvement are not sought or respected (SCMH, 2002; Yasmeen, 2002).

A sensitivity to diet, language, prayer and clothing are important improvements to the experience on the wards, but for many they are not available. While these are important changes, it is not always recognised that culturally sensitive services involve much more than this.

“ *You’ve got halal meat, you get the spiritual stuff but the more meaningful or deeper stuff is not there.* ”

(Pakistani Community Worker, Bradford)

The ‘deeper stuff’ which service users seek is a response appropriate to their cultural and spiritual perspective and their understanding of the world around them (Fernando, 2003; Bracken & Thomas, 2001). Research into the experiences of African Caribbean service users finds that staff were not able to incorporate other belief systems and explanatory models into their view of understanding mental health in Black communities (SCMH, 2002). Service users from South Asian countries experience exactly the same issues:

“ *They keep telling me to ‘play the game’
To put aside the essence of me,
My faith, beliefs, principles and values, whatever that means to me.* ”

(Sarwar, 2005a)

As services fail to engage with service users in their understanding of their own distress, the treatment they provide is not valued, causing low levels of compliance in aftercare and a greater likelihood of further problems. To avoid this, BME service users want staff to build a relationship of trust and work with them to find out what they perceive to be the problem (Secker & Harding, 2002).

“ Find the root cause, don’t just medicate. ”

(Footprints UK, 2003)

The way people from BME groups describe their problems is often associated with daily pressures in their life, including family tensions, spiritual conflict, unemployment, racism, housing, poverty and loneliness. Young people can be under pressure from an early age. Many people from different parts of the world feel that ‘possession’ by evil spirits plays a major role (Bibi, 2002). They may seek help from spiritual healers and other alternatives, with variable success.

People want change within mainstream services and alternative options to be available to them. However, they lack influence to bring these about.

A critical perspective within mental health services

Despite lack of progress in addressing these concerns in a systemic way across the NHS, for many years there have been people within psychiatry who have questioned the relevance of the established way of working for those from non-Western cultures. Many members of the Royal College of Psychiatrists (RCP) give their support to movements which promote new ways of thinking. The RCP and National Institute for Mental Health in England (NIMHE) support debate and initiatives on the role of spirituality in the interpretation of mental health crises and as an aid to recovery from mental health problems. It is worth noting that at its AGM in 2005, the RCP had a ‘critical psychiatry’ day which ended with a seminar on values.

Critical psychiatry is a response to the feelings of fear and poor understanding described earlier in this chapter. It reminds mental health services that their established perspective is derived from a Western – and colonial – history. The impact of colonialism continues to be reflected in our public institutions today, and the NHS is no exception (Fernando, 1988). Services are dominated by the white male middle class and the way they understand the world. Bracken (2001) notes that this understanding underpins psychiatry with a Western ‘world view’ or belief system which is not, contrary to popular opinion, neutral or disinterested. Moreover, the shape of psychiatry is protected by its powerful professional base, its own professional discourse and a billion dollar pharmaceutical industry.

“ The problem is that the world and its problems are being gazed upon through the spectacles of Western psychiatric concepts and theories. There is much room for understanding the phenomenon from different perspectives. ”

(Bracken, 2001)

Critical thinkers note that a central feature of the Western perspective is the value it attaches to materialism over the spiritual, the individual over the community, and the rational over the seemingly irrational. This has resulted in splits, or divisions, between mind and body, and between the individual and society which are not always present in other cultures.

The focus on the individual and the rationality of modern science leads Western psychiatric discourse to emphasise biological disturbance, illness and chemical remedies. This can pose serious difficulties for many individuals from non-Western cultures who value spiritual understandings of distress and

who may not separate their needs and interests from those of their family. Western therapies can be regarded as unhelpful, however sensitively applied.

Valuing the service user perspective

In their efforts to improve mainstream provision, critical psychiatrists encourage the mental health professional to understand and respect individual perspectives including differences resulting from gender, age, family history, chosen allegiances and individual experiences. This approach, argue Bracken and Thomas, may require professionals to think ‘outside the box’ of their own professional discourse to explore what is important to the individual service user in his or her context:

“It requires an ability to set aside models, diagnostic categories and therapeutic techniques, and a concerted effort to get alongside individual service users and groups in their attempts to define their struggles in a different idiom. In fact, it requires the ability to engage critically with one’s own professional background.”

(Bracken & Thomas, 2004)

There is a need to acknowledge that there are two experts involved: the mental health professional and, equally important, the person with the mental health problem. Problems and solutions need to be explored together, so the professional works alongside the service user rather than as the dominant expert. This approach has widespread support far beyond critical psychiatry (Perkins & Repper, 2003), but it is not easy for staff to implement with current structures and staffing levels. It is even more difficult when staff work with people from non-Western cultures whose understanding of the world around them is different from their own.

Recognition for the expertise of service users is demonstrated by the increasing numbers employed within the NHS workforce, the increasing partnerships between services and service user groups and greater credibility for peer support groups (discussed in Chapter 14).

Valuing social, economic and spiritual approaches

Service user researchers and others have shown that non-medical interventions such as physical activity, spiritual nourishment, creative arts and voluntary work contribute significantly to recovery from mental ill-health and many people from all ethnic groups prefer these to medication (Faulkner & Layzell, 2000). Many areas offer these types of opportunity within the statutory and voluntary sector. It appears that people from BME groups have benefited less from these changes than the wider population. Few participate within the service user movement (Wallcraft *et al.*, 2003) and many do not wish to identify themselves as mental health service users. Many are reluctant to access voluntary projects publicly identified as being for people with mental health problems, and so lack access to the alternative options they provide such as sport, leisure, volunteering and work opportunities.

Mental health policies now emphasise the importance of enabling service users to make friends, take part in ordinary social activities and get work (see Chapter 5). Service users from BME groups face additional barriers in this journey, as those charged to help them (mental health and employment staff) often share society’s low expectations of their ethnicity, gender or class. Yet their employment aspirations persist and can be realised given the right support (Rinaldi & Perkins, 2005).

Recognising inequalities

An inequality perspective helps to explain pressures caused by low expectations, discrimination and other oppressive experiences that have an impact on individuals (Williams & Keating, 2005). Many interpret oppression and inequity on one dimension, for instance about gender, ethnicity or disability, but in fact the power structures and arguments used to discriminate in these different ways are similar. The relationship between certain inequalities and mental ill-health is well-evidenced, for instance in the association between racism and ill-health (Chakraborty *et al.*, 2002) and the inequality perspective has gained credence, particularly within health promotion (see Chapter 5). The causal connection can work both ways: oppressive experiences can lead to mental health problems, and use of mental health services can lead to a position of oppression and inequity

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Developing communities to create the changes they want

KEY POINTS:

- ❖ Where 'experts by experience' take a lead role in community development, changes are greater than when activities only involve those who purport to speak for them.
- ❖ It can be an empowering approach which gives experts by experience the opportunity to set the agenda and shape new solutions.
- ❖ This taps into the expertise and strength within BME communities.
- ❖ There are benefits for the individuals involved (social inclusion and increased job opportunities) as well as for the communities concerned.

Community development has a role for people at the grassroots

Throughout its history, community development has shifted from taking a broad approach whereby ordinary people are enabled to create the changes they want, to a narrower, more functional approach focused on implementing specific policy objectives. Its professional bodies state that sustainable and fundamental change can only come about through the active involvement of ordinary people. People from the statutory and voluntary sector interviewed for this study argued for the active involvement of people with direct experience of distress.

The description of Sharing Voices shows how participants take part in many activities including leading groups, speaking to local and national media, speaking to mental health managers locally, regionally and nationally, and training. Interviewees for this study noted how the project gave people of different age, ethnicity and gender the confidence to speak openly about their problems and to describe why the support they received from Sharing Voices worked for them.

In contrast, charismatic and vocal spokespeople (from local organisations, faith groups or councillors) may not have a good understanding of the needs of the most marginalised groups in their midst.

This is not to deny there is a role for people with influence within certain community groups and an understanding of the issues concerned. It is a political skill required of community development workers that they can identify who they need to reach, for what purpose and how to best reach them. It is suggested here that in addition to working with 'leaders with influence', there is a need to give a central role to local people and experts by experience if the purpose is community development.

Community development and community engagement

Community development needs to be distinguished from community engagement. Community development suggests local people are able to identify the problems that need to be addressed and can help to shape the solutions: their agenda is given priority or at least some credence by public authorities. The process of community development is an empowering one, and it brings about some shifting of power and resources.

Community engagement, on the other hand, is a term that can be used to refer to a more reactive process, including user involvement, consultation exercises and service improvement with the agenda largely determined by statutory authorities. Community engagement suggests little exchange of power or influence, and remains at a low level in the ‘ladder of participation’ (see Figure 1 in Chapter 4). Arguably, community engagement is dependent for its effectiveness on there being long-term community development work.

This chapter is about mechanisms and benefits associated with community development.

Community development can be an empowering process

When marginalised individuals, and especially people with mental health problems, take a lead role in identifying and resolving their problems, the impact can be significant. There is an increase in the confidence, skills and assertiveness of those who get involved, and, when the process is successful, a reduction in the oppressive practices of the other party (Henderson & Thomas, 2002).

In the mental health field there is much glib talk of empowerment, but the many definitions of what this process really involves are summarised as follows:

- ❖ Development of new skills and competencies.
- ❖ Increased feelings of control in daily life.
- ❖ Informed choices from a range of options and access to information.
- ❖ Recognition of self-worth and self-esteem.
- ❖ Meaningful participation in decision making.
- ❖ Effecting change within institutions and social groups.
- ❖ Ability to self advocate.
- ❖ A process of growth and change.

(Hitch, 2005)

The involvement of participants at Sharing Voices in the peer groups and community development activities was shown, in Part 2 of this book, to bring about all these features of empowerment. Benefits for the individual included greater opportunities for social inclusion and employment and thereby a reduction in the risk of suicide (*National Standards, Local Action*, DH, 2004c; SEU, 2004). These individual gains are a by-product of the community development process, but are nonetheless important for PCTs who have a concern to improve the experience of individuals as much as community groups as a whole.

It taps into community strengths and expertise

The experience of Sharing Voices and other BME projects has been that many local people are well aware of what will help to reduce the incidence of mental distress in their community and what can help to alleviate it. Often, informal networks are already in place, as mentioned earlier. A lack of resources and recognition of these community strengths prevent local people from organising substantial support services based on their own expertise.

Community development workers can build capacity amongst local people so they gain the resources and infrastructure they need. At the same time, workers can develop the readiness of statutory services to tap into this very different expertise. By acknowledging the value of local expertise and showing a genuine commitment to increasing the power of local people to shape and manage their own solutions, community development workers may escape some of the cynicism caused by many consultation exercises which result in little change.

Choosing the language to engage local people

The importance of language cannot be over-stated. Instead of using the professional discourse of mental health, staff at Sharing Voices framed mental distress in terms of pressures and tensions caused by racism, spiritual conflict, unemployment, family relationships and other ordinary problems in daily life (as described in Chapter 6 p44). During the research programme it was observed that new participants found immense relief in being able to talk about their problems in these terms. It made sense, whereas professional discourse could be confusing and frightening.

Staff reported that people at local events responded to this language, linking it with their own problems, pressures and poor health. Local people, such as the Bangladeshi young men in the Health seminars (described in Chapter 9) proposed solutions when the language framed their problems in non-medical terms they understood. Their solutions – spiritual help and employment support – were equally non-medical. Research evidence shows both of these are effective ways of reducing distress, but it is difficult to get funding for them. Few PCTs fund spiritual or employment services that can be accessed by disengaged young BME men in difficulties, although a number of policies (such as *Choosing Health*, DH, 2004d) might suggest they should be funded.

If local people are not invited to identify and create their own, new solutions, professionals and those who speak for the community may propose resources that are more readily available ‘off the shelf’ such as leaflets or awareness training. The time has come for new ways of working that will make a difference.

Using direct experience to change public attitudes

The fear and stigma associated with mental ill-health has been associated with avoidance of services and a failure to get help, especially so in BME groups. Community development is charged with facilitating earlier access to services. By harnessing the talents of participants to speak in public presentations or sing at events, using a language and framework that local people could immediately identify with, Sharing Voices made a visible impact on local people. During this study, people have been observed in tears after volunteers’ singing and personal testimonies at a local event. Volunteers are encouraged to take part in radio shows and talks with the media. If the project had the resources, they could broadcast further through a website and regular bulletins.

Open dialogue amongst local people increases the likelihood they will acknowledge their problems and find out about sources of help. They are more likely to find out about spiritual healing that has been valued by others, and less likely to resort to harmful so-called ‘healers’ that are able to operate in a secretive environment.

Dialogue within the networks described in Chapter 13 can lead to new kinds of initiatives based outside mental health services, widening the choices available (for instance, a Tai Chi option is under development arising from a contact made at a Mutual Interest Group meeting). This dialogue, exchange of information and increased choice helps ordinary people to come to terms with mental distress more readily and to seek help at an early stage.

Using direct experience to improve the NHS workforce

One of the functions of community development can be to support the NHS workforce to improve their understanding of BME groups. Training and presentations by passionate and articulate service users is known to be more effective than community development workers or community spokespeople speaking about the needs of local people (NIMHE, 2004a).

BME service users and people with a critical perspective encourage mental health professionals to recognise the existence and importance of alternative understandings of the world around them. These are difficult notions to grasp, especially for mental health staff whose training establishes a strong professional culture. Arguably the most effective way of helping people understand and accept the validity of alternative ways of understanding the world is through personal narrative. Personal stories of recovery have already helped many mental health professionals grasp the importance of work, friendship, a home and a decent income.

The aftermath of the London bombings in July 2005 may lead to a greater external conformity by Muslims at school or at work, but no legislation can impose a Western world view in their hearts and minds. If mental health professionals are to improve the well-being of Muslims and many other people from BME groups, they will have to take account of the way they view the world around them. They can only do this by taking an individual approach. Cultural awareness training may bring about stereotyped images if it fails to awaken staff to the deep complexities within every community group and even within each one of us, whereas a few people with direct experience of distress, explaining their tensions, problems and coping strategies can help give some insight into the complexity of cultural and personal identity.

Using direct experience to improve the design and planning of services

Community development workers have a role in increasing the level of public participation in service planning. If they have credibility within local communities they will be able to increase participation in consultation exercises, offering a useful exchange of information but no shifting of power (see the ladder of participation, Figure 1 in Chapter 4).

The ‘Why Bother?’ Participation seminars at Sharing Voices (described in Chapter 9) explored ways of doing more than this, by bringing about a two-way dialogue between managers and BME service users and carers. Feedback suggested this was not an easy challenge to meet, but also suggested there was

a commitment to progressing down this route. Where the hearts and minds of managers are engaged, and they receive support in the process, it is more likely that they will make the effort to bring about the changes local people want. The direct contact between service users and managers gives the dialogue a power and influence it would otherwise lack.

Changing hearts and minds is an important first step

The argument presented here is that a strong voice from the grassroots has more chance of creating change, in people's hearts and minds and in their behaviour, than any amount of education or negotiation. Changes may include a reduction in stigma, more open dialogue about distress, more information about sources of help, earlier access to services and a more appropriate response to BME mental health needs amongst mental health service staff and their managers. However, there are challenges.

Box 11: Challenges in engaging the grassroots in the change process

- ❖ **The time factor:** It takes time to build up the skills and confidence in service users and to create opportunities for dialogue.
- ❖ **Outcomes and outputs:** There may be no identifiable outcomes within a timescale of two or three years. There may be specific outputs, such as events and training sessions, but the involvement of ordinary people needs to be built up on a day to day basis outside these specific activities.
- ❖ **Confusion with provision of a service:** Community involvement was sometimes confused with providing a kind of 'service' although the staff-participant relationship emphasised the ethos of mutual aid. As the 'grassroots' comprised vulnerable people, staff needed to maintain standards of accountability, ensure protection from harm and have a good understanding of mental health issues. There was often close liaison with front line mental health professionals. These factors increased the risk of the work being perceived as a service rather than community development. There may be pressure to maintain targets (numbers of people receiving support), even when funding is for community development.
- ❖ **Service users move on:** Within BME groups anecdotal reports suggest there are high levels of motivation to pursue training and work. New people need to be engaged in the community development process as others are supported to move on. Effective support is needed to ensure this throughput can take place. This might be facilitated by placing community development workers within BME led community projects which do provide a service.
- ❖ **Resources are limited:** Only a certain number of participants could be supported and involved in community development activities at Sharing Voices at any one time.
- ❖ **Commitment from local statutory services:** Short-term funding based around specific community development functions and outputs, with isolated workers and limited infrastructure cannot support this process.