



DRE West Sussex Black and Ethnic Minorities CDW Service **May 2008-April 2011**

Final Report

Access Facilitator:

Identify the different ethnic groups within West Sussex, their structure, leadership and experiences using both statistical data and information gathered during the duration of the contract.

Gypsies and Travellers are the UK's oldest and one of our largest ethnic minority groups, around the same size as Chinese and Bangladeshi communities. With an estimated 1 in 200 people a Gypsy or Traveller in the UK Gypsies and Travellers are the largest ethnic minority group in rural West Sussex.

Appendix 1

The Office for National Statistics

The latest Office for Public Management report on health and social care needs in West Sussex estimates that there are approximately between 3,000 and 3,500 Gypsies and Travellers living in West Sussex, two thirds (approx. 2,000-2,500) of which are housed (OPM 2010).

The FFT CDWs are located within the FFT outreach support team and the majority of the information, data, case studies and anecdotal evidence is gathered from work carried out by CDWs and support staff with clients across Sussex. The outreach team has been running a support service across Sussex since 2003 and supports an average of 500 clients annually. The team continually carries out comprehensive mapping of communities ensuring they are able to support all Gypsies and Travellers throughout Sussex whether they are housed, living on unofficial encampments or on local authority sites. The CDWs were well placed with the FFT outreach team as they had immediate access to and information on approximately 500 clients, including families, children and young people, when the service began in May 2008.

It is difficult to ascribe any formal structure or leadership to the Gypsy and Traveller community, but our work suggests that women are most commonly at the centre of the community and make most family-related health and social care decisions.

Appendix 2

Summary of Awareness Training.

Provide clarification of how the different BME groups view Mental Health and provide snapshots of the experience of the individual groups in relation to accessing of Mental Health Services.

Within Gypsy Traveller communities there are high levels of stigma and fear around mental health. Mental health is commonly viewed in terms of psychosis by Gypsies and Travellers, whereas stress, anxiety and depression are generally seen as having 'bad nerves', part of every day life and something people have to 'learn to live with'.

Many Gypsies and Travellers are also afraid that if they disclose having mental health problems social services will get involved and their children will be taken away. There is a reluctance to contact outside agencies for help given negative past experiences with government authorities. Stoicism and self-reliance are also valued within the community, born out of living within, or on the fringes of, a hostile society.

Identify the barriers for the BME communities to access and make recommendations to identify any areas where there is potential for further development work to be done.

The report "*Fair Access for all? Gypsies and Travellers in Sussex, GP Surgeries and Barriers to Primary Healthcare*" was devised in response to 5 complaints made to FFT's Outreach team about the discrimination some Travellers faced when attempting to register with GP Surgeries. This included being refused registration for having no proof of address, for having a common Irish Traveller name and for living on a Local Authority Traveller site. The report argued that a number of GP Surgeries across Sussex did not adhere to the 2010 NHS Constitution by 'refusing access on unreasonable grounds' and through 'unlawful discrimination...on the grounds of race' (NHS Constitution Handbook 2010).

Through the examination of social and cultural barriers to Gypsies and Travellers accessing healthcare and use of case studies the report also argued that the majority of GP Surgeries throughout Sussex have little or no understanding of the complex needs and experiences of Gypsies and Travellers. Our recommendations are contained within this report.

Appendix 3

Fair Access for all? Gypsies and Travellers in Sussex, GP Surgeries and Barriers to Primary Healthcare

Further work that needs to be done

- More outreach of mental health services to Gypsy and Traveller communities, particularly to those living on both official and unofficial sites

- More information needs to be made available to the community so that misunderstandings about mental health problems are picked up and available treatments are promoted
- Service providers need to work in partnership with specialist organisations, such as FFT, who have a relationship of trust with clients from Gypsy and Traveller communities.

What is the current situation when the contract comes to an end?

When the CDW contract comes to an end there will no longer be staff influencing mental health service provision at a strategic level, which will result in chronically excluded groups such as Gypsies and Travellers continuing to be excluded from many primary health care services and the majority of secondary care health services.

Has there been any increase in access?

As the CDWs do not carry out casework it is very difficult to determine whether there has been an increase in access to services. However, it is clear that there has been an improvement in Gypsies and Travellers knowledge of mental health service provision and progress has been made in terms of de-stigmatising mental health within the communities. The work we have carried out with mental health service providers such as community mental health teams has also broken down barriers between service providers and Gypsies and Travellers as front line staff have had developed an awareness of Gypsy and Traveller communities and thus are better placed to support clients appropriately.

Identified barriers?

Barriers:

- Through our work with the outreach team at FFT it has become clear that even when a person does access a mental health service, often the service itself is very poorly equipped to support people's individual needs. We have focused a lot of work on building capacity within statutory mental health services to work with Gypsies and Travellers, but there is still a long way to go in this domain.
- Cultural stigma attached to mental health and fear of using mental health services.
- Dispersed community that is geographically disparate and often highly mobile makes it difficult to organise and attend focus groups and generally participate in capacity building.
- Gypsies and Travellers with no fixed abode have the most difficulty registering with a GP and thus will find it almost impossible to obtain referrals and secondary care.

Recommendations in relation to overcoming barriers?

- Assertive outreach that is culturally capable and responds to the unique needs of Gypsies and Travellers.

- Ethnic monitoring of Gypsies and Travellers in order to identify needs and for inclusion.
- Health and other support providers to receive cultural awareness training and support from specialist organisations.
- Health focus groups that work in partnership with WS LINKs (Healthwatch) and feed into GP Consortiums.
- Information and advice on services that takes into account low literacy levels and cultural constraints including gender divides.
- Ensure that Gypsies and Travellers are represented in any consultations , so that they are involved in designing local services

Capacity Builder:

Discuss what our understanding is of the different communities and how we interacted with them during the course of the contract?

Both CDWs working with FFT employed volunteers to work with them on the RECC training, cultural awareness training, running stalls at Wellbeing events, working as speakers for events and as members on steering groups. Volunteers have brought a unique perspective to our cultural awareness trainings as participants have been able to engage directly with individuals from communities and this has gone some way to addressing myths and prejudices towards Gypsies and Travellers.

We interacted with the community through the FFT outreach team. We regularly shadowed members of the team which enabled us to build up an accurate picture of the issues that the community faced. We co-ran our cultural awareness trainings with members of the community and we also worked together on ad hoc events and conferences.

Appendix 4

Breakdown of ethnic groups FFT currently work with

Identify the capacity within the BME Communities; explain the process of capacity building, how we have developed and enhanced capacity within the BME Community.

Gypsies and Travellers experience the highest levels of prejudice than any other minority group in the UK (Mori 2003). The prejudice and negative experiences Gypsies and Travellers have endured from statutory services, the media and local communities has meant that it can take many years for services to develop trust and build relationships. During the service FFT CDWs worked with established FFT volunteers to develop information flyers and booklets and consult on research reports. Gypsies and Travellers make up 40% of the FFT staff team and form a majority of the FFT Trustee board and thus Gypsies and Travellers are involved in decision making at many different levels within the organisation.

The flyer, *Know Your Rights and Responsibilities within the NHS: An overview of the NHS Constitution Handbook 2010* aimed at clients, was developed in response to the high

numbers of complaints received through the FFT Outreach Service from Gypsies and Travellers regarding GP Surgery staff unlawfully denying Gypsies and Travellers access to primary healthcare by refusing registration because of a person's name, not having proof of address and by living on local authority Traveller sites.

Appendix 5

Know Your Rights and Responsibilities within the NHS Constitution Handbook 2010 - flyer

Make recommendations re how the available capacity can be maintained without the BME service and how it can potentially be used for future developments/tender process

It will be very hard to maintain the level of service that was provided by the BME CDWS, for a number of reasons. We already know that many BME groups are marginalised in relation to health equity, but there are some groups of people, including Gypsies and Travellers who experience a Chronic Exclusion whereby they are falling even further behind, despite the equalities work. At FFT we believe that this is because many of the existing programmes of support in dealing with equal access to health care have focused on those people who may already have a foot on the ladder. This leaves some people struggling to even get started. It is easier to target those people who are more likely to engage than those who require assertive outreach and community development in order to engage, but without this the equalities gap will widen.

Gypsies and Travellers experience a life expectancy up to 25 years less than their settled neighbours. Infant mortality is three times higher. Mothers are 20 x more likely to experience the death of a child before they reach maturity than the general population. There is some evidence that diseases of poverty and deprivation are more common within the Travelling Community, such as diabetes and coronary heart disease. There is also increasing evidence regarding mental health problems, with high reports of anxiety and depression amongst Travellers and many Travellers dealing with issues of loss and bereavement. There are high suicide rates among the communities and increasing substance misuse. Educational achievements are poor and declining still further, participation in secondary education is low. Racism towards Gypsies and Travellers is still common, frequently overt and seen as justified – trust and confidence in criminal justice and other statutory agencies to protect their concerns and interests is low. The recent Health Needs Assessment of Gypsies and Travellers in West Sussex already indicates that there are particular issues around mental health. The EHRC point out that it is also important to remember that potential impact is not just about numbers. Evidence of a serious impact that may affect a small number of individuals is just as important as a potential impact affecting many people. At FFT we believe that it is imperative that the existing work is enabled to continue. The following points have been identified as being opportunities for development, however, they would still require support and input.

- Volunteers.
- Health Trainers.
- Health Focus Group (managed by outreach staff?).

Identify any areas where there is potential for further development work to be done

- Health trainers.
- Develop health and cultural awareness training toolkits for service providers on new FFT website.
- Further research and development on health inequalities of Gypsies and Travellers and how these inequalities are shaped by chronic exclusion.
- Health focus group in partnership with WS LINKs
- Evidence based project evaluation of current FFT projects and impact these have on health of Gypsies and Travellers – measuring empowerment; case studies and ‘soft outcomes’.

Service Developer:

Provide a breakdown of training provided and statistical information in relation to how useful it has been.

Presentations/Awareness Trainings:

- All West Sussex CMHTs/CAMHs
- All West Sussex Accident and Emergency Teams
- West Sussex IAPT Teams/Assertive Outreach
- West Sussex Approved Mental Health Professionals
- Mind Advocacy/ Action in Rural Sussex/ MS Society
- South East CDW Network
- Arun Community Cohesion Group/Arun & Chichester LSP
- West Sussex Mental Health Development Board
- Lemos Crane Gypsy and Traveller Communities: Effective service models in housing, health, education, and policing National Conference
- SPT Trustee Board/ BME Network/Race Equality Reference Group
- Sussex Probation/Sussex Prisons

Workshops/seminars

- Arun and Chichester Local Strategic Partnership AGM Chichester
- ACERT (Association for the Education of Romany and Other Travellers)

Stalls/events

- National Mental Health Development Unit AGM Westminster
- Arun and Chichester Local Strategic Partnership AGM Chichester
- Horsham District Council Local Strategic Partnership Event
- International Women’s Day Event Crawley
- Brighton MIND ‘Bewell’ Event
- DRE Conference
- Billingshurst Community Event
- "New Horizon" Arun Mental Wellbeing and Health Conference

Appendix 6
Summary of Awareness Training

Make recommendations regarding future developmental and training needs.

Awareness training to be rolled out to housing providers, local authorities, mental health charities, children's and families services.

Make recommendation re: how the capacity developed could be used re future training, tendering processes and development of services.

- Use of volunteers in presentations to potential funders.
- Use of case studies and success stories, i.e. from service user to volunteer to paid member of staff.
- Consultation with service users and volunteers on all FFT publications.

Identify any areas where there is potential for further development work to be done.

- Develop easy read information on mental health service provision – work in partnership with health providers.
- Develop health focus group – work in partnership with WS LINKs.
- Gypsies and Travellers becoming members of LINKs or other participative forums.

Change Agent:

The report will identify community concerns, gaps in services, what work has been done to address those issues and recommendations for future action.

Cultural awareness training, workshops and presentations targeted health providers and front line workers in response to a widespread lack of knowledge of Gypsy and Traveller communities throughout Sussex.

Gypsy and Traveller communities were largely unaware of mental health service provision in their area and thus CDWs have worked with the FFT outreach team to raise awareness of service provision through weekly outreach meetings, monthly staff team meetings and joint project work including client wellbeing groups and events and client information on health provision and healthy living.

CDWs have also worked with the outreach team and community volunteers to develop food and mood booklets, wellbeing CDs and wellbeing information flyers and a Know your rights and responsibilities within the NHS flyer. All of which have improved knowledge of and access to health services in Sussex and given Gypsies and Travellers the information needed to take more control of their health and wellbeing.

Make recommendations re increasing communication between communities and statutory services.

- Develop a health focus group that can work in partnership with WS LINKs.
- Involve FFT and other specialist organisations in the strategic decision making of healthcare service provision.
- Work closely with FFT and other specialist organisations in developing outreach services for 'hard to reach groups', particularly those who experience chronic exclusion.

Discuss change agents /resources available within the community and make recommendations in relation to future tendering processes/ changes to services provided.

Food and Mood Booklet

The Food and Mood booklet was originally conceived because it became apparent to the Wellbeing team that many clients FFT supports did not know about the links between nutrition and mental health, or were misinformed. We knew that often simple changes in a person's diet can significantly impact on their mood. So, through close consultation with the outreach team, we created an easy to use, practical and culturally minded booklet with guidelines and recipe ideas for the Gypsy and Traveller community. These have been a great success, with hundreds of copies distributed throughout the county and a number sent out to other Gypsy and Traveller organisations throughout the UK.

Wellbeing Leaflets

The Wellbeing team also recognised that there was a dearth of culturally appropriate written material for Travellers on mental health and Wellbeing. Much of what is available contains a lot of jargon or is not in places where many Travellers go. Therefore, again with close consultation with our outreach team and Gypsies and Travellers, we created a series of leaflets on what were considered the most common mental health issues within the community. The emphasis was on making the information clear, simple and relevant. Once finalised, these leaflets shall be available to all FFT clients.

Wellbeing CD

This CD was developed after it became apparent that many Gypsies and Travellers were not able to make full use of written material on mental health and Wellbeing, because of low levels of literacy. Furthermore, although some audio materials are available on mental health, they are often not in plain English or language that is culturally accessible for many Travellers.

Therefore, the FFT Wellbeing team secured funding from the Mid Sussex Health Partnership team to create CDs on mental health, which would feature a series of informal conversations between Travellers and Mental Health practitioners. We recorded these and

the “interviews” are currently being edited by a producer from the BBC, and will soon be available to the community in a CD format.

Know your rights and responsibilities with the NHS service user flyer

Over 200 flyers have already been distributed to service users throughout Sussex with further copies printed out monthly. See above for more information on the flyer.

Appendix 7

Food and Mood booklet

Identify any areas where there is potential for further development work to be done.

Conclusion:

What impact has the service made?

Gypsy and Traveller communities know more about what services are available to them in terms of mental health in their locality. We have achieved this by working closely with the FFT outreach team, sharing information of service provision, of changes in service development, and referral pathways. Gypsies and Travellers also know more about services available as we have developed information and advice in a format which takes into account cultural needs and low literacy levels.

We have also trained all the statutory mental health service providers, including frontline staff, in West Sussex on how to best engage and work with Gypsies and Travellers. We are on the West Sussex PCT Mental Health Development Board and Sussex Partnership Trust Race Equality Reference Group, both of which are strategic planners of mental health services in West Sussex. Our involvement has shaped policy and service development in West Sussex, particularly in terms of providing awareness training for frontline staff and Trustees alike.

We worked closely with the Pacesetters programme to develop GP cultural awareness training for all GPs throughout East Sussex and through this involvement the FFT outreach team became distributors of the Hand Held Health Records for clients throughout Sussex.

What is the current capacity within the BME Community? How can it be used in the future?

See above

What will be the impact on the services and communities in relation to the closure of the Service?

There will be no-one representing Gypsies and Travellers at the strategic level in West Sussex or highlighting the serious and specific inequalities that Gypsies and Travellers face in accessing mental health services. Gypsies and Travellers face higher levels of social

exclusion than any other BME groups in the UK (The Health Status of Gypsies and Travellers G Parry et al. 2007) are unique in their needs as the main issues Gypsies and Travellers face are *access* to health services and not necessarily their experience of them.

Recommendations.

See Appendix 3 'Fair Access for all? Gypsies and Travellers in Sussex, GP Surgeries and Barriers to Primary Healthcare'.

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