

Better
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Briefing

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The health of Gypsies and Travellers in the UK

Zoe Matthews

A Race Equality Foundation
Briefing Paper

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Key messages

- 1 The health status of Gypsies and Travellers is much poorer than that of the general population, even when controlling for confounding factors such as variable socio-economic status and/or ethnicity
- 2 Poor access to, and uptake of, health services is a major factor in Gypsy and Traveller health
- 3 Gypsy and Traveller health receives scant attention in policy documents on health inequalities
- 4 Examples of good practice exist, but these need to be funded and replicated across more localities.

Introduction

The UK's 300,000 Gypsies and Travellers have lived, worked and travelled throughout the UK for over 500 years. Gypsies and Travellers form rich, varied and diverse communities and include:

- Romany Gypsies;
- Roma;
- Scottish Travellers;
- Welsh Travellers (Kale);
- Irish Travellers;
- New Travellers;
- Bargees or Boat Dwellers;
- Showpeople;
- Circus People.

Some members of these diverse groups still live a nomadic existence; others may live on authorised sites or within housing. Scottish and Welsh Travellers are not protected by race equality legislation and would require a test case in order to be identified as ethnic Travellers. New Travellers, Bargees, Showpeople and Circus People are identified as Occupational Travellers.

As with any ethnic group, needs will differ between individuals and between communities. It has not always been possible to reflect these differences within this paper. Little research has been undertaken on the specific health needs of each part of the Travelling community.

The Race Relations (Amendment) Act 2000 places a duty on statutory agencies to carry out equality impact assessments on all their policies. Such assessments have highlighted the lack of health service provision to meet the needs of Gypsies and Travellers, which has resulted in a better provision of services in some areas; for example, making sure general practice boundaries include Gypsy and Traveller sites. However, many primary care trusts (PCTs) are still failing to engage with and provide effective health services to Gypsies and Travellers.

The lack of targeted provision for Gypsies and Travellers is compounded by inadequate ethnic record keeping and monitoring. Romany Gypsies and Irish Travellers are a recognised minority ethnic group under the Race Relations Act 1976, but are still excluded from most monitoring data. This adds to their invisibility in terms of mainstream service use and provision.

Despite pockets of good practice, it is known that many Gypsies and Travellers still find it difficult to access health services (Van Cleemput *et al.*, 2007). Lack of access is not simply an issue pertaining to nomadism: it also applies to sedentary Gypsies and Travellers. It is caused in part by a complex relationship of multiple issues to do with discrimination, marginalisation, lack of trust and low expectations on the part of other agencies.

Both Gypsies and Travellers who are highly mobile and those who are settled experience difficulties, but these vary with accommodation status. Those who are highly mobile due to frequent evictions from sites experience high levels of uncertainty and anxiety caused by displacement and, sometimes, separation from their extended family groups. Settled Travellers can experience high levels of depression linked to loss of their traditional lifestyle (Van Cleemput *et al.*, 2007). Both groups experience discrimination.

Poorer health than other ethnic groups

1

The literature specific to the Gypsy and Traveller population indicates that, as a group, their health overall is poorer than that of the general population and also poorer than that of non-Travellers living in socially deprived areas (Parry *et al.*, 2004; Parry *et al.*, 2007). They have poor health expectations and make limited use of health care provision (Van Cleemput *et al.*, 2007; Parry *et al.*, 2007).

Van Cleemput *et al.* (2007) refer to many Gypsies and Travellers sense of fatalism with regard to treatable health conditions and low expectations of enjoying good health (particularly as they age). They also mention the commonly held belief that professionals are unable to significantly improve patients health status and may in fact diminish resilience by imparting bad

Resources 1

Delivering Race Equality

www.dh.gov.uk/en/Healthcare/NationalServiceFrameworks/Mentalhealth/BMEmentalhealth/index.htm

Delivering Race Equality in Mental Health Care is funded by the Department of Health to help mental health services provide care that fully meets the needs of black and minority ethnic patients and to build stronger links with diverse communities. Community development workers have been appointed across England, including a number who work with Gypsy and Traveller communities.

Derbyshire Gypsy Liaison Group

www.dglg.org

The Derbyshire Gypsy Liaison Group (DGLG) provides valuable assistance and information to the Gypsy community in and around Derbyshire, and has close relationships with local authorities and services to aid managing Gypsy culture with knowledge and respect. DGLG has produced a number of health leaflets, which are ready to print in PDF format.

news, such as a diagnosis of cancer. The impact of such beliefs is a heightened suspicion of health professionals and a reluctance to attend for screening or preventative treatment.

The report by Parry *et al.* (2004), entitled *The Health Status of Gypsies and Travellers in England*, shows that both men and women often experience chronic ill health, frequently suffering from more than one condition; that carers experience a high level of stress; and that secrecy about depression keeps it hidden and increases the burden on both the individual and the family as they try to manage. Many Gypsies and Travellers face high levels of bereavement, which is also a precipitating factor of depression. Poor psychological health is often found in the context of multiple difficulties, such as discrimination, racism and harassment, as well as frequent evictions and the instability caused by this.

Alcohol consumption is often used as a coping strategy, and drug use among Traveller young people is widely reported and feared by Traveller elders. Although some research has been carried out on the extent of substance misuse within Travelling communities in Europe (Council of Europe, 2003), there is little research into this subject in the UK. However, anecdotal evidence suggests that it is on the increase, in line with other communities, particularly where families have been housed on run-down housing estates, or where unemployment and depression are common (see Parry *et al.*, 2004, p. 53).

2 Poor access to and take-up of services

Research on health promotion often mentions the need to provide community services. Treise and Shepherd (2006) identify a number of reasons why Gypsies and Travellers are reluctant to access mainstream services. This reluctance is due in part to practicalities, such as complex procedures for registering and accessing services. Other reasons given include: personal experience, or perhaps a relative's experience, of health care provision (e.g. receptionists acting as gatekeepers to medical care by being hostile; rude treatment from practitioners); low expectations on the part of health professionals; and fear of hostility or prejudice (Henriques, 2001; Honer and Hoppie, 2004).

In common with other black and minority ethnic (BME) groups, cultural beliefs are also cited as reasons for Gypsies and Travellers failing to access services (Treise and Shepherd, 2006; Van Cleemput, 2007; Greenfields, 2008). Such beliefs include considering that health problems (particularly those perceived as shameful, such as poor mental health or substance misuse) should be dealt with by household members or kept within the extended family unit. In a

study of attitudes to care and patterns of attendance among Gypsy and Traveller women, Lehti and Mattson (2001) identified other cultural factors also affecting health-related behaviour, such as strict rules for behaviour that may be linked to communities which are both male and elder dominated. This was often compounded by a lack of cultural awareness and sensitivity on the part of health professionals (Goward *et al.*, 2006). Lawrence (2007) also highlights the problems faced by Gypsies and Travellers in accessing or attending minor injuries units and immunisation programmes.

The now disbanded National Association of Health Workers with Travellers (NAHWT) emphasised the need for culturally sensitive staff to engage meaningfully with Gypsies and Travellers. Despite the greater health requirements of these community members, NAHWT highlighted that there was a lower use of mainstream health services by Gypsies and Travellers. Widespread communication difficulties were encountered between health workers and Gypsies and Travellers (Parry *et al.*, 2004). Other barriers to access were also experienced, including a refusal from some GP practices to register Gypsies and Travellers.

A discussion with a representative from NAHWT concluded that the:

Most common problem for Travellers is difficulty in accessing primary care through GPs because of their insistence in having a permanent address. Those who are mobile have the biggest problem and often end up at emergency services such as walk in centres and A&E where there is no follow up or continuity of care. Some outreach services such as health visitors can go some way to plug the gaps for advice or preventative services e.g. immunisation but cannot offer full services for those who are ill. If Travellers are moved rapidly, it can be difficult even for outreach workers to see Travellers that quickly, and so they are never offered any care.
(Source unknown)

Maternal health and women's health

A number of reports on maternal health refer to Gypsy and Traveller women. For example, the Department of Health report *Why Mothers Die* (2001) highlighted that many women who died had found it difficult to access antenatal services. These women, of whom Gypsy and Traveller women represented a percentage, came, in particular, from the most disadvantaged and vulnerable groups in society. This theme was picked up by the Maternity Alliance in their report *Maternity Services and Travellers* (2006). This report highlighted that women from Gypsy and Traveller communities may not gain full access to maternity services for a variety of reasons, leading to a lack of continuity of care, particularly for those who are highly mobile. Gypsy and Traveller communities were seen as being resistant to services and as poor attendees (Reid, 2005) with obvious implications for relationships between

Resources 2

Equality and Human Rights Commission

www.equalityhumanrights.com

The Equality and Human Rights Commission (EHRC) is working to eliminate discrimination, reduce inequality, protect human rights and build good relations, ensuring that everyone has a fair chance to participate in society. The EHRC brings together the work of the three previous equality commissions and also takes on responsibility for the other aspects of equality: age, sexual orientation and religion or belief, as well as human rights. The EHRC will be publishing a report on Gypsies and Travellers in 2009.

Friends, Families and Travellers

www.gypsy-traveller.org

Friends, Families and Travellers is a national charity concerned about the difficulties faced by the Traveller community in accessing adequate and appropriate health care. It aims to explore a new paradigm of health based on a holistic definition. This concept of health, although not new, has yet to be fully developed, and takes its initiative from the New Public Health Movement, which emphasises the key social determinants of health.

health care staff and service users that go beyond maternity care. Mutual understanding of the constraints faced both by Gypsies and Travellers and by professionals, and greater communication between both parties, is required if hostility is to be avoided.

Interruptions or delays to treatments will occur when Gypsies and Travellers are suddenly forced to move from a site. One pregnant woman stated:

The midwife was due to come back and see me. She was going to bring me milk tokens and some baby clothes ... but the police wouldn't let me wait.
(Maternity Alliance, 2006, page unknown)

Reports have shown that there is generally a poor uptake of preventative health care among Gypsies and Travellers, especially well-woman care and immunisation programmes (Scottish Executive, 2006). Friends, Families and Travellers anecdotal evidence suggests that women are more likely to access these services if supported by outreach workers, some of whom are from Gypsy and Traveller communities (Greenfields, 2008). Greenfields (2008) found that among Gypsy and Traveller women, there is support for offering specialist training in basic midwifery to members of their communities to enable them to support mothers in a culturally appropriate manner while assisting them in accessing appropriate care from qualified midwives.

Men's health

Statistics have shown that 63 per cent of Traveller attendees at a clinic in Ireland were women and that only 37 per cent were men (Clohessy McGinley, 2002). It is likely that the figures are similar in the UK. Men generally find it harder to access health services and it is particularly common for Traveller men to be stoical about their health (see Parry *et al.*, 2004; Van Cleemput *et al.*, 2007). The experience of the Sussex Traveller Health Project is that men are reluctant to come forward to discuss health issues, but may seek information through the services that their partners access. Richard O Neil, a Romany Gypsy, advises on and campaigns for better health service provision to men. O Neil is the founder and former volunteer director of National Men's Health Week, an international event (www.menshealthforum.org.uk).

Mental health

It is possible that the barriers to accessing health services, and the high levels of loss and bereavement (see Parry *et al.*, 2004) faced by Gypsies and Travellers contribute to the poor mental health of many of the communities members. The majority of Gypsies and Travellers live in very close-knit families and the sudden loss of a family member can be devastating. There are concerns about the high suicide and parasuicide levels within the

communities, although this is anecdotal and needs further investigation. Goward *et al.* (2006) explored the nature of the mental health needs of Gypsy and Traveller communities in Sheffield and how well local services met those needs. The study concluded that a more joined-up approach to working is required, and that services need to work across boundaries to begin to address the social and economic factors that contribute to the distress of these communities. Providing a comprehensive service at this time would also improve the communication and levels of consistency between primary and secondary health care services. Goward *et al.* also suggested that education, information and training were required to reduce discrimination and increase existing support to meet the mental health needs of Gypsies and Travellers.

A research project carried out by Bristol MIND (2008) looked at the experiences and needs of a small group of Gypsies and Travellers. It was found that attitudes towards mental health and the language used to describe them were culturally specific. For example, terms such as nerves were discussed openly, whereas the term mental was viewed with suspicion, being linked with madness (see Parry *et al.*, 2004). Tellingly, the Gypsies and Travellers said they were not looking for a specialist mental health service tailored to their particular needs: they just wanted the same as everyone else, thus implying that the problem is one of access. However, it is essential that Gypsies and Travellers are provided with culturally sensitive services by people with whom they have built trusting relationships.

A study of the coronary and mental health status of Gypsies and Travellers living in and visiting Wrexham compared to population norms was completed by Cardiff University (Lewis and Adkins, 2007). In their study, the authors also provided a multi-method evaluation of the health initiative, including a study of Gypsies and Travellers culture, lifestyle, experiences of health care and health beliefs. The findings of the report provide further evidence to support the existing evidence on the extreme poor health of Gypsies and Travellers compared to that of the general population.

Palliative care

Researchers have identified a gap in palliative care provision for English Romany Gypsy Travellers. There is increasing evidence that the needs of terminally ill Gypsies and Travellers are being overlooked by hospitals and GPs in the UK (Jesper *et al.*, 2008), a factor exacerbated by current UK law (The Criminal Justice and Public Order Act 1994), which means that many Gypsies and Travellers are highly mobile as a result of enforced eviction from sites.

Enforced mobility is a major problem in access to health care because it limits access to GPs and makes it difficult to organise programmes of palliative care to support Travellers who wish to die at home. Jesper *et al.* (2008) found little

Resources 3

Irish Traveller Movement in Britain

www.irishtraveller.org.uk

The Irish Traveller Movement (ITM) seeks to raise the profile of Irish Travellers in Britain and increase their say in decision-making processes and forums. ITM seeks to challenge discrimination and develop national policies that ensure the inclusion of Irish Travellers in all levels of society.

Pacesetters Programme

www.dh.gov.uk/en/Managingyourorganisation/Equalityandhumanrights/Pacesettersprogramme/index.htm

The Pacesetters Programme is a partnership between local communities who experience health inequalities, the NHS and the Department of Health. The Equality and Human Rights Group at the DH will work with up to five strategic health authorities on the programme to deliver equality and diversity improvements and innovations. This programme targets improving the health status of Gypsies and Travellers as one of their main priorities.

support from health care professionals, and none of the people interviewed had actually been able to use palliative care services for their loved ones. The study also found a lack of understanding of Gypsy and Traveller culture in hospitals. Poor provision for visiting family members and those with limited literacy skills all contributed to Gypsies and Travellers choosing to discharge themselves from hospital early. Participants in the study also described how older patients might feel threatened in a hospital/hospice setting, because many are unable to read and write and are sometimes reluctant to admit this. Inability to fill out menus can add to feelings of being a fish out of water (Jesper *et al.*, 2008). McQuillan and Van Doorslaer (2007) reported similar findings in their study in Ireland.

3 Scant attention in policy documents

The inequalities in health between different social groups are examined in *Tackling Health Inequalities: A programme for action* (DH, 2003). These are summarised as working through the mainstream by making services more responsive to the needs of disadvantaged populations, but there is no specific mention of Gypsies or Travellers. The government is particularly keen to see a reduction in the differences in infant mortality rates among social groups. It is therefore important that Gypsies and Travellers, who experience some of the highest rates of infant mortality in the country, are mentioned. It is worth pointing out that these high rates can be due to infections which are linked, in Neligan's (1993) study, to poor sanitation, bad conditions and poor access to clean water - and not to either a lack of knowledge or a lack of cleanliness.

In fact, the majority of government initiatives fail to mention the specific needs of Gypsies and Travellers at all: see, for example, DfES (2004), DH (2004a) and Scottish Executive (2006). Although there are references to the needs of BME communities, there is little acknowledgement of the needs of people who live a nomadic lifestyle, either through choice or as a result of enforced evictions. It would appear that government policy, in its failure to acknowledge these needs, reflects the invisibility of Gypsies and Travellers.

Reducing health inequalities has been placed alongside health gain, which is the measurement of the efficacy and safety of NHS output, as a core objective of government policy. The Department of Health's *National Standards, Local Action: Health and social care standards and planning framework: 2005/06-2007/08* (DH, 2004b) and *NHS Improvement Plan* (DH, 2004c) highlight the need for health care organisations to provide leadership and, in partnership with educational agencies, to act to reduce inequalities in health. This includes access to, and outcomes of, health and social care, and in-patient experience. Intrinsic to the shift in policy focus from sickness to health and well-being is

the prioritisation of public health. There are also measures to tackle the underlying determinants of poor health, including primary and secondary prevention and a reduction in inequalities. These documents build on the Acheson Inquiry (Acheson, 1998), which was designed to reduce health and social inequalities.

The government's Pacesetters Programme (see Resources) aims to reduce health inequalities and is unusual in that it targets health improvements for Gypsies and Travellers, who were included after the findings of the Department of Health-funded report on the *Health Status of Gypsies and Travellers in England* were published (Parry *et al.*, 2004). However, the Pacesetters Programme is dependent on individual PCTs taking the lead and cascading good practice, rather than being embedded within a national programme.

Replicating and disseminating good practice

4

More attention needs to be paid to coordinating and disseminating good practice in Gypsy and Traveller health to avoid duplication of effort and patchy provision. For example, hand-held records (i.e. records that are held by patients themselves rather than by their GP), which have been piloted in Scotland as well as in maternity services within the UK, could be used by all PCTs rather than each PCT devising separate, costly duplicates. There are pockets of good practice as a result of various initiatives; examples include Pacesetters and Race for Health, both of which are government led. However, there is a need to work more directly with those practitioners and voluntary organisations that have already built up trusting relationships with members of Gypsy and Traveller communities and have developed examples of best practice. Some examples of good practice are mentioned on the following pages.

Resources 4

Pavee Point

www.paveepoint.ie

Pavee Point is a voluntary organisation committed to the attainment of human rights for Irish Travellers in Ireland. The group comprises Travellers and members of the majority population working together in partnership to address the needs of Travellers as a minority group experiencing exclusion and marginalisation. The aim of Pavee Point is to contribute to improvement in the quality of life and living circumstances of Irish Travellers, through working for social justice, solidarity, socio-economic development and human rights.

Race for Health

www.raceforhealth.org

Race for Health is a Department of Health-funded, NHS-based programme that enables primary care trusts to work with local black and minority ethnic groups to improve health, increase choice and create greater diversity within the NHS. Race for Health believes that action is required to implement real change across the NHS to drive forward programmes and legislation that will impact positively on the health of black and minority ethnic communities.

Examples of good practice

Traveller women

A number of initiatives have been aimed at improving the health of Gypsy and Traveller women. Friends, Families and Travellers, also known as the Sussex Traveller Health Project, used a method of peer education, first piloted with very successful results in Pavee Point in Dublin. The project involved working with a Gypsy and Traveller outreach worker to visit both Traveller sites and settled Travellers, and set up support groups in different localities. It then worked with Traveller women to identify their own health needs and priorities, and set up support and training around those needs.

The groups were for women only. Because of strict codes of conduct around gender, many women did not feel comfortable talking about their health issues in front of men (see Lehti and Mattson, 2001). The project worked on the premise that most family members would benefit from the skills that the women acquired, and that information and knowledge would be shared with other members of their communities. Qualitative evaluation undertaken at the end of the project would support this theory. The project has been heralded as a model both of best practice and of innovation by the Department of Health (See Resources, under Pacesetters).

As a result of this initial work carried out by Friends, Families and Travellers, the project was able to better identify and quantify the health and social care needs of Gypsies and Travellers within Sussex. The project now has a dedicated team of nine workers, four of whom are Travellers, and works with Gypsy and Traveller communities to support access to primary health services, adult social care and mental health services, as well as providing community support and young people's services.

There are other examples of positive work being carried out by the voluntary sector, as well as some exemplary projects being supported by PCTs; for example, Travellers Health Partnership, Leeds; Gypsy and Traveller Exchange (GATE) and The Derbyshire Gypsy Liaison Group.

Specialist health workers

Friends, Families and Travellers have two mental health and well-being workers, one of whom is funded as part of the government's Delivering Race Equality initiative to increase uptake of services within BME communities. The BME community development workers facilitate access to services for BME people, including Gypsies and Travellers. The Derbyshire Gypsy Liaison Group hosts a similar post. Work so far has identified a lack of cultural understanding of Gypsies and Travellers and the need to build the capacity of

mental health services to become more effective and sensitive. It is often the case that individuals need help to access services and usually need advocates and support workers during the early critical period of illness and for continued support during recovery (source: personal communication).

The initiatives mentioned in the subsection above have enabled workers to access Gypsies and Travellers hitherto hidden from mainstream health services. This work has evolved from provision of a direct service to facilitating a conduit between the statutory health agencies and the Travelling community, helping to reduce the real or perceived mistrust held by both about the other.

The vast majority of PCTs do not employ specific staff to help Gypsies and Travellers meet their health needs. The National Association of Health Workers with Travellers was disbanded because little statutory support was given to this organisation. In most cases, if specific needs are identified the PCTs add this work on to existing casework, usually alongside health workers for BME groups, homeless people or asylum seekers (Parry *et al.*, 2004). This strategy fails to recognise the unique health needs of the Gypsy and Traveller communities.

Conclusion

Although health policies can create solid foundations for change in health inequalities, they are not sufficient on their own. Implementation and action are key. There is a real need for government to support bottom-up initiatives, which in turn enable community engagement and community development. It is essential that Gypsies and Travellers are involved - and supported to be involved - in all aspects of work around health and social care. It can be argued that it is quicker to make changes in policy than to engage and work with the individuals and families who make up Gypsy and Traveller communities. This takes time, patience and commitment.

Overall, there is a real consensus of opinion about the value of community outreach health projects undertaken in partnership with voluntary sector and local Gypsy and Traveller agencies. A major concern, however, is the short-term nature of many projects. Although evaluations are overwhelmingly positive and indicate significant health gains, the majority of projects run for between one and three years with a risk that the health improvement will be lost once they come to an end. It is therefore clear that a national strategy on Gypsy and Traveller health is needed, supported by dedicated funding, to continue the improvements started by local projects.

Resources 5

Travellers Advice Team

www.gypsy-traveller.org/law/travellers-aid-team

The Travellers Advice Team comprises a dedicated group of solicitors and legal workers who provide specialist legal advice and representation to the Traveller community throughout England and Wales. They provide emergency 24-hour national advice and representation and work closely with other non-government agencies working with Travellers.

TravellerSpace

www.gypsy-traveller.org/travellerspace

TravellerSpace is an independent voluntary organisation supporting Gypsies and Travellers in Cornwall. TravellerSpace aims to find ways of overcoming barriers and improving the quality of life for all Gypsies and Travellers in Cornwall, whether settled on an authorised site, by the roadside, in bricks and mortar or just there temporarily. TravellerSpace supports Gypsies and Travellers in making sure their voices are heard and not ignored.

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Zoe Matthews is a Registered Nurse (Mental Health) and has an MA in Health Promotion (Europe). She has worked for Friends, Families and Travellers for just under ten years: six as Health Improvement Manager working with Gypsies and Travellers in Sussex to address health inequalities.

Readers

Margaret Greenfields
Yvonne MacNamara
Rose McCarthy

We welcome feedback on this paper and on all aspects of our work. Please email briefings@racefound.org.uk

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Race Equality Foundation

Unit 35

Kings Exchange

Tileyard Road

London N7 9AH

T: 020 7619 6220 F: 020 7619 6230

www.raceequalityfoundation.org.uk