Developing the cultural competence of health professionals working with Gypsy Travellers

"It's interesting how people can change their point of view
if they're given enough information"

Christine - Irish Traveller

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Executive Summary

The health status of Gypsy Travellers is considerably poorer than other English-speaking minority ethnic groups (Van Cleemput et al, 2007; Parry et al, 2004; Doyal et al 2002; Royal College of Gynaecologists, 2001). The reasons for this disparity are generally attributed to poor accommodation, poor access to health services and education, and discrimination. Other reasons are thought to be a lack of understanding of the needs of Travellers and Gypsies by health professionals.

This project explored one of the issues affecting access to healthcare services by Gypsy Travellers, namely the cultural competence of health professionals. Evidence suggests that receiving cultural competence training increases confidence and awareness of the care requirements of ethnic minority patients, and so the aim of the project was to support the development of cultural competence in health professionals working with Gypsy Travellers through an exploration of staff attitudes, knowledge and understanding of the cultural identity and health needs of Gypsy Travellers. The three objectives of the project were: -

- To identify the questions and attitudes health professionals had regarding Gypsy Travellers
- To develop an information booklet based on the Frequently Asked Questions (FAQs) of health professionals pertaining to the cultural identity and health needs of Gypsy Travellers
- To develop the content for an on-line cultural competence programme with specific reference to Gypsy Travellers

The project engaged participants from community nursing, including health visiting, and members of the Irish Traveller community. Staff participants provided questions they wished to have answered and data on their attitudes and perceptions of Gypsy Travellers. Irish Traveller participants contributed to the development of the resources by providing answers to staff questions and sharing their life experiences.

The data collated from staff suggested that many participants had perceptions of Gypsies and Travellers that were informed by negative media stereotypes. There was limited understanding of Gypsy Traveller culture, health needs or issues affecting the community, however in subsequent discussions with staff there was demonstrable willingness, not only to challenge themselves, but to also be challenged, and to explore attitudes and the implications for practice.

Although nursing and midwifery health professionals are subject to the NMC Code of Conduct, they are inevitably influenced by, and reflect the wider society within which they live. Within the caring professions the motivation to express professional group norms which reflect the NMC Code of Conduct is high, however it can be argued that having also been influenced by negative societal views, health professionals' behaviour and practice will inevitably be tinged with negative or contentious views to a greater or lesser degree.

This project highlighted the need for staff to have an improved understanding of Gypsy Traveller culture and the issues faced by the Gypsy Traveller community in order to improve access to care by this often excluded and marginalised community. It also demonstrated the benefits of honest, non-judgemental, open discussion within professional forums about the existence and impact of bias and prejudice on practice.

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2.0   Glossary

Bargees or Water Gypsies   Bargees are a distinct group of Travellers who live and work on barges. There are now very few Bargees in Britain as canals are no longer usually used to carry freight.

Country people   A term used by Irish Travellers for the settled community.

Diaspora   Refers to the forcing of any people or ethnic population to leave their traditional homelands, the dispersal of such people, and the ensuing developments in their culture.

Fairground and Showmen   Fair ground people formed the Showmen's Guild. Some of the guild members are from Gypsy decent, others are not but this made them distinct from all other Travellers.

FAQs   Frequently asked questions

Group housing   Housing in bungalow style dwellings with space to keep a touring caravan, pioneered in Ireland for the Traveller community.

Gypsy   Ethnic groups who were formed as commercial, nomadic and other groups travelling away from India from the tenth century and mixing with European and other groups during their Diaspora.

Housed Traveller   A Traveller who is living in housing or "bricks & mortar accommodation".

LBH   London Borough of Hackney

Nomadism   Having the custom of moving from one place to another, rather than settling permanently in one location.

Roma	Thought to have originated in northern India but now are living on all continents as a subgroup of the Romani people (also known as Gypsies), who live primarily in Central and Eastern Europe, as well as in the Balkans.
Romanichals	A term by which some groups of Roma people (often known as Gypsies) found in some parts of the United Kingdom, notably England, refer to themselves in their own language, Anglo-Romany. The name is not universally accepted by English Roma, who will often call themselves "Romany Folk".
Settled people / community	Members of the wider community that live in traditional "bricks & mortar" housing.
Traveller	A member of any of the native European ethnic groups whose culture is characterised by nomadism, occupational fluidity and self-employment.

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Gypsy Travellers

3.0   Introduction

The health status of Gypsy Travellers is considerably poorer than other English-speaking minority ethnic groups (Van Cleemput et al, 2007; Parry et al, 2004; Doyal et al 2002; Royal College of Gynaecologists, 2001). The reasons for this disparity are generally attributed to poor accommodation, poor access to health services and education, and discrimination. Other reasons are thought to be a lack of understanding of the needs of Travellers and Gypsies by health professionals and racism, actual and perceived (Fancione and Fancione, 2007).

This project focused on an issue affecting access to healthcare services by Gypsy Travellers, namely the cultural competence of health professionals. Evidence suggests that receiving cultural competence training increases confidence and awareness of the care requirements of ethnic minority patients. Training enables people to become more reflective about their practice and cultural competence. Developing a comprehensive understanding of a minority group's culture enhances communication and facilitates the flexibility and openness necessary for communication between people of differing cultural backgrounds. (Pearson et al, 2007).

The project was designed to engage with health professionals drawn from community nursing, including health visiting, in order to begin to understand their information needs about, and attitudes towards Gypsy Travellers. The project also engaged with Irish Travellers in establishing the important things they felt health professionals should know about the community, and to answer the questions health professionals had about Travellers.

The data gathered informed the development of a booklet for staff, available from autumn 2010, and the content of an on-line cultural competence programme with reference to Gypsy Travellers.

The focus of this project emerged from my MSc dissertation exploring the factors informing the approach of health professionals when working with Gypsy Travellers. One of the major

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themes that emerged from the data was that of "private views vs. public voice". Despite a theoretical acknowledgement of the need for equity and equality in service provision, this did not always appear to translate into recognition of the possible impact holding negative views and beliefs about a community might have on the way individuals practiced, and indeed how the community might respond as a result.

If individuals fail to acknowledge the pervasive nature of prejudice, discrimination and racism, and the negative impact on practice and the delivery of an equitable service this may have, it will be difficult to move forward to a point where a safe environment can be developed in which to discuss and unpack those issues that inform professional practice when working with Gypsy Travellers. This project was based on the need to, not only provide information about the community, but to also understand the attitudes and perceptions staff had of the community and raise awareness of the impact these might have on practice and service delivery.

This report will review the research on Gypsy Traveller health and look at the local context; detail the project aims, objectives and methodology; discuss the implications for practice and draw conclusions from the findings.

3.1   Key Definitions

3.1.1 Gypsies and Travellers

In the United Kingdom Gypsy Travellers, an umbrella term, consist of Welsh and English Romanichal or Romany Gypsies, Scottish and Irish Travellers and more recently, European Romanichals or Roma. Other travelling communities include Fairground or Showmen, New Travellers and Bargees (also known as Water Gypsies).

Liegeois and Gheorghe (1995) define Gypsies as ethnic groups who were formed as commercial, nomadic and other groups travelling away from India from the tenth century and mixing with European and other groups during their Diaspora. The term Traveller is said to describe a member of any of the native European ethnic groups whose culture is characterised by nomadism, occupational fluidity and self-employment.

More recently, for the purpose of assessing their accommodation needs, Gypsy Travellers were described by the Office of the Deputy Prime Minister (ODPM, 2006) as persons who were habitually nomadic, whatever their origin or race; including people who had stopped

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travelling temporarily or permanently because of educational or health needs. This also included all other people with a cultural tradition of nomadism or living in a caravan. Gypsies and Irish Travellers are recognised as distinct ethnic groups under the Race Relations (Amendment) Act 2000. The term "Traveller", as defined by the Commission for Racial Equality (CRE), describes an ethnic group who have a nomadic way of life firmly embedded in their culture (CRE, 2006).

Despite the fact that many Gypsy Travellers have either been forced or chosen through circumstances to live in houses for all or part of the time, they consider themselves to be Travellers. Nomadism is embedded in the culture and heritage and is not purely about moving from place to place but a way of looking at life and the world (McDonagh, 1994).

3.1.2 Cultural Competence

Campinha-Bacote's (2002) describes cultural competence within nursing practice as an on-going process where individuals reflect on their own culture and seek to understand the culture of others in order to work effectively within the context of the individual patient and their family. Within a broader organisational context Brach and Fraser (2000) define cultural competence as an ongoing commitment or institutionalization of appropriate practices and policies for diverse populations.

In a review of cultural competence frameworks by Jirwe et al (2006), four broad themes emerge; an awareness of diversity among human beings; an ability to care for individuals; non-judgmental openness for all individuals and the enhancement of cultural competence as a long-term continuous process. These themes (See Figure 1) illustrate the various components required for the development of a culturally competent practitioner.

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Figure 1. Culturally Competent Practitioner Development Model (Knight-Jackson, 2007)
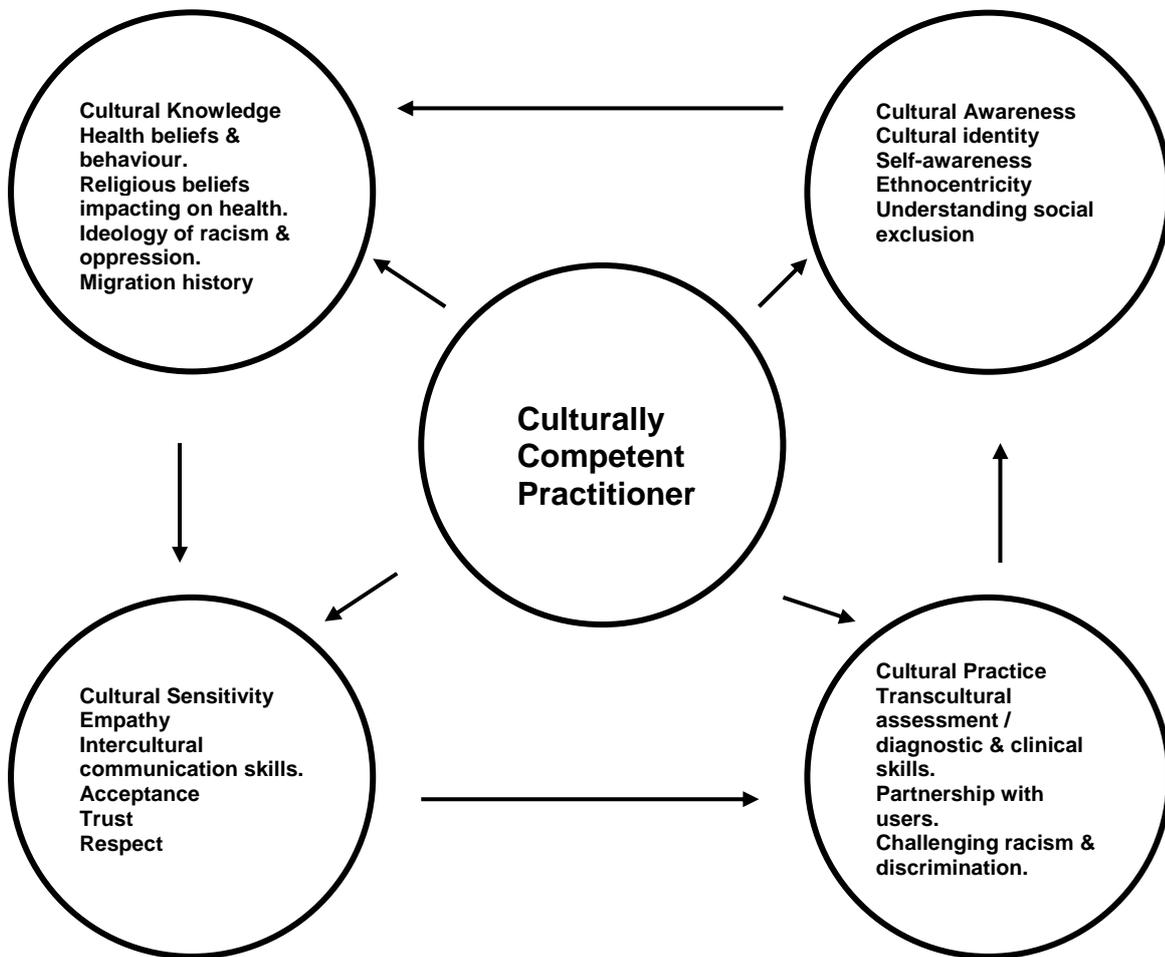
Knight–Jackson (2007) emphasizes the need for the constructs to be viewed holistically, such that practitioners move through all of the interconnected concepts in order to be fully aware of how to work with culturally diverse groups. The development of awareness and knowledge of the self, including ones own attitudes, values and beliefs and their effect on others is part of gaining cultural competence, and enables an individual to be more mindful of their own prejudiced views (Wells and Black, 2000).

Hawes (1997) championed the case for cultural competence training by advocating that training must address the misunderstanding, barriers and hostilities that persist in the delivery of health care, if appropriate services for excluded and marginalised communities are to be developed. It is evident that cultural competence must be addressed on both an individual and organisational level in order to achieve sustainable improvements in service

development and delivery. This project has focused primarily on the needs of individual professionals. However, it is acknowledged that if there is no firm commitment to cultural competence at an organisational level, as individuals move on, good practice may then be lost to organisational memory.

3.2 Background

There have been a number of studies investigating the health of Gypsy Travellers (Barry et al, 1989; Feder et al, 1993; Hawes, 1997; Parry et al, 2004;). The emergent themes are common to other excluded communities; an inverse relationship between health needs and access to or use of services, poor housing conditions, high unemployment and lack of access to education. Concern for the health status of this community remains because, despite the focus of government policy on the reduction of health inequalities, Gypsy Travellers appear not to have benefited from the improvement in health experienced by other communities. Barry et al (1989) showed that their life expectancy was only that of the settled population in the 1940s, with Gypsy Traveller women and men living 12 and 10 years less, respectively, than the settled population. Bunce (1996) reported that they were likely to suffer from conditions linked to poor sanitation, heart disease, chronic disability and chest infections. These findings were thought to be associated with living on unauthorised encampments with little access to utilities or health services.

With regards to mental health and well-being Appleton and Welton (2002) reported findings for anxiety as thirty five per cent in Travellers, compared to twelve per cent in the general population, and for depression, twenty seven per cent in Travellers and four per cent in the general population. A health status survey by Goward and Repper et al (2006) also found higher levels of anxiety and depression and lower social functioning within the Traveller community studied than a comparison group in a neighbouring deprived area. The participants did not report enduring serious mental illness but did describe distressing circumstances that did not fall within the remit of specialist, or secondary mental health care. Goward and Repper et al (2006) acknowledged that there were factors intrinsic to Traveller communities that supported resilience, despite the adverse circumstances encountered. The support of the community and extended family helped to ameliorate some of the effects of certain difficulties, however the criminalisation of some aspects of

Gypsy Traveller culture, namely the ability to roam freely, has contributed to reduced mental health and well-being. The option to resolve conflict simply by moving on has also been curtailed.

Both Pahl and Vaile (1988) and Barry et al (1989) reported higher stillbirth, perinatal and infant mortality rates than that of the settled population. Pahl and Vaile (1986) also found higher infant death rates and stillbirths in women living on private or unauthorised sites than those on local authority sites. They also reported a higher proportion of low birth weight babies in the Traveller community than the settled community. The Confidential Enquiry report into Maternal Death (Royal College of Gynaecologists, 2001) determined that Gypsy Travellers had the highest rate of maternal death compared to all other ethnic groups and also experienced more incidences of miscarriage. Some of these findings were associated with reduced access to antenatal care due to bureaucracy or hostility encountered by Traveller women from health staff, and with women whose access to antenatal care was limited by poor health literacy.

Aspinall's (2005) systematic review investigating the health of Gypsy Travellers, concluded that most studies (with the exception of a few), used methodologies that were not considered robust; principally because many where based on small samples that did not make comparisons with a reference population or use validated or standardised health status instruments. However, Parry et al's (2004) study using both quantitative and qualitative methods was considered more robust and given greater credence as a result. Parry et al found that Gypsy Travellers had higher death rates for all causes and lower life expectancy than the non-Traveller population. This study also found Gypsy Travellers to be more likely to suffer with long-term illness or disability and compared with local and national data, bronchitis, asthma and angina were much more prevalent. Gypsy Travellers also had more problems with mobility, self-care, pain, anxiety and depression. They were also found to suffer high levels of infant mortality and perinatal death, low birth weights and high child accident rates.

When comparing the use of an A&E department by children from two Gypsy Traveller sites with their neighbourhood, Beach (2006) found that the attendance rate of Gypsy Traveller

children, for all reasons, was more than twice that of the neighbouring children. Disproportionate use of A&E is associated with limited access to General Practitioner (GP) services and poor health literacy (Kondilis et al, 2006). For Travellers on unauthorised sites accessing healthcare through A&E, lack of appropriate follow-up is a dominant feature. Government guidance on the management of unauthorised encampments now recommends that the impact eviction might have on the health of those living on the encampment, for example pregnant women or children, is taken into consideration.

In examining the issue of access and utilisation of health services Smaje (1995) contends that the use of services is dependant not only on the availability but also upon the ability or desire to use the service. Several factors influence the uptake of services and these factors need to be examined in relation to equity. For instance, Reid and Taylor (2006) found that women's experiences and expectations of maternity care were largely affected by religious beliefs, peer support and culture. Many norms of the dominant culture were unacceptable, such as breast-feeding and participation of the husband, and so midwives are challenged to acknowledge these cultural differences sensitively. Hawes (1997) suggests that a disservice is perpetrated against Gypsy Travellers in placing the emphasis on ethnological reasons for poorer health status, rather than looking at other factors, such as the health service failure or inability to respond to the needs of nomadic people. Evidence suggests that nomadic families are amongst the unhealthiest in the United Kingdom, however the reason for this health inequality is complex and multi-faceted. In Hawes' (1997) assessment of the problems faced by Gypsy Travellers he acknowledges barriers in the delivery of institutional healthcare, nevertheless he also poses the argument that many other barriers are self-constructed. This then leads to the question of whether institutional change will be sufficient to counter the inequalities suffered. Acton and Mundy (1997) also question whether, or to what extent, Gypsy Travellers contribute to the health disparities they suffer or whether the delivery of health services on an individual or organisational level is in some way responsible. Smaje (1995) suggests that the way services are distributed, the quality of care and racism are also influential in the way or extent to which services are utilized. In service delivery, assumptions about the needs of Gypsy Travellers may be made based on the needs of the settled community and so there is a failure to meet need by way of ethnocentrism. For example, the completion of forms and the need to provide information,

such as dates of birth and medical history may cause difficulties for Gypsy Travellers with poor literacy skills.

Louden (2003) maintains that improving access means that the quality of services must also come under scrutiny. One of the subtler ways minorities are excluded is through continuing to equate use with *effective* use. The way services are delivered may not be culturally appropriate for the service users, but the delivery model remains the same because the needs and views of the users are not sought.

Hennink et al (1993) suggest a possible correlation between the cultural or social views of traditional Travellers and their health status (Table 1).

Table 1. Possible correlation between the cultural or social views of traditional Travellers and their health status (Hennink et al, 1993)

Cultural Issues	Health Problems / Issues
Cultural erosion	Depression, anxiety and marital disharmony
Lack of health education	Lower life expectancy from smoking, alcohol misuse, high intake of fat, salt and sugar, cardiovascular disease
Poor uptake of preventative care	Cervical cancer, dental problems, still birth, neural tube defects
Different concept of time	Taking tablets, keeping appointments
Acceptance of tobacco smoking	Cardiovascular disease, premature death, emphysema, low birth weight babies
Illiteracy	Inability to read health information, instructions or warnings on medication, letters for appointments. Reliance on rumour or media leading to poor understanding of health information. Not knowing where to access health care
Mistrust of immunisation	Poor uptake of immunisations, infections and risk of childhood illnesses
Bottle-fed babies	Eroding of dental health, lower resistance to disease
Consanguineous marriages	Congenital malformations, birth defects, genetic disorders, autosomal recessive disorders

There are some elements in these conclusions that are contentious and appear to be "victim blaming" in nature (Naidoo and Wills, 2005). For example, Gordon and Gorman et al (1991) revealed high levels of consanguinity in the Northern Ireland Traveller community, which they suggested pointed to higher levels of congenital abnormalities. However, the impact of consanguineous unions and conclusions about this particular cultural practice is sometimes used to denigrate Gypsy Traveller culture, rather than to inform the community about the possible need for genetic counselling.

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The focus of the government on reducing health inequalities challenges the National Health Service (NHS) to improve the health of communities with the poorest health outcomes. This challenge can only be met if the NHS seeks to explore all of the issues that impact on both service provision and uptake when commissioning services. Within health services where there is acknowledgement of these inequalities in the Gypsy Traveller community, the focus is primarily on improving access and service provision, as the literature recommends (Doyal et al, 2002; Parry et al, 2004). Within this remit health care interventions include the use of hand held records, mobile health and dental clinics, outreach immunisation programmes, health promotion materials, and the use of specialist health visitors (Aspinall, 2005). Although laudable, targeted services alone may not have the far reaching effects that addressing reduced access to mainstream services may bring. Access to and take up of the full range of mainstream and universal services is required to adequately address the health needs of the whole community.

One of the themes that emerged from the research (Van Cleemput et al, 2004) is that Travellers express the need not to have specialist, targeted services, but that nurses and doctors are just taught to respect people. Where specialist workers were provided Travellers expressed an appreciation, however the expressed need was to experience service on par with other users. There is evidence (Hawes, 1997; Parry et al, 2004; Van Cleemput et al, 2007) suggesting that one of the reasons Gypsy Travellers fail to access health services in a timely fashion is the expectation and past experience of poor treatment. If the experience of some service users is of inequitable treatment, this raises the possibility that a reduced willingness to engage with services in a timely or appropriate fashion is the result. The need then for health professionals to be culturally competent is increasingly apparent as communities become more diverse and health disparities emerge (Gee, 2002; Nazroo, 2003). In support of this argument, Giddings (2005) concludes that nurses require the skills to deconstruct the marginalizing processes that enable inequalities in health care and nursing to be sustained. The marginalisation of Gypsy Traveller communities is deep rooted and although laws legitimising discriminatory treatment, imprisonment and even execution for being a Gypsy were largely repealed during the nineteenth century, the Commission for Racial Equality describes Gypsy Travellers as continuing to suffer from the last "respectable" form of racism (CRE, 2006). It is argued that negative stereotypes

perpetuated in the media influence, the publics' view and attitude toward Gypsy Travellers leading to racist attitudes becoming acceptable and rational (Morris, 2000).

Although race equality schemes exist within the health service these often focus on the employer / employee relationship and the interface between service providers and users revolves around the "valuing diversity" agenda. Although this notion is based on viewing difference and diversity positively rather that as a problem, it still often comes from a perspective that speaks of "tolerating" difference, which is not without intrinsic problems. Tolerance of difference suggests that difference is still wrong or not as good as what is considered the norm or dominant culture, but for the sake of fairness nurses should allow it (Cortis, 2003).

In looking at issues of equality and practice, Aranda (2005) suggests that how community nurses see themselves and the acknowledgment and understanding of these different selves is essential to the process of addressing discriminatory practice. Towards understanding what influences practice, Cortis (2003) suggests that recognising the influence of ones own culture, values and belief system would allow for a more insightful interpretation of the behaviour of others. However, in addition to this, Cortis (2003) suggests that it would be naïve to believe that diversity management might be the answer to dealing with the notions of culture, racism and values and how they relate to nursing practice, and then not to explore the impact of power relations and societal structures. Culley (2006) highlights the need to define people not only in terms of their ethnicity but also as a heterogeneous group with differing gender, generational and social aspirations.

Narayanasamy (2002) suggests that racism is at the root of many barriers to health suffered by black and minority ethnic (BME) people, and concludes that the development of transcultural nursing models and assimilation of these into practice is vital in combating these barriers. Professional development that leads to self-awareness, an awareness of diversity, the ability to care for individuals and being open to other cultures, is a process encapsulated in the notion of culturally competence (Jirwe et al, 2006).

The expectation of poor treatment is cited by Gypsy Travellers as a reason for failure to access services in a timely or appropriate fashion, and so it is with this in mind this project sought to develop resources that would support the professional practice of health professionals in developing cultural competence with regards to the needs of the Gypsy Traveller community.

3.3 Local Context

The project took place within the London Borough of Hackney (LBH) where historically there has been a paucity of local data on Gypsy Travellers; a problem replicated across many local authorities and health services throughout the United Kingdom (UK) where ethnicity monitoring remains a largely twofold challenge. Generally, across the UK, ethnicity codes have not been detailed enough to accurately reflect the numbers of Travellers and Gypsies in the population. However, where acknowledgement of Gypsy Travellers is reflected in ethnic coding, they often refuse to self-ascribe in this way for fear of discrimination. The lack of robust ethnicity data is identified as one of the main challenges when seeking to assess the needs of the Gypsy Traveller community, and may support justification of the failure to make provision or develop strategies that include and address the needs of this community. The Provision of Services to Travellers London Borough of Hackney Consultation Draft (Niner, 2005) was unable to reach firm conclusions regarding the total number of Gypsy Travellers in Hackney. Estimations based on information derived through consultation with local stakeholders, such as the Traveller Education Service (TES) and the Health Worker for Travellers cite their population in Hackney as five hundred individuals. Although the 2007 data drawn from the London Gypsy & Traveller Unit and the TES were an estimated 600 - 800 Irish Travellers in the area, these figures are acknowledged as an underestimation of the size of the Gypsy Traveller community because they account only for individuals and families who were accessing or were known to those services. The 2007 dataset omits the numbers of English Gypsies, Circus and Fairground Families, Barge Travellers, New Travellers and Roma from Eastern Europe residing in the borough.

Within Hackney there are currently four official Traveller sites managed by the LBH, consisting of 25 plots, providing a mixture of traditional pitches for trailers and amenity blocks, and group housing[1]. Three of the four sites were developed as a result of the need to decant Travellers from Waterden Crescent, a large site that sat within the footprint of the 2012 Olympic Park.

More invisible, and harder to reach, are those families living in houses, making up the majority of the Gypsy Traveller community in Hackney. Changes in legislation and the removal of the statutory obligation on local authorities to provide sites and official stopping

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[1] Housing in bungalow style dwellings with space to keep a touring caravan, pioneered in Ireland.

places has resulted in a reduction of the ability of Gypsy Travellers to maintain a travelling lifestyle; subsequently the numbers of Travellers having to move into housing has increased. Where Gypsies and Travellers continue to travel and set up unauthorised encampments the potential for heightened tensions with the settled community and negative media coverage persists. Unauthorised encampments that occur in the borough consist usually of Irish Travellers and New Travellers. The council, informed by reports from four key sources[2], manages these encampments in accordance with the local protocol on unauthorised encampments.

Within NHS City & Hackney and the LBH a joint approach to meeting the needs of Gypsy Travellers has been taken, involving key stakeholders consisting of statutory and non-statutory bodies. The Traveller Health Reference Group, chaired by NHS City & Hackney Community Health Services, exists to support and give guidance on the development of services that effectively meet the community's health needs. The Gypsy and Traveller Strategy Group (Table 2.), in which Travellers are actively involved, is chaired by the local council. This group is currently involved in developing guidance on a strategic approach to delivering equitable universal and targeted services within the borough.

Table 2. LBH Gypsy and Traveller Strategy Group

	Key Stakeholders
1.	London Borough of Hackney
2.	Traveller Service Development Officer, Hackney Homes
3.	Traveller community representatives
4.	The London Gypsy & Travellers Unit
5	The Traveller Education Service, The Learning Trust
6.	Safer Neighbourhoods Team, Metropolitan Police
7.	NHS City & Hackney Community Health Services

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[2] Traveller Education Service, Health Inclusion Worker for Travellers and Gypsies, The London Gypsy & Traveller Unit, Metropolitan Police Safer Neighbourhoods Team

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4.0 Aims & Objectives

4.1 Aim

The aim of the project was to support the development of cultural competence in health professionals working with Gypsy Travellers. To achieve this aim it was necessary to understand the needs of staff and the first objective, detailed below, was identified. Two further objectives designed to increase the understanding health professionals had regarding Gypsy Traveller cultural identity and health issues were identified.

4.2 Objectives

1. To identify the questions and attitudes health professionals have regarding Gypsy Travellers

2. To develop an information booklet based on the frequently asked questions (FAQs) of health professionals pertaining to the cultural identity and health needs of Gypsy Travellers

3. To develop the content for an on-line cultural competence programme with specific reference to Gypsy Travellers

From the questions and data collected from objective 1 the resources would be developed in partnership with the Gypsy Traveller community. The key principles underpinning the objectives 2 and 3 were that the resources were intended to be useful working tools to assist the practitioners / health staff with acquiring a better understanding of the culture and customs of Gypsy Travellers.

5.0 Methodology

Two groups of participants were involved in the development of the resource contents; these were community nursing staff employed by NHS City & Hackney Community Health Services and Irish Travellers within LBH.

5.1 Community nursing participants

Following scrutiny of the project purpose, aims and objectives by the research and development manager, ethics approval was deemed unnecessary.

Forty staff (varying in seniority and including school nurses, health visitors, community matrons, health care support workers and nursery nurses) from different services and directorates within NHS City & Hackney Community Health services agreed to participate. Access to staff was negotiated through team managers and attending team meetings to explain the purpose of the project and to seek participation. Staff agreeing to participate were made aware that they were under no obligation to take part and that any responses they gave would remain anonymous. A mixed method approach, consisting of anonymous survey data, group discussions and one to one sessions was adopted.

In order to ensure the resources developed would meet the needs of users it was necessary to have a clear understanding of how staff viewed the Gypsy Traveller community by finding a way to elicit their private views. An early decision in the project execution was a change to the initial idea of talking to staff in a group setting, to avoid a high probability of self-censorship by participants. The approach selected was to maximise candour by asking staff to take part in an activity that would ensure complete anonymity. Staff were asked to take two pieces of paper: on one they were asked to write down three things, words or statements that came to mind on hearing the terms "Gypsy" or "Traveller". On the other paper they were asked to write down two questions about Gypsies and Travellers that they wished to have answered. The questions were scrutinised and, where necessary, reframed (whilst maintaining the gist of the question) to ensure that the language was not considered offensive.

The two key issues from the vast amount of data gathered were that: (a) a careful consideration of what would be included in the FAQ booklet was needed to ensure that the content was meaningful to practitioners, and (b) they exhibited a range of perceptions of the Travellers' including ignorance about the community. Decisions about the utility of the data (exclusions and inclusions) for the FAQ booklet were made by taking the findings back (in three feedback sessions) to staff. These groups were mixed, consisting of original participants and others who had not previously participated. The feedback sessions (see Table 3.) were used to establish what information staff themselves felt would be useful in addressing attitudes formed from absorbing negative stereotypes. They lasted approximately 1½ hours and began by talking about Traveller culture, health inequalities

Table 3. Content of the feedback sessions

Subject	Content
Research Context	Issues affecting Traveller health – accommodation, education, lifestyle, discrimination
Barriers to access	Cultural competence, health literacy, bureaucracy, discrimination, expectation of poor reception
What does cultural competence look like?	Cultural knowledge, self-awareness, cultural sensitivity and cultural practice
Personal views vs. public voice	Media influence, can we compartmentalize? Do we leak our personal views into practice?
Feedback from staff views and attitudes to Gypsy Travellers	If you knew health professionals held these views about you, how would it affect the way you accessed a service?
Do we need to move from our position?	What if we hold these views, does anything need to change?
What do we need to know to move from where we are?	If you held these views what would need to happen to make you change your mind?

within the Traveller community and the factors that impact on access to health services. Participants gave their views and were also provided with research evidence regarding health status and issues affecting the Traveller community. Participants were then asked to talk about their understanding of cultural competence and what the constituent components might be. This was followed by discussions on how our private views might affect the way we practice and whether it was possible to compartmentalise our personal views and professional practice. There was also some discussion on what informed our

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views; were we influenced by negative media stereotypes, influential "others" or personal experience?

In order to facilitate the reflective process, a brief introduction to Kandola's (2009) work was given. This exposition explored the concept of bias as an intrinsic part of the human condition; which Kandola describes as being "hard-wired" and an essential human survival mechanism. Bias and discrimination are components of typical human behaviour, however what we do about this as it affects others negatively is what must be addressed. In establishing this premise of bias being part of a spectrum of human behaviour it was then easier to have a discussion about the negative views we might hold about a particular group or community. Kandola (2009) argues that recognition of our behaviour and having an increased awareness were essential in addressing the possible effects of bias, such as discriminatory practice.

The participants were given examples of some of the comments written by staff on hearing the term "Gypsy" or "Traveller". They were asked to consider the following: -

a) If you were from a community about whom these views were held and you knew you were viewed in this way, how might it affect the way you accessed a service?

b) If we (health professionals) hold these views do we need to challenge them?

c) If you were a professional who held these views what would need to happen to make you change your mind?

5.2 Traveller community participants

The project was publicised by word of mouth within the Traveller community and members were invited to contribute to the development of a staff information booklet, and asked how they might do this. They were reassured that their comments would remain anonymous, unless explicit permission was given, and that they would be consulted throughout the process.

25 Irish Travellers (20 women; 5 men), aged 20 to 60 years, agreed to take part and were drawn from council run Traveller sites, an unauthorised encampment and from those living in bricks and mortar accommodation. They answered questions health staff posed and

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talked about what they felt health professionals needed to know about their community. This activity took place on a one to one basis and in one small group session. The answers given by Travellers have been used verbatim in the booklet and on completion the Travellers were consulted again to ensure they were happy with the way they were being portrayed and that the content was representative of them.

The data gathered was also used to inform the content of the on-line programme; providing accessible information, using scenarios and questions about the Gypsy Traveller community and aimed at challenging stereotypes.

6.0 Findings

The findings were structured into two areas; one concerning responses of health staff to hearing the term "Gypsy" or "Traveller" (6.1), and the second looking at questions articulated about the Gypsy Traveller community, with Traveller responses to those questions (6.2).

6.1 On staff hearing the term "Gypsy" or "Traveller"

A total of 132 words or statements were generated by participants on hearing the terms "Gypsy" or "Traveller", these were collated into 11 themes (Table 4)

Table 4. Themes from responses elicited on hearing the term "Gypsy" or "Traveller"

Theme	Nos.	Theme	Nos.	Theme	Nos.
Names	1	Exclusion	6	Accommodation	15
Positive	2	Health	7	Way of life	20
Employment	3	Problems	8	Media stereotypes	54
Origins	5	Education	11		

Of the 132 words or statements submitted, two were categorised as "Positive": -

Free thinkers

Once they get to know you, and how you're there to help, they are friendly

The three other smallest categories were associated with "Names", "Origins", and "Employment". These statements reflected knowledge of two constituent members of the Gypsy Traveller community, Roma from Eastern Europe and Irish Travellers. No mention of other Gypsies or Travellers such as English Gypsies or Romany, New Travellers, Bargees, Fairground or Showmen was made.

Words illustrating an understanding of how Travellers might earn a living were limited to three, however the theme entitled "Media Stereotypes" contained several references to theft and stealing: -

Drives (Tarmac / paving)

Jobless

Benefit reliance

6 references to the community being an excluded group who were seen as "hard to reach" were made, explicitly demonstrating recognition that the community was sometimes misunderstood and isolated.

Some responses acknowledged the existence of health problems; these were attributed to non-engagement, aggression towards health staff and refusal to accept interventions, including immunisations.

Some of the statements regarding problems encountered by Travellers implied that these were self-inflicted and based on poor relations with the settled community. Other reasons for problems were said to be disadvantage, related to poor finances and benefit reliance.

Responses relating to accommodation demonstrated limited awareness that the majority of Travellers now lived in bricks and mortar accommodation; entries were restricted to references of no fixed abode, nomadism and caravan dwelling.

There were a moderate number of entries regarding education; referring to poor education, poor literacy and school non-attendance associated with mobility.

"Media stereotypes" was by far the largest theme, containing fifty-four separate words or statements that focused on dishonesty, violence, alcohol misuse, hygiene, rubbish, untidiness and the inadequate care of children.

Within the second largest theme, "Way of life", the main focus was mobility and nomadism. High teenage pregnancy rates were cited and drinking, fighting and being non-conformist were considered prominent features of Traveller life.

6.2 Questions from health staff

The 82 questions posed by staff groups were grouped into 13 themes (see Table 5.)
There were very few questions about Gypsy Traveller origins, what defined Gypsy Travellers and where or whom the local Gypsy Traveller communities were.
The largest numbers of questions were on culture and education. These questions focused on what it was like to be a Traveller, why Travellers lived the way they did and what Traveller values and traditions were.

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Table 5. Themes from questions articulated by health staff

Themes	Nos.	Themes	Nos.	Themes	Nos.
Discrimination	1	Aspirations	4	Nomadism	9
Origins	2	Accommodation	6	Culture	14
Names	2	Services	6	Education	15
Local Travellers	3	Income	8		
Health	3	Exclusion	9		

A small selection of the questions asked and Traveller responses are included here. There was some evidence of recognition that Travellers were an excluded group and that this necessitated finding ways to reach out to the community. Nevertheless some questions were couched in a way that implied self-imposed exclusion.

Staff question 1.

Why do they not mix with those outside of their community?

Traveller response: -

"We do mix…if we get close to a friend. It's not easy because they don't understand the culture, but we like mixing with people who understand us"

Staff question 2.

Why do they like isolated lives?

Traveller response: -

"Sometimes you might feel that it's easier to be with people who understand you…it can be hard mixing…and then you still see signs saying "No Travellers"

Staff question 3.

Do you feel isolated?

Traveller response (Housed): -

"I feel very isolated, not just me but my children…they're lost. My daughter's got a Facebook page for her English friends and another for her Traveller friends and family… she more or less has two identities…I think psychologically

somewhere down the line there's problems with things

like that. That's why I make a conscious effort to show her

more of the Traveller's way of life"

It was evident from some questions that broad assumptions were being made about Travellers' unwillingness to mix with the settled community. Responses from Travellers accepted that there was a preference for mixing with members of their own community; however this was not to the exclusion of the wider community. The apprehension expressed by some Travellers about mixing with the settled community or "country people" was associated with negative past experiences and the need to preserve culture.

Staff question 4.

Do you feel discriminated against?

Traveller response: -

"Yes. Like going to pubs you see the sign "No Travellers",

if you're having a wedding they won't give you a function

if they find out you're a Traveller. When you're walking

on the street sometimes you get racist remarks"

"Sometimes. Like the other day my children were being

called trailer trash, but what's interesting to me was the

week after the programme on Traveller's weddings on

television they got some status in school. It's interesting

how people can change their point of view if they're given

enough information"

Questions were raised suggesting living in accommodation other than a house was abnormal. Inferences drawn from questions about nomadism illustrated a lack of awareness of how deeply embedded within Traveller culture the need to roam might be. There was little expressed that indicated an awareness of the pressures on Travellers to abandon a travelling lifestyle, or a realisation that there were now more Travellers living in houses than on sites.

Staff question 5.

Why are you called Travellers if you're living in a house?

Traveller response (Housed): -

"Traveller's nothing to do with whether you're living in a house or a trailer; it's to do with your blood. It comes from our ancestors so it doesn't make a difference where we have to live or where we stay. We have Traveller's blood"

Staff question 6.

What are the main values of the Traveller community?

Traveller response: -

"Being strict with the children. Making sure they marry within the community, but not necessarily…some do marry outside of the community. Passing on the traditions to the next generation…what was taught to me"

There was also an assumption that education was unimportant to Travellers and there appeared to be limited understanding of the tensions that might exist for Travellers between engagement in formal education whilst preserving the importance of maintaining cultural life and the value of informal education.

Staff question 7.

Why isn't education important to them?

Traveller response: -

"My daughter's at school and I want her to do well but it's important for her to see the other side of life as well…here she doesn't know who she is, she's losing her identity"

Staff question 8.

Why do you allow your kids to miss out on school?

Traveller response: -

"Traveller boys, when they're 14 or 15, they want to do what

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their fathers is doing, so they wanna start working for their

living…because some of them be married at 16 some at 17

or 19. They more or less take up in their father's footsteps.

They learn at a young age at 14 and 15 so they have a trade

when they get married, that's why Traveller children, boys,

doesn't continue school…and girls don't continue school

because they've got to work the way Traveller women work,

they have to learn to cook, clean and provide"

Questions about aspirations spoke of dreams and goals for the future, both for children and for Travellers in general.

Staff question 9.

What dreams or goals do you have for your children?

Traveller responses: -

"I'd want them to follow in our footsteps, but that'd be

their decision, I can't make that decision for them"

"My dreams are their dreams really, there are certain

rules for me and certain things I wouldn't accept them

doing but if they choose to work and have a life before

they settle down then I'm happy for them to do that.

Staff question 10.

What does the future hold for Travellers?

Traveller responses: -

"I don't think about the future much really, I don't, I don't

really get time…to be honest…I just hope for the future

that everyone's happy and there's no tragedy"

"I think we're gonna become extinct, that's exactly my

thoughts. It's ok having four or five sites but there's

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loads of Travellers out there and they're disappearing…

the law's making things hard"

An assumption that Travellers didn't like working was made and questions were asked about how they made money or whether they claimed benefits.

Staff question 11.

Do Travellers have or hold down full time jobs?

Traveller response: -

"We like to work for ourselves…the men will work tarmac,

sell carpets, rugs, sell sofas…going to markets or selling

them door-to-door. They might buy and sell cars"

Regarding health and accessing services, some questions did recognise that a nomadic lifestyle might pose difficulties when trying to access health services, and it was clear that that there was a need to make services more responsive and appealing.

Staff question 12.

What can we do to make services more appealing to you?

Traveller responses: -

"You want to go somewhere where you feel you're

gonna be listened to…you're not gonna be judged"

"I feel if they told us more about the services, if they

came and talked we'd understand a bit more about

them"

Some interest in health issues affecting Travellers was noted, and questions about preferences concerning illness and death and where care was delivered were asked. In addition there were questions about gaining a deeper understanding of Travellers.

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Staff question 13.

What specific health issues do Travellers have?

Traveller responses: -

*"There's loads of Travellers who's depressed,
too much stress, to many problems…and they
won't get help, or maybe they'll get depression
tablets from the doctor but they won't see anyone
else cause if anyone finds out you'll be black
listed…they'll think you're a nutter"*

*"I don't know if we're different from other people…
maybe we take a while to go to the doctor, sometimes
you've that many things to be seeing to, you leave
things to the last minute…when it's really bad"*

Staff question 14.

*What's the most important thing health professionals
should know about Travellers?*

Traveller responses: -

*"Sometimes Travellers need things explained. You'll be
dying of shame and you won't say you didn't understand.
We need things put simply…not so many big words…you
think you're breaking it down for us but you're not"*

*"A lot of us are ignorant of things…we won't get ourselves
checked out, we're afraid…we don't go unless we really
really have to"*

7.0 Discussion

Research evidence suggests the health status of Gypsy Travellers is considerably poorer than other English-speaking minority ethnic groups (Van Cleemput et al, 2007; Parry et al, 2004; Doyal et al 2002; Royal College of Gynaecologists, 2001). The reasons for these health inequalities are recognised as poor access to health services, poor literacy, poor accommodation and lifestyle choices. A lack of understanding about the needs of Travellers and Gypsies by health professionals coupled with discriminatory practices, individually or institutionally orchestrated, is also linked to reduced access and uptake of services by Gypsies and Travellers. Gypsy Travellers often cite past negative experiences and the expectation of poor reception as one of the reasons for failing to access health services in a timely or appropriate fashion. The necessity to unpack aspects of this issue and an exploration of how Gypsy Travellers were viewed by health professionals formed the basis of this project, which included examining attitudes and reflecting on what changes, if any, needed to take place.

During data collection at the point of generating responses to hearing the terms "Gypsy" or "Traveller", some staff queried *Am I doing this with my personal or professional hat on*. The inference from this question suggests a perceived ability to compartmentalise professional and personal views. Whether this is possible, or to what degree this might be done is questionable. Nevertheless the NMC Code of Conduct (NMC, 2008) states that individuals must demonstrate both *a personal and professional commitment to equality and diversity*. Here, no line appears to be drawn between the personal and professional. Although nurses and midwifery health professionals are subject to the Code of Conduct, they are inevitably influenced by, and reflect the wider society within which they live. Within the caring professions the motivation to express professional group norms which reflect the NMC Code of Conduct is high, however it can be argued that having also been influenced by negative and racist societal views, health professionals' behaviour and practice will inevitably be tinged with negative or contentious views to a greater or lesser degree.

Within professional groups the expression of negative views may be suppressed to fit with what is seen as the group norm. Subsequently it may be difficult to conclude whether professionals are genuinely culturally competent or whether they are just expressing views

that support the group norm. Dowden and Robinson (1993) suggest that the suppression of prejudice is not always motivated by personal or professional integrity or an inner hunger for justice or equality. Rather, that the suppression of prejudice is often motivated by an attempt to conform to perceived social or group norms regarding the appropriateness of expressing prejudice. As cultural norms become progressively more negative toward overt prejudices toward ethnic or racial groups, and as people become more sophisticated, they become motivated and skilled at repressing inapt forms of prejudice. Crandall et al (2002) also hypothesized that expressed prejudice was a direct function of its social acceptability and the public expression of prejudice was very highly associated with social approval of that expression. This speaks to conclusions reached by the CRE (2006), maintaining that discrimination against Travellers was the last "respectable" form of racism, resulting in negative views about the Traveller community achieving acceptability and going unchallenged as a result.

Although the existence of "respectable" racism is acknowledged, within professional circles it may still be considered unwise to divulge such views. Jones' (2010) work on unconscious bias concludes that having prejudice is normal but admitting to this is career suicide. This can lead to a culture of denial, which in turn perpetuates failure to explore attitudes and raise awareness of our unconscious biases. He argues that awareness of our bias is therefore pivotal to achieving sustainable and authentic behaviour change, and suggests we develop control our natural prejudicial instincts by accessing our ability to prevent innate reactions becoming behaviour. Jones suggests that, as with muscles, which have memory for repeated actions, we can develop this ability by increasing our awareness of our own prejudices through practice. Self-awareness is an integral part of many cultural competence frameworks, and is indeed fundamental to the reflective process within nursing practice. If individuals fail to acknowledge the pervasive nature of bias, prejudice and discrimination, and the negative impact this may have, both on practice and the delivery of equitable service, it will be difficult to move forward to a point where a safe environment can be developed in which to discuss and unpack those issues that inform professional practice when working with Gypsy Travellers. Currently the main forum where these issues are addressed is within the equality and diversity training agenda, however there is a need for robust and open discussion within the practice arena in order for authentic assimilation of

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cultural competent values to take place (Campinha-Bacote, 2008). There is potential for this concern to be addressed through practice development and clinical supervision forums, however there is a need for "buy-in" at a high organisational level.

Despite doubts about how effective assessment tools are, Brach and Fraser (2002) conclude that a business case can be made for cultural competence training as an effective tool for reducing disparities in health. In examining cultural competence the focus must not only be on individuals within an organisation, but on the organisation itself. Organisations that seek to meet the needs of culturally diverse clients must demonstrate systemic and clinical cultural competence by examining the processes and structures that support discrimination (Betancourt et al, 2002).

Campinha–Bacote (2008) argues that a construct, which has received little attention, is that of cultural desire. Cultural desire is described as the motivation to "want to" take part in the process of moving toward cultural competence, rather than the "have to". This issue appears to be a key factor in unpacking reasons for the gap between knowledge and practice when caring for Gypsy Travellers or members of any BME community.

The NHS and the desire to tackle health inequalities were founded on principles of social justice. Pacquiao (2008) closely links the notion of cultural competence with the pursuit of social justice and a commitment to the protection of human rights. Where the promoted organisational social norms mirror the components of cultural competence frameworks, organisational cultural competence provides a backdrop for staff, and in so doing reinforces social justice values.

The business case for cultural competence training can still be made in financially straightened times, with improved patient care, experience and satisfaction being outcomes which speak very clearly to the quality agenda (Glazner, 2006; Pearson et al, 2007). The development of a more culturally competent workforce leads to more effective care (Brach and Fraser, 2000; Leininger and McFarland, 2002), and services with an awareness of the cultural identity and health needs of Gypsy Travellers are better positioned to provide services that meet the needs of that community (Foster Curtis et al, 2007). Movement of the debate from equality and diversity to that of embedding cultural competence will demonstrate the responsiveness of health services to diverse community needs.

8.0 Development of resources

The development of a Frequently Asked Questions booklet and the content of an on-line programme providing information about Traveller culture and health needs are underway; these are being informed by iterative data collated during two stages (see 5.1) with staff and the Traveller responses to the questions posed to them.

Questions to be included in the booklet have been selected from those provided by staff, with the intention of addressing the information needs of staff and providing a range of views from the Traveller community. The questions fall into the following subject headings: -

- Definitions
- Origins
- Culture
- Nomadism
- Exclusion
- Discrimination

- Health
- Accessing services
- Accommodation
- Education
- Employment
- Aspirations

The answers given by Irish Travellers have been used verbatim; this appeared to be the most effective way of giving a more powerful voice to the community. Throughout the booklet explanations have been added where needed, in order to more fully unpack the issues being addressed, with an expectation that a deeper understanding of the concerns of the Gypsy Traveller community will ensue. Various drafts of the content have been presented to selected members of staff, and members of the Irish Traveller community, for their comments and feedback. The skills of an illustrator / designer have been engaged and in addition local Travellers have provided photographs and agreed to be photographed for use in the booklet.

The content of the on-line programme is being developed using scenarios relating to barriers to accessing healthcare, including attitudes of health staff towards the Gypsy Traveller community, cultural issues, accommodation and health literacy. This content will form the basis of further work to launch an accessible on-line programme.

9.0 Conclusion

The aim and objectives of the project were to support the development of cultural competence in health professionals who might come across Gypsy Travellers during the course of their work.

Data collated from anonymous responses and discussions generated in the feedback sessions suggested that many participants had perceptions of Gypsies and Travellers that were informed by negative media stereotypes. There was limited understanding of Gypsy Traveller culture, health needs or issues affecting the community. The main focus of questions about the community were education and culture, with very few questions regarding health or discrimination.

The development of the FAQ booklet, incorporating the staff feedback sessions in a collaborative manner provided opportunities to share information about the needs of the community. In addition, this also provided opportunities to explore the potential influence of negative media coverage of the Traveller community on professional practice. In reviewing examples of the data during these sessions, many staff commented on how seeing several negative stereotypes together engendered a feeling of uneasiness, causing them to reflect on what this might mean for the Gypsy Traveller community; knowing that others had negative perceptions of them. The feedback sessions demonstrated willingness by staff, not only to challenge themselves, but to also be challenged, and to explore their attitudes.

This project highlighted the need for staff to have improved understanding of Gypsy Traveller culture and the issues faced by the community. It also demonstrated the benefits of honest, non-judgemental, open discussion within professional forums about the existence and impact of bias and prejudice on practice.

Based on the issues identified from the data analysis conducted for this project a number of areas for further work have been identified: -

- Development and delivery of training in partnership with Gypsy Travellers.

- Development of robust cultural competence training programmes, including the use of validated competency assessment tools, firmly embedded within the mandatory equality and diversity agenda.

- Targeted interventions and outreach to raise awareness within the Gypsy Traveller community of available services.

There is potential to improve Gypsy Traveller engagement with services and health professionals, such that community members are empowered to access mainstream services, and in due course contribute to reduced health inequalities. Culturally competent commissioners and providers who are sensitive to the needs of Gypsy Travellers and able to build partnerships across statutory and voluntary organisations and the Gypsy Travellers, will be well positioned to develop joint and effective responses to the health needs of the Gypsy Traveller community.

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*"It's interesting how people can change their point of view
if they're given enough information"*

Christine - Irish Traveller

Gill Francis, Health Inclusion Worker for Travellers & Gypsies