

# **Health & Social Care needs of Gypsy and Traveller Families and communities in West Sussex.**

**Report compiled by the West Sussex Local Involvement Network**  
September 2010 (11 pages)

## **1. Introduction**

The West Sussex Local Involvement Network (LINK) has been working with Friends, Families and Travellers (FFT) to address the issues facing Traveller communities across West Sussex. FFT is a well established organisation working to address such issues and together we have sought to identify and address some of the barriers which are preventing these families from accessing support for their health and social care needs.

With the Equality Act 2010 beginning a new era that puts working effectively with different groups at the heart of the new public sector duty, it is more important than ever for local authorities to map and monitor the needs of different groups so that they can effectively meet their needs. The West Sussex LINK is committed to engaging and supporting local communities to voice their issues and concerns in regards to all of their health and social care needs. It is the responsibility of all to discuss and discover ways to map the equality needs of communities in line with new legislation. The task of improving equality and making our society fairer is highlighted in the coalition Government's recently published programme for Government and it is clear that the expectation of Local Authorities and others is to tackle and improve equality in localities.

## **2. Background**

### **2.1 Recent Events**

FFT have been instrumental in the organisation of 2 recent events in West Sussex – The Gypsy and Traveller Mental Health Event in June 2009 and the Gypsy Roma Traveller Customer Insight Workshop in March 2010.

At these events examples of issues highlighted were as follows:

- Accessing services is difficult for Gypsy and Traveller families as there are high levels of illiteracy – estimates are as high as 62% (Dorset, 2007).
- The incidence of depression is high, in part thought to be due to social isolation.
- There is a lack of trust of Health and Social Care Services.
- Their poor living environment impacts adversely on their mental wellbeing.
- There is a high incidence of domestic abuse.
- Poor physical health impacts significantly upon life expectancy which is up to 10-25 years lower than the UK average (Sheffield University Report 2004).

## 2.2 Development and Support Workers in West Sussex

FFT have a Health and Social Care Team working in West Sussex, consisting of:

- Community Outreach Worker whose role is to support people to access Adults' and Children's Services.
- Community Support Worker looking at Domestic Violence Services.
- Wellbeing Caseworker.
- Young Peoples Worker.
- Sussex Traveller Advice Group also employs a Community Development Worker.
- Rethink also employ Community workers to support Gypsies and Travellers to improve their emotional wellbeing.
- Other work includes the delivery of Cultural Awareness training which has been delivered across West Sussex to Community Mental Health Teams and A&E departments and a wide range of statutory and voluntary services. Residents groups have also been set up on three sites.

## 3. Recent Work

The West Sussex LINK has been working with FFT's Community Outreach Worker. They have been carrying out joint visits to sites in order to gain greater understanding of the health and social care problems of Traveller communities and the barriers they face in accessing services in West Sussex. These site visits and interviews have been unstructured, very much listening to the issues that are foremost for the Gypsy and Traveller communities. In response to the concerns of these communities, it is hoped that a network of Gypsies and Travellers can be developed to represent the views of their community to highlight their issues and concerns in order to make improvements to their health and social care experiences.

The following sites in West Sussex have been visited:

- Tangmere
- Westbourne
- Yapton
- Lancing
- Adversane
- Horsham
- Horsted
- Burgess Hill
- Cousins Copse

These sites vary in size from 3 plots to over 20 plots.

During these site visits many issues were identified:

## **4. Public Health Issues**

### **4.1 Poor Housing Conditions**

These are affecting both the physical health and emotional wellbeing of Gypsies and Travellers.

- For example, one site is situated right next to a sewerage works and refuse tip. A woman in her twenties talked about her mental health issues, her isolation and lack of money. The poor living conditions together with her family responsibilities impacted upon her mental health difficulties. She was unable to work due to her mental health problems and also said that the Gypsy and Traveller culture restricted her in many ways and she found that hard. FFT worked with her building trust, helping her to get her medication sorted out and she has now agreed to work with FFT and is representing the Traveller community at different events to help raise the issues of her community.

- At the same site a single mother with three children described how she felt very isolated and depressed about her living conditions. She explained that she has had to take her children to the swimming pool so they can wash as there are no proper facilities on site and this was causing her a lot of distress as it was so expensive and she could ill afford to do so. She said that they have been promised shower blocks for many years now and nothing has been resolved [There are no washing facilities at all on this site.] They have also experienced many months where their electricity was coming via a generator. The living conditions on this site are very poor and have a considerable impact upon physical and emotional wellbeing.
- At another site, a mother of three children was really depressed about her living conditions for her children - she showed us where she has to shower the children outside in a cold outside toilet with small cubicle for the shower. She explained how awful it was to have to take the children out in the freezing cold weather to wash them. She also mentioned that they couldn't be left outside because they could run off as there was no fencing or gate or anything to keep the children in and safe. There was a playground but she would have to be with them at all times as it was out of sight.
- There are also concerns about security of tenure for their plots as they are only available for their lifetime and there are worries about security for their children.

Families feel very powerless faced with these issues and are unaware of how to change and address these issues. Now, on three sites, resident groups are being supported to develop by FFT and they are beginning to take action – for example in campaigning for better safer play areas for children. Once firmly developed these groups could provide a useful platform for inviting councilors, site managers, and representatives from Family Centres and Adults' Services.

## 4.2 Financial Issues

There is a lack of awareness of entitlement to Welfare Benefits such as Attendance Allowance and Carers Allowance, so many families are struggling on very low incomes. Only in *some* parts of West Sussex has CAB outreach been available.

- Many families have disability issues - for example, in one family the husband was partially sighted, diabetic and had heart problems. His wife was his carer, but was also caring for her mother who has dementia who lives in a trailer a few doors up. Their 16 year old son is a young carer for his grandmother at night and sleeps in her trailer and does jobs for her in the day when he can before and after school. They did not know what financial benefits or other services were available to them.

## 4.3 Social Exclusion

Gypsies and Travellers do encounter racism and it is hard to locate sites because of the resistance of local communities. Where the sites are located, Gypsies and Travellers are often excluded from the local community. Sometimes there is so much antagonism that mediation is required to address this.

Sometimes it is the Traveller family's wish not to be integrated but they still need good access to health, education and employment and many do not know how to access this.

As a result they frequently feel isolated and this can have a significant impact upon their emotional well being. When a Traveller goes into housing, they can feel even more isolated than living on a site – as no one knocks on their door anymore.

## 4.4 Diet and Smoking Cessation

Diets can be poor because of limited income and lack of knowledge about healthy eating. Similarly they would not know how to access advice about smoking cessation. In East Sussex, Health Trainers have started to train Health Champions within the Gypsy and Traveller community in order to address some of these health issues – a useful model for West Sussex PCT to potentially consider.

## **5. Primary Care Needs**

### **5.1 Lack of Understanding**

There is a lack of understanding of the services that are available and how to access them – they don't know what to ask for.

### **5.2 Access**

Access to GP Practices and dentists can be difficult. It has happened that after a GP practice had a bad experience, subsequent Travellers have been refused registration when their address is known. This is not something there is evidence of with the general public living in other residential areas and could be interpreted as demonstrating a racist attitude.

### **5.3 Continuity**

Continuity of health care is a particular issue for 'roadsiders' – particularly for such things as immunisations and health screening better. Some GP practice receptionists seem unaware of temporary patient regulations and 'roadsiders' tend to migrate to areas where there are good walk in services – which meet their needs better or alternatively to use A&E inappropriately instead.

Other minority groups have dedicated services provided by the PCT, a dedicated mobile GP service could meet the needs of this group of people very effectively.

## **6. Secondary Care Needs**

### **6.1 Lack of understanding**

Within the hospital setting there is a lack of understanding of Gypsy and Traveller culture which can lead to difficulties as all members of the community wish to be present to support their relative.

### **6.2 Access**

For families where there are difficulties in accessing primary care, there are clear difficulties in also accessing secondary care services.

## 7. Social Care Needs

### 7.1 Un-met Need

Families have been identified with the following needs whom are not in touch with any support services:

- Severe learning difficulties, visual impairment, physical disabilities, mental health difficulties.
- Following site visits referrals have been made to the following services, in most instances by FFT acting upon the family's behalf – Community Partnership Teams, Carers Support Services, Supported Living, Adult Social Care, Children and Family Centres, Citizens Advice Bureau, Shopmobility, Cruse Bereavement Services, Crossroads. In all the examples below, people have been put in touch with appropriate services.

### 7.2 Mental Health Difficulties

There is a high incidence of mental health difficulties amongst Gypsy and Traveller families:

- For example in one family a mother with 2 young children has severe mental health difficulties and very unpredictable behaviour which is very difficult to manage within a trailer home. Her mother is her carer also looks after the 2 children. The family is under immense pressure as the daughter wanders round the trailer all night cleaning as the family members struggle to sleep.
- In another family a single mother cares for her son of 7 months, her mother who has dementia and her father who has a heart condition. They were not in touch with any services.

### 7.3 Physical Difficulties

Those families affected by physical disability find it particularly difficult to cope in a trailer.

- For example an older man with multiple difficulties was having great difficulty accessing his trailer and also needed support to be independent at home. He was not in touch with services.
- Another older woman also who had a disability and mobility issues which made it very difficult for her to be independent.
- A brother and sister in their thirties who are both morbidly obese both suffer from depression. The brother is completely house-bound, the sister has a mobility scooter but hasn't been able to access her local town for 10 years.

Potentially there is a need for District and Borough Councils to have a strategy for engagement with Gypsy and Traveller Families in regard to Home Adaptation Grants.

An informal survey of District and Borough Councils in the county was undertaken to find out if there an assessment process in place for necessary adaptations for Gypsy and Traveller communities or whether any adaptations had taken place on permanent sites to trailers in response to Occupational Therapist recommendations. It was found that, according to the memories of the responsible officers, two (Chichester & Adur) out of the 7 councils contacted had implemented adaptations (e.g. alterations to bathing facilities and steps) or had an assessment process serving the Gypsy and Traveller community in place. It should be stated however that not all of the Districts or Boroughs have permanent sites for the Gypsy and Traveller community within their areas of jurisdiction.

Nevertheless the informal survey suggests that more awareness is needed on the part of some Councils in this matter.



## 7.4 Learning Difficulties

There is a feeling that families are not listened to when they do contact services:

- A family with a son of 30 with learning difficulties has not received any support for him and he was not accessing any services. His mother said that she has asked for help in the past and has been refused. His father said that he is sick and tired of people coming round with their clip boards and promising things and not delivering or not listening to what they want and telling them what they need for their son.

## 8. What are the Barriers?

### 8.1 Fear and Distrust

- There is a fear of Social Care Services, with families caring for disabled relatives fearing that their relative will be taken away and put into care.
- It is not uncommon for families to fail to follow up with services once a referral has been made – this is a particular issue for mental health services where there is a strong fear of ‘sectioning’.
- Some families have been known to ‘give up’. When phoning Adult Social Care Services, their experience of being asked a lot of questions and then being given another number to phone sometimes results in them not following up with their call. They do not understand who they are giving their information to and can be suspicious about the credibility of who they are talking to.
- There remains a feeling within the community that families should cope with their situation and there can be a reluctance to consider outside support – particularly an issue for older generations who are reluctant to accept new ways.
- Word of mouth is most important – if there has been a good experience word of mouth is extremely important in building up trust.

### **8.3 Lack of Understanding about Services and their Rights**

This is a particular issue for Adult Social Care. Gypsies and Travellers are not aware of what is available, and as levels of literacy are low and they don't know who to ask, they can miss out on services that they are entitled to.

### **8.4 Cultural Differences**

There is a need for culturally sensitive services – in particular culturally acceptable care services. For example, families are very reluctant to accept care from anyone outside the family and it would only be acceptable for male care workers to provide care to men and similarly women care workers to women.

Self Directed Support therefore has a lot to offer these communities, but needs time to build trust and develop an awareness of how it could work positively for their families.

## **9. Other Work Being Undertaken**

The Office for Public Management have been commissioned by NHS West Sussex and West Sussex County Council to undertake a needs assessment for Gypsies and Travellers and this report is due for presentation in September.

## **10. Recommendations**

There is a need to build trust, improve knowledge about services, and explore ways of providing services in a culturally acceptable. Ways in which this could be achieved include the following:

- More outreach services visiting the sites – services which come to them.
- Cultural awareness training for all statutory services (in particular Adults' Services and Health) – to date most training has taken place with the voluntary sector and with Sussex Partnership Trust.
- A programme of joint visits with Adults' Services and FFT to develop trust, explain Self Directed Support and arrange support for families whose needs are not currently being met.

- Developing the role of Health Trainers to train Health Champions within the Gypsy and Traveller community.
- A dedicated mobile GP outreach service
- Site visits by local councillors to view those sites that continue to have poor facilities – a particular issue for families with children where washing facilities are either poor or unavailable and where play areas are either absent or unsafely located. The LINK or FFT would be happy to facilitate and support any visits if required.
- A review of the role of Site Managers. Some site managers do help with form filling and accessing services, but some sites do not have managers or the managers are unable to take on this role. With training, the site managers could be a key resource in ensuring that communities are more aware of services that are available to support them. As an existing service, if reviewed and improved to provide what Gypsies and Travellers need, this could potentially have a significant impact on the health and well being needs of this client group without additional costs.

Many of the issues facing Gypsy and Traveller families arise from a lack of information and understanding about health and social care support – a culturally sensitive approach to these issues working closely with FFT could go a long way in addressing them.

#### References:

1. Dorset Traveller Needs Assessment 2007.
2. Parry G, van Cleemput P, Peters J, Walters S, Thomas K, Cooper C, The health Status of Gypsies and Travellers, University of Sheffield 2004.

## West Sussex Local Involvement Network Friends, Families and Travellers

Report compiled by West Sussex Local Involvement Network - August 2010

Contact: Email: [jane.weston@helpandcare.org.uk](mailto:jane.weston@helpandcare.org.uk) Tel: 01403 787944