

A Collaborative Programme to Improve the Oral Health of the Gypsy and Travelling Communities in Sussex



Photo Simon Evans

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BACKGROUND

This programme was funded by *Communities for Health* following a successful bid by Friends Families and Travellers (FFT) to Brighton and Hove City Council Public Health Programme. Funding commenced April 2009 for one year to March 2010.

This programme was initiated by FFT, a small national charity that works on behalf of Gypsies and Travellers. It has considerable experience and knowledge of this client group and currently runs a health outreach service in Brighton & Hove, East Sussex and West Sussex in order to help Gypsies and Travellers access mainstream health services.



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Their funding proposal highlighted that Romany Gypsies and Irish Travellers are recognised as ethnic minorities for the purposes of the Race Relations Act yet they experience the worst health outcomes of any minority ethnic group in the UK. FFT reported that from their work with Travelling communities over many years there is strong anecdotal evidence that Gypsies and Travellers suffer huge oral and dental health problems resulting in hospital intervention. For example, a case of two children who required over 30 teeth removed between them under general anaesthetic. A referral was made to children's services as the children were being given a bottle of calpol a day in order to quell the pain of their rotten, blackened stubs. One of the children had not eaten a solid meal for a number of years, as it was too painful. Much of this problem is caused by ignorance and a lack of accessible information.

On another occasion a toddler was being fed cola and ambrosia custard through a bottle resulting in obesity problems as well as dental problems. There is evidence of inequity of dental health and dental service use with

more disadvantage being experienced by Travellers on unauthorised and transit sites.

There has been little research into the oral health needs of Gypsies and Travellers, but the research project below correlates with the anecdotal evidence gained from outreach workers and practitioners '*Oral health care in the lives of Gypsy Travellers in east Hertfordshire.*' D.M Edwards, R.G Watt
Department of Public Health, Bedfordshire Health, Luton.

From over five years of outreach work with Gypsies and Travellers across Sussex, FFT have found that a targeted approach using community advocates is the most effective tool for change. This model of outreach work is recognized as a model of innovation and Best practice by the Equalities and Human Rights Department within the Department of Health. The oral health improvement programme was designed to follow this outreach work model.

THE TEAM

As FFT serves communities across the whole of Sussex, this presented an opportunity for the oral health promotion teams in the 3 Primary Care Trusts (PCT) to collaborate in training and resourcing the outreach workers.

Zoe Matthews
FFT Strategic Health Improvement Manager

Marya Sadouni
FFT Outreach Worker

Sarah Benwell
Oral Health Promotion Manager, East Sussex Special Care

Dental Service
East Sussex Downs & Weald PCT

Thelma Edwards
Oral Health Promotion Co-ordinator, West Sussex

Community Personal Dental Services (WSCPDS)
West Sussex Health

Sandy Stillman
Oral Health Promotion Manager, South Downs Health

PLANNING

The team first met in February 2009 to discuss the needs and design a programme to begin to improve the oral health of the families in the Gypsy and Traveller communities in their areas. This programme was to be delivered via the FFT Outreach Workers.

The determinants of poor oral health were identified as:

- Lack of accessible, culturally appropriate information.

- Distrust and negative attitudes – both population and professional.
 - A historical neglect of dental health services in reaching out to the Travelling community.
 - Raised levels of fear and anxiety about visiting the dentist.
 - A transient population.
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- ✓ The team discussed the provision of dental care for Gypsies and Travellers which varied across Sussex. Updated contact details for access to dental care were provided to enable FFT to signpost members of their community to the nearest available access.
 - ✓ A need was identified for cultural awareness sessions for all members of the dental teams as it was acknowledged that this community is still subject to discrimination and their specific needs may not be understood by Reception staff.
 - ✓ Basic oral health awareness training was arranged for the FFT team to enable them to promote oral health opportunistically in their contact with the community.
 - ✓ Additional oral health promotion training was arranged for Marya, the FFT Outreach Worker who would become the Oral Health Advocate.
 - ✓ Marya requested resources she would like to support her role as Oral Health Advocate across Sussex. A variety of resources were identified to enable her to develop her own 'toolkit'. These ranged from story sacks, puppets and games for the children, to models, pictures, and flipcharts for the adults.
 - ✓ It was intended to design a culturally appropriate leaflet with the maximum of pictures and minimum of words as the programme evolved.
 - ✓ Funding was set aside for the provision of toothbrushes and paste to facilitate the OHA to opportunistically raise awareness of the need to care for the children's teeth by regular oral hygiene, understanding the role of sugar in tooth decay and findings ways they can achieve improvements in their diet.

AIM To improve the oral health of Gypsies and Travellers in Sussex.



Photo Eva Sajovic

OBJECTIVES

1. Provide culturally sensitive oral health awareness training for eight members of the Friends, Families and Travellers organisation.
2. Train one of their outreach workers as an Oral Health Advocate (OHA) for her community.
3. Design and print simple and appropriate education materials for use by the outreach workers.
4. Provide visual aids to support the OHA in her work.
5. Encourage the habit of oral hygiene by provision of oral hygiene packs for the OW to distribute as she gives the information on brushing.
6. Provide cultural awareness for dental teams in Sussex.
7. Identify access to dental care across Sussex for the Gypsy and Travelling communities.
8. Write up the programme as an example of good practice and report to SHA and DH.

EVALUATION

It was decided that this programme would require a more qualitative approach to evaluation. The following outcomes were proposed:

1. Knowledge would be gained through the training sessions for outreach workers and could be evaluated post training.
2. The Oral Health Advocate would be trained and working in her community.
3. A leaflet in accessible format would be designed and printed by the end of the year's funding.
4. A visual aid toolkit would be created by the OHA for use in her outreach work.
5. The number of oral hygiene packs distribution, number of people visited by Marya, and number of people signposted successfully to dental care provision will be counted.

6. Arrange cultural awareness sessions for dental teams in Sussex.
7. Map the provision of dental care in Sussex.
8. The final report will include case studies will provide snapshots for process evaluation and recommendations will be made for sustainability of the programme when the funded year is completed.

METHOD

Five review meetings were held to enable changes to be made during the course of the year. These also identified a wider network of meetings to which a representative was sent to raise oral health awareness within the network. Training sessions were arranged for the FFT outreach workers, the OHA became operational and resources created over time. The review meetings also identified opportunities for Gypsy and Traveller awareness to be delivered to the dental teams in Sussex.

During this time, a hand-held health record was being designed, through a Department of Health initiative aimed at addressing health inequalities in different areas. The programme known as Pacesetters produced 'The Blue Book', which is being piloted in East Sussex and oral health issues were discussed as being included in this record book to enable continuity of dental care to be delivered when members of the Gypsy or Traveller community moved area.

THE WEST SUSSEX PERSPECTIVE

At the time of this programme, each of the three areas in Sussex represented by the three oral health promotion teams have different commissioning of dental services. The demography is also very diverse, along with number of sites, access to dental care, and oral health promotion activities undertaken within each area. The detail of the activity within each area will therefore vary. This is the West Sussex perspective.



Photo FFT

reported on. However, in the six months this has been in operation, only four patients from this group have been recorded. It is suspected that these figures are an underestimate. Patients are required to complete a standard NHS paper consent form for dental treatment which asks them to select an ethnic group. Gypsies and Travellers would be included in "Any other ethnic group" and only if this box is ticked, would the dentist ask for further information and record it on the computerised record.

However, since April 2010, the WSCPDS have received a new contract from the PCT commissioners which will affect adults from Gypsy and Traveller families being seen. The Service can now only offer appointments to children and special needs patients. Increased access to NHS dental treatment through contractual arrangements with General Dental Practitioners (GDPs) should enable adults to be seen by GDPs. This will leave the EDS for the treatment of dental emergencies only.

Regular reports were sent to West Sussex PCT over the course of the programme and this secured the highlighting of oral health need within the health needs assessment (HNA) specification for West Sussex. This HNA was awarded after the formal end of the programme but interviews between the researchers and Thelma Edwards took place in June 2010 when more detail of the oral health needs of the Gypsies and Travellers in West Sussex were identified and reference to this collaborative programme was made.

The WSCPDS Oral health promotion team have a strong link with the 60 Children and Family Centres (CFC) in West Sussex and much work has been done to ensure their staff are oral health aware. Some of the rural areas have a mobile used by the outreach workers who take the toy library and become a 'one stop shop' of information. They were welcomed by the Gypsies and Travellers onto two sites in West Sussex and this also provided an opportunity for the oral health promotion messages to be made available by the CFC staff. A small amount of funding was also provided by the CFC to provide oral health packs for these communities. The CFC was also made aware of the contact details of the FFT OHA to enable her to be contacted if support for an oral health need was identified.



Photos FFT

During this time, through word of mouth, it was possible to identify health visiting teams who also visited the Gypsy and Travellers. This was initially difficult to do as there was no formal liaison health visitor and the lack of ethnic monitoring made it difficult for records to show which health visitors had contact with this community as they were absorbed in their case load. However, by the end of the programme, and as many health visitors also link with the CFC, awareness of the provision of packs and the collaborative oral health improvement programme had spread across West Sussex and health visitors were requesting more packs.

Case Study of an example of improved access to dental care for a family in West Sussex as a result of the programme

A Gypsy family accessed the Emergency Dental Service (EDS) one Sunday. It was the 4 year old who was the patient on this occasion suffering a tooth abscess. On examination, the child was also found to have a lot of decay, probably requiring multiple extractions under general anaesthetic. The EDS's role is to get a patient out of pain and refer them back to the own dentist for further treatment. However, this child did not have a dentist so could potentially be lost to follow-up. If she had been from a non-travelling family and she had gone back to her dentist, it was likely she would have been referred back to the West Sussex Community Personal Dental Services (WSCPDS) for assessment for a GA. When this was done, the child's health visitor would have been informed and they could have looked into the oral health needs of the younger sibling. There is evidence that, where one child has poor oral health, their siblings would be at similar risk of tooth decay so may benefit from oral health promotion support. Early intervention could prevent decay. However, this would not happen for this family.

The dental nurse on duty that morning had recently attended a Gypsy and Travellers awareness raising session as part of the pan-Sussex Gypsy and Traveller project and was keen to ensure the family received the dental care they needed so she arranged for the child to be referred directly to the WSCPDS, even though it appeared the family were only staying with a relative in West Sussex. It was thought they usually lived in Kent. The child was later assessed in Haywards Heath Dental Clinic and underwent a general anaesthetic for the removal of multiple decayed teeth in St Richards Hospital,

Chichester. The referring dental officer requested that the opportunity to provide additional oral health promotion messages and support was taken at the time of the general anaesthetic session so a member of the OHP team spent time with the family explaining the importance of oral hygiene, a healthy diet and regular checkups with a dentist. Toothbrushes and toothpaste were also given for the whole family.

The mother expressed a strong desire to see the same dentist for her own dental needs but as this dentist does not see adult patients, only the children were offered appointments at HHHC. However, the family wanted to be seen as unit and this was offered at Crawley hospital. The family said they were very happy to accept this and all the family details including social history, grandmother's address and father's mobile were referred to the WSCPDS clinic at Crawley Hospital. The family had an appointment with for January but they had to cancel on their way to the appointment due to the snow that day. They were given further appointments at that time for 31st March. A message was left on the mobile number to confirm the day before the appointment but unfortunately the appointment was missed. There has been no further contact with this family.

EVALUATION

Objective 1: Provide culturally sensitive oral health awareness training for eight members of the Friends, Families and Travellers organisation.

Outcome 1: Knowledge would be gained through the training sessions for outreach workers and could be evaluated post training. Two training sessions have been arranged and 6 outreach workers have shown an increase in oral health knowledge and awareness.

Objective 2: Train one of their outreach workers as an Oral Health Advocate (OHA) for her community.

Outcome 2: The Oral Health Advocate would be trained and working in her community. Marya Sadouni is now accepted within her community as the 'tooth fairy'. Marya's report is found in APPENDIX 1

Objective 3: Design and print simple and appropriate education materials for use by the outreach workers.

Outcome 3: A leaflet in accessible format would be designed and printed by the end of the year's funding. This leaflet has been designed in consultation with the OHA and can be found in APPENDIX 2

Objective 4: Provide visual aids to support the OHA in her work.

Outcome 4: A visual aid toolkit would be created by the OHA for use in her outreach work. Marya has a variety of pictures, posters, books, and models which she can choose from to enable her to tell stories to the children or discuss oral health with the adults.

Objective 5: Encourage the habit of oral hygiene by provision of oral hygiene packs for the OW to distribute as she gives the information on brushing.

Outcome 5: The number of oral hygiene packs distribution, number of people visited by Marya, and number of people signposted successfully to dental care provision will be counted. The original funding provided for 30 packs all of which have been distributed. Further information on this is found in Marya's report in APPENDIX 1

Objective 6: Provide cultural awareness for dental teams in Sussex.

Outcome 6: Arrange cultural awareness sessions for dental teams in Sussex. This was undertaken at a Study Day in Brighton in April 2009 and informally on further opportunistic occasions.

Objective 7: Identify access to dental care across Sussex for the Gypsy and Travelling communities.

Outcome 7: Map the provision of dental care in Sussex. This was originally undertaken for the programme but recent changes in commissioning of the WSCPDS have made this out of date for West Sussex where only children can be seen.

Provision for Brighton and Hove has been enhanced since raised awareness within the Brighton OHP team and the Special Care Dental Service of the needs of this group. There has not been a problem for Gypsies and Travellers, adults or children to access dental treatment in Brighton & Hove, but now, in the new contracts with the PTC, they are specifically mentioned for dental treatment and OHP interventions. Sarah Benwell, Health Promotion Manager at East Sussex Special Care is now a member of the Children and Families Multi-professional Operational Group for Travellers in East Sussex.

Objective 8: Write up the programme as an example of good practice and report to SHA and DH.

Outcome 8: The final report will include case studies will provide snapshots for process evaluation and recommendations will be made for sustainability of the programme when the funded year is completed. This report will be available on the FFT website: www.gypsy-traveller.org and will be distributed to all PCT leads on Equality and Diversity across Sussex and at the Department of Health. It is also recommended that Commissioners are forwarded this report.

RECOMMENDATIONS

This programme has been successful during the year of funding and met all its objectives. However, sustainability of this process of improvement is fragile. This is in part due to changes in commissioning oral health services in

Sussex. West Sussex Health (West Sussex) and South Downs Health (Brighton) are in the process of integrating to form Sussex Community NHS Trust. Financial constraints have also resulted in service cuts, job freezes and lack of funding for programmes. In addition, the West Sussex oral health promotion co-ordinator is retiring and, to date, no decision has been made regarding reappointing to her role so the West Sussex link with FFT may be lost and further development of this collaborative programme will not be undertaken.

However, the results of the Health Needs Assessment for Gypsies and Travellers in West Sussex currently being undertaken may highlight the oral health needs to the commissioners.

The funding for the OHA came to an end in March but, now she is trained and resourced with visual aids, she will absorb oral health into her normal role as a FFT Outreach Worker.



Photo Chris Thomas milton.contact.co.uk

The CFCs in West Sussex could be encouraged to sustain oral health awareness to the Gypsies and Travellers they are in contact with and funding should be provided for oral health packs of baby cup, toothpaste and toothbrush to support the messages. This could be used as a model for the CFC across the rest of Sussex.

The Health Visiting Teams could also be encouraged and equipped with oral health packs to enable them to highlight the oral health needs of the families they are in contact with.

One potential partner in this programme is the Travellers Education Service but it has not been possible to engage them in this health topic as they perceive their role to be in education. This is a missed opportunity to integrate health into education as the two are well linked in the Healthy Schools Initiative. The same oral health promotion resources used in schools could be available for the TES to use as an occasional topic in their work and they could also be valuable oral health champions who could signpost families to more specific dental services.

The NHS ethnic monitoring form requires to be amended to enable more accurate capturing of the numbers accessing dental care and where they access it. This could be at Accident and Emergency Units, or Emergency Dental Services, or Dental Access Centres, or General Dental Practitioners, or the Special Care Dentistry Service. There is currently little accurate data to show which services are being used. It would appear that, traditionally, this community only access dental care when in extreme need so it could be said a service is available for urgent treatment. This provides a treatment led emergency service and does not improve the oral health of this community by promoting oral health and preventing disease. There remains, therefore, inequity of service provision. This programme began to make improvements in this by using the model of community advocates and outreach work and providing cultural awareness for dental teams to enable a collaborative approach.

The general decline in access to NHS dentists over the past few years is likely to have an even greater impact on highly mobile families [Clark, N](#) 'Wisdom Teeth' *New Statesmen* 4/8/08. On a national level, we would recommend that Commissioners are made aware of their duty to provide specialist services where it is necessary. There is a legal responsibility to ensure that services are responsive to the health needs of Gypsies and Travellers, and other ethnic minorities, as with the case of The Southall Black Sisters' Victory against Ealing Council.



Photo FFT

'There is no dichotomy between funding specialist services and cohesion; equality is necessary for cohesion to be achieved.'

Lord Justice Moses

Appendix 1

Project: Oral Health Report from Marya Sadouni Outreach Worker

Project Dates: January 2009 – December 2009

Area Covered : Brighton and Hove, East and West Sussex

During this project I outreached Travellers living in housing, on permanent sites and temporary unofficial sites. I outreached 31 Traveller sites and many houses. I also supported Travellers living in temporary accommodation and hostels. Whilst out I gave oral health advice and informed people of the project. This was done alongside my community support work. Where necessary I would then support people into local Dentists, Emergency Dentists and Dental Hospital appointments for the most serious cases.

I arranged and supported people to have full mouth extractions and oral replacements; Abscess treatment; Gum infections; Acid Erosion; Emergency care and follow up treatment as long as the Travellers were still in the area. I would make an appointment with a local dentist and accompany them to the appointment. If the client had been sedated or undergone general anaesthetic, I would make sure they had company for at least the following 24 hours. I feel that I have provided a huge amount of useful information around oral health, to a community that did not have access to this information in a language that they could understand.

Some of the family's I have worked with in Brighton and Hove and East Sussex:

I provided information and/or support to **209** people in Brighton and Hove and East Sussex, over 20 families. Most of the families that I work with are very large. Information is passed on through word of mouth within families and between families. So even more than 209 Travellers would have accessed the information I provided.

Some of the family's I worked with in West Sussex:

I have worked with over 26 families in West Sussex where, I provided information and/or support to **475** people. In total I provided information and /or support to **684** to Irish, Romany and New Travellers. Information is passed on through word of mouth within families and between families. So even more than **684** Travellers would have accessed the information I provided.



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