

"Just because we're Travellers, we still need doctors like everybody else..."

A busy summer for the "Stories of Health & Wellness" project...

Our community facilitators have been travelling across Wales during June, July and August, to gather stories from Travellers and Gypsies in north Wales, Roma in Newport and Gypsies in Cardiff. Many hours of recordings have been edited and analysed, giving us a total of seven hours of material that provide a strong evidence base for the experiences of Romani and Traveller families in accessing health and wellness provision. With 73% of the interviews now completed by our six Community Champions, our project

is on track to achieve our target of completing the field research by October 2016.

In carrying out our project, the Community Champions have spent many hours building trust and inspiring confidence in potential interviewees, encouraging young parents to share their experiences of doctor's surgeries, hospitals and ante-natal clinics, inoculation for measles, mumps and rubella, dentist's appointments and emergency (A&E) situations. They have also persuaded older parents to talk about traditional remedies, used by Romani and Traveller people in the past to cure ailments, about their understanding of their own wellness

and about their parent's and grandparent's experiences of health and wellness. In a unique aspect of the project, some Romani and Traveller children have been interviewed to provide a rarely heard voice from Romani and Traveller communities — their own.

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GRT Communities and networks in Wales



One of the aspects of the project that is not represented through the collected interviews, is the importance of networks amongst Romani and Traveller communities across the country. Clearly, extended kinship groups are extremely important in terms of the 'connectedness' of our communities. Development of inter-communal networks that play a complementary role to kinship groups has also emerged over the previous 15 years. In particular, the role of the Gypsy churches, so often recognised in scholarship but largely ignored by government, donors and local authorities, has been crucial. This absence in national strategy and policy needs to be addressed.



Patterns of accessing health provision and services

Summer is the time, traditionally, when many families, both those on sites and those in bricks and mortar dwellings, take to the roads and 'shift up and down' the highways and byways of Wales. Many have travelled to the Gypsy fairs, such as Stow-onthe-Wold, Horsemanden and Appleby, Just as many have visited relatives and friends on other sites or in other towns and villages, maintaining the complex web of relationships that connect the lives of Romani and Traveller people in strong, communal bonds. Some, especially amongst the Roma in Wales, have crossed the continent to visit family in Slovakia, Czech Republic, Rumania and Bulgaria, or to travel to the annual religious conventions and take part in pilgrimages, particularly those associated with the Pentecostal 'Life and Light' movement.

Summer and the travel that many families undertake related to these important cultural activities, is also the time when many Romani and Travellers find that accessing the services they need, is the most difficult and problematic. Whilst some GP's (such as those at the Panton Surgery, Hollywell) provide their Romani and Traveller patients with

prescriptions and medicines to see them through these mobile periods, most do not. Medication for conditions such as diabetes, arthritis, angina and other conditions can be hard to come by if, as many of our stories tell us, GP's are reluctant to register Travellers and Gypsies on a temporary basis. Dentist's too can be difficult to access in an emergency situation, when needed by Romani families. Pressure on health services during these times shifts to the local hospital and A&E departments.

Hospitals and parents

Experiences for Romani and Traveller families, especially those with young children (the primary focus of our project), differ greatly across the country (Wales) and across provision. In a number of interviews, the experiences of attending local hospitals for emergency care has been very difficult, we were told. In one case, an anxious mother took her child to be treated at the local hospital after an accidental fall and was locked in a room by a nurse who was determined to involve the social services in what was immediately suspected as child abuse. Suspicion of Romani and Traveller parents as carers, from health care practitioners is a common theme in our interviews with young families.

Themes

Our project has highlighted a number of very important themes and raised differing issues.

Good practice exists

Examples of positive experiences in accessing health services from north and west Wales tell us that, there is good practice for Romani and Traveller people.

2. GP's are trusted

Local doctors are generally trusted and appreciated by Romani and Traveller families. A number of our interviewees preferred to visit their GP, even in emergency situations.

3. Receptionists

Many Romani and Traveller people have told us that receptionists in GP surgeries behave negatively towards them. Registering was a difficult process for all our interviewees, sometimes as they were rejected by receptionists.

4. Hospitals

Visiting hospitals is one area of potential conflict and misunderstanding, when large family groups come to see sick relatives. Health staff find it difficult to accommodate these visits.

Dentists

Dentists and dentistry are viewed warily, in comparison to doctors and hospitals. Many avoid visits altogether.

Romani and Traveller diet

Hunting rabbits, pheasants and other animals (hedgehog for example), foraging for roots, berries, mushrooms and herbs, picking vegetables and fruits on farms have all featured as part of the efforts to source nourishment in the past. This is very rarely the case now. The impact on wellness has been negative, with what seems to be a greater reliance upon ready meals and take-away foods.







Issues

There are some serious issues that need addressing related to health and wellness for Romani and Traveller people.

1. Reading and writing

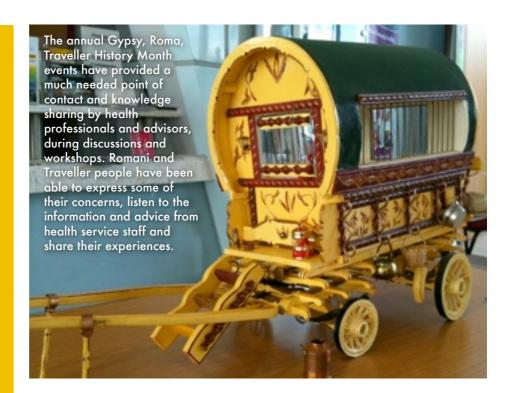
Almost all Gypsies and Travellers interviewed had a low, or no level of literacy, across the age ranges 7-70. This causes real difficulties in reading instructions for taking medicine, filling out registration forms at GP's surgeries, understanding signs in hospitals, following diet sheets or advice on inoculations for babies. The Welsh education system has consistently failed Gypsies and Travellers for the past fifty years in delivering literacy to these communities — why is this the case?

2 Diet

Living on sites for Gypsies and Travellers in Wales has fundamentally changed the kind of diet that families have relied upon. Foraging and bartering for fresh vegetables and meat (rabbits, carrots, onions and potatoes for example) has been replaced by a reliance upon ready meals and take-away foods, with high fat and sugar contents. Childhood dental problems (some of our youngest interviewees told us of having 14 to 20 teeth removed, due to decay), overweight (even obesity), early onset diabetes, blood pressure and heart problems in adult life are all a consequence of these changes.

2 Woman

Romani and Traveller women were, in previous generations, engaged in selling (hawking), fortune-telling, working in agriculture and trading. Presently, restrictions to mobility and street trading or door-to-door selling has concentrated women's roles to the children, caravan and home, with much less engagement outside of the domestic sphere. Agricultural work has become dominated by cheap labour from the EU or Asia. Well-being amongst Romani and Traveller women, has suffered as a result.



Emergency care and pregnancy

Other interviewees have told us of their experience of being discharged very quickly following emergency operations (impacted tooth; automobile accident), seemingly as a result of their identity being understood (registering their address as a site) only to have their conditions worsen and being taken to another hospital where they were better treated. In one particularly distressing episode, a young Traveller mother (18 years) was admitted to hospital late in her pregnancy with complications and had to undergo a very difficult induce birth with a male midwife and many male doctors in attendance. Her family were excluded and she was later put in a ward by herself, 'as she was a Gypsy'. Her husband was not allowed to stay by her bedside and her mother and aunt were restricted to waiting in the corridor overnight (other women in the next ward were allowed husbands and relatives by their bedside for long periods outside visiting hours). Other young mothers have also told us of difficult experiences with health visitors when their children were newborn, being denied supplements when other mothers received them and of receiving better care when they were living in houses as compared to being on sites or mobile.

Romani and Traveller men and health

It is very clear from our interviews that Romani and Traveller men are extremely reluctant to seek out any kind of medical care or assistance. Only when health conditions become chronic (and sometimes not even then) are men in our communities willing to go to a doctor or hospital. One of the consequences is that when they finally do go, they present many conditions and health problems to doctors all at once – seemingly overwhelming their GP. Another is that many have conditions that worsen progressively, sometimes becoming debilitating, which could have been treated earlier and far more effectively. Notions of masculinity are partially at work, but there exists a deep mistrust of health professionals and practitioners, amongst Romani and Traveller men. An example of health provision for Romani men in Rinkeby, Stockholm has demonstrated that targeted health provision has a positive impact upon both male and female health outcomes in Romani communities, through creating better awareness and improving knowledge.

Conclusions

Our project has found that, whilst there are some good examples and a fair degree of satisfaction with the health services provided in doctor's surgeries, by dentists and hygienists, and at accident and emergency departments in hospitals, for many of our interviewees, accessing health care is both difficult and a frequently unpleasant experience. Romani and Traveller families feel frustrated and slighted by the level of discrimination they encounter when seeking medical advice or treatment. Sometimes this is through intermediaries such as receptionists or administrators, but there are interviews with Romani and Traveller mothers and fathers where their lived experience of being stereotyped and excluded comes directly from their encounters with health care professionals and practitioners. These experiences confirm the mistrust that they and their relatives share, becoming part of a 'lore' about what has happened to Gypsies and Travellers at the hands of the 'gorgios'. Whether through an ignorance of particular aspects of Romani and Traveller cultures, or through hostile attitudes born of prejudice, these experiences will continue to ensure that the 'gap' in provision remains and little can be done to reduce it without building understanding and trust.

For Roma, originally form eastern Europe, health services can be far more sinister. In Slovakia and the Czech Republic, Roma women have been forcibly sterilised against their will, whilst Roma children are segregated into substandard education on account of their 'mental disability', diagnosed by biassed medical practitioners and prejudiced special needs educators intent on maintaining cultural boundaries and their own privileges in the education system. Bribery and corruption are present at high levels in the Czech and Slovak health systems, excluding the Roma from all but the most basic care. Profound poverty and emiseration has left a generational legacy of poor health and nutrition amongst Roma in Wales.

Knowledge about availability of health provision is very much lacking amongst all the communities, often because of low literacy or language competences. Information about services is invariably text based and in English and Welsh, with little in the way of visual aids and radio or television used to promote improved access through better reach. Mobile provision, that would effectively address many health and wellness issues amongst Romani and Traveller families, is restricted to health visitors and district midwives following birth of children - though even these services were often criticised by our interviewees, as being infrequent, uneven in their distribution of supplements and obscure in their timetables for service delivery to sites and homes. Aside from these, the extent of mobile provision that could be accessed by Romani and Traveller families is non-existent. To many, if not most of our interviewees, the answer to improved knowledge was through in-person dialogue and regular contact with intermediaries that understood and respected the families they dealt with. Access was often seen as 'blocked' or restricted because of our interviewees ethnicity and identity; in the absence of other communication or explanation (full waiting lists for GP's; pressure on services because of high demand; staff absences and a shortage of critical physicians or anaesthetists, etc.) the assumption of exclusion, based upon previous experiences, proves a ready answer...

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Facts

Our team of six community facilitators and project workers have, during the course of the project:

1. Interviews

Carried out a total of 85 interviews, amounting to a total of 14 hours of recorded material. They have spent a total of 210 hours in meeting and building trust with Gypsy, Roma, Traveller parents and children. Seven of our interviewees have been under 16, four of them under ten years old. The interviews have been conducted in Cardiff, Newport, Bridgend, Hollywell, Conway, Bangor, Swansea and Barry. Individuals and groups have been part of the process in what is the first and most comprehensive research looking at experiences of accessing health services and provision, amongst minority ethnic communities in Wales.

2. Data

They have covered a diverse and fascinating range of subjects connected to health and wellness amongst Romani and Traveller families with young children, from diet and food sourcing to maternity care and gender relations. In total, RCAC now holds 15 gigabytes of data on secure servers, which will provide evidence of health and wellness amongst Gypsies, Roma, Travellers in Wales. Other data can be drawn from this material, such as levels of literacy, numeracy and average length of schooling for children.

3. Parenting

Romani and Traveller parenting has, over the previous fifty years, become more gender segregated as a result of loss of mobility and constraints on economic activities. Travelling engaged the entire family in a range of activities that involved partnership between mothers and fathers to a much greater degree. Children appear, from our interviews, to have been more equally parented in the past.