
Stories of Health & Wellness

AMONGST ROMANI AND TRAVELLER COMMUNITIES IN WALES

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ROMANI
CULTURAL & ARTS COMPANY



The NHS Centre for Equality and Human Rights
Canolfan y GIG ar gyfer Cydraddoldeb a Hawliau Dynol



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To the many Romani and Traveller people who helped us

THE HALF OF THE STORY NEVER TOLD...



Gypsies camping, Swansea, 1953, Geoff Charles © National Library Wales

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To the 'gorgios' and 'gadjó'

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Foreword

THE WELL-BEING OF ROMANI AND TRAVELLER PEOPLE IN WALES

Improving health outcomes for the future generations

The NHS Centre for Equality and Human Rights is delighted to have supported the innovative project, “Stories of Health and Wellness”, in partnership with the Romani Cultural & Arts Company, and the Gypsy, Roma and Traveller communities. We know that these communities face high levels of health inequalities, including shorter life-expectancy, and that they continue to experience high levels of discrimination and prejudice in our society. Through the stories that have been told and collected, we have learned that, whilst there are difficulties in accessing health and wellness services and provision, there exist examples of good practice, which must be built upon for the future. Creating new and different ways for the community to be involved in their health care and well-being is essential if we are to improve health outcomes for future generations of these communities.

We would like to thank the Romani and Traveller communities for sharing their personal stories, and the project team and Community Champions for their energy and time in making a success of this project and giving an authentic voice to the work.

Tracey Good and Voirrey Manson

Joint Interim Directors

NHS Wales Centre for Equality and Human Rights

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Executive Summary

MOVING ON TO BETTER HEALTH AND WELLNESS



Douglas Hern and his children, at Bala, 1953, Geoff Charles © NLW

Our project has told us many differing things in the course of interviewing over one hundred Romani and Traveller people. We have also learned, from the literature survey we carried out, a number of other points related to the health and wellness of Romani and Traveller families, which we can summarise here:

- The health status of Romani and Traveller communities in Wales, is almost certainly much poorer than that of the general population, as recorded in our interviews;
- Poor access to health provision, for a variety of reasons, is a major factor impacting upon Romani and Traveller health, according to our project;
- Mistrust and reluctant uptake of health services in Wales amongst Romani and Traveller families, also contributes to poor health outcomes in the communities, we were told by our families;
- Romani and Traveller communities' health receives little consistent attention in policy and strategy documents on health inequalities in Wales but rather punctuated reporting at various points when advocacy proves effective, as we surveyed the documentation;
- Budgets targeting improving health outcomes for Romani and Traveller families are not clearly defined;
- Examples of good practice exist, as the stories tell us, but these need to be understood and replicated across more localities and incorporated into training for health professionals

The aim of this project has been to explore the health experiences of Romani and Traveller families, specifically in relation to early childhood, in order to understand their perspective around accessing health services and provision, capturing their experiences through storytelling, using digital media. The project also intends to inform future actions of health services and professionals to meet the needs of these communities, appropriately and in a culturally sensitive manner, and strengthen the relationships between Romani and Traveller communities and health services' professionals across Wales. A future development to improve Romani and

Traveller families' understanding of health services and provision, increase their knowledge about access and availability to such services and provision, is an additional, longer term aim.

The outputs for this project include material to develop an e-learning module for NHS staff, a final project report, and dissemination events within the communities and among health professionals – these outputs will help to share knowledge, encourage conversation, and promote positive change in the long term health and wellness of Romani and Traveller communities. The digital stories themselves will form a repository, to be held by the Romani Cultural and Arts Company. A number of the stories, edited and anonymised will be included in the e-versions of this report and other 'products' from the project, online with the NHS Centre for Equality and Human Rights and the RCAC.

Summary of recommendations

There is a need to guarantee access to health services for all Gypsies and Travellers. What once existed and was identified as examples of 'good practice' a decade ago in previous reports, from Wales, has been whittled away by significant budget reductions over a decade and increasing pressure on resources, meaning that 'specialist provision', which facilitated access to health and wellness services for Romani and Traveller communities, has all-but disappeared.

- We believe that specialist services, that can act as a mediator and conduit for information, awareness and assistance, must be in place to facilitate access to health and wellness services and provision for a group of ethnically and socially connected communities that are currently excluded from the full range of services available to the settled Welsh community.
- Specialist provision should not be a replacement for mainstream services, further alienating and excluding the Romani and Traveller communities in Wales, nor should these be an excuse for mainstream health service providers to avoid their responsibilities to deliver high-quality, inclusive and effective provision.
- Such specialist provision should be in the form of a team of Romani and Traveller Community Health Mediators, modelled on the successful Roma Health Mediator programmes in Serbia, Rumania and Slovakia.
- There are cultural issues that impact significantly upon how Roman and Traveller populations access health provision, such as mobility and migration, that must be taken into account in the planning and delivery of services and in the training of health practitioners and professionals in delivery of provision to these communities.
- Languages, literacy and levels of understanding regarding health priorities amongst Romani and Travellers do need to be recognised as existing amongst our communities in ways that have had an impact upon health, well-being and access. Romani and Traveller organisations and programmes have a responsibility to implement a wider dissemination of information and knowledge and encourage our communities to make different choices regarding health and wellness, where they can within the constraints of their environments, circumstances and empowerment.
- Partnership between communities and health professionals is necessary in improving the health outcomes in our communities and political will and commitment to address the particularly low-levels of health and wellness amongst Romani and Travellers in Wales. Effective health education

programmes, developed in co-operation with communities and delivered by Romani and Traveller health mediators, particularly to younger families (to re-start the transmission of 'lost' knowledge between generations) needs to be planned and undertaken.

- Support for parents and carers in Romani and Traveller communities, in increasing awareness about early childhood development and the importance of the role of ECD in the first 1,000 days of life, through positive parenting programmes (such as Parenting With Confidence, or Learning Through Play), that focus upon child development milestones and outcomes need to be put in place in Romani and Traveller communities in Wales.

A short note on terminology

In our project, the terms “Romani” and “Traveller” are used alongside “Gypsy”, “Roma” and “Traveller” as inclusive of Gypsy, Romani, Irish Traveller, Scottish Gypsy-Traveller, east and central European Roma (including *Kalderash, Lovari, Ghurbeti, Rudari, Beyash, Romungro, Vlachi, Xoraxane*) and south-east European *Ashkali* and *Egyptians*, Turkish *Romanlar, Domlar, Lomlar* and Syrian *Domari*, all of whom are present, in differing numbers, in the UK. The ‘lumping together’ of all Romani and Traveller peoples, as an undifferentiated, unitary group, in the acronym “GRT”, is avoided, as this is rapidly creating an elision of cultural and linguistic diversity amongst Romani and Traveller communities, which is ultimately discriminatory in its impact, reducing as it does, complex ethnicities to a formula and potentially promoting the notion that one solution will be successful to address the complex, inter-sectional reality that Romani and Traveller population in Wales (and the UK), face. The analogy would be to describe British Isles populations as predominantly ‘ESWI’ – English, Scottish, Welsh, Irish – no-one suggests this reduction and erasure of diversity in modern Britain, nor that the needs of four quite distinct cultural, linguistic, religious and ethnic populations have exactly matching needs, in health care terms or many other areas, however they may overlap. The descriptions of remaining diverse populations in the United Kingdom are equally compressed into acronyms; BME being the most common and equally inaccurate and inexact. African Caribbean communities may share a great deal in common heritage with West African populations, but the needs of Rastafarian Jamaicans and Muslim Nigerians are likely to be different in approach, if not also in medical treatment. This elision of communities is part and parcel of the ethnically divided vision of British society that further exacerbates health and other inequalities. . .

Introduction

Origins and Romani and Traveller Communities in Wales

MIGRATION, MOBILITY AND ETHNICITY: ROMANI AND TRAVELLER PEOPLES IN WALES



Gypsies and Travellers in Wales, Geoff Charles Collection © National Library of Wales

Early migrations; the Irish Travellers

Romani and Traveller peoples have lived in Wales for centuries¹; Irish Travellers since the 4th century Common Era (CE) and Romani Gypsies since the 17th century.² They are part of the rich, diverse cultural heritage of the country that includes communities present since the late Bronze Age (1,400 - 900 Before Common Era or BCE), such as the Iberian Bell Beaker People, and the central European Celts (La Tène culture) who arrived around 800 BCE. Roman armies began to campaign in Wales, against the Celtic *Silures*, *Demetae*, *Ordovices* and *Deceangli* groups in 48 CE. Migration to that point had been steady and slow, with significant numbers accumulating over time (though not the punctuated, mass migration of peoples that amounted to invasion, once argued by historians³). The raiding and settlement of Irish, Anglo-Saxon and Pict peoples, from 360CE onwards, led to the establishment of post or sub-Roman principalities, amongst which the Irish Kingdom of Dyfed, with its “walking people”⁴ outside of the complex networks of extended kinship and mutual obligation, tributary and rent-paying or vassal (the meaning of *déisi*) communities, was established (360CE to 550CE). Continued migration from Ireland, whether through settlement, raiding or fleeing occupation by Saxon, Viking and Norman raiders, likely added to the population of Irish ancestry, including those that became land-less and forced to travel to exploit economic niches in mediaeval Wales, as metal-workers (*tinklers* or *tinkers* using tin, one of the natural resources

1 All populations in the British Isles are ultimately migrants, as are the Welsh population, as only a very small proportion are descended from ancient, Neolithic builders of Pentre Ifan, Bryn Celli Ddu and Parc Cwm. The Celts, spread from central Europe (the so-called ‘Hallstatt culture’) extended from Anatolia (the Galatians), across central and western Europe (Gauls) and Iberia (Celtici and Gallaeci), to the British Isles (Gaels and Brythonic), c.1,200BCE - c.200BCE. Roman conquest and occupation of Wales (48CE - 380CE) and the Brythonic population (Welsh, Cornish and Breton), made up of Silures, Ordovices, Gangani, Demetae, Deceangli, brought further change, whilst the Irish Déisi migrations (see above), movements of western Romano-Celtic peoples in the face of Angle, Saxon and Jute invasions (c.400CE - 800CE) and Viking assaults (c.850CE) and settlement (c.900 - 1040CE), including in parts of Wales, Norman conquest and settlement (c.1070 - c.1300) continued the pattern of change and diversity that was to go on through the centuries with later African, Caribbean, south and east Asian and English migration and settlement, contributing to the ethnic and cultural mosaic of Welsh society to the present.

2 The Irish Travellers arrived with the Deisi Muman populations in the turbulent post-Roman Britain, from Ireland (modern Eire), c.360-450 CE

3 See Lynch, F., Aldhouse-Green, S. & Davies, J. L. (2000), *Prehistoric Wales*, Gloucs.: Sutton Publi.

4 ‘an lucht siuil’ in Old Irish, the origins of the Pavees, Minceir or Irish Travellers; see Rance, P. (2001), ‘Attacotti, Déisi and Magnus Maximus: the case for Irish federates in late Roman Britain’, *Britannia*, no.32, pp. 244-70

present), herbal remedies and trading livestock and animals. It is also likely that the Celtic or more properly, insular form of Christianity⁵, was spread through south-west Wales by active missionary conversion and transmission from travelling groups, such as the ancestors of the Travellers, many of whom maintain a tradition of pilgrimage across Wales to this day.

The arrival of the 'Egyptians'

The largest arrival of significant numbers of Romani people to the coastal plains, valleys and mountain regions was in the eighteenth century, with the establishment of *Romanichals*, Gypsies speaking *Anglo-Romani* or *poggadi-chib* in the south and west. Prior to this, there had been smaller groups of *Egyptians* or *Gypcians* arriving in Wales in the mid-sixteenth century who had settled and who maintained an inflected form of *Rromani-chib* or Romani language that was close to that spoken in parts of Iberia, in the Finnish lands (then ruled by the Kingdom, or *rike* of Sweden), and in continental Europe. These formed the basis for the *Kalé* communities of north and north-western Wales, with the *Romanichals* in the south and south-west. Small numbers of continental Roma, such as groups of *Kalderash* or *Coppersmith Gypsies*, arrived in the late nineteenth and early twentieth centuries, following the emancipation of Roma slaves in the Rumanian lands of Walachia and Moldavia. Further, smaller movements of Irish Travellers, Scottish Gypsy-Travellers and Romani Gypsies in the 1930's and the 1960's have added to the populations of Gypsies and Travellers, though historically none can be said to be 'indigenous' or even more or less Welsh than others, as all are arrivals at one time or another.

The earliest reliable date for the arrival of the Romani people in Wales (*Kalé*, *Kalá* or *Valsbanange*) can be dated to the 1579, when the Sheriff of (New) Radnor (Maesyfed) requested assistance from the county court in feeding forty 'Egyptians', who were incarcerated in the goal, within the remaining gate-tower of the old fortress⁶, Trefaesyfed. These 'Egyptians' were charged with 'vagrancy', under harsh Tudor legislation that condemned "sturdy beggars", "thieves" and "counterfeit Egyptians", to severe punishments and even death⁷ upon capture by the authorities. A popular 'bawdy' song of the period mentions a 'Lord' of the Gypsies who, with his 'band', roamed and roved in the border areas and Wrexham, contributing to the common (at the time) associations of lawlessness and banditry that accompanied the notion of 'Gypsy'.⁸ The 1530 *Acte concernynge outlandysb people callynge themselves Egipcyans* passed by the English parliament may well have been in response to

5 Wormald, Paul (2006), "Bede and the 'Church of the English'", in Baxter, S. [ed.], *The Times of Bede*, Oxford: Basil Blackwell, p.207; Davies, W. (1992), "The Myth of the Celtic Church", in Edwards, N. & Lane, A. [eds.], *The Early Church in Wales and the West*, Oxford: Oxbow Monograph 16, pp.12-21

6 The intriguingly named Bishop of Lichfield and Coventry, Roland Lee, architect of peace between Henry VIII's English crown and the Welsh princes 1535, wrote of the castle at New Radnor "...Radnor Castle is not to be repaired, but only a prison house amended, which must needs be done, for there have been lost by evil keeping no less than eight thieves, and they have no place to keep them: all may not be brought to Ludlow ...", thereby allowing the town the status of holding the county assizes. By 1543 however, the county court had moved to Prestiegnie. The annual October Fair no doubt attracted many 'Egyptians'; the fees from the fair were part of the income to the lords of the manor. The fair continues, though transferred in 1851 to the parish church of St David's.

7 See Fraser, Angus (1992), *The Gypsies: Peoples of Europe*, Oxford: Basil Blackwell

8 See <http://www.valleystream.co.uk/romany-welsh%20.htm>

numbers of Romani people arriving in the British Isles⁹, whilst the 1554 *Act for the punishment of certain Persons calling themselves Egyptians*, both reinforced the previous act and made it clear as to the intent of these measures in both England and Wales. A period of repression followed, including a further act in 1562, with the wholesale persecution of Gypsies and the atomisation of communities into small, mobile groups avoiding notice and living in woodlands or remote areas. The turmoil of the 17th century began with the 1601 deportation of all ‘blackamoors’ amongst whom many ‘Gypsies’ were included, and Elizabeth I’s persecution of all suspected ‘heathens’ and ‘dissenters’. The English Revolution in the 1640’s and 1650’s added to the overall numbers of displaced and dispossessed people in England and Wales, amongst whom Romani and Traveller communities may have offered some protection to each other living as extended groups.

Abram Wood, the ‘King of the Gypsies’ and his extended family, arrived in mid Wales at about 1730, at Llanbrynmair (later moving north), where the Wood dynasty established itself as fiddlers, harpists and story-tellers¹⁰. The language of the Wood family was recorded more than a century later by John Sampson (1862-1931), an Irish linguist and librarian at the University College of Liverpool, when he was taught Welsh Romani by Edward Wood,¹¹ whom Sampson called, “the Black One of Bala”.¹² The distinct dialect of the Woods family and others in north Wales, contrasted with the gradual loss and erosion of Romani language, or *AngloRomani*, amongst the Romanichals (originally English Gypsies) in south Wales. The Gypsies in Wales were referred to by other writers, such as Joseph Harris (Gomer, 1766-1825), the editor and journalist of Wales’ first Welsh-language weekly newspaper, *Seren Gomer* (The Star of Gomer)¹³ as “... poorly clad and living in squalid conditions in tents... without religion or morals... their only income from stealing, cheating and fortune-telling”¹⁴. Harris referred to “thousands” of Gypsies living in Wales at the time, though with what evidence is not known.

Welsh Romani communities remained an important source of folk-tales and ‘Gypsy lore’, collected by the scholars and amateurs of the Gypsy Lore Society (founded in Edinburgh, 1889) and published in the *Journal of the Gypsy Lore Society*. Sampson, in one of his letters¹⁵ states that he gathered many Romani stories from Welsh Gypsies, such as Cornelius Price, who was told them by his uncle, Nebuchadnezzar Price, and Edward Wood’s stories came from his grandmother, Black Ellen. Increasing urbanisation in the south and west of Wales in the

⁹ Mayall, David (2003), *Gypsy Identities 1500-2000: from Egipcians and Moon-Men to the Ethnic Romany*, London: Routledge, p.57; Thomas Cromwell, Henry VIII’s Chief Minister wrote to the Lord President of the Marches of Wales (1537), with instructions on implementing the legislation.

¹⁰ His descendant, Teleri Grey, lives in Cardiff and still keeps the tradition of story-telling alive. For details about the history of the ‘tuelu’ or clan of the Woods, see Jarman, Eldra & Jarman, A O H (1991), *The Welsh Gypsies: Children of Abram Wood*, Chicago: University of Chicago Press

¹¹ Sampson, John (1926), *The Dialect of the Gypsies of Wales, being the older form of British Romani preserved in the speech of the clan of Abram Wood*, Oxford: Clarendon Press; Francis Hindes Groom, in his ‘Introduction’ to *Gypsy Folk Tales* (1899), wrote of Sampson’s study, “... he has also during the last few years been making a profound study of the ‘deep’ Welsh dialect, the best-preserved of all the Gypsy dialects with the doubtful exception of that of the Turkish Tchingiané (Çingene)”. The work was another 27 years in finishing. Sadly, the dialect of the Romani people in Turkey (Çingene), has all but disappeared.

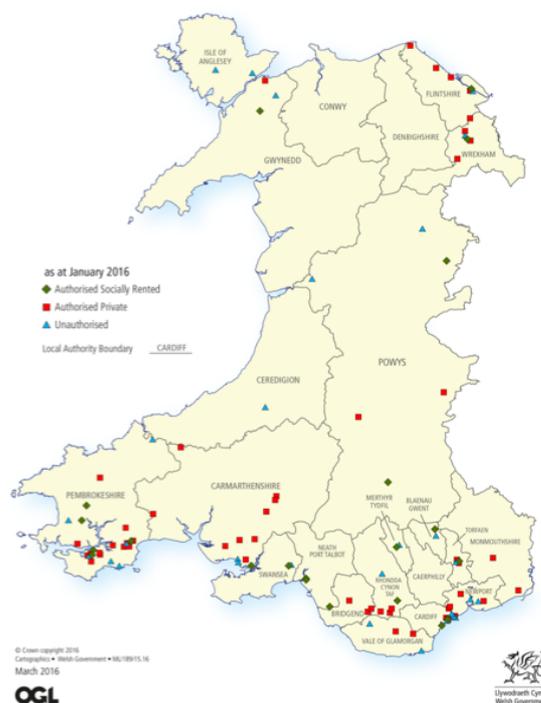
¹² See Garmon-Jones, W. (1932), “John Sampson & the Gypsies of Wales: a review of Romaní Gíllia; Romani poems with English renderings, by John Sampson”, *Welsh Outlook*, a monthly journal of national social progress, vol.19, no.2, pp.52-53

¹³ See the National Library of Wales, <http://newspapers.library.wales/view/4247205> for digitised facsimiles of the paper. Joseph Harris ran the paper from January 1814 until his death in 1825, with a brief interruption, when it became a Baptist magazine, published quarterly from Carmarthen.

¹⁴ 8th January 1820

¹⁵ quoted by Francis Hindes Groome, 1899 in his ‘Introduction’, op.cit.

mid to late 19th century saw Welsh Gypsies and Travellers becoming more visible in parks and on common land, as common land became enclosed through *Private Acts* (1834 to 1849) and then the *Commons Act* of 1879, reducing the overall stopping places by some 6 million acres in the process.¹⁶



Gypsy and Traveller caravan sites in Wales in 2016, according to the Welsh government's count

Modern Welsh Romani and Traveller populations

The present Romani and Traveller populations are currently hard to define, in terms of reliable and robust data regarding them. Aspinall¹⁷ suggests that in 2003, there were 2,000 Romani and Traveller children in Wales, although another survey of local government suggested 1,400 Travellers in total (though only 50% of the local authorities canvassed responded) in the same year. If the average percentage of children amongst UK Romani and Traveller families remains consistent (54%), then a figure of 2,000 children would have given a rough population of 4,000 Romani and Traveller people in Wales. In 2017, the population of Romani and Traveller people is likely to have grown, largely through immigration of east European Roma, as higher infant mortality and shorter life-spans mean the Welsh Gypsy and Traveller population remains approximately consistent (there are an estimated 800,000 east European Roma in the UK).¹⁸ The number of Romani and Traveller families living

¹⁶ Mayall, op.cit. p.87

¹⁷ Aspinall, Peter (2005), "A Review of the Literature on the Health Beliefs, Health Status, and Use of Services in the Gypsy Traveller Population, and of Appropriate Health Care Interventions", Health ASERT Programme Wales; Enhancing the health promotion evidence base on Minority Ethnic Groups, Refugees/Asylum seekers, and Gypsy Travellers, Cardiff: Welsh Assembly Government, p.8

¹⁸ Craig, Gary (2011), "The Roma: A Study of National Policies (United Kingdom)." A paper submitted to Peer Review in Social Protection and Social Inclusion and Assessment in Social Inclusion. A report on behalf of the European Commission DG Employment, Social Affairs and Equal Opportunities, Brussels: European Commission

in houses remains very vague; it may be between 28% and 37%, especially as pressure upon caravan sites has become intense and very few council sites have been built in the last decade.

Families are usually quite large, with 3 or 4 children and 2, or sometimes 3 generations living together or very close to each other. Many families remain commercially nomadic, travelling for work and business, wedding, baptisms, funerals and to comfort relatives during illness. During winter months, families stop on caravan sites, a number of which are provided by local authorities (municipalities). There are not enough spaces on these sites and 'stopping places' (*aitchin than*) are fewer than needed. Unauthorised encampments, forced evictions and confrontations with local, settled communities are frequent. Discrimination against Gypsies and Travellers is widespread in Wales (as across the UK), with abuse, violent attacks and harassment being frequent. The former competence in Rromani-chib or Romani language, is rapidly being lost across all Welsh Gypsy communities. Irish Travellers speak *Gammon* or *Shelta*.

According to the latest Welsh government caravan count, on the 16th January 2016, there were 931 Gypsy and Traveller caravans and 108 sites reported in Wales. Across the twenty-two Welsh local authorities (unitary councils) that participated in both January 2015 and 2016 counts, the total number of Gypsy and Traveller caravans has decreased by 8.7% (eighty-nine caravans) in the twelve months (or the count has been less accurate), and the total number of sites (both authorised and unauthorised) has increased by 8.0% (eight sites). Of the total number of caravans, 84% (782 caravans) were on authorised sites. Of these, 580 (74%) were located on local authority sites and 202 (26%) were on private sites. There are 371 (370 residential and one transit) pitches on Gypsy and Traveller sites provided by local authorities, meaning that there are averagely 1.56 caravans on each pitch, clearly indicating some over-crowding. A total 99% of the residential pitches were occupied. The total number of caravans on unauthorised sites was 15% (26 caravans) lower in the January 2016 count compared to the January 2015 count, though 123 caravans remain on temporary or unauthorised sites, some of which are on land owned by Romani and Traveller people.

There are now approximately 1,750 Roma families mostly from Slovakia (Kosice, Lunik IX) in the south and west of Wales, with a few Rumanian, Bulgarian and Hungarian Roma present. Many survive by selling a newspaper that supports homeless people, "The Big Issue", on the streets of Cardiff, Newport and Swansea, begging, and washing car windscreens at traffic lights. There are no reliable statistics to show where the majority of Roma are living in Wales, though anecdotally it appears the largest community is resident in Newport. These Roma face discrimination as 'Gypsies', beggars and EU migrants, particularly since the Brexit referendum 23rd June 2016. Many of the Roma retain their Romani language, though are not commercially nomadic like Welsh Gypsies and Travellers.

Brief literature survey; health and well-being studies

The literature surrounding the health and wellness of Romani and Traveller communities in England and Wales has provided an overall policy context for this project and built upon the trend that has marked reports since the

Acheson Inquiry began to focus upon healthy living, well-being and ‘choosing health’.¹⁹ The *Marmot Review* strongly suggests that reducing health inequalities in British society is a matter of equity and social justice that must be addressed as a matter of priority,²⁰ and specifically about Gypsies and Travellers, the *Review* argues, that they have higher levels of poverty, lower levels of benefit ‘take-up’ and find accessing the system of support especially difficult.²¹ As a result, the impact of “health-adverse effects” upon Romani and Traveller communities is high.

The 2009 *Equality and Human Rights Commission* research report on the inequalities experienced by Gypsy and Traveller communities, provides a great deal of evidence of the health problems, amongst other challenges, experienced by these communities.²² A small study in the London Borough of Richmond identified that 37% of Gypsies and Travellers reported their health as ‘not good’, a higher percentage than the national census had returned and a much higher percentage than the general population (19%).²³

The *Equal Opportunities Committee in Wales Review of Service Provision for Gypsies and Travellers*²⁴ dedicated a long chapter to health and well-being, before drawing conclusions and making recommendations that, had they been followed, would have had a significant positive impact upon the health outcomes for Welsh Gypsy and Traveller communities.

The need for reliable data about the health and wellness of Romani and Traveller communities in Wales is extremely high; there are very few robust, quantitative studies systematically comparing the health status of Romani and Traveller people in Wales (and none that take into account Roma in Wales, as part of the Romani population or separately), with a consequent dearth of information that can be counted as statistically reliable. Much anecdotal reference is made to the significantly lower life expectancies for Romani and Traveller people; the *AITHS* reports this to be a difference of 15 years amongst Irish Travellers for example, compared to the majority population. Studies in England have reported higher peri-natal and infant mortality rates amongst Romani and Traveller communities, by as much as 1.4 and 2.4 times higher,²⁵ with stillbirth rates even higher.²⁶ Evidence from such studies and drawn from our interviews, reports that serious injuries are generally higher amongst Romani and Traveller children than amongst the wider community, many resulting from the conditions

19 Acheson, D. (1998), *Independent Inquiry into Inequalities in Health Report*, London: HM Stationary Office

20 See Marmot, M. (2010), *Fair Society, Healthy Lives: The Marmot Review, Strategic Review of Health Inequalities in England post-2010*, London: Marmot Review Team

21 *ibid.* p.77

22 See Cemlyn, S. et al (2009), *Inequalities Experienced by Gypsies and Travellers: A Review*, Research Report 12, Manchester: Equality and Human Rights Commission, <https://www.equalityhumanrights.com/en/publication-download/research-report-12-inequalities-experiences-gypsy-and-traveller-communities>

23 Public Health Department (2014), *Gypsy and Traveller Health Needs Assessment*, London: London Borough of Richmond-upon-Thames, p.2

24 *Equal Opportunities Commission (2005), Review of Service Provision for Gypsies and Travellers*, Cardiff: National Assembly for Wales

25 Aspinall Peter (2005), “A review of the literature on the health beliefs, health status, and use of services in the Gypsy Traveller population, and of appropriate health care interventions”, *Health ASERT Programme Wales: enhancing the health promotion evidence base on minority ethnic groups, refugees/asylum-seekers, and Gypsy Travellers*, no.2, Cardiff: Welsh Assembly Government, p.8

26 *ibid.*

that families are likely to be living in, either in poor housing, on the roadside or in caravan sites (many of which are on former industrial 'brownfield' sites). Poor sanitation, lack of access to clean, potable water and environmental conditions (nearby rubbish dumps and landfills), are part of the picture of causes of infection amongst mobile Romani and Traveller people, despite traditional cleanliness practices.²⁷ Damp housing, overcrowding and centuries of poor diet amongst eastern European Roma cause further problems for a community that have, in their countries of origin, been living in appalling conditions where many conditions associated with poverty, environmental degradation and high levels of toxicity, are extremely prevalent.²⁸

Methodology; learning from friends, strangers and others

The core of the methodology used during the project was to model the organic process of developing projects from 'inside out' with community participants, health practitioners and professionals as co-creators, through early surveys and interviews carried out prior to the project beginning.²⁹ The guiding principle of this methodology is embodied in the centrality of relationships between people across community and cultural boundaries, the exchange of narratives and 'deep' listening, and the flexibility around notions of ownership and returning of materials or 'products'. The project thus incorporates principles of qualitative and 'participatory action research' (PAR), and shares the ideas that have emerged from what is often described as an 'indigenous' or 'native' research perspective.³⁰

The project methodology was one that embedded qualitative research approaches, creating or co-creating the final 'product' through a joint process of design and development. The process whereby that is achieved began with community surveys and semi-structured interviews, focus groups, community analysis and participant observation, alongside an 'action linked research'³¹ approach, that constantly reviewed and evaluated the results of the work in a co-operative and trusting environment.³² The purpose of the surveys was to establish the design of the project, in terms that are driven by Romani and Traveller concerns and drafted from the perspective of Gypsy, Roma, Traveller families and communities, informed by the views and opinions of health practitioners and professionals.

The research design involved a qualitative methodological framework, consistent with culturally appropriate research principles, using semi-structured interviews to explore the experiences and reflections of the

27 Referred to as 'mahrimé' in Rromani-chib, a series of practices intended to establish both cultural and practical cleanliness boundaries, similar to Muslim 'halal' practices. The condition of being 'moxadhi' or 'mochadi' is to be 'unclean', to have contravened these practices in some way, that must be ritually cleansed, similar to being made 'kosher' according to some Jewish texts, such as the *Mishneh Torah (Yale Translation)*

28 Many communities in eastern Europe live close to rubbish dumps or highly contaminated environments, such as the Ashkali from Mitrovica, Kosovo living on former lead mines and the residents of Lunik IX, Kosice, Slovakia where piles of rubbish surround crumbling Soviet-era housing blocks. See Artur Conka's film, "Lunik IX"; the Roma documentary photographer and film-maker, Artur Conka, was one of our Community Champions and indicates the calibre of our project workers.

29 The RCAC staff carried out a series of short surveys (30) with Romani and Traveller community members to ascertain what, in terms of form and content, they would wish to see as part of a project looking at health and wellness (October 2015)

30 Hart, 2010

31 Pratt & Loizos, 1992

32 Weiss, 1994; Papdopoulos, Irene (2006), "Transcultural Health and Social Care..."; Szczepura, A. (2005), "Access to Health Care for Ethnic Minority Populations" Postgrad Medical Journal, pp.141-47

participants (parents and carers, with some input from younger children) approached by the project. Interviews were conducted with both individuals and groups of younger parents, older parents and carers. Participants were encouraged to self-select for interview according to their needs and desires to communicate their experiences, in keeping with the principles of empowerment and agency. An introductory letter about the project was given to potential participants and explained to them in their homes, on sites or at the Gypsy churches that proved valuable partners.³³ Interviews were also held with older parents, who often have responsibility for childcare, and the partners in the project, to complete the 'picture' and identify areas of future development in services and approach. Interviews were recorded using simple audio equipment, analysed and some were edited to be used as exemplars.

The project was designed and implemented over a twelve-month period (April 2016 to March 2017) in and amongst the Romani and Traveller communities of Shirenewton site, Rover Way site (both in Cardiff), the Slovak Roma community in Newport, the Traveller communities in Cwmcraehen, Bangor and Pembroke, west Wales. The re-recording, reviewing and editing was carried out by experts at the University of Swansea. The emphasis was upon gathering material that captured the necessary data about health and wellness, early childhood, and accessing health services. Each 'story' of health and wellness was reviewed over two months and ten were edited over a four week period, with a final sharing of these stories as training materials, to be used as part of developing an on-line learning package for health practitioners and professionals. The remainder will be held in trust by the RCAC, and as part of a secure repository of national Romani and Traveller heritage and culture at the St Fagan's Museum of Welsh Life.

There was a focus on capturing as much as possible regarding early years development, health in childhood and Traveller families lifestyles, throughout the project. Through this project, the intention has been to build a strong basis for a future positive parenting programme, securing future support from donors to implement programmes such as "Parenting With Confidence", "Learning through Play", that have health, development and wellness components, in partnership with health and early years practitioners and professionals involved in working with Romani and Traveller communities, in Wales. The local early childhood education and care practitioners would also be involved in a future project, to support Romani and Traveller parents and improve early childhood development outcomes, and the transitions from home to pre-school and on to primary school.

Questions were developed in languages appropriate to the groups that were interviewed (*Rromani-chib*, or *Romanës*, *Shelta* and *Gammon*) and translated by the interviewees, who were themselves from the communities. One of the key understandings that have emerged from the project is that the use of interpreters who are not from the communities, especially the Roma, is not appropriate in building trust and confidence. Many of the Roma have come to Wales from very difficult environments, subject to abuse and violence in their countries of origin (Slovakia, Czech Republic, Hungary, Bulgaria, Rumania). In particular, the health services in the Czech Republic and Slovakia are part of the systematic discrimination against Roma, through misdiagnosis of young

³³ The participation of community members, such as Atahac Ctorhob, Diana Horvathova and others, such as Sarah Burt, who gave their kind assistance in helping identify potential interviewees, through schools and community organisations, helped the project facilitators significantly.

Roma children as having ‘light mental disability’ and being segregated into poor quality, low-standard ‘special’ (now called ‘practical’) education.³⁴ Sadly, there were some of our Roma respondents who told us that their children were being excluded from schools in other parts of the UK,³⁵ and this had brought them to Wales in search of better access to quality education for their children.

Throughout the project data collection period, all project facilitators kept a reflective journal about the process, whether recorded or written. These reflections have allowed us to ‘map’ the process of the project in gathering the stories from interviewees. An addition to the knowledge about the project’s successful methodology, these journals from our Community Champions also give valuable insight into the necessary conditions under which trust and confidence is built up with a community and the additional resources that have to be committed to gathering data in this fashion, in order to build a better, more informed and representative picture of health and wellness experiences in the Romani and Traveller populations.

Extracts from journals

“One of the interviews is a an hour interview... The latter part of this interview is particularly interesting, as it deals with women's health issues specifically and includes subjects women Travellers are usually very reluctant to speak about including female periods, female menopause and the cultural taboo of male doctors and midwives examining female Travellers. Also a couple of interesting interviews about traditional remedies which sadly, seem little used these days. I had to do a lot more socialising this trip with Travellers I didn't know, to build up a relationship with them. Enjoyable and rewarding for the most part, but sometimes frustrating too... I found most of the Travellers extremely warm and friendly and the children absolutely delightful. I received copious amounts of food and tea and also a summer blouse, cardigan and a very comfortable pair of slippers as gifts from the Travellers... For me, a startling fact these interviews are highlighting, is how badly Travellers eat. Poor, high fat diets, takeaway food, lack of fresh fruit and vegetables. Basically, very unhealthy diets...”

“I was very grateful that this very unique project allowed me to make progress in building direct contact with the Roma in Wales (after some support agencies proved difficult by refusing any form of introduction to their Roma applicants). To start with, notions of openness and honesty were the basic requirements for the recording sessions to be conducted in a reliable and trustworthy fashion. Since building trusting relationships through being able to enable Roma to speak up in our mother tongue is such a rarity, the whole interview process brought us more close and in depth conversations...”

³⁴ The European Commission has brought infringement proceedings against both Slovakia and the Czech Republic on the basis of these educational discrimination and abuses of the health system to support this discrimination and exclusion; see <http://www.errc.org/article/slovakia-unlawful-ethnic-segregation-in-schools-is-failing-romani-children/4555>

³⁵ Sheffield, for example; see <http://www.itt.org.uk/news/xeno-racism-and-the-scourge-of-school-exclusion/#comment:1414616>

Health and Wellness

Amongst Romani and Traveller Communities in Wales

“I WAS TREATED THAT WAY BECAUSE I WAS A GYPSY...”



Irish Traveller girls carrying water, Anglesey 1962, Geoff Charles © NLW

Patterns of accessing health services and provision

From our interviews, we have learned that there are patterns of access for Romani and Traveller families, some of which are common with the non-Traveller communities, but others of which are unique to Romani and Travellers, in particular the difficulties faced by mobile members of the communities, when ‘on the road’. Summer is a 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 travel to the traditional and ancient Gypsy fairs, such as Stow-on-the-Wold, Horsemanden and Appleby. Most families will visit 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, kinship bonds. Some, especially amongst the Roma in Wales, cross 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’ movement³⁶ and the famous annual pilgrimage to the Camargue Church of *Les Saintes Maries de la Mer*, in honour of the Romani saint, Kalí Sara (Black Sara)³⁷ and the saints, Mary Magdalene, Mary Jacobe and Marie Salome of the Faith.³⁸

³⁶ See Marsh, A. & Thurfjel, D. [eds.] (2013), *Romani Pentecostalism: Gypsies and Charismatic Christianity*, Frankfurt: Peter Lang; <https://www.peterlang.com/view/9783653990645/body.html>

³⁷ Tradition, recorded earliest in Vincent Phillipon (1521) ‘The Legend of the Saint Marys’, ascribes Sara a role as ‘Egyptian’ (Gypsy) penitent and pilgrim in the Camargue, collecting donations for charitable works amongst the Christian Gypsy community in the region, earning their respect and adoration as a ‘saint’, though another tradition suggests that Sara was an Egyptian (Coptic) servant of the three Marys.

³⁸ The three Marys who, as described in the Gospel of Mark, chap.16, verses 1-8 go to Christ’s tomb to anoint his body following the Crucifixion and Sabbath, to find it empty

Romani and Traveller religiosity in Wales

A charismatic Christian revival is sweeping through the Romani and Traveller communities of Europe. Romani people have been amongst the adherents of Pentecostalism since its appearance in the first years of the 20th century. Since the early 1950s, Roma across Europe began to organise in specifically Romani and Traveller Pentecostal congregations and today, although there are many exceptions, Pentecostalism could be said to be one of the foremost religious orientations amongst Romani people in Europe and beyond. The foremost religious leaders in the UK have been Martin Burrell and Davey Jones (sadly, now deceased), with Stevo Atanasio amongst the Roma in London, establishing the London Gypsy Church. In Wales, the growth of Gypsy churches, as they are called by adherents, has been steady over the past decade, with some 12 established at present. The Romani and Traveller churches are characterised by an emphasis upon the Holy Spirit, the Gospels and the New Testament, glossolalia ('speaking in tongues'), healing and redemption (saving) through testimony. In a challenge to many of the practices that have been seen to be unhealthy, the Pentecostal Romani and Traveller churches prohibit narcotics and substance abuse, alcohol, and domestic violence, whilst tending to frown upon fortune-telling (dukking), any 'gulling' or 'conning' (cheating) of others and cigarette smoking. Literacy is rising amongst Romani Pentecostal and Gypsy churches, as Bible study and prayer reading is valued and promoted. The impact upon wellness and well-being of the Romani and Traveller 'Light & Life' movement has not yet been properly recognised, nor have the health services built connections with the pastors and preachers who make up the leadership of these churches, in promoting messages of well-being and health...

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, we were told by our participants. 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, others 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 (or perhaps their Receptionists) 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, which can result in larger numbers of Travellers coming to the hospitals as both patients and visitors. The latter, when Romani individuals are in hospital for operations or treatment, can cause confusion and conflict, according to a number of our stories, as health practitioners find it problematic when many of their relatives and extended kin come to visit and show respect. 100 Romani and Traveller people arriving throughout the day can cause tensions in the ward and with nursing staff, and our stories tell us that this can lead to conflict. In winter, in common with non-Romani communities, the pressure upon particular health services increases, as many families are living on sites in what are quite poor environmental conditions. Given the difficulty in registering with doctor's surgeries and an unwillingness on the part of many Romani people to trust health practitioners and professionals, that many of the participants expressed in their stories, the tendency to use A&E services for general medical care also increases at this time. In addition, there appear to be higher rates of accidents among Romani and Traveller communities, especially amongst children as a result of environmental hazards on sites and unauthorised encampments, particularly as many of both are near busy roads. This strongly suggests (and our stories support this) that many Romani and Traveller parents (mostly fathers) are engaged in high-risk occupations, such as roofing, tree surgery, tarmac-laying and recycling. It is also suggested that, with regard to children, they may be more physically active (this is because, our interviewees told us, they are outdoors more and rely less upon television, computers and video games, though this is hard to prove) and partly because they often live and play in unsafe areas. The demands of Romani and Traveller children who lack

secure and safe (in the sense that they are free from bullying and abuse from non-Romani children and adults) play areas, has also, it has been suggested by parents, led to increased stress levels amongst mothers. In addition to accidents on that take place on sites, it appears that car and road related injuries and sadly, sometimes deaths, are more common than those kind of accidents amongst the settled communities.

Accessing doctor's services when "camping up and down"

"In north Wales. . . the problems what I've had mostly is when we haven't been able to get onto sites 'cause there's not many sites and when we're camping up and down I've wanted to get medicine when I'm poorly. . . we find it hard to register with the doctor's because we haven't got an address and we have to go into the doctor's as temporary patients and you've got to fill a 'Temporary [Patient]' form in. . . If you want to see a doctor straight away, they say "You've got to fill a form in first, then make the appointment", but we find that difficult sometimes. Sometimes we leave things what aren't really bad, what we could do with getting done. . . we just leave them until something more serious is wrong then when we do go to the doctor's, he doesn't want to know about all of them because there's too many, he probably only wants to deal with two things. . . sometimes he'll only want to deal with one, I've been told before. . . And I explain to him that I've found it very difficult to get here in the first place, to get an appointment with you, and you couldn't sort this out as well. . . It's happened to me before and sometimes they've refused and said, "No, we'll only sort the serious things out", so I've left there and even left them things longer"

It is also clear from our stories that, in terms of patterns of accessing health and wellness services and provision, Romani and Traveller women are far more active in doing so than the men in the community. Pre-natal and post-natal services do have an impact upon young Romani mothers and continue to do so for longer periods, as Romani and Traveller families tend to be larger, offering potentially greater opportunities for interaction and building trust and confidence between health practitioners and professionals, and the communities, over time. The potential also exists for greater engagement with early years professionals and child development practitioners, through working with families in Romani and Traveller communities. At present, there is little contact between early childhood development and health services and Romani and Traveller children from a few months old, when health visitors cease attending infants and mothers, and children beginning school, when conditions that may have been dealt with at a much earlier stage, present themselves during pre-primary assessment. These patterns of Romani and Traveller families accessing health services and provision, as described to our Community Champions, suggest that opportunities exist for improving interaction with Romani and Traveller communities and for increasing understanding of key health and wellness issues in the early years and, therefore, beyond into adulthood.

Stories of Health & Wellness

Welsh Gypsy, Roma, Travellers tales

“SINCE I’VE BEEN SETTLED INTO A HOUSE, IT’S A LOT EASIER”



Douglas and Elizabeth Hern and their eight children, who had been living in a [house] for six years and who were back in their caravans to travel from Bala to Swansea, 1951, Geoff Charles © NLW

What the stories tell us...

Our team of six community facilitators and researchers have, during the course of the project, carried out a total of 107 interviews, amounting to a total of twenty-one hours of recorded material. They have spent a total of 256 hours in meeting and building trust with Gypsy, Roma, Traveller parents and children. Seven of our interviewees have been under sixteen, 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.

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.

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. 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.

However, 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, as they were rejected by receptionists.

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, according to our stories. Some parents have had experiences whereby health visitors have been instrumental in not only delivering services, but in building trust and confidence amongst the community as a whole and becoming someone for whom the Travellers could turn to for advice (in north Wales). Many of our stories suggest that there is a greater tendency among Romani and Traveller families to use accident and emergency (A&E) units to seek immediate treatment. In some cases, A&E does appear to have been used for minor illnesses that might be treated by a GP (in one or two of our stories from south and west Wales), though this assumes that the families concerned had access to GP services in the first place (many of our stories tell us that this is one of *the* most problematic areas to navigate for Romani and Traveller families).

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. Whilst any accident involving children must be examined carefully, as all Romani and Traveller families appreciate, this was an extreme case. Our participants have told us that they feel strongly there is suspicion of Romani and Traveller parents and doubt about their abilities as carers, from health care practitioners. This is a common theme in many of our interviews with young families.

In another case, we were told about the daughter of one family that had had an emergency impacted tooth extraction at hospital and then was discharged very quickly, in north Wales, whereupon she had later collapsed from blood loss and was taken to another hospital. Medical personnel at that hospital, who had dealings on a regular basis with Travellers, had expressed shock at the daughter's state and were critical, we were told, of the previous hospital's lack of care in discharging the patient too quickly. The family felt that it was because they were 'Gypsies' that this had happened in the first hospital and the second showed greater understanding and awareness.

Emergency care and pregnancy

Other interviewees have told us of their experience of being discharged very quickly following emergency operations (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. One or two young mothers have also told us of difficult experiences with health visitors when their children were newborn, being denied supplements when other, non-Romani mothers received them at the

baby clinic and of receiving better care when they (Traveller mothers) were living in houses, as compared to their experiences of being on sites or mobile.

In one particularly distressing episode, a young Traveller mother (eighteen years old) was admitted to hospital late in her pregnancy, with complications and had to undergo a very difficult induced 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', according to our participant. 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), with no explanation as to why there should not be allowed to stay.

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 and have to deal with other patients who may also make complaints about noise and disturbance (whilst some complaints may be motivated by prejudice, large groups in small wards are bound to be somewhat disruptive).

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.

Dentists

Dentists and dentistry are viewed warily, in comparison to doctors and hospitals. Many avoid visits altogether. A number of the children interviewed told us that they had had between ten and twenty teeth removed, due to decay and a lack of oral hygiene. Such stories tell us that poor dental health and poor diet, have left Romani and Traveller children with significant levels of decay and gum disease that they then carry into adulthood. The decline in school dental services has also had a detrimental impact upon Romani and Traveller children's health and well-being.

Knowledge about availability of health provision is very much lacking amongst all the communities, often because of low literacy or language competence, but equally because information is rarely available in forms or languages that are accessible to Romani and Traveller people. Details about the availability of services is invariably text based, and predominantly in English and Welsh, with little in the way of visual aids and radio or television used to promote improved access through better reach (adaptation of materials for people with hearing difficulties, for our communities, would be a relatively simple and cost-effective way of delivering this much needed information).

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...

Conclusions

Recommendations and next steps

“JUST BECAUSE WE’RE TRAVELLERS, WE STILL NEED DOCTORS...”



Selling fox-cubs as household pets, 1956, Geoff Charles ©

NLW

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 from 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 sub-standard education on account of their ‘mental disability’, diagnosed by biased 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 immiseration has left a generational legacy of poor health and nutrition amongst the Roma who now live in Wales.

There are some serious issues that need addressing related to health and wellness for young Romani and Traveller families, that we have identified, drawing upon information from our stories and then extrapolating some conclusions from this. These make up the basis for our Recommendations.

Reading and writing

Almost all Gypsies and Travellers interviewed told us that they could not read or write, or could do so only with great difficulty. Some had learned as adults, through teaching themselves or through learning to read The Bible in study groups with other Romani people. Roma interviewees told us that parents and grandparents had a low, or no level of literacy, in the language of their countries of origin (Czech Republic, Slovakia) and none in English, relying upon their children who were in school to interpret for them (and thereby reducing school attendance and attainment for Roma children). Romani and Traveller parents may themselves have not had access to schooling and may also, as a result of this and other negative experiences of formal education, opt for *Elective Home Education* for their children, to keep them safe, avoid bullying and discrimination and resist assimilation and loss of culture (much more data is needed as to the reasons why this option is taken up by many parents, or why schools suggest this option to them). Parents who we interviewed did express concerns about the safety and security of their children going to school and some told us they had chosen to educate children at home instead.

The reality is that, across the age ranges seven to seventy years old, Romani and Traveller people are not able to effectively read and write. 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 infants, women's health and a host of other necessary information and documentation. The Welsh education system has not fulfilled basic educational needs of Gypsies and Travellers for the past fifty years in delivering literacy to these communities – the question has to be asked as to why this is the case?

Diet

Living on sites for Gypsies and Travellers in Wales has fundamentally changed the kind of diet that families have relied upon. 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. In common with the general population³⁹, the changes in diet and food consumption in Romani and Traveller communities in Wales, amongst children and young people, has seen significant changes in recent times. Half of the mothers our Community Champions spoke to, breast-fed their infants in the past or were doing so presently⁴⁰. Traditionally, in the past, most Romani and Traveller

³⁹ Public Health Wales Observatory (2013), *Health of Children and Young People in Wales*, Carmarthen: Public Health Wales NHS Trust

⁴⁰ "Lack of breastfeeding – and especially lack of exclusive breastfeeding during the first half-year of life – are important risk factors for infant and childhood morbidity and mortality that are only compounded by inappropriate complementary feeding. The life-long impact includes poor school performance, reduced productivity, and impaired intellectual and social development.", World Health Organisation (2005), *Global strategy for infant and young child feeding*. Geneva: World Health Organisation, p.vi

mothers breast-fed infants for longer periods⁴¹ than mothers in many, though not all, other communities. In a recent study, 2.7% of Romani and Traveller infants were breast-fed at birth, which dropped to 0% at eight weeks⁴² in the Traveller community. Attitudes towards breast-feeding amongst Romani and Traveller women, in our interviews (though not in our recorded stories, as our participants asked that we did not record their responses to questions about this), were largely negative, in common with other research amongst Traveller women around this subject⁴³, with comments suggesting that cultural factors, specifically notions of purity and impurity, were behind the change in attitudes towards breast-feeding. This contrasts with attitudes and practice amongst Roma women in Wales, who did continue to breast-feed their infants (largely as a result of poverty and a lack of access to potable drinking water in their settlements, in their countries of origin)⁴⁴ and continued to do so through their migration to Wales. Cultural factors amongst the Roma mothers means that traditionally, they do not perceive breast-feeding or exposure of breasts in public, to be *mabrimé*, or ‘impure’⁴⁵ in the same way as Gypsies and Travellers in Wales. The potential exists for supporting, through positive parenting programmes and Romani and Traveller health mediators in Wales, Traveller mothers to take up breast-feeding and continue to do so for a longer period (9-12 months) in order to ensure a stronger, healthier start for Romani and Traveller infants and young children.

Women

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 and gender inequality has worsened. As mentioned above, the stress of having children contained, without a safe and secure place to play, has added to the burdens on Romani and Traveller women in particular.

Early years education and care

In terms of access to pre-school and nursery places, this is non-existent for Romani and Traveller communities in Wales, with almost no take-up by the community and no outreach from early years programmes (the Welsh government’s ‘Flying Start’ initiative and private early years or nursery provision), to reach Gypsy, Traveller or Roma families. Very little monitoring of Romani and Traveller children’s development is being done by health

41 Pinkney, Kate Victoria (2011), *The Infant Feeding Practice of Gypsy and Traveller Women in Western Cheshire Primary Care Trust and their Attitudes towards Breast and Formula Feeding*, unpub. MSc. dissertation, University of Chester

42 *ibid.* p.27-29

43 Cemlyn, S. *et al.* (2009), *Inequalities Experienced by Gypsy and Traveller Communities: A Review*, Equality and Human Rights Commission Research Reports Series, no.12, Manchester: Equality and Human Rights Commission, pp.54-55

44 Sklenka, M. *et al.* (2014), *Roma Positive Parenting Programme in Five localities in Slovakia: Final Report*, Ziar nad Hronem: Skola Doktoran (Step-by-Step Slovakia)

45 *ibid.*

practitioners or professionals, in Wales (and across the UK generally). Health visitors that used to be a regular and relied-upon component of access to health provision for Romani and Traveller communities, have largely disappeared from the picture.

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 see a doctor or go to a hospital. One of the consequences is that when they finally do seek medical advice, they tend to 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 Traveller and Romani masculinity are partially at work in this case, with traditional gender roles around perceptions of strength and weakness (in comparison to other men), but there also exists a deep mistrust of health professionals and practitioners, amongst Romani and Traveller men.⁴⁶

An example of health provision for Traveller and Romani men in Dublin, Ireland⁴⁷ has demonstrated that targeted health provision has a positive impact upon both male and female health outcomes in our communities., through creating better awareness and improving knowledge and access.

Most of our Traveller men interviewed reported that seeking help for medical conditions was, overall very difficult for them. Many also told us that the vocabulary used by medical staff was difficult, if not impenetrable for them. With almost all reporting low levels of reading and writing, understanding critical information, such as prescriptions, was impossible and in some cases, Traveller men had unwittingly either misused, or over-used medication for long periods that was only meant for short-term treatments. Language barriers for Roma men had left them confused and unsure when it came to directions regarding treatment and medication, and though children in school were often able to interpret for their parents, it was difficult for Roma men to ask for their children's help.

In terms of Romani and Traveller men being engaged in the health and wellness of women and children, it is clear from our interviews that Traveller men would not be present during the birth of their children⁴⁸ and that health care, as parents, is seen as primarily part of the mother's, aunt's or grandmother's role. Older children who needed treatment would be taken to clinics and hospitals by men, with their mothers or other female carer, but the men would not enter and either waited or returned later to collect the mother and child or children. Older children's understanding of reproductive health (in common with a number of other communities) is seen

⁴⁶ The All Ireland Traveller Health Study (AITHS), 2010, concluded that only four-in-ten Travellers trust health service professionals and practitioners, compared to eight-in-ten of the general Irish population

⁴⁷ The Traveller Men's Health Project at Pavee Point has identified that Traveller men are fifteen times more likely to suffer from depression and seven times more likely to commit suicide; see www.paveepoint.ie/project/traveller-mens-health-project/ and <https://www.rte.ie/news/2016/1123/833957-traveller-mental-health/>

⁴⁸ A very few of our male interviewees had, or would be present at the birth of their children and these few were younger Romani and Traveller men

as something extremely private and one of the concerns that Traveller parents have strongly expressed about secondary education, is that sex education in mixed and public classes is culturally unacceptable.

Understanding health and well-being

Without responses from health practitioners and professionals, it is unclear as to the perceptions' of service providers, when it comes to Romani and Traveller people's understanding of health⁴⁹; however, from a number of practitioners who have attended RCAC training days, it is probably safe to say that outside of antenatal care, health service providers see Travellers as having little understanding of health issues, particularly Romani men. Understanding the nature of illness or disease is quite low, according to these professionals and practitioners, whilst knowledge of prevention, in terms of adopting healthy practices and strategies for increasing well-being, is very poor. Education, or rather the lack of it, is identified as a key factor in the levels of awareness around health and well-being, both by health practitioners and by our interviewees. Better accommodation and facilities, in both housing and mobile communities of Romani and Traveller people, was mentioned frequently, in our interviews, more frequently than education⁵⁰, with support and adaptation of information and materials for those (the majority of our interviewees) who cannot read and write⁵¹. In these, as in other factors, there is a gap in perceptions and understandings between health practitioners and professionals, and the Romani and Traveller communities, that needs to be addressed through mediation and inter-cultural navigation.

Romani and Traveller cleanliness codes

It is the case that many of these practitioners and professionals are unaware of Romani and Traveller cleanliness codes, or practises, many of which are designed to prevent the transmission of illness and disease. These traditions, called *mabrimé* in Romani language, are both cultural boundary markers and 'pollution' taboos, to avoid uncleanness or becoming *moxadi* or *mochadi*, that is, to become 'polluted'. Some of these, such as not sharing crockery or utensils with non-Romani people, are designed to create a degree of separation and avoid contamination and transmission of illness. Not washing dirty hands in the kitchen sink, where food will be prepared, is another. Clearly, a system of health information that took into account these preventative practises and addressed other aspects of maintaining a healthy lifestyle, in a form and content that recognised Romani and Traveller cultures, could improve understanding. Similarly, wider awareness amongst health practitioners and professionals themselves, as to these cleanliness customs, might change perceptions regarding healthy lifestyles amongst Romani and Traveller communities, and how to promote them.

⁴⁹ The need for a comprehensive all Wales Romani and Traveller health study, on the Irish model, is clear; see 'Recommendations'

⁵⁰ For those practitioners who have attended RCAC training days, education is the key factor far and away ahead of accommodation, better preventative measures, improved culturally appropriate materials and support for non-literacy, or translation into community languages, such as Rromani-chib

⁵¹ Most of our interviewees were aware of the need for literacy and numeracy in navigating the health system, but were also clear that formal education had been a negative experience and not provided the necessary basic skills, in a culturally appropriate manner

Recommendations

How to implement what we have learned from our project

“THEY PUT ME IN A CORNER, IN A WARD BY MYSELF, TOLD ME I WAS ‘DIRTY’”



Irish Traveller girls carrying water, Anglesey 1962, Geoff Charles © NLW

There are a series of measures that need to be adopted, to improve the overall situation in health and wellness of Romani and Traveller communities in Wales. Most of our stories have given details of lived experiences from Romani and Traveller families, in accessing health services and provision, and many have highlighted difficulties that our communities have in doing so. These stories are supported by other research from health surveys across the UK and Republic of Ireland, demonstrating that these experiences are common and can be addressed through shared approaches.

An All Wales Romani and Traveller Health Survey

In accordance with the need for robust, reliable data regarding health and wellness amongst Romani and Traveller communities in Wales, a national survey, supported by the Welsh government in partnership with Public Health Wales and the Romani and Traveller communities, must be undertaken (following the model of the All Ireland Traveller Health Study (<https://www.ucd.ie/issda/data/allirelandtravellerhealthstudy/>), with the following intended outcomes:

- To further document the health and well-being of Romani and Traveller people living Wales, through a survey of health and illness (to be carried out by Romani and Traveller facilitators)
- To further capture, qualitatively (through collecting stories) the attitudes and perceptions of Romani and Traveller people to health service providers and practitioners

- To count the number of Romani and Traveller people living in Wales, in a **voluntary exercise** (carried out by Romani and Traveller enumerators);
- To assess fertility rates, the number of births (prospectively) and deaths (retrospectively) amongst Romani and Traveller people, in the previous year
- To follow a birth cohort of Romani and Traveller infants over a period of one year, prospectively documenting health and development outcomes, and uptake of early childhood development services including inoculation
- To determine those factors influencing the health and well-being of Romani and Traveller communities
- To assess their access to health and wellness services and provision currently available and utilised by Romani and Travellers, in Wales
- To assess the access and ‘take-up’ of mental health services, for Romani and Traveller people
- The role of health mediators in the delivery of improved health and wellness services and provision
- Other practical, low cost things we could do – led by the community – collaborative working.

Further to this particular recommendation, the following would also be added:

- We believe that specialist services, that can act as a mediator and conduit for information, awareness and assistance, must be in place to facilitate access to health and wellness services and provision for a group of ethnically and socially connected communities that are currently excluded from the full range of services available to the settled Welsh community.
- Specialist provision should not be a replacement for mainstream services, further alienating and excluding the Romani and Traveller communities in Wales, nor should these be an excuse for mainstream health service providers to avoid their responsibilities to deliver high-quality, inclusive and effective provision.
- Such specialist provision should be in the form of a team of Romani and Traveller Community Health Mediators, modelled on the successful Roma Health Mediator programmes in Serbia, Rumania and Slovakia.
- There are cultural issues that impact significantly upon how Roman and Traveller populations access health provision, such as mobility and migration, that must be taken into account in the planning and delivery of services and in the training of health practitioners and professionals in delivery of provision to these communities.
- Languages, literacy and levels of understanding regarding health priorities amongst Romani and Travellers do need to be recognised as existing amongst our communities in ways that have an impact upon health, well-being and access. Romani and Traveller organisations and programmes have a responsibility to implement a wider dissemination of information and knowledge, and encourage our communities to make different choices regarding health and wellness, where they can within the constraints of their environments, circumstances and empowerment.
- Partnership between communities and health professionals is necessary in improving the health outcomes in our communities and political will and commitment to address the particularly low-levels of health and wellness amongst Romani and Travellers in Wales. Effective health education programmes, developed in co-operation with communities and delivered by Romani and Traveller health mediators, particularly to younger families (to re-start the transmission of ‘lost’ knowledge between generations) needs to be planned and undertaken.

- Support for parents and carers in Romani and Traveller communities, in increasing awareness about early childhood development and the importance of the role of ECD in the first 1,000 days of life, through positive parenting programmes (such as Parenting With Confidence, Ages and Stages, or Learning Through Play), that focus upon child development milestones and outcomes need to be put in place in Romani and Traveller communities in Wales.
- Support for Romani and Traveller mothers, in terms of maternal health, breast-feeding and other topics related to women's health overall, should be put in place in Wales, to be delivered through mediators and health visitors to Romani and Traveller communities.

Afterword

Romani and Traveller families and health

Dr Thomas Acton, OBE, Professor Emeritus in Romani Studies, University of Greenwich



The stories in this report reinforce the gathering literature which shows that Roma, Gypsies and Travellers often experience health disadvantages, not just as a result of poor environment and harsh living circumstances, but also as a result of lack of understanding and even active discrimination by personnel in the Health Service. What they do not show, however, is that being Gypsy, Roma or Traveller is a health disadvantage in itself.

In every case, there is a specific cause – past failures in the education system that mean people cannot read information, unhygienic living conditions, prejudiced professionals – but non-Gypsies who suffer from these circumstances, suffer the same problems. When action is taken to remedy them, it is not just Romani people and Travellers who benefit, but all disadvantaged people who need the NHS in Wales to become just that bit more comprehensive.

Adrian Marsh and the team of Community Champions and reporters who put together the data for this report, are to be commended for bringing the lived experience of Gypsies, Roma and Travellers to the printed page. We can all learn from it. . .

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